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Meeting Transcript
September 12, 2008

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SESSION 4: MEDICAL FUTILITY IN CONTEXT: END OF LIFE TREATMENT AND CARE

CHAIRMAN PELLEGRINO: Good morning. I usually say good morning several times, and that gradually will bring together the troops. Good morning. This is the final good morning.

This morning we turn our attention to a new subject, a different subject, a subject of futility, recognition that, as mortal beings, at some point in each of our lives we will be beyond medical rescue. And then the question comes, at least one of the questions, a clinical aspect of it, how do we approach that moment and how do we decide it and by what criteria and what are the ethical considerations and desiderata that one has to take into account.
Our first speaker on this subject is Dr. Linda Emanuel, who is the Buehler Professor of Geriatric Medicine and Director of the Buehler Center of Aging, Health, and Society of the Feinberg School of Medicine of Northwestern University.

I have known for many years. I alerted her to the fact that we would not give a long introduction, so she understands that. But she is a distinguished person in this field. Linda, it is all yours.

PROF. EMANUEL: Mr. Chairman and members of the President's Council, members of the participating group, I'd like to add my good morning to the several we've already had, and I would like to add my thanks for the privilege of addressing you at this point, a full 15 years since the President's Council addressed these issues once before, and I'm acutely aware, having arrived past the 50-year mark in my own life, that it is a rare privilege to mark some of the small steps in historical development of the human struggles with concepts in medicine and concepts in policy as to how we deal with them. So as we take this opportunity to mark some of the progress in the last 15 years, I stand before you with that degree of humility, which is profound.

What we would like to do is consider where have we come from in the issue of futility over the years and, also, where do we go from here? What we'll cover as we consider the question of where we have come from is a little bit of history and background. That will cover some of the technical capacity's evolution, and also the patient/physician relationship and its evolution in significant part in response to the technical capacity's evolution.

We'll look at some of the conflicts that have fueled these developments, and we'll look at the place in which I think it's fair to say we have arrived, looking at the balance of excessive versus insufficient intervention towards that Twilight Zone of life. Once we have done that, we'll take a look at defining medical futility before we go on to consider where we should go from here.

So very briefly, the technical capacity is something that really requires, I think, only a few visual images to remind us of where we have come from, and I personally think that we can mark the beginning of the relevant technical development to the iron lung. And here's a picture of the top of a woman who is in the iron lung. I believe it's a woman. It's not entirely clear.

And I say that because this machine most remarkably engulfs the entire person except for the head and was a striking statement of the way in which our technical capacity took over the rest of our humanity in a really powerful fashion.

As we move beyond the iron lung, we came across the era in which we had discovered how we could start the heart up again that had stopped, and this was a method that was developed, actually, for use in the setting of the operating room with the idea that especially the young and healthy person who may have had a cardiac arrest due to a surgical procedure's intervention could be saved.

The methods, however, were used far more broadly than that. They were used in the emergency department, throughout the hospital, then in the field with EMT training, and now we see it throughout our hospitals and elsewhere. And that picture that is second in the cascade is an illustration of some of the extremely intense activity that happens around a person as they arrive in the emergency department.

Now, the next step was the evolution of our capacity to support life in an advanced life support setting, the evolution of the intensive care unit and in many iterations, first of the development of multiple disciplines within medicine: medical intensive care, surgical intensive care, pediatric/neonatal intensive care. These are all now very well-funded, very well-defined disciplines within medicine.

And, finally, we developed the capacity to sustain life not only in the instant and in the advanced life support setting but in the chronic condition, and the final picture is a picture of a dialysis unit, and there's somebody's kidney or many people's kidneys sitting right there next to an easy chair.

So, now, I'm fully aware that I am addressing people who are well advanced, indeed, national and international leaders in medicine, and I've chosen to describe these technical developments in lay terms not by way of reducing the importance or the sophistication of the understanding, but by way of raising us to a 30,000-foot level. These technical capacities had human meaning, and it's the human meaning that I'm seeking to emphasize in this description of our developing technical capacity.

So how did this correspond to a development in our understanding of the relationship between clinicians and sick people? Well, first of all, it evolved from being the physician/patient relationship to the patient/physician relationship. But then, in addition to that — and I think you had some
considerable thought about the evolution of this relationship yesterday, so I won't dwell on it for long. But the models in which we thought about the physician/patient and patient/physician relationship really evolved.

Along the left-hand column, I've listed some of the models. Along the right-hand column I've listed some of the decision-making methods that illustrate that. So coming into the present era, we arrived with a paternalistic model of the physician/patient relationship in which the notion was that because of his superior technical understanding and medical understanding, the physician was supposed to find the best-interest decision on behalf of the patient.

But as we entered this era, we began to have a very strong push back in the medical profession from our fellow citizens, patients, and their families who wanted a lot more information. They wanted to share that information which had driven the paternalistic model.

So we came to the point where we had an informative model, and here we began to see that the physician was sometimes described as a plumber, even, a technical expert. Now, in today's world of information technology, IT people are not mere plumbers. They're not mere technicians. So we have a more exalted view of what technical expertise involves and don't say "mere" in that fashion.

But then we were looking at what seemed to be a demotion in the role of the physician and a promotion in the role of the patient and the family member. They wanted the information in order to be able to make directives, make the decisions themselves about their own healthcare, and that corresponded, also, to the development of making prior directives, so extending their ability to make decisions to include ourselves, since we will all be patients one day, if we have not already, into the future.

That model clearly had some deficits in that both patients and physicians felt the lack of interaction and discussion. Patients felt the lack of guidance, and physicians felt the lack of ability to discharge all of their duties. And we began to consider the interpretive model, in which the patient and physician would together work on how the information could be used to discern the best decision for that patient.

And here the new standard was substituted judgment, which can in some cases be significantly different from best interest judgment. The judgment to be rendered is a decision that is supposed to be the best possible interpretation of what that patient wants, what that person wants.

Even that model seemed a little inadequate to some folks, and the next model that became a subject of discussion was the deliberative model, in which the patient and the clinician would together discuss not only the information and its interpretation but what would be the best decision for medical health standards. And here the relationship seemed to epitomize a kind of decision-making that used a reasonable person's standard but still specified to that individual patient and their context.

So very briefly, that is a summary of the way in which our relationship evolved, the relationship between ourselves as patients, as family members, and ourselves as physicians and other non-physician clinicians: nurses, social workers, pastors, pharmacists, and so on — quite a different relationship.

And depicting where we have arrived in visual form, I think we can see it in this diagram, where the patient sits firmly at the center. And we talk a great deal now about patient-centered care. But the patient is also embedded in the context of family and of community, and the lines depict the clinician. And the notion there is that the clinicians provide a safety net and set of directions and a network of care that embraces not just the patient but also the context in which the patient lives. And this whole thing is embedded in a larger society context.

So I think that this is a fairly settled understanding, now, of the way in which we relate. I don't say it's a simple understanding, but I do say that at this point I think it is fairly settled.

So what were some of the conflicts that fueled the discussion and fueled this massive evolution, subtle, yes, but massive, also. Some of the landmark cases I'm just going to put biopsies, if you will, in front of you because you know these cases very well.

There's the case of Dax Cowart. He at the age of 25 was a — I believe a Navy but certainly a military enlistee, survived a fiery accident in which 60 percent plus of his body was burned, and he lost the sight of one eye and had a very, very difficult recovery in which he repeatedly asked for his treatment to be withheld and to be allowed to die. He was overridden. He recovered. He went to law school, where he continued to try to take his life and eventually became a lawyer who, while saying that he
appreciated his life, still argues that it would have been more right to withhold his intervention and allow him to die back then.

Then there is Karen Ann Quinlan, a case in 1976, a young woman who, through mixing drugs, arrived at a cardiac arrest and was resuscitated and maintained in a persistent vegetative state until finally the Supreme Court said that a surrogate, the parents, could withdraw life-sustaining treatment.

So these prompted a great deal of discussion and debate, and shortly after that, the 1983 President’s Council report on decisions to forego life-sustaining treatment was published.

This is a very brief summary of a report that you know perhaps better than I, but I wanted to highlight some features, all of which are in its own summary of itself because we all return to this at the very end.

The report definitely and firmly and persuasively put the individual's voluntary choice at the center, consistent with that visual that we've just seen. It did also outline some constraints on the individual's voluntary choice, including the physician's conscience, possible resource constraints, and the need to never abandon a person who has declined life-sustaining intervention.

It had what in retrospect was a heroic and almost beautiful attempt to summarize palliative care in one of its appendices. This was, looking back at it, a very touching synopsis of guidance to physicians as to how to provide care to patients who were declining life-sustaining treatment.

It was also an endorsement of the use of surrogates, proxy decision-makers for those who could not make their own decisions, and it endorsed the use of best-interest standards. As we've seen from the prior discussion and slide on the relationship, maybe those standards are by now a little dated. That is what the '83 Council report recommended.

It did also endorse advanced-care planning but clearly as a second best, saying that the surrogate has a better capacity to decide than advance directives. And, finally, it endorsed the use of a do-not-resuscitate order and indicated the importance of physicians assessing every hospitalized patient for what their status with respect to resuscitation should be.

And each one of these points except the first one has an update that I think the current President's Council may want to visit as we go forward. So that's the summary that I'd like to leave in your heads for just a moment until the end of my presentation.

So in the meantime the conflicts that fueled the discussion continued. We had the case of Cruzan. We had the case of Martin. And basically those cases were testing out whether states could limit the right of a surrogate to withdraw treatment, and, by and large, the ability to withdraw life support was upheld. But then we had an interesting turn of events. In '95 we had the case of Gilgunn and Wanglie, and then later on we had Schiavo - Terry Schiavo, and we were being presented with a situation where, although the Schiavo family was in disagreement amongst itself, basically the families were demanding continued life support.

So these were the cases that continued to fuel our discussions, and, in addition, for those of us who are in clinical practice, they were the day in, day out, every hospital, every clinician was confronted with a case of a similar kind that had perhaps less limelight but no less human suffering, no less tragedy, and no less sense of dilemma for all who were involved.

And I say "all" advisedly. It's not just the patient. In fact, the patient in a vegetative state was probably suffering the least. It was the family members, it was the people providing care, the nurses, doctors, and so on, as well as the institutions around them that were suffering.

So when all was said and done, I think that the grand realization that was staring the clinicians starkly between the eyes was that whereas those of us who had been raised on a diet of scientific enthusiasm, that we could save lives and stamp out disease, had to confront the possibility that excessive intervention is a real problem, but then also confronted with the possibility that too little intervention could be a real problem, as well.

So we were confronted with this very basic understanding that we somehow felt we had been freed from for a short while that both excessive and insufficient intervention are wrong. And so there we were in that Twilight Zone between life and death trying to navigate these narrow straits with appropriate care for the individuals.

And so with that backdrop it became very important to try and understand what is futility, when is
something futile, and when is it not. And people valiantly came up with a variety of definitions. And they went something as follows.

There was the professional definition. And, in essence, the idea with the professional definition is that the medical profession can create standards as to what is futile and what is not because the medical profession knows what works and what doesn’t work. Now, unfortunately, professionals didn’t agree. We varied amongst ourselves as to what might constitute futility, and so that definition did not carry very much weight.

Nancy Jecker and her colleague, Schneiderman, came up with a numerical definition. Basically the idea there was that any intervention that has not worked for the previous 100 attempts can be considered futile. Again, that turned out to be not terribly helpful because we differed on the ways in which an intervention could be considered to have counted as one of the previous 100, and many of the interventions hadn’t even been tried 100 times before. So it turned out just to be not terribly practical and therefore not very helpful.

Then the reasonable person standard was the idea that we could define what futility is by trying to put a hypothetical reasonable person into a scenario and decide whether that person would want the intervention or consider it futile. Now, the reasonable person, of course, is a hypothetical person, and in reality, individuals vary too much, and so that didn’t hold very much weight for us, either.

There was some very worthy attempts to reach social consensus as to what is considered futility. Indeed, there was an attempt in Puget Sound to list interventions that should be reimbursed, and out of that is a somewhat implicit notion as to what would be considered not worth the social resources and therefore, perhaps, futile. That seemed to be impracticable. The process was very labor-intensive, fraught was disagreement, and didn’t seem to help very much at the bedside in the end, either.

So what we ended up with was this patient-centered goal-guided — and we’ll talk a lot more about goal-guided in a moment — definition of what constitutes futility. And, again, here’s the visual. This is the decision-making model, and it was applied to futility, as well.

So at the end of the day, at the end of the debate about futility, we had people saying that the whole notion of futility is itself futile. It hasn’t helped us. And a framework of understanding what this debate was really about was a psychological one, a relational one, in which it was discerned that the problem was that with these situations where people were sustained in a Twilight Zone there was an incursion on other people.

No patient goes into a state as dire as that without drawing people with him or her. Family members were drawn in. Physicians were drawn in. Nurses were drawn in. Social workers were drawn in. Lawyers were drawn in. The community was drawn in. This was making an incursion on other people, as well. It was also making an incursion on other values.

So the value of sustaining life was the value that was being honored where life support was continued. But the values of other things was being incurred on, and those values might be other people's ability to continue with life, a use of resources for other things, quality of life over quantity of life. Those were all values that people cared about, as well. Incursion on others' resources was another source of frustration, and incursion beyond patient boundaries that may have been unwelcome was another source of frustration.

So that's a story of where we came from in the futility debate, and where do we go, then, from here? And in this section I’d like to cover the following three topics: The notion that there might be such a thing as a differential diagnosis of futility claims was a very powerful one, and we'll go into that; the notion that we may be able to have approaches to it, therefore, that fall within the medical paradigm turned out to be quite powerful; and, thirdly, I’d like to spend a moment talking about whether there are persisting dilemmas and whether we can resolve them. I’d like to put before you the notion that, indeed, we can, and perhaps with the help of the President's Council going forward.

So first of all, what prompts assertions of futility? A wonderful, I think, definitive article by Susan Dorr Goold and her colleagues in JAMA that I have provided and I think is in your packets indicated persuasively that the vast majority of cases that were termed futile could be understood within the context of a differential diagnosis no longer than three long.

There were family features that were often driving futility cases, and those family features involved things like difficulty understanding or gathering appropriate information. So there were misunderstandings involved, things like guilt within the family, things like difficulty letting go, and things like different expectations about what was possible. Those were some of the family features
that could drive futility cases.

Then she pointed out that this is not just about family. This was also about physicians. This was a physician group writing, and so pointing the focus on ourselves was a very important step forward and that some of the features that she pointed out is that we are not comfortable with the prognostic uncertainty at the Twilight Zone of life, and that's our issue; that we have our own attitudes and expectations about what should happen that we impose, and that's our issue; that we have inadequate skills or we had at the time inadequate skills for dealing with such cases, and those were our issues, as well, to say nothing of the stress of our day-to-day professional lives.

And then, too, she pointed out that there were social and organizational features such as resources, some of the way in which hospitals are set up, lack of visiting hours, and arrogation of decision-making that left out people with a great deal of interest in the decision-making, legal fears, things like that, which kind of set us up for controversial cases that became dubbed futility cases.

And I think a broader differential diagnosis really is consistent with that. I think we can see that for the most part futility cases can be considered either cases where there is a mismatch of expectations — perhaps personal adjustment is not complete, the difficult realities of our mortality and our disability, perhaps information. Perhaps it's cultural conflict. But one way or another there's a different set of expectations.

Or there are relationship problems. Communication is inadequate. The respect that we offer one another was perhaps inadequate or inadequately conveyed so that the trustworthiness was at stake.

But, too, in addition to that, there were genuine dilemmas — rare, but there were some where there were genuine differences in beliefs, genuine differences in values, and genuine differences in approaches to the phenomena of life, including perhaps whether or not miracles exist.

So how do we approach futility cases? With the understanding that if we can approach it with a differential diagnosis and we can apply, in the same way that we do with all of medicine, a preventative approach, we have suddenly a whole lot more power and capacity. And I would like to emphasize, especially for the President's Council going forward, that this preventative approach is absolutely characteristic of medicine, and I would suggest — I would hazard a guess that perhaps more than 80 percent of the success of medicine is attributable to preventive medicine.

So, too, here in the cases of futility, if we can predict what kind of situations come up, we can see what's coming down the pike, we can prevent most of them and manage others of them, we are going to be in a much, much better state.

So with an emphasis on communication we began to teach our colleagues about the term "realistic hope," and we began to experience and try and provide for ourselves and our patients and our community members something that I like to call existential maturity, an ability to live with the nature of our mortal condition that is mature as opposed to immature.

And advanced-care planning, including the use of thresholds — I'll spend a little bit longer on that in a moment — is one of those mechanisms. These are all preventive medicine mechanisms.

For those cases where there is, indeed, a genuine dilemma that is irresolvable, the Council on Ethical and Judicial Affairs came up with a report that's also included in your packet that provides a due process approach to managing these situations.

And basically the steps involved in this were to communicate ahead of time, to deliberate ahead of time so that all possible conflicts could be preempted. Then joint decision-making was encouraged as far as possible, and negotiation was encouraged, including with consultants as fitting.

If that's not possible, then the Ethics Committee was recommended. And, finally, if the Ethics Committee was not able to produce a resolution that all parties were comfortable with, then it recommended transfer of care, either transfer of care to a different attending physician within an institution, or if that's not possible, transfer to another institution.

Recognizing that that's not always possible, it did bite the bullet and ultimately said that if all of these features have been tried and it's still a question of whether or not life support can be withdrawn, it is permissible to withdraw life support. So that's the opinion of the Council on Ethical and Judicial Affairs in '96.

Okay, with that in mind, I'd like to spend just a moment longer talking about some of the other preventive mechanisms. We'll spend less time than more on this, not because it's unimportant but
because I think by now it's very well promulgated. Teaching our colleagues how to communicate effectively has been clearly given a great deal of attention and clearly triggered, I think, by the seminal work by Susan Goold and others.

Robert Buckman has put out a six-step protocol for communicating effectively, and this is the framework that is variously adapted for various different settings now to help us communicate so that our patients — and ourselves if we're the patients — understand the necessary information in order to be a member of the participatory decision-making team making good decisions.

What I'd like spend a little bit more time on is advanced-care planning, or perhaps this title should have said "Advance Directives." Advanced-care planning is a discussion process, and I think that's motherhood and apple pie, and no one believes that that's a bad thing. Everyone believes that that's a good thing.

But the question of directives has been more controversial, and I'd like to make a case for an enhanced understanding and an enhanced role for directives, recognizing, of course, that a set of directives is not a panacea.

But the main problem with advance directives is that they are time bound. And I'd like to make the argument that being time bound is an intrinsic limitation but not sufficient to undermine the merit of advance directives. I would like to indicate that the data that we've gathered over the years make it clear that these commitments work at least as well as other future-oriented commitments.

One example is marriage. Not all marriages last, but we honor the commitment of marriage. And to perhaps make it more vivid, getting on a plane is also a time-bound commitment. In this era we all know that when we get on a plane, if a disaster happens in the middle of the air, we live with our commitment, and we die with our commitment. So I think that we should not cast out the notion of advance directives because of the nature of our existence in a time-bound reality.

The notion of advanced-care planning is a discussive process that aids in our ability to come to terms with and understand our mortality, our need for working in a team of decision-makers, and our need for communication is also a well-proven case and one that we need to give additional honor to.

What I'd like to spend just a little bit longer on now is an update for the Council on the use of personal thresholds and goals that are durable and interpretable in the medical context.

So here's an example of one way in which a person is being asked to think about what their goals for treatment would be. There's a well-defined situation, succinctly stated, and then there are goals that the person can select or further specify.

And in a study by Gary Fischer in '97, it was empirically determined that these goals are not only durable over time but that they can be accurately used to predict intervention preferences. Now, this is a very important concept because of the way in which it will allow us to relate proxy roles with directive roles.

So if a person can articulate their goals, they are durable over time, and they are consistent with the specific treatment choices that they make. And here's a worksheet that shows several different scenarios. It's a worksheet. It's got a pencil with an eraser at the top of it showing that it's a worksheet, and this particular worksheet has been filled out with two different scenarios with two different goals, indicating that people do change from one goal to another, depending on the circumstance. And then below are the different interventions, and this person has, as yet, not filled those out. But in the next depiction the person has filled them out, and, indeed, they are consistent. But, furthermore, it's quite clear that there's a threshold somewhere in the middle of that set of three scenarios.

Not only have the check marks moved from one to another for the specific interventions, there is a specific set of instructions added to one situation in the middle, and that person has indicated that that person's threshold is right there in situation E. That's where there's ambivalence. That's where there's a shift from one set of preferences but not yet the goal to another, and that's where specific modifiers are being put in place.

Empirically, the vast majority of people do reveal a threshold when they're given a set of scenarios to look at, and those thresholds and those goals, then, provide us with a sort of set of ordinates, kind of like the latitude and longitude in a global position, that allow us to understand something fundamental about the values and wishes of a person.

So I'd like to put that forward, then, as an argument that proxies and directives need to be
understood as two sides of one coin. Proxies are enhanced by having directives, and directives are enhanced by having proxies.

We need to keep in mind that a proxy has a very, very burdensome role and is greatly assisted by having directives to help understand that person’s narrative role, help understand that person’s values and wishes.

And, similarly, the directive that sits there as a piece of paper, as an inanimate object, is incapable of doing the fundamentally important task of engaging in deliberation with the physicians and other members of the team who are making decisions. The two must go together is the point that I would urge upon the Council.

One way in which we see that this advanced-care planning discussion has moved forward is also in the area of the do-not-resuscitate order. Again, to remind you, the Council report of ’83 focused on the do-not-resuscitate order.

I’d like to point out that empirically, the decisions that people make about a resuscitation order are the most unstable of all decisions made about life-sustaining treatment. And thinking about it, we can understand why. Personally, if I were asked if I wanted to be saved at the point of falling off the edge of a cliff, I would of course say yes. But if then I go back and think about the context of that decision and I realize that all kinds of other things are pertinent, I might return to my earlier decision of not wanting resuscitation.

So we can understand, I think, that we ask people a very unfair thing when we ask them to make decisions about resuscitation that are isolated from the full context of their healthcare. And, indeed, I personally teach physicians that whenever they see a DNR order that is isolated from other life-sustaining orders on a medical record, that is a flag for lack of having a palliative care plan. That is a flag for suboptimal quality of treatment and care.

An attempt to move us out of that quandary was a wonderful one by a group in Seattle. They proposed the physicians’ orders for life-sustaining treatment, which is basically a bundle of key life-sustaining decisions. And the notion there is that one physician can make a POLST form, and then that POLST form, with suitable state sanction, can move with the patient and be considered valid and authentic even as they move from one place to another. So both it prevents the isolated DNR order and it overcomes some of the problem of discontinuity of care.

That POLST form has been advanced on by others. We call it a medical orders for life-sustaining treatment, or MOLST, form. And still more people are working on a palliative care pack or a bundle of seminal issues in key domains that need to be addressed for all patients.

The overall theme of this slide, though, is that the narrow focus on the DNR order is now out of date and we need to move forward to something that is a better preventive measure for futility cases.

So with that in mind, let’s examine for a moment whether there are persisting dilemmas, and I’m going to list three. One may be the question of food and water — is it medical or is it ordinary? I think there’s considerable consensus that both food and water become medically contraindicated for many patients during the last stages of their life.

And as this emerging consensus became widespread, all of us were a little surprised when the Pope’s encyclical on the subject indicated an imperative to use food and water for comfort even in the persistent vegetative state.

However, the Pope’s encyclical, I’d like to argue, did not undermine in any way the recognition that it’s medically contraindicated in last stages for many people, nor did it undermine the consensus that incursion past a person’s boundaries without consent is a violation.

So just to reinforce, medical contraindications to food and fluid are for the following reasons: Toward the end of life there is very often an extravasation, a leaking of fluid from the blood vessels in the lungs leading to fluid on the lungs, which leads to an extremely distressing inability to breathe.

It also is the same phenomenon in the periphery of the body, so that leakage of fluid into the tissues leads to swelling that can cause a breakdown in the skin and wounds that are very painful. So both of those clearly do not aid the comfort of a person near the end of life. There’s also often nausea and vomiting, and there can be gastrointestinal paralysis and blockage, which makes food and fluid through the GI tract contraindicated.

Here’s an excerpt from the encyclical, and I don’t expect you to read this by any means in any detail. I
just wanted to emphasize that at the top with the first question, "Is the administration of food and water to a patient in a vegetative state obligatory" includes the exception "when they cannot be assimilated by the patient's body or cannot be administered without causing significant physical discomfort."

And, similarly, in the second question there are these important writers that I think allow us to find a way that this, too, can be accommodated within the emerging consensus.

A word, too, on these personal boundaries. When a percutaneous endogastric tube or PEG tube or a tube is inserted past the body boundary directly into the gastrointestinal tract or when a central line is inserted into the blood vessels or even when a person with Alzheimer's is spoon-fed and they bite down on the spoon and don't let you put the food into their mouth, those are all transgressions of bodily boundaries, and if they're done without consent, they remain a violation.

So we have esteemed colleagues such as Kevin O'Rourke publishing as recently as this year on the subject, and I think that we should be optimistic that these issues of food and water are well on their way to being resolved.

Another persisting dilemma of whether a person changes who they are — and I'd like here to note that Rebecca Dresser is the person who really pioneered the philosophy and thinking behind all of this. What happens when a person is so changed by a mental illness such as Alzheimer's or by stroke that they are indeed no longer the person that they used to be?

What happens, for example — and I call it the sunset syndrome — when a person was in passionate belief that when they got to a certain point of advance dementia they wanted to be allowed the first possible natural exit from life but then discovered that they were quite happy to enjoy the sunset sitting on the balcony of the nursing home and that life did, indeed, have meaning? What happens then? What happens when Dax Cowart says, "Yes, I'm happy to be alive, but I should have been allowed to die back then because I wanted it and it was my right"?

I'd like to suggest that Dax Cowart's position can be internally coherent and that what we need to do — and I think this is consistent with Rebecca Dresser's position — is honor the most recent iteration of the person, and the proxy is there to use substituted judgment, if necessary.

But nonetheless, very often we have to do the best we can, and we do want to make a construction for ourselves and for those for whom we're beholden of our narrative that takes into account the whole narrative and allows that we do live in a time-bound existence in which time-bound commitments is the best we can do. And so that there is a very real role for both the advance directive and the proxy that overrides them by use of substituted judgment, if necessary.

Finally, is there a slippery slope, and do we have to worry about futility with respect to this question? I think the worry is that a futility discussion might allow philosophical positions that would perhaps devalue life if it went in one direction or perhaps foster a kind of anticipatory desperation for those who have great worries about living in a state worse than death.

So at the end of the day I think that there may well be slipperiness, and there is always slipperiness, but it's not at all clear whether assisted suicide and euthanasia would be more likely or less, depending on how the futility debate is handled.

Rather, I think the answer to this question is palliative care's approach to physician-assisted suicide, which acknowledges that most requests come from nonphysical suffering, from psychological suffering and social suffering, and provides a stepwise, nonjudgmental approach to treating the root cause of suffering and that that approach can take care of the vast, vast majority of requests.

And palliative sedation, with careful adherence to the doctrine of double effect, is also a possibility, if necessary, especially for physical suffering. So I think that situation is also ready for update and close to full resolution.

So in closing, I would like to say a few words about the path forward and leave the rest, obviously, to the President's Council. What is not futile about futile? What has been productive about this debate? And I would think that we can agree a great deal has been productive.

One is the understanding that our goal is to find a very specific individual goal for all people for whom we care about their medical care. So a person-centered approach to goals is one important piece. Now, please note here that what we are saying, and it's implicit in this understanding, that we are not arguing about the preciousness of life, sanctity of life in some people's terminology. We can all agree about the preciousness of human life.
What we are talking about is the quality with which we accept our mortal condition. And we do not argue about our mortal condition. We're talking only about the quality of the way in which we approach it.

I don't think anyone from any religious tradition or from a nonreligious tradition would imagine that their life would be judged for its worth on whether they lived an extra day, an extra week, or an extra month or not, but on the way in which they handled the mortality that we have, complete with life, and complete with the necessary condition of letting go at our end of days.

So with that in mind, we can say that our medical standards are now new and improved. We have made progress and that we can also continue the progress we've made culturally as a society, and we can also look at our policy and law, most of which I'll leave for my next colleague, who will be speaking more about it.

So in finding a care goal for all people, I think that we are looking for something that translates differently for different people. Some people call it a state of holiness between life and death, others a state of settledness, peace, love, bliss.

Wherever we come from, I think we can understand that we're looking for the silver linings that come with our mortality. We're looking for a kind of transitional readiness, a kind of ability to complete the tasks of the dying so that we can become part of the continuum of the mortal multi-generational human condition, walking offstage in a suitable fashion when our time comes.

The medical standards that we're looking for are those that are free of unwelcome incursions onto other people, onto their resources, onto their values, and past people's boundaries, all of which can be done without ever abandoning a person. And we can do this by promoting palliative and hospice care even more than it's already promoted, and we're doing well in this.

We can do this by promoting preventive practices for futility where goals are continuously elicited and updated as part of routine medical care. Communication skills are considered essential, and advanced-care planning using proxies and directives is also part of routine care where conflict resolution and other parts of due process are also routinely institutionalized.

Our cultural growth is perhaps beyond the call of the President's Council, but I think that we can look for continued growth beyond our social death denial that we have lived in and struggled in, in the last 15 years. And by promoting more exposure to the process of dying, we can achieve a kind of social existential maturity that will be very helpful.

It was very striking. As I came in yesterday and went past the ceremonies marking 9/11 and reflected on our fall from power and our fall from prosperity and, most importantly, our fall from a sense of immunity, I think that we can find a silver lining in 9/11 which is our ability, perhaps through the media, perhaps through arts, to embrace our existential maturity.

So as we consider policy, I would promote the idea that the President's Commission thinks carefully about how to promote palliative and hospice care widely, to promote an ideal form of advanced-care planning that is updated from its previous iteration, that we should refine state laws so that not only are there proxy laws in every state but laws that enshrine the ability to have a combination of proxy and directives, and that the POLST form is indeed legally honored in all states. Currently it's only honored in some and with the strengthening of due process at every hospital level.

So this is a summary of the recommendations. It's a repetition of what I have said before, and it's on your printed handout, so I won't go through it again. But I would like in closing, finally, with my last slide to go back to the '83 President Council's report. And here I've highlighted in color some of the things that I think need attention and updating to go forward.

The individual's voluntary choice still remains central, but the constraints now need updating. It goes beyond physician conscience. It goes beyond resource constraints, and it goes beyond the need to not abandon, to all of the things that we have talked about, the need for palliative care in its fullness to be promoted, not as an almost now quaint and touching appendix that summarize the essence of it, but in its fullness as a full discipline as something that every member of the American society should be able to access.

Surrogates should still be endorsed, but they should use the standards that now reflect our more sophisticated understanding, not only best interest — best interest when it is relevant but substituted judgment more often and collaborative with directives not as a second best but as a co-equal.

The DNR assessment for all hospitalized patients needs to be expanded to a full bundle of palliative
care considerations. So with those thoughts, I thank you for taking the time and listening to me, and I would like to close here. These are references for the work that I have cited in my comments.

CHAIRMAN PELLEGRINO: Thank you very much, Dr. Ben Carson, member of the Council, has asked to open the discussion.

DR. CARSON: Well, thank you, for that very thorough and thoughtful presentation. I, looking at the subject, thought I would have a lot of things that I would disagree with, but I really don’t because it was really done in a remarkably thorough way.

I would say that a lot of these issues are a little more difficult to grapple with than perhaps they seem. And a lot of it has to do with our lack of complete knowledge as physicians.

I remember a few months ago a baby with Pfeiffer’s 2 syndrome, and all the neonatologists and geneticists said, "They all die. There’s really no point in doing anything.” And I got into a fairly substantial argument, to put it mildly, and I said, "The reason they die is because you don’t do anything. Maybe you should do something. Maybe we should be more aggressive.” And after some significant discussions, we proceeded. We’ve had to do so far five operations on that baby, but the baby is thriving.

And a lot of times I think we have to put these things into context of our increasing knowledge and not allow ourselves to sort of stop and say, “Well, this is how it is and this is how it has been,” recognizing that those things are going to continue to change.

As far as the proxies and advance directives are concerned, I’m a big advocate of those because we get into extremely complex situations. But one of the problems, of course, is that they don’t take everything into account.

And perhaps a very well-known case involves the Bijani twins, the Iranian young women who were joined at the head. Their desire was to be separated. And I was involved in that case. And after doing the initial operations to create new vascular channels, which clotted off, it became very clear that they had another way of draining their brains because their brains remained healthy.

And I and a couple of other people felt that it was prudent that we stop the operation at that point, figure out what was going on because we had a pretty good chance. Well, they had a prearrangement that we would not stop. They would either be separated, or they would die.

So we went out to talk to the proxy who said, ”I’m sorry, I can’t change that,” when, in fact, the clinical situation had dramatically changed. And that’s a situation where sometimes their advance directives and proxies don’t work, and we have to certainly integrate into that a mechanism to allow for the knowledge and skill of the medical profession to make adequate changes. And it’s a very difficult thing to account for.

But in the long run, pragmatism I think is the thing that helps us resolve these kind of issues. We just have to look at them in a logical way. We have to integrate compassion into that. And I think utilizing the principles that you have articulated, we’ll be well on the way.

CHAIRMAN PELLEGRINO: Thank you very much, Dr. Carson. Linda?

PROF. EMANUEL: Thank you for your comments. I would just want to make one commentary on your comments with respect to the Bijani twins and the intraoperative decision that you were faced with. There’s a sense of regret in me that it wasn’t possible to have explained to the proxy that the role of the proxy is, indeed, to not apply directives rigidly but to apply them as one source of understanding as to what should happen in real time and to recognize that at some point substituted judgment does kick in and that the most important time when substituted judgment kicks in is when the reality has changed.

The person has changed, in the case of Dax Cowart, but the medical situation in the case of the Bijani twins. So had that been something they had understood ahead of time, you would have had a better deliberative partner.

CHAIRMAN PELLEGRINO: Thank you. Rebecca?

PROF. DRESSER: As usual, you’ve given us a very clear, thorough presentation and a good overview of kind of the foundation situation for futility as an issue. We actually put out a report about three years ago called “Taking Care: Ethical Caregiving in Our Aging Society,” and we kind of go through a lot of the general issues about directives and decision-making and so forth. And I’d be...
interested in your reaction to that part.

So I guess I’d like to get you to focus a little bit more on the futility situation because I understand that that’s what our next report or White Paper will focus on, is that right?

So I wondered if you could talk about two things. One is what about the advance directive that says, “I believe decisions about my life are in the hands of God or whoever, and I want the doctors to do everything”? So following the directive would require doing some things that many professionals might disagree with.

And, secondly, it might be useful for you to maybe — if you have a case example of a futility case that you’ve been involved in, sort of how you worked through it. I think that would help educate us more specifically about this particular kind of dilemma.

**PROF. EMANUEL**: Thank you, Rebecca. As always, you go to the point of urgent need. And this is no exception. So when a person has an advance directive that says, "My life is in the hands of God, and that means do everything," you’ve already gone one step forward because you know a little bit about what that person means when they say, "My life is in the hands of God" because two people can say that same thing, and it might mean something very different to them. So you already know that that means to them that they want everything done.

The specific case that immediately comes to mind that is the second part of what you asked me to go through is not dissimilar, so I’m going to kind of fuse them. The specific case I was involved with that comes to mind was a young man who was in the terminal stages of HIV/AIDS, had had cerebral involvement, and was unconscious on a ventilator.

This was at a fairly early stage in the whole AIDS epidemic, and this was a homosexual young man with a stable partner, a sister who had previously died of HIV/AIDS from intravenous drug use, and a mother who was involved and devoted, but not very stable socially with respect to her son.

And the patient had had two different advance directives, and they didn’t agree. And one advance directive said that he wanted everything done, and then the other one said that he wanted something short of everything done. The proxy did not understand that that’s what the patient wanted.

The proxy understood that the proxy was doing the bidding of his mother, who wanted everything done. The proxy understood that, like his sister, he really would have wanted to have life support withdrawn. So in the context of that disagreement we engaged the discussion of what does it mean to do everything.

So the way in which that discussion went was initially there was a discussion about — and this is the good part. The rest of it didn’t happen so well in that we had to go to the Due Process Ethics Committee portion. But that was part of it, and it went, and so perhaps it went well in that regard.

But the discussion part that was optimistic from my point of view is that we were able to say, "I fully respect your belief. It may not be all of our beliefs, but we fully respect it. We fully respect the sense that doing everything is part of honoring your religious relationship to God. We’d like to understand exactly what that means, because we also understand when you say ‘doing everything’ that you don’t mean doing things that are cruel and inhumane."

What would it mean to have gone beyond doing something desirable to doing something that’s abusive? And so we were able to get some thresholds there that eventually brought consensus.

Now, we didn’t reach consensus at that point, but eventually when we had gone to the Ethics Committee and there was discussion between the head of the Ethics Committee and the proxy and the mother, there was agreement that what they meant by doing everything short of being abusive involved not maintaining the respirator. So eventually the respirator was withdrawn, and he did die. He would have died shortly, anyway, but perhaps not for quite a while.

**CHAIRMAN PELLEGRINO**: Thank you very much. Yes, Ben?

**DR. CARSON**: Two weeks ago I had a situation where there was a newborn baby who had about two dozen brain abscesses, MRSA. So this was not a good situation. And we all knew what the outcome of that situation was. But the parents said, "Well, there are miracles, right? God does work miracles. So we need to do everything. We need to drain all the abscesses. We need to put tubes into the ventricles," et cetera.

And I resolved that issue with them by simply saying, "Does God need us to do a miracle? He doesn’t
really need us, does he?" And as they thought more about it they said, "No, I guess not." And they backed off of that. So even in those situations I think sometimes you can reason with them if they truly do have a good concept of God.

CHAIRMAN PELLEGRINO: The time is a little short, so I’m going to do the following: I have three Council members who wish to comment, and I will ask them to do so, and then you can respond as you hear their questions. First to Dr. Meilaender and Dr. Landry and then Dr. Gómez-Lobo.

PROF. MEILAENDER: Yes. Let me just make a couple of comments, and you can respond to them or not as you wish. They mainly go toward suggesting that I wouldn't be as optimistic as your presentation couched it. I did want to note, as Rebecca did, that the history of national reflection on these matters did not end in 1983. And we, in that "Taking Care" report, had a somewhat different slant on the usefulness of advance directives, and I think it needs more attention and maybe would undercut the optimism a little bit.

I just wanted to point to a few things. What we've got is a process solution that I think doesn't finely overcome every substantive question, and I just note a few. I think you're way too optimistic that you've got a reading of that Papal allocution that will work. And I'm not a Roman Catholic, but, yes, the exception clause recognizes what I think one should recognize, that there may be moments near the very end of life when there's good reason to withdraw them.

But the kinds of cases that are really under controversy that exception clause is not going to solve at all. So I just don’t see the optimism there. I think that buried deep in this argument and almost impossible to sort out is a distinction between a treatment that is futile and a life that is thought to be futile. And these get blurred together all sorts of times.

You know, you tell me this treatment is futile, but perhaps, in fact, what somebody thinks is that it's just not much of a life worth sustaining. And that constantly needs clarification, I think, and I just don’t know that a process alone — a process of getting an advance directive — solves that.

And then you talked about sort of existential maturity in the face of death and used the phrase "completing the task of dying." I don’t actually think that would be a sign of existential maturity, to think that I should complete the task of dying. I think it would be a sign of maturity to regard it always as an enemy, though it may be one that you finally had to admit had defeated you. There's a rather different attitude toward that.

There's just all sorts of important kinds of philosophical differences buried here that I just don't finely think a process solution is going to solve, and that's why I'd be a little less optimistic.

CHAIRMAN PELLEGRINO: Dr. Landry?

DR. LANDRY: I'd also like to echo thanks for a spectacular review. Professor Meilaender anticipated one of my comments, which is that many of the interventions are never futile. You know, dialysis works. Unless you've exhausted vascular access and the system is clotting very frequently and you really can't get a treatment completed, dialysis will work, and fluid will be removed, solids will be cleared.

The overall condition of the patient, however, will not change, and if death is imminent, that will not be altered. But the term futility is thrown out there, and it, strictly speaking, is not a futile intervention. Maybe the goal is futile, the overall objective is futile.

The other comment I have is the issue of psychiatric illness and depression as coloring the patient's perceptions. My experience caring for — I'm basically a basic scientist, but my clinical outlet is ICU nephrology. And in 20 years' experience, the role of depression coloring patients' desires and perceptions can't be underestimated.

CHAIRMAN PELLEGRINO: Dr. Gómez-Lobo.

PROF. GÓMEZ-LOBO: I really have an information question and perhaps a comment. I'm looking at your slide that has the text of the Congregation for the Doctrine of the Faith. I don't believe that's an encyclical. I think it's called a dubitum. A question was asked, and it was responded.

And my very narrow question is whether a patient in a vegetative state can feel discomfort or whether a patient in that condition can suffer in a way that a different patient would suffer in the case of starvation and dehydration. So that's a very narrow medical question.
The broader question I think coincides to a great extent with Gil’s worries. But my sense would be to talk about futility of a treatment towards a specific medical goal, and then I wouldn’t talk about the futility of the life but perhaps the futility of the whole situation.

There was a recent case in Italy. I think the name of the woman was Eluana, who has been 16 years in persistent vegetative state. And do you see any way of dealing with that question? I know it’s not a narrow medical question, but it is the question that leads the general public to think of the application of modern technology as leading to situations that have, I would say, a coloring of futility in them. What’s the sense of this?

CHAIRMAN PELLEGRINO: ?

PROF. EMANUEL: That’s a tall order, Dr. Pellegrino. They’re all multi-part questions that are, of course, as profound as the qualifications of the people articulating them, so I’ll do my best.

I do absolutely agree that you have picked up on the issues that we’ve dealt with in the report on aging. I took my cue from what I thought was my mandate to address the ’83 report. So my apologies if I misunderstood that.

The point that process will not always overcome a disagreement I think is clearly correct, and I did not mean to sound such a note of optimism that all would be solved and controversies would never come up but rather that many of them now have a very adequate framework for thinking about them, most of them, indeed, and that for the remainder we still have to use due process.

Not everything will be solved, but those things that cannot be solved we do now have a well-articulated due process that if it were well-enshrined in institutions would be the best possible resolution that we can get. So that was my hope for that.

The distinction between whether a treatment is futile, a life is futile, or a situation is futile still seems to me to go backwards into the use of the concept of futile, in a futile way. So although I don’t feel that the whole debate on futility was futile, I think it was very productive. I think it’s moved us forward.

I do think, along with Susan Dorr Goold, that the concept of futility itself does not do adequate work for us, and that we need to take each situation as it presents itself and go for the differential diagnosis of its root causes, prevent as many root causes as we can, manage those that we can’t, and use due process for the remainder.

So whether it’s the treatment that’s futile or the goal that’s futile or the person that’s futile or the situation that’s futile is to me not the right question. The question is why are people using that word, why are they distraught enough to use that word, and what are those sources of depression.

So we could argue about whether or not assisted suicide is ever moral, and I can guarantee that half of us would find it sometimes moral and half of us would find it never moral. But palliative care has chosen not to engage that debate at all but rather to use a nonjudgmental approach to the root causes of someone being distressed enough to ask for assisted suicide. And I found that very helpful.

I have my own views about assisted suicide, but my views were not helpful. Neither were anyone else’s views helpful in the patient/clinician context. And just to illustrate that a little bit more, in one situation where a patient asked for assisted suicide, imagine that I say, ”Yes, I agree with that. I think that’s a good idea.” That patient would probably feel that I just affirmed that patient’s worthlessness, and I would have been way out of my appropriate role.

So what happened if the other way around I say to the patient, ”No, no, I never do that. That’s immoral”? I will have just made that patient feel morally unworthy. So I would have again stepped outside of my appropriate role as a healer.

So in the same sense that assisted suicide is not helped by the moral debate, as important as it may be in its own right, in the public and medical setting it’s not helpful. In the same sense, I would urge on you that trying to figure out whether it’s the person, the goal, situation, or the treatment that’s futile is not helpful for us.

The question is why is anybody involved in that scenario using the term futility. The term futility is a marker for distress because something has been violated. The person has been violated. The values have been violated. Other people have been violated. Resources have been misused in someone’s view. And the question is how to deal with that issue. So that’s my hope for the use of the term futile is that it has seen its day.
The question of depression is always there. The question of the psychological state of the person is always there. And I think that we have to use a similar understanding of that in the non-pathological state that we've used for Dax Cowart and for transitions in personhood. So long as it's not a pathological state, then we consider it a form of thinking that we have to respect. If it's in the pathological state, as our colleagues in psychiatry would describe, we try and side on the side of a person's mentation that is healthy. And we try and treat the depression before we honor the directives. So there's nothing new about that position.

And people that persist in a vegetative state, as far as we know, cannot suffer because they're not sentient, but depending on one's definition of suffering, perhaps there can be controversy on that. But I think by definition if it's a true vegetative state and suffering is understood and here in the individual, then the patient is not capable of suffering. Those around that person are capable of suffering, and that's really what the discussion is about.

CHAIRMAN PELLEGRINO: I think we have reached the point of the break. We want to thank you, very, very much.

[Applause]

CHAIRMAN PELLEGRINO: And we'll revise our schedule and reassemble at 10:45.

SESSION 5: MEDICAL FUTILITY: INSTITUTIONAL AND LEGISLATIVE INITIATIVES

CHAIRMAN PELLEGRINO: Our next speaker on the subject of medical futility, institutional and legislative initiatives is Thaddeus Pope, lawyer and philosopher, J.D., Ph.D., associate professor of law at Widener University Law School. Dr. Pope?

DR. POPE: Good morning. It's quite a privilege to be invited here to address this quite distinguished body and to be among the other quite distinguished speakers. Thank you for inviting me to speak, and it's nice to be back just a few hundred yards where I started the systematic study of ethics, in fact, as a teaching assistant for Prof. Gómez-Lobo.

I cut a few slides out. So on the hard copies that you have, you might have to skip ahead at just a couple of points. I want to proceed in just six steps. I want to first illustrate and define a futility dispute and then, second, identify the causes of futility disputes, and, third, most are resolved through consensus, there is a significant and growing subset of disputes that remain intractable. And the focus of my remarks is on those intractable disputes.

Fourth, in response to the intractable disputes, professional medical associations and individual institutions have developed policies on when providers could refuse treatment, but those policies lacked legal backing.

So fifth, many states passed statutes to give that backing, but those statutes were not well drafted and failed to provide safe harbor protection. So across the United States providers are legally chilled from practicing the medicine that they consider appropriate.

And finally, sixth, the one major exception to that is Texas.

So what's a futility dispute? And this is probably superfluous, but just to frame and orient things, this is a relatively high media profile case from Texas. Emilio Lee Gonzales was born generally healthy, but when he was about one year old Emilio was diagnosed with Leigh’s disease, a neuron metabolic disorder that affects the nervous system.

In December 2006 Emilio was admitted to the PICU at Children's Hospital of Austin, where his neurological status continued to worsen as his brain atrophied. He was dependent upon a mechanical ventilator, nasojejunal tube. He was semicomatose. He could not empty his bladder. He was having frequent seizures, and providers had great difficulty keeping his lungs inflated.

