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Meeting Transcript
September 7, 2006

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INDEX

- Session 1: Ethical and Philosophical Issues in the Definition of Death
- Session 2: Living Organ Donation: Outcomes and Ethics
- Session 3: The Ethics of Organ Allocation
- Session 4: Organ Transplantation Policies and Policy Reform

WELCOME AND ANNOUNCEMENTS

CHAIRMAN PELLEGRINO: Good morning. Try to keep our custom of beginning on time and we plan also to end on time.

I’d like to welcome you all to a meeting of the President’s Council on Bioethics. My first action has to be to make us legal. To be legal, we have to recognize the presence of the Designated Federal Official, Dan Davis, who is the Executive Director of the President’s Council.
SESSION 1: ETHICAL AND PHILOSOPHICAL ISSUES IN THE DEFINITION OF DEATH

I think we can proceed to the meeting itself. We have revised the agenda in just one case. Moving the discussion of living donation to session two and the discussion of the criteria for death to session one. That is to accommodate some of the people who will be opening the discussion. I hope that is acceptable.

Our previous discussions have been focused largely on organ procurement and today we have a number of relatively unexplored but very essential areas especially in the light of a potential report by the Council, and I say potential.

We will be looking at today the criteria of death, the question of living donation, the ethics of organ allocation, and some reflections on current and proposed policy.

We will be proceeding in the following way. The staff has been working hard all summer on preparing summations of each of those issues which have been distributed to the members of the Council.

Staff members will be here available for clarification but the work they have done is a summation of discussions with all the members of the Council — not of the Council, excuse me, of the staff during the summer but reflecting on the discussions and contributions of the Council members in the meetings that led up to the summer.

I want to express my gratitude to all the staff who have worked hard during the summer to put this material together. We hope that it will serve to bring you up to date on where we are at the present time and to lay open the areas we need to discuss further and the ethical issues, particularly those that may not have been addressed by other groups who are also studying this very, very important question of organ donation and procurement.

We are not looking forward to the outcome from this meeting of a set of recommendations by any means but rather an intermediate step in which we step back and look at where we have been, what the issues are before us, and what directions we might take in the future and how much emphasis we might put on each one of these subjects which I have enumerated for you at the beginning of the session.

I’d like to begin with the first session on the criteria for death. And that paper has been prepared by Alan Rubenstein. Alan is here at the table. Eric Cohen, who acted as overall editor of all of these papers, is also to my right. And, again, I re-emphasize, they are here to respond to questions of clarification.

The papers have been distributed and our interest really is the response of the Council members and to give them an opportunity to give their thoughts on these issues which we have raised.

To open up the discussion, we have asked individual members of the Council, and they will be enumerated later on as they come up to their subjects, to open the discussion, to provide us an entry into it. And from that point on, it is open to the Council members to carry the discussion further.

Our first discussion catalyst will be Dr. Ben Carson, a member of the Council. It has been our custom, for those of you who are here for the first time, not to provide extended autobiographical or biographical summaries. And, therefore, we will not repeat what is in the book itself.

Dr. Carson will open this discussion. And I will ask him to bring us into the issue and, as they say... in medias res.

DR. CARSON: Well, thank you very much.

You know this is — first of all, let me congratulate the staff for being able to take so many philosophical opinions and boil them down to a 50-plus-page treatise here. That is quite a task.

You know one thing becomes apparent and that is it is very difficult to gain uniformity in terms of defining anything. And as a neurosurgeon, obviously I’ve unfortunately had to deal with the whole issue of when someone is dead frequently, principally surrounding brain death.

In this paper, we talked about different types of brain death: whole brain death where really nothing intercranially is functioning in any adequate way versus, you know, the British standard of brainstem death which is mostly the only things that are left are reflexic in nature.
And each of them has, you know, their advantages in terms of trying to define things. And there is, you know, physiological criteria of death as put forth by, you know, the Harvard criteria.

I don't know that we will have the possibility of really being able to define which one of those things is real or is the most factual because one thing becomes clear.

And that is people's religious beliefs, their feelings of whether their moral standards are being violated, questions of whether scientific standards are being violated enter into each one of these things. And I don't know that there is any way to bring that all under one umbrella.

There is quite an extensive discussion on sort of to get around some of those moral issues, donation after cardiac death. That way if you allow the heart to stop beating and, therefore, the brain to stop being perfused and all the other organ systems to die in the most traditional sense of death, then you remove a lot of the moral issues that have made this so controversial.

Now obviously, the issue there being now you are beginning to compromise organs that you clearly want to donate. Now interestingly, some people have said let's just go around the whole idea of when death occurs and let's think about what is practical. And let's think about how we are not violating the rights of any of the interested people.

Let's say, for instance, an individual has decided that they want to be an organ donor. They have indicated that on their driver's license or elsewhere. The family is in agreement. But they are clearly not brain dead. Why not go ahead and procure those organs? And, you know, a very, you know, cogent argument was made for that.

You know I can remember an instance several years ago when I was a resident, New Year's Eve when a very prominent lawyer in the Baltimore area was involved in a motor vehicle accident and became a C-1 quadriplegic. And he still had full retention of his mental faculties and requested that life support be withdrawn.

And the question comes up could a person like that who has full retention of their mental faculties also request that their organs be donated? And I think that is a very legitimate question.

There was a footnote that mentioned that possibility but there was really no discussion in this paper but I think that is something that is worth discussion because we are looking at the ends.

And in the end, his request was granted after a great deal of ethical discussions with everybody on the face of the Earth. But if he is allowed to die, why wouldn't he be allowed to allow his organs to be gathered? And this is not something that I can see that has been discussed in a very important way.

The whole idea of the rights of the family enters this and really makes it complex because — and I certainly have been in this situation where you have to give, you know, bad information, bad news to a family. And then in the next breath, you know, ask them for organs. That is a very, very difficult thing to do.

And, you know, if we can come up with — if anybody could come up with a way to make that easier, it would obviously help the situation. A lot of times rather than go through that, medical professionals simply don't ask for the organs because it puts them into such an uncomfortable position. And I can certainly understand that.

So the bottom line in looking through all this is we have to ask ourselves the question how do we get the organs without violating our moral sensibilities and, you know, that is the crux of this entire compilation. And hopefully what we will discuss.

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

Dr. Meilaender?

PROF. MEILAENDER: Well, I also agree that it is a very nicely done paper. It gives us a certain sense of historical development of how we got to where we are in these discussions now. And it is thorough and thoughtful.

And, in fact, I couldn't quite decide what sort of comments from me would be most useful as a way to begin the deliberations. So I want to do a couple things.

First, I want to point out — and, I mean, this is in the paper — it's not something original with me, but I just want to point out why we might be tempted to punt on this issue. I think there is a
I'm not sure I think we should punt on it but I just thought it would be useful to highlight this fact
that the paper itself has. And then after that, I'll mention just a few — three theses that seem to me
to be truths to which we should adhere, however we go along, though they may not seem to truths to
you. You will have to see whether that is the case or not.

But first why we might be tempted just to sort of take a pass on this. I think what the staff paper very
nicely shows is that we find ourselves right now in a situation characterized in this way.

One the one hand, the issue of brain death as a theoretical question is by no means settled. It turns
out to be more unsettled than people had thought or liked to think for a while. So it is a very much a
live question with the problem under dispute.

And on the other hand, brain death, the notion of brain death has come to be rather generally
accepted in our law and in our practice, even if people in every day life don't always think in those
terms, but nevertheless in our practice we have accepted it.

And it is that fairly settled practice that allows organ transplantation to proceed if not perfectly or in
the numbers that some would wish, at least relatively undisturbed.

And to push on the theoretical question is to disturb that relatively settled practice. I mean I think
the paper did a nice job of showing that. We could reach conclusions if we really think it through
that are fairly unsettling for our current practice.

We could, for example, decide that the current practice of declaring death on the basis of neurological
criteria is incoherent and mistaken, which would throw an enormous monkeywrench into our
current practice of transplantation.

Or we could decide that a person who has irreversibly lost simply higher brain capacities, as they are
called, was dead, which would alter current practice in a very different and equally unsettling
direction.

So when you think about those possibilities, we might just be tempted to let sleeping theoretical dogs
lie. And not do anything. And that may be — I mean I don’t know, we'll have to see. That may be
what we decide to do.

As I thought about it though, it seemed to me that in some ways the temptation to do that probably
needs to be resisted. At least one shouldn't give in to it too quickly. And there may be short of, as it
were, resolving the issue, which I suspect is beyond us, there may be some things that — some sorts
of contributions that we can make.

And the first thing, it seems to me, is that we can take the critique of the current use of neurological
criteria, we can take that critique seriously.

I think there is nothing more frustrating for people than to make a really serious case, to have serious
claims, to have others acknowledge that these are serious claims, and then to have those others just
keep on proceeding the way they have been doing as if, you know, you just wasted your time talking.

I do think that this is a serious critique made by serious people. And at the very least, we owe it
attention and not just to punt on it.

Another thing we could do, I mean perhaps we could — it might be useful just to make clear that at
best, we are simply looking for a criteria for when someone is dead. We're not trying to solve the
deply metaphysical question of exactly how we define it. We talk about definition here a lot of	imes but maybe the more modest notion of just finding criteria for when that once animated body is
no longer moved by its anima would be a sufficient thing to do.

We could — another thing we could do if we thought it possible although again this may be beyond us
— we could try to offer a better account and defense of the current fairly settled practice if we think
that neurological criteria are persuasive.

The staff paper has a nice account of the somewhat different British approach. We could think about
that possibility for instance so that could be done. Or we could offer several alternative approaches
just trying to advance the discussion.

But my tendency, at any rate, is to think that it is both deeply tempting to just bypass this question
but probably not what we should do. So that's sort of the first thing that I say.
And then the other thing is that just in thinking through where the argument takes us, what the staff paper had to say, it does seem to me that there are three things that I would hope we affirm, whatever sort of impenetrable difficulties we may encounter, whatever incoherences in our current practice we cannot fully solve.

There may be more than these but I'll hold my relative certainties here to three that I'll mention although as I say, they may not be certainties for you.

The first one in my own mind is that I think it is important to know when someone is still alive and when someone is dead — to have criteria that mark that out for all of us however difficult it may be to find the right way to do that.

However true it may be to say that in some context anyway that in a certain sense we all die by degrees, however much our individualistic tendencies might tempt us just to invite everybody to decide for themselves when they should be considered dead.

I think we should want to know when another human being is no longer a living human being. We should know this, in part, because so long as they are still living, they have a claim on us in certain ways for the rights and respects that we owe other living human beings. And also because when they are dead, they actually still have claims on us of a different sort for taking leave and burial and so forth.

So I'm not very drawn to what the staff paper describes as the new pragmatism approach to these questions. I, myself, do not find that very persuasive.

The second thing I'd say is that it seems to me unwise to forget that whatever else we may be, we are also animals. That is to say we share a kinship with the other animals and death, for us, must bear some similarity to what death for them means.

And I am, therefore, not drawn at all to the higher brain criteria for death which focus only on those capacities which we may not share with the other animals. If you have lost — thank you, I appreciate that. It's always nice to get affirmation from wherever it comes.

If you have lost a higher brain capacity but you are still breathing independently of mechanical assistance and your heart is beating, then yours is, as far as I'm concerned, still an animated body with the anima still present. That would be my view.

And then the third thing, a slightly different point, I think we shouldn't lose sight of the fact that among the things this staff paper takes up, there are some important questions that aren't just questions about sort of deciding when somebody is dead or dead enough for transplantation to take place.

And in particular, and I don't know that all of you will share my relative certainties on this, but with respect to that newly reemerging emphasis on donation after cardiac death that we talked a little bit about last time, in fact, with the Institute of Medicine Report, to me there is a different kind of issue that really one shouldn't just let get buried here.

I mean I don't doubt that these people from whom organs are taken after they are declared dead are dead. I mean there is that tricky issue about permanence and irreversibility and so forth. And I don't say there are no complications.

But I don't doubt that they are dead but I do wonder whether we may teach ourselves to come to think of their dying as just a technicality that must be dealt with — kind of get past in order to get their organs that we need. And whether or not it is dehumanizing in some ways to orchestrate death with that purpose in mind.

One of the primary moving factors that got sort of a bioethics movement off the ground in this country, you know, 30 or 40 years ago was the sense that medicine had sometimes so imposed its technical capacities on dying that the human meaning of one’s death was lost.

And it would be a shame if we backtracked and lost that important insight it seems to me. So that's a different kind of issue but I think it also warrants our consideration and attention.

CHAIRMAN PELLEGRINO: Thank you very much. Now open for general discussion.

Dr. Gómez-Lobo?
DR. GÓMEZ-LOBO: Well, actually it is the case that I share most of Gil’s relative or new certainties. But I’d like to contribute to the discussion initially from a slightly different perspective. In other words, I would like to make first a conceptual point and then talk about a general ethical principle.

The conceptual or analytical point is that in looking at the history of the discussion of brain death and all that, I see that there is a lot of confusion about what is being done. I don’t mean that this is going on in the paper. I found the paper extremely lucid in this regard.

What I mean by that is the following. It is more or less common to talk about a new definition of death and that is something that appears over and over again. And I think that helps to confuse the issue because I really doubt that that is a correct way to view it.

To define a term "death" is to give the meaning of the term. And if we give a new definition, we are giving a new meaning. We are talking about something different. Now that certainly I find unconvincing because in order for us to have a discussion, we have to have a settled meaning. We have to be talking about the same thing.

So my first point would be that there is a stable definition of the everyday term "death." And I agree with Gil that however it is explained, the meaning of death, it has to match at least mammalian animals and beyond. In other words, death — when we talk about death, we talk about something that happens not just to humans but to other living beings. So that would be my first point. I would insist on that.

The reason why sometimes the confusion arises is because we do use the verb to define in the sense of to draw a boundary. And, of course, what is being attempted in these discussions often times it is to draw a boundary. And in that sense, it is not incorrect.

But it is not the same to define criteria, i.e., to determine criteria as to define what death means. Now that said, I would insist on the notion that death is a negative term. It is what is called traditionally a privation. And Aristotle would call it a steresis, which means that there is, so to speak, no nature of death. Just as blindness has to be defined by reference to sight, there is no nature of blindness. It is just the loss or lack of sight. Likewise, it seems to me, the common sense understanding of death is the loss or cessation of life.

And just for the fun of it, even such an authority as our very own Leon, actually because of that makes a slip in his comments, for instance — and this is actually in praise of him — he says the orthodox defense insists on offering the conceptual definition of death as “integrated function of the organism as a whole.”

Now, of course, that’s not death. That is life. That is an integrated functioning of the organism as a whole. So the deep philosophical question then becomes what is the deep underlying essence of life and not the definition of death.

Now that brings us, of course, into very complicated issues and I agree that it may not — we may not need to go into it as a Council or even as a country because what really matters are the criteria. Now we have to have some understanding of the life of an organism to even come to settle on criteria. To say if these conditions hold, then the organism is alive. If they no longer hold, if they are lost, if something has ceased to be, then we know or we have criteria to determine that.

In Capron and Kass’s original article, I think this overlaps with what they call general physiological standards and criteria or operational criteria. I think that the two can more or less be taken together.

And then, of course, comes the further element of the tests and procedures to determine whether the criteria have been met. But to speak of criteria is not to speak about a definition. It is to speak about the considerations that should enter into the question of whether a given definition previously has been met or not met.

So that is sort of the overall proposal in terms of conceptual clarification. And that is why I like the Institute of Medicine proposal and the paper also does this is talking about neurological criteria or cardiac criteria — not cardiac — I’m sorry, not a new definition of death.

I don’t think that brain death defines anything. It just provides a criteria. But even brain death is, in itself, a philosophically questionable concept.

Now, of course, this can be further refined. And I think that in a report on the Council, it should be
refined and spelled out. I think that just clarifying the terminology of cloning was an important contribution of this Council made in our first report.

Now the second point I want to make is not a point in concepts but rather a point in ethics. And it is that it seems to me that the dead donor rule should not be abandoned. We’ve heard proposals to abandon the idea that a person has to be dead in order for it to be legitimate to harvest organs from her.

In the original article, Capron and Kass were very clear on this. That the need for organs and now the so-called crisis in the need for organs should not drive our criteria to determine when someone is dead. On the contrary, I think we should insist on the idea that we have to rethink, perhaps reconsider the criteria, perhaps require more accurate tests to be able to see if someone satisfies the criteria.

But all this done independently of the further intention of harvesting organs. That seems to me is very important. And then, of course, there is this possibility of someone saying I want to donate organs. My inclination would be say that is fine but only after life has ceased.

It seems to me that to go into a living body to extract organs is a major ethical trespassing into the goods of human beings. Thank you.

CHAIRMAN PELLEGRINO: Thank you very much. Anybody else?

Dr. Eberstadt?

DR. EBERSTADT: I’d like to begin by saluting the staff for a fine paper which introduces us to a very important and also very complicated issue and one, I agree, that we should not turn our eyes away from.

I have four initial reactions or initial thoughts to offer my colleagues. First, simply to state the obvious, there is an intense, and I think we can expect increasing pressure for what to paraphrase Daniel Patrick Moynihan we might call "defining death down."

And this pressure comes not only from the demands and realities of the circumstances for the organ donors but also from the increasing medical expenditures which attend our economy with end-of-life issues. I think that we will see this economic pressure continue to grow. That does not mean that we accede to that pressure but simply that we recognize it.

Secondly, for that very same set of basic economic reasons, I think that we can expect to see increasing material pressures to conflate questions of death and viability. And some of those issues are mentioned in the paper I think very well. This is, again, something that I think we must be very careful to separate the questions of death and viability.

Third, I agree with Gil that we should not proceed as if death is a matter of taste. It is a universal human experience and condition. It should be recognized as such. And thus, I think there probably should be universal human death — an issuance of phenomenon.

Fourth, Leon Kass is not here but in the paper that he provided us with, he mentioned one thing in particular that I think might be apposite to add to our discussion. And that’s the discussion of the human soul.

Leon mentioned in his paper that if you asked most people in this country or others — uninformed, non-medical specialists, they would describe death as the point at which the human soul or human spirit departs from the body.

And, I don’t think that that is specific to the traditions of — what would we call that — the Abrahamic faiths, Judaism, Christianity, Islam. I think one would find that also in Hindu tradition, in parts of the Buddhist tradition, in many of the animist traditions around the world.

Being — and I think that that whole question of the human soul is one that we would be — it is very difficult to integrate into our discussions today but it is also one that we might also wish to be mindful of.

CHAIRMAN PELLEGRINO: Dr. Carson and then Dr. Lawler.

DR. CARSON: One thing that, you know, becomes apparent in looking over all of this history and attempts to define death is that, you know, in the time before we had the ability to intervene with all of our technological advances, it was a fairly simple thing to know when somebody was dead.
And I suspect as we move further into the future, the definitions that we come up with today are going to, you know, fade into oblivion as well. I mean there may well come a time when, you know, cloning becomes an accepted norm. And then people say you are only dead when your cells can’t be cloned any more.

I know it sounds strange to us today but that could well become the case. So I think it is really sort of a moving scale that is largely based — or can largely be based on technology. And I guess what I’m trying to say is you know we shouldn’t allow ourselves to be propelled along, you know, that line of redefining things as technology comes along.

There should be a better sense. And it really gets back to what you were saying, you know, about the soul or about that part of us that when gone, no longer allows you to function as a human being. And, you know, maybe we need to be looking that way rather than at the things that are created by technology.

CHAIRMAN PELLEGRINO: Thank you very much.

Dr. Lawler?

PROF. LAWLER: I agree with the consensus that death is something real. This post modern thing doesn't work with death. You can put soul in quotes. You can put truth in quotes. But you really can’t put death in quotes. Like some people say he is "dead."

In fact, we are pretty sure that many, many people are dead. It is not really a matter of an opinion. And the death we die is real. And it is the death of an animal.

Ben is correct to say there is something creepy about technology because it used to be death was less controversial. We knew who was dead. We didn’t have to give it much thought. But now with ventilators, we are not so sure because we have made discoveries we wouldn't have made had it not been for the existence of technology.

So human death has become different from dog death for this reason. Even in an era of pet cemeteries and all that, we’re not putting dogs on ventilators. So we're not going to make the same sort of discoveries, I hope, when it comes say to our pets.

So we have this ambiguity. The argument for brain death was without a brain, you can't function as a whole. But it turns out due to the ventilator, we have discovered that you can, at least to some extent.

So the organism can be a whole and in a certain way from the traditional point of view, without a soul in a way, in a controversial way, because the organism then becomes no brain and all body. And it keeps going. It keeps ticking literally. So this presents us with a problem.

The brain death definition, which we thought was true in a less uncontroversial way than we do now, was very convenient for the harvesting of — I don’t like the word harvesting — for getting organs for transplant because it is easier to get the organs, obviously, if the heart is still ticking. And if we abandon brain death, there is a pragmatic problem of we will have fewer organs.

So we are kind of stuck — we have Gil’s let sleeping dogs lie issue comes up in this way. We can either abandon brain death in light of the new evidence that is pretty persuasive in the great paper or we can absorb the new evidence and succumb to the temptation of taking organs from beings who we don’t really think are dead in the full sense.

And that would be a fatal compromise, a succumbing to the new pragmatism actually to take vital organs from beings who aren’t dead. So A, we compromise death; or B, we have fewer organs.

Now when the libertarian Professor Epstein was here, he said Reason No. 906 I am for organ markets is you will soon get so desperate without them that you will start to mess with death. And unfortunately, the new evidence presented by the great report suggests that if we stay with brain death, and we look at the facts, this is, to some extent, messing with death a little. We are keeping the status quo while ignoring the new troubling evidence about, you know, the fact the human being is not as brainocentric as we thought the human being was.

So what do we do about this? This is not so clear to me what we do about this. Leon Kass in the memo he sent us thinks we should work harder in defending brain death.

And he does it in this way — that maybe we can define death as number one, the permanent cessation
of spontaneous respiration. The organism can never again breathe on its own or without the ventilator. And permanent cessation of wakefulness without which an organism cannot perceive anything.

So any being who cannot breathe on his own and cannot be awake ever again is dead. And all we have to do is come up with the neurological criteria that shows us when this being is in this situation of not being able to breathe again and not being able to be awake again.

The trouble is we are stuck with this. The heart is still beating and the organism keeps on ticking. And now we know this. So what do we do?

It's not that clear to me what we do given that brain death is more controversial than it used to be except to say if we abandon the standard of brain death, the result will be fewer organs acquired and the pressure will be greater then to engage in organ markets and such because it will look really perverse if we A, come out against organ markets and number two, make it harder say to get cadaver organs of one kind or another.

So there is a strong argument for letting sleeping dogs lie but unfortunately, we know sleeping dogs, due to the great report and the recent studies, we know sleeping dogs are sleeping dogs.

So I'm against the new pragmatism that dumbs death down and makes death a matter of opinion. Death, as everyone knows — I'm not an M.D. but I think people know death is not a matter of opinion. Each human being cannot define death for him or herself in any strong way.

On the other hand, I'm not so against the technological orchestration of death in order to maximize the number of organs we can get. I think getting organs for transplant is a great human good. And we should knock ourselves out to get as many as possible without compromising death. So I am a bit confused on this.

CHAIRMAN PELLEGRINO: Thank you.

Dr. Meilaender?

PROF. MEILAENDER: I note for Peter that some people have tried to clone their pets. I don't know about the ventilators yet but you just might keep that in mind.