Emilio’s health care providers determined that his condition was irreversible and that the continued treatment “would only serve to prolong his suffering without the possibility of cure.” They felt that “the burdens associated with his current care plan outweigh any benefit Emilio might have been receiving” and that “his aggressive treatment plan amounted to a nearly constant assault on Emilio’s fundamental human dignity.” But Emilio’s mother, Catarina, refused to consent to the withdrawal of life-sustaining treatment. She insisted that Emilio’s provider sustain him until Jesus takes him. During the winter of 2007 the care team and Catarina had multiple conferences to discuss his condition and his treatment plan, but they could not reach any consensus.
This is a futility dispute where the patient, whether herself or, more often, through an advance directive or through some form of substitute decision maker, wants to continue aggressive life-sustaining medical treatment. But the provider, on the other hand, thinks that that is inappropriate and does not want to give it. Now, that model presumes a certain unity among surrogates and a certain unity among providers. And, of course, certainly two daughters may disagree or two physicians may disagree, but the paradigm futility dispute is between the surrogate on the one hand and the provider on the other hand, and that's what I'm going to focus on.

I'm not going to address macro issues about how Medicare should make coverage determinations. I'll leave that to the Congressional Budget Office and ARC. In last month's archives, a surgery survey showed that 44.3 percent of physicians of professionals — thought that patients have the right to demand care that their doctors think will not help. Many argue that that figure — 44 percent — is too high and that more physicians should cancel their subscription to the technological imperative.

I'm not focusing — let's go back to the same survey. I'm not focusing on whether physicians give too much inappropriate care. I'm focusing on the spread here. There are many more patients and surrogates who think that they have a right to demand inappropriate care than there are physicians who think that they have that right. And just another question from the same survey. Even where doctors believe there is not hope of recovery, 21 percent of people think that all efforts should continue indefinitely.

So to understand the causes of conflict we have to look at both the reasons surrogates insist on continued life-sustaining treatment and the reason that providers resist those demands. Religion is a big one. In many intractable disputes, including some of the most famous — Baby K and Emilio Gonzales — surrogates request continued treatment because it's called for in their religious or cultural tradition. Only God can give and take life. Another survey showed that a lot of people, 60 percent, believe in miracles, believe in divine intervention.

In addition to religion, in this study in *Critical Care Medicine* nearly 90 percent of participants expressed doubt in physicians' ability to prognosticate. With greater access to the information — on the Internet, for example — people have a greater awareness of uncertainty in medicine, and they're more confident in opposing health care providers. There's a substantial body of evidence that shows African Americans are more likely to request unconditional prolongation of life-sustaining medical treatment, less likely to agree with the health care recommendation to stop.

And today, where the incentives of managed care are well known, even non-minorities are distrustful. Grief, guilt, family dynamics, some of the other reasons that Prof. Emanuel had referred to. And it's easy for surrogates to act on all these reasons because the costs of their decisions are externalized largely to the payers and to the nursing staff.

Now, conflict requires two parties, so here it's not just that surrogates are more likely to insist on continued treatment, but it's also increasingly likely that providers will resist. And a key reason is they want to prevent a patient's suffering. They want to and Prof. Curlin really got into this yesterday — they want to preserve the integrity of the medical profession. They also want to prevent moral distress. Providing futile care is the highest and most significant source of moral distress among nurses. Providers want to be good stewards of health care resources.

And finally, providers want to honor patient wishes. Most futility disputes are between a provider and a surrogate, not the patient him or herself. But surrogates are often wrong about what patients would want. Therefore, to resist the surrogate's decision may actually promote, not thwart, the patient's preferences and the patient's interests. So that's the causes.

Now, the good news is that most futility disputes are resolved informally through good communication and mediation. Consensus is reached more than 90 percent of the time, but there's this core subset of disputes that remain intractable. In this study [referencing slide] four percent, two percent, seven percent, two percent. Now this range, this rate of intractability, will probably decrease, will probably shrink with better end-of-life communication, but it won't be eliminated. So there's always this range even though we can achieve consensus most of the time, there's always this subset of intractable disputes.

So professional medical associations and individual institutions developed policies to address how to resolve the intractable disputes. And there's a whole bunch of them, but obviously for the sake of time I have to focus on just one, and I'll focus, as Prof. Emanuel, on the AMA's. A little over ten years ago the AMA recommended that all health care facilities adopt a futility policy, and it promulgated for them a model policy, a seven-step approach. The first five of seven steps were all directed at what lawyers refer to as internal dispute resolution, trying to resolve things informally and internally...
using deliberation, negotiation, communication. And if the care team can’t do it themselves, then in Step 3 you bring in the assistance of consultants, bioethics mediators, social workers. If that doesn’t work, even Step 4: use the ethics committee.

But in the intractable disputes, none of the first four steps work, and so you go to Step 6: try to transfer the patient to another institution that is willing to provide the requested treatment. If you can’t find a willing provider — and you usually cannot, so this is a big contrast to the discussion yesterday in the contraceptive situation where you can usually find somebody else; here, you usually can’t make a transfer. Then, the AMA writes, the intervention need not be offered. So for these two percent, four percent, seven percent of intractable cases that can’t be resolved with internal mechanisms, the AMA says the provider can just refuse.

But — the very next line — the AMA writes that legal ramifications of this course of action are uncertain. And indeed, by the 1990s many damages had been paid in cases that had been litigated. Now, based on the outcomes of several particularly well-publicized cases and a big pile of medical journal articles, commentators conclude that the courts have almost universally sided with the family and against health care providers. In fact, when you look at the body of litigated cases, providers have won the overwhelming majority of litigated futility cases. But the salience of the reported cases combined with misinformation created a perception of broad liability exposure. Plus, providers aren’t just liability averse; they’re litigation averse.

This perceived legal risk had a material impact on provider behavior. In 1996 a group of researchers at St. Louis University — “SLU,” as they refer to it — surveyed 2,000 large hospitals in the United States. Of 537 respondents, only 29 had futility policies. Moreover, most of these 29 envisioned primarily a consensus-building approach. So almost none included the AMA’s seventh step.

So providers give in. They don’t want to, but they do. In 1976, providers were reluctant to withdraw life-sustaining treatment with consent, with the authorized consent, because they didn’t have clear legal authorization. Today they’re reluctant to withdraw treatment without consent because they lack clear legal authorization for that.

So by the early 1990s protection was on its way, the legal protection that they wanted. Many states enacted statutory safe harbors, which basically — and this is pretty accurate. They basically tell the provider, “Look, if the surrogate is asking you to do something — aggressive life-sustaining treatment that you feel is inappropriate professionally — you don’t have to do it. If you can’t transfer the patient, you may unilaterally stop, and you have civil, criminal, and disciplinary immunity from doing so.”

At least ten states have very similar statutes because they adopted their statutes all based off the Uniform Health Care Decisions Act. And that act — this is New Mexico, which I’m using because I was just there, which basically — and this is true of most state laws, not just the uniform health care — that basically say the general rule is you, the provider, you should comply with decisions made by the patient or made on the patient’s behalf. But there’s an exception: except as provided in Sections E and F. So in F — I’ll just read it. “A health care provider or health care institution may decline to comply with an individual instruction or health care decision that requires medically ineffective health care or health care contrary to generally accepted health care standards.”

And, importantly, if you’re going to use that exception, you’re not subject to civil or criminal liability or to discipline for unprofessional conduct. So it seems to be just what providers were looking for. But the safe harbors proved to be illusory. They have for the most part failed. Providers continue to accede to surrogate demands. They are chilled from doing what they want to do. Health care providers are very litigation averse, so in order to work, safe harbors have to be clear and precise so providers know what they need to do to be protected.

The safe harbors here, in contrast to, for example, peer-review safe harbors, are neither clear nor precise. The key language here is quite vague. What is a “generally accepted health care standard”? What is a “significant benefit”? Worse, this language basically folds into a malpractice standard, which means providers need not give care that is outside the standard of care. But since the care is provided and has been provided, providers are continuing to create the very standard of care from which they want to escape.

Vagueness means uncertainty, and uncertainty means no futility policies are written. And if they are written they’re not used up to the point of the seventh step. Now, we can’t fault the state legislatures too much because this vagueness — and we heard this earlier from Prof. Emanuel — the vagueness was unavoidable. We can’t agree. We have no consensus on what the standards of medical inappropriateness are. Maybe with these tiny exceptions — a brain death, although that may be
collapsing as we speak, anencephaly and physiological futility. But even there, even with brain death, for example, we continue to have litigation, or threaten litigation, to keep dead patients on life support.

We can't agree on a quantitative standard, and we can't agree on a qualitative standard. And as we heard yesterday, we basically cannot agree on the very goals and ends of medicine itself. Is the mere prolongation of corporeal existence a goal of medicine? Therefore, we've basically arrived at the point where we've determined that futility must be identified as Justice Potter Stewart identifies pornography: “I know it when I see it.”

So in the intractable cases, providers cave in. Right? And do what the surrogate wants. And this may seem like a small circle, and maybe we should say, “Well, it's such a small circle. What's the harm?” Well, it's growing. Surrogates are increasingly likely to make demands that their providers determine are inappropriate. When we ask people, “Should we do everything to save a life?” fifteen percent said yes in 1990; 22 percent in 2005. Same thing from other studies. People are more likely to demand inappropriate care. Plus there are more and more elderly patients, and there's more and more technology available to sustain them. And again at the same time, on the other side of the equation again, providers are increasingly likely to resist these demands. They're more willing to stand up for what they believe is professionally appropriate.

So more surrogate insistence combined with more provider resistance leads to more intractability. So that's the general situation in the United States. And what I want to do is just note two exceptions to this general cave-in rule, and then I want to finish by describing how things work in Texas.

First exception is that if the provider thinks that the surrogate's request is inappropriate — really inappropriate — then maybe that person shouldn't be the surrogate. Now, famously in the Wanglie case, which was mentioned earlier, the patient's proxy would not consent to stopping life-sustaining medical treatment, which was the recommendation of Hennepin County Medical Center. So the providers petitioned the local probate court to appoint a professional conservator to make decisions on behalf of the patient instead of the person who was. But the probate court denied. Right? Because the current decision maker was the husband of 53 years and the probate court said, “He's a fine decision maker. I'm not going to replace him.”

But more recently courts have been more willing to replace surrogates. In one Boston case the court replaced — and there's a lot of Boston cases. The court replaced an agent because he was in denial about the deterioration in his mother. He did not give full consideration to acceptable medical alternatives.

And just a few weeks ago, a New York court replaced a daughter who was the — not only was she the daughter, but she was appointed in the advance directive as the agent — replaced her because she failed to appreciate her mother's true medical needs and lacked the objectivity to make the necessary decisions. So that's — if you don't like what the surrogate is asking you to do, find a new surrogate.

Second exception to the sort of general cave-in rule in the United States is that because providers perceive little legal authorization to resist surrogates openly, many do so clandestinely. Surveys indicate that many withhold or withdraw life-sustaining medical treatment without the knowledge of the patient or surrogate. And so this is a lot like the early 1980s where we had — the New York cases where we had the purple dots, where we indicated who was going to be DNR status. We didn't have DNR orders but that's the way we did it, and then take the purple dot off afterwards. And, of course, these things still persist even today: show codes, slow codes, Hollywood codes — secret, masked withdrawal and refusal of inappropriate treatment. Obviously very dangerous, but it's certainly happening.

Now obviously I'm painting with a really broad brush. I'm describing 49 different states altogether in one fell swoop, but the differences between and among those 49 states and DC pale in comparison to any of those in Texas. Texas providers recognized the vagueness problems in other states' safe harbors, so they abandoned any effort to define the circumstances under which treatment could be refused. Instead they defined a safe harbor — defined and earned solely by the satisfaction of procedures.

Texas's act, the Texas Advance Directives Act, grants total and complete deference to the treating physician as long as the physician's recommendation is confirmed by an ethics committee. The surrogate is given 48 hours' notice of the ethics committee. The surrogate is given the committee's written decision, and the surrogate is given ten days to try to transfer the patient to another facility, assuming the ethics committee has decided that that facility is not going to give the treatment. Now, there's a section, 166.046, that defines those procedures that must be satisfied. And in the
immediate prior section, 166.045 says if you use 166.046 you are not civilly, criminally liable or subject to review or disciplinary action. There’s no substantive standards. It says all you have to is comply with the procedures and you’re safe.

So in contrast to the approach in all the other states, the Texas act makes no reference to health care standards, only to procedures: 48 hours, meeting, decision, ten days. Right? These are concrete. They are measurable. Providers know when they’ve earned safe harbor protection. So let me just quickly illustrate this in operation, as used in the Gonzales case. So there’s Emilio Gonzales. They had — the treatment team thinks it’s causing suffering and there’s all these patient care conferences, but the mother remains adamant. So the hospital invokes step one of the formal process. They give Catarina this letter telling her there’s going to be an ethics committee meeting. The ethics committee has its meeting. Catarina attends. The committee decides to support the physician. It agreed that the suffering outweighed any benefit. The result of the ethics committee is usually agreement with the physician.

The decision of the ethics committee is memorialized into a written decision. That’s handed to Catarina. And at this point, upon the service of the ethics committee decision, Catarina — the ten-day clock starts to run. So she has ten days to look for a transfer, some place that’s willing to give the treatment that Children’s Hospital of Austin is unwilling to give.

Usually the ten days comes and goes and families are unable to find a transfer facility. When that happens, on the eleventh day the treating facility can withdraw the life-sustaining treatment, and there’s no other recourse for the surrogate. The Health Care Ethics Committee decision is final. You cannot go to court to question the ethics committee. The Texas mechanism has been involved thousands of times, often even in the face of intense negative press coverage.

The Texas statute is perceived as a success by the provider communities. Studies show that the Texas statute improves the rate of the informal resolution, the first five steps of the AMA process. Intractable disputes, when they are intractable, they get decided in favor of providers. And the health care ethics committees don’t always — it’s not a hundred percent. It’s more like 80 to 90 percent. They don’t always agree with the providers, so it looks like they are weeding out. The cases we’re stopping is now truly inappropriate. For these reasons it’s perceived as a success, and other states — including other countries — are looking to Texas as copying its statute.

Now, I just want to say a couple of things about Texas. This has all been descriptive, but this is a little bit of tiny normative point right at the end. Where you have fundamental and irreconcilable values the best you can hope for is process, but if process is all you have it has to be fair both for public trust but also it affects the very validity of the law.

In its current form, it’s extremely unlikely the Texas statute will last another six months. First, it doesn’t comport with the requirements of Constitutional procedural due process. Forty-eight hours’ notice for the final life-and-death decision is too short, and the ethics committee is not sufficiently neutral. Apart from judicial challenges, it’s likely that the legislation will either be amended or repealed in the last regular session of the Texas legislature in 2009. It almost happened in 2007, where they were at least going to make these changes.

A process-based approach may be the way to go, but we have to attend to procedural fairness. They’ve been around for 30 years, but health care ethics committees are not ready. They don’t have the competence, they don’t have the neutrality to exercise the sort of decision-making authority that the Texas statute has given them.

Thanks.

CHAIRMAN PELLEGRINO: Thank you very much, Dr. Pope. Prof. Peter Lawler has consented to open the discussion.

PROF. LAWLER: Thanks so much for a fabulous presentation. I learned a lot. I’m not a physician. I’m a mere political scientist. So — still a doctor, though. And there is a principle of political science here that you’re calling attention to, and that is procedure can simply be a way of resolving a fundamental dispute when it comes to substance. When fundamental values disagree, it’s still possible to have a process-based resolution. But in political science we say there are really definite limits to that. There can be some disagreement but not too much. So the Americans disagree on a lot of things, but the Americans have to agree on limiting government, freedom of religion, and all these things. So there has to be a whole lot of substantive agreement before you can turn it to process.

Too much substantive agreement can’t be solved by process alone. And you’ve been telling us, as a lot of the other speakers we have had have been telling us, the medical profession is plagued by a lack of
consensus and, in fact, an increasing lack of consensus. At the end of your fine article you say we don't have any consensus on the proper ends of medicine. And we heard yesterday this is getting worse. We no longer know what health is, and we're no longer even sure health is in the area of enhancement and catering to the patient's needs and so forth.

We no longer even know whether health, strictly speaking, is the end of medicine. So, A, we don't know what health is, and if we did know what health is we wouldn't be so sure health is the end of medicine. And your second point is we may have to ration medical care. We already are in some ways. But we have no consensus on the acceptable criteria for rationing. So can process really resolve that?

And we somehow know there should be legitimate restrictions, number three, on patient autonomy, and providers really want there to be restrictions on patient autonomy because, to speak plainly, sometimes providers think that patients are nuts, causing cruel and unusual suffering for no good reason. But we have no clear criteria for those limitations.

And not only that, you told us the situation is getting worse. The patients are getting more insistent that everything be done. The providers are getting more resistant. So you have kind of a culture war between patients and providers. And then you have this very word *futility*. We have no idea what that means, so we have this futile quest to define *futility*. Gil Meilaender said in the last session it's very questionable what *futility* means in this sense. Someone might says this: “It's never futile to sustain human life. In fact, it's a sign of emotional maturity to get over your personal suffering, your personal squeamishness, and go ahead to affirm the infinite value of the life before you by sustaining it.” But others would say it's very immature to sustain life that ain't never going to come back, that's always going to be unconscious. But then Gil might respond, “Futile becomes a little blurry the more you think about that because it might come back a little, or there might be a small chance it will come back.”

So with all this in mind and even real, radical disagreements about what existential maturity means and what cultural growth means, because you say even in your article that this consensus is not imminently forthcoming. That may be deep irony. Or you may agree with the presentation this morning that as cultural growth really starts to kick in these consensuses we're looking for will forth come. But I doubt it. I tend to think that the situation — as medicine gets more powerful, as Leon Kass well said, the purposes of medicine are going to get more blurry, as we've seen so many examples of the last day or two.

So I'm little bit doubtful that process can simply resolve all this, and *process* seems to me to mean, in the final analysis the physician in 80 or 90 percent of the cases backed up by the ethics committee, his view of futility or her view of futility and appropriateness is what triumphs. I forgot this was *Jeopardy*. I haven't put this in the form of a question, but let me just say a little bit more to show me that process can really overcome this problem of not only incompatible values, but values get more incompatible all the time.

**CHAIRMAN PELLEGRINO:** Thank you, Peter. Dr. Pope responds, and then we'll return to the Council for further comment.

**DR. POPE:** I'm not sure that I agree that there's a limit to what process — I mean, I'd be real interested to see that literature that suggests that when substantive agreement reaches a critical point that process —

**PROF. LAWLER:** For example, there are limits to toleration. You can't tolerate people who don't accept your fundamental principles. So Democrats and Republicans can have process-based solutions. Democrats, Republicans, communists, and fascists, and throne and altar monarchists, there probably can't be a process-based resolution to all their differences.

**DR. POPE:** Maybe we're not on the same page, because maybe when you say “process-based,” the object of the process — maybe what you're thinking is consensus, while the outcome of the process here is certainly not consensus. It's like the court system. It's process-based. We don't have ex ante standards that tell us the answers to lots of different sorts of disputes, but we're reasonably happy with the process.

And so I guess I think that a process-based approach is inevitable. The real question is really what the form of the process is. Are we going to create — are we going to empower ethics committees, or are we going to retreat from where we went to in the 1970s and send end-of-life disputes to the courts? We didn't think that was a good idea because we thought courts don't have the competence. They're too slow or they're too expensive. But maybe we trust courts. That's a process-based dispute
But I agree that given a lot of the points that you mentioned that it doesn’t look real promising. In fact, for that reason it looks like this discussion about how providers and patients should resolve these sorts of disputes will probably in a temporal context be overtaken by the payers. In other words, since we are so slow — and you’re right that the disputes are so intractable and growing in their ferocity that it’s going to take us time to work that out. In the meantime, when Medicare starts to consume 90 to 100 percent of the entire federal budget, decisions will be made. So things may just end up being resolved that way.

CHAIRMAN PELLEGRINO: Thank you very much, Dr. Pope. Dr. Meilaender?

DR. MEILAENDER: I’d like to make — these aren’t really questions. They're two comments, and they may seem perverse. You may make of them what you will. But I start by saying that I don’t actually for a moment think — it’s not that I think doctors must do whatever patients want. I don’t think that at all. But I just want to note a couple of things that are puzzling to me.

You described — I don’t have the exact thing, but I scrawled it down. When you were describing the notion of a safe harbor, it was that I’m asking you to do something that you think is inappropriate professionally. You don’t have to do it, and we provide you with a safe harbor that protects you in that decision.

The strange thing to me — and I don’t quite know what’s going on — is that in our discussion yesterday about a different set of issues in reproductive medicine, the pressure seemed to be that if I ask you to do something that you think is inappropriate you should do it anyway. And now in the end-of-life decisions the pressure seems to be that when I ask you to do something you think is inappropriate you don’t have to do it.

Now maybe there’s an explanation to work that all out, but I think there’s more going on here than has come to the surface and that there are, in fact, buried judgments about moral positions that are at stake that aren’t going to be sorted out simply through an appealed process. That’s my hunch. And I just noticed the kind of puzzling phenomenon of putting yesterday afternoon and this morning back-to-back.

Then the other thing that puzzles me is that when advance directives first came on the scene after perhaps an initial period in which physicians weren’t too positive toward them, they gradually became much more positive, I think, and the working assumption was that patients would use them to refuse treatments. Now all of a sudden, when we have by your data an increasing number of patients or surrogates using them to ask for continued treatment, they’re not so good anymore. But a process solution — the advance directive was a process solution from the perspective of the patient, and I don’t think it’s worked that well. Why should we assume that a process solution that kind of immunizes the physicians is going to work well?

Years ago in the early years of thinking about advance directives, Robert Burt wrote a book called *Taking Care of Strangers*, and the title had a double entendre in it. It was about patients whose condition makes us uneasy, and you say, “I’ll take care of them.” And that can mean several different things. And one thing it can mean is “I’ll see to it that they go away.”

Burt’s claim was that what one needed was to force conversation. And I realize that it can go on a long time; it can seem impossible. But these are all attempts, whether from the standpoint of the patient or now from the standpoint of physicians, all attempts to end conversation. And I don’t know whether that’s the best way to deal with these problems. Neither of those comment exactly, but they’re just matters that seem puzzling to me, and I’d welcome anything you want to say about it.

DR. POPE: I think there’s a big difference between advance directives and calling that a process-based approach and calling this a process-based approach, because this is a process-based approach to conflict resolution. Advance directives may be a process-based approach, but it had nothing to do with conflict resolution. I mean, we always agreed on the goal, which is we want to do — or we will do (is it a matter of public policy?) — what the patient wants. And so advance directives were just a vehicle for us to understand what it is the patient would have wanted had she not lost capacity.

DR. MEILAENDER: I don’t think so. It was a way of getting an over-bearing medical profession off of patients’ backs. I mean, that's conflict.

DR. POPE: I guess my view of advance directives was that they came after the concept of informed consent. So we already have the principles. Advance directives were merely a vehicle for getting at it. It’s an evidentiary vehicle but not really changing the principles. But one thing to note is, even in
Texas the main defenders are very — it's not built into the statute, and it should be. But the main defenders ascribe to the AMA process, because that's where they got the statute from, and the statute in turn came from Texas. So it's a big loop. But they follow the first five steps of the AMA process, so it's not that we're jumping straight to the ethics committee invoking this formal dispute resolution.

There's a great deal, sometimes weeks or months of patient conferences, lots of communication, lots of mediation before the formal process even begins. So we're not preempting communication.

CHAIRMAN PELLEGRINO: Thank you. I am going to take the same approach I took with the last speaker since we have a time bind. We have three council members — Prof. Dresser, Eberstadt, and Gómez-Lobo — so, Dr. Pope, would you mind if we have them make their comment and you respond? First we'll ask Dr. Dresser.

PROF. DRESSER: Thank you. You have a great overview and really, I think, educated us on this. A couple of points. One is this Texas bill. It's interesting, to amend the statute. It's sort of — the idea of a process-based approach in the hospital is to avoid going to court, but in order to be acceptable as a process-based solution it has to get more like a court in that notice and five or more helpers. Is that really in the statute, five or more helpers — or the bill?

DR. POPE: The word may not have been “helper,” but it is sort of like the advocate. In other words, it doesn't need to be counsel. It could be a rabbi or anybody.

PROF. DRESSER: I see. I just wondered if you have any thoughts about what procedural protections are needed. If you were writing the bill, what would you put in there? And then secondly, just to observe that there is this overlap between conscientious objection and futility where the issue is whose view should prevail, the physician's or the patient or the patient's surrogate?

So yesterday we were talking about — some people were saying, well, the doctor's view should prevail, especially in reproductive decisions. And I think that view is influenced by a substantive view that — you know, a pro-life approach. And then today with futility we have a struggle, and the pro-life approach is against letting the doctor decide; it's going with the patient.

And so I just want to mark that. I'm not sure where to go with that, but I think certainly if we do a report on both of these issues we ought to point to the commonality and the differences and whether our views on who gets to decide are influenced by our substantive views on the particular issue they're arguing about.

CHAIRMAN PELLEGRINO: Thank you, Dr. Dresser. Dr. Eberstadt?

DR. EBERSTADT: First I want to commend you for that very informative and comprehensive presentation. I thought that was very useful. I wanted to make an observation to which you may or may not choose to respond. It's an observation about medical contraindication of food and water, which takes a theme from the previous section and which also comes up in your presentation.

In one of the slides you presented at the slide that says “Step 3: Hospital Ethics Committee Decision,” the recommendation is outlined here: “Treatment plan for the patient be modified to allow only comfort measures such as hydration, pain control, and other interventions designed to decrease the patient’s suffering.” It looks to me like a striking oversight that food isn’t mentioned in there, that hydration is mentioned but not food. If it is not an oversight, it seems to me to be even more troubling.

I am not a medical professional. I am a consumer of medical services, but I don’t regard food and water as medical services. There are an enormous number of life-extending measures that have been developed by humanity's ingenuity over the past generations — antibiotics, dialysis, heart and lung machines, other sorts of life-support systems — but food and water existed before human ingenuity in medicine came in to open these sorts of options for the prolongation of life.

It looks to me as if we have a paradox confronting us today with this consideration of medical contraindication of food and water, and the paradox seems to me to be this: for convicted criminals in our penal system in the United States, the idea of sentencing someone to death by starvation or by dehydration would be absolutely inconceivable, yet that possibility is not entirely remote for people in certain sorts of medical extremes. I suggest that there ought to be a sort of an ethical line in the sand regarding food and water for patients in distress.

Thank you.

CHAIRMAN PELLEGRINO: Thank you. Prof. Gómez-Lobo?
PROF. GÓMEZ-LOBO: I’m looking at your article in the Tennessee Law Review. It’s really very clear. You gave a very clear presentation of these mirror-image situations where the patients or the proxies of the patient want to continue treatment; the physicians think it’s futile. On the other hand, we have the physicians wanting to carry on and maybe the patients wanting to let the person die. Now, both situations for me are very troublesome, of course, and they lead me to try to understand the force of technology and of medical technology, above all, sort of driving our culture at this very moment.

The question is a very simple one. Of those two situations, which is the most common one? The reason why I ask is because I think the popular perception is that there is more of the situation in which the technologist insists on using the technology, and it’s the lay persons who want to resist that. I’ve been relatively close to two cases like that. So just an approximate sense that you might have of what’s the more frequent situation.

CHAIRMAN PELLEGRINO: Dr. Pope?

DR._POPE: With respect to Prof. Dresser’s comment about how to fix the ethics committee without basically converting it into a court, first I think that completely apart from the futility dispute, they need to be significantly strengthened, as do IRBs in terms of their training and their competence, their composition, and their methods. But we have models. We certainly have models to make them more fair without making them into courts. Right? We have peer review in hospitals, which works perfectly fine. We allow judicial review but we only allow the courts to peek in. So we can sort of have our cake and eat it too, which is what we can say to the critical care intensivists, who are typically the ones who bring these cases to the ethics committee — the ethics committee is basically the last word. We will allow some judicial review, but that need not chill you because they are only going to check a tiny bit to make sure the proper procedures were followed.

Same thing in the business context, right? We have the business judgment rule. If you are suing the directors of your corporation because you — for example, Disney because you think they shouldn’t have paid Michael Ovitz this incredibly large golden parachute — “That should have been my dividend, not his paycheck.” — again we defer. The courts won’t take that because they will say that was a business decision; that was for the board of Disney to decide, not for me to judge. They will peek into the decision but only to make sure: “Did you bring in the investment advisors? Did you bring in the economists? Did you have a basis? Did you deliberate and have some information to make the decisions?” I think there are models to look to to strengthen the ethics committee without basically converting it into a court.

For Prof. Eberstadt, I don't understand sufficiently the medicine to understand when artificial hydration is medically contraindicated. But your analogy with the convicted prisoners, I don't think that's terribly informative because the difference, of course, here is that with the advance directives these are people who wanted this. They consented to being dehydrated. And so I don't think that there's a big difference when you consent to it and when you don't consent to it. I guess what you're now judging is the prisoner and the person you subject to this Texas mechanism so that they are both involuntarily being deprived, except again the difference is that there has been a great deal of multi — assuming a good ethics committee, lots of medical expertise and lots of multidisciplinary input that this is in their best interests, while if we did do that it would violate the Eighth Amendment if we did it in a prison context. But if we did do that for prisoners, that determination would never have been made. That wouldn't have been part of the conviction process.

I think the difficulty in answering Prof. Gómez-Lobo's question is that you may be right that there may be — the bigger problem out there may be the aggressive doctor, not the aggressive surrogate. The problem is, to get data on that is very difficult because the aggressive doctor is going to get consent. So you don’t have conflicts that are crystallized so that you can identify them. So if your oncologist says, “Look, we've had three rounds to achieve remission. Let's try a fourth round.” I mean, hardly any oncologist would probably do that, but then the patient says okay. So if you convince using — you pitch that to the patient, framing it in a way that's going to solicit an affirmative answer, you have a consensual situation, so you don’t have any conflict.

So the problem is, I think there probably may be more futility conflicts than the classic right-to-die conflicts in today’s world because we have such a good structure with our health clinician’s laws, POLST, MOLST, and so forth that we understand that if the patient wants to stop they get a right to stop. And so when the physician is pushing, they get consent. So you don’t actually have a conflict. We don’t have numbers to compare there.

CHAIRMAN PELLEGRINO: Thank you very much, Dr. Pope. Are there any more comments? We have just a few moments left. If not, we’ll move directly to the public testimony session.
CHAIRMAN PELLEGRINO: In this part of the meeting, we proceed as follows. Each of you has registered, and only those registered will be called upon to comment. Because of time limitations, we customarily allow five minutes. I will call you your name and your affiliation and suggest, I hope, with apology, that brevity, focus, and clarity is the best way to get your message across. It will get into the record and will be available. Without further ado, we ask you to try to – not only try to but to keep the five-minute limit. First I will call on Gretchen Borchelt – forgive me if I've mispronounced the name – of the National Women's Law Center.

MS. BORCHELT: Thank you, and I will try to keep to five minutes, as requested. My name is Gretchen Borchelt, and I am a senior counsel with the National Women's Law Center here in Washington, DC. The center has been in existence since 1972, working to improve the lives of women and girls in this country. We're a nonpartisan, nonprofit organization.

A major focus of our work has been the issue of religious refusals to provide health care services. And our main goal is to ensure that religious restrictions on health care are not imposed to the detriment of women's health. And I did provide written comments which focus on the impact of religious restrictions on health care services for all patients, and in particular the impact on women's reproductive health.

But I was wanting to speak today about something else that is in my written comments, which is the legal landscape. I think it's particularly relevant given yesterday's discussion. We heard a lot of talk yesterday about the issue of accommodation and whether religious beliefs and patient's needs could be accommodated. And I think we could look to the law and find an answer there, which is that Title VII, which is the federal law that prohibits employment discrimination on the basis of religion, has been in existence. It's part of the Civil Rights Act of 1964. And what is says is that employers cannot refuse to hire or cannot fire employees based on their religious beliefs or practices. It also says employers cannot discriminate or treat employees in an unfavorable manner in the terms of employment, such as assignments and benefits, because of the employee's religious beliefs.

And so courts that have interpreted Title VII have said that an employer has a duty to provide a reasonable accommodation to employees who have religious beliefs as long as that accommodation does not constitute an undue hardship on the employer's business. So courts have said — it's very clear that Title VII is a working accommodation system that provides a careful balance between an employer's need to protect an employee's religious beliefs and the needs of the people that the employer serves.

And I would say that this accommodation system does work, and we heard yesterday from Dr. Brody, who said that in the Michigan legislature, when they were considering a very broad refusal bill, none of the legislators could actually come up with an example of someone who had been fired or discriminated against or forced to perform a service that he or she didn't believe in. And I believe that's because Title VII is working, and in the employment context you are seeing accommodations being made. So I would urge the Council to, when you're thinking about an accommodation system, to look at Title VII and how it's been used in the health care field, because it actually has been. There have been many cases about health care providers' religious rights to refuse and how the patient needs to be accommodated.

The other thing that I would like to mention today briefly is the proposed regulation that the Department of Health and Human Services put out last month, which I know is included in your briefing materials. And I would just say the proposed rule, according to HHS, is meant to inform providers about their legal obligations under three laws. And you heard about the laws yesterday. They're also in your background materials. They're the Church Amendment, the Coats Amendment, and the Weldon Amendment, and they give providers the right to refuse to provide abortion or sterilization services.

Now HHS says that the intent of this regulation is to clarify existing law, but in fact it would do just the opposite. The language is very expansive and very ambiguous, and in fact it would cause confusion for health care providers, for state and local governments, and for research institutions. And one of the problems is that the proposed rule doesn't include a definition of abortion, and it leaves the door open for insurance plans and hospitals and other entities to define abortion in any way they choose, and that could reach common forms of birth control.

Another problem with the proposed rule is that it doesn't talk about how it interacts with Title VII. It
seems that it could even be meant to upset the kind of careful accommodation system that Title VII has put into place and which is working. And so it’s very disturbing that Title VII isn’t even mentioned in this rule at all, which, again, will lead to confusion in terms of how the system is already working.

The proposed rule also undermines patients’ access to information, to counseling and to referrals, and it also says nothing about protecting patients in emergency situations. And I know those were all situations that were discussed yesterday.

And then finally, I should mention, just as troubling as that, the rule would expand the realm of who can refuse and on what circumstances. So Dr. Paris yesterday questioned how far the Church Amendment could go, and he wondered whether it should apply to, for example, staff stocking pharmacy shelves or staff who administer claims in the office. And this proposed rule would reach all of those types of employees and many more.

So we are very troubled by this proposed rule, and I urge the Council to consider it carefully and to make its views known to HHS in terms of how far-reaching and unnecessary this proposed regulation is.

Thank you very much.

CHAIRMAN PELLEGRINO: Thank you very much. Next on our list is –

 PROF. ROWLEY: Can I ask a question? Did you say that you have a fuller statement that’s been submitted to the Council?

 MS. BORCHELT: Yes.

 PROF. ROWLEY: And I guess the question is, do we have it in our briefing books?

 DR. DAVIS: It will be appended to the transcripts. We have a number of them, and they’ve been coming in in series. We couldn’t get all in the briefing books. So what we’re going to do is append them to the transcript. They’ll be part of the official record. They’ll be available to you as well as the public.

 PROF. ROWLEY: Thank you.

CHAIRMAN PELLEGRINO: Next on our list is Lois Uttley. I’m sorry – again, I apologize if I’m wrong – of the Merger Watch Project.

 MS. UTTLEY: Yes. It’s Uttley. Lois Uttley. Thank you very much, Chairman Pellegrino. I’m the director of a project called Merger Watch, and the project is about protecting patients’ rights and access to care in situations where religiously sponsored hospitals are merging with nonsectarian hospitals, and helping to devise ways of balancing these conflicting rights and obligations.

I’ve come this morning to talk mostly about the discussion you had yesterday about provider conscience and reproductive care, but I do second the comments of Dr. Dresser about how there are some interesting implications for end of life care as well in which providers may not wish to honor patients’ wishes.

My written testimony, which I submitted, uses a case example to take you through the situation of a rape victim who goes to the emergency room and is not provided with even information about emergency contraception. I cannot go through that whole case this morning in my brief opportunity, but I recommend that you take a look at it.

I just want to hit a couple of key points, though. As your council discusses the issue of provider conscience, I really urge you to consider another imperative to protect the rights of patients to receive accurate medical information in need of treatment in a timely manner and to use their own ethical beliefs in medical decision making.

I was quite struck yesterday with a discussion about patient-centered care, which I had assumed was something that most of us agreed with and is an aspiration of the profession, but there was some suggestion yesterday that perhaps it would lead to the subjugation of a physician’s clinical judgment to the uninformed demands of a patient or turn the physician into a mere technician filling consumer demands.

I think you might all agree that the Institute of Medicine definition of patient-centered care is more appropriate: health care that establishes a partnership among practitioners, patients, and families to
ensure that physicians respect patients’ wants, needs, and preferences.

So I want briefly to comment also on the health and human services regulations that have been issues that are in your packet. Secretary Levitt has insisted that he proposed regulation would not in any way change a patient’s right to a legal procedure, would not limit patient access to care. And I think you’ll see from the analysis I’ve presented of the rape victim case that that really is not the case. In fact, those regulations would allow health care practitioners and health care institutions to violate a patients’ right to informed consent by refusing to tell the patient about those potential treatment options that the provider finds objectionable, would allow health practitioners to refuse to provide patients with any medical services or information the provider finds morally objectionable even for reasons that are completely contrary to medical science or based on discriminatory views.

Further, it would allow the health practitioner to refuse to even provide the patient with a referral to another practitioner. It would obligate nearly 600,000 health care institutions to certify that they do not discriminate against practitioners with moral objections to certain services but with no similar obligation to certify that patients’ medical needs will also be met.

So I want to recommend that this Council carefully look at those HHS regs, and I would urge that you recommend maybe withdrawing and giving future consideration. And I want to recommend that you also, in drafting any white paper about provider conscience, put in some ways in which patients’ rights should be protected, including patients’ right to informed consent must be considered paramount, acute care hospitals and other health care facilities that are licensed to serve the general public and receive patients needing emergency care must be expected to provide such care immediately.

I wish you would protect the ability of nonobjecting health practitioners to fulfill their duty to their patients when they are working in facilities that wish to gag them and prevent them from fulfilling their duties.

And, finally, I would urge that for nonemergency care referrals to alternative practitioners or facilities must be expected in situations in which the institution or provider disagrees for a moral reason.

So thank you so much for the opportunity to present this testimony.

CHAIRMAN PELLEGRINO: Thank you very much. Our next speaker is Stephen Mikochik of the National Catholic Partnership on Disability.

MR. MIKOCHIK: Thank you, Dr. Pellegrino, for the opportunity to speak. Unfortunately I don’t have a PowerPoint presentation. I want to speak for a few minutes, if I could, on the issue of futile care and the concerns that we disabled people have about the practice. And we’re talking about care, particularly the withdrawal or withholding of life support by a physician contrary to the wishes of their patients or their surrogates.

Just to introduce myself, my name is Steve Mikochik, and I’m a professor of Constitutional law at Temple Law School in Philadelphia. I’m also the chair elect of the National Catholic Partnership on Disability. This is an organization that was established by the United States Catholic Bishops to implement their pastoral statement on the rights and needs of persons with disabilities.

We are – “we” meaning the 14 million American Catholics, who we represent – concerned about futile care. And, simply put, we’re concerned that cost containment and the pressures to contain costs are going to have a strong influence on doctors in the future, as they do presently, to withdraw or withhold life support, not because they think it’s futile in prolonging the lives of disabled people, but because they think the lives that such treatment prolongs are themselves futile.

Doctors are human, and they share to some extent the same negative attitudes that pervades society concerning disability. And if you couple that with cost containment, it poses a problem. I think it blinks reality to ignore or deny the fact that physicians in the future will make decisions about life support for disabled people based on the physician’s perception of the quality of that life. And, more disturbing, I think, insurers are going to be, I think in the future, far less likely to pay for that support than they are now for disabled people to continue their lives.

I think particularly the problem of insurers less likely to pay might offset the reluctance physicians have – as pointed out by Dr. Pope – to resist the requests, particularly of surrogates. If insurers are less likely to pay for the continued life support, that’s going to be an additional incentive on the part of physicians to decline, withhold, or withdraw it. The landscape legally is very receptive now to that type of decision by physicians.
I find it very uncomfortable to disagree with someone named Pope, but I do have to disagree to some extent with his characterization of the Texas law. This was a 1999 law that Texas passed. It as a compromise provision. We in the National Catholic Partnership on Disability were informally but substantially involved in 2007 with the Texas Catholic Conference on this issue. The reason is because the Baby Emilio case arose from a Catholic hospital in Austin.

Dr. Pope is right to say that there is no definition of appropriate or inappropriate care in the Texas statute, but he didn’t mention that the statute only applies to the withholding or withdrawal of treatment if the patient is qualified. And the statute says to be qualified a patient either has to have a terminal condition or the patient has a condition that is permanent and prevents the patient from making decisions for herself or for caring for herself and would prove fatal if the life support in question was removed.

Now you can kind of sit back and think about horrible hypotheticals – you know, somebody who is profoundly developmentally disabled is unable to make decisions for themselves. Or somebody who is a quadriplegic and has problems breathing is unable to care for themselves. You’d say to yourself, “Well, the legislature never intended the statute to apply to that situation.” Except the Supreme Court of Texas has said if a statute is plain on its face – and this statute is – a court cannot look at the legislative history. Right? So the statute is to be applied on its own four terms. And obviously this is an open invitation to making quality of life decisions concerning futile care, concerning the perpetuation of life support for disabled people. And, as Dr. Pope indicated, it understates the broad flexibility given to physicians to withdraw life support because they consider it inappropriate or ineffective.

Now, I’m not trying to criticize Dr. Pope. I know he’s making a good-faith effort to deal with these issues. But I gather from what he was saying, the less standards the better because the process should deal with it without any intervention of external standards. The problem with any process-based determination is that it perpetuates prejudices concerning what is reasonable. This is why, for example, historically we haven’t let legislatures make decisions concerning the free exercise of religion, because their decisions would promote the exercise of a majority of religions, but religions like Jehovah Witnesses or Seventh Day Adventists that aren’t majority religions wouldn’t get the same accommodation because they don’t fit into the kind of basic notion of what is a reasonable religious practice. We don’t let legislatures historically make those judgments. We require that they adhere to external standards. You shall not prohibit the free exercise of anyone’s religion, majority or minority.

If we’re talking about ethics committee decisions – and remember in Texas they’re not subject to judicial review. Courts in Texas can review only whether there are alternative placements available. They cannot review whether the decision to withdraw treatment is inappropriate. An ethics committee is quite likely to carry forward the same prejudices concerning disability as are pervasive in the rest of society.

Now, we know this is a terribly difficult issue. We've submitted for your review a statement that we developed and approved this summer trying to lay out standards that call for a strong presumption in favor of continued life support. We’re not experts in the area. You are. But we ask you, in considering what policies to recommend to the President on the issue of futile care that you recommend policies that strongly presume in favor of life support so that the decision to withdraw or withhold treatment is made not on the quality of the life involved but on the quality of the treatment at issue, because we think that it’s not too much to say that the lives of countless disabled people hang in the balance.

Thank you very much.

CHAIRMAN PELLEGRINO: Thank you very much. Our next speaker is Dr. Hanna Klaus of the National Family Planning Center of Washington. Dr. Klaus.

DR. KLAUS: Thank you very much. I appreciate the fact that I’m allowed to speak with you. I’m sorry that Dr. Lyerly is not here, because I want to comment on the ACOG committee decision, the ethics committee. I’m a life fellow of ACOG, a longtime obstetrician/gynecologist, and I’ve seen ACOG change completely from the focus on saving the mother and the child to disregarding the child entirely, even though ACOG still has the logo of a woman holding up her baby.

But listen to this. Obviously I think we’ve already said that if someone is opposed for any reason to doing an abortion, they cannot be forced to do it. But more and more people who are opposed to abortion are sort of forced out of this specialty, limiting the choice of doctors available to patients. Not a week goes by that I don’t get asked, “Can you recommend a pro-life...
obstetrician/gynecologist?” And, by the way, I live in this metropolitan area. “Can you recommend someone who will treat natural family planning choices with respect?”

I wish there were far more people who are doing that. And that brings me to the question of “Who defines the standard of care?” We've shifted in the last half century from restoring health or at least alleviating disease and preventing death to providing technical support for lifestyle changes, some of which involve considerable long- and short-term risks to life and health.

Fertility is not a disease, yet we have attacked it as if it were. When treating pathology, the physician weighs the possible benefits against the possible risks, but there is no risk in possessing normal fertility, whose control can be managed easily with modern natural family planning methods.

Examples abound of instances where drugs with long-terms risks of pathology are prescribed or dispensed on demand. For instance, in Los Angeles a contraceptive steroid is given regularly to women of Mexican extraction even though it is known that they are quite likely to develop diabetes mellitus Type 2 within 15 to 20 years. Another example of that is the treatment of polycystic disease of the ovary. I realize I am getting into specialty areas here, but this is widely known and yet women and girls continue to receive contraceptive steroids because they might get pregnant, as I heard at a specialty meeting. Never mind that in 15 or 20 years they're going to be at high risk for diabetes and all the costs to them and to society, plus the fact that when contraception is made widely available the result is promiscuous behavior and tremendous rise in sexually transmitted diseases and also a lot of unplanned pregnancies.

Fifty-eight percent of woman who came for abortion, according to the last national survey of Family Growth, were using contraception during the month of conception. So that's no great triumph. The same thing happened in Scotland, when they gave women emergency contraceptive pills and the abortion rate didn't go down. And this is a very large study through a WHO.

I would also submit that the articles which the ethics committee selected were [strategically] selected [to support only one point of view]. They did not show anything, for instance, that would cause anyone to suspect that emergency contraception with Plan B was not the only way to go. In fact, it isn't. EC does not have that high a success rate either. It's only useful if it's given before the final phase of ovulation begins, and yet this is being put out as if it were a wonderful thing, frankly to profit many people who provide pills.

So I would suspect that we need to ask, first of all, for support for physicians to practice according to their conscience and to make sure that physicians who have that conscience position are available to women who want that same choice.

Thank you very much.

CHAIRMAN PELLEGRINO: Thank you very much, Dr. Klaus. Our next speaker is Dr. Sandy Christiansen of Care Net.

DR. CHRISTIANSEN: I think I can say good afternoon, Chairman and distinguished members. It is my privilege to be here.

As an obstetrician/gynecologist who has chosen not to perform elective terminations of pregnancy, I can attest to the difficulties and pressures that physicians face when attempting to practice according to their conscience. When I began my residency in 1986, I fully expected it to be physically and emotionally draining, but I wasn’t prepared for the intolerance and hostility that I would face because of my faith. I was the only intern who elected to not perform abortions, and it was understood that it was because of my Christian convictions. One of my fellow interns was frequently given the opportunity to scrub in on gynecologic cases, and I approached my chief resident and inquired, “I would like the same opportunity.” And she said, “Well, this person was working hard at doing the abortions, and so she gained this privilege, which you refused to do, so you do not get the perk.” At the time, I did not question this injustice, believing I didn’t have any recourse, but since then I’ve come to understand that I missed learning opportunities simply because of my values.

Another incident that occurred during my residency training is a flagrant example of discrimination and disrespect. I was chief resident at this time now. Several years have gone by, and I was in charge of the obstetrical service. A patient came to the labor floor who was to have a late mid-trimester abortion, and I approached my attending physician and explained that I was uncomfortable participating in this patient’s care because of my beliefs, but I had made arrangements with another resident to take care of this patient. She proceeded to reprimand me loudly in front of my team of residents, interns, and students, accusing me of abandoning my patient, of shirking my responsibilities, and being insensitive to my patient. Not once did she acknowledge the legitimacy of
my action or the fact that this patient was being well taken care of. I was stunned by this outburst, which not only denigrated my values but my character and professionalism as well.

Today, these are not isolated incidents, sadly, but part of increasing pressures that health care professionals are facing to conform to the socio-political dogma of reproductive rights, of which the November 2007 ACOG Ethics Committee Opinion is a good example. A recent survey from the Christian Medical and Dental Association noted that 40 percent of respondents had experienced some level of discrimination during their lifetime based on their pro-life views.

Recently I spoke to a group of students from the University of Maryland and Johns Hopkins School of Medicine. Our future health care providers, doctors, nurses, and scientists are also concerned about these issues, and that's partly why I'm here today — for them. My hope is that through Secretary Leavitt's proposed regulations that our future health care providers will be free to practice according to their conscience without the fear of loss of learning opportunities, reprimand, or loss of their very jobs.

This is not just simply a religious issue nor simply a reproductive rights issue. I believe it speaks to who we are as a society and what we value. Last week Los Angeles Times included an op-ed from someone named Crispin Sartwell, who identified himself as a pro-choice atheist but went on to say that he supports Secretary Leavitt's proposed regulations, which I believe are designed to bolster existing laws supporting conscientious refusal. I couldn't agree more with his statement, and I quote:

*The extent to which an institution seeks to expunge individual conscience and moral autonomy is the extent to which it is totalitarian and dangerous. The idea that I resign my conscience to the institution or to the state is perhaps the single most pernicious notion in human history. It is at the heart of the wars and genocides of this century and the last.*

In closing, last week, I read about Randy Stroup of Oregon, who was diagnosed with metastatic prostate cancer and applied for health insurance, which the state denied because it was calculated that he had less than a five percent chance of surviving. But the State had an alternative solution for him: they were willing to pay for his physician-assisted suicide. Brave New World, here we come.

Lastly – I'm about to close here. I feel that we really have fallen so far from the ethical and moral principles that founded the practice of medicine, and I will close with a comment about Francis Schaefer's and C. Everett Koop's 1979 book *Whatever Happened to the Human Race*. They wrote of society being on the edge of a great abyss, and from my view I feel that our ride on the slippery slope in fact is taking us into the abyss. And it is my hope that someone — and hopefully this group here — will throw us a big rope, because I believe that supporting physicians' First Amendment rights protects the First Amendment rights of us all.

Thank you very much.

CHAIRMAN PELLEGRINO: Thank you, Dr. Christiansen. Our next speaker – yes, sir?

DR. HURLBUT: Could I ask the speaker where your training took place, where those incidents took place?

DR. CHRISTIANSEN: I'll say Philadelphia.

CHAIRMAN PELLEGRINO: Our next speaker is Susan Fogel of the National Health Law Program.

MS. FOGEL: Thank you, Dr. Pellegrino and Council members for this opportunity to speak on this really critical issue of patient care and refusals.

I'm an attorney with the National Health Law Program. We're a national public interest law firm that works to improve access and quality of care for low-income people, minorities, people with disabilities, and the elderly. And we approach the issue of refusals and religious restrictions from that perspective.

I also want to echo some of the comments that have been made that raise concerns about the HHS regulations. I think everything that I want to say again emphasizes why those regulations really threaten quality and predictable delivery of health care. I have also submitted written comments, so I just want to make a few points.

We've already heard — and you all know — that the basics of modern health care delivery are evidence-based practice, patient centeredness, and prevention, which collectively are intended to
ensure quality of care. Failure to adhere to prevailing standards of care and accepted medical practice really harm individual patients in very concrete ways.

I think too often the analysis of health care refusals becomes a debate that sounds like a moral contest between providers and patients, and what gets left out of the conversation is the real medical consequences to patients. There is real patient harm that needs to be considered in this analysis. Certainly the individuals for whom we advocate are the most vulnerable and really suffer the greatest consequences.

This debate often seems to rest on certain assumptions that we think really need deeper analysis. One is that the services to which people are objecting or refusing to deliver are optional elective lifestyle, not necessary to health or well-being, and are based on just whims and desires of women. The second challengeable assumption is that there only limited or acceptable burdens on people. And third is that the patient can obtain these services elsewhere.

I think that for low-income women in particular all of these assumptions are erroneous. Lower income women often don't have access to health care, they are locked into managed care plans, they perhaps can’t afford to pay for treatment out of pocket, and they – even in urban areas, if they have health insurance we know that limits their treatment options. So we don’t want to think about this as an abstract or philosophical debate but really something that has real impact on patients.

In addition to health care refusals there’s been a lot of talk about individual providers. I want to make sure that we also look at the other side, which are institutional restrictions which prohibit providers from offering care that they and their patients may have decided is appropriate in accordance with medical standards of care.

There was an article in the American Journal of Public Health just last month, I think, looking at miscarriage management and real incidents of what has happened in hospitals that prohibit physicians from acting what they consider to be in the best interest of their patients.

There’s a story about a doctor. All of the names in the study are anonymous, but he had a patient who was 19 weeks pregnant. She had a premature rupture of her membranes. The fetus was not yet viable. The patient was septic. She had a dangerous infection that was threatening her life, but the fetus had a heart beat, and the hospital refused to allow him to terminate the pregnancy. And, as he said, we were giving her medication to keep her blood pressure up, using a cooling blanket to keep her temperature down. The woman was dying before our eyes, and still the termination was not approved. The outcome is the patient was in the ICU for ten days. The fetus died in utero, and she suffered significant health – long-term health problems.

We also want to look at the fact that in a health care patient provider relationship there is an inherent imbalance of power. Part of that power is based on the knowledge and judgment of the health care provider. It is erroneous to suggest that patients come into this relationship in an equal balancing position. Also, restrictions on information services don’t take place in an open marketplace. We know patients don’t really have – often don’t have good choices.

So contrary to the modern trends of health care delivery of evidence-based, patient centered, health care refusals and denials of care really are taking women’s health backwards to a paternalistic health care system where treatment decisions are made by physicians and systems, not by physicians and patients.

Medical guidelines give us some really concrete guidance, I think, and ways to analyze the impact of these restrictions. I just want to give a couple examples, not of what medical associations say about refusals, but if we think about the fact refusals are permission to opt out of providing care that would otherwise be accepted medical practice.

So what do they say? We know they all talk about informed consent. Informed consent is intended to help begin to balance the relationship between providers and patients. The American Medical Association says the physician’s obligation is to present the medical facts accurately to the patient. The physician has an ethical obligation to help patients make choices among the therapeutic alternatives. Obviously if providers are allowed to opt out of even discussing those alternatives, we really have to question whether there is even a possibility of real, informed consent.

There also are many medical conditions for which contraception and pregnancy termination can be medically indicated. I think a recent study showed there were 11.7 million prescriptions for potentially teratogenic medications filled every year by women of reproductive age. Now, needless to say those women need access to contraceptives to protect their health.
In fact, you may all know about Accutane. It’s an acne medication. The impacts on a developing fetus are so significant for women taking Accutane that the FDA has a program called I Pledge where women actually – and physicians – are supposed to sign in and register. Women are advised, they have to be on two forms of contraceptive, and the FDA says that natural family planning is not an effective method of birth control.

In examples of pregnancy termination, even when there is an intended or a wanted pregnancy, there are times when pregnancies go awry. We know that women with serious cardiovascular conditions, women with lupus, women with epilepsy may face a difficult decision about whether or not to terminate a pregnancy. Premature rupture of membranes, preeclampsia. These are all conditions where women need to get good information, be well counseled, and she and physicians need to make good decisions about whether they want to continue a pregnancy to term by balancing women’s health versus the potential for a viable birth outcome. But religious restrictions and refusals take those decisions away from women and away from providers and put those decisions back in the hands of – often in the hands of institutions that are making decisions based on religion and ideology and moral beliefs but that have nothing to do with evidence, have nothing to do with patient-centeredness.

So in conclusion, we just want to bring the conversation back to what happens to patients, real health outcomes, and look at those qualities when we’re analyzing refusals.

Thank you.

CHAIRMAN PELLEGRINO: Thank you very much. Our next speaker is Irum Taqi. Again, if I’ve mispronounced it, I apologize.

MS. TAQI: Good afternoon. You pronounced it correctly, actually. My name is Irum Taqi. I am Assistant Director of Public Policy at Physicians for Reproductive Choice and Health. Physicians for Reproductive Choice and Health is a national nonprofit organization based in New York City comprised of doctors who support evidence-based reproductive health care for every American. We work with governmental entities, the media, the public, and our colleagues to ensure that all patients have access to quality services as well as the knowledge and freedom to make their own decisions about their reproductive health.

Dr. Anne Davis is an associate professor of Obstetrics and Gynecology at Columbia Presbyterian Medical Center in New York City, and she is also the medical director of Physicians for Reproductive Choice and Health. Dr. Davis could not be here today, so I am going to read an abridged version of her written testimony on her behalf addressing the specific issue of conscientious refusal in the provision of reproductive health care.

“I am an academic obstetrician/gynecologist and specialist in family planning. In my practice, I provide the full range of contraceptive services, including birth control pills, patches, rings, injections, emergency contraception, IUDs, and surgical sterilization. I also provide medical and surgical abortions. I work with women who have commercial insurance and Medicaid, as well as uninsured women. When patients come for consultations, I provide complete and factual information about their options. Some talk to me about reproductive health issues as they relate to the practice of their religion. My practice includes Catholic, Jewish, and Muslim women. Others discuss their moral or ethical concerns. In every case, we decide together on the care that best meets their medical, religious, and moral needs. If they need a service I cannot or will not provide, I refer them to doctors who can. The principles I follow — helping my patients make informed decisions about their health and ensuring that they get what they need in a timely, sensitive manner even when I am unable to provide it — keep people safe. These principles are not unique to me, nor are they radical. They are the underpinnings of the medical profession.

“Yet recently the Department of Health and Human Services (HHS) has threatened to cast these principles aside. The department has proposed regulations that could allow hospitals, doctors, and other health care workers to deny women access to effective birth control, regardless of the consequences for their health. These regulations would protect clinicians who refuse to provide patients with factual information about or referrals for basic health care services like sterilization and abortion and would even protect workers who are not directly involved in patient care.

“The HHS regulations allow healthcare professionals to stonewall my patients whose chronic illnesses make pregnancy potentially lethal by withholding information about contraception or abortion. I am reminded of my patient Sara, an orthodox Jewish woman who has seven children and a diagnosis of breast cancer. In consultation with her husband and her rabbi, we chose an IUD as the appropriate contraceptive method to maintain her health and accommodate her religious beliefs. If
the regulations go into effect, women like Sara could be left unprotected and at risk of worsening illness and even death.

“Physicians for Reproductive Choice and Health and I believe that individual physicians may refuse to perform medical procedures that conflict with their religious or moral beliefs. Existing law amply protects this right, allowing individuals to abstain from providing abortion and sterilization services while simultaneously honoring patients’ rights to reproductive health care. The proposed regulations, however, would sacrifice the patient’s well-being in favor of the provider’s conscience.

“Physicians have a professional duty and obligation to tell their patients if their religious or moral beliefs might compromise the patient’s access to comprehensive and timely reproductive health care — and yet the HHS regulations make no mention of this obligation. If a physician refuses to prescribe birth control pills, perform a tubal ligation, provide medical or surgical abortions, or discuss emergency contraception, women have a right to know this prior to accepting treatment by the physician. If doctors fail to disclose that they do not provide the range of family planning services, patients might face misinformation, additional costs, dangerous delays in care, unintended pregnancies, and less safe abortions. I have had patients whose medical problems are accompanied by enormous turmoil and pain, and I want to help them as quickly as possible. But the HHS regulations would only make these situations worse, adding to patients’ confusion, frustration, and desperation.

“As an ob/gyn, my primary obligation remains with my patients. If I were a neurologist or a podiatrist, I would uphold the same standard. Physicians do not have the right to impose their beliefs on patients.

“Accordingly, physicians who refuse to provide health care must, at a minimum, be required to refer their patients to a doctor who can provide them with accurate information and medical care in a timely, appropriate, and respectful manner.

“Physicians for Reproductive Choice and Health supports the American College of Obstetricians and Gynecologists committee opinion issued last year.

“In conclusion, I'd like to say that women in the United States already face a host of legal, financial, and logistical obstacles in obtaining the full range of reproductive health care. We should make basic health services more accessible, not undermine the doctor-patient relationship and cause harmful delays in treatment.

“The HHS regulations would limit patients’ access to medical information and basic services, and my conscience refuses to go along.”

Thank you.

CHAIRMAN PELLEGRINO: Thank you very much. Our next speaker is Dr. Donna Harrison, President of the American Association of Pro-Life Obstetricians and Gynecologists.

DR. HARRISON: Members of the Council, thank you for allowing me to address you. My name is Dr. Donna Harrison. I’m a Diplomat of the American Board of Obstetrics and Gynecology. I am also president of the American Association of Pro-Life Obstetricians and Gynecologists. AAPLOG is one of the largest special interest groups within the American College of Obstetrics and Gynecology, and I address you on behalf of our membership of 2,000.

On behalf of the AAPLOG membership I am asking the President’s Council to consider writing an opinion on three ethical questions pertaining to the attack on our rights of conscience as health care workers: number one, the attack on our right to conscientious refusal to perform or refer for abortions; number two, the use of the power of a professional licensing board to discriminate against physicians who do not comply with a controversial ethical position; and, number three, the use of flawed and biased ethical analyses as the basis for judgment of health care providers’ ethical character.

All of these current issues arise from the continuous professional harassment which pro-life physicians experience from the American College of Obstetrics and Gynecology. Now in conjunction with the wording of the new maintenance of certification requirements of the American Board of Obstetrics and Gynecology, I have attached in paper format and electronic format – I’ve submitted to this council documentation of what I’m saying in this report.

ACOG’s effort to eliminate pro-life obstetricians and gynecologists from practicing is long standing. We have been battling the right of conscientious refusal for the last twenty years, as illustrated by the
past and current continuous effort to make participation in abortions mandatory for Ob/Gyn residents in training programs. I also experienced very similar harassment as Dr. Christiansen during my residency program.

However, the latest effort has been to officially attack the ethical character of pro-life Ob/Gyns who refuse to perform or refer for abortions. In January of 2008 the American Board of Obstetrics and Gynecology, which is the professional body determining board certification and which should be separate from ACOG, stated in writing that noncompliance with ACOG “ethical statements and principles” would be grounds for revocation of board certification. Board certification is necessary for an OB/Gyn to obtain hospital privileges nationwide.

Despite numerous letters from AAPLOG, pro-life physicians, and organizations across the country, the American College of Ob/Gyn has not rescinded its controversial ethical statement 385, which states that, number one, pro-life physicians must refer for abortion; number two, patient autonomy trumps physicians’ conscience; number three, conscientious objections to abortion amount to subjective feelings on the part of the physician; and, number four, pro-life physicians should relocate next to abortionists to facilitate referrals.

As long as ACOG ethics statement number 385 holds and the wording of ABOG’s maintenance of certification, which requires compliance at the price of board certification, pro-life ob/gyn’s are at risk of bogus accusations of “unethical professional behavior,” and they risk their board certification suspension for years while under “investigation.”

AAPLOG appeals to the President’s Council for Bioethics to investigate this abuse of power in the name of medical ethics. We have detailed our concerns and have electronically submitted them to you as well as submitted some of what I submitted electronically in writing. It should be attached.

Thank you on behalf of pro-life obstetricians and gynecologists.

CHAIRMAN PELLEGRINO: Thank you very much. Our next speaker is Kimberly Goulart of Compassion & Choices.

MS. GOULART: Thank you, and I apologize ahead of time. I’m getting over a cold.

Thank you, Chairman Pellegrino and Council members. My name is Kimberly Goulart, and I have the honor of working with Compassion & Choices and its more than 35,000 members to improve end of life care options for Americans. Compassion & Choices is the oldest and largest organization in the country focused on ensuring that Americans have access to the full array of end of life care options, including palliative care, improved pain care, hospice care, and legal aid-in-dying. Compassion & Choices has more than 25 years of experience in advocacy and service. Much of the work we do is accomplished through grassroots efforts of our members and volunteers, who generously give their time and support to strengthen communities through direct service to terminally ill patients and their families. Compassion & Choices also works with policy makers on the local, state, and federal levels to ensure that the law facilitates an environment where patients are fully informed of all their options and are empowered to make their own decisions about their end of life care in consultation with family and medical providers.

Since its inception, Compassion & Choices has focused its resources on arming patients and their families with the tools to effectively and openly discuss the medical options available to them at the end of life. As we encountered an increasing number of patients around the country, we have learned that dying patients needlessly suffer due to a lack of essential information. As a result, many spend their last days in agony. Too many patients make one of the most important decisions of their lives – how they will live their final days – without being fully informed of their legal rights and, in some cases, all of their medical options. Doctors have a responsibility to put the information and power to choose in the patients’ hands.

Refusal clauses, sometimes referred to as conscience clauses, can undermine the very basic principle of being fully informed of and having access to all of their medical options. These clauses allow physicians and other medical professionals to refuse to perform a procedure for moral or religious reasons. Depending on how they are written, these policies can allow medical professionals to refuse to provide a referral to another medical professional that will provide a particular service or even to inform the patient of the option of that procedure. While these refusal clauses frequently specifically address the religious and moral objections to sterilization procedures and abortion, they are often broadly drafted to extend to any procedure which may be controversial or viewed as morally objectionable. In the area of end of life care, institutions and individuals opposed to withdrawing feeding tubes, aggressive pain care management, providing support to a patient choosing to
voluntarily stop eating and drinking, or to the practice of palliative sedation could claim these are objectionable and are thus within the scope of refusal laws.

This is particularly worrisome for patients at the end of life who are often unaware of their options, hesitant to initiate conversations with their providers about certain options, and often unable to remove themselves from their current health care setting in order to seek treatment elsewhere. When dying patients are suffering in the final stages of terminal illnesses, they should be able to receive counseling on a full range of options. This thereby empowers them to make fully informed medical care decisions, including the legal and medically accepted options of refusing life-prolonging interventions, opiate pain management, palliative sedation, and voluntarily stopping eating and drinking.

It is well documented that pain is frequently undertreated despite requests by patients and families. Some health care professionals, including those at the bedside, have personal and religious beliefs opposing pain relief, even in circumstances in which professional norms require it to be offered. These laws can remove any obligation on behalf of any employee of a health care entity to inform patients of all of their treatment options or to refer a patient to another provider. This very notion of denying patients access to any such information runs afoul to the fundamental healthcare principles of autonomy and informed consent.

Many patients trust their provider to give them the full range of information on all of their end of life options. Refusal clauses that empower providers to deny patients appropriate counseling and referrals leave many patients unaware that their options are even available or that they have a right to seek treatment elsewhere. At a minimum, we would ask that in order to maintain at least some level of autonomy, patients should have the notice that a facility or provider might refuse to offer information or referrals regarding certain types of treatment based on the provider’s personal moral and religious views.

The right of medical professionals to exercise their moral and religious beliefs should not be accommodated at the expense of the right of the patient to have access to a the full array of medical care, and in particular the right of dying patients to be given the information and access to services they deserve to be able at the end of life with as much self determination, peace, and dignity as possible. We at Compassion & Choices will continue to fight to ensure that all Americans have access to the full range of end of life care options, and we will continue to advocate against policies that limit patient access to information or services as they approach the end of life.

I thank you for this opportunity to address the panel.

CHAIRMAN PELLEGRINO: Thank you very much. Our next speaker is Sondra Goldschein of the American Civil Liberties Union.

MS. GOLDSCHEIN: Nobody ever pronounces my name correctly, but you did. Thank you very much.

Good morning. My name is Sondra Goldschein, and I am the Director of State Advocacy for the American Civil Liberties Union's Reproductive Freedom Project. As you know, the ACLU is a nationwide nonpartisan, nonprofit organization of more than 500,000 members dedicated to protecting the principles of freedom and equality that are set forth in the Constitution and the various civil rights laws. I thank you for the opportunity to talk with you today about the issues raised when religious belief affects decision making about reproductive health care.

Now, the ACLU has grappled with this question for many years, and it is particularly important to us because of our long-standing commitment to both religious liberty and reproductive freedom. And to give you just a taste of our work in both areas, the ACLU was a founding member of the coalition that supported the Religious Freedom Restoration Act, which is a law to preserve or restore the highest level of Constitutional protection for religious exercise.

Across the country we have a full docket of cases where we represent persons challenging burdens on the exercise of their religious beliefs. For example, we have sued to protect the right of Jewish students to wear a Star of David pendant to school. We have sued to defend the right of conservative Christian activities to broadcast on public access television. We have sued to protect the right of a Christian inmate to preach in his correctional facility.

And we have been equally vigilant in our advocacy of reproductive freedom. The ACLU fought long and hard to persuade Congress to pass the Freedom of Access to Clinic Entrances Act, the FACE Act, to protect reproductive health clinics, patients, and professionals from deadly violence. We have participated in nearly every critical Supreme Court case protecting reproductive freedom, from Roe
versus Wade to Planned Parenthood versus Casey to Gonzales versus Carhart.

And when we began to hear stories of religiously based refusals to provide reproductive health care, we quickly realized that we needed to develop a framework for analysis that would protect both of those core values to the greatest extent possible. And I will briefly describe our framework and then offer some concrete examples so you can see our framework in action.

So our framework centers around two key questions. First we ask whether the refusal places burdens on people who do not share the beliefs that motivate the refusal. And second we ask whether the objector is a sectarian institution engaged in religious practices or whether it’s an entity, whether religiously affiliated or not, that provides services to the general public. The more that services are made available to the general public and the less the services relate to an institution’s religious mission, the less acceptable an institution’s claimed right to refuse.

What does this mean in application? Let’s start with an individual health care provider's refusal. We think that an individual health care providers' refusal to provide a health service should be protected, but in order to lessen the burden on the patient, that individual health care provider should be required to give complete and accurate information, to give appropriate referrals, to effectuate informed health care decisions, and to provide care in an emergency. That is a true balance for us between reproductive freedom and religious liberty. And the same can be said of institutions whose primary purpose is to practice and teach religion, like temples, churches, and mosques. Those institutions should not have to provide health care coverage or health care that violates their religious beliefs. But when institutions, such as hospitals, health care plans, pharmacies or other corporate entities serve and employee diverse populations, their refusal can impact a wide number of people who do not necessarily share their beliefs. So when those institutions move into the public world, they have to play by public rules.

So some real examples. We believe that a doctor, nurse, or pharmacist who cannot in good conscience participate in abortions or contraceptive services should be allowed to refuse so long as a patient is ensured safe and timely alternative access to treatment, but a hospital shouldn’t be able to refuse to provide emergency contraception to a rape survivor. A hospital employs people of diverse faiths, and it serves people of diverse faiths.

A church, though – an opposite – should not have to purchase contraceptive coverage for its employees, but an administrative assistant that’s working at a Catholic university or a Catholic hospital shouldn’t have to pay for her contraceptives out of pocket. So the factors that we identified, those two questions, will lead to these kinds of fair results.

And so I just want to briefly say that based on this framework, we've looked at the proposed HHS regs, and we do not think that those regs provide an adequate balance of reproductive freedom and religious liberty. The proposal suggests that religious refusals should trump patients' basic health care needs, and we do not think that's an appropriate balance of religious freedom and reproductive rights.

So thank you for your time today, and we recommend that the Council advocate for solutions that appropriately balance patient access to health care with religious liberty, and we have a report that I have back there if anyone is interested in learning about this framework in more detail. Thank you.

CHAIRMAN PELLEGRINO: Thank you very much. Our next speaker is Jonathan Imbody of the Christian Medical Association.

MR. IMBODY: Thank you, Dr. Pellegrino, and thank you, members, for staying around to hear from the grass roots. I appreciate that and postponing your lunch to do so.

The argument has been advanced that protecting the civil rights of health care professions will somehow decrease patient access to health care. In fact, the opposite is true, and an email recently received from a medical student helps illustrate why. Medical student Trevor K. Kitchens writes: “I am a first-year medical student in the beginning stages of deciding which specialty I would like to pursue. I am currently very interested in OB/GYN, but I am afraid of the relationship between this field and abortion.” Then he adds, “By the way, I am a hundred percent against abortion, and there is no way I would perform one. Moreover, there is no way I would tell a patient that abortion is an option under any circumstance, because I do not believe it is an option.” And then he continues, “My concern is that I will start a residence and would subsequently be required at some point to give a patient the option of abortion, which I would refuse.” And Trevor says, “My fear is that taking this stand would cost me my residence position.” Now, if that is what it comes down to, he says, “I will be glad to take the stand for Jesus Christ and give up my position.
However, I would really like to be able to avoid this situation and complete my residence so that I could go on and serve the Lord in that field.”

Now, Trevor is a medical student whose life-honoring values are consistent with the long-standing medical tradition of Hippocrates. Yet he senses that his life-honoring views will ironically disqualify him from a profession in obstetrics and gynecology because of the climate of discrimination, heavy-handed politics, and coercion in that field.

Well, Trevor’s fears seem well-founded. We’ve heard about the ACOG and the ABOG statements, which would essentially make obstetricians choose between following long-standing medical ethics codes or losing their board certification and essentially their careers.

Two out of five of the members of the Christian Medical Association report being pressured to compromise their adherence to ethical standards. Residents report losing clinical privileges for refusing to perform abortions. Physicians report losing their positions for refusal to participate in life-ending prescriptions and procedures.

Well, as life-honoring medical students, residents, physicians and other healthcare professionals are systematically forced out of the field of obstetrics and gynecology, their loss ultimately impacts patients. Their loss will impact life-affirming pregnant women who specifically seek physicians, as my wife did, who share their views and do not participate in abortions. Their loss will especially impact poor patients, since faith-based and other conscientious physicians and institutions are among the most likely to be caring for the underserved. And their loss will impact the medical community, which is enriched by the reminder that time-tested objective standards of medical ethics protect patients and constrain the physician to first do no harm.

Thank you.

CHAIRMAN PELLEGRINO: Thank you very much. Our final speaker is Dr. Karl Benzio of the Christian Medical and Dental Association Lighthouse Network.

DR. BENZIO: Thank you very much, Chairman and Council. I am honored and humbled to be able to serve here today.

Right of conscience versus right of convenience. We are here because certain groups want to perform procedures or enact processes that are unconscionable, unethical, and convenient. They need to remove conscience in others, which they can’t, or legislate against conscience to advance their agenda. There is so much evidence against this abolition of conscience from medical practice, I am going to present a few of those arguments.

Starting with the Hippocratic Oath, certainly in 400 B.C., there was erosion of health care, the doctor-patient relationship, and the action of physicians. Hippocrates made a moral pledge to his gods and to society to do no harm by not being complicit in abortions, killings by physicians, or breaking confidentiality.

Second point is, if you strip conscience rights, it’s a mixed message to physicians. Society, professional organizations, and law makers want physicians to have a conscience, values, morals as evidenced by Stark laws that legislate against kickbacks, self-referrals, and other financial incentives that would potentially interfere with patient care. There’s legislation that polices pharmaceutical and medical device company incentives for product use. There’s rules against sexual conduct with patients. There’s whistle blower protection laws against people that express their conscience.

Probably the most egregious event was Auschwitz where, because of unconscionable and unethical methods, we had a very hard time accepting all this unbelievable science that we garnered due to the horrible ways that we were able to come upon that evidence. Now, telling me that I can’t practice because of my conscience sort of goes in the face of these other examples and messages.

We certainly want doctors that have a conscience and use their ethics, morals, and principles. If we were in a car accident an unconscious, we would certainly want a physician to be taking care of us that would have morals, values, and a code of conduct to be able to treat us. We wouldn’t want financial incentives, insurance interests, medical device companies, research results, fame, political gain, or other people’s finances or needs to interfere with a decision-making process that would be ethical and appropriate.

As a teenager in Northern Jersey as an Italian with friends involved in organized crime, I was approached to go to medical school for free, residency for free, undergrad for free, and have a very nice practice. In response, I would be able to give certain care to their constituency as well as cover
up mistakes. Interestingly, they approached me because of my trustability, then asked me to practice unconscionably as a result.

When physicians do lethal things, it erodes the trust that doctors and patients have in each other. It interferes with the openness of communication that patients can have. It also opens the door wide open of the slippery slope that lead to other, more egregious behaviors in that, as Dr. Pope presented, that bubble of intractable cases grows and grows and grows larger.

To get an idea of what happens when you remove ethics and conscience from a profession or system, we just need to look at the terrible state of affairs of or legal system, where the goal is pursuit of truth and honest discourse, but there's laws and different elements that preclude against the evidence and the truth being presented clearly and openly. As a result, people don't trust lawyers, the legal system. There's ridicule of the system and attempts to circumvent the system. I would not want to see that happen to our medical system, which unfortunately is heading in that direction and/or some of those elements at this point.

The government is also another system where conscience is sometimes missing or at least perceived to be missing, and we see the contempt and the apathy by our society with regard to the government situations.

As far as my personal practice, I am a psychiatrist. As a parent we know that giving things isn't always the compassionate and loving thing. To give the 12-year-old the keys to the car certainly is not the loving, compassionate thing. As far as abortion, doing the compassionate, loving thing isn’t always complying with the request for an abortion. I have treated women that have had abortions. I've treated fathers of aborted children and dealt with their sequelae of post-traumatic stress disorder and depression and suicidality.

Giving emergency contraception is another one of those convenient things that isn’t necessarily the loving and compassionate act. I've treated rape victims that have had abortions and the negative outcomes from that. I've treated rape victims that have carried their child and have wonderful experiences with loving that child, the child loving them, and the trend is growth that happens relationally, psychologically, and spiritually by trying to figure out, well, why did this happen, then, if I had this positive outcome?

We talked about patient-centered medicine, but as a psychiatrist I unfortunately impose my conscience on patients at times because I stop them from committing suicide. That's their wish, and I either commit them or hospitalize them against their will to stop them from imposing what they would like to do. We're also called by law to – the Tarasoff law to stop people from killing others, and the duty to inform is again imposing my conscience on theirs.

Certainly legal commitments to hospitals and psychiatric settings again is me imposing my conscience. Finding people incompetent to then undergo procedures that are presumed in their best interest is another area where we impose our conscience values over the requests or the process of the patient.

People want to go to physicians with similar beliefs. Especially as a psychiatrist we’re involved significantly in their decision-making process, in the values that move their life forward. So I had a patient referred to me who wanted to have an abortion or was on antidepressant, got pregnant, and her psychiatrist told her that she needed to have an abortion. And she was able to find me out through her church, and we were able to see the pregnancy through, a very healthy, very wonderful result.

Another patient was referred to me and was being called psychotic by their psychiatrist and was on medications that they didn't need to be on because the psychiatrist didn't understand their ability to communicate because of their faith, which some of this phenomena was.

Many patients haven't pursued addiction or mental health treatment because of the fear that the care they get or the counsel they get will be contrary to their beliefs regarding sanctity of life, marriage, and that man is made in three spheres, and all three spheres of spirit, mind, and body need to be addressed.

There is also much from a scientific standpoint that I won't be able to go into now because of time, but there is much information and evidence about SPECT scans. The evidence of SPECT shows us about the need for morals and values in decision-making and effective decision-making on brain chemistry and healthy brain chemistry production.

In summary, the conscience rights are the last wish for those who can't speak for themselves, such as...
unborn babies, the mentally retarded, terminally ill, disabled, incompetent, elderly, the unconscious, mentally ill, slaves, illegal immigrants, or those ignorant of the complicated system.

Society and our U. S. Constitution originally taught us to protect that voice, and physicians are often the last audible voice. Taking away conscience rights silence that voice. Please don’t, because some day that voice could be the last advocate and morals between you, your spouse, your parents, your kids, and inhumane, unconscionable, and unethical actions or policies.

Thank you.

CHAIRMAN PELLEGRINO: Thank you very much. Thank you very much, Dr. Pope. Thank you to the members of the Council. And we will adjourn our meeting. Have a good trip home.
EDMUND D. PELLEGRINO, M.D.

COUNCIL CHAIRMAN

Dr. Pellegrino is Professor Emeritus of Medicine and Medical Ethics and Adjunct Professor of Philosophy at Georgetown University.

He has served as Director of the Center for Clinical Bioethics at Georgetown University; head of the Kennedy Institute of Ethics and director of the Center for the Advanced Study of Ethics at Georgetown; President of Catholic University; President and Chairman of the Yale-New Haven Medical Center; Chancellor and Vice President of Health Affairs at the University of Tennessee; founding Chairman of the Department of Medicine at the University of Kentucky; and Founding Director and Vice President of the Health Sciences Center, State University of New York, Stony Brook, where he oversaw six schools of health sciences and the hospital, and served as Health Affairs Dean of the School of Medicine.

He has authored or co-authored 24 books and more than 550 published articles; is founding editor of the *Journal of Medicine and Philosophy*; a Master of the American College of Physicians; Fellow of the American Association for the Advancement of Science; member of the Institute of Medicine of the National Academy of Sciences; recipient of a number of honorary doctorates; and a recipient of the Benjamin Rush Award from the American Medical Association, and the Abraham Flexner Award of the Association of American Medical Colleges.

In 2004, Pellegrino was named to the International Bioethics Committee of the United Nations Education, Scientific and Cultural Organization (UNESCO), which is the only advisory body within the United Nations system to engage in reflection on the ethical implications of advances in life sciences.

Throughout his career, Dr. Pellegrino has continued seeing patients in clinical consults, teaching medical students, interns and residents, and doing research. Since his retirement in 2000, Dr. Pellegrino has remained at Georgetown, continuing to write, teach medicine and bioethics, and participate in regular clinical attending services.
BENJAMIN S. CARSON SR., M.D.

COUNCIL MEMBER

Benjamin Solomon Carson Sr. is the Director of Pediatric Neurosurgery at the Johns Hopkins Medical Institutions, a position he has held since 1984. He is a professor of neurosurgery, oncology, plastic surgery, and pediatrics.

In 1987, he gained worldwide recognition as the principal surgeon in the 22-hour separation of the Binder Siamese twins from Germany. This was the first time occipital craniopagus twins had been separated with both surviving. In 1997, Dr. Carson was the primary surgeon in the team of South African and Zambian surgeons who separated type-2 vertical craniopagus twins (joined at the top of the head) in a 28-hour operation. It represents the first time such complexly joined Siamese twins have been separated with both remaining neurologically normal.

He is noted for his use of cerebral hemispherectomy to control intractable seizures as well as for his work in craniofacial reconstructive surgery, achondroplasia (human dwarfism), and pediatric neuro-oncology (brain tumors).

Dr. Carson is a recipient of numerous honors and awards including more than 20 honorary doctorate degrees. He is a member of the American Academy of Achievement, the Horatio Alger Society of Distinguished Americans, the Alpha Omega Alpha Honor Medical Society, and many other prestigious organizations. He sits on many boards including the Board of Directors of Kellogg Company, Costco Wholesale Corporation, Yale Corporation (the governing body of Yale University), and America's Promise.

He is the president and co-founder of the Carson Scholars Fund which recognizes young people of all backgrounds for exceptional academic and humanitarian accomplishments.

He is the author of Gifted Hands, THINK BIG, and The Big Picture.

Dr. Carson has been married to Candy Carson for twenty-five years and has three sons.

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**REBECCA DRESSER, J.D., M.S.**

**COUNCIL MEMBER**


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Nicholas Eberstadt is the Henry Wendt Chair in Political Economy and Government at the American Enterprise Institute in Washington DC. He is also Senior Adviser to the National Bureau of Asian Research, and for many years was a member of the Harvard University Center for Population and Development Studies.

His areas of inquiry include demography, economic development and international security. He has served, inter alia, on the Board of Scientific Counselors for the US National Center for Health Statistics, the Visiting Committee for the Harvard School of Public Health, and the Global Leadership Council of the World Economic Forum.

His many books include *Poverty In China*, *Fertility Decline in the Less Developed Countries*, *The Tyranny of Numbers*, *Prosperous Paupers and Other Population Problems* and *The Poverty of “The Poverty Rate”: Measure and Mismeasure of Want in Modern America*.
Alfonso Gómez-Lobo, Dr. phil.

Council Member

Alfonso Gómez-Lobo, Dr. phil. Ryan Family Professor of Metaphysics and Moral Philosophy, Georgetown University. Professor Gómez-Lobo specializes in Greek philosophy, Greek historiography, the history of ethics, and contemporary natural law theory. He is the recipient of several awards, including a research fellowship from the Guggenheim Foundation. His latest book, *Morality and the Human Goods*, was published by Georgetown University Press in 2002.
WILLIAM B. HURLBUT, M.D.

COUNCIL MEMBER

William B. Hurlbut, M.D. Consulting Professor, Department of Neurology and Neurological Sciences, Stanford Medical Center, Stanford University. Dr. Hurlbut's main areas of interest involve the ethical issues associated with advancing biotechnology and neuroscience, the evolutionary origins of spiritual and moral awareness, and the integration of philosophy of biology with theology. He has worked with the Center for International Security and Cooperation on a project formulating policy on Chemical and Biological Warfare and with NASA on projects in astrobiology. He is the author of "Altered Nuclear Transfer," a technological proposal to our nation's impasse over stem cell research.

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DONALD W. LANDRY, M.D., PH.D.

COUNCIL MEMBER

Donald W. Landry, M.D., Ph.D., is Professor of Medicine, Director of the Division of Experimental Therapeutics, and Chair of the Department of Medicine at Columbia University. Dr. Landry completed his Ph.D. in Organic Chemistry under R.B. Woodward at Harvard University in 1979 and obtained the M.D. degree from Columbia University in 1983. After completing Residency in Internal Medicine at the Massachusetts General Hospital, he returned to Columbia to join the faculty of Medicine. His basic research program focuses on drug discovery and artificial enzyme approaches to intractable drug targets, e.g., cocaine addiction. His clinical research and clinical practice centers on his discovery in critical care medicine that vasopressin insufficiency contributes to vasodilatory shock and can be treated by vasopressin infusion. He and Columbia colleague Howard Zucker pioneered the alternative, embryo-sparing approach for the production of human embryonic stem cells based on the harvesting of live cells from dead embryos by extension of the established ethics for the harvesting of essential organs from deceased donors.
PETER A. LAWLER, PH.D.

COUNCIL MEMBER

Peter Augustine Lawler is Dana Professor and Chair of the Department of Government and International Studies at Berry College. He teaches courses in political philosophy and American politics and has won several awards from Berry for doing so.

He is executive editor of the acclaimed quarterly journal, Perspectives on Political Science, and has been chair of the politics and literature section of the American Political Science Association. He also serves on the editorial board of the new bilingual critical edition of Alexis de Tocqueville’s Democracy in America and on the editorial boards of several journals. He is a member of the Society of Scholars at the Madison Center at Princeton University, the George Washington Professor on the American founding for the Society of Cincinnati for the state of Georgia, and he is a member of President Bush’s Council on Bioethics.

He has written or edited ten books. His newest book, Aliens in America: The Strange Truth about Our Souls is a starred, featured selection in Booklist, the journal of the American Library Association. Another recent book, Postmodernism Rightly Understood, was also widely reviewed and praised. His very long introduction to a new edition of Orestes Brownson’s The American Republic is now available.

His American Political Rhetoric (edited with Robert Schaefer) is used in introductory American government courses at a sizeable number of colleges and universities. The fifth edition was just published.


Some of the topics of his recent articles and chapters include Shakespeare’s The Tempest, William Alexander Percy, Walker Percy, Alexis de Tocqueville, biotechnology, bourgeois bohemian virtue, religion and conservatism, compassionate conservatism, conservationism, the filmmaker Whit Stillman on nature and grace, disco and democracy, Casablanca and the American dream, the future of human nature, the utopian eugenics of our time, the rise and fall of sociobiology, Richard Rorty, grade inflation and the Ivy League, Harvey Mansfield and Carey McWilliams, caregiving and the American individual, Christopher Lasch, virtue voters, culture wars, Flannery O’Connor and nihilism, Orestes Brownson, and postmodernism rightly understood.

Lawler has given invited lectures at more than 50 colleges and universities. He has received a large number of grants from both the Liberty Fund and the Earhart Foundation, as well as numerous other foundations.

PAUL McHUGH, M.D.

COUNCIL MEMBER

Paul R. McHugh, M.D. is the University Distinguished Service Professor of Psychiatry at the Johns Hopkins University School of Medicine. He was the Henry Phipps Professor of Psychiatry, Director of the Department of Psychiatry and Behavioral Sciences at the Johns Hopkins University School of Medicine, and psychiatrist-in-chief at the Johns Hopkins Hospital from 1975-2001. He is the author of 4 books and more than 150 papers.
Gilbert Meilaender, Ph.D.

Council Member

Gilbert Meilaender, Ph.D. Richard & Phyllis Duesenberg Professor of Christian Ethics at Valparaiso University. Professor Meilaender is an associate editor for the Journal of Religious Ethics. He has taken a special interest in bioethics and is a Fellow of the Hastings Center. His books include Bioethics: A Primer for Christians (1996, 2005), Body, Soul, and Bioethics (1995). He has recently edited (together with William Werpehowski) The Oxford Handbook of Theological Ethics.

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Janet D. Rowley, M.D., D.Sc. Blum-Riese Distinguished Service Professor of Medicine, Molecular Genetics and Cell Biology, and Human Genetics, Pritzker School of Medicine, University of Chicago. Dr. Rowley is internationally renowned for her studies of chromosome abnormalities in human leukemia and lymphoma. She is the recipient of the National Medal of Science (1999) and the Albert Lasker Clinical Medicine Research Prize (1998), the most distinguished American honor for clinical medical research.
FRIDAY, SEPTEMBER 12, 2008

Written Public Comments

American Association of Prolife Obstetricians and Gynecologists

American Civil Liberties Union

American Society for Reproductive Medicine

Catholic Medical Association

- John F. Brehany's Introductory Statement
- Statement 1
- Statement 2
- Statement 3

Christian Medical Association Policy Analysis

Compassion & Choices

Concerned Women for America

The MergerWatch Project

National Catholic Partnership on Disability

- 2008 Statement on Futility
- September 2008 Testimony

National Health Law Program

Natural Family Planning Center of Washington, D.C.

National Women’s Law Center

Physicians for Reproductive Choice and Health

Sound Choice Pharmaceutical Institute [AVM Biotechnology]

Additional Email Submissions
September 12, 2008

Dear Members of the President’s Council on Bioethics,

This letter represents the combined request of over 2000 members of the American Association of Prolife Obstetricians and Gynecologists to the Council on Bioethics to consider writing an opinion on three ethical questions pertaining to the rights of conscience of health care providers:

1. Restriction of the right of conscientious refusal to perform or refer for abortions
2. The use of the power of a licensing board to discriminate against physicians who do not comply with a controversial ethical position.
3. The use of flawed and biased “ethical analysis” as the basis for judgment of health care providers’ ethical character.

1. Restriction of the right of conscientious refusal to perform or refer for abortions.

AAPLOG is one of the largest special interest groups within the American College of Obstetrics and Gynecology (ACOG), but we stand opposed to the pro abortion activism of the ACOG. The pressure on pro-life physicians within ACOG to perform or refer for abortions has been longstanding, but only recently has emerged as a threat to remove pro-life physicians from practice. AAPLOG is writing to request the analysis of the President’s Council on Bioethics of this issue.

As you are probably already aware:

In November 2007, a position statement of The Committee on Ethics of the American College of Obstetricians and Gynecologists (ACOG), "The Limits of Conscientious Refusal in Reproductive Medicine" declared that:

a. **Pro-life physicians must refer for abortion:** "Physicians…have the duty to refer patients in a timely manner to other providers if they do not feel they can in conscience provide the standard reproductive service that patients request."

b. **Patient autonomy trumps physicians' conscience:** Physicians may not exercise their right of conscience if that might "constitute an imposition of religious or moral beliefs on patients."

c. **Conscience amounts to a subjective feeling:** "An appeal to conscience would express a sentiment such as 'If I were to do 'x,' I could not live with myself / I would hate myself, I wouldn't be able to sleep at night."

d. **Pro-life physicians should relocate to refer patients to nearby abortionists:** "Providers with moral or religious objections should … practice in proximity to individuals who do not share their views…"

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The American Board of Obstetrics and Gynecology, (ABOG) which is the professional body responsible for “board certification” of obstetricians and gynecologists throughout the U.S. followed up on the American College of Obstetrics and Gynecology (ACOG) missive within 6 weeks. Effective as of Jan 1, 2008, the ABOG 2008 Maintenance of Certification Bulletin 2 (MOC) decreed that physicians may now lose their certification (without which ob/gyn physicians may not obtain hospital privileges) for "violation of ABOG or ACOG rules and/or ethics principles….”

The pertinent parts of the ABOG MOC are as follows:

1. The sections immediately prior to page 10 give the possible outcomes for an ob/gyn seeking recertification, of which one outcome is revocation of certification. Page 10 provides detail as follows:

"Page 10 Section 5. Revoked Certificate

a. An individual has had their Diplomat status revoked by the American Board of Obstetrics and Gynecology for cause.

b. Cause in this case may be due to, but in not limited to, licensure revocation by any State Board of Medical Examiners, violation of ABOG or ACOG rules and/or ethics principles or felony convictions.

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The MOC process will commence on Jan 1, 2008. Recertification will NOT be available after this date. This means that Diplomats with time-limited certificates that expire in 2008 and thereafter must enter the MOC Process in January of the year their certification expires. This is a transitional period for the former ABC recertification process for time limited certificates. The ABC process has become MOC Part II-ABC.

Page 26, Third paragraph

"If a physician is involved in litigation or investigation regarding ethical or moral issues, the individual will not be scheduled for examination and the application will be re-examined. The Credentials Committee usually will defer such a decision for one year to gain further information."

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It is of interest that the wording for the last at least seven years (2000 to 2007 MOC bulletins) of the cause for revocation due to ethical breach used to read:

"the physician shall have violated any of "The Ethical Considerations in the Practice of Obstetrics and Gynecology" currently published by the American College of Obstetricians and Gynecologists and adhered to by the Board"

But, the 2008 MOC Bulletin, issued just six weeks after the ACOG Ethics Statement #385, changed the wording to include revocation for “violation of ABOG or ACOG rules and/or ethics principles”.

This new wording includes quite a bit of slippage, since it fails to refer to a published document, but rather to refer to a vague “rules or ethics principles”; a sort of “living document” interpretation which predicates the board certification of thousands of ob/gyns on the whims of the “ACOG Ethics Committee”, a body of a handful of ob/gyns without any particular mandate for representing the views of the ACOG membership. In fact, ACOG members have never been polled for our views on this subject.

Looking at the ACOG Ethics Committee Statement #385 combined with the new Maintenance of Certification (MOC) Bulletin which is the official rules of how to maintain board certification, it is clear that these documents have the potential to force ob/gyns who will not perform or refer for abortions out of the practice of obstetrics and gynecology. When summed together, these documents provide legal grounds for revoking the certification of any physician who refuses to perform or refer for abortions.

This has huge implications, since most hospitals use board certification as a proxy for competence. To obtain hospital privileges, most physicians fill out a questionnaire which asks: “Have you ever been removed from a professional society or had your board certification revoked?” A "yes" to this question almost always results in denial of hospital privileges, and therefore loss of livelihood.