I find myself in the, for me, unusual position of wanting to issue a caution with respect to language that is often thought of as religious. That is to say the soul language though, of course, it doesn't have to be necessarily religious language. It can be sort of a purely philosophical language.

But I was sitting here when Ben was talking, thinking about the danger of this language is that people are going to connect soul language to certain kinds of higher brain capacities. And think that the loss of the soul is the same as that.

And then sure enough, five minutes later, Peter talked about a functioning body from which the soul or the brain is gone. I think that is a mistake. And I don't think that is the way the soul language needs to be understood. I just want to point out that it is a danger.

From my perspective, any proper understanding of soul language is such that if you got a living human body, there is a soul there, you see, and you actually don't know that the soul is gone unless and until you don't have a living human body by whatever criteria you determine that any longer. If it is animated, the anima is there.

And I thought it might be useful — I mean I don't know but just a certain kind of illustration — we tend commonly, those of us who use soul body language at all, and, of course, there are people who don't, but those who do tend commonly to think of it sort of like these two things temporarily join together, which then could be separated and maybe could be reunited or something like that. Sort of like a rider mounted on a horse.

And that image won’t work because it is as if you could shoot the horse out from under and leave the rider perfectly unscathed. Or as if you could kill the rider and just have an animal left or something like that. Whatever exactly this language means, you have to think of it more like a centaur. You see the union of man and horse in such a way that you couldn't just kind of shoot the horse out from under and everything stays the same.

And if you think of it that way, then we will have less inclination to connect soul language with those peculiarly higher capacities of the brain. And I don't think anybody ever really made that connection prior to about the 18th century, in fact.
But I obviously don’t really have a problem with the language. I just think that it can lead in some directions that, from my perspective, are unfortunate, actually, here. And so we need to be cautious about how we use it. And careful.

CHAIRMAN PELLEGRINO: Thank you very much.

Dr. Bloom?

DR. BLOOM: Well, perhaps I am the only one who feels this way but I do not accept the scientific arguments put forward that challenge the concept of brain death. It seems to me that the definition on page 18 of the text defined by Dr. Pallis holds. And until I hear an argument to the contrary, I see no reason to have this loss of confidence in the brain death definition.

PROF. MEILAENDER: Can you say a little —

CHAIRMAN PELLEGRINO: Gil?

PROF. MEILAENDER: — more about what you see as the defects of the challenge rather than just affirming the Pallis —

DR. BLOOM: Well, the fact that the heart will continue to beat without the brain does not, in itself, constitute life as we know it. The fact that the guts will continue to digest food and that the liver will continue to metabolize carbohydrates and fat is not life as we know it. It is cellular metabolism. But it is not human life.

The fact that the body cannot respond to the lack of oxygen and initiate breathing combined with the loss of consciousness represents to me a dead person.

The last argument that Dr. Shewmon made, which is that vasopressin, an antidiuretic hormone, can be secreted is not much different than the body reacting to hypoxia to try to initiate breathing. When the salt and water balance of the body are effected, a nonconscious hormonal reflex causes vasopressin to be secreted. That does not represent human life.

So I did not find Dr. Shewmon’s word game with a variety of concepts of integration of the whole to be a convincing argument against this very simple and straightforward definition: the lack of consciousness combined with the lack of ability to generate spontaneous breathing is death.

DR. FOSTER: Along the same lines just quickly, I mean we take cells out of bodies all the time that metabolize carbohydrates and fats and make lactic acid. They do every single thing that the arguments were used against this. They just don’t hold I don’t think. I’m just agreeing with Floyd’s assessment here.

CHAIRMAN PELLEGRINO: Dr. Schaub?

PROF. SCHAUB: Ben Carson gave me my opening by saying that in the past death was more clear cut. I have two passages from long ago that I want to throw into the mix. One is from George Washington. George Washington, on his deathbed, gave the following last orders: "Have me decently buried and do not let my body be put into the vault in less than three days after I am dead. Do you understand me?"

Apparently he feared being buried alive. So it has long been understood that life can imitate death.

Edgar Allen Poe, the other passage that I want to toss in, is the master of telling about the horrors of being buried alive. I just have one paragraph from a story called "The Premature Burial."

To be buried while alive is beyond question the most horrific of these extremes which has ever fallen to the lot of near mortality. That it has frequently, very frequently so fallen will scarcely be denied by those who think the boundaries which divide life from death are, at best, shadowy and vague. Who shall say where the one ends and where the other begins? We know that there are diseases in which occur total cessations of all the apparent functions of vitality and yet in which these cessations are merely suspensions, properly so called. They are only temporary pauses in the incomprehensible mechanism. A certain period elapses and some unseen mysterious principle again sets in motion the magic pinions and the wizard wheels. The silver cord was not forever loosed nor the golden bowl irreparably broken. But where meantime was the soul?

So, I mean it seems that in the past, it was a matter of waiting long enough to be sure that the vital principle was extinguished and not just in abeyance. But now the push is entirely in the other
direction. We want to speed up the determination of death — speed it up as much as we can.

And it does seem to me that there is something unseemly about that push to speed up the determination of death. And so I guess I would be in the favor of erring on the side of life and pursue rather conservative policies, certainly sticking to the dead donor rule and setting very stringent criteria for death.

The Shewmon article, one thing that it points out other than this issue that Dr. Bloom just raised, but the Shewmon article points out that the current criteria don’t fully match the whole brain death definition. And so it seems that there might be work in sort of refining the criteria.

I did also just have a question about the comparison between the U.K. standard and the United States standard. And I take it, Floyd, that you were embracing the U.K. standard.

Can somebody explain a little more clearly to me what the differences would be? I mean it did seem as if the U.K. standard would somewhat expand the class of people classified as dead in comparison to the United States standard. Is that correct?

CHAIRMAN PELLEGRINO: Alan, would you clarify that issue for us?

MR. RUBENSTEIN: I’ll do my best.

The clinical bedside tests that are performed to determine if a person is brain dead test brainstem functions. So it tests brainstem reflexes, it tests for apnea, inability to breathe on their own when the ventilator is removed. There is also other tests which are not called clinical tests: lab tests or something else which involve EEGs or testing for intracranial blood flow.

Those tests aren’t done in Great Britain. If a person meets the clinical tests for brain death, then that is sufficient. So theoretically, there could be someone who, in the United States, is not classified as brain dead because something comes up on the EEG or something comes up in one of these other tests that shows that although from the brainstem perspective, they are completely gone, from the whole brain perspective, they are not completely gone.

My impression from the literature and someone should correct me is that it is very rare that someone who would be considered dead in the U.K. — in the class of brain dead — would not be considered so in the United States.

There was a significant stir in the literature when it was discovered that there is still this ADH secretion going on in some brain dead patients which is a secretion of a hormone which pretty conclusively shows there is something going on in the brain although the person has passed all of the tests for brainstem death.

So, again, how to interpret what that means is a little bit unclear. But for the British standard, and this is actually said by Christopher Pallis in papers, he said well, that is just not a problem for us. So there might be a little bit of continued activity in the brain demonstrated here but we were only ever concerned about the brainstem anyway.

So it kind of shows you where there is conceptually, at least, a difference.

CHAIRMAN PELLEGRINO: Thank you, Alan.

Dr. Schaub, did you want to comment? Dr. Hurlbut?

DR. HURLBUT: It seems to me that if we do enter this realm of discourse on the definition of death, we are dealing with a lot more here than just the questions associated with organ donation. We are dealing with a realm where a lot of strange and perhaps even ghoulish concerns may arise. And yet a lot of positive possibilities that would allow good advance of science.

And I am thinking here of the — it’s not a large-scale phenomenon but there are some new inquiries into physiological functioning on otherwise dead or dying bodies. And there would be scientific value in doing some physiological studies on a respirator-sustained corpse, if you will.

I think also there are going to eventually be some very strange questions about the borders of organ versus organism as we start to develop technologies to produce organs and maybe even organ systems apart from the body as a whole. Who knows whether these will turn out to be feasible but my guess is that they will.

When you talk with people who are working with — in stem cell research, they speak optimistically
about being able to identify those combinations of cells independently produced when put together spontaneously generate portions of organs and perhaps even whole organs.

That seems to me to be a physical phenomenon that we could eventually study and master. And, by the way, that has nothing to do with having to sacrifice embryos to get those cells. You could perhaps get that whole scientific progress in place without ever going through an embryo.

So the point is that eventually we may have some very strange questions coming that cause us to want to know what is the definition of life, organism and human organism. And we would do a service to the society to initiate the discussion on this because these are going to be very difficult issues.

It is clear that having used a very productive heuristic of a body-mind dualism, that now it is starting to cost us. And it is time to reexamine the meaning of embodiment. And if we don’t do it now, then it will eventually fall to others.

But it is such an advantage to doing things before you are under the pressure of the politics and the pressure of the pragmatic possibilities. There is a bit of theoretical distance that we have an advantage of from the present. So that is the first thing.

Oh, by the way, another interesting border and boundary of humanity question that would be somewhat at least tangentially relevant and implicitly covered in this kind of discussion would be the question of human-animal chimeras which, I’m going to say tomorrow, I think is a subject we ought to address that Diana has done some very good thinking on that.

But the single thing I think we could gain by entering this inquiry, and this is a little bit broader than just what we are talking about right now, but it is clear that there is the fundamental question of the protection of human life.

But it would be a helpful contribution to our culture if we would clarify and define the secondary moral and prudential concerns associated with it. And draw a distinction between the absolute protection of life and the violation of human dignity and the sensitivity of human process.

I’m thinking here of the more — the issues of semiotics, that kind of symbolic significance of the body and the personal feelings that attend. We obviously have natural moral sentiments that are shorthand for large questions. They function for us but they are not exactly scientific categories.

I guess what I’m really trying to say here just to sum it up is that in trying so hard to stay away from the word "soul," which we have done diligently in this Council, reflecting on how we avoided that terms when we were talking about cloning took some dancing but we did it, but trying to avoid the word soul, we have lost the functional shorthand for what a lot of people — what relates to a lot of people’s concepts of what is going on in these realms.

If we could in a gingerly sort of way reenter into that category without any disposition of prejudice toward any one formulation, we might really come to some valuable insight and help our society reformulate what was meant by soul but in a more pluralistic and more material physiologically-related description.

In other words, I think we might be offered the unique opportunity to clarify the meaning of soul and psyche in modern terms would be a really wonderful thing to do because there is a lot that is being lost by not using the word soul.

CHAIRMAN PELLEGRINO: Thank you, Bill.

Dr. Lawler?

PROF. LAWLER: That would be a big job for us but a good job perhaps.

I raised my hand a while ago to say I agreed with Gil that I don’t — you know you can’t talk about the human soul in the absence of a human body as if the soul and the body weren’t a whole. Now you can call the whole the soul because the danger in talking about the soul as if it were something different from the body is you might end up distinguishing between human life and life.

So human life is worth legal protection but not life. And so you can conceive of the possibility of something that is alive, a being who is alive but is not human. And the studies before us present us with this possibility. I mean a real possibility of this being who is somehow still an organism but without a brain. So is this a human life? A being that is somehow still an organism but utterly without a brain?
But I think it is dangerous, horrible to distinguish between human life and life for reasons we have all talked about in different ways. So — right, so I would be — if we can show that this being — and I agree with some of the doubts that have been expressed. I’m very unsettled on this. I’ve just learned about these studies lately.

That this being who has a beating heart and is in some way an integrated organism but really doesn’t have a brain, if we can show this being is alive, I would agree with Gil. This being has a soul and we should call it a human being. And so worthy of legal protection. But I think the jury is out on this for now.

Now Diana is right that we do rush to judgment now when it comes to death. And there is something utterly unseemly about this. So you might want to say that the only way to avoid this is to completely detach our understanding of life and death from any consideration concerning the donation of organs, the acquisition of organs.

Now the problem with this is that would diminish the number of organs we get or acquire that will benefit others. So there is a kind of understandable pragmatism here. We don’t want to do the wrong thing — that is take organs from living human beings.

On the other hand, we want to get as many organs as we can. And so we are kind of stuck with this rush to judgment with respect to death. We need to know exactly what death is more than ever because we can’t afford to wait around if we regard acquiring organs as a human good. So we need to know what death is more precisely than ever now. And because of the ventilator, we are less sure than ever what death is now.

So — and I’m scared if Bill is right and the line between life and non-life is going to get fuzzy on us. Because, in fact, life is already mysterious enough. We really don’t understand where animation comes from or how something suddenly gets animated. Why in a lifeless universe did life emerge? Now we don’t understand that and that causes problems.

But if it turns out there is categories that aren’t clearly in life or non-life, then our whole moral system explodes on us sort of.

CHAIRMAN PELLEGRINO: Thank you very much, Peter.

Dr. Carson?

DR. CARSON: You know the surgeon in me says, you know, if somebody is irreversibly injured, they are not going to come back to a functional state and if somebody else who could use their organs, we should take the organ and give it to the one that can stop going through all this silliness.

But I recognize that I’m not speaking as a surgeon today. I’m speaking as a member of the President’s Council on Bioethics. So, you know, let’s go back and hash this out a little bit, you know, in terms of living versus not living, being human versus being not human.

You know we all remember back in high school in our biology classes that we took the heart out of a frog and put it in a vat of lactated Ringer’s [solution] and it continued to beat. Does that mean that frog is still alive? Well, maybe you say it takes more than a heart so, you know, let’s connect the liver and the intestines with it. Maybe then it is alive.

I mean where do you stop, you know, when you start dealing with that kind of an argument. And, you know, I have to agree with Dr. Bloom. You know the brain really is the thing that distinguishes from a mass of cells. It is the thing that makes us into human beings, that makes each person.

And getting back to what Gil was saying, it is also what makes an animal into, you know, an individual animal. And if you take a dog’s brain out, you have got the same situation. A mass of cells, a mass of organs, but, you know, does it matter if they are inside the cavity of a body versus in a petri dish?

CHAIRMAN PELLEGRINO: Dr. Meilaender?

PROF. MEILAENDER: I am coming back to Floyd’s comment just to note one thing.

I would be very happy — and his comment seconded by Dan actually — I would be very happy if it turned out that we thought we could come up with a good defense of something like the current understanding of not so much definition of death but criteria for determining death. I mean that would solve a lot of problems.
My only concern back from my opening comments is that we not, as it were, just pretend that there hadn’t been a serious challenge mounted to it. Now you didn’t seem to want to take it seriously and maybe if I knew as much as you I wouldn’t either, I don’t know. But I do want to try to take the challenge seriously.

One way to take a challenge seriously, of course, is to reject it finally. And that would be possible. The one thing I wanted to notice in — if, you know, we think this through and turn in that direction is that there is something I’m not clear on with this British definition which does have the sort of admiral quality of sort of simplicity to it, the loss of the capacity for consciousness and the loss of the capacity to breathe.

I just would notice that that formulation from the paper is a little different — a little different from the way Leon reformulated it in the comments he left with us because he put it in terms of the loss of the capacity for respiration or spontaneous respiration and permanent cessation of wakefulness.

Wakefulness and consciousness are not precisely the same. Now it may be that given that you have got the coordinating conjunction combining that with spontaneous respiration, it may be that practically speaking they would come to the same thing. But that is, I think, something that would have to be sorted through in thinking about this.

I do not think that a capacity for consciousness and a capacity for wakefulness come to the same thing since, as I understand it, and it is subject to being corrected by more knowledgeable people, the PVS patient, for instance, is a classic case of someone who has permanently lost all awareness but has periods of wakefulness.

So one would need a certain kind of just clarity about how we formulated that. And I don’t know, it may not be accidental. But Leon’s formulation was a little different. And maybe it is entirely accidental. I don’t know.

CHAIRMAN PELLEGRINO: Thank you, Gil.

Dr. Bloom?

DR. BLOOM: Well, the reason I prefer the Pallis definition to Leon’s is that I could imagine a state like REM sleep in which one would have conscious awareness of past memories but could not wake up. But loss of consciousness requires being awake. Consciousness requires being awake. I misspoke.

PARTICIPANT: I was trying to figure that one out.

DR. BLOOM: Yes, sorry.

PARTICIPANT: You had us for a minute there.

DR. BLOOM: So to me, the original Pallis definition seems to me to be more coherent and consistent with what a physician would want to find to declare that person dead: loss of consciousness combined with the inability to generate spontaneous respiration.

CHAIRMAN PELLEGRINO: Thank you.

Dr. Schneider? Then Dr. Foster.

PROF. SCHNEIDER: I just have a few thoughts that I feel obliged to reveal to the world.

The first is that we have been talking as though almost everything about the definition of death is ultimately being driven by our desire to transplant more organs. And I certainly agree that historically that has been one of the things that has moved changes in the definition along.

But I think that the other thing that has been very powerful that way has to do with something that is a much more frequently occurring kind of problem. I mean very few organs are transplanted but people worry about when someone is dead all the time.

Millions and millions of people die with concerns about at what point the relatives and the physicians and possibly the patient decide that human life in some meaningful sense is no longer present.

And I think that an awful lot of what drives the ordinary person’s feelings about the definition of death have to do with a sense of the absence of the things that were important about the person at some physiological point.
And that leads me to my second kind of concern which is that I think that a large part of the problems that we saw, for example, around the Schiavo case grew out of the fact that understandings about when we are going to treat people as dead are very different in professional communities and in the rest of society.

We have allowed these changes in understandings to take place differentially in a way that leaves the ordinary person completely aghast when they discover the way that professionals, lawyers, ethicists, doctors think about these things.

And I think that there is a significant social cost to pay when you have a disjuncture between professional thought and the thought of the human beings who are actually involved in these cases.

And that leads me to my third point which is a point I make as a lawyer. Whatever you do, it is very important to produce definitions that people can understand. Even the brain death definition has not been understood by substantial proportions of the medical community.

There was an interesting study by Youngner and a colleague or two that suggested that physicians and nurses widely misunderstand what brain death as ordinarily understood is supposed to be.

So my plea here is that whatever definition one might think it wise to come up with, it, as a practical matter, has to be a definition that people can understand and apply in some reasonably comprehensive, comprehending way.

Thank you.

CHAIRMAN PELLEGRINO: Thank you.

Dr. Foster?

DR. FOSTER: The late Richard Feynman, the great physicist who won the Nobel prize, had a famous statement which said that we ought not to tell nature what to do but we ought to listen to nature. And I just want to make a brief comment teleologically in support of Ben and Floyd's primacy of the brain.

If the blood pressure falls, then the body does something very interesting. It stops — it doesn't stop completely but it shunts blood away from the liver and the kidney in order to preserve it for the brain. In other words, it will say I will let the kidney die and I will let the liver die if I can protect the brain.

Along the same lines, in starvation, for example, the liver stops making many proteins but it doesn't stop albumen because albumen is what sustains the volume of blood to protect the brain. In other words, the body teleologically says it will do everything to protect the brain at the expense of other things, kidneys and so forth, it will sacrifice them.

So we talk about many times the multi-organ failure. Much of that is done to protect the brain. I mean if you just listen to nature without all the philosophical arguments at all, it will tell you that in all animals and in humans, the prime event teleologically is to protect the brain.

And so I'm just saying this in simple terms that I think everybody would understand. If you can't breathe, then you can't do it. That's brain death. And so I'm not —

And there are many reflexes — I don't want to be ghoulish but the antidiuretic hormone which is meant to preserve water it also sustains the blood pressure. So any time the blood pressure falls, you are going to release antidiuretic hormone automatically. There are cells that contract in all sorts of ways to do this. It's nothing funny.

Many times, you might argue, just because people — that there is a release of stool or urine at the last thing, that's not because the GI tract or the bladder are still alive, they are just contracting in terms of a reflex thing.

So I think we ought to listen to nature about what's — and that is sort of silly to talk about that because everything is important for life, I mean, but nevertheless in life, the body tries to sustain the brain above all things.

So I think that the idea of focusing on the brain is a perfectly scientifically correct way to do — I'm not saying it is the only thing that counts but nevertheless that is what Feynman would say: listen to nature and it will tell you what's most important.
CHAIRMAN PELLEGRINO: Thank you, Dr. Foster.

Further comments? Questions? I saw Dr. Lawler and Dr. Hurlbut.

PROF. LAWLER: Okay, in my confused thinking on this, I notice that all the M.D.s are in agreement. And so maybe we should listen to them in addition to nature.

PARTICIPANT: That's always a good idea, listen to us, right?

PROF. LAWLER: I don't do that when it comes to my personal health but with respect to these big issues maybe we should.

And, of course, as usual, Dan engaged in this self-deprecating irony about being philosophical as if it embarrasses him. But listening to nature is philosophical. So what you were saying — and I'm saying very tentatively is here is the opinion, so to speak, of the body. We exist for the brain. And so mainly we defend the brain.

If the brain ain't there, then we're pointless. We have no business being around. And so if we look to the teleology of the body, the body understands itself as mainly a defense mechanism for the brain. Is that right?

DR. FOSTER: It is very simplistic. But I mean I was very simplistic, not you. I was very simplistic. But I think that yes, one should pay attention to what nature tells you. That was Feynman's argument and that is the argument that I think all three of us are making here, yes.

CHAIRMAN PELLEGRINO: Dr. Hurlbut?

DR. HURLBUT: Well, this is just a little addition to what Dan said and continuing with what I said earlier.

I think Leon's distinction between brain death and death of a human being, there is something good in pursuing that distinction. And in reading over the working paper and Shewmon's article, it struck me that Alan Shewmon has a lot of interesting stuff to say to us. And yet I also had the feeling that if we took it and thought deeply collectively about it, we might actually be able to come up with something that preserved Leon's insight of what the death of the human being actually is.

And I'm not convinced we don't have the increasing insight into what is a reasonable physiological criteria for making those distinctions now. I mean we have an increasing understanding of systems biology and a sensitivity to what relationship of the parts produces a whole.

And I mean I don't know it is at least worth exploring whether we might thoughtfully reconsider what defines a human life. And take on this hard problem. I mean at least we could look to see whether it was tractable or not.

That seems to be a very worthwhile thing to do. If a body like ours isn't willing to do that working on the kinds of insights that Dan just said, then who would do it. And we have a range of perspectives here that — and also recognize the pragmatic implications of this both for organ donation and beyond that there is something that feels very consistent with our mandate as a Council here. This feels like the kind of issue we were meant to take on by our composition and original Executive Order what we were supposed to do — deal with these cutting-edge issues. Well, that says it.

CHAIRMAN PELLEGRINO: Thank you very much.

Dr. Meilaender?

PROF. MEILAENDER: Well, given that our numbers are a little smaller today and that we may be close to exhausting our collective wisdom, I wonder you may not want to but I wonder if you, as the Chairman, would have anything to say on this.

I would be interested to hear, if you are willing, given, you know, you have got years of clinical experience, you have watched the development of this argument over several decades. Are you interested in commenting on it? What angle would you take on it?

I personally would be interested to hear if you are — since there is nothing more for you to moderate right now, I would be interested to hear it.

CHAIRMAN PELLEGRINO: Will somebody ask to speak so I don't have to?
No, thank you, Gil. I have been following the general policy of not making many comments because I think the job of the chairman is to see that everybody else has an opportunity to speak. And also, I have no claim on any special wisdom. And many years of clinical experience does not necessarily make me an authority on this question.

Obviously you have been talking about a question which has been vexing us as clinicians for a long time. And it is a question that I think will go on. I doubt that we are going to be able to arrive at a definition everybody would agree to.

I do think we could perform a very useful function by laying out the issues in clear form as I think this Council has done in the past in its previous reports, which I think are exemplary in laying out the issue.

My own point of view: I am very, very leery of brain death criteria purely from the side of what are the consequences that may follow from them. I know the arguments...

I think this and a lot of other questions in bioethics are extraordinarily difficult because we must act in the presence of uncertainty. And I think that situation is going to persist for a long time.

So my own take, if I may say, Gil, is rather to look at the question as a bedside question, if you will, of how do I act in the most defensible, morally, ethically defensible way, when I have to make decisions that involve questions that have a lack of absolutely certainty.

Those of you who are clinicians know that that is what we do all the time. Clinical medicine is the science of probabilities, certainly not of certitudes.

I don't mean to preach here or to dodge the question but from my own point of view, I would still think in terms of the very, very old fashioned [criterion of] cessation of respiration and of circulation. And without trying to defend that at the moment. Just to respond to your question, Gil.

From the point of view of what the Council ought to do, I am inclined to agree with Bill Hurlbut that we ought to take a look at this question. As I said, lay out the issues. We may not be able to, if I [understand] your discussions, I doubt that we will come to a consensus in the true sense of that word. But I do think we can add to the discussion the issues that you have brought up [to claim] the question if not the answer.

Well, without going on and on, Gil, my own feeling is to look at this as a clinical question (with all of the philosophical issues in the background) where we must act in some way and we must find out how do we can act with the most defensible position from the ethical point of view.

So, therefore, I think an ethical analysis of the lack of certitude and the question of how we act without knowing exactly what the answer is would be important. I have myself, for my own thinking, come to look more in terms of the fact that there comes a time in the natural history of any disease when we have to decide that medicine has nothing more to offer.

In many of the cases you are talking about, we could change the circumstances of the decision from the question of "is the patient dead?" to the question of "are we justified in continuing treatment?" because I do believe there is a [clinical] principle that says that if there is nothing to be achieved by what we are doing, we don't have a moral obligation to do it.

Without going into detail — I have talked to my colleagues about this — I think there is a way to get around some of these questions without getting to the ontological question of whether the patient is alive or dead.

From the ontological point of view, I believe that death occurs when the soul leaves the body. I take the Aristolelean point of view on the soul and the unity of body and soul, as some of you [have already] said. And I don't think we are going to be able to discern that moment by any test that I know.

So let me just close by saying that I think A., we need to act. And, therefore, the question of what are the criteria that constitute a morally permissible act at this point given the uncertainties and the likelihood that those uncertainties are not going to be resolved.

The second question of perhaps looking at a decision-making process [in a different way] that doesn't say "is the patient alive or dead?" But rather says, "are we justified in continuing treatment or have we not reached that point where ethically one may say we should allow the natural history of the
disease to evolve?” And is that natural history being impeded by the use of technology to no end and purpose?

Now there is a lot in that. And I don’t mean to convince you that that is the way to go. But that is the kind of thinking I’m going through at the moment.

Yes, Peter?

PROF. LAWLER: So I have to add our M.D.s don’t exactly agree after all. But more than that, you point to a problem. The cases discussed in the paper, in every case, everyone would agree further treatment is pointless. You can remove the ventilator. In no case do we have anything controversial there.

What is controversial is sometimes you want to keep the person on the ventilator, not for the person’s own good but to facilitate the acquisition of the organs. Do you think this is morally defensible?

CHAIRMAN PELLEGRINO: I think that if you have arrived at that point where you can say that we have reached the limits of anything that medicine can contribute — that is to say in the way of good or benefit to the patient — and where the burdens may overcome the good [according to] the principle of disproportion, under those circumstances you could say well, we are justified in removing the respirator.

Now having made that decision, I don’t — I think it is defensible to say we can now have a controlled dying process. That we can remove the respirator in such a way that with all the things that go with it, we can remove the organs [after the heart and breathing stop]. And you haven’t had to ask the question is the patient dead? You’ve decided you are going to allow the natural history to emerge.

I think that is another way of looking at it. And personally when I’m doing ethics consults and so on, I lean in that direction. I think that is defensible.

DR. GÓMEZ-LOBO: This isn’t a question what do we do by ignorance, of course, but isn’t it the case that in order even to deliberate about removing say extraordinary means, you are asserting that the patient is, indeed, alive?

In other words, I side with Leon, I think, on this one that the question about end-of-life treatment is a different question conceptually speaking from the question of whether the patient is alive or no longer alive.

CHAIRMAN PELLEGRINO: Well, I think you are right about that. It is a different question. But given that we cannot answer that question in the ontological sense (to speak philosophically about this), and we have a practical decision to be made, and we are in the realm of the bedside, clinical decision-making process, given those things, it seems to me that the approach that I have suggested doesn’t have to answer the question “is he alive or dead?”

If you are saying “is he still alive?” I’d say yes, that is right. But let’s take a situation that Dr. Carson faces, I suspect, quite a few times. A young person riding a motorcycle, the death instrument, and hits a concrete abutment. Now they keep him alive long enough to come to your attention.

And then...someone... would say, “Well, there is so much damage here to the brain physiologically and pathologically and so on, to the best of my clinical judgment — and we are human and our clinical judgment is just that — we are assuming you are well qualified — this patient cannot recover.”

And anything we do for this patient will be — I’m going to use a word that is very, very much debated — futile. I’ll define that if you want but, again, I’m not here to [defend this point].

Under those circumstances, that young man is living but [the clinical judgment is that] there is no future for him. And in [the physician’s] best judgment, that patient will die [no matter what we do medically] within a period of five or six hours let’s say.

And under those circumstances, we could discontinue treatment as being of no [medical] value to the patient. Being perhaps, for many, many reasons, not beneficial [but burdensome disproportionally]. They are two different things — effectiveness and beneficial. And then allow that patient to die.

And in the process, begin to prepare him for the taking of his organs. That is the question. . . [H]e is alive, yes. But we allow people to die [to permit] the natural history of that disease to express itself.
DR. GÓMEZ-LOBO: But Dr. Carson would not extract organs before the patient —

CHAIRMAN PELLEGRINO: I’m sorry?

DR. GÓMEZ-LOBO: Dr. Carson would not extract organs before the patient has died according to your criteria which are basically cardio-respiratory criteria, right?

CHAIRMAN PELLEGRINO: Oh, yes. Well, under those circumstances — I didn’t go into all the details of what I would do under those circumstances. You decide — you’ve got everything ready. You’ve decided that this is the time to remove the respirator and the other support mechanisms [not to remove organs, but because the patient is dead].

Follow the electrocardiogram for three to five minutes. If you get no sign of electrical activity, then you can say — you can say he is dead. [H]e is at the point where you can take the organs.

I think that is why I fall back on cardio [pulmonary criteria for death to be pronounced].

DR. CARSON: I was going to say what actually is done in that case because it does come up. And what actually is done is we determine whether, in fact, the patient has any cerebral blood flow. You know we would do an EEG. We would do an apnea test. And we’d talk to the family.

And if the family says, you know, they are willing to donate organs, that the team is called — the procurement team is called. They take the patient to the operating room. They procure the organs. And that is standardly done.

CHAIRMAN PELLEGRINO: But you have a set of criteria that you follow, right?

DR. CARSON: Yes. They have to meet the criteria.

CHAIRMAN PELLEGRINO: I didn’t go through all the criteria. What is happening here is why I have —

PROF. SCHNEIDER: Oh, I was just going to say that I’m the local prosecutor and I’m sitting here around here with my definitions of death and I’m asking whether when you start extracting the organs after two minutes or five minutes or four minutes, whether you are actually committing homicide or not. And I have a good case to make that you are as long as you are using your — as you described them — old-fashioned criteria.

CHAIRMAN PELLEGRINO: Well, the heart, of course, would have stopped by this point. You have — the electrocardiogram is flat. You’ve got no evidence of any other criteria you are talking about. So I wouldn’t be committing homicide.

PROF. SCHNEIDER: I need to know that they have irretrievably or irreversibly stopped. I mean this obviously comes up with the Pittsburgh Protocol.

CHAIRMAN PELLEGRINO: Well, I think again the clinicians here can argue with me but I think the criteria are clear that if you do not get electrocardiographic evidence of activity — electrical activity — for three to five minutes, and five minutes is the upward limit [after the heart and breathing stop], the possibility of returning is — and again we haven’t got certitude — the possibility of returning is so low that one may proceed.

And, therefore, I would plead, sir, Prosecutor, I’m not guilty of homicide.

PROF. SCHNEIDER: It certainly makes a big difference how many minutes you are going to use here. And the minutes that are actually used in real fact can be smaller than the number of minutes you are suggesting, raising these problems of definition in a legal sense that become quite difficult for the poor prosecutor to resolve as well as the poor doctor to anticipate.

CHAIRMAN PELLEGRINO: You know, I think you are absolutely right. But I think it will show in three to five minutes.

The other thing is I guess I’ve had a little personal work in this but for some years I did electrocardiograms on dying patients to see what did happen — whether they did return. I’m not saying that my data should solve the problem but others have done it of course.

But many, many years ago, that concerned me. And three to five minutes is a pretty good period of time of no activity — complete lack of electrical activity. [Following cessation of cardiac and pulmonary activity.] Anyways, this is only a hypothesis.
The government representative has just pointed out to me that I've talked too long. And we are going to extend our break. I promise to be silent from here on in.

(Whereupon, the foregoing matter went off the record at 10:39 a.m. and went back on the record at 11:02 a.m.)

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SESSION 2: LIVING ORGAN DONATION: OUTCOMES AND ETHICS

CHAIRMAN PELLEGRINO: Thank you for reassembling so promptly, keeping us on schedule.

Before we take up the next item, I want to remind you, Council members, that you have two statements from the transplant community as background to refer to, one having a consensus statement on the Amsterdam forum on the care of the live kidney donor and then an ethics statement of the Vancouver forum on the liver, lung, liver, pancreas and intestine donor. They're brief and they're to the point and I think they'd be very relevant to your discussions and contemplations of the issue.

Our next item is the discussion of the question of living organ donation, the outcomes and the ethics, referring to some of the data that now exists on the practice of living donors.

In this case, as in previous ones, a staff summarization of where we are has been presented and distributed to the Council members in advance for their consideration and our procedure will be as before, I will ask Council Member Dr. Robert George to open up the discussion and then we will open up the rest of the discussion to the Council members.

Robby?

PROF. GEORGE: Thank you very much, Ed, and let me begin with a special word of thanks to you and to Dan Davis for accommodating my need to have the schedule shifted around this morning in anticipation of being held against my will for 45 minutes or an hour in some place like New Carrollton which, in fact, happened. I asked Ed and Dan if it would be possible to switch the first two sessions and they were very generous and accommodating that, so thank you.

Thanks, too, to Ginger for a wonderfully clear paper where in brief compass she not only gave us the facts, but laid the ethical issues out for us.

Well, let me begin by introducing something very familiar to all Americans, something called the general libertarian position. And that is the position that as long as there is no coercion or deception, a potential donor should be able to donate any organ to anyone and even make nondirected donations as he chooses. This would include choices to donate organs such as the heart, where the donation would result in the donor's death. It would also include the right to sell one's organs.

A small, but not insignificant number of Americans hold or are inclined toward the general libertarian position and even people who reject it see its attractiveness and often have difficulty explaining why they reject it, at least judging from my discussions with students in class, they have difficulty seeing or explaining why they reject it.

Some accept the premise or at least purport to accept it that people "have a right to control their own bodies." Or "have a right to do as they please with their bodies so long as they do not harm others." But they nevertheless worry that accepting the libertarian principle, as the ground of public policy in this area and others, for example, think of the question of regulation of hallucinogenic and other recreational drugs or the question of prostitution, would be a mistake because of the practical difficulties with preventing coercion and deception.

What I'm suggesting here is that a lot of people who think that the basic premise is sound, that people should be able to do with their bodies whatever they please, so long as there's no coercion or deception, nevertheless worry that we can't eliminate or even significantly restrict coercion and deception if the general libertarian position would be used as a basis for public policy.

Indeed, as they note, there are difficulties even in defining coercion and deception and in saying what is to account as coercion or deception. In the case of coercion, what is to account as psychological pressure? In the case of deception, what is to account as disclosure of relevant information?

Now, of course, there are others who reject the moral premise of the general libertarian position.
They recognize a legitimate realm of freedom or autonomy in matters concerning the body, including centrally-made decisions about health care and even declining treatments. But they do not have a view, according to which legitimate exercises of rights to choose are instanciations of a broader, more general or abstract right to control one's own body or to do as one pleases so long as there is no harm to others. They don't accept the premise of the general libertarian position.

In rejecting the concept of the body as a form of property, belonging to the person whose body it is, so called self-ownership, they do not embrace the view that the body is the property of the state or society or in many cases even of God, rather, they hold an understanding of the body as an aspect of the personal reality of the human being such that it is not properly regarded as property at all or the property of anyone including oneself.

For people who take this position, and I take it to be Leon's position, it's certainly own my position, the fundamental concern about live organ donation is a concern to avoid a social sliding into the commodification of the body and of bodily organs, whether or not there is an exchange of money involved. The question for people like Leon and me is then how to justify living organ donation in cases where it strikes us as plainly justifiable and even laudable, in view of the fact that the donor's health is always impaired at least temporarily in the process of donating an organ. I take that from Ginger's paper.

Having in mind the general principle of medical ethics that, as Leon puts it, "a physician should not violate the bodily wholeness of a patient for someone else's benefit." Now I agree with Leon that the attempt and I'll quote him again, "to get around that wise constraint on physicianly power by invoking general beneficence and the moral, psychic and spiritual well-being of the donor seems a large stretch."

I agree with Leon that we do not want physicians making decisions to remove healthy organs based on the physician's assessments of whether the act of organ donation will serve the moral and spiritual well-being of the donor in ways that compensate for the damage that will be done to the donor's physical health in the operation to remove the organ for donation.

But then where does that leave us? Perhaps, perhaps we are left with Leon's somewhat startling conclusion, "I would much prefer to say that the operating on live donors is an out and out violation of the traditional medical ethic, yet then argue that it is humanly justifiable in some, but not all, cases, especially spousal donation and parent-to-child donation".

Now this is certainly not a conclusion I like. Nor I gather is Leon himself comfortable with it. Before embracing it, I would want to consider as carefully as possible justifications for living organ donation that conceive the surgeon and those assisting him as serving the common good of the donor and recipient as friends. And here I am using the term in its richer, Aristotelian sense. So in this sense, even parent and child are friends in the relevant sense. Spouses are friends in the relevant sense.

But without the reduction of the benefit to the donor to the status of some sort of psychic satisfaction or even moral or spiritual betterment. I do want to resist what Leon wants to resist in that area.

Now perhaps no such justification can be made to work, and we are left with Leon's conclusion. But I wouldn't want to say that before hearing from Gill and Alfonso and Diana and Peter. I'm singling them out as the Council colleagues that I know have thought about this question, but my other Council colleagues, too.

Thank you, Ed.

PROF. SCHNEIDER: Since somebody needs to start us off, I would be happy to try to do so. And I have tried to think about this since our last meeting. I found myself somewhat at sea because I recognized so little of the arguments that were being made.

Let me try, as briefly as possible, to tell you some of the ways in which I approached this from I think quite a different point of view. Let me first confess any conflicts of interest that I have and tell you what my experience is that illuminates what I'm saying.

I am the relative of a recipient of two transplants, and I have done a very great deal of my research some years ago amidst dialysis patients who were of course themselves primarily anxious to receive transplants and many of whom had received transplants. I spent enough time amongst them that I became good friends with a number of them. I hope they would think so too. It is their lives and experiences that animate what I am going to say.

The first thing is I guess while I admire all of the papers that I've read emanating from the Council
for their intelligence and their scholarly achievement, if I were writing them I would have written them in a very different sort of way.

First, I find an absence of a really passionate sense of the good that transplants can do. There is, of course, an acknowledgement that transplants may improve health. It’s really a lot more than that. First of all, of course, for many kinds of transplants, it’s not a question of improving the recipient’s health. It’s a question of improving — of making possible the recipient’s continued life.

Even with kidney transplants where life itself isn’t at issue, the difference between being on dialysis and having an actually functioning kidney is huge. People who are on dialysis actually report levels of happiness that are not all that distant from those who are ordinarily healthy people. When they receive a transplant, they report that their lives have been transformed, that they had lost track of what it really means to be healthy, and they glow with the satisfactions of discovering what health can be like.

Similarly, I think that I would have been somewhat less ambitiously concerned with detailing the disadvantages of donation from the donor’s point of view. For example, the questions about the risks to the donor are questions at least for the kidney transplant that have been thought about for a long time and it’s not a question where you can ever say that you have fully been able to establish all of the possible risks, but the suggestion that there are some long-range risks that are so ominous that they need to be taken very, very seriously strikes me as being overdrawn.

There is even some interesting literature from Sweden, I think, that suggests that the mortality rates of donors are about a third of those of the population and that is if you ask at a particular point in time after the donation whether the donor is still alive, the donor is much more likely to be alive than the average citizen, similarly situated citizen would be. And of course, that’s in substantial part because donors are picked rather carefully.

But one of the standard suggestions is that donation is about as risky as extending your commute by a certain number of miles every day. In other words, it’s within the range of risk that people take all the time without ever thinking about having done so.

More to the point, what I think we don’t hear very much about is other kinds of effects that the donation has in other parts of the motivation that people have for donation. And one of the things that has puzzled me the most is what I would describe as something almost approaching, certainly is a very stringent level of skepticism about altruism and a kind of suggestion that it’s hard to understand people who are behaving altruistically by donating organs.

The response that you get from donors when you ask them whether they would do it again is somewhere ordinarily in the 90s, 90 percent of the people say they would be happy to do it again. It’s very hard in social science literature to find rates of response in the 90s for almost anything, much less something as dramatic as giving an organ.

In fact, what a substantial number of donors say is that they have never done anything in their lives that is as gratifying and important to them as having donated the organ. And some of the studies suggest that donors turn out on average to be happier people, possibly because of the donation and the satisfaction that people get from having done good in the world.

Similarly, there is an emphasis on the problem of coercion, whether donors are somehow being coerced. Well, to some extent I have to say leaving aside questions of what coercion might mean, a certain amount of familial pressure does not seem to me to be entirely out of place in these circumstances, and I’m prepared to live with a certain amount of what you might call coercion.

In any event, the attempts to ferret out coercion have not been very successful and here, I’m relying on the most extensive study of this which is the Simmons study which is a book on — which tries to investigate the problems that may arise with donors of inter vivos kidneys.

The next set of questions where I find myself a little at sea have to do with the — I guess it’s the social consequences of a system in which organ donation is possible. Some of that is put in terms of a fear of commodification. Some of it is put in terms of the moral and I guess cultural and psychological importance of embodiment.

I’ve struggled hard to understand these arguments. I went back and I read Leon’s arguments in the other papers. Leon says that his arguments rest on ideas, on I guess intuitions that are hard to articulate and if they’re hard to articulate, I guess it’s not quite so puzzling that they’re also hard to understand.
I think that they turn on a false perception of the actual psychology of donation and reception. When people think about giving organs, I don’t think that they think in anything like the terms of commodification or of some violation of themselves. I think they think in quite personal and direct terms about the good that they can do in the world, sometimes for easily identifiable people and sometimes for people more generally.

So I think that it’s important to understand what the actual psychology of donors is and that psychology is one that does not focus on these questions of mutilation and does not focus on questions of transfer of property, but rather focus on the things that human beings can do for each other.

I guess the last thing I want to say is one more word about altruism. I would like to see the altruism sort of what I would describe as the anti-altruism argument described more thoroughly. It seems to me to start, but also if I’m understanding it correctly, almost to stop with the suggestion that there are some kinds of altruism of which we would not approve and the usual example is that you would not approve of a donation of a heart.

Well, even there, I would like to say that there are all kinds of sacrifices of life that we do approve of, sacrifices of life for other people and even for causes. The Christian tradition surely begins partly “greater love hath no man that he would give up his life for his neighbor.” So, even with the extreme version, I’m not quite so comfortable that it’s a straightforward, obviously this is impossible, so let’s not think about it.

But the kinds of donations that we’re talking about, livers and kidneys and so on, are not intent to be donations in which life is sacrificed. They’re very far from that and then I’m not sure why — I’m not sure what the argument, as you might say — against altruism would be? A number of other questions, but I think I’ve said enough for now.

CHAIRMAN PELLEGRINO: Thank you very much.

DR. FOSTER: I have a question about just one point. I presume that most of your conclusions here about living donors have been in family situations and people who are known to each other, not just — most of these are probably not anonymous donors along these lines.

Do you think the argument would still hold about the altruism and so forth if we moved into the next discussion, that is, that this was commercialized in terms of paying for organs. In other words, what I’m trying to ask at the beginning is are the conclusions — I’m perfectly willing to accept the safety things that you have talked about and never thought about the commute thing which is interesting, but would the supply in another set of donors that would be probably quite different from the living donors that we now experience?

PROF. SCHNEIDER: Obviously, there’s a lot less literature, as you’re suggesting, on the nondirected donation. I don’t know of any literature that suggests that those are so radically different from the other kind.

I do want to say that I think that there is a danger in thinking about sales. And I see it in a lot of the papers. The suggestion seems to be that if something is in commerce that it is being regarded as what a lawyer, an economist would call a fungible economy. Here is a bushel of wheat. Bushels of wheat are pretty much — it doesn’t matter which grains you’re getting, it’s just a bushel of wheat. And that people regard something that they’re selling as something that isn’t really very important and isn’t really very valuable except in a very commercial sort of sense.

I just don’t think that that’s an accurate description of the way, the many kinds of ways that people can relate to things that they’re buying and selling.

Yesterday, I arrived a little early in town and I went down to M Street to an antique store that I’m very fond of and there are some things that I would like to buy that would mean a very great deal to me and that I would cherish, if I persuade myself that I can do this. And I think that it’s quite possible that if people are in some sense paid for their donation that the real motive for it will not be I want the money, but will be much more important and admirable kinds of reasons.

So until we know at least a lot more about how such transactions would work, I’m very leery of assuming that they will work like a wheat market.

CHAIRMAN PELLEGRINO: Dr. Schaub?

PROF. SCHAUB: Robby has given new meaning to Aristotle’s assertion that friends hold all things
in common. I'm not sure that's what Aristotle meant when he said that. I mean it may be that
friends strive to hold all things in common, but in this case, in the case of organ donation to
effectuate their generosity, they need the cooperation of doctors. And I'm sorry to say that it does
seem to me that live donation is a violation of the medical ethic, so I think I agree with Leon about
this.

And if live donation is a violation of the medical ethic, I don't see why it's allowable, why the violation
is allowable in some cases, family and friends and not allowable in other cases. I don't see how to
draw the line between family and friends and non-family gifts.

If the reason that we make this exception is because of the generosity of the act and generosity is a
virtue, it's just as generous, maybe more generous to give the gift of life to a stranger. There's
certainly more self-interest involved in a family donation and we see that doctors have not been able
to enforce this distinction. There has been a steady increase in nondirected donation. Nondirected
donation was apparently at one point heartily resisted, but that resistance has crumbled.

Let me sketch a scenario. We know that all of the major religions have now approved of live
donation. What if a particular sect were to go further and strongly encourage or maybe even require
live donation? Some denominations have first confession or first communion. This denomination
would have first donation. All men are brothers. This group of believers love their brothers enough
not just to turn the other cheek, but to offer up the other kidney. Would there be any reason why
transplant surgeons should decline to accept those offerings?