A second aspect to gutting pro-life ob/gyns from the medical profession is the impact on patients. The practice of obstetrics and gynecology is unique within the medical profession, involving a tremendous degree of trust in the judgment of the ob/gyn on the part of the woman patient. Many of our patients come to us because they know we value the life of their unborn child as they do. Most of our patients are fully aware of, and share our pro-life worldviews. To make it impossible for pro-life ob/gyns to maintain board certification will be to leave a large number of pro-life women without obstetrical care.

Further, it is our very commitment to the lives of patients that causes many of our members to serve in underserved areas. The same ethical principles which cause us to work for the safety and health of the unborn child also cause many of us to serve in places which are not physically or financially attractive: because it’s the right thing to do.

AAPLOG would appreciate from the President’s Council an ethical analysis which takes into account all of these aspects of the current actions of ABOG and ACOG.

2. The use of the power of a licensing board to pressure physicians into complying with a controversial ethical position.

The second ethical question we would like the Bioethics Committee to address goes beyond the narrow issue of abortion to wider bioethical issues in health care:
Does a professional society have the power to bind the ethics of ALL PHYSICIANS, including those physicians who have chosen not to be members of that professional society specifically because that society does not represent their own ethical position?

Putting the question in other words: it is one thing for ACOG to say “If you want to be a part of the ACOG, you must adhere to these principles.” It is quite another thing for the American Board of Obstetrics and Gynecology (ABOG) to say to ob/gyns (who have chosen not to be part of ACOG because of ACOG’s rabid pro abortion activism) “You must comply with ACOG ethics or you are not competent to practice obstetrics and gynecology”. Does a voluntarily composed professional society (ACOG) have the power to bind the ethics of non-members by its influence on the professional certifying body (ABOG)

And, more importantly, should a certifying body like ABOG, which is entrusted nationwide to decide the medical competence of ob/gyns use compliance with the controversial ethical statements of another voluntary professional association (ACOG) as one of the criteria for competence, especially when that controversial ethical position contradicts Hippocratic medical tradition in force for the last 2000 years at least, as well as the tradition of established Western medical ethics for the last 1900 years?

By making compliance with controversial ACOG ethical principles grounds for revocation of board certification, ABOG infringes the ability of a physician to the free exercise of her/his trade, an implication not unnoticed by Mr. Leavitt of HHS. (His letter attached in e-copy). ABOG is also discriminating against physicians not on the basis of medical competence, but on the basis of worldview. It is from just such abuses of power that the proposed HHS regulations will protect health care workers.

3. The use of flawed and biased “ethical analysis” as the basis for judgment of a health care provider’s ethical character

The recent article by Chervenak well outlines the stance of the ABOG and ACOG regarding abortion referrals:

“Referral of patients for termination of pregnancy by physicians morally opposed to the procedure is ethically controversial, with polarized positions taken by physician organizations. … Direct referral is beneficence based and requires the referring physician to ensure that the referral occurs. Indirect referral is autonomy based with a beneficence based component that requires that the physician provide information to the patient about health care organizations that will provide competent care. … Conscience based objections to direct referral have merit; conscience based objections to indirect referral do not.”

AAPLOG would maintain that it is not “beneficent” to the patient to aid her obtaining a procedure which will prove lethal to her unborn child, and increase her own risk of suicide, major depression, and preterm birth in subsequent pregnancies. The whole

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“beneficence” argument rests on the assumption that abortion is “medical care”, which it is not. Abortion does not cure any medical illness. Abortion is an attempt at a surgical solution to a social problem. The mere fact that a patient requests a procedure does not make the performance of that procedure necessarily beneficent.

In fact, there are many instances in medicine where a physician will refuse something that a patient requests. For example, if a patient requests prescriptions for narcotic pain medicine, and in the physicians’ judgment, that pain medicine is not indicated, and is in fact harmful, it would be unethical to simply give the patient a prescription simply from the “beneficence” of fulfilling her request. It would also be unethical to refer that patient to a physician willing to give her narcotic pain medications without an indication. So, the perceived “beneficence” rests on the judgment of the physician as to whether or not the procedure will do the patient good or harm.

In the case of abortion, there is another ethical consideration, and that is the ethical duty of the obstetrician gynecologist to first do no harm, and then to do good to both of her/his patients: the fetus and the mother. In the case of abortion there is the aspect of patient abandonment which the physician commits when she/he refers for or performs abortions. There is a need for a thorough ethical analysis on this aspect as well.

AAPLOG would greatly appreciate the President’s Council analysis of the attached e-document “Ethical analysis of ACOG Ethics Committee #385”. This was not written by AAPLOG, but contains an ethical critique with which we agree.

In closing, we are including a portion of one of the letters written from an AAPLOG member to the President of ACOG.

RE: “The Limits of Conscientious Refusal in Reproductive Medicine”
ACOG Committee Opinion #385, November 2007

Dear Dr. Hale,

I have just reviewed the current committee opinion published by the ACOG ethics committee entitled “The Limits of Conscientious Refusal in Reproductive Medicine” and I am absolutely appalled that this was published by ACOG. As an ethicist who has chaired a hospital bioethics committee for years, I am absolutely trembling at the total disregard of ethical principals in this article. This is not an ethics committee opinion, but rather a document disguised as an ethics statement that promotes the pro-choice right-to-abortion-on-demand stance of ACOG.

Every first semester student of ethics learns that autonomy must be balanced by the other principles of ethics. Any one principle of ethics cannot trump all of the others, otherwise there is distortion of truth
and the dominant principle ends up skewing the analysis. The end result often is anything but ethical. ACOG’s committee opinion #385 is an excellent example of the collapse of ethical decision making when patient autonomy is allowed to dominate over every other principle of ethics.

I have been a member of ACOG since I was a junior fellow, and have served in ACOG committee membership and leadership roles for my entire professional career. Never before have I had such a pit in my stomach about the extreme divergence that the college continues to take, alienating physicians from membership who continue to have high moral values and the integrity to maintain those values. ACOG seems to have no issues with enforcing its own collective moral conscience, or lack thereof, on me and other physicians like me.

Publishing such a document is irresponsible and reprehensible. The most appropriate action by the College would be to rescind this document.

AAPLOG appreciates the opportunity to raise these questions before the President’s Council on Bioethics. We are requesting that the President’s Council on Bioethics consider the ethical questions raised in this letter, and we would value your written opinion in this matter.

Sincerely,

Donna J. Harrison

Donna J. Harrison, M.D.
Diplomat, American Board of Obstetrics and Gynecology
President, American Association of Prolife Obstetricians and Gynecologists
The American Civil Liberties Union

Statement
For

The President’s Council on Bioethics
Meeting on the Issue of “Conscience.”

Friday, September 12, 2008

Caroline Fredrickson, Director
ACLU Washington Legislative Office

Vania Leveille, Legislative Counsel
ACLU Washington Legislative Office

Louise Melling, Director
ACLU Reproductive Freedom Project

Sondra Goldschein
State Advocacy Director
ACLU Reproductive Freedom Project
On behalf of the American Civil Liberties Union (ACLU), a nationwide, nonpartisan, nonprofit organization of more than 500,000 members dedicated to protecting the principles of freedom and equality set forth in the Constitution and in our nation’s civil rights laws, we are pleased to submit this statement to the President’s Council on Bioethics for the public meeting being held today.

As the Council begins to explore issues relating to ethics, medical reform, and religious refusals in the health care context, we ask that special attention be given to understanding the issues raised when religious belief affects decision-making about reproductive health care.

In this statement, we will tell the story that alerted us to the issues raised by the intersection of these two interests, highlight the ACLU’s longstanding commitment to reproductive freedom and religious liberty, outline the framework we use for analyzing the appropriateness of religious refusals to provide reproductive health care, and briefly discuss why related regulations proposed by the Department of Health and Human Services (HHS) could be harmful to patients.

_A Hospital’s Refusal_

In 1994, a nineteen-year-old Nebraska woman was admitted to the emergency room at a religiously affiliated hospital with a blood clot in her lung. Tests revealed that she was approximately ten weeks pregnant, and that the clotting problem resulted from a rare and life-threatening condition exacerbated by the pregnancy. The hospital immediately put her on blood-thinners to eliminate the existing blood clot and to help prevent the formation of more clots that result in death.

Her doctors told her that she had two alternatives. She could stay in the hospital on intravenous blood-thinners for the remaining six-and-a-half months of her pregnancy and have an umbrella-like device inserted into one of her veins designed to catch blood clots before they reached a vital organ. Or she could have a first-trimester abortion, switch to oral blood thinners, and be released from the hospital. She decided to have the abortion. She wanted to go home to care for her two-year-old child.

On the morning she was scheduled to have the abortion, the hospital lawyer appeared in the operating room. He announced that the hospital would not permit an abortion on its premises - even though four doctors had certified that an abortion was necessary to save her life. The procedure was canceled and ten days of dangerous delay followed.

She wanted to be transferred to a facility that would perform the abortion, but the transport increased the risk that a blood clot would kill her. And her doctors felt that the procedure should be performed in a hospital because the blood-thinners she was taking made her prone to excessive bleeding. But the hospital refused to reconsider its decision not to allow the abortion on its premises. Notwithstanding the risks to her health, she was ultimately transferred by ambulance to her doctor’s office. He performed the abortion and sent her back to the hospital.
This patient was lucky in the end. She survived the risks she faced when this hospital refused to treat her. But the risk itself was unacceptable.

Commitment to Religious Liberty and Reproductive Freedom

The ACLU has a long, proud history of vigorously defending religious liberty. In Congress and in the courts, we have supported legislation providing stronger protection for religious exercise - even against neutral, generally applicable laws. For nearly a decade, the ACLU fought to preserve or restore the highest level of constitutional protection for claims of religious exercise. We were founding members of the coalition that supported the Religious Freedom Restoration Act in 1993, and we were instrumental in urging Congress to enact the Religious Land Use and Institutionalized Persons Act of 2000. We have also represented persons challenging burdens on the exercise of their religious beliefs. For example, we have sued to protect the right of Jewish students to wear a Star of David pendant at school; we have sued to defend the right of conservative Christian activists to broadcast on public access television; we have sued to protect the right of a Christian inmate to preach; and we have filed a brief in support of two women who were fired for refusing to work at a greyhound racetrack on Christmas Day.

We have been equally vigilant in our advocacy of reproductive freedom. The ACLU fought long and hard to persuade Congress to pass the Freedom of Access to Clinic Entrances Act to protect reproductive health clinics, patients, and professionals from deadly violence. We are currently key supporters of the Responsible Education About Life Act, which will ensure that teens receive complete and medically accurate sexuality education vital to protecting their health and lives. We have participated in nearly every critical Supreme Court case protecting reproductive freedom, from Roe v. Wade to Planned Parenthood v. Casey to Gonzales v. Carhart. This history makes the ACLU well-positioned to assist the Council in its consideration of how to address religiously based refusals to provide health care.

Framework for Analysis

The framework we propose for analyzing religiously based refusals to provide health care balances protection of public health, patient autonomy, and gender equality with the protection of individual religious belief and institutional religious worship. We reject the imposition of religious doctrines on those who do not share them, especially at the expense of the public health. At the same time, we seek the maximum possible accommodation of an individual's religious or conscientious objections, so long as patients' rights are not compromised as a result. We also seek to insulate churches, houses of worship, and similarly situated institutions from having to comply with laws that interfere with their religious practices.

The ACLU framework centers around two critical questions. First, we ask whether the refusal places burdens on people who do not share the beliefs that motivate the refusals. The more the burdens falls on such people, the less acceptable any claimed right to refuse. Second, we ask whether the objector is a sectarian institution engaged in religious practices, or is it instead an entity – whether religiously affiliated or not – that provides services to the general public. The more that services are made available to the general public and the less the services relate to an institution’s religious mission, the less acceptable an institution’s claimed right to refuse.
In the reproductive health context, it is often possible to accommodate individual – as opposed to institutional – refusals to provide certain health care services without imposing inappropriate burdens on others. But there must be adequate safeguards if an individual health care provider refuses to provide a service. Whatever their religious or moral scruples, health care professionals should give complete and accurate information, make appropriate referrals, effectuate informed health care decisions, and provide care in an emergency.

In the reproductive health context, the risk of imposition on those who do not share the objector's beliefs is especially great when an institution – such as an employer, hospital, health plan, pharmacy, or other corporate entity – refuses to provide a reproductive health service. The refusal of such institutions directly affects employees, patients, enrollees, and customers of diverse backgrounds and faiths. The law should not permit an institution's religious strictures to interfere with the public's access to reproductive health care. While entities operating in the public world ought to play by public rules, churches, temples, mosques, and other institutions whose purpose is to practice and teach religion ought generally to be able to refuse to provide services to which they have a religious objection.

Concrete examples may be clearer than general principles: every rape survivor ought to be offered emergency contraception to protect herself from getting pregnant as a result of the assault, no matter where she is treated; an administrative assistant working at a Catholic university should not have to pay out-of-pocket for birth control pills because her employer believes contraception is a sin; but a church should not have to purchase contraceptive coverage for its ministers and other clerics; and a doctor, nurse, or pharmacist who cannot in good conscience participate in abortions or contraceptive services should be allowed to opt out, so long as the patient is ensured safe, timely, and financially feasible alternative access to treatment. The factors we identify for evaluating refusal clauses should lead to these kinds of fair results.

Proposed Religious Refusal Regulations

Based on the framework outlined above, the ACLU is currently opposing a rule proposed by the Department of Health and Human Services. Last month, HHS released proposed regulations to address religious refusals to provide certain health services. Unfortunately, the rule does not strike the appropriate balance between patient access and religious liberty and could seriously undermine women’s ability to obtain essential reproductive health services. The rule leaves open the possibility that – based on religious beliefs – health care providers, including hospitals, insurance companies, and pharmacies, could deny women access to birth control. In addition, the rule may permit health care providers to withhold information and counseling about a wide range of health care services, including birth control and abortion.

To the extent that the regulation permits health care providers to withhold basic information and counseling from their patients, the proposed rule essentially abandons patients in the face of a health care provider’s refusal. Legal and ethical principles of informed consent require physicians to inform patients about all treatment options, including those to which the physician objects or those which he or she does not provide. Yet the proposed rule seems designed to do away with these essential safeguards. Instead, as a direct result of the proposed rule, patients
may never be able to access the refused health care – or even know about their right or option to
do so – due to geographic, economic, or health plan limitations. This proposal suggests that
religious refusals should *trump* patients’ basic health care needs; this is not an appropriate
balance of religious freedom and reproductive rights.

In conclusion, we recommend that the Council advocate for solutions that appropriately balance
patient access to health care with religious liberty.
Comments from the American Society for Reproductive Medicine

The ethics committee of the ASRM has addressed the issue of infertility treatment in patients with a very poor prognosis. Our committee concluded it was ethical for physicians to refuse treatment to patients whose prognosis for success was very low, provided they fully inform the patient and provide referrals, if appropriate. The committee reminded our member physicians that decisions about treatment must always be patient-centered. I am happy to provide copies of that report to you.

Our ethics committee has not yet done an explicit report on provider conscience; however, the concepts of autonomy- the right of the patient to make decisions regarding his or her own care- and full informed consent permeate its work. While we understand that there are some decisions patients may make with which their doctors will disagree, providers who have moral objections to providing certain medical care have an equally compelling obligation to refer a patient seeking that care to an individual or facility that can provide it.

We do not believe individuals should be forced to undergo or perform medical procedures against their will. We fully support the right of individuals whose religious or moral beliefs lead them to consider contraception unethical not to use it or even to decline to help others obtain it, but such individuals should inform patients that their personal beliefs influence the advice they are giving, that others might give different advice, and that the patient might consult another provider. We would also suggest that such individuals choose not to work in a contraceptive clinic. The right of a provider to decline to prescribe or provide care he finds conscientiously objectionable does not equate to the right to obstruct a patient’s knowledge of or access to care the patient requests or needs.

We hold that when an individual undertakes work in the health care field, they agree to put the interests of the patient ahead of their own. Although physicians should not be forced to offer infertile patients assisted reproductive technology (ART) if they believe that act to be sinful, we believe it is unethical for a physician to refuse to offer or to withhold information about such a service from a patient who could benefit from it, particularly if that physician is representing themselves as a specialist in reproductive disorders. Infertility is a disease recognized by the World Health Organization. And while most patients who are unable to conceive children without medical assistance resolve their infertility though the use of ovulation induction drugs, artificial insemination, or surgery, many others, for whom these means are ineffective, have successfully added children to their families through ART.

We find the full treatment of this issue by the ethics committee of the American College of Obstetricians and Gynecologists to be persuasive.

Thank you.
The Catholic Medical Association (CMA) is the largest association of Catholic physicians in North America. The CMA is concerned about attacks on the conscience rights of physicians, above all by the recent initiatives of the American College of Obstetricians and Gynecologists and the American Board of Obstetricians and Gynecologists.

The CMA's letters to ACOG and ABOG are attached. Please enter them into the public record of the deliberations of the President's Council on Bioethics on this important issue.

Thank you very much.

Sincerely,

John F. Brehany, Ph.D.
Executive Director
Catholic Medical Association
Kenneth L. Noller, M.D.
Board President
American College of Obstetricians and Gynecologists
409 12th St., S.W.
Washington, D.C. 20090-6920
February 28, 2008

Dear Dr. Noller:

On November 7, 2007, the American College of Obstetricians and Gynecologists (ACOG) Committee on Ethics released an Opinion, “The Limits of Conscientious Refusal in Reproductive Medicine” (the “Opinion”), which attempts to resolve the issue of ethically appropriate limits of conscientious judgments in reproductive medicine. This is an issue that demands serious attention and sustained dialogue. Unfortunately, however, the Opinion not only fails to provide helpful guidance, but is so flawed that it threatens the reputation of ACOG itself. The Catholic Medical Association urges ACOG to rescind this opinion immediately.

The Committee on Ethics’ Opinion exhibits three fatal flaws: (1) it is woefully inadequate in basic ethical theory and analysis; (2) the “considerations” advanced to limit conscientious judgments are so vague and contentious that they cannot meaningfully function as ethical or professional guidelines; and (3) the solutions proposed are unjust, unworkable, and harmful to the profession of medicine. We elaborate on these points briefly below.

1. Flaws in Ethical Analysis. The Opinion contains a seriously flawed and gratuitously condescending approach to conscience. The Opinion describes conscience in limited, negative, emotional terms, emphasizing such terms as “private,” “sanction,” “sentiment,” and emotions such as self-hatred. At best, the Opinion notes, “Personal conscience, so conceived, is not merely a source of potential conflict.” In fact, however, while conscience is a personal, subjective judgment, it is not merely “private” or relativistic. Conscientious judgments provide guidance both for good actions that should be done and unethical actions that should be refused. It is true that conscientious judgments are at times accompanied by emotion, particularly in conflict cases. Still, conscience is not a matter of feeling, as the Opinion suggests, but a judgment about moral truth.
In addition to providing an inadequate description of the nature and role of conscience, the Opinion fails to do justice to the ethical issue of cooperation in evil raised by providing referrals for abortion and, indeed, dismisses concerns about complicity in gravely immoral actions.

This disregard for the harm caused by complicity in moral evil is particularly hard to understand given the painful lessons the medical profession learned from physicians’ silent tolerance of, or complicity in, the crimes against humanity in Nazi Germany. Here in the United States, in the infamous Tuskegee Syphilis Study, U.S. Public Health Service physicians denied treatment to patients with syphilis so they could study the late stages of the disease. Moreover, physicians participated or acquiesced in involuntary sterilizations under color of law in more than 30 more states between 1907 and the early 1970s. All agree now that these practices were unethical and a violation of patients’ rights and that physicians were wrong to cooperate, even tacitly, or to remain silent, even when they were not direct participants.

The Opinion mentions, but fails to describe, what it means by the “set of moral values – and duties – that are central to medical practice.” Since the Opinion goes on to list four “criteria” that ostensibly trump physicians’ ethical convictions, it appears that these are the moral values and duties the Ethics Committee has in mind. Inexplicably missing in this section of the Opinion is any mention of respect for human life, which has been recognized by most physicians across centuries and cultures as a fundamental value and duty that is central to the practice of medicine.

Finally, the Opinion attempts, in several ways, to legitimize a moral duty to provide any requested “reproductive service.” The Opinion appeals to terminology such as “standard care,” “standard reproductive services,” and “standard practices” without ever defining who or what has established these standards. The Opinion attempts to conflate the duty to provide treatment in an emergency with a new obligation – to provide “medically indicated and requested care” where failure to do so “might” negatively affect a patient’s “mental health.” This so-called obligation is unnecessary and completely unfounded. Our position is that elective abortion is not healthcare, nor does it qualify as an emergency. In a true emergency, where a pregnant woman’s life is in danger, physicians can and should strive to save the lives of the mother and her unborn child.

2. Considerations Limiting Conscientious Refusal. The “considerations” that the Opinion claims limit conscientious judgments are so vague and contentious that they cannot meaningfully function as ethical guidelines. For example, the Opinion cites the “degree of imposition” as a criterion for overriding the ethical and professional judgment of physicians. It is
not clear at all what kinds or degrees of “imposition” will trump ethical judgment, much less why they should. In appealing to the criterion of “effect on patient health,” the Opinion unfairly assumes that all requested reproductive interventions (including abortion or egg harvesting) are in fact good for the patient’s health. Moreover, it unfairly implies that physicians with ethical objections to such practices are not motivated precisely by concern for the patient’s short and long term health. In appealing to the category of scientific integrity, the Opinion overstates the certainty that current science can provide about the mechanism of drugs (such as those used in Plan B). And it fails to recognize that the real “possibility of postfertilization events” inherent in the use of such drugs is a valid matter for a professional’s clinical and ethical judgment. Finally, in appealing to “matters of oppression,” the Opinion injects a dubious political criterion into the heart of medical decision-making.

3. Solutions Proposed. The Opinion proposes solutions that are unjust, unworkable, and harmful to the profession of medicine. The Opinion unfairly dictates that only physicians who oppose a specific set of medical “services” should be required to provide patients with “prior notice of their personal moral commitments.” We think that all physicians should be ready to explain, whenever appropriate, their ethical convictions with regard to medical practice and care. To suggest that providers with prolife ethical convictions “practice in proximity to individuals who do not share their views” is unworkable.

The solutions proposed in the Opinion are not only unjust and unworkable, but harmful to the profession of medicine. First, by negatively and narrowly defining conscience and by suggesting that judgments of conscience are best left to “organized advocacy” groups, the Opinion tacitly discourages physicians from thinking and acting in accordance with their judgment of what is ethical or unethical. The demand that physicians provide “professionally accepted characterizations of reproductive health services” shows distrust of professionals and of the quality of the medical profession as a whole. Second, in appealing to the vague criterion of past discrimination allegedly suffered by some people, the Opinion allows values and considerations extraneous to the practice and profession of medicine to dictate treatment modalities.

Third, the Opinion invites lawmakers to enforce compliance with these vague and contentious notions. This would run counter to AMA Code of Ethics Opinion E-10.05: “[I]t may be ethically permissible for physicians to decline a potential patient when . . . [a] specific treatment sought by an individual is incompatible with the physician’s personal, religious, or moral beliefs.” Moreover, this expressly contradicts ACOG’s own Statement of Policy on Abortion: “The intervention of legislative bodies
into medical decision making is inappropriate, ill-advised and dangerous.”

Such legislation could not help but undermine the freedom and integrity of the profession of medicine and invite additional litigation and legislation that have nothing to do with promoting the health of women. Indeed, ACOG should be aware that legislation attempting to enforce this Opinion would violate constitutional and statutory protections of physicians’ freedom of religion and conscience rights at federal and state levels. Finally, driving out physicians who respect the value of every human life – born and unborn – from the profession of obstetrics and gynecology would harm the profession and the health of many women and children.

There is a great deal of work to be done in assisting members of ACOG to practice medicine conscientiously, and to educate patients on what this means and why it is important. We stand ready to assist in this task. However, to be valid, any effort will have to be based on sound ethical analysis, undertaken in a spirit of dialogue, with respect for diversity in beliefs. The Committee on Ethics Opinion No. 385 falls significantly short in all these respects. Therefore, it should be rescinded immediately.

Respectfully,

Kathleen M. Raviele, M.D., F.A.C.O.G.
President, Catholic Medical Association

John F. Brehany, Ph.D.
Executive Director, Catholic Medical Association

cc:

Anne D. Lyerly, M.D.
Chair, ACOG Committee on Ethics

Hal C. Lawrence, III, M.D.
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Ms. Mary Mitchell
c/o ACOG Ethics Committee
Kenneth L. Noller, M.D.
Board President
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409 12th St., S.W.
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May 13, 2008

Dear Dr. Noller:

Thank you very much for your letter of March 26, 2008. We appreciate the consideration which the ACOG Executive Board and the Committee on Ethics gave to the input on “The Limits of Conscientious Refusal in Reproductive Medicine” (Opinion #385). We appreciate the fact that the Committee on Ethics was instructed to meet and reevaluate Opinion #385 as soon as possible. At the same time, however, there are still some critical issues of content and process regarding Opinion #385 that must be resolved in a timely manner. These critical issues include:

1. **The need to rescind Opinion #385.** First, we respectfully insist that ACOG Committee on Ethics rescind Opinion #385 when they meet to reconsider it. If the Committee on Ethics refuses to do this, the ACOG Executive Board should take action. This opinion manifests so many substantive flaws that it cannot be fixed. Whatever the motives of Committee members, Opinion #385 is not respectful of conscience. The description of conscience provided on page 2 is overwhelmingly negative. Indeed, physicians are encouraged to leave issues of conscience to professional advocacy groups (e.g., “moral distress for providers” . . . is “best met through organized advocacy on the part of professional organizations”). Moreover, there is no respect for the deep conscientious convictions of many pro-life ob-gyns. The “ethical considerations” proffered to guide the application of conscience are so vague and contentious that they cannot function as ethical guidelines. Finally Opinion #385 contradicts other ACOG ethics statements as well as AMA standards that address respect for physicians’ ethical convictions. In sum, Opinion #385 is so flawed that it should be rescinded immediately.

2. **Clarification regarding referral for abortion.** While we appreciate your statement that “the Opinion does not compel any Fellow to perform any procedure which conflicts with his or her conscience . . .” your letter does not address the issue of referral for abortion. Opinion #385 dismissed the ethical significance of referral without adequate analysis and demanded referral as a minimum level of response to a request for abortion. Many ob-gyns appropriately view referral as a form of facilitation of the procedure to be done. In short, to demand that a physician violate his or her conscience and facilitate the performance of abortion by providing a referral is neither just nor necessary. The consciences of competent physicians must be respected in this matter.
3. **Providing clarity regarding ethical standards.** It is critically important that you provide clarity regarding which ethical statements and standards of ACOG are binding on Fellows. This is particularly important given the change in ABOG’s Maintenance of Certification Bulletin for 2008. That Bulletin states that “cause” for revocation or withholding of certification may include “violation of ABOG or ACOG rules and/or ethics principles . . .” (page 10, emphasis added), rather than citing “The Ethical Considerations in the Practice of Obstetrics and Gynecology currently published by The American College of Obstetricians and Gynecologists and adhered to by the Board” (as did the Maintenance of Certification Bulletin for 2007, page 27). Your March 26 letter does note that Opinion #385 is not part of the “Code of Professional Ethics of the American College of Obstetricians and Gynecologists” and that it “was not intended to be used as a rule of ethical conduct which could be used to affect an individual’s initial or continuing Fellowship in ACOG.” However, the status of Opinion #385 is still unclear, and legitimate questions remain about what status similar kinds of ethics opinions might have in the future. We urge you to publicly clarify this issue both to Fellows and to the American Board of Obstetricians and Gynecologists.

4. **The need for due process.** This controversial opinion was adopted without sufficient input from Fellows. When establishing ethical standards for the profession, it is essential that ACOG address these in a manner that respects the requirements of due process, including soliciting input and approval from Fellows.

Respectfully,

Kathleen M. Raviele, M.D., F.A.C.O.G.
President, Catholic Medical Association

John F. Brehany, Ph.D.
Executive Director, Catholic Medical Association

cc:

Anne D. Lyerly, M.D.
Chair, ACOG Committee on Ethics

Hal C. Lawrence, III, M.D.
c/o ACOG Ethics Committee

Ms. Mary Mitchell
c/o ACOG Ethics Committee
Dear Dr. Gant:

On November 7, 2007, the American College of Obstetricians and Gynecologists (ACOG) Committee on Ethics released an Opinion, “The Limits of Conscientious Refusal in Reproductive Medicine” (Opinion #385), which attempts to resolve the issue of ethically appropriate limits of conscientious judgments in reproductive medicine. Unfortunately, however, Opinion #385 not only failed to provide helpful guidance, but expressed opinions and recommendations that threaten to violate the rights of conscience and religious freedom of many ACOG member physicians. The Catholic Medical Association (CMA) has urged ACOG to rescind this opinion immediately (see our letter to ACOG, enclosed).

Our members, and many other pro-life physicians, are concerned that their certification or re-certification by the American Board of Obstetricians and Gynecologists (ABOG) will be jeopardized by ACOG’s Opinion #385. Their concern is heightened by a lack of clarity in certain statements in ABOG’s Maintenance of Certification Bulletin for 2008.

In discussing “Status with the Board: 5. Revoked Certificate,” ABOG’s Maintenance of Certification Bulletin for 2008 states,

a. An individual has had their Diplomate status revoked by the American Board of Obstetrics and Gynecology for cause.

b. Cause in this case may be due to, but is not limited to, licensure revocation by any State Board of Medical Examiners, violation of ABOG or ACOG rules and/or ethics principles or felony convictions (page 10, emphasis added).

Later, the Maintenance of Certification Bulletin for 2008 states,

If a physician is involved in litigation or investigation regarding ethical or moral issues, the individual will not be scheduled for examination, and the application will be re-examined (page 26, emphasis added).
There is no explanation in this Bulletin exactly which ACOG “rules and/or ethics principles” provide guidance for such an important decision.

This lack of clarity is particularly important to resolve in light of the March 26, 2008 letter sent by Kenneth Noller, M.D. to ACOG Fellows. In that letter, Dr. Noller notes that “This Committee Opinion is not part of the ‘Code of Ethics of the American College of Obstetricians and Gynecologists’.” This distinction might have been dispositive if ABOG had retained language from its Maintenance of Certification Bulletin for 2007. That Bulletin stated in section 3.f that disqualification or Diplomate revocation would occur if a “physician shall have violated any of ‘The Ethical Considerations in the Practice of Obstetrics and Gynecology’ currently published by The American College of Obstetricians and Gynecologists and adhered to by the Board.” However, since ABOG has broadened its language, as noted above, it is possible that the conscientious refusal of a physician to comply with a given provision of Opinion #385 could be interpreted by some as a “violation . . . of ACOG rules and/or ethics principles . . . ,” thus constituting “cause” for revocation of Diplomate status. It is critically important that ABOG clarify exactly which “rules and/or ethics principles” provide the standard in determining cause for denial or revocation of ABOG certification.

Your March 19, 2008 response to Health and Human Services Secretary Michael Leavitt makes several notable points, e.g.: (i) that there is no evidence that ABOG has ever asked physicians “to violate their own ethical or moral standards”; (ii) that ABOG has “taken no stand . . . against individual physicians who choose to or choose not to perform abortions or to refer patients to abortion providers”; and (iii) that refusal to perform or refer for abortion “is not a consideration in the applications or in the examinations administered by the American Board of Obstetricians and Gynecologists in any of its certifications or in its Maintenance of Certification requirements or examinations.” However, you do not clearly state that ABOG will not make maintenance of certification decisions based on Opinion #385.

Most public statements to date have focused on the egregious violations of conscience rights and religious freedom that would result from forcing physicians to perform or refer for abortion. However, the flawed ethical analysis and the ideological arguments advanced in Opinion #385 provide a framework for discriminating against physicians based on their religious beliefs or ethical convictions. The Opinion simply dismisses ethical concerns raised by referral for procedures a physician deems unethical. Moreover, it attempts to establish an expectation that a wide variety of elective reproductive services shall be offered to patients even if they violate the ethical convictions of physicians. The Opinion does this by characterizing elective reproductive procedures as “standard” and “indicated,” then dictating “considerations” that can override physicians’ ethical judgments. These considerations, however, are so vague and contentious that they cannot meaningfully function as ethical or
professional guidelines, much less justify overriding a physician’s conscientious, professional judgment.

Given the many significant flaws in the content, and process of approval of Opinion #385, and given that enforcing compliance with this Opinion will compel physicians to choose between violating deep conscientious and religious beliefs and their practice of medicine, it is critical that the American Board of Obstetricians and Gynecologists clearly affirm that the ethical “standards” listed in this Opinion will not be used, now or in the future, in ABOG certification. This should not be difficult since Dr. Noller stated, in his above-referenced letter, that: “This Committee Opinion was not intended to be used as a rule of ethical conduct which could be used to affect an individual’s initial or continuing Fellowship in ACOG” (emphasis added).

Therefore, we urge you to clearly affirm that Opinion #385 will not be cited or relied upon in any way by ABOG in certification or re-certification decisions.

Thank you.

Respectfully,

Kathleen M. Raviele, M.D., F.A.C.O.G.
President, Catholic Medical Association

John F. Brehany, Ph.D.
Executive Director, Catholic Medical Association
April 4, 2008

Norman F. Gant, MD.
Executive Director
American Board of Obstetricians and Gynecologists
2915 Vine St.
Dallas, TX 75204

Kenneth L. Noller, MD, MS,
President
The American College of Obstetricians and Gynecology
409 12th Street, NW
Washington, DC 20090-6920

Dear Drs. Gant and Noller,

As the nation’s largest public policy women’s organization, and as patients of obstetricians and gynecologists, we have great concern that our ability to choose doctors we trust will be severely limited or become non-existent due to an opinion by ACOG.

Many women, and virtually all of our members (approximately 500,000), select their doctor by the values they hold highest. Chief among them is the sanctity of life. Many women, especially as they are nurturing their son or daughter within them, need to fully trust that their doctor will treat their baby with the same concern and care as they provide other patients.

How can a woman trust a doctor to determine the best care for the child she is carrying if that doctor will destroy a baby at the request of a patient? That is the question that drives many women to choose only obstetricians and gynecologists that will not commit abortion, nor refer for a child to be aborted.

However, ACOG Committee Opinion, Number 385, titled “The Limits of Conscientious Refusal in Reproductive Medicine” would deny women this ability. This opinion claims it is unethical or violates the standard of care for an obstetrician and gynecologist not to commit abortion or refer for abortions, and doctors “with moral or religious objections should ... practice in proximity to individuals who do not share their views.”
Shortly after ACOG’s Opinion was released, ABOG’s 2008 Maintenance of Certification Bulletin declared that physicians may lose their certification for “violation of ABOG or ACOG rules and/or ethics principles…”

If followed to its logical conclusion, obstetricians and gynecologists who respect the life of unborn children and refuse to destroy them at the request of a patient, or is unable or unwilling to relocate to be near an abortionist, would be considered in violation of ACOG’s opinion and possibly driven out of practice.

In the name of women’s choice, this would leave us – women who more than want these professionals as our doctor, we need pro-life doctors in order to fully trust ourselves to their care – with no choice. Women who do not live near a doctor who commits abortions would also be denied access to a pro-life doctor, since under ACOG’s Opinion pro-life doctors would have to relocate.

The ACOG Committee Opinion neglects to consider patients who choose doctors who will not commit or refer for abortions. And this includes patients who may be personally “pro-choice” but, for a variety of reasons, want their own doctor to hold the highest of ethical standards that treat all human beings with equal respect. Women who have had difficult pregnancies, or unable previously to get pregnant, are especially sensitive that their doctors respect the life within them and do not treat their child as disposable.

We entreat you to disavow ACOG Committee Opinion, Number 385, on “The Limits of Conscientious Refusal in Reproductive Medicine,” and affirm the right of obstetricians and gynecologists not to commit abortions or refer for abortions, and to be free to practice where they choose and where needed by patients. While no doctor as yet has been denied certification for their moral or ethical beliefs on abortion, these documents taken together have set a new standard. We seek assurance that both ACOG and ABOG specifically reject the views in ACOG’s Committee Opinion, Number 385.

Sincerely,

Wendy Wright
President
Testimony Submitted by:

Dr. Theresa A. Deisher
Sound Choice Pharmaceutical Institute
President
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CEO and Managing Member
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Biography:

Theresa Deisher, Ph.D. (President, Sound Choice Pharmaceutical Institute, CEO and Managing Member, AVM Biotechnology). Dr. Deisher, an expert in the field of adult stem cell therapies and regenerative medicine, brings 18 years of experience in scientific and corporate leadership positions involving research, discovery, production and commercialization of human therapeutics. Dr. Deisher’s penchant for groundbreaking scientific discovery and her distinguished scientific research has resulted in 23 patents issued in her name. She has published numerous scientific manuscripts and is a frequent invited lecturer and guest speaker in the area of stem cell technology and regenerative medicine. Throughout her career, Dr. Deisher has been recruited by some of the country’s top biotechnology companies, including Genentech, Repligen, ZymoGenetics, Immunex and Amgen. She has managed and mentored undergraduate honors students, post-doctoral fellows, scientific executives and over 20 research assistants/scientists at all levels of responsibility.

Dr. Deisher graduated with honors and distinction from Stanford University, and obtained her Ph.D. in Molecular and Cellular Physiology from the Department of Molecular and Cellular Physiology, Stanford University.

Subsequent to obtaining her Ph.D from Stanford, Dr. Deisher was recruited by Repligen Corporation (Cambridge, MA) and accepted a position as Research Scientist where she managed a staff of associates and scientists and directed the development of research and clinical assays in support of Phase I and Phase II clinical trials for various Repligen developmental efforts. Additionally, Dr. Deisher was selected by Sr. Management to participate in strategic alliance initiatives, including serving on the Repligen / Lilly joint development committee.
Following Repligen, Dr. Deisher accepted a position at ZymoGenetics, Inc (Seattle, WA) as Sr. Scientist, Cardiovascular Biology. While at ZymoGenetics, Dr. Deisher’s research and discovery in the area of cardiovascular biology led to the filing of dozens of patents. Dr. Deisher was the first person world-wide to identify and patent stem cells from the adult heart, including what are now called ‘very small embryonic-like stem cells’. Her discovery remains one of the most significant discoveries in the area of stem cell research. Within the field of regenerative medicine, Dr. Deisher is also a patented inventor of the most potent mesenchymal growth factor ever identified (licensed to Serono for clinical development), and of the use of cytokines to mobilize adult embryoid-like cells.

Following ZymoGenetics, Dr. Deisher was named Sr. Staff Scientist, Vascular Biology at Immunex (Seattle, WA) where she was the project leader for both the Antithrombotic division and the Inflammation and Myocardial Repair division.

Dr. Deisher was named Principal Scientist at Amgen, Inc. (Seattle, WA) following Amgen’s acquisition of Immunex. She led multi-disciplinary teams working on the biology and commercial development of novel co-stimulatory pathways involved in the initiation and progression of cardiac failure. Her research interests encompassed stem cell therapies for myocardial regeneration. Additionally, Dr. Deisher’s team introduced revolutionary non-invasive imaging technologies for pre-clinical research to the company, including ultrasound (echocardiography) and near-infrared imaging. As a result, the company was honored as an official ‘Site of Excellence’ by Philips Medical for her department’s pioneering work.

Most recently, Dr. Deisher served as Vice President of Research and Development for Cellcyte Genetics Corporation, a post she held until October 2007 prior to founding AVM Biotechnology and Sound Choice Pharmaceutical Institute.

Testimony on Conscience Rights related to biologic drug disclosure and alternative drugs.

I would like to discuss Fair Labeling and Informed Consent for our medicines, and to ask for your support for studies to examine the health consequences of having contaminating aborted fetal human DNA in our medicines and vaccines. It is a matter of conscience, whether for moral reasons or safety concerns, that a consumer should be informed of the source of contaminants in our medicines, and of alternative medicines that may be available that would not be morally or philosophically objectionable to them.
Some childhood vaccines that are mandated prior to entering kindergarten are only available in the US produced using aborted fetal cells, these include MMR (mumps measles rubella) and chickenpox. Other mandated childhood vaccines are available from both animal or human sources, and yet parents and grandparents are not informed of this so that they can choose a vaccine compatible with their consciences.

When pharmaceutical companies switched from using animal cell lines to using aborted human fetal cell lines to produce these vaccines, in the mid to late 1970s, they assumed, without any evidence, that using aborted fetal cells would result in a more efficient production system. Brief discussions about potential adverse health consequences of using aborted human cell lines for vaccine production were captured in minutes from FDA advisory meetings about this switch. However, no studies have been done to actually measure the extent of those potential adverse consequences.

Vaccines and biologics (engineered proteins as drugs) are too large to make in a test tube, so companies harness the normal machinery used to make these, cells. No final drug is ever completely ‘pure’ and you will find contaminating DNA and cellular debris from the production cell in your final product. When we switch from using animal cells to using human cells we now have human DNA in our vaccines and our drugs.

Shouldn’t parents and grandparents know that when they immunize their children with a particular vaccine they are also injecting their children with DNA from an aborted fetus? Yet there are no laws that require drug manufacturers to inform the public of this. The package insert for the MMR II vaccine (mumps, measles, rubella) states: “MERUVAX* II (Rubella Virus Vaccine Live), the Wistar RA 27/3 strain of live attenuated rubella virus propagated in WI-38 human diploid lung Fibroblasts”, but doesn’t tell you that contaminating DNA from the WI-38 propagation strain is found in the final product. The package insert for Varivax, a chickenpox vaccine, states that the vaccine contains “residual components of MRC-5 cells including DNA and protein”, but how many parents or grandparents, let alone pediatricians and pharmacists, would know that MRC-5, or WI-38, is a cell line derived from an aborted fetus, and that the contaminating DNA and protein listed on the package insert is the DNA and protein of an aborted fetus? If we have the legal right to know what is in our Big Macs, don’t we have the right to know what is in our vaccines and medicines? Contaminating human DNA in these vaccines has the potential to trigger auto-
immune responses and also the potential to become incorporated into our own genes, a process called homologous recombination.

Time magazine’s June 8 2008 cover story highlighted the increasing numbers of US parents opting out of the recommended vaccine schedule due to, among other reasons, their perceived concern about a link between vaccines and autism. According to the Time article and CDC statistics, on average, 10% of US children are not fully vaccinated, and in some states the rate is much higher. For instance, Washington State has a reported vaccination compliance of only 70%. Vaccine compliance rates this low raise the specter of epidemic outbreaks of diseases such as measles that could cripple local and state economies. Parents, led by celebrities such as Jenny McCarthy, are demanding ‘green’ vaccines. These parents, however, don’t know what it is that will produce ‘green’ vaccines. They don’t know what to demand. How could they? They don’t actually know what is in the vaccines.

The perceived link between childhood vaccines and autism has generated significant press and controversy since 1992. The suggested link has been, and is today, the MMR vaccine. Since 1983, the MMR vaccine in the US has only been produced using aborted fetal cells. Coincidentally, severe autism began to rise in the US in 1983, increasing from less than 1 child per 10,000 to 16-17 children per 10,000 (or about 1 in 500) by 1990. The aborted fetal produced MMR was introduced to the UK almost a decade later, and an immediate rise in autism levels was noted, which lead to the suspected link between the vaccine and autism.

International studies have been performed to refute this link, focusing on Thimerosal (mercury) found in the vaccine’s buffer, and on the measles component of this vaccine. Studies that have been conducted have not found an association between mercury or the measles component and autism. The published conclusions, including a recent Washington Post story, have been that the MMR vaccine is therefore not linked to autism. And yet, parents remain fearful and unconvinced, and justifiably so. The only conclusions that can be drawn from the studies that have been done is that neither mercury nor the measles virus in the vaccine can be associated with autism. One cannot conclude from the studies that there is no link between this vaccine and autism. I find it fascinating, perplexing really, that such a broad conclusion “MMR vaccine is not linked to autism” has nevertheless been spread to the public, to the scientific community and to public officials. No well designed studies, either
retrospective or prospective, have been done to truly examine this potential link. No studies have been done to examine the link between vaccines containing human aborted fetal DNA and epidemic levels of diseases such as autism.

How might the human DNA contaminated vaccines contribute to human disease? First, there is the potential for the contaminating DNA to be mixed with our own genes by a process called homologous recombination. Homologous recombination is an established biologic phenomenon in which a segment of a cell’s DNA is substituted by another segment of DNA that is similar. This can occur during cell division or DNA repair. Homologous recombination occurs naturally to create genetic diversity in our offspring, and is also conveniently harnessed by scientists to introduce experimental DNA into cells or animals. We do not yet know if this occurs with the contaminating human DNA found in some of our vaccines, and if so, to what extent. Imagine the potential consequences of human DNA from a vaccine, a vaccine that is given to children at an average age of 15 months, being incorporated into a child’s developing brain. One does not need to be a rocket scientist to know that this potential has to be studied.

In addition to the potential for homologous recombination, DNA is known to be a powerful immune stimulant. Diseases like graft versus host, juvenile (type I) diabetes, multiple sclerosis, lupus and some forms of arthritis are what are called auto-immune diseases. What these are are diseases driven by immune attack from our own immune system on our own organs, a system normally responsible to attack invading bacteria and pathogens. Targeted self-destruction, if you will. Science does not yet know, except for graft versus host disease, what triggers the auto-immune attack. We certainly lack studies that have examined the relationship between immune responses to human DNA containing vaccines and auto-immune diseases.

I would ask all of you to support FLICA legislation, Fair Labeling and Informed Consent, to insure that consumers, whether for moral, philosophical or safety reasons, KNOW what they are giving their children in vaccines. The FLICA legislation would require not only informed consent, but education of each parent about alternative vaccines. With the approval of the creation of HUMAN-ANIMAL hybrids by the UK this past spring, this legislation is now gaining bipartisan and pro-choice support. Wouldn’t you want to know if your medicine contained DNA from a human-animal hybrid?
Aborted human DNA in our vaccines is not the end, it is only the beginning, as the creation of human-animal hybrids demonstrates. A new aborted fetal cell line has been developed, called PerC6, and licenses have been taken by over 50 partners, including the NIH and the Walter Reed Army Institute, to use this cell line for new vaccine and biologics production. The goal of the company that created the PerC6 is to become the production cell line for ALL vaccines, therapeutics antibodies, biologic drugs and gene therapy. We must know the consequences of contaminating human DNA before we wake up and discover that all newly approved recombinant drugs are produced by aborted fetal cells.

Aborted fetal cells are also now used to discover new food additives and flavor enhancers. Imagine that; the cells from an aborted fetus used to make your candy sweeter. Isn’t that disgusting? And furthermore, as the company that performs this research states, one may never know these additives will someday be in our food products due to the current labeling guidelines which would allow these new additives to be captured under the generic label of ‘artificial flavors’.

The conscience rights of almost half of the US population are being denied by our current labeling guidelines for biologics and food additives. A lack of information forces people to be complicit in a practice that many would find reprehensible if they only knew that aborted fetal cell lines are being used for drug discovery and production.

Thank you for your attention.
The following are copies of emails sent to the President’s Council on Bioethics in order to be considered part of the “written testimony” record for our September 11-12, 2008, meeting.