So I mean it seems that what we've done is we have allowed this argument from generosity to
override the medical ethic and once we've done that I don't see how we set bounds to generosity.
And I guess I would argue that the natural check on generosity, if it is in need of a check should be
the ethical principles of the professions. So if you looked at the criminal justice system, there might
be plenty of mothers out there who are willing to take the murder rap for their guilty son, but
prosecutors are bound by the evidence. They're bound by guilt and innocence. And in the same way
doctors in the past were bound by this medical ethic that disallowed certain natural generous
impulses of people.

CHAIRMAN PELLEGRINO: Thank you.

Dr. Schneider?

PROF. SCHNEIDER: It would help me a lot to know what this medical ethic is and where it comes
from and whether it still makes sense and if there is such a medical ethic and if it's a medical ethic
that really made sense at one time, did it partly make sense at that time because organ
transplantation wasn't possible and there was no other reason that physicians would be chopping
away at one person on behalf of another.

Medical ethics have changed an awful lot in the last century. What principle of medical ethics is it
that is so worthy of preservation and does it still make sense?

CHAIRMAN PELLEGRINO: Does someone want to answer that?

PROF. SCHUA: Yes. I would — Leon spells it out briefly in his note on this paper. He goes back
to the Hippocratic Oath. He does not think that the Hippocratic Oath has been superseded and he
says that the principle is that the physician acts always and only for the benefit of the sick, not the
family, the hospital, the larger society or in the present case, for some other sick person. And he
certainly would not violate the bodily wholeness of the healthy patient for someone else's benefit.

DR. FOSTER: But I think that — I mean if you go back to the Hippocratic Oath, it really
fundamentally comes out to the primum non nocere, first do no harm. But that doesn't hold — we
do harm all the time every time we do chemotherapy, we do harm to a patient in the hope of a
greater beneficence there. So I think that Leon and I think he's talking about not doing any harm
here. I may be wrong, but that's what I think.

PROF. SCHUA: I think not, actually. I mean it's interesting at the beginning of this, it's just one
paragraph here from him, but he says that he doesn't believe this principle of "do no harm" plays
such a magisterial role in medical ethics or medical practice, so he is not hinging his exception on
"do not harm." He's hinging it on what he says is the duty of the physician to act always and only for
the benefit of the sick.

CHAIRMAN PELLEGRINO: I have Dr. Lawler and Dr. Meilaender and then Dr. Schneider. And
then I'd like to make a quick note about the principle, the first principle of medical ethics.
PROF. LAWLER: I almost want to hear the footnote first.

(Laughter.)

DR. LAWLER: But Diana was very eloquent. On the other hand, the objection that was raised last time still stands. How then do we justify cosmetic surgery? How then do we justify nipping and tucking which doesn't affect — do the patient any good, and in fact, there's an element of coercion there. People get nipped or tucked and so forth to be more competitive in the marketplace. So chemotherapy is to do harm in the hopes that you do good, right?

But plastic surgery, cosmetic surgery, not reconstructive, but designer cosmetic and plastic surgery is hard to know how we justify that. And an obvious point would be some of that surgery is more dangerous and some of that surgery I think is more dangerous than being the surgery required to be a kidney donor and obviously the surgery required to be a kidney donor does someone some good. Nipping and tucking, strictly speaking, does no one any good except in an amorphous of aesthetics in a way.

So I agree, at least with the one point that was made, that maybe the reports are a little bit weak on discussing the good that we pursue through the donation of kidneys. And maybe they're a little weak on really outlining the dilemma presented to us by the stage of science we're at now and it's something like this. Kidney transplantation is getting better and better. The side effects are managed, better people are living longer.

Dialysis remains relatively constant and whatever the studies show about the subjective happiness really a very brutal thing, a brutal debilitating and really over a long — over some period of time, a killing thing. And because transplantation is getting better, dialysis remains constant, more and more people want transplants. The waiting list is getting longer and preventive medicine, I think Dr. Hippen was right to explain, although I'm all for better medicine, although I may not look like it, I really wouldn't change the fundamental situation of the waiting list getting longer. And so given the very specific bad situation we're in, maybe we do need to say more about the good that is a transplant.

And so I actually — I think I agree with Leon that finally you can't reconcile the ethical injunction of the profession and with donation. On the other hand, there's something to be said as Robby said for the freedom people have to do good for their friends, especially when the good is quite good and the risk isn't, in a certain way, all that great. And so all professional principles have to be applied prudentially. So I see the problem in principle. It's not that dramatic to me in practice.

So I'm certainly all for, I'm not for like commanding it, but I can see the good that is done when you donate organs to friends or even to strangers, although the objection Diana raised with the religion that would require it is troubling. Doctors are good at many things, but they may not be so good at discerning the intention of their patients or making decisions on the basis of intention. So I do see the slippery slope here.

Nonetheless, I'm not as troubled by it, given the dilemma that has been presented to us by a very specific stage of scientific development.

CHAIRMAN PELLEGRINO: Dr. Meilaender?

PROF. MEILAENDER: You wanted to come back to the question of just what it is that the physician's principle is. I don't think — I think Leon was right. The issue here is not first do no harm, it's be wholly attentive to the well-being of the patient. And if the friendship language is appropriate anywhere here, it's actually sort of physician as friend. Just as the lawyer needs to be wholly attentive to the well-being of his client, not the larger question of whether society would be better off he weren't so attentive to the well-being of this client, so the physician is not to regard his patient as a public resource, but rather as someone to whom he gives his best skill and attention.

I think that's the issue and that's what causes the difficulty for living donation. It's not just that you're cutting somebody as in cosmetic surgery, it's not just that in a certain sense there's a physical harm being done. It's that it raises questions about whether we have compromised that single-minded attentiveness that physicians are to give their patients.

Now that gets compromised in some other ways sometimes, but we nevertheless continue to be committed to it in many ways and actually, most of us who are patients rather like, would rather like to think that our physicians are pretty committed to it as well.

So I think that's the principle and then it seems to me whatever we end up saying about this, about
living donation, where I’d want to back off, Carl, from the direction that you were pressing us is that I wouldn’t want to pretend that this wasn’t a serious question or that I couldn’t understand it. I can understand it pretty well. When I go into the doctor’s office, that’s exactly the attitude I’m looking for from him. So that if it’s to be compromised, if there’s an important good here that’s to be compromised, then I want to think through the good.

I don’t want to take for granted that because we’ve got a practice that seems to compromise it, the practice must be okay and we can just proceed. Maybe it is okay and maybe we can go a better job of explaining why it’s okay than has been done before.

That’s perfectly all right, but there is an important good there and it would be very, kind of thin gruel we were to offer if we didn’t try to think our way through that, I believe. That’s what I think is at stake.

CHAIRMAN PELLEGRINO: Thank you.

PROF. SCHNEIDER: Well, first, since my attention has been drawn to the duty of the lawyer to be only in the service of his client, it’s not true. It’s radically not true. The lawyer is also an officer of the Court and the lawyer has ethical obligations not just to the client, has ethical obligations to the system and has ethical obligations to the people that the client may be dealing with. The lawyer has obligations to report some of the illegal and demoral things that the client may be involved with, has an ethical obligation not to do what would be in the interest of the client, for example, like putting the client on the stand to commit perjury and the lawyer is widely thought to have an obligation to try to maintain a distance from the client exactly so as to be able to try to repress the client’s desire to do bad things, not just illegal things, but bad things in dealing with other people.

Now you can say that in some sense that’s in the true interests of the client. The client certainly doesn’t think so and the lawyer often doesn’t think so, but my question is still about this duty of the doctor to serve only the interests of the patient and — or in this case it says the benefit of the sick. And I’m not sure how that applies in this situation.

I mean the fact that the Hippocratic Oath is, I believe, almost never any longer exacted from future doctors and new oaths have been substituted, am I not correct?

CHAIRMAN PELLEGRINO: No, it is given in most schools, but it is highly modified.

PROF. SCHNEIDER: Okay. Highly modified. And as Oliver Wendell Holmes said there is no more revolting justification for an idea than it was the practice in the time of Henry IV.

It seems to me that this rule is hard to understand in this sense. This is being done for the benefit of the sick. It is being done — the operation is being performed for the benefit of the sick. And in an important sense it’s being done for the benefit of the person who is being subjected to the operation. If there is one thing that modern bioethics seems to say with force and unanimity it’s that we want the person affected to be deciding what is valuable to him or to her and this donor has decided that this is something sufficiently valuable, this is something the donor wants to do.

So I’m not clear that this is a principle of medical ethics that applies very aptly in this new situation.

CHAIRMAN PELLEGRINO: Dr. Meilaender.

PROF. MEILAENDER: I have some other things I’ll get on the list for, but if that is the thing that modern bioethics above all wants to say, then we should set our face squarely against that. That’s an arguable principle and we should by no means just acquiesce.

CHAIRMAN PELLEGRINO: Dr. Carson?

DR. CARSON: First of all, on the Hippocratic Oath, I give two or three medical school commencement addresses each year and [in] almost every one [it] is still administered.

And also, I have to say it was very wonderful to hear Dr. Schneider talk about what lawyers are supposed to be like. It’s very nice to hear that.

(Laughter.)

PROF. SCHNEIDER: Spoken like a true physician.

DR. CARSON: That’s refreshing. Now I had a patient a few years ago, a teenager, who had a brain tumor. We took it out. He did extremely well. Several months later to be involved in a horrendous
automobile accident in which he lost one of his limbs and had severe injuries to others.

His mother decided that she would donate two nerves, very long segments of nerves — some of you might have seen the story in the news — which meant that certain parts of her body would be without sensation. And it was done. The grafting turned out to be quite successful. One could make the argument that she should not have been allowed to do that because she was in some way damaging her body. And yet, you could also look at the bigger picture here. She was doing something very important for her son and she was doing something very important for herself psychologically. So I think you always have to look at the big picture issues here.

You know, going back to surgery that may be dangerous. Peter appropriately pointed out some of the things that happened with plastic surgeons and cosmetic surgery. But as a pediatric neurosurgeon I’m guilty of cosmetic surgery too because sometimes we have children with significant cranial facial abnormalities. These are things that would harm them, in any physical sense, but they would be horribly harmed by the emotional trauma that they go through because in school other children are not kind to them. And we can greatly ameliorate that situation with surgery that, in fact, can be life-threatening.

So all of these things have things that you have to look at. You know, even the concept of giving one’s life for another. In the military, when someone throws themselves on a hand grenade to save their colleagues, they’re given a Medal of Honor. So why is it so different when somebody wants to give a portion of their body to save someone else? I just think it’s a big picture issue and when you try to just take one segment of it, it becomes more complex.

CHAIRMAN PELLEGRINO: Thank you very much. Dr. George.

PROF. GEORGE: Well, I hope that someone will try to assist with my proposal to seek a justification for living organ donation that does not involve what I’ve described as Leon’s startling conclusion that we accept that living organ donation violates the principle of medical ethics, but we should go ahead and be willing to violate it in certain cases because of the competing goods to be achieved.

But let me just say why I think there is a serious issue here. I guess this is sort of a response to Carl. I think I’m basically on Carl’s side, on the underlying substantive question of living organ donation as I gather Leon is. But I do think there is a serious issue here that really can’t be waved away. The ethic makes sense, I think for the reasons Gil articulated and others. That’s fundamentally why I would like to find a justification that doesn’t involve compromising it.

I don’t think it’s sufficient as a reply, Carl, to Diana’s challenge, to say that well, the operation of removing the healthy organ from the donor, is for the benefit of the sick. I think the reason that’s not responsive is that the operation with respect to the donor himself and in respect of his health only diminishes it.

So yes, you’re going to improve the health. That’s the whole objective and everybody here, the donor, the physician, everybody involved is collaborating toward that objective, is to improve the health, perhaps even save the life of the person for whom the donation will be made.

But with respect to the individual on whom the doctor is now laying hands, to remove the organ to be donated, I think it’s fair to say that his health is only diminished, maybe not much, but only diminished, unless — unless we’re willing to say what Leon rightly in my view wards us off of saying which is that well, his overall well-being is improved, his now being the donor, his overall well-being is improved because while his physical health might be damaged at least to some extent, that’s got to be taken as part of a whole package which includes the psychic, perhaps moral, perhaps spiritual betterment and achieving an objective that he himself has which is to make the donation.

I think Leon’s right not to want to go there with that expansive definition of well-being that would enable us to comfort ourselves by saying well, the physician actually isn’t doing any harm to the donor. He’s just providing a net benefit to the donor since the psychic and moral and spiritual betterment outweighs any damage to physical health.

I do think it’s important to reaffirm that the goal, the object, the justifying point of medicine is health. I think it’s also very important to reject any utilitarian approach to these questions which would try to justify the direct doing of harm by reference to an overall net advancement of some conception of a greater good. There are independent reasons I think that won’t work. I mean we can go into them if people want to argue about that.

So where does that leave us? Well, it either leaves us in Diana’s situation or Leon’s. I take the
difference to be that Leon is willing to compromise the medical, the principle of medical ethics and Diana is not willing to do that. Or, we need some other justification which is what I was trying to invite my colleagues to help me to construct that would enable us to say truthfully that there is no compromising of the traditional medical ethic despite the diminution of the health or the damaging of the health of the donor, not because the psychic benefits outweigh it, but because of something having to do with the common good of the donor and the person he will be benefitting which is advanced by the physicians assisting them in moving the kidney from donor to beneficiary.

As I say, I don’t know that such a justification is possible, but I think it's worth thinking about and trying to construct, trying to understand. Before we say that either we have to compromise the traditional principle of medical ethics or we’re going to turn our faces against, what strikes me intuitively is the very great and laudable practice of living organ donation.

CHAIRMAN PELLEGRINO: Thank you.

PROF. MEILAENDER: I want to make a number of points, some of them come back to take up some of Carl's comments and others move beyond and none of them as a real long point, but just various issues.

The point, true enough I guess, that Carl made that donation is within the range of risks that people take all the time, though true, doesn't seem to me to get at the kind of moral question one asks. We don’t just ask questions about range of risks, we ask about the kind of risk, is it the same kind of risk or not. That’s what we need to think through and that’s what all this talk about the body and the relation of the body itself is about, whether it’s the same kind of risk as increasing one’s commute. And I don’t actually think it is. I’m not trying to argue that it’s different right now, I’m just saying that that’s the question that would need to be answered. It’s not sufficient to show that statistically it might be about as risky as something else that we do.

Another one of your formulations, Carl, and I believe it’s true that the actual psychology of the donor is that they’re focused wholeheartedly on the good that they can do in the world. And God bless them, that’s a good thing, no doubt. But again, it’s by no means the only moral consideration.

If, in fact, you ever ran into a person whose sole moral consideration was the — was sort of the good that they can do in the world, they would be extraordinarily inhumane. You have to ask about how you do this good. Dickens had fun with purely philanthropic characters. So again, it’s one consideration, but it’s by no means the only kind of moral question that we ask ourselves.

I want to say one more word on the doctor being sort of devoted to the good of the patient and not regarding the patient with justice or resource for the good of others. I think even — for better or worse, and I mean there are complicated questions, but even in the practice of living donation, we can see that come out. We’re told that sometimes, for instance, doctors will say that a potential donor is not a good tissue match because of a sense whether on the basis of something fully articulated or only partly articulated, that this person has hesitations and reservations about actually doing it.

Now whether that’s the right way to handle that question, I don’t know and it’s not a very straightforward way to handle it, but it’s a sense that there’s a kind of a good owed to this particular person, even if some other good that they’d like to accomplish can’t come out of it. I think you can see it there and I think it does remain important, even if it’s not the only consideration.

One of the deeper issues that Carl raised was about altruism and sort of why be skeptical about people being altruistic. Actually, of course, there are a lot of reasons to be skeptical about altruism on many occasions, but this particular instance, why be skeptical about it. And it isn't so much, I think, I don’t think the issue here is being skeptical about it as wondering about what altruism does or does not justify.

If we’ve got five people here, all of whom could efficiently use one of my kidneys, and one of them is my daughter, I not only don’t think I have to randomize the choice among those five, I think I ought not randomize the choice among the five. That is to say I think there are certain kinds of special obligations that weigh in in a way that some sort of general altruism doesn’t. That’s why even Robby picked up Leon’s child/parent donation. Parent to child has a slightly different ring and is not quite the same.

I think one has to think through all these different kinds of things, not on the basis of just of some general altruism, but on the basis of particular relationships in which we stand and how those do or do not bind us.
And then the last thing I’d say, I mean I think Robby is not wrong to continue to press the point he's pressing and I’m not terribly persuaded that the move to a friendly, although ingenious that you tried at the start works, I think I would rather try to make the case on the basis of generosity, which his a word I like a little better than altruism in this context, but understanding it as a human generosity that does have limits, may have limits in terms of to whom it should be directed. Certainly has limits with respect to what organs it would be appropriate to use. That’s not unproblematic. It does teach us to sort of think with the body as just a thing that we use in some ways and so there are dangers in it.

It raises questions about the professional ethic, but the professional ethic of doctors like all professional ethics doesn’t exist entirely in a vacuum. It’s not the whole of the moral life. And so one could go to work on that. But if I were going to try to make the case, I think I’d make it on the basis of generosity, but a limited generosity appropriate to human beings who are embodied, who do stand in special relationships to particular people and therefore who have obligations of different kinds. That seems to me to be the better way to try to go.

CHAIRMAN PELLEGRINO: Okay. Professor George, you might want to respond.

PROF. GEORGE: Well, I just want to make sure that the recorder got the ingenious part.

(Laughter.)

PROF. GEORGE: Gil, I like the approach and I appreciate your taking up my suggestion that we try to think about a way to preserve the traditional medical ethics principles while justifying living organ donation. But I would want to hear a bit more and I’m very, very open to being persuaded on this. I’d want to hear a bit more about what it is about generosity, especially if it were abstracted from considerations of the common good of friends, again, in this Aristotelian sense, that would do the work of justification in an analysis that took as its starting point the problem created by the fact that the surgeon's operating on the donor does nothing but nothing but diminish or damage the health of the donor, at least nothing in respect of the health of the donor, but diminish it.

CHAIRMAN PELLEGRINO: Dr. Gomez-Lobo?

DR. GÓMEZ-LOBO: Let me take a stab at Robby's challenge. How about a simple-minded solution along these lines? I would say it is sometimes reasonable to give up a good, sometimes an important human good for the sake of another good. There are people, for instance, who renounce having children or having a family which is a very important good for the sake say of a task which requires them say to travel far and to dangerous places, something along those lines. So I would think the person who is a donor is someone who is giving up a very important good for the sake of very precise good of another person. That could be my first step.

Now the next step which is a troublesome one would be to say that there is a principle, a traditional principle of medical ethics to which, of course, I generally subscribe, but which governed the actions of physicians before the existence of transplants. I think that the care for the patient’s good, for my own patient, as a physician is I find very solid. But then I would like to say but it does not cover these new cases, so that a physician would not be held accountable by that principle to the action she's involved in now because what the physician would be doing would be pursuing the good of the recipient and would just engage in an action of well, instrumental action which would be an action of renunciation on the part of the donor.

PROF. LAWLER: Right. I’m not sure how this is good for the physician because physicians are here all about health, right? But of course, there are human goods higher than health like friendship, like moral virtue, the moral virtue of generosity. But the moral virtues and the common good sometimes conflict with health because they’re based on the opinion that health is not the highest thing, but it puts a physician in kind of a problem, right? Because as Diana pointed out, in order for me to exercise my moral virtue of generosity and give you my kidney, I require the assistance of the physician whose bottom line is health.

So as a physician, is a physician allowed to surrender the bottom line of health in order to facilitate my pursuit of moral virtue?

DR. GÓMEZ-LOBO: No, my point was precisely to describe the action as a pursuit of the health of the recipient.

PROF. LAWLER: But there are obvious limits to that, right? I can’t you my heart, we agree on this, right? But can the physician even recognize that? When treating me, can the physician take into account the health of someone else?
PROF. GEORGE: Alfonso, I think if we go down this road, we would probably be pressed to conclude, be forced to conclude logically, that there actually wouldn't be anything intrinsically wrong with someone donating a heart at the cost of his own life and there wouldn't be anything intrinsically wrong with a physician performing that operation. But we might nevertheless conclude while there's nothing intrinsically wrong with the act, it's an act that nevertheless should be prohibited because the social consequences of accepting it would be so grave as to put a lot of people at risk and perhaps also have deleterious effects on the medical profession and on individual doctors and so forth.

Maybe one thing we ought to get clear about in the argument when we use as the limiting case the donation, the possible donation of an organ like the heart where the donation result will result in death, maybe we should get clear on whether our opposition to that is based on the judgment that it is intrinsically wrong and as a matter of strict principle it would be wrong to do it, or based rather on a prudential judgment that it would be an unwise policy that would permit it.

DR. GÓMEZ-LOBO: I would stick to the strict principle. And the way of blocking the slippery slope there would be to say that the action of the physician and the extraction of the heart is killing, whereas the extraction of the kidney, it would not be.

PROF. GEORGE: I am not sure about that, Alfonso. The jumping on the grenade is not an act of suicide. Now the removal of the heart will result in death, just the way the jumping on the grenade will result in death, but the removing of the heart, the death that results from removing of the heart might be an instance of indirect killing, just as the jumping on the grenade is a case of indirect self-killing or indirect killing because after all, it's not part of your objective to get the person dead. In removing the heart, if miraculously the person continued to live, without the heart, you would have accomplished everything you set out to accomplish, the death not being necessary as part of what you're actually trying to achieve.

PROF. MEILAENDER: I'm not sure about the effect on that one, Robby. I don't think so. I think that — remember, the description of the act is not just what you want in some general sense, it's a description of the act itself or the intention understood in that way and I don't think that you're going to be able to conflate the heart excision with the kidney one.

PROF. GEORGE: Can you distinguish the jumping on the grenade then?

PROF. MEILAENDER: The death is not just the result of the act, it's the aim of the act.

PROF. GEORGE: That's not true in jumping on the grenade.

PROF. MEILAENDER: I agree with you on the grenade.

PROF. GEORGE: So what's the difference between the two cases?

PROF. MEILAENDER: Because all he's doing in jumping on the grenade is shielding his comrades with the foreseen result of death, if he has time to think about it which he probably doesn't. But what you're doing is you're aiming at the removal of the organ necessary to continue life.

PROF. SCHNEIDER: I still find myself baffled with need of help here. As I'm understanding the position at the moment, it sounds to me like the position that is simply based on an asserted definition. The physician is interested in the health of the physician's particular patient and health defined in a pretty physical sort of way. What I am trying to understand is why that is the definition of the physician's purpose we have to understand.

I do not understand it to be a correct description of the way that physicians actually act when they make decisions. Physicians make decisions about social welfare against their own patients' welfare — or at least perceived welfare — all the time. They have to make rationing kinds of decisions. They have to make decisions about the use of antibiotics that may seem to be beneficial to one patient and not beneficial to patients as a whole. So my question is why do we accept this definition? And should we accept this definition?

CHAIRMAN PELLEGRINO: Dr. Carson?

DR. CARSON: You know, going back to Robby's issue and distinguishing, I want to again bring up the example that I gave early on about the lawyer who was a C-1 quadriplegic who basically persuaded all of the reluctant medical profession to take away his life support and I think he was allowed to die. If, in fact, in his request for death he had decided that he wanted to give his heart to his daughter, I have a hard time distinguishing how that would be any different than just letting him
die, number one.

Number two, I know an awful lot of transplant surgeons and to be honest with you, when someone is willing to donate an organ, they don't go through a lot of philosophical machinations. They go through the standard let's check this patient out. Let's make sure there's no coercion. Let's make sure that they're medically sound and all of those things are done, but it does not become a big philosophical argument.

CHAIRMAN PELLEGRINO: Thank you. Anyone else?

PROF. GEORGE: Your footnote, Ed.

CHAIRMAN PELLEGRINO: The footnote is awfully long.

(Laughter.)

CHAIRMAN PELLEGRINO: It's a little bit like the footnotes in the Hamburg, that the Germans — for that, more footnote.

Just quickly, I have difficulty — Leon is not here, so I have difficulty criticizing the reasoning he put forth, so I'm reluctant to do that. All I would say is I think what's going through my mind is that the conclusion to do wrong so that good may come from it is an intutional feeling he has, I think is a very bad way to argue the case because if we go to intuition modifying a principle, then I think that's not a justification, number one.

Number two, I do believe it can be reconciled and some of you have already touched on this, but I would say the first principle of medical ethics is not *primum non nocere*. It is to the principle of beneficence, that is to say to act in the way that will benefit the patient most. We can justify that if you want.

Dr. Schneider, I've got reams of things I've written which I don't want to repeat here on the fact that I think there's a moral foundation for the precepts that bind us in medicine. It isn't a social construction. That's an inflammatory statement, I realize, but I think it can be done.

Not to waste time here, I think that we need to look at the good of the patient as something more than the medical good. I think that's the restriction on Leon's argument, that he's at the level of medical good only.

I think of four levels of the patient's good. The medical good is the lowest. The second is the patient's conception of what is good. The third is the good of the patient as a human being, the good for humans, as we know it in classical philosophy. And then the spiritual good, which is the highest good.

Now you can make arguments at the top three levels that you're doing good for the patient by taking a kidney, providing there's some proportionality between the risk and the good to be done. Autonomy of the patient does not mean that the physician has to do it. So you have the question then it's more complex than we've been talking about it here. A physician has to decide whether in fact it does fit his notion of the good of the patient.

So I think all these things need to be discussed and I don't want to take your time now. But for me, this act would be justifiable, largely in terms of the upper three levels of the good of the patient, rather than just the medical good and the physician is charged with more than just the medical good. That's a summarization of how I'd respond to it.

Yes?

PROF. LAWLER: What is it in the physician's training that allows the physician to discern the spiritual good of the patient?

What is it in the physician's training that allows a physician to be particularly good at discerning the spiritual good of the patient.

CHAIRMAN PELLEGRINO: They're not. The physician doesn't determine the spiritual good. The patient determines the spiritual good. But it is a fact from the good of the patient. So for an example, let's take the situation you brought up. There was a spiritual sect that said that one ought to donate kidneys. For that patient, that would be the highest good. If you take the Jehovah's Witness, the highest good for that person is not to have blood. It violates Books, I think it's 3 and 9, of Leviticus. We may or may not agree with that, but the patient sees that as his highest good, so
high that he will sacrifice his life. Now whether I do it or not is the autonomy of the physician. In
consideration of autonomy, ... the patient and the physician both have autonomy interacting.

So that spiritual good then is determined by the patient, however he wants to do that. I don't have to
go along with it, but I do have to respect the patient and not impose my will upon him.

PROF. LAWLER: But you as a physician still have to have spiritual knowledge just to know
whether or not the patient is nuts, right? In other words, you have to determine whether or not to go
along with it.

CHAIRMAN PELLEGRINO: No, no. That isn't a determination. The determination of whether I
think I am able to do that to maintain my own personal and professional integrity. That's the side of
the autonomy of the physician — to protect his or her professional and moral integrity. That's why
when you ask for assisted suicide I have to say, "No, I'm sorry. I can't do that."

PROF. LAWLER: Then in some deep way you might agree with Diana because it may be her
spiritual good to donate a kidney, but from the point of view of your autonomy as a physician, you
can't recognize that higher good because you still can't do her any harm.

CHAIRMAN PELLEGRINO: That's why I have to say no to the patient, but it's on the basis of a
principle, not the basis of intuition.

PROF. SCHNEIDER: May I add one more footnote to the footnote which is permissible in some
scholarly traditions?

(Laughter.)

PROF. SCHNEIDER: I was provoked by this constant reference to primum non nocere to go look
it up and see how ancient it is. In fact, it's hard to trace its usage in any kind of common discourse
about medicine until well into the 20th century. You can trace it back to Hippocrates in his non-oath
form. But it then seems to pretty much vanish from medical discourse until the late — mid to late
19th century where you get little shavings of it in that it enters more largely into discourse, into the
20th century. And it can't mean that a doctor can't do harm because doctors do harm in a large,
large proportion of their treatments. So it must mean harm in some other way and my own
suspicion is that it's simply good prudential advice to doctors to be a little careful.

CHAIRMAN PELLEGRINO: I think, and this is not the place to do it, I would argue with you
historically.

PROF. SCHNEIDER: I'd be happy to provide footnotes.

CHAIRMAN PELLEGRINO: I'm happy to provide them on the other side. No, but I think it is a
much taxed point, I would agree with that. But I think there's evidence on both sides.

PROF. GEORGE: Well, just for the record, I think another argument we need to have is over the
meaning of "do no harm." I would want to contest some points I think with both Dan and Carl about
the meaning of that.

CHAIRMAN PELLEGRINO: We are on the subject. It could go on and on and on.

Yes, please.

PROF. SCHAUB: Just a quick question that maybe one of the paper writers could answer. Can
individuals make a second or a third donation? In other words, could a kidney donor a year or so
later donate a liver or a lung?

CHAIRMAN PELLEGRINO: Does someone want to respond to that? I've been talking too much.

MS. GRUTERS: As far as I know that is possible, but again, they would have to go through the
donation process and dependent upon the donation center and the transplant surgeon who would be
willing to do that. Now with pancreas donation, partial pancreas donation, that usually is done with —
if someone needs a kidney, then someone can also donate part of their pancreas. That's becoming
less common according to statistics, but that is definitely the preferred method if there is going to be
a pancreatic transplant. So they would also donate one kidney and part of their pancreas and please,
any —

DR. CARSON: I can answer that.
MS. GRUTERS: Okay, wonderful.

DR. CARSON: What happens after the first donation is you have to go through the complete donation process for each subsequent organ and the fact that you've done any previous donations diminishes the likelihood that you're going to be accepted. So there are certain cases in which it happens, but in a large number of cases, it can't happen because you're placed in a different medical category.

PROF. SCHAUB: Why would it diminish the likelihood that you would be acceptable?

DR. CARSON: Because, for instance, if you've given a kidney, then you've already compromised your body's reserve. So —

PROF. SCHAUB: So there is an understanding that harm has been done to the donor?

DR. CARSON: There is an understanding that there's not as much reserve there as there was before.

PROF. MEILAENDER: And on some of the arguments we've followed, there's really no reason not to give a second kidney.

CHAIRMAN PELLEGRINO: Dr. Gomez-Lobo, last word?

DR. GÓMEZ-LOBO: Yes. Just a clarification, please on page seven, I was puzzled by the claim "it is also possible to donate all or part of the liver, lung, pancreas, intestine and heart." Can you actually donate part of the heart?

MS. GRUTERS: Yes. Now I don't understand the actual medical how they do that. There's very little literature that I've found that discussed it, but it's part of the heart. Is that correct?

DR. CARSON: Pericardial donation. But in terms of continuing to live other than the pericardium, you know, there's no donations that are done.

CHAIRMAN PELLEGRINO: Thank you all very much. We'll reassemble at 2 p.m.

(Whereupon, at 12:20 p.m., the meeting was recessed, to reconvene at 2:00 p.m.)

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SESSION 3: THE ETHICS OR ORGAN ALLOCATION

CHAIRMAN PELLEGRINO: Thank you very much for returning so promptly.

We will turn to the procedure we were using this morning of a paper having been prepared by the staff summarizing our positions, that is to say where we are chronologically rather than position. And the topic for this afternoon is the ethics of organ allocation and again, prepared by a member of the staff and the discussion will be open on this particular paper by Professor Alfonso Gómez-Lobo.

DR. GÓMEZ-LOBO: The excellent staff working paper provides a clear and well-organized information on the current system of organ allocation and the legal and ethical framework within which it functions.

The paper also describes the main ethical controversies surrounding the allocation policies and ends with a chapter on suggestions for inquiry and discussion on the part of the Council, so it gives us a task so to speak.

The backdrop against which the issues of organ allocation arise, of course, is scarcity. Demand outstrips supply. In the face of this fact, the U.S. has developed a legal system to assign available organs to the patients needing them. As the helpful appendix to the paper shows, the system is quite complex because it must take into account multiple variables. Allocations vary by organ, urgency, waiting time, blood type, compatibility factors, age and geography.

The expectation, however, is that the system will satisfy moral principles of utility and equity. The former entails that waste be avoided and benefits be maximized. Equity requires that the location be fair and just.

The working paper indicates, the demands of autonomy are all expected to be satisfied, that is, that the autonomous choices of donors be respected. The chief controversies arise in the interpretation and application of the principles, especially when conflicts seem inevitable, for example, when a fair
distribution appears to be inefficient or when maximization of benefits could be obtained by restricting autonomy.

Now what should the Council do? What would be the task for us? As I indicated, the paper makes some suggestions, namely in three areas where the Council from a national or federal perspective, so to speak, ranging above the states, could make significant contributions.

One would be the ethics of allocation by geographic proximity; the second one the ethics of directed donation and preferred status; and, third, the ethics of discretion exercised by physicians to promote the good of their individual patients.

However, discussing these three areas of concern makes sense, it seems to me, only if the broader context remains stable. If the donor rule is upheld while the neurological criteria to determine that are abandoned, the problems of allocation may change substantially if they’re abandoned at all.

The same is true, I believe, if a market system, even a limited one becomes socially and legally acceptable.

In my view, the weight of geography and allocation calls most obviously for a critical examination of this, the review. The wide disparities in waiting time in different jurisdictions for patients in a similar state of need seem to be unfair and hard to justify.

But in order to seriously consider the moral arguments on both sides of the issue, two points should be clarified ahead of time in my view. One is the extent to which geographical proximity was chosen because of viability of the organs, whether they really hold long distance transportation. In other words, one has to raise the question as transportation of harvested organs become efficient enough for it to be irrelevant whether a liver reaches New York City from New Jersey or from San Francisco.

A second point that should be examined in my opinion is whether the appeal to regional community in contrast with a tightly knit familial community is an idealization of virtually nonexistent relationships or is strong enough to carry moral weight of the debate. Preferred status raises, in turn, moral issues that directed donation, for instance, within the family does not and surely deserves to be examined.

Finally, clinician discretion, trying to improve the chances for transplantation of his or her personal patient is a matter of concern that calls for further refinement of objective criteria to guarantee equity, but I personally thought that the broad guidelines need to be changed or that there’s a major ethical problem.

Finally, my own inclination would be for the Council to take, as we have been doing, a broad view of transplantation as such, but of transplantation in an aging society and within that context I would suggest that we take a special view of the weight of age in organ allocation.

CHAIRMAN PELLEGRINO: Thank you very much, Dr. Gómez-Lobo.

Any questions? There must be some question about the paper. Content.

Gil, you look like you're moving toward the microphone? Thank you.

PROF. MEILAENDER: I think it caught us all by surprise because I was psychologically prepared for a second commentator before I had to, as it were—

CHAIRMAN PELLEGRINO: You had a footnote, right?

PROF. MEILAENDER: — think. Yes. I would just say two things. First, just to say I sort of stand in awe, Dan, of your ability to clarify the procedure here. What I don’t know is how the people who actually do it stay clear on what they’re doing, but that was very nicely done. Obviously, having gotten that, the crucial questions for us in some ways come later. And I was just wondering. I don’t know if we have a clear sense of the relative importance of these several questions, but the geography one which may be most people don’t — the geography sort of appeals to me in a way, although I was going to say most people don’t think it’s the most important of them, and for a reason that relates to some of the things, relates in a way to some of the things we talked about this morning.

If the issues are only the ones Alfonso focused on, just how efficiently can you transplant an organ, or transport an organ for a transplant from one location to another, that's one thing. But if the issues are is it — does it have to do with is it fair that those who live in one place should have a better chance than those who live in another to get an organ, then we're back to questions about whether we have sort of greater responsibilities to certain people, saying now those who live in proximity.
I like the Walzer stuff that you drew on. Or whether our responsibilities are just sort of universally distributed. And if universally distributed and if we for a moment just bracket the transport problems, if universally distributed, then it’s not quite even clear why national boundaries are supposed to make so much difference in this kind of case. So that whether others think it’s the most important question or not, I think it actually raises some very fundamental questions about the nature of moral obligation here, whether one has greater obligations to certain people or not.

And I have to say that in a case like this they’re quite puzzling questions actually.

CHAIRMAN PELLEGRINO: Alfonso?

DR. GÓMEZ-LOBO: Well, indeed, I saw that as a very serious problem, but let me be very candid about how I see it. I said there that I distinguish between the regional community and the tightly-knit familial community. To me, it seems that, of course, the obligation towards the family, the immediacy in that sense is out of the question. Of course, that’s there.

What I have serious doubts about is what I would call the idealization of community in 21st century America, because how would I put it? I just don’t see it. The fact that someone from New Jersey, from northern New Jersey would get a kidney from someone in southern New Jersey, I mean what community is there and why couldn’t someone in Oklahoma receive it? They don’t know each other. There isn’t much of a community anyhow, so either I have a total misperception of life in America today or I don’t quite get it.

Let me tell you, Gil, what my backdrop for this is. For instance, if someone said in Greece in the ‘50s, look people in this town should get preference, that makes total sense because people in rural towns in Greece did know each other. They went to school together. They did all of these things. So there, there is a real sense of community. In a country where or in regions where there’s a high turnover every year, let’s say because of labor opportunities, etcetera, it just doesn’t seem to me that the argument is as strong as it would be if you had these smaller communities where people do know each other.

CHAIRMAN PELLEGRINO: Peter.

PROF. LAWLER: I am perplexed by all of this, including those reasons, but in general, it’s hard to know what equity — I don’t think there’s any uncontroversial way of looking at this in terms of who is the most worthy and what’s the most equitable. For example, with respect to kidneys, you’re put on a waiting list and that seems fair, wait your turn. But it seems very unfair because the longer you wait, the more your health is debilitated and the less likely you are to actually benefit from the kidney.

So if we were all about prolonging lives and improving health, we would give a kidney as it becomes available to the first person, the most recent person to hit the list who’s probably the most healthy, the person who has not been debilitated by dialysis and so forth. Yet, that would be monstrously unfair to the good American from this or that community who has been waiting for years to get one.

I don’t know of any objective way to reconcile this. If your goal is to use public resources, if that’s what kidneys are, to maximize the health of the population, then, in fact, you should give them to the most healthy people who need them. On the other hand, you want to be equitable to all Americans, you should give it to the person who has waited the longest, who is probably pretty darn sick and may not benefit all that much. So how, in fact, do you resolve this?

CHAIRMAN PELLEGRINO: Dr. Eberstadt?

DR. EBERSTADT: To follow up on Peter’s comment, I was not sure whether my comments would be more appropriate for this session or the next one, but we’ve gotten into this part, why not here?

If you were to consult with literature described as health planning or with certain parts of the health economics literature, the criterion which might be suggested there would be some sort of measure of lives saved or health maximized. And there are different sorts of particulars that aren’t identical that could be offered there as utilitarian, actuarial sorts of criteria. And one would be actual episodes of death averted or what we call life saved. It’s really life continued or death postponed.

Another would be years of potential life maximized. There’s a rather highfalutin concept in health economics called DALY, Disability Adjusted Life Years, which is more obvious in theory than in practice, but it might also suggest as a sort of — a health planner might suggest a desideratum DALYs maximized in this sort of circumstance.
Is this sort of life expectancy or health expectancy maximization desideratum criterion which we should apply to these decisions or if is not the sort of criterion we should apply why shouldn’t we? I can see some arguments against it as well as for it, but if we’re going to make the arguments against it, I think we have to be pretty explicit because there’s an increasing presumption, at least in the economic side of literature, that this is the way we should focus on our observations.

CHAIRMAN PELLEGRINO: Alfonso?

DR. GÓMEZ-LOBO: Let me react very briefly. I think that from reading Dan Davis’ paper which taught me a lot, the reality is that people who have sat down to think about these things have taken all of that into account. In other words, the result is a very, very complex algorithm. It’s a system of points where different things are taken into account. And reading everything in good faith as I think I should, there is a genuine effort to meet demands of utility and to meet demands of equity.

And I personally could not improve of the system as it exists, nor I’m sure we could as a Council because I think a lot of experience and years of looking at statistics and availability of organs and times the graft survives, etcetera, have been taking a look at. It did seem to me, and there was a public debate on that which I became aware of through that, that geography was one of the last outstanding points where there was a genuine conflict.

In other words, once everything else is taken into account, you know need, prospects of years of survival, age, and all that, there still seems to be this great disparity between living here and living 30 miles north of here. The waiting times are just, you know, completely different. So that is the only point where at least I saw a moral question. I mean, is that acceptable or should efforts be made to factor this into the whole equation in such a way that the allocations become more equitable?

CHAIRMAN PELLEGRINO: Peter and Gil. Yes, I said Gil first.

PROF. MEILAENDER: I will come back, I want to come back to the utility/equity question that Peter raised. Although I’m still, I seem more sympathetic to the geographical difference, Alfonso. But I mean obviously it would be hard to argue either that one should only pay attention to the considerations of utility or that one should only pay attention to considerations of equity here. Although trying to do both does give us this very complex system that Dan sorted out.

But I don’t know, I think I would want to argue that in of what exactly this would mean for policy. I don’t know, we would have to think it through, but that in some way or another equity has priority over utility. If utility has priority, then we’re back to thinking our fundamental thought is here are these kidneys a public resource? And I think I just wish to resist that way of thinking about as the bottom line way of thinking about what is happening.

I wouldn’t deny that you cannot afford to pay no attention to considerations of utility. You can’t do things that just seem foolish finally and don’t seem to accomplish much of anything. But if one of these has a kind of prior claim on us, I think it’s equity and I think it’s got to do with the fact that there’s some reasons not to think about bodily organs just as a resource whose efficiency should be maximized.

CHAIRMAN PELLEGRINO: Peter?

PROF. LAWLER: I’m just going to agree with the last two comments. Number one, the system is hopelessly complex. I’m not sure I fully understand all these point things. This obviously evolved through experience taking equity and utility and geography into account. It’s unreasonable to expect perfect justice from it because you really do have competing claims for justice.

And insofar as you have to choose, you choose equity over utility because people have to trust this theory is fair. And if you want to cause people to think something is unfair, turn it over to economists who will think too abstractly about the resources or not enough about their particular people.

So I’m bothered by the geography thing. I’m not sure I understand fully why the disparity exists. It would be my own opinion that this is something our Council cannot address very effectively finally partly because the system ain’t that broke and partly because the whole thing is too complex, and not morally questionable but morally ambiguous or something for us to really be able to find out how to fix it, if it needs fixing which it doesn’t that much.

CHAIRMAN PELLEGRINO: Anyone else on this point?
PROF. GEORGE: This is going to be a blunt assertion. What if there were a national wait list for organs? Because right now the people are waiting, according to their regions, and according to their need if an organ shows up in a certain region, the most needed person in that region gets a first shot at it. If the surgeon rejects it, then it goes to the broader region and then even broader. But what some people argue is if you have a uniform list, assuming that transportation problems aren't there, then with a complex system of planes, you could possibly achieve more equity than the present system.

CHAIRMAN PELLEGRINO: Gil.

PROF. MEILAENDER: Just a quick question. Just as a purely theoretical matter, for a moment, granting that there might be all sorts of practical arguments involved, what would be your objection to an international system?

DR. GÓMEZ-LOBO: You know that I am very favorable to something like that. But, of course, we are here trying to deliberate about this polity and I would not like to overstep the boundaries of that polity.

CHAIRMAN PELLEGRINO: Peter?

PROF. LAWLER: But then you also say the regions aren't real, in a certain way. America is not a country divided into regions. But the country is real and in some deep, metaphysical way it's an arbitrary distinction. But wouldn't a global market just be unmanageable finally?

DR. GÓMEZ-LOBO: That is why it's Gilbert's fault to go into the global market. I don't want to go there. No, but within the U.S. it does not seem to me either impossible nor unreasonable to go for a national wait list. Now again, I'm going to speak from my experience. I've lived in four different states in the U.S., and I've never lived in Indiana and I think I have a much closer relationship with someone from Indiana than I have with many people who live, you know, forty yards from me.

CHAIRMAN PELLEGRINO: Bill Hurlbut and then Dr. Carson.

DR. CARSON: I think it is probably important to go back and look at some of the economics involved here because you know when an organ becomes available and it is distributed on the basis of first come first serve, regardless of the region, it requires a transport team for that organ, which can be quite an extensive organization. From getting that organ into the proper solutions and into a cooler, transport team. And I've seen these transport teams. They go through the airport in a limousine. I don't know why they need a limousine, but they do. Then a private jet. This stuff costs money. It costs all of us money. When someone in the same town who also needs an organ, but is lower on the list, you know, it's those kinds of policies that I think are driving us into the ground economically, and you know at some point there needs to be some logic injected into the whole argument.

CHAIRMAN PELLEGRINO: Dr. Schneider?

PROF. SCHNEIDER: This helps convince me that Peter is right, that for us to try to imagine what a sensible system was, even trying to fix the regional problem you can't do it without factoring into account all of the other issues. And even if we got it exactly right, the chances that the world would change enough to require a change in the system, reasonably soon afterwards, strike me as being pretty good. So I think Peter has spoken with the voice of wisdom.

CHAIRMAN PELLEGRINO: Anyone?

PROF. MEILAENDER: Well, then what would Council members -- let me start that over. Assuming that we're hoping to produce some kind of a report on this general matter that we're working on. What would Council members see us doing with the material gathered in this paper?

I thought it was very good in many ways, both just in terms of clarifying with respect to what we're doing and with respect to clarifying certain kinds of deep tensions built into what we're doing, not necessarily that we can overcome them, but that they're just there in a way. That all seemed to me to be useful. How would you use it? How would you use this material in some product that we produced?

CHAIRMAN PELLEGRINO: Dr. Schneider?
PROF. SCHNEIDER: Do we need to? I take it this is anticipating a little bit our discussion of tomorrow, but we have very limited resources and there are a lot of places where we could put those resources that I think might result in a genuine change in the way that the world works and an important change in the way the world works.

I agree that it's a valuable thing even just to clarify, but it's not at all clear to me that that's the best use of limited resources.

CHAIRMAN PELLEGRINO: Peter.

PROF. LAWLER: As a wise person, let me disagree just a little and say that maybe Gil is right. It's a wonderful right presenting a lot of useful information that on balance would cause you to trust the system we have more, precisely because as Alfonso says, there's a genuine effort to try to balance the conflicting claims to justice.

The system is imperfect. What system isn't? And I was against making any specific recommendations to improve it, but there's a lot to be said in making the nation aware of what we have now and why it is the system is the way it is now. And it's not horribly corrupt or unfair. It just embodies attentions that would have to be embodied between utility and equity and between efficiency and equity too. There is an argument for giving a kidney to the guy down the street because it's much cheaper and perhaps he would be more likely to benefit from it actually. And these problems don't go away. There's not some kind of theory of justice that would resolve all of these tensions.