**Sept. 12, 2008**

I recently received an email that new legislation may be put into affect that would directly impact my pro-life values as well as the values of our pro-life doctors. It is not fair to require doctors of faith and moral conscience to do things that go against their moral/religious beliefs. We have a right to pro-life doctors.

The pro-choice agenda's main argument is that everyone has a right to chose what happens to their bodies. Why should there be a double standard for those following their moral and religious teachings? We have a right to doctors that will not compromise our beliefs on abortion, contraception, IVF, et cetera.

Please consider what I and other pro-lifers have said. Let's work to keep this country free for all, as this is in accordance with the pro-choice agenda.

God Bless!

**Jill Syrigos**

**Sept. 11, 2008**

Please protect the right of conscience for health care providers. Medical professionals need to have the right to deny services that go against their beliefs. The President's Council on Bioethics should protect their rights.

**-- Ernest Fernandez**

**Sept. 10, 2008**

I am emailing to voice my opinion that American OB/GYN's should be able to practice without performing abortions and or administering the "overnight pill. Please fight for the freedom to allow the MD's and their patients to have the choice to choose what they believe is morally right.

Thank you,

**Wendy Kiser**

Louisville, KY

I am writing The President's Council on Bioethics in regards to the recent opinion on The Limits of Conscientious Refusal in Medicine. This opinion states that all OBGYN's must refer clients for abortions as well as perform abortions even if the OBGYN has a personal conviction/core value that abortion is, in fact, taking a life. America's founding fathers clearly intended that freedom of conscience to determine such choices as these remains within the realm of personal liberty. As an American, I value having Pro-Life OBGYN's in practice. It provides viable options for women who otherwise would perhaps not realize there are other choices besides abortion. Ironically, in this age where 'Pro-Choice' means allowing one to choose, this opinion to dictate moral decisions of all OBGYNs on the specific practice of abortion betrays an inclination bordering on dictatorship indicating some would impose that abortion be a standard operating period procedure, a matter of business as usual if you please, leaving no other options on the table (no pun intended). I, for one, would be sad to see such a mentality be the 'guiding light' of medical practice. It betrays the Hippocratic oath and the very idea of civilization.

Respectfully submitted,
Lorie Foucault

Please preserve the right of health care providers to follow their conscience in not performing services or not making referrals for services for such things as abortions or artificial insemination, in vitro fertilization, and emergency contraception.

If health care providers are required to perform or refer to services which violate their consciences, many will leave the health care profession. I want to be able to choose a doctor whose values I trust.

Sincerely,

Constance Downing
Kodiak, AK

Sept. 9, 2008

Everyone in this country deserves to have reliable health care...this includes those of us who place a high value on life.

When I go in to get ob care I want a doctor that will value and fight for my child's life as much as I do. That child is NOT a replaceable commodity! When I take my parents and my grandparents in for care I want a doctor that will genuinely help them, not just some doctor that will ignore their health issues and prescribe something just to "get them by" until they die, or even worse when they become critically ill completely refuse them basic care so they do die! Doctors who will do their best to care for each of us as babies, children, handicapped, and elderly, because we are a human life, not because the doctor or some insurance company has determined that our life is worth living. Any physician that performs abortions and/or euthanasia has proven that he or she does NOT place a high value on human life. He or she has proven that they cannot be considered reliable or trustworthy in anyway. When anyone in our family or our extended family needs health care, we need to be able to trust the physician and care providers that we have placed in care of our love ones. We need and have a right to doctors and other health care providers we know place a high value human life!

Doctors, health care clinics and hospitals, pharmacist, and other medical personnel must be allowed to conscientiously refuse to perform, prescribe, or refer patients to treatments that they cannot morally or ethically recommend for them. That is the only way we can ensure the availability of reliable, trustworthy health care for everyone not only at the present time, but especially in the future as society in general continues to devalue and put a price tag on human life. Please help us by protecting their vitally important right to conscientiously refuse when morally and ethically needed.

Sincerely,

Christina Farrier

Please protect the health care providers whose consciences dictate respect for the life of the unborn.

Thank you

Catherine

Please protect the conscience of health care providers, particularly in supporting life.
George Maloof, M.D.

Allow medical professionals right to conscience!
Sheryl O'Neal
Citizen/ I vote!
Johns Island, SC

Please know that we need our Catholic doctors. Please do not force them to perform abortions against their conscience and please don't force pharmacists to fill prescriptions for morning after pills and contraceptives against their moral compass. There are other doctors and pharmacists that are willing to take up the slack.

Thank you, and God bless you,
Rava Graves

Please hold a position of respect and complete protection for life, born and unborn, old and young, in your work in Bioethics.

There is only one Creator: The Lord God Almighty, and we -- His creations - have made it clear that He and only He is to give life and take it away. I believe this also means that we are not to tamper with creation in any way whatsoever.

Thank you for your support in this critical area.

Sincerely,
Duval B. Acker
Mt. Pleasant, SC

Just a quick note to urge you to make available to all of us in the USA health care providers that are: Traditional Catholics, Evangelical Protestants, Pro-Life and/or other doctors of faith (in God) to care for us in the fields of Ob/Gyn, Family Practice and Geriatrics. This is extremely important to all citizens in the USA.
Respectfully submitted,
Shawn Dady

I am emailing with regard to the right of conscience for health care providers. Medical professionals should have the right to deny services that go against their beliefs. Please take this into consideration!
Sincerely,
Joan Vitalo

I support the right of conscience for health care providers. Medical professionals should not have to provide services that are against their beliefs.

Sincerely,
Mary Alice Truesdale
Hanahan, South Carolina

On behalf of all of the members of the NJ Natural Family Planning Assoc, Inc., I respectfully forward our strong endorsement in support of the right of conscience for healthcare providers and medical professionals.
Providing excellent healthcare is intimately connected with a provider's belief that they are indeed providing excellent healthcare. The freedom for our medical professionals to discern, select, and provide the best care for the best patient outcomes is fundamental to our system - the best medical care system in the world.

The right of a doctor or nurse to practice in accord with their beliefs is inseparable from their desire to provide patients with the best possible outcome. I trust a doctor or nurse with this integrity. I simply cannot trust a doctor or nurse who I know can practice medicine against their beliefs.

Please protect our medical professionals right of conscience clause.

Thank you for your work in protecting this fundamental freedom.

Please support our NJNFP mission,
Damon

Damon C. Owens, President
New Jersey Natural Family Planning (NJNFP)
P.O. Box 510, West Orange, NJ 07052
(973) 847-0165 office (815) 366-8235 fax
info@njnfp.org www.njnfp.org

NJNFP is a non-profit, tax-exempt charitable organization recognized under Internal Revenue Code section 501(c)(3). Our mission is to advance cultural awareness of natural family planning and the important role it plays in healthy and effective fertility management. Please visit us at www.njnfp.org and consider a tax-deductible donation in support of our mission.

I am writing as a private citizen and as a clinical psychologist to voice my opinion that medical professionals should have the absolute right to deny providing medical services that go against their moral beliefs. To do otherwise is to impose the values of the government on medical professionals. There is no reason to believe that the health care system would fall down if this were allowed. It would, however, ensure that individuals with a wide variety of values feel comfortable entering into the medical profession.

Sincerely,

Susan Styles, Ph.D.
Licensed Clinical Psychologist, SC

With a due respect for the office you hold. We must maintain separation of church and state. The government should not be allowed to step in and legislate the ethics of medical professionals.

A medical professional should never be made to go against their own ethics.

To do so would not only be political suicide but, we would lose many more people in this wonderful field.

To tell you the truth, the thought of it is positively frightening. It is a slippery slope and the only way is down.

To some degree this has already happened. It is already in some of the guidelines for Medicare. You don’t know how many times I have heard medical professionals say that a patient needed to stay longer in the hospital but, were sent home because their "days" for that particular illness were numbered and they did not have a long enough stay to go to a skilled care center from the hospital. This happened to my mother.
We need checks and balances within our systems. We need to have those who are an advocate for the patient. Those advocates are medical personnel with knowledge of the patient as an individual and direct access to patient records.

There is enough working against patients and impairing their right to physical support and nutrition while they die. Simply dying at home is not an option for some.

We fight insurance companies every time we have a procedure. As it is, they decide what we can and cannot have in the way of care. They are in control of patient care, hospitalization and what medications we can have.

We need to also consider the culling of embryos and the use of their stem cells. Stem cell embryos have been known for a long time now not to produce the desired effects of healing.

http://www.msnbc.msn.com/id/15385500/

They have caused cancer in patients. Read Isaac Asimov’s theory of decay. No one should be made to cull embryos or harvest embryonic stem cells.

No one should be made to perform an abortion.

No druggist should be made to sell products which they consider against their ethics.

All medical professionals should have a chance to “opt out” of certain procedures and decisions, which go against their ethics, and philosophies without out loss of income or tenure. We need to make certain that we understand our strength is in our diversity and do our best to prevent totalitarianism from ever taking a foothold in our medical system.

Laura Clements
Phil and Carolyn Reuther
Daniel Island, SC

I urge you to support the Rights of Conscience of Pharmacists and other Health Care Workers.

I do not look on abortion as a right. I believe that abortion, euthanasia, and physician assisted suicide each to be murder!

It is a basic American Freedom that people cannot have their freedoms of speech and religion dictated by the government. Why then should a person in the healthcare profession, be forced to distribute or administer drugs which go against their conscience. Why should they be forced to distribute drugs which would cause the death, of an unborn child, a person who is kept on a ventilator or fed through a tube, or a person who does not want to face a natural death. To force a pharmacist, doctor, nurse or any other health practitioner to conduct any of these, further causes them to be complicit in the murder of the individual, and that is just plain wrong. Especially in the case of a person who is in medical training and forced to perform or observe abortions.

When I was growing up the first thing I learned about the medical profession was that they swore an oath to do no harm. Abortion, Euthanasia and Assisted Suicide are all harmful, they end a human's life.

Very respectfully,
Timothy J. Kenefick
As you meet this week to discuss a serious topic concerning medical professionals, I want to make my voice heard on the subject. Medical professionals need to have the right to deny services that go against their beliefs. What freedom of religion do we have if we are forced to do things that explicitly cause us to do sinful actions against the very core of our beliefs?! A person should be able to seek a livelihood in a healthcare field without fear that they will have to comply with morally evil deeds. The oath “First do no harm” means nothing if we are forced to comply with a “dis-service” by lowering our Christian standard to meet the “wants” of all. Please fight for our freedom to uphold our faith and high standards to provide excellent healthcare.

Please make our voices heard!!!

Kindest regards,

Bebe Norris
Greer, South Carolina

This email is in support of Health Care Providers given the right to DENY SERVICES THAT GO AGAINST THEIR BELIEFS. Thank you.

Patricia Vitkovic

Doctors and other Health Care providers should not be forced to forego their deeply held moral convictions in exchange for the privilege of continuing their career. Those advocating "pro-choice" are only for "choice" if it involves supporting abortion on demand.

I am a member of ACOG and was deeply disturbed by their Committee Opinion limiting conscience rights and suggesting that it is unethical to maintain moral convictions against patient demand.

I am pro-life and I will not prescribe any medication or perform any procedure that will interfere with life from conception onward. And yes, this includes birth control pills and IUD's. For years, ACOG has changed the definition of pregnancy to one that only begins after implantation. By doing so, medications that can destroy life from the time of conception to implantation (birth control pills, IUD's, morning after pill, Depo-Provera) are no longer abortifacients but contraceptives. Now that this Provider Conscience Regulation has come up, ACOG was forced to admit that these agents can be both abortifacient and contraceptive. TRUTH IS TRUTH.

I will continue to practice the truth no matter what because the gifts that I have to practice come from God and I will not violate the commandment to "DO NOT KILL."

While my colleagues do not share my opinions, they understand the importance of exercising one's rights of religion.

Women travel HOURS to see me because I am one of the few pro-life physicians in the area. I will not refer for or perform abortions, refer for or perform IVF, or prescribe contraceptives (see www.creightonmodel.com)

If the Provider Conscience Regulations are not in place, I am confident that ACOG will proceed with it's desire to rid the specialty of those not supporting abortion by limiting board certification.

Sincerely,

Inge Collins, M.D., FACOG, CFCMC
Kings Mountain, NC

Sept. 8, 2008

As the father of five boys, I am writing to urge the Bioethics board to require a conscience clause exemption for doctors. While doctors don't have the right to refuse treatment, some modern medical procedures (IVF, abortion, cloning, among others) present serious moral problems for
many doctors -- in fact, the medical profession would have, as a whole, found these procedures utterly repugnant, and would shudder that they should be mandatory.

We train our doctors to make judgment calls all the time. If in their medical and ethical judgments they can not perform a procedure, isn't it a bit silly, not to mention a violation of common sense and, I hope, medical ethics, to require them to perform it?

Try these three examples for comparison. Would it have been ethical for doctors to refuse to participate in the Tuskegee syphilis experiments? Of course it would. Was it moral, ethical or common sense if any doctor were compelled to take part? I trust that the answer is no. Doctors in some parts of Asia sometimes perform "female circumcision" -- a barbaric procedure. Is it right for medical boards or governments to compel the doctors to do this? Is it meritorious for doctors to refuse to cooperate? Should doctors have collaborated with Joseph Mengele in the mistreatment of Jews?

Chris Garton-Zavesky

As you meet this week to discuss a serious topic concerning medical professionals, I want to make my voice heard on the subject. Medical professionals need to have the right to deny services that go against their beliefs. What freedom of religion do we have if we are forced to do things that explicitly cause us to do sinful actions. A person should be able to seek a livelihood in a healthcare field without fear that they will have to comply with morally evil deeds. The oath "First do no harm" means nothing if we are forced to comply with a "dis-service" by lowering our Christian standard to meet the "wants" of all. Why is it ok to tear down Christian beliefs but not touch a Muslims beliefs. Please fight for our freedom to uphold our faith and high standards to provide excellent healthcare.

Sincerely,
Lisa McMahan

Religious and moral beliefs of all individuals, most especially health care workers should be protected at all costs. Christian employees in healthcare cannot be forced or otherwise coerced into aiding or abetting any patient who wishes to secure an abortion or sterilization. Both are grievous sins in Catholic church teaching and Catholic healthcare workers cannot ethically be forced to participate in practices that are diametrically opposed to their beliefs.

The healthcare workers’ vow to first do no harm is woven into the fiber of their being. And Catholic church teaching is that such acts (abortion and sterilization) are intrinsically evil.

Please pass this message along to whomever will be participating in the hearing on the right of conscience for healthcare providers.

Thank you.

Mary Pat Arostegui
Matthews NC

We have inalienable rights and the right to liberty and the pursuit of happiness both imply the use of conscience. Please respect that right.

John E. Reagan

One of the basic characteristics of a human is that a person has a conscience. It is a God-given guide and a right the government cannot take away or treat lightly.

Sincerely, Barbara Reagan, a voting American who has paid her dues in more ways than one.
In your important hearing on the right of conscience for health care providers this Friday, I strongly want medical professionals to have the right to deny services that go against their beliefs. It is important in a free country.

Thank you.

William Chimiak, Ph.D.
Greenbelt, MD

Dear Bioethics Committee,
(and I do hold you ‘dear’ as you are dedicated to a work we all need accomplished for the sake of humanity)

I received an Email from my friends Sue & Dale Rodwick regarding the ACOG’s scandalous attempt to take this country one more step toward the black hole of oblivion. As I read their Email and downloaded the ACOG’s document and read it, terrible scenes of the ‘evil’ that darkened Earth during the entire Twentieth Century flooded my mind: hatred, violence, war, starvation, torture, oppression, and depravity on every continent, against peoples of every race and religious belief, committed by people of every race and religious belief. We like to point our finger at individuals like Franco, Hitler, Stalin, Mao, Castro, Pol Pot, Amin, Hussein, but behind everyone of them was a party of supporters. People may laugh at my comments which seem alarming and radical, but watch your step... the signs say, ‘Slippery Slope!’ Perhaps the megalomaniac personalities that I named above did surpass the intentions of their supporters, but once they gained total power... all hell broke loose. However, these evil men did not just surface mysteriously and take over. They rose up upon the shoulders of people who listened to their evil rhetoric and held the same beliefs.

Evil men and women will promise anything to gain power, and most often it involves riding the wave of change and the overthrowing of traditional beliefs and values. What has been happening in the United States since the ‘coming of age’ of the Baby Boomer generation (to which I belong) has been non-stop, full scale Revolution. It has been so invasive and diffused throughout society that it has been more like a smoldering blanket, than a wildfire blaze. The result has been a desensitizing of the older vanguard generation and a brainwashing of the upcoming latest adult generation. Who is to blame? How did it happen? It is too complex to answer and we haven't the time to analyze it. It is like a many headed monster with far reaching tentacles, that has picked up the great land that was America after WWII, ripping it off its base, shaking its foundations and turning it upside down. The monster is the enemy of Freedom, the opponent of Truth and the destroyer of Life. We can't run away in fear; it won't help to bury our heads and hope it will go away; and worst of all, we must not be convinced that it doesn't exist. Therefore, we must stand our ground and fight. We must confront the evil monster wherever it shows itself. It has shown itself to be clearly present in the document written by the ACOG, ‘The Limits on Conscientious Refusal in Medicine.’ If it gets to the Bill stage in Congress, it will be time for a Filibuster. It may take an all out campaign in the media through advertisements, day and night, no matter the cost of the battle. We'll need Pro-life 'Generals' with Big Guns and even Bigger Wallets to lead the charge!..... OR ...... We can do all that is possible to see that the Democrats do not win the White House on November 4, 2008
!!!!!!!!!!!!!!!

That's my opinion,
Suzanne Malavasic

Just a quick opinion.

While a doctor needs to administer to save a life regardless of his beliefs, I firmly believe he does not have to sacrifice his moral principles in the case of elective procedures. The constitution guarantees this. If a doctor or pharmacist doesn't want to provide a service that he believes is immoral, he doesn't have to do it. God knows that there enough low moralled MD's and Pharm. that will do it as long as it pays. Good doctors are hard to find. Please don't chase them away with this new regulation.

Thank You
Stan Sleeman
I want medical professionals to have the right to deny services that go against their beliefs.

thank you.

Colleen [Loiselle]

Planned Parenthood has political clout way out of proportion to the number of Americans who share their views. The majority of Americans, who love this country because of the freedom it gives them to follow their consciences, are too busy to spend their lives lobbying.

That's why we need you to stand up for conscience laws. You've been identified as worthy of this responsibility for your strong judgement, willingness to fight for what is right, and to represent all those Americans w/o the time to lobby.

I hope you will do all that is necessary to protect doctors' freedom of conscience.

Sincerely,
Matt Bowman
Managing Editor, AlwaysOn Network

September 8th, 2008

Kyle Beiter, MD
6901 Mercy Road
Omaha, NE  68106
402-390-6600

The President’s Council on Bioethics
Edmund D. Pellegrino, MD  Chair
Diane M. Gianelli, Director of Communications

1425 New York Avenue, NW
Suite C100
Washington, DC 20005

Council Members,

I am a gynecologist who neither provides nor refers for elective abortions. As you may know, the American College of Obstetricians and Gynecologists recently published their Committee Opinion #385 regarding “The Limits of Conscientious Refusal in Reproductive Medicine”. In it, they basically seek to establish abortion, sterilization, and contraception as the standard of care for health care providers. This could prevent those providers who do not provide or refer for these services from attaining board certification, hospital privileges, and insurance reimbursements.

I want you to know that I recently wrote a letter to ACOG asking them to rescind Committee Opinion #385. When I asked others if they wanted to cosign the letter, the response was overwhelming. Over 800 people have responded to date, many of them physicians, nurses, medical students, and pharmacists. Many women also responded, indicating that they desire medical professionals who respect life.
I have copied the letter and the signatures below for you. Please support us in acting in accord with our consciences to provide women and families with life-affirming medical care.

Sincerely,
Kyle Beiter, MD
Omaha, NE

August 14, 2008
Kyle Beiter, MD
6901 Mercy Road
Omaha, NE 68106

American College of Obstetricians and Gynecologists
Dr. Douglas H. Kirkpatrick, President
409 12th St., S.W., PO Box 96920
Washington, D.C. 20090-6920

Dr. Kirkpatrick and the ACOG staff,

We represent a growing number of health professionals in women's health and laypeople who disagree strongly with the ACOG Committee Opinion #385. There are many among us, strongly committed to providing health care to women, who believe that elective abortion, sterilization, and contraception promote disrespect for women and children and destroy families. Your efforts to establish these services as the norm in women's health care will reduce women's access to providers who support their well-being and that of their families in ways that pro-abortion providers cannot.

We ask you to rescind this opinion immediately.

Sincerely,
Kyle Beiter, MD Omaha, NE

William Chavira, MD, Fellow, American College of Obstetricians and Gynecologists
Phoenix, AZ
Michael S. Parker, MD, Fellow, American College of Obstetricians and Gynecologists
Gahanna, OH
Stephen Pavela, MD La Crosse, WI
William V. Williams, MD Havertown, PA
James J. Schuh, MD Iowa City, IA
Samuel F. Castillo, MD Phoenix, AZ
Maralee C. Bowers, MD Hinsdale, IL
Leonie S. Watson, MD Mountainside, NJ
Richard J. Petersen, MD Tempe, AZ
Robert C. Pivonka, MD
Dominic M. Pedulla, MD, FACC Oklahoma City, OK
Daniel Bejarano MD, MS, MS Eng. Dayton, OH
Betsy Liliana Cote de Bejarano MD, MPH Dayton, OH
Thomas Lutz, MD Grayslake, IL
Edwin T. Anselmi, MD
George Delgado, MD San Diego, CA
Cynthia Miley, MD Tucson, AZ
Carlos Vera, MD Denver, CO
Jesse Gorley, MD
Jennifer P. Althoff, MD Newton, IA
Stephen P. Billion, MD  Sioux Falls, SD
Diane Elmore, MD  Scottsdale, AZ
Armando D. Garza, MD  San Antonio, TX
Robert H. Bullington, Jr., MD  Phoenix, AZ
Aime L. Nuar, MD  Manassas, VA
James Franklin Wharam, MD  Boston, MA
Patrick Yeung, Jr., MD  Durham, NC
Amy Hogan, MD  Great Bend, KS
Larissa M. Meyer, MD  Phoenix, AZ
Theresa Stigen, MD  Omaha, NE
Leslie E. Wilson, MD  Houston, TX
Christine M. Zainer, MD  Wauwatosa, WI
David Born, MD  Newark, OH
Barbara Rose, RN, MSN, FCP  Jenkintown, PA
Laura Castillo, RN  Phoenix, AZ
Maria Jimenez, RN, BSN  New York, NY
Anne Hanley, RN, BSN, FCPI  St. Louis, MO
Cheryl Fonseca, RN  Columbus, OH
Kathryn Beiter, RN  Lancaster, OH
Alanna Wendy Sorauf, RN  Mesa, AZ
Ila A. Sowins-Dunmire, RN, OCN
Terri Vyner, RN, M. Bioeth  Aurora, CO
Phyllis Amrick, CRNP  Nazareth, PA
Andrea R. Polito, RN, BSN  Annandale, VA
Mary E. Ho, RN, FCP  Blairstown, NJ
Lauren Turner, RN, BSN  Lancaster, OH
Mary Beth Pavela, RN  Madison, WI
Michelle D. Griffin, RN  Newtown, PA
Elizabeth Lynch, RN  Iliion, NY
Annie Surine, RN  Baltimore, MD
Gregory D. Holden, BS, RN  Phoenix, AZ
Christine O'Brien, RN  Beverly, MA
Elizabeth Turajski, RN  Seattle, WA
Denise Ferrell, RN, BSN
Patricia Calascibett, RN  Sun City, AZ
Rev. Dennis R. Schuelkens, Jr., MA, MDiv, BSN, RN  Wheeling, WV
Elizabeth Turner, RN, BSN  Wake Forest, NC
Leah Getts, RN, BSN  St. Louis, MO
Batrice Adcock, BS, RN  Charlotte, NC
Sharon Page, RN
Cynthia S. Bullington, RN, MS  Phoenix, AZ
Alicia Ruiz, RN, BSN  Manassas, VA
Carolyn Bartal, MSN  Columbia, MO
Nancy Sandrock  RNC, CNM, MSN  Weslaco, TX
Elizabeth Schleeter-Steier, CNM  Paradise Valley, AZ
Mary Hyland, RN  Phoenix, AZ
Susan Lawruk, LPN
DelRonda Boyd, RN  Tempe, AZ
Jackie Knight, RN  Hayden Lake, ID
Phyllis Harden, RN
Barbara J. Rodriguez, RN  Eagle, ID
Barbara S. Johnson, RN, BSN  Brookfield, WI
Bob Guastalli, RN  St. Anne, IL
Emily Sparks, RN  Woolwich, NJ
Sharon La France, RN (ret)  Sun Lakes, AZ
Francie Tyler, RN, BSN  Moscow, ID
Judith Gibson, RN, BSN  Pasadena, MD
Maggie Davis, LPN  Strawn, IL
Jill Deras, BSN  Omaha, NE
Donna Luebbert, RN  Westphalia, MO
Magdalene Uhlenkott, RN, BSN  Seattle, WA
Catherine Lavigne, BSN, RN  Naperville, IL
Agnes E. Bayer, CPNP  New York, NY
William J. Guy, Jr., RN  Philadelphia, PA
Laura Duarte, RN  Fairhaven, MA
Anne Fountain, RN, MA
Marilyn A. D. Yee, PharmD  AZ
Anthony Bartal, Pharmacist  Columbia, MO
J. David Luckhardt, Pharmacist  OH
Annette Tipton, Pharmacist  Pierre Part, LA
Jaime Rehmann, 4th year Medical Student  Athens, OH
Matthew Uhlenkott, 4th year medical student  Seattle, WA
Anna Kernytsky, 4th year Medical Student  Rockledge, PA
Rebecca M. Restivo, MBA, 4th year Medical Student  Kansas City, MO
Rachel Kotor Langley, 2nd year medical student  Kansas City, MO
Candace Murray, 4th year medical student  Chicago, IL
Neethu Mappadhyil, Medical Student  Chicago, IL
David Theis, 4th year Medical Student  Athens, OH
Warren K. Spellman, Chief Executive Officer, Holy Cross Hospital  Taos, NM
Bishop Thomas J. Olmstead, Roman Catholic Diocese of Phoenix, AZ
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Sheila Parkhill, Esq.  CA
Thomas M. Lynch, Esq.  Annapolis, MD
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Lisette Lange, Esq.  San Antonio, TX
Edward T. Mechem, Esq.  New York, NY
Elizabeth Rockwell Brown, Esq.  North Bend, WA
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Stephen J. Koob, PhD  Dayton, OH
Philip J. Mango, PhD  New York, NY
Rev. Robert A. Connor, PhD  New York, NY
Elizabeth A. Komives, PhD  San Diego, CA
Steven Smith, PhD  New York, NY
Gary Somers, PhD  Phoenix, AZ
Chris Alario, PhD  Hermosa Beach, CA
Jocelyn Edathil, PhD  Hershey, PA
Christina Schuerger, LCSW  New York, NY
Peg Burson  Columbus, OH
Sue Fryer  Vancouver Island, Canada
Jo Ann Alicia Foley  Glenside, PA
Michael Joseph Bouchard  Phoenix, AZ
JoAnne Bouchard  Phoenix, AZ
Cassandra McCullers  North Wales, PA
Mary Peterson  Phoenix, AZ
Ted Bauer  Rochester, MN
Sarah Bauer  Rochester, MN
Laura Ewing  St. Clairsville, OH
Linda Milano  Sickleville, NJ
Helene Hallowell  Holmes, PA
John Hallowell  Holmes, PA
Maria Dorsaneo, PA-C  Philadelphia, PA
Melissa L. Schools  Lowell, MA
David Burson  Berne, IN
Jennifer Ellis  NJ
Christine DeMuro  Naperville, IL
Julie Schuerger
James McCormick  Sellersville, PA
Stacey McCormick  Sellersville, PA
Jenni Maas  St. Paul, MN
Stephen Maas  St. Paul, MN
Angela Rizzo  Rockville Center, NY
Pat Lencioni  Alamo, CA
Jo Rhoades-Cokonougher  Greenfield, OH
Jennifer L. Siekmann  Phoenix, AZ
Laurie Murdock  San Francisco, CA
April Yeager  Phoenix, AZ
Denny Daugherty  Columbus, OH
Diane Toler  Glenmoore, PA
Donna Ellingsen  Lewisville, PA
Stephanie Barbara  Bridgewater, NJ
Joshua Griffin  Levittown, PA
Caitlin Griffin  Levittown, PA
Lisamarie Beiter  Omaha, NE
Mariangela Cavazos  Austin, TX
Joan Beiter  Lancaster, OH
Daniel Hedrick  Omaha, NE
Kathleen Hedrick  Omaha, NE
Joe Plasha  Lansdale, PA
Laureen Plasha  Lansdale, PA
Lisa M. Pollard  West Pittston, PA
Josie Genovese  Plymouth Meeting, PA
Madeleine Heck  Phoenix, AZ
Miranda Peterson  Phoenix, AZ
Erin Schanne  Havertown, PA
Amy Nelson  Glendale, AZ
John A. Griffin IV  Levittown, PA
Teresa Praasterink  Phoenix, AZ
Cindy Ortega, MC, NCC  Phoenix, AZ
Heather Ermine  Philadelphia, PA
Sharon O'Donnell  Ashburn, VA
Carolyn J. Tucker  Jefferson City, MO
Katherine R. McCormick  Perkasie, PA
Laura Rieder  Newtown, PA
Susan Kaness  Philadelphia, PA
Richard Gisondi  Chalfont, PA
Victoria Gisondi  Chalfont, PA
Katherine Andrzejewski  Baltimore, MD
C.M. Hurry  Chandler, AZ
Ray Dugandzic  Mesa, AZ
Wendy Wood  Phoenix, AZ
Fr. Clarence E. Wiederholt
Elvia Roche  Phoenix, AZ
Jarrod Townsend  Chandler, AZ
Maria M. Vaughan  Chandler, AZ
Mark Moore  Chandler, AZ
Mary Moore  Chandler, AZ
Maria Elena Townsend  Chandler, AZ
Kathy Enzweiler  Tempe, AZ
Meghan Kunzl  Vaughn, WA
Seth Kunzl  Vaughn, WA
Danielle O. Bermudez  Bellingham, WA
Brendan O'Rourke  Lancaster, OH
Katy Callum  Chalfont, PA
Michelle Hawkins  Phoenix, AZ
Joanie Falconer  Portland, OR
Joyce M. Faith  Mesa, AZ
Celesta Duchesneau  Newtown, PA
Christy Kishel  Downingtown, PA
Claudia Henrie  West Chester, PA
Mark Henrie  West Chester, PA
Christina Rock  New Castle, DE
Mary Gajewski, DDS  Westby, WI
Mary Jean Stumpff  Plattsburgh, NE
Brian Buckley  Detroit, MI
Melanie R. Quin, LLMSW  Howell, MI
John J. Auer
Mark Murphy  Marion, IA
Mary Leuer  St. Michael, MN
Gina Watson  Tempe, AZ
William T. Morrissey  New London, CT
Michael P. McCormick  Sellersville, PA
Deborah S. Perez  Phoenix, AZ
Barbara Austin  Lovettsville, VA
Brad Sheguit  Philadelphia, PA
Jessica Sheguit  Philadelphia, PA
Glory Sheguit  Philadelphia, PA
Fr. Raymond Greco, O.S.B.
John Harney  Tempe, AZ
LaVerne L. Schueller  Cedar Rapids, IA
Madeline D. Maj, RD  Lansing, MI
Mary Schneider  Milwaukee, WI
Owen Vyner  Aurora, CO
Shannon Collins  Sacramento, CA
Alli Casiello  Fairfax, VA
James Fair  Phoenix, AZ
Deacon Joe Cady  Chandler, AZ
Deacon Chuck Shaw  Phoenix, AZ
Doris Martinez  Scottsdale, AZ
Jo Tolck  New Hope, MN
Christina Cossell  Glendale, AZ
Mary Griffin  Levittown, PA
Raquel Okyay  Wallkill, NY
Paul M. Polito, CPA  Vista, CA
Jim Skelly  Scottsdale, AZ
Craig Hintze  Chandler, AZ
Msgr. Joseph Supa  Wickenburg, AZ
Daniel Schreck  New York, NY
Constance L. Fenwick  Scottsdale, AZ
Pauline M. Fenwick  Scottsdale, AZ
Angela Meyer  Chester, PA
Peter Meyer  Chester, PA
Jeannie McLean  North Wales, PA
Colonel Herb Edwards USAF (ret)
Mrs. Herb Edwards
Jeanne-Marie Motley  Hatfield, PA
Marie Larson  Brooklyn Park, MN
Dianna Contreras  Tempe, AZ
Edmund Tynan  Scottsdale, AZ
Judith Tynan  Scottsdale, AZ
Michael Rimbey  Mesa, AZ
Melanie Pritchard  Tempe, AZ
Ann Minton  Roseland, NJ
Deacon Nick Bonaiuto  Goodyear, AZ
Dannie Smith  Wheeling, WV
Joseph Williamson
Conni Knoblach  Chandler, AZ
Shanna M. Buck  Weirton, WV
William A. Buck  Weirton, WV
Genevieve Buck  Weirton, WV
Lucinda Buck  Weirton, WV
Keith Nissen  Columbus, OH
Andrea D. Thompson  Phoenix, AZ
Margaret M. Bacon, BSW  Chevy Chase, MD
Caroline Guy  Philadelphia, PA
Matthew Vajen  Lancaster, OH
James McCormick, President, McCormick Brothers, INC  Sellersville, PA
Rose Anderson  Arvada, CO
Gary Chatel  Phoenix, AZ
April Chatel  Phoenix, AZ
Susan Loughnane  Harrison City, PA
Anne Marie Kresge  Gilbert, AZ
Claudia Mayer  Tempe, AZ
Ellen Chamblee
Joanie K. Katzenberger  Glendale, AZ
Deacon Richard D. Rein  Phoenix, AZ
Sharon Lee Rein  Phoenix, AZ
Marie Wilkes  Goodyear, AZ
Mr. Charles Johnson  Hurst, TX
Mrs. Charles Johnson  Hurst, TX
Sr. Bibiane Roy  AZ
Edward Cole  Sun City, AZ
Barbara Cole  Sun City, AZ
Charla Cupit
Lousie Molnar  Summersville, WV
Kathy Gabrielson  Phoenix, AZ
Pam Carballo  Chandler, AZ
Cindy Oliver  Weirton, WV
Kathy Luksich  Alpine, WY
Sunny Turner  Tucson, AZ
Martha V. Tanuz
Karen Avila  Glendale, AZ
Francis V. Saporito  Cottonwood, AZ
Edward T. Donahue
Constance Donahue
Katherina Carballo  Chandler, AZ
Margaret A. Gallegos  Tucson, AZ
Vanessa Ferrero  Chandler, AZ
Martha Bragg  Mesa, AZ
Theresa Alt, PT  Marion, IA
Claire Aragon  Tucson, AZ
Leslie Pechkurow  Tempe, AZ
Alice Hamilton  Summersville, WV
Melissa Hickson  New Bern, NC
Peter Hickson  New Bern, NC
Fr. Timothy J. Grassi  Thomas, WV
Christylee Watson  Chandler, AZ
Ann Downey  Tucson, AZ
Paul Uhlenkott  Front Royal, VA
Kristin (Hickson) Uhlenkott  Front Royal, VA
Monica Davis  Phoenix, AZ
Brian J. O'Sullivan  Phoenix, AZ
Jeannette Williams  Perkasie, PA
Mary Ruth Hackett  Tempe, AZ
Daniel Forbes  Gilbert, AZ
Jeanne Fernando
Diana Heilman  Laveen, AZ
Frances Barba  Oak Lawn, IL
Barbara Ewing  Gilbert, AZ
Kathryn Melchi
Suzanne M. McGuire  Columbus, OH
Kathleen Demalja  Mesa, AZ
Sara Demalja  Mesa, AZ
Ken Mazwell  Gilbert, AZ
Mary Ann Mcowen  Levittown, PA
Brendan O'Brien  Vernon Hills, IL
Maria O'Brien  Vernon Hills, IL
Keith Brant Berube  Columbus, OH
Joelle Elliott  New York, NY
Stephanie Buches
Mary Raasch
Nancy M. Czerwiec  Oak Lawn, IL
Patricia Martin Mayro  Jenkintown, PA
Joanna Nycz-Wasilec, MS, FCP  New York, NY
Deacon Larry Gray  Surprise, AZ
Elizabeth Gray  Surprise, AZ
Brigid Sweeney  Denver, CO
Genevieve Matthews  New York, NY
Paulette F. Helfers  Warner Robins, GA
Leslie R. Helfers  Warner Robins, GA
Catherine Petrescu  Havertown, PA
Laruen Gentile  Riverdale, NY
Linda J. Spellman  Taos, NM
Kathleen S. Spellman  Steubenville, OH
Mary K. Spellman  Nashville, TN
Linda-Anne Marie Spellman  Taos, NM
Andrew J. Spellman  Oklahoma City, OK
Sarah Spellman  Oklahoma City, OK
Matthew Stachowiak  New York, NY
Elizabeth Remmes
Joseph Villarin  New York, NY
Fr. Joseph Klee  Portsmouth, OH
Jennifer Blackstad  Gilbert, AZ
Melissa Conway  Canal Winchester, OH
Lizet Constanza Diaz Mueller  New York, NY
Anthony DeShetler  Hoboken, NJ
Gerald Allen Heitzenrater  Galloway, OH
Selena Heyer  Bexley, OH
Bonnie Strube  Gilbert, AZ
Paul Strube  Gilbert, AZ
Mario Chavez  Davenport, IA
Therese Chavez  Davenport, IA
Deacon Robert Olberding  Flagstaff, AZ
Genny Jones  Phoenix, AZ
Arlene Pogue  Scottsdale, AZ
George Pogue  Scottsdale, AZ
Melissa Veselovsky  Mesa, AZ
Julie Engelbert  Littleton, CO
Thomas Phelan  Mesa, AZ
Marianna Phelan  Littleton, CO
Melissa Veselovsky  Mesa, AZ
Paul Melanson  Parkville, MD
Barbara Melanson  Parkville, MD
Gene Procopio  Phoenix, AZ
Mary E. Rapp  Mesa, AZ
Shellie Ford  Seattle, WA
Maria Gallagher  Harrisburg, PA
Doug Ritchey  Columbus, OH
Virginia Flores  Richmond, VA
Mary Ellen Smith  Burlington, VT
Mei-Lei Beane  Kilmarnock, VA
Janet Hartmann  Sun City, AZ
Anthony J. Brown  Katy, TX
Janelle Roberts  Mesa, AZ
Christian Meert  Colorado Springs, CO
Christine Meert  Colorado Springs, CO
Jennifer Donovan  Plain City, OH
Judy Kanya  Burlington, VT
Anne Quick  Columbia, MO
J. Kelly Quick  Columbia, MO
Anne M. Williamson  Denver, CO
Ann Johnson  Bothell, WA
Dorothy Barewicz  Burlington, VT
Sarah-Lynne Carrara  Brandon, VT
Geoff Gentile  Riverdale, NY
Vicente A. Sanchez  Phoenix, AZ
Rafalita Sanchez  Phoenix, AZ
Rob Estes  Gilbert, AZ

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Rev. Charles H. Ranges  Essex Junction, VT
Martha Ritter  Normandy Park, WA
Thomas Ritter  Normandy Park, WA
Judith Reichsman  Brattleboro, VT
Rev. Thomas Campbell  Tucson, AZ
Cindy M. Campbell  Tucson, AZ
Virginia Dziekonski  Seattle, WA
Sarah Torzala  Gilbert, AZ
David I. Hong  Tucson, AZ
Pamela M. Houston  Tucson, AZ
Drusilla Barron  New York, NY
Amy Thompson  Chandler, AZ
Michelle Byrne, CPA  Phoenix, AZ
V.J. Byrne  Phoenix, AZ
Janet Manecke  Chandler, AZ
Jeanette M. Cohn  Severna Park, MD
Mary D. Leonard
Joseph Rayen, CPA  Columbus, OH
Peter J. Nero  Brattleboro, VT
Kerrie Ritchey  Powell, OH
Margaret S. Wehrung, MA  Burlington, VT
Cynthia Miley Hong
Carolyn McMurray  Arlington, VT
Gerald McMurray  Arlington, VT
Judy Kanya  Burlington, VT
Carla Schaefer  Phoenix, AZ
Carolyn Fantz  Morrison, CO
Linda Jiner  Denver, CO
Natalie Chiappone  Denver, CO
Alan Clune  Newark, OH
Paul Houser  St. Louis, MO
Georgia Varvarelis Fliakos  Bethlehem, PA
Adam S. Faizi  Bradenton, FL
Jamie Gautreau  Houston, TX
Tony Weston  Chicago, IL
Sarah Kinsella  Washington, DC
Luis Garcia  Philadelphia, PA
Justin Warix  Fort Lauderdale, FL
Charlene Vestermark  Philadelphia, PA
Elizabeth Noel Brown  Kansas City, MO
Vincent W. Tio  Fort Lauderdale, FL
Natasha Zumberger  Botkins, OH
Tiffany Thompson  Pelham, NH
S. Wharam  Timonium, MD
Rev. Donald P. Baker
Samuel Merenda  Orlando, FL
Shelly Merenda  Orlando, FL
Jennifer Lynch  Annapolis, MD
Katherine P. O’Brien-Johnston, MA  San Diego, CA
Kevin C. Fitzpatrick  Corpus Christi, TX
Kristina Forbes  Gilbert, AZ
Alex Soberon  Escondido, CA
Sharon Soberon  Escondido, CA
Robert Drechsler  Tempe, AZ
Kathleen Shimkaveg  Lutherville, MD
Janet S. Crook  Madison, CT
Joan M. Dent  Cordova, MD
Judy Brown
Don Nietz  Zumbro Falls, MN
Patricia J. Lea  Highland, CA
Saundra Tanner  Phoenix, AZ
Barbara Butler  Mt. Belvieu, TX
Angie Vaughan  Mesquite, TX
Elizabeth Felderhoff  Everett, WA
Patricia Suma  Peoria, AZ
Luis Howard  Sahuarita, AZ
JoAnne Howard  Sahuarita, AZ
Tony Howard  Sahuarita, AZ
Katherine Howard  Sahuarita, AZ
Melanie L. Yonushonis  Philipsburg, PA
Pamela Berube  Columbus, OH
Blandina Miller
Carol J. Patterson  Jefferson City, MO
Helen Valenza  St. Louis, MO
Rachel Uhlenkott  Grangeville
Robert Wildrick  Bellevue
Anneke Wildrick
Shelia Wharam  Timonium, MA
Rebecca Phelps  Colorado Springs, CO
Greg Mueller  Nashville, TN
Karen Mueller  Nashville, TN
Peter Mueller  Nashville, TN
Paul Carlson  Kankakee, IL
Mrs. Paul Carlson  Kankakee, IL
Geraldine Plynton  New York, NY
Dena Maciborski  Minto, ND
Rachel Larpenteur  Bothell, WA
Scott Russell  Batavia, IL
Jennifer Russell  Batavia, IL
Richard O. Gallagher  San Rafael, CA
Meredith A. Good  Escondido, CA
Teresa Mahony, LCSW  Kankakee, IL
Michael Mahony  Kankakee, IL
Alan Pickett  Bourbonnais, IL
Pam Pickett  Bourbonnais, IL
Marie Hackert  Tucson, AZ
Dick Mackey  Phoenix, AZ
Sue Mackey  Phoenix, AZ
Wayne Clement  Pierrepart, LA
Patrick Hanson  Little Rock, AR
Teresa Hanson  Little Rock, AR
Mayra Santiago  Tucson, AZ
Jose Santiago  Mesa, AZ
Veronica Santiago  Mesa, AZ
Steve Santiago  Mesa, AZ
Dennis Ferrell
Val Guastalli  St. Anne, IL
Alan Aversa  Tucson, AZ
Mark Beaulieu  Stanwood, WA
Merle Shythe  Salem, OR
Carol Shythe  Salem, OR
Jim Styer  Sarasota, FL
Deacon Tony Salamone  Phoenix, AZ  
Roberta Salamone  Phoenix, AZ  
Gabriel Starczewski  Great Barrington, MA  
Keith Beiter  Flushing, MI  
Brianne E. Hurst  Mesa, AZ  
Jo-Ann Trevizo  Gilbert, AZ  
Susan E. McClernon  
Thomas C. Lankford  Kansas City, MO  
Elva Buckwalter  Phoenix, AZ  
James F. McElwee  Wake Forest, NC  
Peter Park  Houston, TX  
Sarah Park  Houston, TX  
Steve Skojec  Manassas, VA  
Michelle Duncan  Houston, TX  
Brian Duncan  Houston, TX  
Eric Johnson  Burbank, CA  
Anna Belasquez  Houston, TX  
Christine T. Shoen  Chagrin Falls, OH  
Elizabeth Kuetemeyer  Thornton, CO  
Christine Melchior  Houston, TX  
Polly Christensen  Irving, TX  
Joe Christensen  Irving, TX  
Jennifer Kruekeberg  Woonsocket, RI  
Theresa Fernandes  Steubenville, OH  
Brian R. Duncan  Houston, TX  
Jennifer McDonald  Houston, TX  
Brandon Oberlin  Indianapolis, IN  
Mary Millikan  Scottsdale, AZ  
Dennis Ryan  Scottsdale, AZ  
J.W. Millikan  Scottsdale, AZ  
L.J. Mangini  Scottsdale, AZ  
B.J. Mangini  Scottsdale, AZ  
Erik Tozzi  Yonkers, NY  
Anne Tozzi  Yonkers, NY  
Laura Martin, PT  Houston, TX  
Jerry D. Pion  Troy, VT  
Maria Hare  Springfield, PA  
Laura S. Moore  Richmond, VA  
Mary B. Wingfield  Houston, TX  
Frances Stluka  Houston, TX  
Jose Urdanivia  Houston, TX  
Anne Quinn  New York, NY  
Christine Ruby  Baltimore, MD  
Sonja Novo  Houston, TX  
Rosemary L. Seidl  Tucson, AZ  
Coleene Jimenez  Escondido, CA  
Bobbie Valente  Temecula, CA  
Deacon Michael-John Elmore  Scottsdale, AZ  
Lani Bogart  Phoenix, AZ  
Erin Campbell  
Marla Kayser  Prescott, AZ  
Ron Kayser  Prescott, AZ  
MariBeth Smith  Mesa, AZ  
Dawn Phillips  Gilbert, AZ  
Javier Carranza  Apache Junction, AZ  
Joalyce Carranza  Apache Junction, AZ
Madelyne Cheroske
Jim Jacobs Scottsdale, AZ
Therese Jacobs Scottsdale, AZ
Cynthia A. Nuttall Apache Junction, AZ
Phillip Austin Gilbert, AZ
Coleen Austin Gilbert, AZ
Joyce Fenwick Phoenix, AZ
Ann Thirkhill Tempe, AZ
Misty Jacobs Scottsdale, AZ
Sheryl Johnson Mesa, AZ
Danise Mombleau Freeport, IL
Jane Kosco Prescott, AZ
Joan Mick San Marcos, CA
Ruth Gillum Columbia, MO
Cheri Gillum Columbia, MO
Danielle Adams
Patrick M. Feeley Prescott, AZ
Donna L. Feeley Prescott, AZ
Victr Ess I. Jenkins
G. Flaum Redondo Beach, CA
Greg Kunasek, BA, MBA Mansfield, TX
Brenda Cunningham Mesa, AZ
Kathleen Forte Chatsworth, CA
Kevin Pilon Duluth, MN
Mark Giroux Queen Creek, AZ
Heidi Giroux Queen Creek, AZ
Lisa Browne Willow Grove, PA
Mairin Espericueta
Raul Espericueta
Amber Martin Gilbert, AZ
Judy Casey Chandler, AZ
Susan Wallace Greenville, PA
Denise Ebipane San Diego, CA
John Paul Foley West St. Paul, MN
Beth Gehring Dallas, TX
Kirk Kuykendall Irving, TX
Tamara Kuykendall Irving, TX
Mark Walsh Oakland, CA
Michael Wojcik Vista, CA
Michele Wojcik Vista, CA
Madeleine Heck Phoenix, AZ
Stephanie Antonov Ocala, FL
Jessica Spinharney Eden Prairie, MN
Sarah Michelle Moore Dayton, OH
Ann Gehring Lodi, OH
Scott Whitfield Scottsdale, AZ
Lisa Whitfield Scottsdale, AZ
Dolores Meehan San Francisco, CA
Lisa Johnston, CPA Phoenix, AZ
Alia Keys St. Louis, MO
Timothy Keys St. Louis, MO
Daniel Schreck New York, NY
Eileen Beiter Charlottesville, VA
Adriana James, PhD Student Washington, DC
Sr. Mary Elizabeth Wusinich, SV New York, NY
Julia Heitzenrater Columbus, OH
Joseph Heitzenrater  Columbus, OH
Alyssa DeSocio  New York, NY
Steve Orton  Valley Center, CA
Suzanne Orton  Valley Center, CA
Thomas Lester  Ave Maria, FL
Theresa Lester  Ave Marie, FL
Kay Painter  Nampa, ID
Phyllis Sawyer  Eagle, ID
Jennifer A. Gustke  Prescott Valley, AZ
Brian A. Gustke  Prescott Valley, AZ
Roma L. Davidson  Nampa, ID
Anita Usher  Chandler, AZ
Elizabeth Hickson
Linda Nicholson  Nampa, ID
Jason Herring  Eagle, ID
Carol Yalbuw  Grangeville, ID
Laurie Rockwell  Grangeville, ID
Peter Rockwell  Boise, ID
Kathleen Sorge  Eagle, ID
Adrian S. Benson  Fredericksburg, VA
Gerald Aycock  Middleton, ID
Charlene Aycock  Middleton, ID
Betty Alm  Grangeville, ID
Florence M. Johnson  Georgetown, CA
Sheryl L. Nuxoll  Cottonwood, ID
Judyth E. Anderson  Meridian, ID
Maureen Palmer  Brea, CA
Don DeArmond  Grangeville, ID
Charlotte DeArmond  Grangeville, ID
Ed Graveline  Las Vegas, NV
Andre Gray
Sandy Gazda  San Antonio, TX
Scott Turner  San Antonio, TX
Sharon Turner  San Antonio, TX
Adriana Mayor  Mesa, AZ
Raymund Mayor  Mesa, AZ
Mary Foresman  Centennial, CO
Rose Matosich  Prescott Valley, AZ
Chuck Taylor  Gilbert, AZ
Michelle Taylor  Gilbert, AZ
Audra Cardona  San Antonio, TX
Anne Van Der Linden  Temecula, CA
Carmen G. Torres-Wilson
Kristen Hussle Fisher  Ellicott City, MD
Jennifer Schuberth  Ellicott City MD
Erin Cooney  Catonsville MD
Ona Corkrin  Catonsville MD
Holly Navotny  Catonsville MD
Sue Smith  Ellicott City MD
Andrea Hussle Brown  Westminster MD
Cecilia LeChevallier  Camden, NJ
Michele Thomas  San Antonio, TX
Bridget Alario  Hermosa Beach, CA
Kelly Prenger  Jefferson City, MO
Randy Prenger  Jefferson City, MO
Donna Prenger  Jefferson City, MO
Kevin Prenger      Jefferson City, MO
Julie Prenger       Jefferson City, MO
Brian Prenger      Jefferson City, MO
Stanley Prenger   Jefferson City, MO
Rachel Prenger    Jefferson City, MO
Cheryl Davidson    Springfield, MO
Jason Davidson      Springfield, MO
Renata Jasinska Philadelphia, PA
Ken Stubbers Cottonwood, ID
Shirley Stubbers Cottonwood, ID
Thomas Victor Cunilio Gainesville, FL
Linda Geidl Troy, ID
Emily Rice Narberth, PA
Paul V. Hursh Mesa, AZ
Alice Kremer
Valerie Giglio Peoria, AZ

It is imperative that the government at every level allow doctors to follow their consciences and refuse to do procedures they believe to be immoral. There are far too many docs and others who will do anything for the buck. Those who won't need to be respected and allowed to practice their form of medicine.