So this part of the report, in my opinion, would be largely descriptive. This is what we have.

CHAIRMAN PELLEGRINO: Thank you. Alfonso?

DR. GÓMEZ-LOBO: Not to over elaborate, but there seem to be problems of inequity which perhaps could be solved taking into account the transportation issue in terms of preservation of the organ and cost. I'm certainly partial to taking a very close look at that. But I'm looking at the figures provided, for instance, one recent report found that the median waiting times for livers at one of the centers, we're talking about the State of Kentucky, was 38 days while there was 226 days at another. Or in the New York City metropolitan area, the median wait for liver transplant for patients with blood type O was 511 days in New York City versus 56 days in adjacent cities in New Jersey. So we're not talking about big distances, etcetera. But it seems to me, at least on the face of it that there seems to be a problem there and that there have been calls to face the problem in the past.

Dan knows more about this. So while — of course, the report is wonderful and presents a wonderful description of it. There may be some normative questions that it makes sense to address.

CHAIRMAN PELLEGRINO: Dan, do you want to make a point of clarification here?

DR. DAVIS: That's the reason I included this because the question about geography is unresolved. The final rule still stands. UNOS does have subcommittees for each type of organ that work on a continuous basis revising the allocation algorithm, just as you noted on the basis of outcomes data, etcetera. I know, for instance, that there is a proposal that's now on the table for revising the kidney allocation to include points for QALYs, Quality Adjusted Life Years. Now whether that goes forward, I don't know, but evidently that proposal will go to the Board of Directors.

What continues to be resisted is the mandate in the final rule which is not to produce a national list, but to reduce geographic inequity. And when you probe people as to why is that the case, usually what you learn is it's because of the political power of the transplant surgeons and certain OPOs. If we move toward that sort of system, the smaller OPOs will be disadvantaged and that collectively they have quite a bit of political power and they exert it.

And the argument that's usually made in favor of the current system that by allocating organs within particular localities, you give an inducement to donation, there's no empirical data whatsoever to back that up.

CHAIRMAN PELLEGRINO: Dr. Carson?

DR. CARSON: I actually have a question for you, Dan. Because I don't know if this is true or not. I saw it on a morning news show, so you know —

(Laughter.)

DR. CARSON: But they were saying that for organs, people on organ waiting lists that people in the
state penitentiary were at the top of the list. They got priority. Is that true and if so, why?

**DR. DAVIS:** I don't know if that's exactly true. I do know that UNOS has a policy of nondiscrimination against prisoners, so that would suggest that they could indeed make their way on to the list and if they're on the list, then they are going to be prioritized by the other criteria.

There have also been proposals that that not be the case, that if you were a prisoner, if you have been convicted of some felony, that you should not have access to transplantation.

**DR. FOSTER:** Just a local statement about this inequality, the difference between getting a kidney in Tarrant County in Fort Worth and Dallas is pretty enormous, so the biggest private hospital in Dallas, the mother hospital, the Baylor Hospital system opens a transplant service in the small town over the border of Tarrant for economic reasons because in most hospitals transplantation is the most profitable thing that is done.

I mean anywhere you go, Baylor Hospital I was talking about; Barnes Hospital, so this is an enormously profitable thing for a hospital to do. So they move a whole hospital program into Grapevine, Texas so that they can get kidneys five times faster or whatever it is now, than they can do 15 miles away in Dallas.

These things are very real. I don't know what you can do about it, but they certainly, the reason that you just said, there are political reasons why these things exist. They're not rational reasons why they exist.

**CHAIRMAN PELLEGRINO:** Dr. Schneider?

**PROF. SCHNEIDER:** Could I just ask then how feasible a national system would be, not just economically, but also medically? Because any system that's less than a national system I would suppose would encounter some very difficult line-drawing problems and you're always going to produce some inequities because whatever line you draw is going to produce some arbitrary results. So is this remotely a possibility of a national system?

**DR. DAVIS:** I don't know. We are going to be meeting on of Transplantation for Health Resources and Services Administration, who is the director of that division has been very much involved, in particular fight. He was the president of UNOS at one time and Federal Government. And that's one of the questions we want to ask them is where does this debate, as far as you're concerned now stand, and what is the viability — again not necessarily of moving toward a national system, I think we have to be careful there — but of reducing the geographic inequities that continue.

So I do think it's important to make that sort of distinction and we'll try to get some sort of answer to you. I'm not sure that the data exist to make that judgment, but we'll certainly find out.

**CHAIRMAN PELLEGRINO:** Gil?

**PROF. MEILAENDER:** Just to keep pressing the question a little bit, why would if not removing at least decreasing the geographic inequities in this instance be an important thing to do, a more important thing to do than reducing the inequities in funding of public school systems in states, for instance.

In other words, what makes this the kind of issue that should be treated more universally, more at a national or a federal level as opposed to a state level? Is there something that distinguishes it from say public funding for education, which is remarkably different from one state to the next?

**CHAIRMAN PELLEGRINO:** Alfonso.

**DR. GÓMEZ-LOBO:** I really don't know how to answer that. It seems to me, well, if there are inequities in other areas of public life, that does not make inequities in the next area justifiable.

**CHAIRMAN PELLEGRINO:** Dr. Schneider.

**PROF. SCHNEIDER:** If I understand the question, I think one part of the answer is if we're distinguishing between policies that are produced by state governments and the inequities that those produce, then we may be responding to the federalism problems that we talked a little bit about last time. Here, I take it is not a question of the authority of states to regulate their own populations, but a question of sub- and supra-state equity.

**CHAIRMAN PELLEGRINO:** Bill, Dr. Hurlbut.
DR. HURLBUT: Well, just an obvious comment, some practical issues like the size of the pool versus the probability of an immune compatible match. Also, the time of transport is relevant. Maybe Ben can clue us in a little better on some of the time issues involved in that, but they are certainly relevant, aren't they? Which by the way would probably make an international pool impractical.

DR. CARSON: I can just tell you, it's a multi, multi-hour process. Frequently, I've seen organs, for instance, go from Baltimore to Minnesota. It's a lot faster than, you know, the normal transportation system. There's no question about that.

(Laughter.)

You know, you don't have to get screened and stuff like that, because everything is done privately. So if it wasn't so much of a time factor that I was bringing up as it was the expense factor, which is you know beyond the pale.

CHAIRMAN PELLEGRINO: Other comments? Other issues besides the geography issue which has occupied a significant bit?

And I guess Gil's question of the allocation between transportation, let's say, education, other social needs, and transplant?

PROF. MEILAENDER: I will just do one more. I don't wish to press it, if I'm the only person that seems to feel the real tug of the limiting factors here. But take the physician digression issue, which we haven't said much about at all. If I needed a kidney and were willing to take a transplant, the question is to be decided there yet, but if I did, I'd really like my physician to, as it were, be strong and personal an advocate as possible for me.

That would seem to me to be part of what I wanted from that physician as physician. I have no objection to, you know, all of us as citizens or what else constructing a system that may constrain the physician in certain ways because we think that fairness requires it. But not only does physician digression seem to me to be a hard thing to really remove, I don't think it would be desirable to remove it either. So it's just another sort of particular factor, that I would at least want to see a certain virtue, and I think that's what when one of my kidneys is failing, that's what I'm looking for from the doctor.

CHAIRMAN PELLEGRINO: Thank you. Yes, Dr. Eberstadt.

DR. EBERSTADT: There is a great big elephant sitting over in that corner of the room. And that elephant's name is economic reasoning and market forces. Because like it or not, everything that we're talking about is conditioned by these two parts of our environment that are all around us like ether.

From an economic standpoint, as Alfonso mentioned at the very beginning of his eloquent remarks of the organ donation transplantation dilemma is described in economics as an economics of rationing situation.

In very first introductory lectures in economics, one is treated to the problems and inequities that rationing circumstances make for those who live in societies where rationing is imposed. Again, the introductory remedies that are offered are an increased introduction of market forces, market competition, and all of those other things which you know and appreciate.

In a small and immediate sense, one might expect more market forces or more market competition to reduce some of the geographic disparities that Peter was talking about. But that's not the greater game. That's possibly a play. That's not the elephant that's off in the corner of the room. The elephant in the corner of the room is the idea of a marketization or a commoditization of the prospect of an organ market in the United States or even as Richard Epstein was suggesting two sessions ago, a global market of the sort.

Now from a — again, from the desiderata or criteria of years of potential life lost or qualities or DALYs, one can imagine how that sort of a market in theory might reduce deaths or maximize life expectancy. But there are an awful lot of other things that would also come along with that sort of a market in theory.

And if I am correct that the forces of marketization in the world in which we live are pretty relentless at this point, that's part of the discussion which I think our Council could be very profitably applied to thinking about how this currently affects us, how this may affect us in the future, and of what the
CHAIRMAN PELLEGRINO: Thank you. Peter?

PROF. LAWLER: Well, I don’t agree that the market is a solution to this problem, but this problem is a problem because of the lack of a market requires us in a very un-American way to think about justice when we usually just leave these things to the market.

Right, so no doubt if there were a market in kidneys, I guess, these geographical disparities would take care of themselves in some way. But we can’t turn to that. So in a certain way, it’s remarkable how good the system is we have given the fact that we can’t rely on market forces to have these things kind of resolve themselves in some cases.

That leads to the other question that perhaps that we should leave to the next session, except it comes up at the very end of Dan’s paper. And that is to what extent here do we have a crisis? And then gives us a lesson, the meaning of the word, crisis and compares this crisis to — this alleged crisis to other crises like the Cuban Missile Crisis and hurricanes and such.

It’s really, I think, worth talking about. To what extent is this a crisis, right? Because in the absence of the technology, people would just die of kidney failure. And part of the crisis is the crisis of dialysis. You know, in a certain way I’m not endorsing it. But dying of kidney failure in a certain way is not as bad as deaths go. You MDs talk about that.

But, in fact, the crisis here is a crisis with expected kidneys engendered by huge numbers of people on dialysis waiting and hoping that they would be removed from dialysis. So the crisis is caused by, and again I am very sympathetic to those who don’t think this is a crisis like the Cuban Missile Crisis is a crisis, or even the crisis in health care is a crisis in general. But except to say that the perception of the crisis depends upon the things Dan talks about here in the end that we have this wonderful and very profitable technology, transplantation technology, that depends upon — and again, I don’t want to use the phrase natural resource. But it depends on natural materials.

There is a scarcity of natural materials and our perception of the crisis is the scarcity of the natural materials and a professor of economics most naturally would say well, one way to overcome these problems of scarcity is to introduce market forces.

And I’m not endorsing introducing market forces, but you could see how someone would say that. Once you buy the crisis thing, then the most obvious resolution is the introduction of the market forces to overcome the scarcity in the natural resource.

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

DR. EBERSTADT: Peter, I would say that the market forces are there like them or not. It’s just how they affect things.

PROF. LAWLER: In general, I like market forces. Not for everything.

DR. GÓMEZ-LOBO: One afterthought with regard to what Gil was suggesting a little bit earlier, the question of physician discretion. It seems to me, surely one would like one’s physician to do the best for oneself. But what we’re talking about here is actually the possibility of cheating. That is of putting people ahead on the list by claiming say a condition in the patient that the patient doesn’t have. So from the point of view of ethical thinking, I don’t think there’s a big problem here.

The main question here is that the system have clear guidelines that can be say more or less objectively checked so that that doesn’t happen. It seems to me that you know it’s a system that’s perfectible, but apparently already has good instances of control.

CHAIRMAN PELLEGRINO: Gil?

PROF. MEILAENDER: This is really more a question than specific-wise, because it has been a few days since I have read this. I didn’t think the issue turned simply on the questions of physicians cheating, did it? You set it up as distributive versus commutative justice, and no form of justice would involve cheating finally.

Now insofar as they were cheating, then it would beyond the pale. But no doubt there are lots of cases, I don’t know, there certainly are in other realms of life and there must be here when exactly one shades the interpretation of a patient’s condition cannot be said to be lying or cheating, but there are different ways of shading it that might make it seem more or less worse and make the person more or less eligible.
I was not endorsing, did not think I was endorsing cheating in wanting to take seriously the kind of physician discretion. But I think that once again that's part of the doctor-patient relation, that the doctor is in some ways an advocate, just as I would like my doctor to get a hospital bed for me if I need it, without denying that as citizens we have to make decisions about how many hospital beds we're going to have and maybe I'm not fortunate to get one, but I sure would like the doctor to try to get one.

Same thing here. That's all I was drawing out of this.

**DR. GÓMEZ-LOBO:** I had no doubt that that's what you meant.

**DR. FOSTER:** Well, I think in regard to your question, for example, you can only move up on a heart transplant list if you're in an intensive care unit. So one way, you know, if you've got really bad heart failure you're going to do better in an intensive care unit than you will be at home, no matter, instead of bouncing back and forth to the hospital, you'll do better.

So it's fairly common to see physicians do what may be arguably the best thing for their patient with end-stage fatal heart disease to put them in the ICU, but hiding in the background is also the knowledge that the only way that you can move up to get a heart is to be in the intensive care unit.

And I don't think you'd want to call that cheating, but not everybody is — if you're in a smaller town, there may not be an intensive care unit you could go into if you're in a 60-bed hospital or something.

The larger question here, I think that Peter oftentimes says these very wise things, I mean compared to the way the world is, this is not a crisis, okay. We've got 90,000 people and a significant number of them are alive on dialysis. They're not in immediate, they're not happy, I agree with that. They're not in the immediate form of death. What we're — I mean, what we have to say is and I think this is what Nick was saying here is that if you really want to increase the number of kidneys which is what we're really addressing here, because that's the bulk of people which are there, you're going to have to use a different system than what we have.

There's no way — I mean we already heard this at the last meeting or the time before that some hospitals, 70 percent of the brain dead donors give. Other places it's 50 percent, but at the most you're only going to double what you have from that.

So if you really want to do something about this from a medical standpoint for these people to have a better quality of life or to live longer and so forth, then as with any scarcity phenomenon you have to pay for it. I mean if people are worried about oil, they pay $3 for gas or it goes from 10 cents to whatever it is in Iraq right now. You've got scarcity to do that. And if you pay enough, you can get the organs, you know. I mean you can do that. I think Alfonso is not sure that even if we had a market system that you would do it, but it would drive up — there are people who are willing to pay huge amounts of money for certain things to happen.

So the only solution to the problem would be to as Mr. Epstein said to us is that you're going to have to pay for this. Now the consequences of that are multiple. If it moves to a really high level to get kidneys fast, then the rich will get them and the poor won't already. You can usually get a kidney for poor people, but you can't get a liver for poor people because it costs too much to do.

So that puts a problem into it as well. I mean totally apart from the fact that if you had a market system and you were able to pay for it for the poor, that might, in fact, help the poor because that might be the only chance that they would get a kidney.

I think the question really is, and we're just diddling around geographic things and all that. That's not going to have anything to do with this organ thing. The issue is you're either going to come for saying we're going to modify it, if you want to use that term, we're going to buy things and if it's not, the problem is not going to be solved. You'll just have to say we're going to live with this the way we do it and it's not so bad.

So in one fundamental sense, the Council has to decide whether they think this is an important enough issue to take a radical step, that is to say, as some people in the nephrology community do, we ought to do like we solve most other problems of scarcity, that we ought to go ahead and make it possible to make this available.

I'm not sure where I stand on this at all. When we first started this, I was hoping just to increase the brain-dead donors. I think there are a lot of issues as to both in terms of cost and fairness and so forth to do it, but that's the realistic question. I mean there's no point in dodging it. I mean why dodge it? The dodging question is whether or not we want to do something about organs or that the
nation should. Or is it an ethical demand for us to increase these organs? It may not be an ethical
demand. There are some things you just can’t do.

But I think that’s what we better settle. I don’t think that trying to redirect UNOS or something like
that is going to in the end mean anything. You could still write a great report saying this is where
things are and this is what the answers are, but we don’t think that you ought to take that. I think we
ought to deal with that and I don’t know that we’re ready to make that decision. We’ve got another
session coming up. I don’t know whether we’re going to make that decision or not. But that is what
I think we have to deal with.

CHAIRMAN PELLEGRINO: Dr. George?

PROF. GEORGE: I would be grateful if Nick could say a bit more about the way market forces
affect things under the current dispensation, the current scheme of regulations and norms. And in
particular, Nick, if you could indicate if there are any points just on the descriptive analysis. I’m not
asking whether you agree with Richard Epstein’s policy prescriptions, but we heard the fascinating
presentation he made and part of it was just descriptive about the role of market forces in the
current regime of regulation.

Do you agree with the description, is that uncontroversial among scientists and does the controversy
only come in when we move from the descriptive to the prescriptive or are there points on which
economists disagree amongst themselves descriptively?

DR. EBERSTADT: You can always get economists to disagree, but I would say that probably
descriptively the core insight that Richard Epstein brought to us two sessions ago was that a —
whatever you would call it, a marketization, a commoditization of organ donations and transplants
might bring a substantially greater supply of organs to the fore, to the situation.

He posited in his discussion, he did not prove, he posited that such marketization would have no
impact on the existing generosity or altruism of persons who are already involved. That’s an
empirical question, not one that can be posited. But I would think that that was probably the — that
would have been the central issue that economists would have noted in his description.

PROF. GEORGE: And is that the sort of thing that can be known with some degree of confidence
or is it just necessarily a guess because there’s no way to test it or do an experiment that would
enable us to reach a secure conclusion?

DR. EBERSTADT: I suppose in places like Iran and elsewhere there are on-going market
experiments which would provide some sort of very distant or in the case of China somewhat
appalling metrics to this.

I don’t know that one could —

PROF. GEORGE: It would have to be very distant indeed, wouldn’t it, just because generosity
would itself be colored by and influenced by so many cultural factors.

But is there a way — do we just have to go with Professor Epstein’s gut or with our own gut when it
comes to making a judgment about that or is there any way that our knowledge can be more secure?

DR. EBERSTADT: I think that if you asked different specialists in health economics, they might be
able to come up with some, if you will, some sort of proxy parallels to this or some other analogies
that might be informative without actually running the human experiment that we’re talking about.
It would, of course, be speculative. It would have to be speculative.

PROF. GEORGE: Do you yourself have a view on this? I realize you say it’s necessarily a
speculative one, but what’s your own, do you think Epstein’s probably right about that?

DR. EBERSTADT: My guess is that he’s — that in the descriptive sense, he’s right. I just don’t
have any idea of what the coefficients would be on any of that and let me also say, Robby, in talking
about market forces, market forces are always a tool. They should always be a tool for society as they
should not be the master of societies.

We know that in other areas there are things that we don’t commodify. We don’t sell our children.
We don’t sell people into slavery. The question is to what extent would economic reasoning and
market forces improve the objectives of society rather than dominate them?

CHAIRMAN PELLEGRINO: Thank you both for the comments. Bill? Dr. Hurlbut?
DR. HURLBUT: This may have been said before. I came in a little late from lunch, but this is a very broad comment, but it seems to me that one of the things that should be relevant to the allocation system is first the way we want to frame the nature of what we want to encourage by way of attitude towards donation. It seems to me that if the generosity concept is fundamental, then the kind of dialogue you were having earlier about the local environment makes more sense. Of course, that’s already happening with live donations, designated donations, but it could also play a role in the larger process of any kind of allocations.

It seems to me that as we’ve reflected on this subject for the last several meetings that one thing that keeps coming down to my mind is this intangible element that’s in the economics of all of this.

How can you best balance both the moral goods, the medical goods and the economic goods? Even if you were just trying to write a realistic equation without giving any priority to those, you still might come up with something that would put a very strong priority on the generosity factor in which case your allocation system might be somewhat different.

CHAIRMAN PELLEGRINO: Dr. Meilaender?

PROF. MEILAENDER: Just a very brief comment about sort of this material again, thinking about the conversations that have just taken place. It seems to me that as I think about what we might produce by way of a report, if we were to decline to endorse the notion of some kind of market in organs which I hope we would decline to endorse, but I don’t know, we’ve got to see what as a body we did. But just hypothetically, if we declined to endorse that, then that establishes the context for this material as not just a kind of clear explanation about what we’re doing right now, but why we’re forced into such a complex system, namely that another way of trying to solve an allocation problem that we use for all sorts of goods and services doesn’t seem acceptable here.

And so we not only — then it’s not only a sort of explanation of what the system is, but it clarifies why. We’ve been pushed to this complicated way of dealing with these several different kinds of moral considerations in allocation because in this particular case it seems inappropriate to buy and sell. And that, to me, I mean it just puts it in a context that would make sense of what this stuff is about.

CHAIRMAN PELLEGRINO: Further comments? Alfonso.

DR. GÓMEZ-LOBO: This is an information question. I don’t know if Dan or someone else can answer it. What do the waiting lists that are part of these so-called crises look like? In other words, is it the case that they’re being inhabited more and more by elderly people? In other words, is there an age distribution such that people waiting for organs are people of advanced age who thanks to modern medicine have not died of other illnesses before? Do we know anything about the distribution of the waiting lists? Because that would bring the crisis into a broader context, similar to what we did in the report on aging society.

DR. DAVIS: I don’t have the exact statistics, but I believe the bulge is in middle ages, not older and not younger, but 35 to 50 and 50 to 60-65.

DR. GÓMEZ-LOBO: Why do you think that is?

DR. DAVIS: The bulge is in the middle.

DR. FOSTER: In fact, you can get around it, but in heart transplant, there’s an upper limit of age in which you can — in which they will normally accept to doing. It’s not a real old age. It may have changed a little bit. The last time I looked at it, it was about 60 years, is that right, for hearts? I think 60 years. So you’re not talking about old people for hearts here. You’re talking — and it has to do also with — we were just talking at lunch.

I mean the longest, as far as — Tom Stossel, one of the great transplant surgeons out in Pittsburgh, has said recently that the longest kidney he had transplanted went 37 years and I’ve personally seen 32 years. They just wear out. It’s just entropy. They don’t get rejected. It’s not a rejection. But hearts don’t last that long. You’re talking about a few years, you know. Maybe five years or something like that. So there’s limit there.

I think the kidneys would be just as Dan said, but it’s not an old folks things here.

DR. DAVIS: I will clarify that for you, Alfonso, and distribute those statistics to you.

CHAIRMAN PELLEGRINO: Other questions or comments? Issues that haven’t been addressed
that this raises?

Why don’t we have — for once, we have more time than we have used, but I don’t think that means we need to go on. We can break a little earlier and return a little, say at 3:30. Is that acceptable?

Before I do that, let me just once more... are there further questions here? It's a very important issue and this infers big questions as you all know and have raised those questions.

Could I ask this, just for the moment, what part of the report, this summarization should we explore further? We've had a few suggestions. Have we exhausted your suggestions on where we need more data or need more consideration?

And a second question would be are we anywhere near this being some kind of a report or white paper or anything of that kind? I'm being a little provocative here, but I'd like to get your opinion.

PROF. MEILAENDER: I am only going to repeat myself, but I see this part of a larger project that would both explain what the current system is, but how I was thinking about this discussion between Peter and Robby and Nick and so forth that would help to clarify why one is forced into these impossible trade offs between utility and equity, for instance, and so forth, forced into it because if you've got a shortage of a desired resource and some other way of solving the shortage is ruled out, then you're stuck with these complicated questions.

It seems to me in that sense it would be a very useful part of a report. Whether we're going to have something more to say about the geography question that Alfonso is worried about or something, that I don't know.

DR. HURLBUT: Would it be reasonable to ask Eric and Dan to make some comments after working so hard on this what they see as the valuable ways to approach further discussion and what kind of report?

CHAIRMAN PELLEGRINO: No problem. Dan?

DR. DAVIS: I don't want to back off, but I think that question would be better posted after the next session because the next session is really the session where we lay out what's the current policy landscape and what are the proposals that are now on the table and I think we'll do a better job of responding to that question after that particular session.

So my suggestion would be that we postpone that.

CHAIRMAN PELLEGRINO: Postponed. Well, let's break and reassemble at 3:30.

(Off the record.)

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SESSION 4: ORGAN TRANSPLANTATION AND POLICY REFORM

CHAIRMAN PELLEGRINO: Our last session of the day is organ transplantation policies and policy reforms. This paper, like the others, reflects where we are from the point of view of the research being done and I invite you once again to think about the paper with reference not only to the content, but where do we go from here, given that the report, looking at the state of the question.

My mic isn't working. I hope they heard me. Peter is going to start the conversation.

PROF. LAWLER: Okay, first of all, let me praise the report, partly because it was excellent and partly because it was written largely by a graduate of Berry College and a former faculty member of Berry College who got the huge promotion to come up here.

And what I’m going to try to do is to give the political theory of the information presented in the report. So this report presents our current policy concerning organ donation and transplantation in terms of three standards we hold in common: health, freedom and dignity. These are the standards that guide our political life.

The first two standards, health and freedom, are at the heart of our legal tradition, the unalienable rights of life and liberty that we find in the Declaration of Independence. The place of the third standard, dignity, is real, but less clear.

When Leon Kass writes a book called *Life, Liberty and the Defense of Dignity*, we can't help but
notice he played with the text of the Declaration, replacing happiness’ pursuit with dignity’s defense.

But it is clear that our policies, the policies described in the report, are based on the premise that
dignity can limit and sometimes trump what we freely can do in pursuit of health.

So in pursuit of health, our policies facilitate and to some extent encourage organ donation. We have
the technology to transplant organs, but its effectiveness is limited by the number of organs
available, and there never are enough available. So our policies have many donation friendly
features and we’re increasingly open to more.

But if health were our only standard, we might well require citizens to donate organs to their fellow
citizens. We might, in fact, conscript organs, compelling, as the report speculates, that all healthy
young Americans participate in a kidney lottery to generate the 90,000 or so healthy kidneys that we
would need to take care of everyone on the waiting list. We know we sometimes have to conscript
young citizens to defend our health and safety through war.

If we can conscript whole, human beings, why not just kidneys? But, in fact, we don’t conscript
kidneys, either living or dead. Even when the citizen clearly doesn’t really need the kidney at all
anymore. So we don’t regard organ donation as a duty of citizens. Freedom for us trumps health.

Respect for the free choices of individuals and families diminishes the number of kidneys available,
for example, for transplant.

People may donate their kidneys and other organs, but they don’t have to. And the default position
basically is that consent can’t be presumed. People aren’t even commanded to decide for or against
the donation of their organs at death. They are free to leave that decision to their families or not to
be made at all.

Sometimes a principle seems to be my kidney is my property to be disposed of as I or my family sees
fit. But in fact, our law does not understand my kidney is my property to deal with as I please. I can
and to some extent am encouraged to give one away. The law in some cases is in the process
apparently of removing disincentives to donation, through for example, time off with pay.
Occasionally, I’ve found out from the report, we might even be honored publicly, say with a medal,
for selfless service to others.

But nobody, of course, would donate a kidney just to get a paid vacation or pick up a medal. But
what we really think is no one acting either publicly or privately can make my kidney donation worth
my while or not really a donation at all. So the premise of our law is that the offense against my
dignity that would lead me to think of my allegedly surplus kidney, or even my cadaver kidney, in
terms of its net worth in dollars is so great in the defense against dignity, that it trumps health and

freedom.

Our law concludes that maximizing the number of lives saved or restored to health is meaningless if
it is at the expense of what gives dignified meaning to human life. So the understanding of freedom
that guides our organ donation policy turns out to be the one Gil favors. The very old-fashioned
one. It identifies freedom with dignified liberality or generosity with the freedom of moral virtue.

Our law commands even against our individual rights of life and liberty that what may be given may
not be sold. Today, there is increasing pressure on us to think of that old-fashioned defense of
dignity, of virtue, as a cruel, irrational prejudice. The pressure is on to transform our law to allow for
a regulated market in the sale of live, seemingly surplus kidneys.

And the two challenges to our accepted understanding of our dignity come from, of course, health
and freedom; our need to for health and our right to liberty. Let me talk about each of those just for
a second.

First, health. The number of people on the waiting list for kidneys is increasing rapidly, much more
rapidly than the number of kidneys conceivably available from cadavers or as uncompensated gifts
from live donors. So as Dan said, we’re kind of diddling if we just kind of concentrate on picking that
number up a little.

The truth is people are needlessly suffering on dialysis and dying prematurely because kidneys aren’t
available. For more and more of them, the wait is hopelessly long. The technology to extend and
improve the quality of these people’s lives is getting better, but it still depends on the scarce natural
material.

Not to use market forces to increase kidney supply, the argument goes, is, how can I put it, is pro-
death. In this respect, market kidneys are — the market forces are in fact pro-life.
And the other argument goes something like this. Our understanding of liberty is changing. Our country is getting more and more libertarian. The Supreme Court said in the case *Lawrence v. Texas* that what our necessary and proper limits to liberty to one generation are, in fact, offenses against liberty to the next.

So the history of our country is the history of perfecting our understanding of the free individual.

So the argument that we've never allowed a market in kidneys is somewhat unpersuasive to us because of this constitutional view that liberty changes. Liberty deepens over time. So if you think about health, this alleged scarcity of kidneys, this alleged crisis, and if you think about evolving and increasingly libertarian view of liberty, clearly the fact that we've never had a kidney market before is seen not as a argument. If we're not going to have a kidney market, we have to give an argument on behalf of dignity. An argument so powerful that it trumps both health and liberty to some extent.

Now Leon Kass and the powerful message that he sent us about this report said that the pressure is so great that the only alternative is to find another way of dealing with end-stage renal disease. And surely someday there will be another way. Xenotransplantation, regenerative medicine. I mean, who knows? But that day, the coming of that day is pretty unpredictable. So the big question is what do we do now when we're stuck with a growing number of people on dialysis and we seem to be stuck with an understanding of liberty that allows market forces to go places market forces have never gone before.

I'm not endorsing a system that would allow me to count my kidneys as part of my net worth in dollars. But I'm saying it's going to be harder and harder to resist it and if we're going to resist it, we're really going to have to give a powerful argument. Thanks.

**CHAIRMAN PELLEGRINO:** Thank you, Peter. Anyone want to get into a discussion?

Robby? I'm sorry. Dr. Bloom, sorry. Well, one of you has to go first. Robby, you go.

**PROF. GEORGE:** I was pointing at Floyd. I didn't think you had noticed. It wasn't my hand in the air.

**CHAIRMAN PELLEGRINO:** Okay.

**DR. BLOOM:** I would just like to bring up a point we brought up when we discussed this at the last meeting and two meetings ago. As long as we're in the crisis mode of thinking about the growing gap between the need and supply of organs to be replaced, we're eliminating a large fraction of what we could do as scientists in the 21st century.

We understand that many of the causes of end stage nephropathy that require the kidneys to be replaced are controllable, medical illnesses for which the person's health liberty has allowed them to avoid their responsibility for health maintenance and physician care.

As long as we limit our policy recommendations to dealing with just the gap between the need and the supply, we're eliminating those alternatives that Peter loosely referred to.

Regenerative medicine is one, but preventative medicine is one that we have known about for years and which the country has refused really to take any credence for. So a large part of this growing gap is, in principle, controllable, but with a great deal of lag time because we have to implement that in a way that is serious. But to get serious about this, we need to get serious about the other half as well.

**CHAIRMAN PELLEGRINO:** Thank you. Peter.

**PROF. LAWLER:** Now there is a lot of wisdom in that, and once again I want to endorse for others preventative medicine.

(Laughter.)

Except to say this, in our book last time, our briefing book, there was this letter from Ben Hippen who denied that preventative medicine really would do much to solve this problem. It's true that preventative medicine, an aggressive program for preventive medicine, would save many people from the consequences of diabetes, which includes kidney failure.

On the other hand, to some extent, perhaps, our long list of people needing kidneys comes from the success of our medical system. And here I'm going into deep waters because I'm not an M.D., but it
seems to me that something like this is happening, too. More people are experiencing kidney failure precisely because of the success of our heart treatments. The natural thing for someone with high blood pressure or kidney disease, and Dan correct me if I’m wrong, to do would be to die of a heart attack or a stroke.

But now we have statins. We have very effective blood pressure medications. So isn't it the case that precisely because of some of our preventive medicine, more and more people will go all the way to end-stage renal failure. So what Floyd says is good, but I remind you that Ben denied that this would really make much of a difference at the end of the day. The list will still get longer.

The list will get longer partly because of the failure of our preventive medical system. But it will get longer partly because of the success of our medical system that's producing an aging population.


PROF. GEORGE: Now my hand is in the air.

CHAIRMAN PELLEGRINO: Okay, now you want to go.

PROF. GEORGE: Nick, can I put you on the spot again as our resident economist?

It would certainly be a little easier for me; it's not as if s can be made to go away for reasons that Peter indicated, but it would be for me to assess, do my own assessment at least of the ethics of moving, if I knew with greater confidence what the social consequences would be. And I'm just not clear what they would be and I'm economists can and cannot tell us with confidence, or any other wise who is involved in the business of trying to predict consequences of policy change, what we can know with confidence and what we just can't know and therefore would have to speculate about going into the system.

Now I gather that one thing that people agree on is that the number of organs available would increase. Dan said that today I think and Richard Epstein plainly was asserting that. Is that one thing we know for sure? If the market will just make that happen. It's just what markets do.

DR. EBERSTADT: If this market is like other markets previously known, that's what we would expect to have happen.

PROF. GEORGE: Now is there any reason to think this market is not like other markets we have known?

DR. EBERSTADT: Well, the qualification there that I can think of off the top of my head, and others may have other qualifications, would have to do with the substitutability between the impulse of generosity in kind of a commoditization of supply. One would, if you had some — if you had some extraordinarily unusual, but I suppose not theoretically impossible consequence where the commoditization of organ, this organ market, drove out all of the generosity based supply, then possibly you could end up with a lower supply until you got to certain price levels. But that's kind of searching for kind of contrarian answers.

PROF. GEORGE: You don't think that there's much of chance that that would actually happen. You're quite confident that that would not happen, that we'd have the opposite result which is more organs available?

DR. EBERSTADT: I think that would be the first premise. I think certainly the working hypothesis would be that the supply would increase.

PROF. GEORGE: Okay, and having in mind the various — oh Dan, did you want to come in on that point?

DR. FOSTER: Just in passing, one of the things I've thought about, I'm not absolutely sure that this would increase it, I think the arguments are likely.

But one thing that might actually happen is there are a lot of people to use Gil's term generosity, let's say for a gift to somebody that was not family and so forth, but thought that that was sort of a humane thing to do, that they wanted to pay back the country, or pay back God, or whatever motive they said.

It's conceivable to me that then adding onto that payment might, in fact, be the extra ounce on the decision to go. So I think it's possible that instead of decreasing the gifts that now go on, it would increase that. You know, let's say you go to church, Robby, and so forth and somebody, you know,
your church wants to feed the poor and so forth. But they're also wanting you to give more money to the budget and so forth.

You might and, in fact, get two things done. You give more money and then you always want to feed the poor. I think that a financial incentive might make the difference of a donor among us. I don't know that, but I suspect that you'll have two forces because we already know that the number of people who are offering their kidneys to people that they don't know has been increasing. It's not a huge number, but I think we're doing it. So I think that might happen, but I don't think anybody can answer the question for sure what's going to happen.

You know, you might build a car that looks like the best thing in the world. The Edsel, yes. You built an Edsel and everybody that was going to take over the car market, and it was just a flop. You know?

PROF. SCHNEIDER: Sorry, I wanted to add to that in a couple of ways. First, I think that one thing that is very likely to be a disincentive to donate now is that it's a very costly thing to do, that you lose four, six, eight weeks of income and possibly more than that. And that's something that most people can't afford to do.

So it might well be that instead of thinking that you have a market here, is that what you have is just a reimbursement of costs that were previously preventing people from donating.

The other thing that I think makes it very hard to answer your question is that we're kind of acting as though there were such a thing as a market and the market would work in the usual sort of way.

We're obviously talking about a very highly regulated market here. And the nature of the regulation will determine an awful lot of the questions.

PROF. GEORGE: Thanks, Carl. That actually leads right to my next question, which is having in mind the various protective mechanisms, regulations for protecting against exploitation that have been proposed by people who are favorable toward the idea of a market. What can we know with any confidence about the efficacy of those regulations?

In other words, could we go forward in a market with confidence that we would have protections against exploitation that really would work. And would work in such a way as to not impede the functioning of the market to produce a greater supply of organs, the point Carl was just talking about.

What do we know and what's really speculative?

DR. EBERSTADT: What we know is that any sort of market or regulated market solution like the existing market arrangements, and we can call them a market. They don't just work like ordinary markets. It's a rationed market. They always have inadvertent consequences.

So really, Robby, I think you put your finger on it what we want to think through is what some of the inadvertent consequences of that form of marketization would be.

I haven't worked those through myself, but I think that's what we would have to be alert to.

PROF. GEORGE: Is there a good body of literature on this? Have these questions been debated? I know, obviously, Professor Epstein has written on the subject. We read some of his work. Perhaps the staff could pull together for us or even out of the bibliographical materials we have. What's that? Yes. Well, I think that would be obviously something useful to have.

CHAIRMAN PELLEGRINO: Your point, Gil? Bill Hurlbut is ahead of you, but —

DR. FOSTER: Could I just comment on this last thing that Carl said? There's no doubt that this will be a regulated market. If you go back, you may remember in the National Commission, when one of the issues that they talked about was the doing research with prisoners, and it turns out a remarkable thing. Everybody thought that prisoners would be taken advantage of if they did risk research. And these are all in the reports and so forth, but when you visited the prisons, one of the things that was most apparent was that prison is really complete boredom.

And it turns out that the prisoners were very excited, in general, to want to participate in research. In the first place, it would probably keep them out of washing clothes and a variety of other things. But the National Commission discussed this: Would this be taking advantage of prisoners to have them participate in medical research?
And so what they ended up doing was saying that well, you couldn’t pay a prisoner more to participate in research or relatively as much as you did if Pfizer was going to do a trial in your medical school or whatever. In other words, the prisoners were basically, that you had to give it at least as much to the prison for that. I said that wrong. At least as much because the prisoners would probably have done it for free, you know, just to do it. But it had to be regulated because it looked like it might be a disadvantage, you know, taking advantage of the prisoners to do that.

So there will be — I think many — I talked this week relative to this thing to one of the members of the Commission. There was a huge argument about this, you know, and some people thought that just Robby — what people ought to do, they’re free to do, whether they’re in prison or whatever they want to do, but it will be tightly regulated and that might also be one of the main things that would keep it from — if you put a maximum amount of what you would pay, then it’s not likely that it would go as much as if you let the market itself decide it would be.

I think that’s one of the things that I worry about is this regulation here, even if you decided to do it and yet none of us would want it to be done without rigid regulation, I think.

CHAIRMAN PELLEGRINO: Dr. Hurlbut?

DR. HURLBUT: With regard to Dan’s comment earlier, we had a testimony in a meeting before this from a woman who said that had there been a system of commercial inducements, payment for kidneys, she wouldn’t have given hers. And there’s the other side of that. And I talked with her afterwards and I actually found her statement fairly compelling, that she said I wouldn’t want — I wouldn’t feel the same about it and second, I wouldn’t want people to look at me and think that I gave my kidney just for money. And she said it would besmirch all those who did it without getting paid and therefore would decrease certain portions of the pool also.

And I was thinking about this week because I read somewhere or another, I think the figure was there were last year 14,000 egg donations in the IVF industry and I remember in the early years when women were donating eggs, there was a sense of kind of altruistic calling or generosity to help other women have children. And now when I think about eggs, people being super-ovulated for their eggs, and I think most of us now think of it as a commercial operation because it’s gotten the news from the embryonic stem cell thing and if feels very different to me now when I hear about somebody being super-ovulated to give eggs.

And you can just feel how these things change when the commercial equation enters the thing in a disproportionate way. So I don’t know how you would measure that.

Nick, have you got any ideas on how you would even evaluate such a factor in talking — talking purely pragmatically here.

DR. EBERSTADT: There is a whole set of techniques in market research that can possibly be applied in surveys and things like that, that’s one way. There are probably other ways I’m not thinking of off the top of my head, but since it’s not an experiment one is actually doing it’s inescapably speculative in the final analysis. You don’t know if the rubber were ever to hit the road, whether any of your survey estimates would comport with reality.

CHAIRMAN PELLEGRINO: Dr. Hurlbut?

DR. HURLBUT: You know, it seems to me — I may have said this last meeting, but you don’t want to over-coerce people in any way. The commercialization, you probably have all seen these television documentaries on these matters of women in India selling their kidneys and some of them are really horrifying to see because you know very well that wasn’t a completely uncoerced donation. And in some cases anyway. I don’t want to generalize, but you get the point.

It wouldn’t be in our civilization either. And the things for which people feel the need to gain money or even gain a break from their work might not be the right motivation for this whole field, this whole approach.

And the other side of the thing is it just strikes me that before one ventures into such a territory, one ought to explore more thoroughly that an increase of the efforts to increase the awareness and altruism, for example, a really good compelling movie out of Hollywood about donation might do a lot. Of course, that could be coercive too, so you have to be very careful not to hyper-idealize something.

On the other hand, this is a — there’s a certain beauty to this when done in the right spirit and I think
that we sometimes under-estimate the power of really good and beautiful motives in our civilization and the commercial thing would pollute that really fast.

So for whatever it is worth.

**PROF. LAWLER:** I think that Robby's point is well taken. In fact, we don't know how it would work out, but Dan said in the previous section, on the other hand, we really don't believe that all the proposed reforms to increase donation really would produce that many more kidneys either. And so in order to resist commercialization we have to be fairly okay with a shortage and a fairly long waiting list, maybe an increasingly long waiting list.

On the other hand, when Ben Hippen presented his idea of the regulated market, it really was something like this. It sounded almost too benign. Right now we have the entitlement for dialysis. It costs the government well over $100,000 a year for each person on dialysis, so Medicare can quite reasonably and do the taxpayers a great favor by paying $75,000 per kidney which seems like a pretty impressive price, so it's not really much of a market. It's not really a regulated market. It's a market premised in entitlement.

Now here's what I would fear among many other things. Increasingly aging population, we may not be able to afford Medicare forever, but we will have become used to a market in kidneys and in the absence of the Medicare entitlement propping the price up in a global market, what would kidneys be worth then? I can't help but think the kidney price would plummet.

**CHAIRMAN PELLEGRINO:** Dr. Carson?

**DR. CARSON:** I am going to ask a very politically incorrect question here. I haven't really formulated an answer myself, but you know in the automobile industry insurance rates are based upon how people drive. Now in this organ donation market place, I see into the foreseeable future a disproportion of people who need them versus available organs.

The question is like the automobile industry, I wonder if things should be taken into consideration such as individuals who have led a deliberately destructive lifestyle and have therefore ended up in a situation where they need an organ, should they have the same right to that organ as someone who is in that circumstance through no fault of their own?

**PROF. GEORGE:** That is really a politically incorrect question, but thanks for putting it on the table. We should discuss it.

**CHAIRMAN PELLEGRINO:** Gil?

**PROF. MEILAENDER:** The Council will obviously discuss whatever it wishes to discuss, but I'd like to try to re-direct the discussion just a little bit. Ben's point was actually on a different issue, because we've mostly been talking about market in organs. And I don't think we'll end up turning in that direction. I hope we don't end up turning in that direction because I think it would be wrong and it would certainly, I'd rather save myself the trouble of writing a long dissenting personal statement.

(Laughter.)

But I just point out that it's only if we don't turn in that direction that all sorts of things in this staff paper on board for this session become relevant to talk about. And the last section too, in fact. I mean if you just say get a market in organs, we don't have to talk, worry about allocation, we handle it in a different sort of way. Similarly here. Now there are some things discussed in this staff paper that would seem to me for one reason, for different sorts of reasons to be kind of beyond the pale.

I'm not really prepared to endorse organ conscription, for instance or for very different reasons, I'm not a big fan of public honors for organ donors which was the Mister Rogers approach to organ donation.

But I just want to point out that if we don't endorse a market, there are all sorts of things here that need our attention. Floyd did mention the prevention issue already as one, but presumed consent, it's not like organ conscription, that's not beyond the pale in my way of thinking. It's something you could talk about, for instance.

The question about — that we dealt with in previous session about criteria for determining death would be important insofar as that has ramifications on the supply of organs.

The notion of preferred status for those who have already donated. The notion of paired exchanges
which is an exchange of a way, although not precisely a market mechanism or maybe not precisely a market mechanism. It seems to me some of those don’t seem to me to need a lot of discussion. I don’t feel a need for a long discussion about organ conscription as I said, but some of the others seem to me to merit thought.

I have no idea what the rest of you think about many of them and I just think at least with some of them it might be good for us to pursue them a little bit, though of course, I could be entirely wrong and we could end up just recommending a market in organs and making these issues irrelevant. But if we don’t do that, some of these issues are relevant and it would be good to push on them a little bit.

CHAIRMAN PELLEGRINO: Thank you.

DR. GÓMEZ-LOBO: Fate has it that Gil said a number of things I wanted to say, but what can you do?

In fact, I started to become worried about the creeping acceptance of markets when we haven’t explored other alternatives. I recall that Professor Veatch when he spoke to us talked about the nuclear option. I think he referred to conscription really, but not to the Spanish presumed consent. In fact, something like that is worth exploring because insofar as you’re free to opt out of it or with the Swedish system, insofar as you exercise your free choice of staying in and out, some of the worrisome or the main worrisome problem with conscription just evaporates and again, this is all very tentative, but I would feel a lot more comfortable with presumed consent than with initiating a market no matter how deeply regulated.

My main worry about markets is the fact that since we’re not placed equally in the marketplace, those who come into it in a disfavorable position in a way, although apparently they’re making free choices. I think they’re being really compelled — I’ve seen this very clearly in the labor market, so whereas it seems to me that the kind of presumed consent in which you could opt out it would be I think fairly simple and easy to explain exactly what you’re doing when you opt out, that that would be vastly more acceptable than the market solution. That would be, of course, for cadaveric donation, but given the amount of people who die every year, it seems to me that there’s chances that the supply would or that there may be some empirical evidence that the supply may rise dramatically.

CHAIRMAN PELLEGRINO: Professor George?

PROF. GEORGE: Well, the concern that I have, especially after the very helpful responses I’ve gotten from Nick to my questions really have to do with the unpredictability of consequences of moving to a market system.

Now, of course, a proponent of the market system might very well respond by saying well, there are some things we know with certainty and that is under the current system we have a lot of people who are suffering and dying and who need to be helped and weighed out against the certainty and go forward. But I am worried about the unpredictable consequences.