John F Kippley, President
NFP International
www.NFPandmore.org
"Sex and the Marriage Covenant: A Basis for Morality" (Ignatius)

I strongly support the right of conscience for healthcare providers. I feel that it is definitely wrong to make anyone go against their moral conscience, particularly in cases where their religion or ethics dictate that certain actions on their part may directly or indirectly cause the termination of an innocent human life.

We hear much about the "Right to Choose", but there is no such right. If the claim is that there is such a right, then why cannot healthcare providers use that right in such cases where others want to deprive them of that right.

Joseph H. Hewes
Seneca, SC

Hi. I definitely support that health care providers and pharmacists should have the right to refuse to provide services for things that go against their beliefs. Doctors should have the right to refuse to prescribe contraceptives, to refuse to perform abortions, etc. Pharmacists should have the right to refuse to fill a prescription for contraceptives, RU 486, etc. To force these people to go against their values and morals is a violation of free speech.

Thanks for your attention to this matter!

Rebecca Whisonant
Rock Hill, SC

I am writing about the issue of conscience in Medicine. As a pro-life, NFP-only Family physician in Lenoir City, TN outside of Knoxville, I have enjoyed the freedom to not have to check my faith at the door of my private practice. I am a Roman Catholic fully in support of the teachings of my Church regarding birth control, sterilization, in vitro fertilization and abortion. I do not prescribe contraceptives, write Viagra or like drugs for unmarried men, and I do not refer patients for sterilization or directly refer for invitro fertilizations.
While I do not expect any of my patients to agree with my faith, they on the other hand do not expect me to violate it any more than someone who is Jewish would be expected to be force-fed pork ribs at a luncheon. If that happened the media would be all over it. But let a doctor refuse to inseminate a lesbian, and the courts allow the radical left to pounce all over him or her for refusing to materially cooperate in something they do not wish to do.

My patients have told me that while they may not agree with me, they respect my right to conscience in these matters. There are always other medical providers to be had, some conveniently, some not. But even if I were in a more rural area, I should not be forced to provide a form of care I disagree with. This violates the very heart of a basic freedom guaranteed by our Constitution, Freedom of Religion.

From the medical/professional side of things, I alone should be able to decide what is in the realm of my personal practice, no matter what the "demands" of a patient who hits the door. Unless their life (not their "health" as defined by the abortion community) is in immediate danger or they collapse right before me, I should have the right of refusal according to the dictates of my conscience or medical opinion. Otherwise a patient could simply walk in, decide they want something that they read about, even though it is not appropriate for them, and I would be forced into the role of a drive-through prescription service. I did not study long years for the government to tell me how to practice medicine!

Speaking from a purely business perspective, it is afforded to restaurants and any other business "the right to refuse service to anyone". They can hang that sign and enforce it as they see fit for the good of their business. Why should doctors be any different? It is long past time to stop pandering to the far left liberal pro-abortion faction in this matter.

Abortion was made legal in this country as a private matter between a woman and her doctor. Not that I agree with that legality, but I am realistic enough to know exactly where this push to do away with conscience is coming from. If one uses the same logic, whether or not to prescribe any drug for any reason, is a private matter for the doctor, who should not even be required to refer the patient for an abortion or contraception or whatever it is they disagree with, but the doctor should simply inform the patient that they do not perform the requested service. The AMA code of ethics used to say that, I wouldn't know about their current code because I stopped giving their pro-abortion organization my money a long time ago. They don't represent the heart of medicine anymore, just the radical left.

Next thing you know you are going to be requiring doctors to write antibiotics for common colds just because "the patient wants it". Or, back to our restaurant analogy, how about let's tell Chick Fil A to serve beef burgers just because a group of people demand it? Is this a country founded on "free enterprise" or is it turning into a radical-left-only way of doing business?

Medicine is a business as well, and the employees or owners of a business ought to be able to work without having their beliefs violated. One wouldn't expect a waitress at a restaurant to have sex with a patron "just because he asked!" This issue of conscience is every bit as morally serious to those of us who do not practice medicine that way. To change our practice would be in our faith (not Nancy Pelosi's brand of "cafeteria Catholicism") a mortal sin and we will not do it. It amounts to asking us to "get in bed" with the devil himself. We don't expect everyone to agree with us, the freedom of belief is afforded to everyone. Free will is the inalienable right of every human. We simply want to preserve ours as well.

I do hope that you have some people on this committee with the good sense to restore the rights of practicing physicians to be free to practice medicine as they personally see fit, not the way that a far left radical minority would prefer it. My patients have been supportive of my decisions because they know I answer to a higher power before anyone. That basic right, freedom of religion, should not be interfered with, period.
Gail-Marie Walter MD

Please do all you can to protect the right of conscience for our medical professionals so that they have the right to deny services that go against their beliefs.
All life is valuable...
Thank you
Laure Thorpe

We are writing to ask that you vote this Friday, FOR the right of medical professionals to deny participating in services that go against their beliefs.
Thank you,
Ralph and Dianne Hoffmann
Charlotte, NC

I wanted to quickly share my belief that medical professionals should not be told they must provide treatment contrary to their conscience. To me, that is stealing their soul. I've had doctors ask me my religious beliefs as they relate to treatment, what's wrong with a doctor informing patients what they will and will not do?

Thanks
Alexis Castellana

We strongly urge you to uphold religious freedom and to never allow medical professionals to be coerced by a "government religion" of secularism to violate their religious beliefs.

A medical conscience clause is imperative in protecting innocent life and maintaining quality of care in the U.S. Please ensure its protection.

Thank you for your consideration,
Jean Aberle

Please support the rights of individuals to follow their beliefs and withhold services or prescriptions that would take away a human life.
Tami Kiser

I want to voice my opinion toward your vote on Friday:
I want medical professionals to have the right to deny services that go against their beliefs.

Michelle Buckman
www.MichelleBuckman.com
Fiction that rethinks Life

I would like to voice my support of allowing healthcare providers the right to decide which services they are willing to provide. I believe a lot of the issue lies around ones who are unwilling to provide abortions. And by abortions I include "birth control" pills which actually don't prevent conception, but do abort the baby once the egg has been fertilized. Thank you for allowing them to follow their conscience. And, for those who would look to obtain the pills, it is not like they don't
have other options to go to. So by removing these providers from services, you are also affecting people who aren’t looking for these pills, but are happy to have the provider to go to.

Steve [Brock]

Please vote to allow medical professionals to have the freedom to deny services that go against their personal belief’s.

Thank you,

Terri DeLuca
Midland, NC

Please do all you can to ensure that physicians can follow their conscience and the teachings of their church in their medical practice. According to the Roman Catholic Church, it is a grave evil to prescribe contraception and to perform abortions or to participate in euthanasia, and to do so is a mortal sin and puts our eternal salvation in jeopardy. Additionally, our patients deserve to be treated by physicians who are supportive of their own beliefs. Physicians who do not perform abortions or prescribe contraception or participate in euthanasia are not “out of the mainstream” and in fact there are several polls that show a slight majority of our population favors restrictions on abortion. It is established biological fact that life begins at conception, and not implantation. We should not drive pro-life physicians or physicians who limit their practice due to conscience and religious affiliation out of practice.

Rob Chasuk MD
Director
Family Medicine Residency Program
Baton Rouge General Medical Center

As the Council convenes for the hearing on the right of conscience for health care providers, I implore you to allow medical professionals to exercise the freedom this country was founded on. To strong arm a doctor to perform a procedure that he is morally opposed to is denying him the freedom to practice his religion. You are not taking side by voting to uphold the right of conscience. You would be doing what is right for all.

Thank you,

Kathy Schmugge

Of course members of the medical profession do have the right to deny to provide services that violate their professional and personal ethics. This is not something that anyone has the right to legislate. Please make sure that it does not happen.

There are plenty of other people who do not listen to the voice of God in providing services that go against His will. Please leave those who do listen alone.

Thank you,

Mary F. LeBlanc Creger

As the Council convenes for the hearing on the right of conscience for health care providers, I write expressing my strong opinion that medical professionals should unequivocally be granted freedom of conscience and the ability to deny services that go against their beliefs.

In a society that promotes life, liberty, and pursuit of happiness, will we not honor the liberty of the individual health care provider to pursue his own beliefs without being forced to contradicts them in his actions?

Thank you for hearing my concern.
Marie Connelly  
Candidate for Juris Doctorate, Notre Dame Law School

I'm writing to ask that you vote in favor of allowing doctors the right of conscience in all areas of science. This has been the basis of the Hippocratic oath for over 2000 years and serves as our protection. We take this right away and our moral foundation will begin to unravel. This is a very serious matter.

Sincerely,

Laura Howard

Sept. 07. 2008

I recently learned of legislation that is being put through that would prohibit doctors and other health care professionals from exercising a right of conscience about specific issues, mainly abortion. I am a practicing Catholic who is very pro-life. In fact, I choose my internist and, especially my OB-Gyns, with this in mind. I do NOT want to go into a doctor's office and have them push their views on me, especially when it means that they believe that I should not have more children. I know that my beliefs about abortion and especially contraception are a minority. I understand that many people don't agree with me on these issues. However, these people who don't agree seem to have the right to find doctors that support their opinions, ones that will dispense birth control, perform abortions, and agree with them on end of life issues. As a citizen of the United States of America, I believe that I have this freedom as well. I don't want my freedoms to find the doctors that support my views to be removed. I understand that you may object to this strict view of this legislation, stating that the OB's and internists that are pro-life can still work. However, I tell you that for the pro-life doctors, their belief that these procedures they are asked to perform is wrong is so strong that they will choose not to practice medicine. They would prefer to stop practicing rather than be forced to refer for abortion even though they, themselves, would not be performing the action. I ask you, is that what we want in America? With the economy the way it is currently, do we really want to force more people out of work? Do we really want to back people who have a conscience into a corner and in a sense, force them not to practice medicine, when many are very qualified and competent doctors. I WANT a right to choose a doctor that I agree with, one that will support me on my decisions, one that will give me the best medical care that I can receive. And for me, that means that they are not encouraging me to abort, or encouraging me to do other practices that I don't agree with. For me, that means that they are exercising a conscience. That is my right as a citizen and I expect you to protect it. I also believe that is their right as a professional and one that you should be protecting as well.

Thank you

Kristen Colton

When I was fellow in Maternal Fetal Medicine, residents told me that since I did not perform abortions, I should not be allowed to practice Maternal Fetal Medicine. This was coming from women MDs, who it was previously alleged faced barriers to professional advancement because of their gender. Rather than have compassion for me, they wanted to eliminate people like me.

In my residency I refused to perform abortions. While I survived, nurses had been previously fired for not doing abortions. Residents had been hounded out of the program for not performing
abortions.

I knew another doctor who was fired from her family practice residency, 3 months before she graduated, because she did not prescribe contraceptives.

One family practitioner was kicked out of UCLA genetics program for not being sympatheic to abortion.

One family practitioner was kicked out of Montana and had to relocate to Florida for his beliefs.

Three OB/GYNs had a successful practice at a Catholic Hospital. They were hounded out by sham peer review and each had to leave.

Another OB/GYN stopped prescribing contraceptives. Despite this she had a very busy practice. She was forced out of the hospital and had to leave town. Despite the unfair circumstances of her departure, The hospital demanded loan repayment for her early departure.

Despite being an excellent surgeon, and being very successful at attracting a large following of patients, one Ob/GYN was hounded out of two different locales for her beliefs.

I attended a conference at the Vatican on rights of conscience for OB/GYNs around the world. From all around the world and all across America came sad, tragic tales of persecution, discrimination, sham peer review, and maltreatment. Physicians were hounded out of their practices, their hospitals, their careers, and even their countries. These sad tales came not from communist countries, but mostly from so-called democracies.

If one should not be mistreated and discriminated against becuase of one religion or beliefs, then why are physicians persecuted for their beliefs.

Only about 1/2000 OB/GYNs does not prescribe contraceptives. In one area of downton LA, near 6th and westmoreland, there seem to be more abortion providers than gasoline stations. If 1.4 million abortions occur every year in the united states, how can one say there is a shortage of providers. Many patients travel 6 hrs by car from Chicago to Granite City Illinois for abortions at the notorious "Hope" clinic. No one needs an abortion as an emergency. To say that there is a critical shortage of such providers is as dishonest as saying the sun is purple. Anyone who really wants one can get one. If abortion should be "safe", "legal" and "rare", then a shortage of such providers would be something to be hoped for, but certainly not a reality today.

For MDs who do not prescribe contraceptives, both OB/Gyn and Family practice, there have been many examples in my experience or those I personally know, where they were kicked out of training programs, hospitals, medical practices, etc., for not prescribing contraceptives or doing abortions.

Many have complained about repeated ethical lapses and scandals among the medical profession. These had lead to the proliferation of programs of medical ethics. The Oath of Hippocrates was a response to widespread unethical behavior among the medical profession in classical times. Certainly, ethical doctors are needed. In fact, ACOG and ABOG demand that their doctors be ethical, even while demanding that they perform or refer for abortion and contraception.

If we do not force doctors to be ethical, we should at least allow them to be ethical.

Paddy Jim Baggot MD
I was contacted by AAPLOG that there will be a meeting this Friday to discuss the physicians' right of conscience. I am attaching letters we sent from the Catholic Medical Association to ACOG and ABOG re their attempt to force ob-gyns to at refer for abortions, practice near abortionists, and even perform abortions. ABOG two months later made it a requirement that all ob-gyns being certified or recertified comply with the ethics opinions of ACOG which would have put pro-life ob-gyns out of business. I hope the President's Council on Bioethics can help these groups understand the importance of conscience, especially for physicians making life and death decisions for patients.

Sincerely,

Kathleen M. Raviele, M.D. F.A.C.O.G.
ravielek@gmail.com
President, Catholic Medical Association

I am concerned that there appears to be an effort among physicians, nurse practitioners and especially ACOG members to force other physicians, nurses, etc. to abrogate their consciences when it comes to abortion. This is striking at the very fabric of a person's right to be in consonance with her Faith, her morals, her values. It further seems to be a concerted effort to drive Muslims, Catholics, Orthodox Jews and others of faith (or of no faith but who abhor abortion) out of medicine.

Such an effort has far-reaching consequences for patients as well as physicians. Are we now about to mandate abortion of infants with special needs, infanticide, and euthanasia? This is truly a Pandora's box and I would expect the President's Bioethics Committee, under your leadership, to come out clearly and completely in support of a person's right to follow her or his conscience.

Thank you… for standing up for the rights of individual citizens.

Therese T. Maes
San Jose, CA

We would urge you to respect the rights of medical practitioners to practice medicine in accordance with their consciences. It is extremely difficult and close to impossible for us as people of faith to find doctors who respect our religious beliefs in our care and the care of our children. The first amendment of the Constitution states that "Congress shall make no law …prohibiting the free exercise [of religion]". This right must be preserved for all American citizens, including those in the medical professions.

Thank your for your attention to this matter.

Mrs. Elizabeth Smith
Mr. David Smith

Please do not destroy our society by forcing our Christians physicians to perform the type of medicine that is against their conscience, all humans have a right to LIFE, and LIBERTY. Some of our technologies today are not what they appear to be, some of the long term and future side effects are not known, some of the very severe emotional consequence are known: PLEASE do not pass this lack of conscience clause.

Thank you

Theresa Mitchell
I want to voice my support for medical professionals to not be forced to violate their conscience. I am tired of being belittled by medical professionals because I use natural family planning which has proven its usefulness and effectiveness but because it isn’t the norm and involves the following of conscience by trying to follow my religious beliefs is ridiculed. I want medical professionals who respect the fact that my values and morals are a part of who I am and that you cannot violate a person’s conscience without also violating the person. I want my “choice” of a medical professional who will respect me and share my moral convictions when making my medical decisions.

Thank you and may God's peace and blessings be always with you.
Carolyn Susin

Sept. 06, 2008

Please let me state that ObGyn and Family Practice (Catholic) doctors are few and far between. It would be most appreciated if my family and I could have access to the services of such doctors, who share our values. I ask that you act in support of the people, my family and myself, and do not allow the persecution of Catholic doctors. Losing ones ACOG, board certification, hospital privileges, etc. because they are pro-life is unethical and unfair.

Thank you for your time,

Mrs. Valerie Burkart

I am writing to state the necessity - and, personal desire- that I have, for Catholic physicians to be present in such fields as Family Practice and OBGYN. More specifically, such physicians must be allowed to treat their patients, and conduct their practices, as their conscience requires.

The life issues (abortion, contraception, emergency contraception) are not negotiable items for Catholic men and women, and we deserve access to physicians who respect the Natural Moral Law, as much as we do. We will not compromise on these key issues, and our physicians should not be forced to do so, either.

Thank you for taking the time to read this letter, and I hope that you will understand the sincerity with which it was written.

Sincerely,
Ashley McGlone

I am a recent graduate of the University of South Carolina, and one who feels strongly about the sanctity of human life. I feel that it is important for medical professionals to have the right to refuse to perform services that go against their beliefs (particularly, I feel it is important for a physician to be able to refuse to perform an abortion if it is against his/her conscience), and that they should be able to do so without forfeiting their jobs. I encourage you and the other members of the Council to support these physicians in their decisions.

Sincerely,
Sarah Nyikos
Good morning and thank you Chairman Pellegrino and Council Members. My name is Kimberly Goulart, and I have the honor of working with Compassion & Choices (C&C) and its more than 35,000 members to improve end of life care options for Americans. C&C is the oldest and largest organization in the country focused on ensuring that Americans have access to the full array of end-of-life care options including palliative care, improved pain care, hospice care, and legal aid-in-dying. Compassion & Choices has more than 25 years of experience in advocacy and service. Much of the work we do is accomplished through the grassroots efforts of our members and volunteers who generously give their time to support and strengthen their communities through direct service to terminally-ill patients and their families. C&C also works with policy makers on the local, state, and federal levels to ensure that the law facilitates an environment where patients are fully informed of all their options and are empowered to make their own decisions about their end of life care, in consultation with family and medical providers.

Since its inception, C&C has focused its resources on arming patients and their families with the tools to effectively and openly discuss the medical options available to them at the end of life. As we encountered an increasing number of patients around the country, we have learned that dying patients needlessly suffer due to a lack of essential information. As a result, many spend their last days in agony. Too many patients make one of the most important decisions of their lives – how they will live their final days – without being fully informed of their legal rights and in some cases, all of their medical options. Doctors have a responsibility to put the information and power to choose in the patients’ hands.
Refusal clauses, sometimes referred to as conscience clauses, can undermine that very basic principle of being fully informed of and having access to all of their medical options. Refusal clauses allow physicians and other medical professionals to refuse to perform a procedure for moral or religious reasons. Depending on how they are written, these policies can also allow medical professionals to refuse to provide a referral to another medical professional that will provide a particular service, or even to inform the patient of the option of that procedure. While the refusal clauses frequently specifically address the religious or moral objections to sterilization procedures and abortion, they are often broadly drafted to extend to any procedures which may be controversial or viewed as morally objectionable. In the area of end of life care, institutions and individuals opposed to withdrawing feeding tubes, aggressive pain care management, providing support to a patient choosing to voluntarily stop eating and drinking, or to the practice of palliative sedation could claim these are objectionable and are thus within the scope of refusal laws.

This is particularly worrisome for patients at the end of life who are often unaware of their options, hesitant to initiate conversations with their providers about certain options, and often unable to remove themselves from their current health care setting in order to seek treatment elsewhere. When dying patients are suffering in the final stages of terminal illnesses, they should be able to receive counseling on a full range of options. This thereby empowers them to make fully informed medical care decisions, including the legal and medically accepted options of refusing life prolonging interventions, opiate pain management, palliative sedation, and voluntary stopping eating and drinking (VSED).
It is well documented that pain is frequently under-treated, despite requests by patients and families. Some health care professionals, including those at the bed side, have personal and religious beliefs opposing pain relief, even in circumstances in which professional norms require it to be offered. These laws can remove any obligation on behalf of any employee of a health care entity to inform patients of all of their treatment options or to refer a patient to another provider if that patient requests treatment options with which that employee does not personally agree. The very notion of denying patients access to any such information runs afoul to the fundamental healthcare principles of autonomy and informed consent.

Many patients trust their provider to give them with the full range of information on all of their options. Refusal clauses that empower providers to deny patients appropriate counseling and referrals leave many patients unaware that other options are even available or that they have a right to seek treatment elsewhere. At a minimum, and in order to maintain at least some level of autonomy, patients should have notice that a facility or provider might refuse to offer information or referrals regarding certain types of treatment based on the provider’s personal moral or religious views.

The right of medical professionals to exercise their moral and religious beliefs should not be accommodated at the expense of the right of the patient to have access to a the full array of medical care, and in particular the right of dying patients to be given the information and access to services they deserve to be able to end their life with as much self determination, peace and dignity as possible. We, at Compassion & Choices, will continue to fight to ensure that all Americans have access to the full-range of end-of-life care options, and we will continue to advocate against policies that limit patient access to information or services as they approach the end of life. Thank you for this opportunity to address the panel.
Thank you for the opportunity to testify about the concerns we disabled people have regarding futile care.

My name is Stephen Mikochik. I am a professor at Temple Law School in Philadelphia and the chair-elect of the National Catholic Partnership on Disability.

NCPD was established by the U.S. Catholic Bishops in 1982 to implement their Pastoral Statement on People with Disabilities. A central aim of our mission is "to increase the public's sensitivity toward the needs of ... [disabled] people ... and support their rightful demand for justice."

On behalf of the 14 million American Catholics with disabilities, we ask you to consider our concerns about futile care. Specifically, we fear that the pressure to contain cost will increasingly influence physicians to withhold or withdraw life-support from disabled patients, not because they consider such measures futile in prolonging our lives but because they consider futile the lives such measures prolong.

We recognize that there comes a time when physicians should “shift the intent of care” away from “further intervention to prolong ... life” and “toward comfort and closure.” Yet, we must equally acknowledge, as did the New York State Task Force on Life and the Law, that "physicians’ judgments about the value of continued life for the patient will be shaped by the physician’s own attitudes about illness, physical dependence, pain, and disability." Moreover, we cannot ignore the pressures physicians face today to contain costs. As the AMA observed, "[w]hen deciding whether to order a test or procedure for a patient under managed care, the physician must consider whether the slot should be saved for another patient or not used at all to conserve the plan’s resources." It would blink reality to deny that more physicians will rest such determinations on “quality of life” considerations in the future and that insurers will become less inclined to pay for treatment for patients with severe disabilities.

The legal structure that would allow this is largely in place. Texas, for example, permits physicians to withhold or withdraw life-support they judge inappropriate from patients with conditions that render them permanently unable to care for or make decisions for themselves and would be fatal without such support, an open invitation to forgo life-support for patients with severe disabilities on “quality of life” grounds. And Texas is

2 AMA Opinion E-2.037 “Medical Futility in End-of-Life Care.”
not unique in this regard. According to the Robert Powell Center for Medical Ethics, statutes in many other states give physicians wide discretion to disregard their patients' requests for life-support.6

Simply put, we fear that these factors will combine to make futile care for disabled patients a mere euphemism for euthanasia by omission. We urge you to avoid these ends by avoiding these beginnings and recommend policies on futile care that strongly presume in favor of continued life-support. We have detailed our approach in a statement our Governance Board adopted this August that we have submitted for your review. Though we rely on official Catholic teaching, the principles we use are distinctly rational. I will briefly set forth our conclusions.

Clearly, if it were immoral for the patient to forgo care or treatment, it would be equally wrong for the physician. We believe it is immoral for patients, and thus for physicians, to forgo ordinary means of preserving life. We agree with recent Catholic teaching that such means include artificially supplied nutrition and hydration, unless altogether useless in sustaining life, substantially and intractably painful for the patient, or productive of serious ancillary complications.7

On the other hand, it is morally permissible for patients to forgo extraordinary means of preserving life. Extraordinary means are those that "in the patient’s judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community."8

In striking this balance, however, we believe that a physician's standing is not the same as the patient's. For example, given that the physician has already assumed responsibility for the patient's care and thus owes him a high professional duty, the physician does not have the latitude a patient has in deciding whether the hope of benefit, weighed against the anticipated burdens, is sufficiently reasonable to warrant commencing or continuing treatment.

Accordingly, we believe first that physicians can withhold or withdraw life-support, not otherwise burdensome, only when they can demonstrate that such measures provide no real benefit to the patient because death is inevitable and imminent-- inevitable, to avoid "quality of life" rather than quality of treatment decisions, imminent, to ensure that the terminal condition, not the withdrawal of treatment, is the cause of death.

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7 See Address of John Paul II to the participants in the International Congress on "Life-sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas," #4 (Mar. 20, 2004); Responses to Certain Questions Concerning Artificial Nutrition and Hydration with Accompanying Commentary, Sacred Congregation for the Doctrine of the Faith (Aug. 1, 2007).
By contrast, since their duty is ultimately to the patient and not the patient’s family, physicians can withdraw life-sustaining measures, even over family objections, when such measures cause substantial, intractable pain. Physicians can legitimately presume that incompetent patients would not desire such treatment, provided there are no reasonable grounds to believe a patient would wish otherwise.

Physicians, however, are obviously in no position to second-guess the impact of patient care on family finances, particularly when their judgment goes against the family’s wishes.

Further, we note that the overall cost of providing ordinary care to patients on life support often far exceeds the expense of life-sustaining measures themselves. However, to withhold or withdraw such measures because a patient’s earlier death may obviate the need for such ordinary care and hence ease financial burdens on health care providers or the community at large would effectively constitute euthanasia.

Alternatively, where life support itself proves exceptionally costly, patients, in their free and informed discretion, can selflessly forgo it to save the community expense; but no one can make this choice for another. Thus, without clear evidence of their patients’ intent, we believe that physicians can withhold or withdraw life-support because of expense only when the cost is so disproportionate to its hoped-for prolongation of life that it would be plainly unreasonable for patients to have chosen otherwise.

Finally, we note that procedural safeguards are often as important as substantive requirements. Consistent with a strong presumption in favor of continued life-support, the procedures outlined in our statement place a heavy burden of proof on those seeking to withhold or withdraw such measures.

Undoubtedly, identifying when physicians can ethically withhold or withdraw life-support they consider futile is an urgent task. It is not too much to say that the lives of countless disabled people hang in the balance.
National Catholic Partnership on Disability
2008 Board Statement on Futile Care

Introduction

Every principle tends “to expand itself to the limit of its logic.”¹ The principle that one may sometimes allow removal of treatment that sustains human life illustrates this point. Over the past three decades, the United States has witnessed a near stampede in the extension of patients’ legal right to refuse life-sustaining measures,² beginning with the removal of respirators³ to the more recent controversy over withdrawing food and hydration from those in a “persistent vegetative state.”⁴ The latest stage in this development concerns the issue of “futile care”—specifically, whether health care providers are ever justified in withholding or withdrawing care or treatment that they consider inappropriate against the wishes of patients or their surrogates.

The use of the term “futile care” generally refers to the claim that “Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients.”⁵ Unfortunately, there is no agreement within the medical community as to when such interventions lack sufficient benefit to be judged futile. For example, “[s]ome physicians use ‘futile’ narrowly, considering treatments to be futile if they would be

¹ BENJAMIN N. CARDOZO, NATURE OF THE JUDICIAL PROCESS 51 (1949).

² See Cruzan v. Director, Mo. Dept. of Health, 497 U.S. 261, 277, 278 (1990) (“[T]he common-law doctrine of informed consent is viewed as generally encompassing the right of a competent individual to refuse medical treatment. ... The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.”).


⁴ See Cruzan, 497 U.S. 261; Schiavo Family Marks Her Death Anniversary; Anti-Euthanasia Effort Announced, WASH. TIMES, Mar. 31, 2006. See also Address of John Paul II to the participants in the International Congress on “Life-sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,” #4 (Mar. 20, 2004) (“[T]he artificial administration of water and food should be considered, in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality ...”), available at http://www.vatican.va/.../john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html (last visited Nov. 5, 2007). We will use the term “persistent vegetative state” because it is accepted in the medical profession, putting it in quotations, however, since we agree with John Paul II that it “is certainly not the most felicitous when applied to human beings.” Id. at #3.

⁵ AMA Opinion E-2.035 “Futile Care,” available at http://www.ama-assn.org/ama/pub/category/2830.html (last visited Dec. 5, 2007). Though the term “futile care” generally refers to medical treatment, it has also been used to justify the withdrawal of food and hydration, whether or not artificially supplied, which official Catholic teaching considers, not a medical act, but rather ordinary and proportionate care. See infra note 46.
physiologically ineffective or would fail to postpone death. ... Many [other] physicians embrace a broader, more elastic understanding of the term. ... [A] treatment might be seen as futile if it does not offer what [these] physicians consider an acceptable quality of life.”

We have a vital interest in the outcome of this question, given its obvious importance for the lives of countless critically ill and disabled people. We offer the present statement to explore what light Catholic moral teaching sheds on whether health providers can ever withhold or withdraw life-sustaining care or treatment they consider futile. Though we will continue to use the label “futile care” because it is an accepted term of art, we reject any implication that the lives involved, rather than simply their care or treatment, are futile. We maintain at the outset that all human life, no matter how disabled or critically ill, is of quality and incomparable worth and no less entitled on that account to adequate health care.

We begin our discussion of the question of “futile care” by reviewing recent developments in Texas.

Background

Under a 1999 amendment to Texas’ Health and Safety Code, attending physicians are permitted to withhold or withdraw life-sustaining treatment, contrary to patients’ or their surrogates’ wishes, when such physicians consider that treatment inappropriate. The authorization applies to “qualified patients” with “terminal” or “irreversible” conditions and includes the

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7 We do not mean to imply that health providers are obliged to deliver services not readily available or outside their area of specialization. Our inquiry centers on whether a patient otherwise qualified to receive the type of services a health provider supplies can be deprived of these services because the provider considers them, in this patient's case, futile.

8 As with “persistent vegetative state,” we will refer to the term “futile care” in quotations.

9 See Ethical and Religious Directives for Catholic Health Care Services, U.S. Conference of Catholic Bishops, Gen. Intro., ERD 3 (4th ed.) (June 15, 2001) (“[T]he person with mental or physical disabilities, regardless of the cause or severity, must be treated as a unique person of incomparable worth, with the same right to life and to adequate health care as all other persons.”), available at http://www.usccb.org/bishops/directives.shtml#introduction (last visited Jan. 9, 2008).

10 See V.T.C.A., Health & Safety Code § 166.046(e) (“If the patient or the person responsible for the health care decisions of the patient is requesting life-sustaining treatment that the attending physician has decided and the review process has affirmed is inappropriate treatment, the patient shall be given available life-sustaining treatment pending transfer ... . The physician and the health care facility are not obligated to provide life-sustaining treatment after the 10th day after the written decision ... is provided to the patient or the person responsible for the health care decisions of the patient unless ordered to do so [by an appropriate state district or county court].”).

11 See id. § 166.031(1).
artificial provision of food and hydration. An ethics committee must review the decision, and life-support must continue pending review. If the decision is affirmed, patients will receive life support pending transfer but only for ten days after receipt of the committee’s determination.

A private survey of five years’ operation under the Amendment found that 974 ethics committee reviews were held on medical futility cases, affirming treatment-cessation decisions in 65 instances and resulting in the ultimate removal of life-support for 27 patients. While the survey did not distinguish between patients with terminal and irreversible conditions, there is some evidence that those in a “persistent vegetative state” were among the subjects of such decisions.

Texas’ procedure attracted national attention when Children’s Hospital in Austin proposed removing a respirator from a 17-month-old baby, Emilio Gonzalez, diagnosed with Leigh’s disease, a fatally degenerative brain disorder. The hospital, operated by the Sisters of Charity, contended that the treatment was painful and merely prolonged the child’s death. The hospital’s position was supported by the Catholic Bishop of Austin who appealed to standards established by Catholic moral teaching. The child’s mother, however, insisted that the treatment continue

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12 “Terminal condition” means “an incurable condition caused by injury, disease, or illness that according to reasonable medical judgment will produce death within six months, even with available life-sustaining treatment[.]” Id. § 166.002(13).

13 “Irreversible condition” means “a condition, injury, or illness:

(A) that may be treated but is never cured or eliminated;

(B) that leaves a person unable to care for or make decisions for the person’s own self; and

(C) that, without life-sustaining treatment provided in accordance with the prevailing standard of medical care, is fatal.” Id. § 166.002(9).

14 See id. § 166.002(10) (“‘Life-sustaining treatment’ includes both life-sustaining medications and artificial life support, such as mechanical breathing machines, kidney dialysis treatment, and artificial nutrition and hydration.”).

15 See id. § 166.046(a) (“If an attending physician refuses to honor a patient’s advance directive or a health care or treatment decision made by or on behalf of a patient, the physician’s refusal shall be reviewed by an ethics or medical committee. ...The patient shall be given life-sustaining treatment during the review.”).

16 See supra note 10.


18 See id. Cf. Bills Challenge Limits for Terminal Patients: Some Say 10 Days to Transfer Isn’t Enough Before Treatment Ends, Dallas Morning News, Feb. 15, 2007 (reporting that patient’s treatment removal was based on diagnosis of an irreversible “vegetative state” and possible suffering, but further asserting that patient was dying).

19 See, e.g., Case Puts Texas Futile-Treatment Law Under a Microscope, WASH. POST, Apr. 11, 2007.

and was joined in her efforts by the Texas Right to Life Committee, the ACLU of Texas, and various disability groups. After an unsuccessful search to find another facility willing to continue treatment, a probate judge granted the child’s mother a temporary restraining order. The trial was set for May 30th, 2007, but Emilio died of natural causes eleven days before trial.

Emilio’s case served to galvanize opposition to the existing procedure for termination of treatment in the Texas General Assembly. One bill that would have increased the period for treatment pending transfer from 10 to 21 days, and exempted food and hydration from the list of treatments eligible for termination under this procedure, received unanimous support from the Texas Conference of Catholic Bishops. A rival bill would have required the provision of life-support until a transfer actually occurred. Ultimately, time ran out before any remedial legislation could be passed. The Texas legislature is likely to reconsider the issue when it reconvenes in 2009.

As indicated, existing Texas law authorizes health providers to withhold or withdraw life support they judge inappropriate from patients with terminal conditions, or with conditions that render them permanently unable to care for or make decisions for themselves and would be fatal without such support. It would permit withholding or withdrawing food and hydration, for example, not only from patients in a “persistent vegetative state” or suffering advanced dementia, but arguably even from those with cerebral palsy or developmental impairments who may require food and hydration administered artificially because of the severity of their conditions. With so broad an approach to what constitutes “futile care,” current Texas law is an open invitation to withhold or withdraw life-support from patients with severe disabilities on “quality of life” grounds.

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23 See Futile care law is getting 1st aid/Medical groups will compromise in order to save contested statute, HOUS. CHRON., Apr. 25, 2007.

24 There are presently two reported court cases under the Texas statute. See Hudson v. Children’s Hospital, 177 S.W. 3d 232 (Tex. Ct. App. 2005) (involving the attempted withdrawal of a respirator, apparently because too painful, from an infant diagnosed with “thanatophoric dysplasia,” a fatal tissue abnormality); Nikolouzos v. St. Luke’s Episcopal Hospital, 162 S.W. 3d 678, 683 (Tex. Ct. App. 2005) (involving the termination of life-support from an adult male described as not meeting “the criteria for ‘brain death’ because cerebral blood flow was present.”).

25 See supra notes 12 & 13.

26 These examples fall within the exact terms of § 166.002(9). See supra note 12. Whether proponents originally intended so broad a scope for that provision is irrelevant since, “[i]f the disputed statute is clear and unambiguous extrinsic aids and rules of statutory construction are inappropriate[.]” Cail v. Service Motors, Inc., 660 S.W.2d 814, 815 (Tex. 1983).
Texas, however, is not unique in that regard. Statutes in many other states give health care providers wide discretion to disregard advance medical directives requesting life-support. Although patients can transfer if they can find another provider willing to honor their wishes, few states guarantee life-sustaining treatment pending transfer. Given that care of patients on life support can prove costly, health care providers have a strong incentive to resort to laws authorizing withholding or withdrawing care or treatment more frequently in the future.

27 See “Will Your Advance Directive Be Followed?” (Appendix of State Statutes), supra note 6. Six states (Alaska, Connecticut, Delaware, Michigan, Texas, Virginia) permit health care providers to disregard an advance directive requesting life-support if they judge it medically inappropriate. Id. Four states (Colorado, Missouri, Massachusetts, New York) permit health care providers to disregard an advance directive if honoring it would violate religious beliefs central to their operating principles. Id. Statutes in two states (Nebraska, West Virginia) list both of the aforementioned grounds, either of which would permit health care providers to disregard an advance directive requesting life support. Id. Two states (New York, New Mexico) allow health care providers to disregard an advance directive requesting life support for reasons of conscience or if it is considered medically inappropriate. Id. In the majority of states (Alabama, Arizona, Arkansas, California, Florida, Georgia, Idaho, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Minnesota, Mississippi, Montana, Nevada, New Hampshire, New Jersey, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Vermont, Washington, Wisconsin, Wyoming, and likewise District of Columbia, Guam, Virgin Islands), physicians or health care facilities may disregard an advance directive if they are “unwilling to comply” or “decline to comply,” sometimes for reasons of morality or conscience. Id. North Carolina has no statute concerning when health care providers are permitted to disregard an advance directive requesting life-support. Id. Our reservation about these statutes is not that they recognize a right of conscientious objection in cases where providers consider the proposed life-sustaining measures to be inherently immoral, so-called life saving abortions, for example, and the like. Our concern rather is that providers can argue that these statutes also grant them the right to object to providing treatment on quality of life grounds.

28 See id. at A11-A14 (setting forth the statutory provisions of 11 States (Alabama, Florida, Kansas, Maryland, Massachusetts, Minnesota, New Hampshire, New York, Ohio, Oklahoma, Wyoming) requiring life-preserving treatment pending transfer, with no time limit); id. at A10 (setting forth the statutory provisions of 2 States (Texas, Virginia) requiring life-preserving treatment pending transfer, but only for 10 & 14 days respectively).

29 See, e.g., Boy At Center Of Ethics Case Dies: Dallas Mother’s Fight For Life Support Brought Attention To Law, Dallas Morning News, May 31, 2007 (reporting that the cost for Emilio’s 142 days of ICU care reached $1.68 million).

30 “Managed care plans ... encourage physicians to make cost-conscious treatment decisions through the use of financial incentives. ... [Such] plans typically use incentives for physicians to limit their use of diagnostic tests, referrals to other physicians, hospital care, or other ancillary services. For example, managed care plans often pay bonuses to physicians, with the amount of the bonus increasing as the plans’ expenditures for patient care decrease. Or plans often withhold a fixed percentage of their physicians’ compensation until the end of the year to cover any shortfalls in the funds budgeted for expenditures on patient care. If there is no shortfall, or the shortfall can be covered by part of the withheld fees, the remaining withheld fees are returned to the physicians.” Council on Ethical and Judicial Affairs, AMA, “Ethical Issues in Managed Care” 2 (1995), available at www.ama-assn.org/ama1/pub/upload/mm/369/ceja_13a94.pdf (last visited Mar. 11, 2008). By 1995, “[m]ore than half the states ha[d] passed laws restricting money-saving methods of health maintenance organizations[.]” States Take Aim at HMOs, Balt. Sun, May 7, 1995. A particular focus of legislative activity was the twenty-four hour limit HMOs began to impose on reimbursement of hospital stays for routine vaginal deliveries. Critics argued that mothers often needed more time to rest and to master breastfeeding techniques, while some complications newborns encountered did not show up immediately. See Mother and Newborn: How Long in the Hospital?, N.Y. Times, Aug. 20, 1995; Physicians Protest Maternity Insurance, N.Y. Times, Mar. 5, 1995. In response, several states mandated longer minimum reimbursed hospital stays. See Moms’ Waits Prevail; Nine States OK Laws Extending Maternity Stays, West’s Legal News, Apr. 18, 1996 (listing enacted and pending legislation).
Likewise, few providers have an incentive to accept such patients once their original provider refuses to continue treating them.

We offer the following analysis of issues surrounding “futile care” that we believe is consistent with our advocacy for critically ill and disabled people and with our Catholic faith.

“Futile Care” and Catholic Moral Teaching

We begin by setting forth the general principles that have guided our consideration of this issue. The first is that “[w]e have a duty to preserve our life and to use it for the glory of God, but the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome.”31 The second is that “the value of a man’s life cannot be made subordinate to any judgment of its quality expressed by other men[.]”32 The last is that the first duty of health care providers is to promote the best interest of their patients, not their patients’ families or the community at large.33

Whether health care providers can withhold or withdraw life-sustaining treatment they consider futile is largely unresolved in official Catholic teaching. In a 1957 Address to an International Congress of Anesthesiologists,34 Pius XII did indicate that physicians could licitly withdraw mechanical respiration under circumstances where their patients, if competent, could ethically make that choice, but his comments provide limited guidance for the problem of “futile care.”35 He addressed only whether physicians could cease resuscitation efforts that merely prolonged the death of unconscious patients, with no hope of regaining spontaneous respiration, at the insistence of their families and apparently where the patients’ own wishes were unknown.36


32 Address of John Paul II to the participants in the International Congress “On Life-sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,” #6, supra note 4.

33 See “Ethical Issues in Managed Care,” at 4 (“While this responsibility to guard society’s resources is an important one, physicians must remain primarily dedicated to the health care needs of their individual patients.”), supra note 30.


35 Pius XII was addressing the following questions concerning whether physicians could terminate efforts at resuscitation: “[D]oes one have the right, or is one under obligation, to remove the artificial respiration apparatus when, after several days, the state of deep unconsciousness does not improve if, when it is removed, blood circulation will stop within a few minutes? What must be done in this case if the family of the patient, who has already received the last sacraments, urges the doctor to remove the apparatus? Is Extreme Unction still valid at this time?” Id.

36 Cf. id. (“In general ... [the physician] can take action only if the patient explicitly or implicitly, directly or indirectly, gives him permission.”).
In addition, the Declaration on Euthanasia of the Sacred Congregation for the Doctrine of the Faith does permit physicians to interrupt what is considered experimental treatment, but only “with the patient’s consent[.]” All the same, the Declaration further provides that, “for such a decision to be made, account will have to be taken of the reasonable wishes of the patient and the patient’s family, as also of the advice of the doctors who are specially competent in the matter.”

In their Ethical and Religious Directives for Catholic Health Care Services, however, the U.S. Bishops do provide a framework for addressing the issue. The Directives state that Catholic health care providers should normally comply with the informed judgments of competent adult patients concerning the use or withdrawal of life-sustaining procedures, unless aimed at suicide or otherwise contrary to Catholic moral teaching. With the same qualifications, they should likewise honor the advance directives of incompetent patients or the judgments of their designated surrogates who must decide on life-support consistent with the patients’ wishes. Where no such authorization exists, those family and friends most familiar with the incompetent patient’s wishes should participate in the treatment decision. In what follows, we discuss whether providers are ever justified under these Directives in withholding or withdrawing life


38 Id. (“[Such doctors] who are specially competent in the matter ... may in particular judge that the investment in instruments and personnel is disproportionate to the results foreseen ... [or] that the [experimental] techniques applied impose on the patient strain or suffering out of proportion with the benefits he or she may gain from such techniques.” Id.).

39 See Ethical and Religious Directives for Catholic Health Care Services, Pt. Five, ERD 59, “Issues in Care for the Dying” (“The free and informed judgment made by a competent adult patient concerning the use or withdrawal of life-sustaining procedures should always be respected and normally complied with, unless it is contrary to Catholic moral teaching.”), supra note 31.

40 See Ethical and Religious Directives for Catholic Health Care Services, Pt. Three, ERD 28, “The Professional-Patient Relationship” (“The free and informed health care decision of the person or the person’s surrogate is to be followed so long as it does not contradict Catholic principles.”), available at www.usccb.org/bishops/directives.shtml#partthre (last visited Nov. 5, 2007). We are mindful that the wishes of an incompetent patient to authorize refusal or withdrawal of life-support may have changed from the time an advance directive was executed. Given the consequences, we think health care providers should follow such free and informed decisions, if not otherwise contrary to Catholic moral teaching, only where there are no reasonable grounds to believe that the patient would now wish otherwise.

41 See id. ERD 25 (“Decisions by the designated surrogate should be faithful to Catholic moral principles and to the person’s intentions and values, or if the person’s intentions are unknown, to the person’s best interests.”).

42 See id. (“In the event that an advance directive is not executed, those who are in a position to know best the patient’s wishes—usually family members and loved ones—should participate in the treatment decisions for the person who has lost the capacity to make health care decisions.”).
support they consider inappropriate, contrary to their patients’ known wishes or in cases where, for reasons of infancy, incompetence, patients’ oversight, or the like, such wishes are unknown.

Clearly, if it were immoral for the patient to forgo care or treatment, it would be equally wrong for the provider to withhold or withdraw such measures.\footnote{See Pius XII, Address to an International Congress of Anesthesiologists (“The rights and duties of the doctor are correlative to those of the patient. The doctor, in fact, has no separate or independent right where the patient is concerned.”), supra note 34.} Under Catholic moral teaching, it is immoral for patients, and thus for health care providers, to forgo ordinary or proportionate means of preserving life.\footnote{The term “proportionate means” is more consistent with current usage. See Declaration on Euthanasia, Pt. IV (“[S]ome people [today] prefer to speak of ‘proportionate’ and ‘disproportionate’ means.”), supra note 37.} Such means include artificially supplied nutrition and hydration, which official Catholic teaching considers ordinary and proportionate unless altogether useless.

\footnote{See, e.g., id. at #4 (indicating that “ordinary and proportionate” means of preserving life are morally obligatory); Responses To Certain Questions Concerning Artificial Nutrition And Hydration, Sacred Congregation for the Doctrine of the Faith (Commentary) (Aug. 1, 2007) (referring to The Address of Pope Pius XII to an International Congress on Anesthesiology, supra note 34 (“On the one hand, natural reason and Christian morality teach that, in the case of a grave illness, the patient and those caring for him or her have the right and the duty to provide the care necessary to preserve health and life. On the other hand, this duty in general includes only the use of those means which, considering all the circumstances, are ordinary, that is to say, which do not impose an extraordinary burden on the patient or on others.”), available at www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070629_commento-responsa_en.html (last visited Nov. 5, 2007); Ethical and Religious Directives for Catholic Health Care Services, Pt. Three, ERD 32, “The Professional-Patient Relationship” (footnote omitted) (“[E]very person is obliged to use ordinary means to preserve his or her health ...”), supra note 40; Id. at Pt. Five, ERD 56, “Issues in Care for the Dying” (footnote omitted) (“A person has a moral obligation to use ordinary or proportionate means of preserving his or her life.”), supra note 31.}

\footnote{See Address of John Paul II to the Participants in the International Congress on “Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,” #4 (“[T]he administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.”), supra note 4; Responses To Certain Questions Concerning Artificial Nutrition And Hydration (Response to First Question) (“The administration of food and water even by artificial means is, in principle, an ordinary and proportionate means of preserving life. It is therefore obligatory to the extent to which, and for as long as, it is shown to accomplish its proper finality, which is the hydration and nourishment of the patient.”), available at www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20070801_risposte-usa_en.html (last visited Nov. 5, 2007). Both of the above statements are couched in general terms and, though responding to the specific condition of “persistent vegetative state,” do not appear limited to that immediate context. Nor does it occur to us why such general principles concerning “a natural means of preserving life” should be so limited. Cf. Ethical and Religious Directives for Catholic Health Care Services, Pt. Five, ERD 58, “Issues in Care for the Dying” (“There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient.”), supra note 31. We understand that at their June 2008 general meeting, the U.S. bishops voted to begin the process for amending this Directive to bring it into more explicit conformity with the recent statements by John Paul II and the Congregation for the Doctrine of the Faith.}
in sustaining life,\textsuperscript{47} or substantially and intractably painful for the patient,\textsuperscript{48} or productive of serious ancillary complications.\textsuperscript{49}

On the other hand, it is morally permissible for patients to “forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient’s judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community.”\textsuperscript{50}

In striking this balance, however, a health care provider’s standing is not the same as its patient’s. For example, given that the health care provider has already assumed responsibility for the patient’s care and thus owes him a high professional duty,\textsuperscript{51} it does not have the latitude a patient has in deciding whether the hope of benefit, weighed against the anticipated burdens, is

\textsuperscript{47} See Responses To Certain Questions Concerning Artificial Nutrition And Hydration (Commentary) (recognizing the permissibility of withdrawing food and hydration when, “due to emerging complications, a patient ... [is] unable to assimilate food and liquids, so that their provision becomes altogether useless.”), supra note 45; Q & A Regarding The Holy See’s Responses on Nutrition and Hydration for Patients in a “Vegetative State,” U.S. Conference of Catholic Bishops, Committee on Doctrine and Committee on Pro-Life Activities (Q & A #5) (recognizing the permissibility of withdrawing food and hydration “if the available means for administering ... [them] were not effective in providing the patient with nourishment (for example, because the patient can no longer assimilate these.’), available at www.usccb.org/comm/hydrationq&a.doc (last visited Nov. 5, 2007). See also Address of John Paul II to the Participants in the International Congress on “Life-sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,” #4, supra note 4. We would also consider the provision of food and hydration “altogether useless in sustaining life” if patients would die from some underlying pathology before death would result from dehydration or starvation should such care be withheld or withdrawn.

\textsuperscript{48} See Responses To Certain Questions Concerning Artificial Nutrition And Hydration (Commentary) (recognizing the permissibility of withdrawing food and hydration when, “in some rare cases, artificial nourishment and hydration ... [is] excessively burdensome for the patient or ... cause[s] significant physical discomfort, for example resulting from complications in the use of the means employed.”), supra note 45; Q & A Regarding The Holy See’s Responses on Nutrition and Hydration for Patients in a “Vegetative State” (Q & A #4) ("[A] dying patient, or others who can speak for the patient, may [permissibly] decide to refuse further feeding because it causes pain and gives little benefit.")., supra note 47.

\textsuperscript{49} See id. (Q & A #5) (recognizing that the withdrawal of food and hydration is permissible “if the means itself constituted a burden (for example, because the feeding tube is for some reason causing persistent infections.").

\textsuperscript{50} Ethical and Religious Directives for Catholic Health Care Services, Pt. Five, ERD 57, “Issues in Care for the Dying” (footnote omitted), supra note 31. See Declaration on Euthanasia, Pt. IV ("[Refusal of] a technique which is already in use but which carries a risk or is burdensome ... is not the equivalent of suicide; on the contrary, it should be considered as an acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected, or a desire not to impose excessive expense on the family or the community."); supra note 37; Ethical and Religious Directives for Catholic Health Care Services, Pt. Three, ERD 32, “The Professional-Patient Relationship” (footnote omitted) (“While every person is obliged to use ordinary means to preserve his or her health, no person should be obliged to submit to a health care procedure that the person has judged, with a free and informed conscience, not to provide a reasonable hope of benefit without imposing excessive risks and burdens on the patient or excessive expense to family or community."); supra note 40.

\textsuperscript{51} See, e.g., AMA Code of Ethics, “Principles of Medical Ethics” (Preamble) ("[A] physician must recognize responsibility to patients first and foremost ... ") & (Principle VIII) (“A physician shall, while caring for a patient, regard responsibility to the patient as paramount.”), available at www.ama-assn.org/ama/pub/category/2512.html (last visited Aug. 26, 2008).
sufficiently reasonable to warrant commencing or continuing treatment. Furthermore, “physicians’ judgments about the value of continued life for the patient will be shaped by the physician’s own attitudes about illness, physical dependence, pain, and disability.”  

Accordingly, we believe first that a health care provider can withhold or withdraw life-support, not otherwise burdensome, only when it can demonstrate that such measures provide no real benefit to the patient because death is inevitable and imminent.  

By contrast, since its duty is ultimately to the patient and not the patient’s family, a health care provider can withhold or withdraw life-sustaining measures, even over family objections, when such measures cause substantial, intractable pain.  

Accordingly, we believe first that a health care provider can withhold or withdraw life-support, not otherwise burdensome, only when it can demonstrate that such measures provide no real benefit to the patient because death is inevitable and imminent.  

Death should be inevitable, to avoid “quality of life” rather than quality of treatment decisions. It should be imminent, to ensure that the terminal condition, not the withholding or withdrawal of treatment, is the cause of death.


53 *Cf. Declaration on Euthanasia*, Pt. IV (“[In those circumstances when inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.”), supra note 37.

54 Since there is no medical reason for commencing or continuing such treatment, providers can withhold or withdraw life support under these circumstances in the absence of or even contrary to patients’ known wishes. This would be a case where care is “futile” in the strict sense of the term.

55 *Cf. Ethical and Religious Directives for Catholic Health Care Services*, Pt. Three, ERD 33, “The Professional-Patient Relationship” (“The well-being of the whole person must be taken into account in deciding about any therapeutic intervention or use of technology. Therapeutic procedures that are likely to cause harm or undesirable side-effects can be justified only by a proportionate benefit to the patient.”), supra note 40. In contrast, withholding or withdrawing life-sustaining measures because patients consider their lives, and not such measures, unbearably painful would constitute euthanasia. Such a standard, though seemingly humane, is so open-ended and subjective that it could authorize death on demand.

56 As for those [patients] who are not in a state to express themselves, one can [in addition] reasonably presume that they wish to take ... painkillers, and have them administered according to the doctor’s advice. *Declaration on Euthanasia*, Pt. III, supra note 37.

57 Whether a treatment is psychologically repugnant involves deeply subjective judgments that carry a high risk of reliance on “quality of life” considerations. We, therefore, do not believe it should constitute grounds for health care providers to withhold or withdraw life support, unless there is clear evidence such treatment is repugnant to a particular patient.

58 *See John Paul II, Evangelium Vitae*, no. 65 (Mar. 25, 1995) (“While praise may be due to the person who voluntarily accepts suffering by forgoing treatment with pain-killers in order to remain fully lucid and, if a believer, to share consciously in the Lord’s Passion, such ‘heroic’ behavior cannot be considered the duty of everyone.”),
A health care provider, however, is obviously in no position to second-guess the impact of patient care on family finances, particularly when its judgment goes against the family’s wishes.

Finally, we note that the overall cost of providing ordinary or proportionate care to patients on life support often far exceeds the expense of life-sustaining measures themselves. However, to withhold or withdraw such measures because a patient’s earlier death may obviate the need for such ordinary care and hence ease financial burdens on health care providers or the community at large would effectively constitute euthanasia. Alternatively, where life support itself proves exceptionally costly, patients, in their free and informed discretion, can selflessly forgo it to save the community expense, but no one can make this choice for another. Thus, without clear evidence of their patients’ intent, health care providers can withhold or withdraw life-support because of expense only when the cost is so disproportionate to its hoped-for prolongation of life that it would be plainly unreasonable for patients to have chosen otherwise.

Required Procedures

Clearly, procedural safeguards are often as important as substantive requirements. Accordingly, we believe that attending physicians who wish to withhold or withdraw life-support against their...
patients’ expressed or implied wishes should first use their best efforts to find a provider willing to fulfill such wishes. If this is unsuccessful, all necessary life support should continue pending institutional review, where a patient advocate is available to represent objecting parties who have not secured counsel. If the attending physician’s decision is affirmed, such life support should continue for a time sufficient for patients, their representatives, or the institution to pursue alternative placements or judicial review in which the institution should have the burden of proving that, to a reasonable medical certainty, continued life support would constitute “futile care” in accordance with the standards set out above.

Conclusion

Undoubtedly, there comes a time when health care providers should “shift the intent of care” away from “further intervention to prolong ... life” and “toward comfort and closure.” We believe that the vast majority of providers make this decision with competence and compassion. Yet we must equally acknowledge the pressures that providers face today to contain costs. For example, according to some policies, “[w]hen deciding whether to order a test or procedure for a patient [under managed care], the physician must consider whether the slot should be saved for another patient or not used at all to conserve the plan’s resources.” It simply acknowledges reality to expect that more physicians will rest such determinations on “quality of life” considerations in the future, and that insurers will become less inclined to pay for treatment for patients with severe disabilities, in effect bureaucratizing euthanasia by omission. Thus, identifying when health care providers can ethically withhold or withdraw life-support they consider inappropriate is truly an urgent task. It is not too much to say that the lives of countless critically ill and disabled people hang in the balance.

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62 The same procedures are called for when physicians seek to withhold or withdraw life support in the best interest of children, incompetent adults, or other patients whose wishes are unknown.

63 We do not mean to imply that physicians who withhold or withdraw life support on conscientious or religious grounds, because they consider the proposed means to be inherently immoral, are also obliged to refer to a willing provider.

64 AMA Opinion E-2.037 “Medical Futility in End-of-Life Care,” supra note 5.


66 “Ethical Issues in Managed Care,” at 2-3 (“[Under managed care,] physicians are expected to balance the interests of their patients with the interests of other patients.” Id. at 2), supra note 30.

67 Cf. Cessario, Romanus, O.P., “Catholic Considerations on Palliative Care,” The National Catholic Bioethics Quarterly (6:4, Winter 2006), p. 649 (footnote omitted) (“The danger exists, as Mary Ann Glendon reports from a recent meeting of the Pontifical Council of Social Sciences, that euthanasia will be imposed. This unhappy circumstance may emerge not because of the successes of the Compassion in Dying Federation but because of the implosion of the social welfare services. According to Alan Greenspan, the country ‘will almost surely be unable to meet the demands on resources that the retirement of the baby boom generation will make.’” ).
See “Concerns About Decisions Related to Withholding/Withdrawing Life-sustaining Treatment and Futility for Persons with Disabilities” (literature review concluding that “futile care” may prove a greater threat to disabled people than the legalization of assisted suicide), supra note 65.
To: Members of the President’s Council on Bioethics

Response re: Conscience in the Practice of the Health Professions.

The Opinion of the ACOG Committee on Ethics: The Limits of Conscientious Refusal in Reproductive Medicine published in the November 2007 *Obstetrics and Gynecology* states that any physician whose conscience precludes providing services which the Committee has declared to be standard must refer said patient to a provider of said service.

This is objectionable on several grounds:

1. If a physician truly believes that participation in, for instance, abortion is always gravely wrong, said physician cannot be forced to become complicit in its provision by referring for it, without gravely violating his/her freedom to practice according to conscience.

2. If only physicians whose conscience does not revolt at the killing of the innocent unborn are the sole providers of reproductive health care, patients’ choice of care givers will be so gravely constricted that many will choose to go without professional care rather than risk putting their lives in the hands of a physician who, being willing to kill their baby early on, may also be willing to let a term baby die if it appears to have a congenital defect or suffers from oxygen loss during delivery, thus preventing need for costly health care, and avoiding possible litigation. Many also ask for doctors who will respect their choice of natural methods of family planning, and there are far too few.

3. Who defines what is standard of care? In the last half century our specialty has shifted from restoring health or at least alleviating disease and preventing death whenever possible, to providing technical support for life style changes, some of which involve considerable short and long term risks to life and health. Fertility is not a disease, yet we have attacked it as if it were. When treating pathology the physician weighs the possible benefits against the possible risks. But there is no risk in possessing normal fertility, whose control can be managed easily with modern natural family planning methods. Examples abound of instances where drugs which risk long term pathology are prescribed or dispensed on demand. For instance in Los Angeles contraceptive steroids were given to women of Mexican extraction even though it was known that they are likely to develop diabetes mellitus Type 2 within 15-20 years. Another instance is the common practice of treating PCOD (polycystic disease of the ovary) with contraceptive steroids when the underlying pathology 90+% of the time, is insulin insensitivity, which, untreated, will also lead to diabetes mellitus. This type of “standard practice” adds not only to the women’s, but to the public’s disease burdens and costs. In addition, the ready availability of contraception has increased sexually promiscuous behavior enormously, with concomitant increase in sexually transmitted diseases as well as unplanned pregnancies, many of which are then aborted. Doctor, in Latin, means teacher. Heedless provision of life style drugs is not good medicine. Physicians are not technicians. The fact that something can be done does not mean that it should be.
None of this is news to this Council, but it appears to be to our ACOG Committee on Ethics, and to those, like the Physicians for Reproductive Choice and Health, who have circulated alarmist literature claiming that the HHS regulations reaffirming the right of professionals to be free to practice in conformity to their conscience would reduce not only women’s access to abortion but deprive them of medically accurate information. In fact, these regulations are badly needed to protect women’s right to access to a physician of their choice

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Testimony of Susan Berke Fogel, J.D.  
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Good morning. Thank you Dr. Pelegrino and Council members for the opportunity to offer comment this morning on the impact of refusal clauses and institutional restrictions in the delivery of health care services.

I am Susan Berke Fogel, J.D. I am an attorney with the National Health Law Program, a national public interest law firm that seeks to improve health care for America's working and unemployed poor, minorities, the elderly and people with disabilities. NHeLP serves legal services programs, community-based organizations, policymakers, the private bar, providers and individuals who work to preserve a health care safety net for the millions of uninsured or underinsured low-income people.

We approach refusal clauses and denials of care from this quality and access perspective. We also understand that low-income women and other marginalized populations experience greater health disparities that are exacerbated by restrictions on care.

The basic principles of modern health care delivery are evidence-based practice, patient centeredness, and prevention, collectively ensuring quality care. Failure to adhere to prevailing “standards of care” harms the individual patient in real and concrete ways, undermines the medical system, and jeopardizes the health of the general public. These principles may be compromised by a range of structural factors such as lack of insurance, restricted geographic access, cost, language barriers, and immigration status. We are hoping that current political movements will be successful in promoting strategies to address these structural barriers to quality of care.

At the same time, health care refusals and denials of care are proliferating in the U.S. based on personal religious and moral beliefs that have nothing to do with scientific evidence, good medical practice or the needs of the patient. These restrictions and denials of care, which most often are related to reproductive health and disproportionately affect women, should be scrutinized to assess their impact on quality health care and redressed when they fall below the standard of care.

Analyses of health care denials traditionally construct the issue as a conflict of rights within the provider-patient relationship: the health care provider’s right to exercise individual conscience
vs. the patient’s right to exercise her autonomy. The question becomes how best to balance the rights and obligations within the relationship. This framework, while a common starting place, also needs to incorporate attention to the special context in which the debate is occurring: health care. The public discussion often fundamentally obscures the question of patient health by making it appear as if there is a moral contest between the patient and the provider.

Public discourse on refusals also relies on assumptions that we believe are subject to challenge:

1. That the services are optional, elective, not necessary to health and well-being, or based on the whims and desires of women;

2. That there are only limited or “acceptable” burdens on patients when providers refuse; and

3. That the patient can obtain the needed services elsewhere.

For low-income women in particular, these assumptions are often erroneous. While the health services impacted by refusals are most often related to reproductive and sexual health, they are implicated in a wide range of common health treatment and prevention strategies. The burdens on low-income women can be insurmountable when women and families are locked into managed care plans that do not meet their needs, or they cannot afford to pay out of pocket for services, or they cannot travel to another location. Last, in rural areas, or even in urban areas where insurance limits access, patients may simply be unable to obtain health and life preserving medical care.

These issues are not theoretical or philosophical for the real patients whose health is significantly impacted by refusals to provide information, referrals and care. The sources of such restrictions arise in two intersecting spheres of health care delivery:

1. Refusal clauses or so-called “conscience clauses” where institutions and individuals are shielded from liability for failing to provide health services, counseling and/or referrals as expected under generally accepted medical guidelines because the individual or institution has an objection to the service.

Carla¹ who lives in eastern Oklahoma thought she had the flu. Her family doctor referred her to an Obstetrician/Gynecologist (OB/GYN) who discovered she was pregnant and that she had a large mass growing on her uterus. Carla’s youngest child was already 16, and she decided to have an abortion, but when she went to the abortion clinic she was told that she needed to have the mass removed before she could have the abortion. Then her encounter with health care refusals began. The OB/GYN refused to remove the mass because it would endanger the pregnancy. The anesthesiologist in the practice group refused to give her any drugs that would harm the pregnancy. At this point the mass was shutting off her colon and bladder. Eventually Carla found a doctor an hour and a half away in another city, but due to the substantial delay, he had to remove her uterus, a procedure that would have been unnecessary if the abortion had been performed earlier in her pregnancy. Carla and her family were left with $40,000 in medical bills.
2. Institutional restrictions, which often remain under the radar in public discussion, that prohibit the provision of certain services in their facilities, refuse to cover those services in their insurance products, or otherwise restrict services that meet evidence-based standards of care. In these situations, the individual provider may want to deliver the service to her patient, but is prohibited from doing so.

Dr. Smits was a physician at St. Mary’s hospital in a large Eastern city. The patient was 19 weeks pregnant and her membranes had ruptured. This is called pre-mature rupture of membranes or PROM. The fetus is not yet viable at that point. The patient was septic – a dangerous infection was in her system as a result of PROM. Dr. Smits and the patient wanted to end the pregnancy to save the woman’s health, but the hospital ethics committee refused to approve the termination because the fetus still had a heartbeat. Dr. Smits was giving the woman medications to keep her blood pressure up and using a cooling blanket to keep her temperature down. As Dr. Smits said, “this woman was dying before our eyes.” And still the ethics committee refused to approve the termination.

Outcome: Patient was in ICU for ten days, and nearly died. The fetus died in utero. The woman had substantial internal bleeding, developed pulmonary disease, and wound up being oxygen-dependent.

Critically assessing both of these situations is important because institutions that impose ideological restrictions on health care delivery have assumed increasing control of hospitals and managed care systems in the United States. According to Modern Healthcare, one in six Americans is treated in a Catholic hospital each year.

**Using a Standards of Care framework to analyze refusal clauses and denial of care**

Since refusal clauses are essentially permission to opt out of providing a service that would otherwise be required or expected, it is useful to analyze, “opt out from what?” Standards of care or professional practice guidelines are commonly understood to mean the practices that are medically necessary and the services that any practitioner under any circumstances should be expected to render. Standards of care statements are created to indicate the level of clinical practice endorsed by scientists and clinicians and grounded in evidence from investigations of a particular area of practice. Generally, standards are based on large quantities of evidence from studies (e.g. data generated from studies of practice or clinical trials), but clinicians’ experience in practice may also form the basis for evolving standards when no evidence exists to guide care. Clinical guidelines are often used to indicate the consensus among an expert panel of clinicians and researchers, drawn from clinical practice experience, data from studies, and discussion/agreement among experts.

The provider-patient relationship is inherently unequal, and the denial of information or services directly impacts the patient’s health and well-being. Health care is not like other fields. The delivery of health care is highly regulated, with good reason. Patients can only obtain certain care from professionals who are extended that privilege by the state through the laws of professional licensure. The standards of care also help to appropriately frame the boundaries of the provider-patient relationship, which our society views as one founded in trust, where the patient’s interests are paramount. The basis for this relationship is recognition of the imbalance
of the provider’s and patient’s level of knowledge as well as respect for the patient’s trust that the health professional’s judgment is based on scientific principles.

Restrictions of information and services do not take place in an open marketplace. Placing decisions to allow health care refusals and restrictions only in a philosophical context fails to place the health of the patient as the highest priority. Instead of an evaluation of health care denials and restrictions as a balancing of rights, the consequences of denials of care are more fully understood in the context of quality and standards of care, and should be analyzed using the same yardsticks used to assess health care quality generally: evidence-based practice, patient-centeredness, and prevention. In this way health care denials may come to be understood as potential violations of the standard of care rather than as moral contests.

The traditional doctor-patient relationship based on a hierarchical arrangement is now viewed as insufficient and out-of-date. Evidence-based practice, patient-centeredness, and prevention are emerging as the new frameworks for delivering health care, transforming the provider-patient relationship to optimize health.

Evidence-based practice requires that health care decision-making is based on the best available scientific research, seeking to improve the quality and decrease the cost of health care by ensuring that patients receive treatments known to be effective and do not receive those treatments proven to be ineffective or harmful. Patient-centered care developed out of the institutionalization of informed consent as a means to achieve patient autonomy and address cultural variation. Evidence-based practice and patient-centered care work in tandem to ensure that patients receive care which is both scientifically sound as well as reflecting personal preference. In this way, care is individualized within a boundary of effectiveness and safety. Complementing these approaches is the burgeoning attention to prevention which focuses on optimizing health outcomes before the onset of disease.

Contrary to the trends in modern health care delivery, health care refusals and denials grounded in personal and religious beliefs rather than scientific evidence negate evidence-based practice, patient-centered care, and prevention. They take women’s reproductive health backwards to the discredited model of paternalistic health care where treatment decisions are made by physicians and health systems regardless of patient needs and preferences, and they negate patients’ capacity to make informed decisions.

Access to scientifically-grounded health care information and services related to contraception and pregnancy termination are critical to the health of women, as is care and information related to fertility attainment and healthy sexuality. Decisions to deny information and services based on personal and religious beliefs rather than scientific evidence ultimately result in poor health outcomes for women.

The standards of care help to establish parameters for fair access to health care. In a society concerned with fairness and equality of opportunity and the redemptive powers of science, health care is different from most other goods and services, and that equitable access to health care services is critical. The concept of justice, or equitable access to health care, encompasses not only the level of health care services that ought to be available to all, but also the extent to which
burdens can be imposed on those who seek access to services. If some health care providers fail to provide information regarding, and access to, specific types of health care based on factors other than patient need or scientific evidence as to the effectiveness of the health care service, affected patients will bear unreasonable burdens.

For example, an ectopic pregnancy is a pregnancy that develops outside the uterus, most commonly in the fallopian tube. If not removed, the ectopic pregnancy poses a serious risk to the woman’s health and could result in death. The American College of Obstetricians and Gynecologists, Cochrane Review, and Royal College of Obstetricians and Gynecologists all recognize three medical approaches to terminate an ectopic pregnancy: drugs to dissolve the pregnancy, minimally invasive laparoscopy, or invasive surgery to remove a portion of the fallopian tube. All of these medical guidelines require that the decision of which procedure to use be based on the patient’s medical condition and preference. Catholic hospital restrictions take that decision out of the hands of patients and physicians and impose their religious interpretation of what constitutes an abortion to limit the treatment options available to physician and patient, even though an ectopic pregnancy will never result in a viable pregnancy. This restriction may deny the patient the least invasive and best option to preserve her future fertility.

Refusals and restrictions on providing full and complete information

Informed consent is at the core of the individual’s right to self-determination and to make his or her own decisions about medically appropriate health care. This right is conditional upon two factors: access to relevant and medically accurate information about treatment choices and alternatives; and provider guidance in helping patients make decisions about treatment options based on generally accepted standards of practice. Both factors make trust between patients and health care professionals a critical component of quality of care. According to the American Medical Association, “The patient’s right of self-decision can be effectively exercised only if the patient possesses enough information to enable an intelligent choice.”

Informed consent is intended to help balance the relationship between health providers and patients, wherein patients authorize specific interventions. Disclosure of medical information is an essential component of the provider-patient relationship, and is embedded in medical and research codes. Informed consent also requires that physicians respect a patient’s right to refuse treatment, but does not require that physicians provide treatments that a patient desires but that are outside acceptable practice or unnecessarily draw on limited resources.

Informed consent is a core ethical as well as legal tenet for physicians according to the American Medical Association: “The physician’s obligation is to present the medical facts accurately to the patient or to the individual responsible for the patient’s care and to make recommendations for management in accordance with good medical practice. The physician has an ethical obligation to help the patient make choices from among the therapeutic alternatives consistent with good medical practice.”

The American Nursing Association similarly requires that patient autonomy and self-determination are core ethical tenets of nursing. “Patients have the moral and legal right to determine what will be done with their own persons; to be given accurate, complete and
understandable information in a manner that facilitates an informed judgment; to be assisted with weighing the benefits, burdens and available options in their treatment.”

The American Bar Association (ABA) has adopted policy in opposition to refusal clauses that restrict information that patients need to make sound medical decisions, stating “the ABA opposes governmental actions and policies that interfere with patients’ abilities to receive from their health care providers, including health care professionals and entities, in a timely manner: (a) all of the relevant and medically accurate information necessary for fully informed health care decision-making; and (b) information with respect to their access to medically accurate care, as defined by the applicable medical standard of care.”

The Conflict between Professional Practice Guidelines and Refusals or Denials of Care

Listed below are just a few examples of professional practice guidelines in women’s health that require health care professionals to provide information, counseling, and access to contraception, sterilization and abortion. They illustrate how refusal clauses and institutional restrictions fail to meet the standards of acceptable medical practice.

Contraception

There are many medical conditions for which pregnancy prevention is an important component of disease management. For example, for women with chronic diseases such as diabetes, epilepsy, depression, lupus, some forms of cardiovascular disease, and other conditions, pregnancy may worsen a woman’s condition. Medical practice guidelines for the use of many pharmaceuticals require that women not become pregnant during their course of treatment.

According to a recent study, 11.7 million prescriptions for potentially teratogenic (causing impairments in the developing fetus) Class D or X medications are filled by women of reproductive age in the U.S. every year. Women taking these drugs who might be at risk for pregnancy are advised to use a reliable form of contraception to prevent pregnancy. In addition, the medical guidelines referenced below all require that health care providers inform their patients about the risks of pregnancy and the importance of contraception.

- **Isotretinoin**, sold under the brand name Accutane® or as a generic under the names Amnesteem, Claravis, and Sotret® is a known human teratogen - an element that can cause multiple major fetal impairments, such as craniofacial, cardiac, thymic, and central nervous system malformations. Isotretinoin is associated with a pattern of fetal impairment in more than 35 percent of infants whose mothers take the drug during pregnancy. The concerns about Accutane® are so significant that the FDA instituted a risk management plan, called iPLEDGE, to ensure that female patients do not become pregnant while taking this drug. Female patients of childbearing potential must have a series of pregnancy tests, be counseled on contraception, and use two forms of contraception. The FDA clarifies that “natural family planning (rhythm method), fertility awareness, and withdrawal” are not reliable forms of contraception.

- **Iodine-131** used to treat thyroid disease, which is the second most common endocrine disease facing women of reproductive age. Hyperthyroidism occurs when the thyroid
produces excess thyroid hormone, producing symptoms ranging from mild nervousness, weight loss and insomnia to a dangerously fast heart beat which can be life-threatening. A radioactive form of iodine, Iodine-131, has been used for 40 years to treat hyperthyroidism and thyroid cancer, and in small doses, to test thyroid function.

The American College of Obstetricians and Gynecologists (ACOG) warns that women taking Iodine-131 should avoid pregnancy for a minimum of 4 months after completing the treatment because Iodine-131 may destroy the developing fetus' thyroid. ACOG recommends that women taking Iodine-131 who are at risk for pregnancy should also be prescribed contraceptives. Moreover, if a woman becomes pregnant during Iodine-131 treatment, and her exposure is at 10 weeks gestational age or less, the physician should advise the woman of the risks to the fetus so that the patient can decide whether to continue the pregnancy.

- **Chronic Disease** Millions of women live with chronic conditions such as cardiovascular disease, diabetes, lupus, and epilepsy, which if not properly controlled, can lead to maternal risk or even death during pregnancy. The CDC recently released its *Recommendations to Improve Preconception Health and Health Care* to identify specific interventions to improve birth outcomes and maternal health. The CDC notes a range of conditions that should be addressed before pregnancy in order to improve pregnancy outcomes. The goal of these interventions is to reduce health conditions that are amenable to preconception care while preventing pregnancy until the conditions are controlled to support healthy pregnancies and optimal outcomes under the circumstances.

  During “Preconception care” and “interconception care” women are advised to use effective contraceptive methods to prevent pregnancy until chronic conditions that could lead to adverse birth outcomes or threaten maternal health are brought under control.

**Pregnancy Prevention: Sterilization**

Sterilization is the most common method of contraception in the United States. According to ACOG, sterilization accounts for 39 percent of contraceptive method use: 28 percent of women have had tubal sterilization and 11 percent have male partners who have had vasectomy. Tubal sterilization is more effective than short-term contraceptive methods and equal in effectiveness to Interuterine Contraception (IUC). ACOG recommends that women who have completed their families should be informed about the option of sterilization.

The American Society of Anesthesiologists Task Force on Obstetrical Anesthesia found that post-partum tubal ligation can be safely performed within eight hours of delivery. In addition, sterilization may be recommended for women with certain chronic diseases such as some forms of diabetes and cardiovascular disease for which pregnancy can be medically very risky. In all cases of sterilization, there is a heightened need for fully informed consent to ensure that fully informed consent is given voluntarily.

ACOG also suggests that women with certain complications associated with pregestational diabetes (i.e. serious vasculopathy) or who have completed their families consider sterilization.
Emergency Contraception for Victims of Sexual Assault

In 2005, 189,000 sexual assaults and rapes were reported. It is estimated that 12,500 resulting pregnancies could have been prevented with timely access to emergency contraception. These numbers do not account for the numerous sexual assaults and rapes that go unreported. The professional guidelines that require health providers to offer and provide emergency contraceptives in all cases of unprotected sex often make specific references to the standard of care to offer and provide emergency contraception to victims of sexual assault. According to the American College of Obstetricians and Gynecologists, “Emergency contraception should be offered to all victims of sexual assault if they are at risk of pregnancy.” Practice guidelines from the American College of Emergency Physicians state, “Victim[s] of sexual assault should be offered prophylaxis for pregnancy and for sexually transmitted diseases, subject to informed consent and consistent with current treatment guidelines.”

The American Medical Association policy states, “it is the policy of our AMA: . . (3) to recognize that information about emergency contraception is part of the comprehensive information to be provided as part of the emergency treatment of sexual assault victims.”

Pregnancy Termination

In 1995, the Institute of Medicine urged a new national norm establishing every pregnancy as a wanted pregnancy. Key to achieving that norm is access to contraception and access to abortion. Abortion is a common health care service in the United States and the one of the most common surgical procedures for women. In 2000 over 1.3 million pregnancies ended in abortion. In 2002, 20.8 out of every 1,000 American women aged 15–44 had an abortion; in 2003, 23.8 percent of pregnancies (excluding fetal losses) were terminated by abortion.

Women who obtain abortions reflect the diversity of the American population across age, race, ethnicity, religious affiliation, and geographic location. Over sixty percent of abortions are among women who have had one or more children. Reflecting a significant disparity in health, the abortion rate among women living below the federal poverty level is more than four times that of women about 300 percent of poverty.

While most often associated with factors related to an unintended pregnancy, abortion care is also needed for women with medical or fetal complications associated with a wanted or intended pregnancy. Eight percent of the pregnancies ending in abortion that women reported in the face-to-face interviews for the National Center of Health Statistics 2002 National Survey of Family Growth were described as intended. However, because abortions are substantially underreported in the National Survey of Family Growth, analyses based on these reports are likely to be unreliable. Thus while it is unknown the exact percentage of women who undergo abortions for medical or fetal indications it is important to explore the extent to which denials of care specifically affect these populations.

Once a woman has decided to carry her pregnancy to term, there are still a number of medical developments that may put her or her fetus at significant risk. Medical standards developed by American College of Obstetricians and Gynecologists, Royal College of Obstetricians and
Gynecologists, and Cochrane Collaboration all recognize that in these situations, the patient must make a serious decision about balancing her health and life - with a full understanding of the medical consequences of her decision - with the prospects for fetal survival. Universally, these practice guidelines place that decision in the hands of the patient. They also charge the physician with giving the patient full and complete medical information about her treatment options.

- **Premature Rupture of Membranes (PROM)** Premature rupture of membranes occurs when the amniotic membranes surrounding a pregnancy rupture before the pregnancy has reached term (at 37 weeks). Complications due to premature rupture include severe bleeding (hemorrhage) and infection. Risk of chorioamnionitis, a serious infection of the placental lining and fluid, increases dramatically when patients with PROM do not receive prompt care. Intraamniotic infection occurs in 13-60 percent of women with preterm PROM. Maternal sepsis is a rare, but very serious complication of untreated PROM. Sepsis is an infection of the body which involves all major organ systems. If left untreated or diagnosed too late, this condition can be fatal. Risk to the fetus is infection, compression of the umbilical cord reducing nutrients and oxygen, and neurological impairment.

The incidence of infection increases for women whose pregnancies are at lesser gestational ages. The American College of Obstetricians (ACOG) and the American Academy of Pediatrics (AAP) recommend that women whose fetuses are previable (<24 weeks) should be counseled regarding the health impact of immediate delivery (pregnancy termination) and the potential risks and benefits of “expectant management.” ACOG practice guidelines require that the pregnant woman should participate fully in the decision regarding her pregnancy.

- **Pre-eclampsia and Eclampsia** Pre-eclampsia and eclampsia are serious and related pregnancy complications, generally experienced after 20 weeks gestation, although they may manifest earlier in a pregnancy. Each of these conditions can pose serious risks to maternal and fetal health. Pre-eclampsia is a hypertensive condition which affects about 8 percent of pregnant women in the U.S. and is a major cause of maternal and fetal death. The American College of Obstetricians and Gynecologists and the American Academy of Pediatrics (ACOG/APA) note that the risks to the woman from persistent severe pre-eclampsia are such that delivery (pregnancy termination) is usually suggested regardless of fetal age or potential for survival.

ACOG and the Cochrane Review analysis state clearly that the only known cure for pre-eclampsia or eclampsia is delivery. The ACOG/AAP guidelines further recommend that the decision to terminate a pregnancy take into consideration factors such as severity of pre-eclampsia, gestational age, maternal condition, fetal condition and prospect for fetal survival. ACOG recommends management only if the pre-eclampsia is mild.

- **Anencephaly – Fetus incompatible with life** Anencephaly is a neural tube defect of the developing fetus, where the head end of the neural tube fails to close. As a result, the forebrain and cerebrum of the brain fail to develop, and the fetus is missing major portions of the skull and scalp. An infant born with this disorder is usually blind, deaf, unconscious, unable to feel pain, and likely to die within hours or days of birth. Anencephaly can be diagnosed as early as the 10th – 12th week of pregnancy, but is more often diagnosed through
prenatal ultrasound between 15 – 18 weeks. There is no treatment for anencephaly. Many professional organizations recommend abortion to reduce the potential of complications for the woman carrying the pregnancy and to alleviate maternal distress and anxiety.  

**Conclusion**

Refusal clauses and denials of care undermine standards of care by shielding providers from delivering health care services and information that would otherwise be required by generally accepted practice guidelines. The consequences of public policies that allow health care denials or restrictions that do not meet the relevant standards of care are that patients do not have the information they need to make informed treatment decisions and the care they do receive may result in poorer health outcomes.

The current public discourse about refusal clauses and restrictions is poised as a moral contest between the providers’ “rights of conscience” vs. the autonomy and self-determination of patients. This discourse takes place in a theoretical and ideological framework without a full understanding of the impact on women’s health, and without due regard for medical quality and patient well-being. The authors of this report hope to start to change how policymakers, providers, and the public view ideologically or religiously based care denials and restrictions as violating the medical standards of care and jeopardizing patient and public health.

As state and national policymakers consider health reform proposals, it is important that refusal clauses and denials of care, as well as prospective hospital mergers, be evaluated using the same measurements used to evaluate quality generally:

- Evidence-based
- Patient-centered
- Prevention

Only with full information on the table can the medical community and policymakers make decisions about where to draw these lines.

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1 This is a fictitious name to protect the family’s privacy; cited in Freedman, L., Willing and Unable: Doctors' Constraints in Abortion Care, PhD Dissertation, University of California at Davis, Department of Sociology (June 2008).
2 Names and location have been changed to protect the privacy of those involved; cited in Freedman Willing and Unable.

American Bar Association, Policy # 05M104 (2005).


U.S. Food and Drug Administration, iPLEDGE Update (March 23, 2006).

iPLEDGE replaces the System to Manage Accutane Related Teratogenicity (S.M.A.R.T.) pursuant to an FDA assessment in 2004 and recommendations of an FDA Drug Safety and Risk Management and Dermatologic and Ophthalmic Drugs joint advisory committee which determined the need to include mandatory registration of all participants and to link negative pregnancy testing to prescription dispensing for female patients who can become pregnant. U.S. Food & Drug Admin., Accutane (isotretinoin) Questions and Answers (Oct. 28, 2005).

A prescriber must determine if a female patient is of childbearing potential before she can be enrolled in the iPLEDGE program. A female patient with “childbearing potential” is defined as someone who is nonmenopausal who has not had a hysterectomy, bilateral oophorectomy, or medically documented ovarian failure. This includes a young woman who has not yet started menstruating. A woman who has had a tubal sterilization is still considered to be of childbearing potential under this program. iPLEDGE, Guide to Best Practices for Isotretinoin. (2005) at 16.

iPLEDGE, Frequently Asked Questions at 12


Centers for Disease Control and Prevention "Recommendations to Improve Preconception Health and Health Care." MMWR 55(RR06);1-23 (Apr. 21, 2006).

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American College of Emergency Physicians, Management of the Patient with the Complaint of Sexual Assault, Revised and approved by the ACEP Board of Directors October 2002. This statement replaces one with the same title originally approved by the ACEP Board of Directors January 1992 and reaffirmed June 1999 (Policy #400130, Revised October 2002).


28 Finer and Henshaw.
31 Finer and Henshaw.
37 American College of Obstetricians and Gynecologists/American Academy of Pediatrics at 136.
39 American College of Obstetricians and Gynecologists Practice Bulletin No. 33 at 8.
September 10, 2008

Religious Restrictions Disproportionately Affect Women, Impeding Their Access to Needed Health Care Services

More and more, religious restrictions are limiting patient access to critical, necessary care. Both institutions – such as hospitals, HMOs, and employers – and individual health care providers impose their beliefs on patients seeking services or reimbursement for services. The refused services might include abortion, contraception, sterilization procedures, infertility treatment, counseling on the use of condoms to prevent the spread of HIV and STDs, research or treatment involving fetal or stem cells, and certain end-of-life care. Patients may also be denied information, referrals, and counseling on these services.

A major source of religious restrictions on health care services is the sale, merger, or affiliation of secular health care providers with providers who adhere to religious restrictions on services. While many different religions provide health care services, the largest systems – and those with the most restrictions on services – are Catholic owned and affiliated. Catholic hospitals are subject to the Ethical and Religious Directives for Catholic Health Care Services, which bar the delivery of vital health care services, including contraceptive services, sterilization, infertility treatment, abortion, and certain end-of-life care. Catholic facilities operate in every state in the nation, and according to the most recent data available, 15.1 percent of all hospital beds are in Catholic hospitals.

Religious restrictions are not a problem faced only in Catholic hospitals. Rather, patients may face refusals in a variety of settings. For example, pharmacists in retail pharmacies have refused to dispense legally valid prescriptions because of their personal beliefs. In one instance, a medical technician imposed his religious beliefs to the detriment of patients. Similarly, there

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1 Religious hospitals constitute seven of the ten largest nonprofit health care systems, based on number of acute care beds. Five of the ten largest healthcare systems, as measured by patient revenue, are Catholic affiliated. Modern Healthcare’s Annual Hospital Systems Survey, MOD. HEALTHCARE, June 6, 2005, at 32.
5 Grant v. Fairview Hosp., 2004 WL 326694, 93 Fair Empl. Prac. Cas. (BNA) 685 (D. Minn. 2006) (concerning an ultrasound technician who claimed a religiously-based need to “counsel” pregnant patients who were considering abortions).
have been instances of EMT workers and nurses putting their religious beliefs before patients’ needs to receive medical care, including emergency care.\(^6\)

While all patients may face religious restrictions, women are overwhelmingly the victims of refusals in health care settings. This is because women’s reproductive health care services are the subject of the vast majority of refusals. For example, women living in communities where a Catholic and non-Catholic hospital merge have been left without access to abortion, contraception, sterilization, and infertility treatment services.\(^7\) Women seeking treatment for miscarriages at Catholic hospitals have been denied the standard of care and placed in life-and health-threatening situations.\(^8\) Rape survivors seeking emergency care at Catholic hospitals have been refused information about and access to emergency contraception (the morning-after pill).\(^9\) Women seeking to fill their legally valid prescriptions for birth control have been refused by pharmacists,\(^10\) and pharmacies have refused to stock certain contraceptives altogether.\(^11\) Women workers are denied coverage for their prescription contraceptives under their employer’s prescription drug plan, even when the plan covers other prescription drugs.\(^12\)

Women denied needed services are forced to bear the burden of additional costs, delays, and health risks incurred by going elsewhere. Some may be prohibited from going elsewhere, if their insurer imposes the restriction or prevents them from seeking care outside the plan. These burdens fall most heavily on poor women and those living in rural areas, but the reduction of available health services adversely affects all women in need of reproductive care.

**Existing Law Provides Protections for Health Care Provider Refusals and Carefully Balances the Right to Refuse with Patients’ Needs**

**A. Existing Federal Law**

Federal civil rights law has struck a careful balance between respecting employee’s religious beliefs and employers’ ability to provide their patients with access to health care. Workers who wish to assert a religious objection to a job assignment currently have protection under the federal law prohibiting employment discrimination on the basis of religion, Title VII of the Civil Rights Act of 1964.\(^13\) An employer cannot fire (or refuse to hire) an employee based on his or her religious beliefs or practices; nor can an employer treat an employee in any unfavorable way in any of the terms and conditions of employment, such as assignments or

\(^6\) See, e.g., Shelton v. University of Med. and Dentistry of N.J., 223 F.3d 220 (3d Cir. 2000) (concerning a labor and delivery nurse’s refusal to participate in emergency procedures to terminate pregnancies).

\(^7\) For examples, see MergerWatch’s materials on their Hospitals and Religious Restrictions website, http://www.mergerwatch.org/hospital_mergers.html.


benefits, on the basis of religion.\textsuperscript{14} Title VII has been applied in many cases involving the religious rights of health care workers.\textsuperscript{15}

Cases interpreting Title VII have consistently held that employers have a duty to provide a reasonable accommodation of an employee’s or applicant’s religious beliefs or practices, if an accommodation does not place an undue hardship on the business. This gives current and adequate protection to employees whose employers do not reasonably accommodate their religious beliefs. But Title VII precedence also shows that employers are not required to make accommodations that would prevent patients and customers from securing access to health care products and services in a timely and respectful manner.\textsuperscript{16}

The Equal Employment Opportunity Commission (“Commission”) has just released a new section of its compliance manual in an effort to remind employers and employees about these existing rights and responsibilities under Title VII. Approved unanimously by the bipartisan Commission, the manual recognizes that the cases protecting patients’ access to care strike the proper balance between respect for religious beliefs and employers’ need to serve their customers and patients.\textsuperscript{17}

Health care providers also receive protection under three additional federal statutes. The Church Amendment, enacted in 1973, prevents any court, public official, or public authority from requiring any individual health care provider or entity who receives certain public funds to perform in, assist in, or make available abortion or sterilization procedures against their moral or religious convictions. It also prevents institutions receiving certain federal funds from taking action against personnel because of their participation, nonparticipation, or beliefs about abortion or sterilization.\textsuperscript{18} The Church Amendment concerns only the provision of services, and does not address refusals to provide information or make referrals. The Coats Amendment, enacted in 1996, prohibits federal, state, or local government from discriminating against any entity or individual that refuses to receive or provide abortion training, perform abortions, or provide abortion referrals or referrals for abortion training.\textsuperscript{19} The Weldon Amendment of 2004 prohibits federal, state, or local government from discriminating against any entity or individual on the basis that the entity or individual refuses to provide, pay for, provide coverage of, or refer for abortion.\textsuperscript{20}

It is worth noting that the right to refuse health care services granted in these three statutes is limited to abortion and sterilization. Additionally, these statutes must be read

\textsuperscript{14} Title VII exempts religious employers from the religious discrimination provision. A religious employer is defined as “a religious corporation, association, educational institution, or society with respect to the employment of individuals of a particular religion to perform work connected with the carrying on by such corporation, association, educational institution, or society of its activities.” 42 U.S.C. § 2000e-1(a).
\textsuperscript{16} See cases referenced in supra note 15.
\textsuperscript{17} See http://www.eeoc.gov/policy/docs/religion.html.
\textsuperscript{18} 42 U.S.C. § 300a-7.
\textsuperscript{19} Public Health Service Act § 245, 42 U.S.C. § 238n.
alongside other federal laws that protect patients. This includes the Emergency Medical Treatment and Labor Act (EMTALA), which governs when and how a patient may be refused treatment or transferred from one hospital to another when s/he is in an unstable medical condition.\(^{21}\)

**B. Existing State Law**

In addition to federal legal protections, individual health care providers and health care entities who object to abortion and sterilization also receive protection from state law. Forty-six states allow some health care providers to refuse to provide abortion services; 17 states allow some health providers to refuse to provide sterilization services.\(^{22}\) Only a few states allow refusals beyond abortion and sterilization. For example, only 13 states allow some health care providers to refuse to provide services related to contraception.\(^{23}\)

For the most part, states have taken action to protect women’s access to contraception. This has involved a careful consideration of the balance between religious beliefs and women’s access to the care they need. For example, 24 states have passed laws that require insurance plans to cover prescription contraceptives to the same extent other prescription drugs are covered.\(^{24}\) Eighteen of those states have exceptions to the mandate for religious employers or insurers whose religious tenets prohibit the use of contraceptives. It is important to note that in some states with such a religious exemption, the religious entity is required to provide clear notice of its refusal to cover contraception. And in a few states, like New York and Hawaii, the law goes even further and allows individuals of religious employers to purchase contraceptive coverage directly from the insurance company.

Additionally, states have acted to guarantee that rape survivors who visit hospital emergency rooms for care receive information about and access to emergency contraception (“EC”), a time-sensitive method of preventing pregnancy. Currently, fourteen states have laws that require hospital emergency rooms to provide information about or access to EC to sexual assault survivors.\(^{25}\) None of the fourteen states allows institutions to opt out – all health care

\(^{21}\) 42 U.S.C. § 1395dd.
\(^{23}\)  Id.
facilities specified in the laws must comply. Arkansas’s and Colorado’s laws allow individual health care professionals to refuse to provide information about EC if the refusal is based on their religious or moral beliefs, but does not exempt any religiously-affiliated hospitals from having to provide the information. Connecticut’s law allows health care facilities to contract with independent providers to ensure compliance with the law, so that religiously-affiliated hospitals do not have to have their own employees provide the medication.

States have also taken action to protect women’s access to contraception at the pharmacy. Seven states require pharmacists or pharmacies to provide medication to patients. An additional seven states have a policy allowing an individual to refuse, but prohibiting pharmacists from obstructing patient access to medication or from refusing to transfer or refer prescriptions to another pharmacy.

**Health Care Professional Organizations Have Adopted Policies that Recognize Both Providers’ Right to Refuse and Providers’ Responsibility to Patients**

The careful balance between an individual right to refuse and patients’ right to care that is codified in federal and state laws is also translated into specific guidance for health care professionals by national and state based professional organizations. The Ethics Committee of the American College of Obstetricians and Gynecologists (“ACOG”), for example, released guidance on conscientious refusal in November 2007. In the guidance, ACOG recognizes the importance of conscientious refusal while at the same time saying that such rights should be limited if they “constitute an imposition of religious or moral beliefs on patients, negatively affect a patient’s health, are based on scientific misinformation, or create or reinforce racial or

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socioeconomic inequalities.” ACOG explains that when an individual refuses to provide standard reproductive services to a patient, s/he has a “duty to refer patients in a timely manner to other providers.” ACOG further recognizes that in an emergency situation, providers “have an obligation to provide medically indicated and requested care.” The American Nurses Association’s Code of Ethics similarly recognizes a nurse’s right to refuse to participate in treatments to which s/he objects on moral grounds, but also recognizes the patient’s right to care, by stating that “[t]he nurse is obliged to provide for the patient’s safety, to avoid patient abandonment, and to withdraw only when assured that alternative sources of nursing care are available to the patient.” Likewise, the American Pharmacists Association “recognizes the individual pharmacist’s right to exercise conscientious refusal and supports the establishment of systems to ensure patient’s access to legally prescribed therapy without compromising the pharmacist’s right of conscientious refusal.” The organization notes that the patient should not have any awareness that the pharmacist was refusing to fill the prescription.

29 Id.
30 Id.
31 Id.
A Recent Proposal to Expand Existing Federal Law Would Significantly Undermine Patient Access to Vital Health Services and Information

Recently, the Department of Health and Human Services (“HHS”) proposed the “Provider Conscience Regulation” (“Proposed Rule”). The Proposed Rule would significantly undermine patient’s access to vital health services and information by greatly expanding the Church, Coats, and Weldon Amendments, which were intended to govern the right to refuse to provide abortion care. By failing to provide a definition of abortion consistent with accepted medical standards, the Proposed Rule opens the door for doctors, nurses, insurance plans, hospitals, and nearly any other employee in a health care setting to deny access to most forms of birth control. The Proposed Rule is unnecessary in light of Title VII, which already adequately and appropriately protects worker’s religious freedoms. The Proposed Rule fails to even mention Title VII or the balance between employers’ accommodation of an employee’s religious beliefs and the needs of the people the employer must serve. The expansive language of the Proposed Rule could lead to an erroneous interpretation of existing law that would allow any employee of a health care provider to refuse to treat, or provide information to, any individual receiving any service – if doing so would violate his or her moral beliefs – without regard for the needs of patients.

Conclusion

The National Women’s Law Center respectfully requests that the President’s Council on Bioethics recognize the disproportionate impact of religious restrictions on women’s access to health care services; the need for a careful balance between religious beliefs and patient care, which already exists in law and policy; and the far-reaching nature of the proposed HHS regulation.

Thank you for the opportunity to submit comments on this important issue. If you have any questions, please do not hesitate to contact Gretchen Borchelt, Senior Counsel of the National Women’s Law Center at (202) 588-5180.

A Christian Medical Association  
Policy Analysis

The Limits of Conscientious Refusal in Reproductive Medicine  

A Critique of ACOG Committee Opinion # 385, November 2007  
By Robert D. Orr, MD, CM

A. This detailed opinion on the right of conscience contains several flawed assumptions:

1. **Patient autonomy is the final arbiter of treatment decisions**
   
   - For several hundred years, physician beneficence was believed by all to be the final arbiter of treatment decisions. This was meant to reflect the generally accepted belief that whatever the physician felt was in the patient’s best interest was what should be done.
   
   - In western medicine, this imbalance began to change in the 1960’s and 1970’s such that patient autonomy, i.e., the right to self-determination, was appropriately accorded much greater weight.
   
   - Currently, patient autonomy is felt to outweigh the physician’s concept of patient beneficence in most instances. But patient autonomy is not absolute. There are times when the physician’s exercise of beneficent care is supported and even lauded, e.g.,
     - treatment and prevention of suicide
     - imposition of life-saving treatment when a patient has made an irrational refusal
     - imposed isolation of a contagious patient who endangers society
     - imposed immunizations.
   
   - This flawed assumption is exemplified when ACOG states “[a]lthough respect for conscience is important, conscientious refusals should be limited if…[4 broad criteria offered].” The criteria offered are overly broad and biased. (see critique below) While equally, physician autonomy is not absolute, this tipping of the balance so strongly in favor of the patient based on assertions is ethically troubling.

2. **Negative patient autonomy (the right to refuse) and positive patient autonomy (the right to demand) are morally equivalent**

   - Negative patient autonomy is nearly inviolable; it is rarely justified to impose unwanted treatment (see above for examples).
   
   - However, positive patient autonomy carries much less moral weight. Patient demands are routinely denied by conscientious physicians for such things as unnecessary surgery, unwarranted antibiotics, assisted suicide, etc., even in those situations where the requested treatment is within the bounds of
accepted practice or in instances when other (ignorant, sloppy, or unscrupulous) physicians might accede to the request.

- Such physician refusals are generally based on patient beneficence. However, for decades, a physician has also been permitted to decline a patient’s request based on his or her conscience. To not do so implies that the patient’s right to access to specific treatment options outweighs the physician’s right to avoid moral complicity in an action that he or she believes to be immoral.

- This ACOG opinion supports this incorrect implication, as noted by its repeated referral to physicians as “providers.” There is a major conceptual difference between a professional who professes allegiance to standards (those shared by the profession, as well as personal standards) and a “provider,” a technician who merely provides whatever is requested of him or her.

3. **Matters of conscience for the professional are matters of personal opinion**

- The (limited) concept of conscience as “self-knowledge” is expressed by ACOG when they define it as the “private, constant, ethically attuned part of the human character.” This is a truncated and incomplete view of conscience. A person’s conscience is inseparable from his or her worldview or religious beliefs.

- “In the history of ethics, the conscience has been looked upon as the will of a divine power expressing itself in man’s judgments, an innate sense of right and wrong resulting from man’s unity with the universe, an inherited intuitive sense evolved in the long history of the human race, and a set of values derived from the experience of the individual.” (Columbia Encyclopedia, 6th ed.)

- Recognizing this divine origin of an individual’s conscience, a conscience clause is defined as “a clause in a general law exempting persons whose religious scruples forbid compliance therewith…” (Webster’s Revised Unabridged)

- ACOG reiterates its incomplete view of conscience when they claim “…not to act in accordance with one’s conscience is to betray oneself.” They admit to no betrayal outside the self.

4. **Prima facie values can and should be overridden in the interest of other moral obligations that outweigh it**

- ACOG admits that respect for conscience is a value, but they go on to say it is only a *prima facie* value. This is not so much a flawed assumption as one that is distorted.

- A *prima facie* value is one that is accepted on its own merit, without need for proof, though it may be contested and shown to be invalid in a particular circumstance.

- By emphasizing the possibility of override, and claiming conscience is only a *prima facie* value, they imply that this is of little consequence.
B. Comments on the four criteria ACOG uses to determine appropriate limits to claims of conscience.

1. **Potential for Imposition**
   - This section of the Opinion conflates refusal to provide a requested service by the professional with imposition of the professional’s beliefs. It is instead an instance of negative professional autonomy. The professional’s refusal does not preclude the patient from seeking or obtaining the requested service elsewhere. Geographic or sociologic constraints are separate and distinct.

2. **Effect on Patient Health**
   - While an important point could be made when considering significant bodily harm to the patient (pain, disability or death), ACOG expands the definition of “health” to include “a patient’s conception of well-being.” Thus they again assert, incorrectly, that the patient’s wishes, whatever they may be, trump professional autonomy.
   - In addition, they define the physician’s fiduciary duties to include an obligation “to protect patients’ health.” Again, they could make this point vis a vis an obligation to protect from bodily harm, but they distort it by implying the patient’s autonomy takes precedent over the physician’s conscience. The example they use here is a conscientious refusal to do a tubal sterilization at the time of Cesarean section, claiming that the “attendant and additional risks” of a second surgical procedure should override the physician’s conscience. Thus their assumed threshold is exceedingly low.
   - ACOG minimizes the physician’s obligation to promote fetal well-being. Though initially couched in terms of “protect[ing] the safety of women,” the implication is that this protection includes the “patient’s conception of well-being” invoked earlier.

3. **Scientific Integrity**
   - ACOG correctly speaks against support for conscientious refusal based on invalid consequential reasoning. Some claims of conscientious objection are not genuine. If a physician has a conscientious objection for personal involvement, he or she should so state rather than trying to hide behind a potential adverse outcome. However, in regard to this consequential reasoning, ACOG goes on to incorrectly infer that uncertainty of evidence should be ignored.
   - Such consequential claims by physicians may, however, have a legitimate place in decisions about public policy.

4. **Potential for Discrimination**
   - Again, ACOG begins with a valid argument --- like patients should be treated alike, without discrimination. Thus a physician who claims conscientious objection to doing a certain procedure is not justified in refusing the procedure for one patient while providing it for another.
equivalent patient. However, the example they use is fallacious --- refusing to provide contraceptive assistance to an affluent patient who may be able to procure it elsewhere may be justified, they say, while doing so for a poor young mother without transportation is not because it is unjust.

• The Opinion goes on to claim as “oppressive” the denial of reproductive services for a homosexual couple while providing the same for a married heterosexual couple. The AMA clearly states in its Principles of Medical Ethics that “A physician shall…except in emergencies, be free to choose whom to serve…” Assisted Reproductive Technology is not an emergency service.

C. Critique of ACOG’s Recommendations

1. “In the provision of reproductive services, the patient’s well-being must be paramount. Any conscientious refusal that conflicts with a patient’s well-being should be accommodated only if the primary duty to the patient can be fulfilled.”

• Reproductive services are rarely matters of life and death. This assertion, then, is that a physician’s “obligation” to provide elective reproductive services for a patient is greater than his or her conscience. This is patently false.

2. “Health care providers must impart accurate and unbiased information so that patients can make informed decisions about their health care. They must disclose scientifically accurate and professionally accepted characterizations of reproductive health services.”

• This is a reasonable recommendation. A duty to present accurate information does not, however, prevent him or her from expressing his or her moral beliefs on the matter.

3. “Where conscience implores physicians to deviate from standard practices, including abortion, sterilization, and provision of contraceptives, they must provide potential patients with accurate and prior notice of their personal moral commitments. In the process of providing prior notice, physicians should not use their professional authority to argue or advocate these positions.

• This is not an unreasonable recommendation in situations of individual practitioners in an elective healthcare setting. It becomes problematic and probably unworkable in situations of cross coverage and in emergency settings.

4. “Physicians and other health care professionals have the duty to refer patients in a timely manner to other providers if they do not feel that they
can in conscience provide the standard reproductive services that their patients request.”

- This recommendation totally ignores the issue of moral complicity. Some physicians may be willing to follow this, but others believe their involvement in the referral process involves moral wrongdoing --- without their involvement, the morally troublesome procedure would not have happened. [Orr RD. The role of moral complicity in issues of conscience. *American Journal of Bioethics*, November 2007, in press]

5. “In an emergency in which referral is not possible or might negatively affect a patient’s physical or mental health, providers have an obligation to provide medically indicated and requested care regardless of the provider’s personal moral objections.”

- This recommendation is valid, though such emergency circumstances in reproductive health care would be very rare indeed. An example would be when a surgeon with moral qualms against ending the life of a living fetus is caring for a woman with a life-threatening ruptured ectopic pregnancy, and he finds at surgery that the fetus is still alive. He is obligated to save the woman’s life, even if it means violating his moral understanding of the sanctity of fetal life.

6. “In resource-poor areas, access to safe and legal reproductive services should be maintained. Conscientious refusals that undermine access should raise significant caution. Providers with moral or religious objections should either practice in proximity to individuals who do not share their views or ensure that referral processes are in place so that patients have access to the service that the physician does not wish to provide. Rights to withdraw from caring for an individual should not be a pretext for interfering with patients; rights to health care services.”

- This is a claim with no foundation. Patients in “resource-poor areas” may well be without access to a neurologist, vascular surgeon, dermatologist, or perhaps even a general surgeon. There is no professional requirement that all health care services must be available to everyone at all times. Certainly a physician in such an area must be willing to provide all emergency services in which he or she is adequately trained. However, there is no such obligation for elective procedures, even if he or she is capable.

7. “Lawmakers should advance policies that balance protection of providers’ consciences with the critical goal of ensuring timely, effective, evidence-based, and safe access to all women seeking reproductive services.”

- The comments to Recommendation #6 apply equally here. There is equally no societal obligation to ensure convenient access to all elective health care services for everyone.
My name is Dr. Anne Davis, and I am an Associate Professor of Obstetrics and Gynecology at Columbia Presbyterian Medical Center in New York City. I submit this testimony as an experienced healthcare provider and as the medical director of Physicians for Reproductive Choice and Health.

Physicians for Reproductive Choice and Health is a national nonprofit organization comprised of doctors who support evidence-based reproductive healthcare for every American. We work with governmental entities, the media, the public, and our colleagues to ensure that all patients have access to quality services as well as the knowledge and freedom to make their own decisions about their reproductive health.

Thank you to members of the President’s Council on Bioethics for holding this meeting about the exercise of conscience in the practice of the health professions. My remarks address the specific issue of conscientious refusal in the provision of reproductive healthcare.

I am an academic obstetrician/gynecologist and specialist in family planning. In my practice, I provide the full range of contraceptive services: birth control pills, patches, rings, injections, emergency contraception, IUDs, and surgical sterilization. I also provide medical and surgical abortions. I work with women who have commercial insurance and Medicaid, as well as uninsured women. When patients come for consultations, I provide complete and factual information about their options. Some talk to me about reproductive health issues as they relate to the practice of their religion—my practice includes Catholic, Jewish, and Muslim women. Others discuss their moral or
ethical concerns. In every case, we decide together on the care that best meets their medical, religious, and moral needs. If they need a service I cannot or will not provide, I refer them to doctors who can. The principles I follow—helping my patients make informed decisions about their health and ensuring they get what they need in a timely, sensitive manner even when I am unable to provide it—keep people safe. These principles are not unique to me, nor are they radical. They are the underpinnings of the medical profession.

Yet recently, the Department of Health and Human Services (HHS) has threatened to cast these principles aside. Secretary Mike Leavitt has proposed regulations that could allow hospitals, doctors, and other healthcare workers to deny women access to effective birth control, regardless of the consequences for their health. These regulations would protect clinicians who refuse to provide patients with factual information about or referrals for basic healthcare services like sterilization and abortion. The regulations would even protect workers who are not directly involved in patient care. For instance, a receptionist could refuse to schedule appointments, health insurance agents could refuse to process payments, and operating room staff could refuse to clean equipment based on their conscientious objection to certain medical procedures or services.

The HHS regulations would even allow healthcare professionals to stonewall my patients whose chronic illnesses make pregnancy potentially lethal by withholding information about contraception to keep them from getting pregnant or abortion if they do get pregnant. I am reminded of my patient Sara, an orthodox Jewish woman who has seven children and a diagnosis of breast cancer. In consultation with her husband and her rabbi, we chose an IUD as the appropriate contraceptive method to maintain her health and accommodate her religious beliefs. If the regulations go into effect, women like Sara could be left unprotected and at risk of worsening illness and even death.

Physicians for Reproductive Choice and Health and I believe that individual physicians may refuse to perform medical procedures that conflict with their religious or moral

1 “Sara” is not her real name.
beliefs. Existing law amply protects this right, allowing individuals to abstain from providing abortion and sterilization services while simultaneously honoring patients’ rights to reproductive healthcare. The proposed regulations, however, would sacrifice the patient’s well-being in favor of the provider’s conscience.

Physicians have a professional duty and obligation to tell their patients if their religious or moral beliefs might compromise the patient’s access to comprehensive and timely reproductive healthcare—and yet, the HHS regulations make no mention of this obligation. If a physician refuses to prescribe birth control pills, perform a tubal ligation, provide medical or surgical abortions, or discuss emergency contraception, women have a right to know this prior to accepting treatment by the physician. If doctors fail to disclose that they do not provide the range of family planning services, patients might face misinformation, additional costs, dangerous delays in care, unintended pregnancies, and less safe abortions. I have had patients whose medical problems are accompanied by enormous emotional turmoil and pain—I want to help them as quickly as possible, and I wish the same for women across the country. But the HHS regulations would only make these situations worse, adding to patients’ confusion, frustration, and desperation.

As an ob/gyn, my primary obligation remains with my patients. If I were a neurologist or a podiatrist, I would uphold the same standard: *Physicians do not have the right to impose their beliefs on patients.* Indeed, the Code of Ethics adopted by the American Medical Association on the patient-physician relationship states:

> The relationship between patient and physician is based on trust and gives rise to physicians’ ethical obligations to place patients’ welfare above their own self-interest and above obligations to other groups, and to advocate for their patients welfare.

> Within the patient-physician relationship, a physician is ethically required to use sound medical judgment, holding the best interest of the patient as paramount.²

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Accordingly, physicians who refuse to provide healthcare must, at a minimum, be required to refer their patients to a doctor who can provide them with accurate information and medical care in a timely, appropriate, and respectful manner.

The regulations proposed by HHS build on existing law and would allow physicians to withhold referrals. This is tantamount to substandard medical practice. HHS’s regulations conflict with the position of major medical associations, including the American College of Obstetricians and Gynecologists (ACOG), a national organization representing more than 45,000 members. ACOG, of which I am a member, issued the following policy in its Committee Opinion entitled “The Limits of Conscientious Refusal in Reproductive Medicine,” adopted in 2007:

Physicians and other health care professionals have the duty to refer patients in a timely manner to other providers if they do not feel that they can in conscience provide the standard reproductive services that their patients request…. In resource-poor areas, access to safe and legal reproductive services should be maintained. Providers with moral or religious objections should … ensure that referral processes are in place so that patients have access to the service that the physician does not wish to provide.3

Physicians for Reproductive Choice and Health wholeheartedly supports ACOG’s position, particularly its balance between physicians’ conscientious objection and the needs of patients, some of whom have little or no choice in healthcare providers.

In addition to interfering with the medical profession’s core values, the HHS regulations—and the laws they are meant to enforce—extend the same protections to hospitals, clinics, and other institutions that they grant to individuals. When entire entities can refuse to discuss or provide birth control, sterilization, or abortion, some women will be left with no alternatives to unintended pregnancies, creating a situation that is likely to cause more abortions than it prevents. Our current healthcare system already has too many obstacles for patients, requiring that they navigate complicated health maintenance and managed care organizations, often with few options for choosing

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physicians and hospitals. My patients often tell me about their Byzantine searches for authorizations and referrals, and I marvel at their ability to get to a doctor at all. In this environment, we should be removing, not creating, barriers to healthcare. Physicians for Reproductive Health and Choice opposes institution-wide restrictions on contraception, sterilization, and abortion. Such policies block women’s attempts to get information and care and further reduce physician autonomy, inhibit medical education, and interfere with medical research.

HHS would be well served by looking to Portugal for another approach to the balance between conscientious refusal and patient health. Portuguese physicians who will not provide abortion on grounds of conscience must register as conscientious refusers of care. They are then prohibited from advising women who are contemplating abortion. Moreover, when individual physicians refuse to provide specific services, the Portuguese healthcare system is obligated to ensure that patients receive care within a time frame that meets their health needs. This emphasis on the duties of the healthcare system as well as the individual physician is a significant reframing of conscientious refusal and is worth further examination by this Council.

While Portugal and other countries improve their healthcare systems, HHS is attempting to move us backwards by imposing more barriers. Women in this country already face a host of legal, financial, and logistical obstacles in obtaining the full range of reproductive healthcare. As increasing numbers of Americans struggle with rising healthcare costs or are uninsured, we should make basic health services more accessible, not undermine the doctor-patient relationship and cause harmful delays in treatment. HHS would limit patients’ access to medical information and basic services, and my conscience refuses to go along.
Protecting Patients’ Rights When Health Providers Refuse Care

Recently, a great deal of public attention has been focused on what the Secretary of Health and Human Services has described as an urgent need to protect health providers who object to providing certain services or medical information because of their ethical or religious beliefs. As your council discusses this issue, I urge you to consider another imperative – protecting the rights of patients to receive accurate medical information and needed treatment in a timely manner. In a pluralistic society such as we have in the United States, public policy must carefully balance the needs and rights of all affected parties.

Let’s use an example to make this discussion very concrete:

A 19-year-old rape victim – let’s call her Sally -- is brought to a hospital emergency department by the police. The physician who treats her numerous injuries – Let’s call him Dr. Brown -- omits any mention of the potential to prevent pregnancy from the rape by using emergency contraception, because he does not approve of it for religious reasons. Many hours later, Sally leaves the hospital without being informed about emergency contraception, or offered the medication. A friend takes her back to the college dorm where they live and Sally, exhausted, falls asleep for 24 hours. Because emergency contraception is the most effective when taken shortly after unprotected intercourse, Sally’s opportunity to prevent pregnancy has now been greatly diminished.

What has just happened? Is this proper medical care? What are Sally’s rights? What are Dr. Brown’s? And, how should they be properly balanced?

The patient’s rights

Let’s start with Sally. After all, the patient is supposed to be the focus of what the health professions refer to as “patient-centered care.” Patient-centered care is not, as one presenter before this council seemed to suggest yesterday, the subjugation of a physician’s clinical judgment to the uninformed demands of a patient. It does not by any means turn the physician’s role into that of a technician responding to consumer demand. Instead, according to the Institute of Medicine, “patient-centered care is defined as health care that establishes a partnership among practitioners, patients and their families (when appropriate) to ensure that decisions respect patients’ wants, needs and preferences and
solicit patients’ input on the education and support they need to make decisions and participate in their own care.’” 1

One of the central tenets of patients’ rights and “patient-centered care” is the right to informed consent. For a patient to make an informed decision about medical treatment, he or she must have knowledge of all potential treatment options, and their risks and benefits. George Annas, a bioethicist and professor of health law at the Boston University School of Public Health, has written that, “In the most important study of informed consent to date, the President’s Commission for the Study of Ethical Problems in Medicine concluded that informed consent has its foundations in law and is an ethical imperative as well. It also concluded that ‘ethically valid consent is a process of shared decision making based upon mutual respect and participation, not a ritual to be equated with reciting the contents of a form that details the risks of particular treatments.’ Its foundation is the fundamental recognition ‘that adults are entitled to accept or reject health care interventions on the basis of their own personal values and in furtherance of their own personal goals.’”2

In this case, the rape victim has not been informed about an important potential treatment option – use of emergency contraception to prevent pregnancy. As it happens, Sally is one of the millions of American women of reproductive age who are not aware of EC.3 So, Sally has had no opportunity to consider this option or use her own moral, ethical or religious perspectives to decide whether she wishes to risk the chance of bearing the child of a rapist. Further, she has had no chance to discuss with her physician the potential medical complications of an unplanned pregnancy, in view of her existing medical conditions, which include diabetes.

Sally’s experience in the emergency department falls far short of what George Annas describes as the goal of the doctrine of informed consent: “to enhance and encourage a responsible patient-doctor partnership designed to share information and to provide the patient with the right to make the final decision about treatment.”4

How could this violation of patients’ rights be corrected? The simplest method would be to require all hospital emergency department personnel, including Dr. Brown, to always offer EC to rape victims who are of reproductive age.

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Physicians’ rights and responsibilities
But now, let’s focus on Dr. Brown. A fundamentalist Christian, he believes that emergency contraception is the same thing as abortion, even though medical and scientific experts say that is untrue\(^5\) and the FDA has stated unequivocally that emergency contraception prevents pregnancy and does not cause an abortion.\(^6\)

Dr. Brown argues that requiring him to give emergency contraception to Sally would violate his religious beliefs. “I shouldn’t have to give up my religious freedom in order to be a doctor,” he says.

Let’s pause for a moment to consider whether personal beliefs that are unsupported by medical science should be considered valid reasons why a licensed medical professional should be permitted to refuse to provide needed medical care, especially in an emergency situation in a facility that serves the general public. There was discussion before this Council yesterday of how to deal with “erroneous” or “faulty” conscience claims, and whether a conscientious objection can be considered authentic even when it is based on misinformation. One could hope that Dr. Brown would be able to modify his position, when presented with accurate information about emergency contraception’s mechanism of action.

But what if he does not? How far should we allow Dr. Brown or one of his colleagues to go with conscientious objections? What if they are masking discriminatory views? If Dr. Brown also believes that AIDS is a just punishment from God for perverted behavior, should he be allowed to refuse to treat any patients with AIDS? What if one of his colleagues believes that under Islamic law, anyone who committed murder should be sentenced to death? Should he be permitted to refuse to treat suspected murderers who are brought to the emergency room for treatment of wounds suffered in the attack? Where should we draw the line between acceptable and unacceptable moral reasons for refusing to provide care? There are no easy answers here. Unfortunately, the Secretary of Health and Human Services’ new proposed regulation on provider conscience reflects none of this complexity and essentially treats all claims of health provider conscience as being equally deserving of government protection.

In the interests of moving our analysis along, however, let’s set that issue aside and see if there is a compromise we could arrive at that would permit Dr. Brown to refuse to give EC to Sally, while still ensuring that she gets the medication in a timely manner. What if we just require Dr. Brown to refer Sally to another physician or a nurse in the emergency department who could provide her the emergency contraception if she wishes to use it?

\(^6\) See for example, 62 FR 8610-01
That, too, is unacceptable, Dr. Brown says, because it requires him to cooperate in helping the patient receive treatment he finds morally objectionable. “I cannot be implicated in any way in helping her commit an immoral act,” he states.

One could argue that Dr. Brown’s professional responsibilities to his patient should obligate him to provide Sally with at least a referral in such a situation. Indeed, the American Medical Association’s “Principles of Medical Ethics” states: “A physician shall, while caring for a patient, regard responsibility to the patient as paramount.”

But, under the proposed “Provider Conscience Regulation” issued by the U.S. Department of Health and Human Services (HHS) on August 26, 2008, no entity receiving federal funding (such as the hospital where Dr. Brown works) could require him to give Sally the medical information or referral she needs if he claims a religious objection. To attempt do so would be to “discriminate” against him, and could result in the loss of federal funding, according to the rule. Not a single other physician or nurse in the hospital could be required to step in and give Sally what she needs, if that health professional held the same views as Dr. Brown.

Moreover, HHS has proposed a very expansive definition of the term “assist in the performance of” to permit refusals for “participation in any activity with a reasonable connection to the objectionable procedure, including referrals, training and other arrangements for offending procedures.” Arguably, this definition would permit a pharmacy technician to refuse to stock emergency contraception in the hospital pharmacy, or a hospital purchasing agent to refuse to order it. Again, we face the question of where we should draw the line between acceptable and unacceptable refusals. The proposed HHS rule would seem to draw no line at all, instead allowing medical professionals and hospital personnel to use personal moral or religious beliefs to exempt themselves from any medical obligations to their patients.

Let’s consider another alternative – requiring the hospital to be responsible for ensuring that Sally’s rights as a patient are protected.

**Hospital responsibilities**

Arguably, the hospital *should already* be responsible for ensuring that Sally’s medical needs are met. In order to participate in the federal Medicare program, and to be reimbursed under the Medicaid program, hospitals must adhere to “Conditions of Participation.” These conditions are meant to ensure that patients’ rights are respected and they received medically appropriate care. For example, hospitals are required to:

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9 42 C.F.R. § 482.13, 482.55 and 482.25
• “Honor a patient’s right to make informed decisions regarding his or her medical care.”
• “Meet the emergency needs of patients in accordance with acceptable standards of practice.”
• “Have pharmaceutical services that meet the needs of patients.”

One might also argue that the hospital is responsible under the provisions of the Emergency Medical Treatment and Active Labor Act (EMTALA). All hospitals that accept Medicare and Medicaid have a duty to screen and stabilize individuals who arrive at their emergency department requesting medical treatment, as mandated by EMTALA. Since a rape victim of reproductive age who was forced to have unprotected intercourse is in danger of becoming pregnant, it could be argued that in order to “stabilize” her condition, and prevent pregnancy, she should be offered emergency contraception.

But since neither EMTALA nor the Medicaid/Medicare Conditions of Participation has yet been enforced to require the provision of EC to rape victims, a number of states have enacted so-called EC in the ER or Compassionate Care for Rape Victims laws. These statutes specifically require hospitals to offer emergency contraception to rape victims, or, at minimum, inform rape victims about the potential to use the medication to prevent pregnancy.11

How should the hospital go about fulfilling these responsibilities for patients like Sally? Should administrators fire Dr. Brown and replace him with someone who will dispense EC to rape victims? No, that would not be the preferable way of dealing with this situation, because there are far less drastic options available.

Instead, the hospital could offer Dr. Brown a transfer out of the ER into another unit of the hospital where he would not be expected to dispense EC, and replace him in the ER with someone who has no objections to EC. Such an arrangement would be an example of a “reasonable accommodation” under Title VII of the Civil Rights Act of 1964, which requires employers to reasonably accommodate an employee’s religious beliefs or practices, unless doing so places an “undue hardship” on the employer’s business. This type of careful balancing of competing rights is a hallmark of American public policy.

But, Dr. Brown might argue that he is being discriminated against even by such a reasonable accommodation, because it removes him from the practice of emergency medicine, which he sees as his mission in life. The proposed HHS rule might give him ammunition to do so, because it lacks any attempt to balance his rights with the patients’ rights and the obligation of the hospital to serve its patients.12

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11 11 states require hospitals to dispense emergency contraception on request to rape victims, while another four require hospitals to provide information about emergency contraception. State Policies in Brief: Emergency Contraception. The Guttmacher Institute, September 1, 2008. Available at http://www.guttmacher.org/statecenter/spibs/spib_EC.pdf
12 Provider Conscience Regulation, RIN0991-AB48
HHS Secretary Michael Leavitt, in a press conference to release the department’s proposed rule, went so far as to frame the issue this way: “Freedom of conscience is not to be surrendered upon issuance of a medical degree.” He told reporters, “This is about protecting the right of a physician to practice medicine according to his or her moral compass.”

Is there another solution? How about requiring the hospital to have a routine protocol of offering EC to all rape victims, and designating someone on each shift who does not object to EC to step in, inform the patient about EC and offer it? This surely would be somewhat cumbersome, and would require careful management of hospital staffing schedules. It also would require that Dr. Brown and any other hospital emergency department personnel who have objections to dispensing EC disclose those objections up front, so that hospital administrators can make appropriate scheduling decisions.

**Religious hospital claims to “conscience” rights**

But what if the hospital as an institution operates under a religious doctrine that expresses grave reservations about the use of emergency contraception? Let’s put Dr. Brown and Sally in the emergency department of St. Mary’s Roman Catholic Hospital. Like other Catholic hospitals, it is governed by the *Ethical and Religious Directives for Catholic Health Care Services* (ERDs). The ERDs offer this guidance about the use of emergency contraception at a Catholic hospital:

> A female who has been raped should be able to defend herself against a potential conception from the sexual assault. If, after appropriate testing, there is no evidence that conception has occurred already, she may be treated with medications that would prevent ovulation, sperm capacitation or fertilization. It is not permissible, however, to initiate or recommend treatments that have as their purpose or direct effect the removal, destruction or interference with the implantation of a fertilized ovum. (Directive 36)

There are no existing medical tests that can show within 72 hours of unprotected intercourse – the time frame in which EC is effective -- whether conception (fertilization) has occurred. A pregnancy test shows that a fertilized egg has become successfully implanted in the uterus, but such a blood or urine test cannot be performed until 6 to 12 days after ovulation.

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Given this difficulty, Catholic theologians, individual Bishops and administrators of Catholic hospitals have come up with a variety of ways of interpreting Directive 36.16 Some Catholic hospitals provide EC to all rape victims. Some administer a pregnancy test, even though such a test would only be able to detect a pregnancy that was established prior to the rape (and if the woman is already pregnant, she does not need EC). Some require the rape victim to undergo an ovulation test. If the test comes back positive, EC is denied because of the hypothetical possibility that there might be a fertilized egg in existence. Still other Catholic hospitals refuse to offer EC at all.17

St. Mary’s Hospital, as it happens, is one of the Catholic hospitals that refuses to allow any dispensing of EC. Moreover, the hospital does not permit staff to even discuss EC with patients like Sally, citing another two of the ERDs:

“Free and informed consent requires that the person or person’s surrogate receive all reasonable information about the essential nature of the proposed treatment and its benefits; its risk, side-effects, consequences and cost; and any reasonable and morally legitimate alternatives, including no treatment at all (Directive 27, with emphasis added);

“The free and informed health care decision of the person or the person’s surrogate is to be followed so long as it does not contradict Catholic principles.” (Directive 28, with emphasis added).

Under a new state law taking effect in six months, St. Mary’s and all other hospitals in this state (including Catholic ones) will be required to offer EC to rape victims. Dr. Gray, a colleague of Dr. Brown’s in the emergency department, is happy about the new law, because he believes it is his professional and ethical obligation to serve the patient’s medical needs, and he wants to be able to offer EC to patients like Sally. He is upset about what he views as the hospital’s violation of his rights to use his own ethical beliefs and his medical training in deciding how to treat patients. (The proposed HHS regulation, it should be noted, does not seem to protect physicians like Dr. Gray, who wish to provide medical treatment, not refuse it, but are stymied by institutional religious restrictions.)

St. Mary’s, which opposed the new law, hopes to argue that since it considers emergency contraception to be an abortifacient, it cannot be compelled to obey the law.

17 A 2002 telephone survey of 597 Catholic hospital emergency departments found that only a small percentage of Catholic hospitals were routinely offering EC in an unrestricted manner to women who had been raped. Of the 23% of Catholic hospital emergency rooms that said they offered EC to rape survivors, only three percent offered it without restriction. The others required pregnancy tests (13%) or that the rape be reported to the police (.5%). Most significantly, the study found that 66% of Catholic hospital emergency rooms did not provide EC to rape survivors at all or had policies that are sufficiently unclear as to make provision of EC unlikely. Second Chance Denied: Emergency Contraception in Catholic Hospital Emergency Rooms Ibis Reproductive Health for Catholics for a Free Choice. 2002 http://www.catholicsforchoice.org/topics/healthcare/documents/2002secondchancedenied_001.pdf
Administrators of St. Mary’s plan to cite the proposed HHS rule which, in seeking to enforce compliance with a longstanding federal law allowing federally-funded hospitals to refuse to perform abortions or sterilizations, seems to leave the definition of abortion open to interpretation.

The regulation, as promulgated, dropped a definition of abortion that had appeared in an earlier draft that had attempted to conflate contraception with abortion by including anything that could interfere with a fertilized egg. But, as the Washington Post reported, supporters and critics alike agreed that the language remains broad enough to apply to contraceptives. HHS Secretary Leavitt, in response to reporters’ questions about the proposed rule, acknowledged that there was no definition of abortion and that some medical providers may want to “press the definition” and make the case that some forms of contraception are tantamount to abortion, according to the Wall Street Journal.

Does this mean that state health officials who try to enforce the new state law at St. Mary’s—in order to ensuring that all rape victims are offered emergency contraception—might risk being found guilty of “discrimination” against St. Mary’s. Could the state lose all of its federal health funding as a result? Is that really the outcome we should be seeking in federal policy?

If St. Mary’s were to be successful in its claim, what would happen to rape victims who need emergency contraception? Should they be expected to go to drugstores to buy it, even though they have just suffered a traumatic attack, may have had their clothes torn and may have been robbed of their purses, their money and their car keys? What if the local pharmacy also objects to emergency contraception? The proposed HHS rule, which purports to be about protecting health providers from having to perform abortions and sterilizations, extends provider conscience protections to pharmacies (and also, it should be noted to a wide variety of other health care institutions, including nursing homes and dentists offices).

Should rape victims be expected to leave St. Mary’s and go to a different hospital, again in a traumatized state? What if St. Mary’s is the only local hospital? A national study conducted by my organization in 2002 revealed that there were 48 religiously-sponsored hospitals in the United States that were recognized by the federal government as being the sole providers of hospital care for a geographic region.

Conclusions

To hear HHS Secretary Leavitt and his colleagues tell it, the department’s regulatory might and funding power must be marshaled behind medical professionals in this country

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18 The Church amendment (42 USC 300a-7).
who, they contend, are at serious risk of retaliation, firing or being forced to surrender their medical licenses for exercising their religious consciences. The department’s introduction to its proposed rule on provider conscience states, “There appears to be an attitude toward the health professions that health care professionals and institutions should be required to provide to assist in the provision of medicine or procedures to which they object, or else risk being subjected to discrimination.” The Department’s commentary, however, did not supply a single example of a health professional who actually had been discriminated against.

Secretary Levitt claimed at his press conference releasing the proposed regulation that "there is nothing in this rule that would in any way change a patient's right to a legal procedure" and that "this regulation does not limit patient access to health care.”

But, as the story of Sally, Dr. Brown and St. Mary’s Hospital has demonstrated, that would not be the case. In fact, the proposed HHS rule has the potential to seriously undermine the already fragile balance between providers’ rights and patients’ rights in the American health care system. It would tip the scales far over in the direction of objecting health providers, and leave patients at risk of going without needed medical information and care. It would allow providers’ personal moral beliefs to come before patients’ rights and would take American health care in the opposite direction from “patient-centered care.” To summarize, it would do so in the following ways:

- Allow health practitioners to violate a patient’s right to informed consent by refusing to tell the patient about those potential treatment options that the provider finds morally objectionable;
- Allow health practitioners to refuse to provide patients with any medical services or information a provider finds morally objectionable – even for reasons that are completely contrary to medical science. Because of the broad language of the proposed rule, it is entirely conceivable that this “refusal permission slip” could extend well beyond abortion and sterilization to potentially encompass contraception, emergency contraception, STD treatment, end-of-life decision-making and even refusal to treat patients whose lifestyles are objectionable to the provider;
- Further, permit health practitioners to refuse to provide the patient with a referral to another practitioner who would be willing to meet the patient’s needs;
- Obligate nearly 600,000 health care institutions (not just hospitals, but also insurance companies, pharmacies, dentist offices, nursing homes and other facilities) to “certify” that they do not discriminate against practitioners with moral objections to certain services, with no similar obligation to certify that patients’ medical needs will always be met;
- Leave these health care institutions in complete confusion about how they, as employers, must go about meeting the needs of these objecting health practitioners, since the proposed rule makes no reference to the types of reasonable accommodations that have been customary under the provision of Title VII of the Civil Rights Act of 1964;
• Invite religiously-affiliated health care institutions to file challenges to state laws, such as EC in the ER or Compassionate Care for Rape Victims Laws, which have been enacted by elected representatives of the people after careful weighing of religious freedom claims against the need to serve a public good of protecting the health needs of rape victims.

Recommendations
Clearly, the proposed HHS rule, as it has been promulgated, should be withdrawn. It is both unnecessary -- given the existence of underlying legal protections -- and overreaching in its broad interpretation of those existing statutes. I urge your council to so recommend to the Secretary of Health and Human Services.

But, I also recommend that your council consider ways in which public policy could more strongly protect patients’ rights and access to care, without unduly burdening individual health practitioners who have moral objections to providing certain medical services. What would be some ways of doing this?

• **Patients’ right to informed consent must be paramount.** Patients must be informed of all potential treatment options so that they are able to give fully informed consent, based on medical recommendations and the patient’s own ethical or religious beliefs. Compliance with fully-informed consent requirements should be a condition of institutional participation in Medicaid and Medicare programs. The existing informed consent language for those programs should be strengthened to explicitly state that information about treatment options may not be withheld from patients because of hospital ethical or religious policies or the objections of individual health practitioners. Individual health practitioners should be expected, at minimum, to refrain from expressing personal opinions about potential treatment options and to provide the patient with an immediate referral to another practitioner who will explain all of the potential treatment options and provide requested treatment.

• **Acute care hospitals and any other health facilities that are licensed to serve the general public and receive patients needing emergency care must be required to provide such care immediately.** When time-sensitive emergency care is needed -- such as for rape, an ectopic pregnancy or a miscarriage -- a hospital must be required to provide it immediately on site. In such an instance, a hospital should not be permitted to refuse the care or attempt to send the patient elsewhere. The patient’s need for emergency care must take precedence. New or enhanced language under the Medicare and Medicaid conditions of participation should specify this requirement. In such situations, the health facility should attempt to accommodate any objecting individual practitioner on duty in the emergency room by substituting a non-objecting practitioner, provided that doing so will not delay or compromise the patient’s care. Anticipating such situations will enable a hospital to arrange staffing schedules accordingly.

• **The ability of non-objecting health practitioners to fulfill their duty to their patients must be safeguarded.** Physicians and other caregivers must be guaranteed the right to discuss all treatment options with patients, regardless of
whether those options are permitted at the hospital or other health facility, and must be able to assist patients in obtaining desired treatment at alternate facilities. It is unacceptable for hospitals that serve the general public and receive public funding to impose “gag orders” on physicians and other caregivers. Hospital policies must explicitly spell out protections of caregivers’ rights to discuss all treatment options with their patients. These protections must not be countermanded by conditioning admitting privileges or staff employment on caregivers’ adherence to religious or ethical policies of the institution.

- **When health institutions serving the general public have treatment restrictions based on religious or ethical principles, they should be expected to disclose those policies to patients and individual health providers.** Patients cannot make informed choices about where to seek treatment in non-emergency situations if they are unaware of service restrictions at certain institutions. For example, a woman who is delivering a baby and wishes to undergo a post-partum tubal ligation must be able to select a hospital that will permit this choice and avoid those hospitals that prohibit it. Similarly, a patient with a terminal disease who does not wish to be placed on artificial nutrition and hydration must be informed if a hospital will not honor such a choice. Disclosure of restrictive hospital policies should be carried out prior to admission, and repeated following admission in the event of a conflict between hospital policy and the patient’s desired course of medical treatment.

- **For non-emergency care, referrals to alternate practitioners or facilities must be made if treatment is being refused.** Referrals to alternate providers are essential to ensure that patients are fully able to exercise their right to pursue courses of treatment not offered at a particular health institution or by an individual practitioner. Acceptable referral practices must include providing the patient with the names, addresses and phone numbers of alternative providers; ensuring that the patient is able to travel to at least one of these other providers and has insurance coverage (including Medicaid) which will be accepted there. It should not be permissible medical practice to simply refuse treatment and send the patient away.

The MergerWatch Project is a national initiative dedicated to protecting patients’ rights and access to care. The project, based in New York City, assists communities in securing such protections when religious and non-religious hospitals merge and in such other situations as when pharmacists or pharmacies refuse to dispense medications on religious grounds or when insurance companies or employers use religious doctrine to restrict coverage. To learn more about our work, visit our website at www.mergerwatch.org.