Now I want to put on the table some worries about some consequences that are even more intangible and therefore I won’t even subject Nick to questioning about them because I know how unpredictable they are.

Here’s how one might think about them. We know that our understandings of ourselves, of the value and dignity of ourselves as human beings, of valuable institutions that we form to achieve our goals and to realize fundamental forms of human good are affected by social norms, they’re shaped by social norms, those understandings and expectations can vary from culture to culture depending upon the norms that are in place in the culture. Those norms themselves can be shaped, very often will be shaped, sometimes shaped rather quickly, sometimes misshapen, by laws and policies. What’s forbidden, what’s permitted, what is encouraged, what is discouraged by law and public policy.

So the worry — the really deep worries I have, have to do with how moving to a market in organs might affect our understanding of ourselves as embodied creatures and our understanding of the relationship of ourselves to our bodies, our understanding of our own bodiliness.

We know, for example, that people's understanding of the meaning of their sexuality can be altered significantly by the acceptance or rejection of say the commercialization of sex in a culture, so that when prostitution is legalized, at least in some circumstances that will result in change, alterations of attitudes toward sexuality and toward marriage and family and so forth. And we can debate whether
those changes are good or bad, whether they represent a diminution in our sense of human dignity or whether they represent a kind of liberation from outmoded social norms. People debate those sorts of things.

What I think is less debatable is the question whether changes, in fact, occur; whether changes in social norms which are themselves the fruit of changes in legal norms and policies alter people’s understandings of themselves and of their relationship with others and valuable social institutions such as marriage and the family.

So my deepest problem, my deepest worry about the move to a market in organs is the unpredictability of the consequences at that level, that is, the unpredictability of the consequences for our own self-understanding.

DR. CARSON: The whole concept of markets for organs for some reason just doesn’t seem correct to me. It doesn’t mean it’s not correct, but it doesn’t seem correct to me.

I wonder if it would be prudent to try to think of ways to get people to think about the value of an organ that they would donate to someone else by thinking about how valuable the organ is to themselves. And what I mean by that is enacting some type of a policy where you simply say no one has to donate organs, so like is it Spain I think — no Sweden, in Sweden where the government has actually asked you to decide one way or another will you be a donor or will you not be a donor. But then it stops at that point.

And I think maybe it should be taken one step further than that. You say you don’t have to be a donor, but if you decide you’re not going to be a donor, then you’ll not be eligible to receive an organ either. I think if you do that, it starts making people think about how valuable those organs actually could be to them and they also then begin to think about it.

CHAIRMAN PELLEGRINO: Any questions? Dr. Hurlbut.

DR. HURLBUT: Just to add one more layer on what Robby said, in my medical experience and I’d like to hear what Dan thinks on this, I’m continuously aware of how the realm of medical matters is different than many other areas of human existence and one of the things that strikes me, as I reflect on my experience in clinical medicine is what an intrinsically moral realm it is. Patients come into the hospital and even if they’re in there for something that isn’t highly significant for their future life, they’re suddenly aware of something of large realms of reality, at least they’re aware of their own mortality, even if they’re not there with a fatal disease.

We wear white coats. That’s quite different than wearing plaid coats or something like that. There’s an intrinsic purity in medicine. There’s — medicine is a realm of part of our national identity or cultural identity. It is a noble realm. And I think my sense of watching people’s response to their own medical experiences including some of the more edgy parts of medicine, especially modern changes in medicine would suggest to me that if you did have a commercial market in organs that you might at least for a certain percentage of people be setting them up for an event that happened at a certain time in the sort of changing curve or landscape of their psychic life, but that they might come to regret it later or be personally humiliated by it.

I don’t know quite how to weigh that exactly except that I think this is a real consideration. People — this is not just like something they did in adolescence or something where they can just sort of blow it off because they were young or something, presumably this would be in middle life, but most of the donors are in middle life and I get the feeling that there would be some problems here, people having regrets. We all know that there are regrets. People have regrets about their medical — the process of their medical decisions in life. Without getting too specific, I think you all know the kind of thing I’m referring to.

So what do you think, Dan?

DR. FOSTER: I have always thought that Sir William Osler’s speech in 1902 where he described the profession as a noble profession is the model that it should be. Sometimes — and I think there are long — there’s a long line of true physicians who have been noble in the way that they deal with people. These life events are very, very different, so I don’t disagree with you at all in the sense that it’s sometimes a little bit different from other professions.

CHAIRMAN PELLEGRINO: Peter?

PROF. LAWLER: Robby put forward, as a great lawyer that he is, two kinds of arguments against an organ market. One is the unpredictability of it, practically or prudential argument. It wouldn’t be
prudent to try something like that. But the other is it would involve a change in our self understanding and an undignified change in our self understanding with unpredictable consequences. And I think we have to work on how to articulate this, so I agree with Gil, it’s unlikely we’re going to come down on the side of the market.

On the other hand, we have to reach some kind of relatively sophisticated agreement on why we don’t come down on the side of the market. And I also agree with Gil that we need to talk about these alternatives, these innovations proposed in the report. I think we might reach agreement on presumed consent, because the theory of presumed consent is it’s a presumption that organ donation is a good thing, but falling short of conscription which is too un-American and sort of repulsive in certain ways.

On the other hand, most of us go as far as this to say that we should compensate organ donors for their time, not pay them enough to make it worth their while to give the organs to make a profit, but to ensure they don’t incur a loss, that they get time off with pay in every respect. They don’t lose anything material with being a donor.

I remember Leon Kass and his comment, he said that, in fact, would be going too far. I’m more ambivalent about this, but I would like to hear the opinion of others on this. Because I do think we have to do everything we can coming up short of the market to increase the number of organs available.

CHAIRMAN PELLEGRINO: Any comments?

Dr. Schneider?

PROF. SCHNEIDER: I am not sure that I know what to make of this conversation because it’s being carried on at such a level of generality that I feel entirely removed from the human beings who are going to be reacting to any policy.

I don’t think it’s enough to say that if something becomes associated with a market that it becomes degraded because I think that the way that people are going to respond to markets has a lot to do with sociology, anthropology and psychology much more than just knowing that there is going to be some exchange of money.

And I agree with everybody, we have a very limited basis for predicting how people are going to behave. And I think that that also means we don’t know that they’re going to take a market badly. I’m not arguing in favor of the market, but I did want to express my discomfort with a conversation about how people are going to react in which individual human beings and the way they think can never be mentioned, but I think with one exception of one woman who tried to at least describe the way that she personally was reacting to the market proposal.

CHAIRMAN PELLEGRINO: Comments?

Dr. George?

PROF. GEORGE: I don’t know, Carl, who that was directed toward, but I certainly would not want to be interpreted as saying that introducing a market degrades whatever subject matter the market is being introduced to distribute or distribute from. I think there are some places where it does, selling human beings; perhaps selling organs, that’s the issue that’s on the table now, selling sex. And in others, like selling fishing rods, even selling services, selling insurance, it doesn’t. So we have to perceive retail here, rather than wholesale. I think it would be a very bad mistake to suppose that the market degrades whatever it touches, [but it] would be an equally bad mistake to suppose that the introduction of commercialization cannot degrade.

CHAIRMAN PELLEGRINO: Maybe the question should get down to the marketplace, in general, degrades whatever it touches, but rather are there some things which are more susceptible to corruption and I think that — I try to repress myself, but I say here we do have evidence of what commercialization is doing to medicine. If you’ve ever been a patient in this system, you will know what I’m talking about and as a physician we feel it daily.

Now I’m not arguing one way or the other, but there is evidence that commercialization has changed the whole face of medicine and particularly changed the relationship between the physician and the patient and the institution and the patient. So that even Adam Smith, I think those of you who are more familiar with him than I am, did point out that there are some things so vitally important to the public good that they ought not to be regulated by the marketplace. I’m glad to see you nodding assent.
So I think we need to step back and look at commercialization as it exists and what it would do in this field of transplantation.

To take my own position very bluntly, I honestly and truly believe that not just organ donation, but the whole field of medicine has shown an increasing adulation of the marketplace which I think has been deleterious. And therefore, I would certainly be opposed to adding to the marketplace the field of transplantation. Not only that, we’re being driven into that by the need for organs and the question is that an appropriate and justifiable reason for violating what I think is a principle we’ve already compromised severely, namely to commercialize something which I think should not be commercialized.

Is health care a commodity? Does it satisfy the criteria for a commodity?

Now some of those criteria would be economic, but there are other reasons where some things are not part of the market and I go back to Adam Smith. So I think, yes, all the questions you’re raising become very important and this particular question of the market raises significant questions that are much broader than transplantation as well. Sorry for the long footnote.

(Laughter.)

Anybody? Yes.

**DR. EBERSTADT:** A very important footnote indeed. I concur with that. And we find ourselves in the United States in a situation now where, like it or no, we have this commoditization, commodification of health care, where our health system accounts for $1 out of every $6 now it’s generated and spent in our national economy. So it’s far from a trivial problem for our society as a whole.

I think that the discussions of the last little while suggest to me the sort of comparative advantage that the Council might well have in addressing the whole question of marketization or commoditization of the question of organ transplantation. Whether we address the phenomenon or not, the phenomenon is there. My guess or my fear that the waiting list and the lines are going to be growing smaller before we come to the technical fix that Peter and others have talked about that might allow us to relieve this situation and one way, as part of a broader treatment or by itself, one way we might be able to serve the public benefit is by putting forward the strongest arguments for, if you will, commodification or marketization, but then also putting forward the reservations and the problems that come with this, strive to have two different sets of contending perspectives.

Maybe this suggestion should properly have been offered tomorrow morning when we’re talking about the research agenda, but the discussions of the last little while bring that to mind.

**CHAIRMAN PELLEGRINO:** Thank you. Other comments?

Dr. Gómez-Lobo?

**DR. GÓMEZ-LOBO:** Yes. I think we shouldn’t lose sight of the reason why we’re discussing markets in the first place. And it is the shortage problem and the expectations that the market is going to solve that.

Now I’m thinking about Robby’s arguments which I respect very much, but it seems to me that in the public marketplace of ideas the fact that say the introduction of markets may change or may affect our perspective of ourselves, I am afraid that’s the kind of argument that many people are going to find just tenuous and vaporous, particularly when confronted with the concrete suffering of the people that are waiting for the kidneys.

So it seems to me that the important thing is to explore the alternatives and I’m back to Spain. Why not take a serious look at a model like that which, it seems to me, has many advantages over going into the market solution. It does not require exchange of money, it seems. Perhaps some compensation for expenses for the family involved, although not necessarily if indeed it is the person who decides by not opting out of the system that his or her organs may be taken after death.

Now I can immediately imagine some problems, but I don’t see as many problems as I would see if we go down the market route. Of course, a lot of it will have to do with how the corpses of the dead are treated, how the family deals with it, but on the other hand, if we’re talking kidneys, perhaps a *modus vivendi* can be found that allows for the harvesting or the obtention of these organs upon death of a person and yet allow for the rights and proper burial, etcetera.
So I would rather start here, start at the presumed consent end of the spectrum and then if we find that that is not advisable, move to the possibility of introducing market consent.

**DR. FOSTER:** I think one point I want to make maybe speculatively is the assumption is that there could be some program that would significantly, I mean Alfonso is mentioning, would increasingly make organs available for transplantation.

One of the problems with that and one of the reasons that I am very skeptical about that doing any good to the problem, I think we have to decide well, we just can’t deal with this or we do, because as all of you know, the life expectancy at the turn of the century last time was 40 years and it's just continually increasing, in terms of transplant and so forth, more and more people are dying beyond the age of the transplantation and the people who are dying when they're younger are increasingly dying outside the hospital where recovery of organs is very difficult. You can do it. We heard the argument about this before, to try to do this with cardiovascular death.

It may well be if the life expectancy continues to increase and as you postpone the death events, oftentimes, most of the time, they're going to be for cancer or other things that will disqualify one for transplantation. So I'm enormously skeptical of the hope that one can increase and approach this problem by saying well, all we have to do is to increase the people who are going to donate. Well, they're not going to donate until they're dead and so if the dead are not increasing, then where are we going to get these? If it's not from living organs, in some sense, I think it's just hopeless to believe that you're going to do anything about this problem for these reasons, because I mean all the evidence is against that.

Now if all of a sudden you know there's huge epidemics of bird flu that kill lots of people. Infection is going to keep you from transplanting anyway, even if you have a big epidemic. Or if you have a terrorist attack — you're not going to do anything with that.

So you know, there's — Alfred Schutz talked about reality. He used to write about reality and he'd find paramount reality as being wide awake in the everyday world. And sometimes our conversations are not wide awake in the everyday world of the average person which is out here. So I'm also sympathetic to the view that may be a vaporous discussion about human dignity. They don't want to know about — I don't think — I'm not nephrologist, but I still, because I take care of diabetes, I have a lot — I don't think they're interested in anything about human dignity. I think they're interested in whether they can get a kidney or do something about this.

So I just don’t want us to be living in an unreal world. If you look at the statistics, it seems highly unlikely that the number of people who are going to die with diseases that will allow you to transplant at an age that you'll be able to transplant is, it might happen, but I think it's very unlikely.

**CHAIRMAN PELLEGRINO:** Dr. Meilaender?

**PROF. MEILAENDER:** I find myself sitting here wondering what our highly paid staff is going to do with the conversation that we've been having since they're supposed to take this and turn it into something or try to turn it into something.

I thought I would just sketch out the kind of thing that it seems to me they might be able to do for us that would pick up on the discussions we've had that would be in continuity with the kind of reports we've offered in the past and so forth.

And it seems to me that — and I will make certain normative judgments along the way here and of course, you might disagree with them, I understand that. But it seems to me a report that began by just — I was going to say outlining, but I mean something richer than that, outlining what we have taken on other occasions called the human goods that are involved here, this last policy paper talked about health, liberty and dignity. Leon suggested, I think rightly, the generosity needs to be added. I’m not sure exactly what it is, but in other words, why do we care about this? What is the human importance? Is it stake here and so forth?

Something that started there and that acknowledged the fact that any direction in which one turns is going to failure to kind of accomplish everything we want to accomplish with respect to all these human goods.

And then at that point, now my own inclination, this is where you might get off the train already, but my own inclination would be explain not in some highfallutin philosophical terms necessarily, Dan, but in terms that ordinary people do think, in moral language, explain why bodies aren't the sort of things that we want to turn into commodities for sale and purchase and so forth, why that system which might, even granting the unknowns, which might solve the problem is unacceptable, why we
Then we’ve got all the stuff from Dan’s staff paper that that contest, why do we have this complicated system? Well, because we’re willing to turn in the direction of the market. It leaves us with an ersome system in some ways, but one that’s trying to do justice to all sorts of competing moral concerns, so we could take that stuff and sort it and maybe connect it with some of the stuff from this policy paper that just gives the historical background or the background of the current state of regulations, some of which are at the state level and federal level and so forth, that kind of thing.

Then it seems to me that we really ought to discuss, without trying to resolve a few of the issues, maybe in just a pro/con sort of way, we need to pay some attention to that brain death issue. I don’t actually think the brain death term is the right way to get at it, that gets us into some trouble, but that one we should pay some attention to. We should sort out the living donor issue. We had a long discussion. I guess that was the previous session about it.

What is it that has caused reluctance about it, how does one overcome that reluctance? Can one overcome it without seeming to commit physicians to doing things of the sort that they have not normally done? We don’t have to solve those questions. I think we have to help people understand why they’re deep, important and rich questions.

And then I would hope, maybe, that we would have on some issues that aren’t quite so deep, some recommendations to make. Maybe on the allocation side, the geography issue. I might be the dissenter, but maybe the geography issue on the allocation side. On the procurement side, we still never got around to talking about something like the paired exchanges, but it’s a fairly modest kind of issue, for instance. I think we ought to, even if it’s not going to solve the problem and if it’s long range, we ought to say something about the preventive issue that Floyd raised, so that there are some more narrowly focused issues on which you know we might be able to make recommendations. They wouldn’t necessarily have to be unanimous, but majority recommendations.

And something like that, it seems to me, with what we’ve got in these very well done papers for discussion and our discussion is something like that it seems to me is where the staff might turn its energy. That’s my notion of where we are. You may not agree. That’s quite possible. But something like that is where it seems to me the staff might turn its energies to kind of move us forward, to take what we’ve got and turn it into something that we can really work more on.

CHAIRMAN PELLEGRINO: Thank you very much.

PROF. SCHAUB: Yes, not on Gil’s comment but in response to Alfonso. Since Alfonso tried twice to get us to take up the topic of presumed consent, I’ll very briefly try to take you up on your invitation. I guess it seems to me that presumed consent is presumptuous and in a statistical direction. And that my worry would be that it really goes against the notion of gifting and that it endangers that generosity, that if you presume virtue, you don’t really end up with virtue and so what we want is a system that allows the freedom for that generosity to show itself.

CHAIRMAN PELLEGRINO: Alfonso, would you like to respond?

DR. GÓMEZ-LOBO: I appreciate the replies received from Diana and from Dan. Dan’s point that most people are going to die pretty old anyhow is a very serious objection. I think it’s something to think about. Actually, what I had in mind is something like people dying in accidents, in car accidents, if indeed organs could be retrieved. Now I was aware then that those objections were going —

DR. FOSTER: What we ought to do, let me interrupt, we ought to have a national law precluding the wearing of helmets on motorcycles, for example.

DR. GÓMEZ-LOBO: Yes, that’s good state policy. Yes, no I’m aware of that objection. On the other hand, I think that if we’re talking about living donation, generosity is the virtue; for deceased donation, I’m not worried about virtues any longer. I think the person is no longer there to be virtuous. So I would think about them in different terms.

PROF. SCHAUB: But because the presumed consent, I mean it might be written in such a way that
it overrules the family’s role in it. I mean, in other words there’s a role for family generosity perhaps.

**DR. GÓMEZ-LOBO:** Yes, that’s why there is a mention here that there were two systems. There’s a strong and a weak. Given my character, I will go for the weak.

**PROF. SCHKAUB:** Can I ask one quick question of Sam? Could you say something about the circumstances in which we do allow for a kind of operation of presumed consent? There’s one paragraph here that says that under certain circumstances medical personnel can allow OPOs to remove organs from the deceased without securing consent.

**DR. CROWE:** Sure. Basically just for those that don’t remember this section, all 50 states and the District of Columbia, they’ve enacted what’s called the Uniform Anatomical Gift Act, or some version of it whether it be the 68 or the 87. And within, buried within that Act, most especially the 87 but also a little bit within the 68 are three forms of consent. First person consent, which is where we would turn to legally in most states first. Then to the family and then actually the rights of disposition devolve to the state finally. And in certain situations where there’s a specific request for an organ, the state or the actor of the state, whether it be the coroner or a procuring physician, can actually take the organ without explicit consent either from the individual or the family members of the deceased.

That’s not done as far as I know very often.

**PROF. SCHKAUB:** But when would it be done?

**DR. CROWE:** When the individual does not make a declaration, when the family members are not around or cannot be found. Again, in this situation they say that they have to give a certain amount of effort [to find the family]. It’s not specified how much. And then again, if the individual doesn’t say this is what I want you to do with my body, if the family isn’t there to say this is what we want to do with the body, then who is going to do it?

I mean, that’s the logic I would think of the law.

**PROF. SCHNEIDER:** As I recall, there is another situation and that is in a number of states, coroners can have the corneas removed and donated without any particular fuss.

**DR. CROWE:** Would you like me to clarify? As far as I know, there’s primarily two states, Florida and Georgia, good Southern states do this it seems. In these states, they’ve had cases where — again, a specific instance. If the person is deceased and then the deceased goes for an autopsy, then the coroner can procure or take the corneas without permission.

But again, you have to remember that these kinds of circumstances are not as — they don’t happen very often.

**CHAIRMAN PELLEGRINO:** Peter.

**PROF. LAWLER:** So deep down, the law does presume consent then finally, because the other default position, if no one speaks, it’s a good thing to take the organ.

You don’t end up saying well, I can’t get anyone to consent, therefore, I’ll just let it go. So the ultimate default public policy position is it’s a good thing to acquire organs. So I’m halfway between Alfonso and Diana on this that the giving of a live organ is — should be understood as an extraordinary act of generosity. But I still fall back to what I said before, giving up my dead kidney is the weakest act of generosity I will ever perform in my life. If I buy you a coke, I will have done more. That would be more generous.

And so from that point of view, I’m more inclined to think that presumed consent, when it comes to cadaver organs is less an offense against the American character than Diana does, but I appreciate her concern. Let me sneak in here a question I was going to ask Bill that I forgot and now I remembered. A problem we have in our libertarian society is how can we explain to people if women can sell their eggs, why they can’t sell their kidneys, because isn’t it true that your eggs are much more a part of your being than your kidneys? For example, I have two kidneys today, I hope. Tomorrow, I may have one, I’m the same guy. A woman giving up eggs is giving up something more essential to her being. So you might come out against both of them and I think I would too, selling either kidneys or eggs.

But nonetheless, how do we explain to America that it’s okay to sell eggs, but not kidneys?

**PROF. LAWLER:** Well, I’m glad you asked me that question because I was just going to suggest
that — Dan is going to think that this is really what not clear thinking in the real world or whatever — let's be realistic about this. The whole realm of body parts and transplants is expanding. And there is work in animals on ovary transplants now and even womb transplants. They've, I believe, successfully gestated a sheep or a goat in a transplanted womb, if I have that right.

Floyd, do you know if that's true?

So look, it's not obviously a major medical problem as currently defined. Infertility is a huge problem. There's a lot of surrogacy. Will we one day get to the point where womb transplants are another medical discussion? I think we at least ought to think about that, add that into the mix of concerns.

So in a way, this is a bigger topic than just the compelling power of imperative, very poignant situations where people are at end stage renal disease.

**DR. FOSTER:** In addition, Peter, you know, we sell sperm. We sell sperm and some religious views think that involves the sin of Onan, because you get the sperm by masturbation, you know, so — but we also sell blood and parts of blood. We already commercialize and commodify many things that if it's a principle that you're talking about, rather than what's going, then we have already crossed that line, I mean qualitatively speaking if you do that.

I'm not arguing for this, please, I'm only arguing for two things, one, I don't think we can solve this problem and I just think that we also need to be very clear that we have crossed a number of ways. We sell skin. We don't sell organs, but we sell essentially everything — we sell hair, you know. Those are all parts of the body, I presume.

**CHAIRMAN PELLEGRINO:** I wonder if we couldn't raise my question once again of urging you to think about Gil's suggestion. Anyone would like to at least pick up on it or add to it or new directions on that point?

Dr. Schneider?

**PROF. SCHNEIDER:** Anything to oblige. My own assumption is that when we put a lot of effort into something, we want it to be something where we can produce something that we're fairly confident we have something useful to say on and I would also think fairly confident that something is going to come of what we have done.

And I think the chances of producing something like that that meets those two criteria where we are able to feel that we really understand the nature of all of these, it seems to me, enormously complicated problems and that we can find some sort of thing to say that people will listen to in the first place and that people actually respond to given the enormously complicated political situation in which all of this takes place. Chances that we can do all of that strike me as being infinitesimally small and as I will try to suggest and I'm sure many other people will tomorrow, I think that there are a number of areas very comparable devotion of energy would produce something much more likely to make the world a better place.

So I have benefitted enormously from the conversation. I've learned a lot. I've had a great time, but I think that continuing to work on this problem is unlikely to produce anything we could easily agree to and that would meet the other criteria.

**CHAIRMAN PELLEGRINO:** Thank you.

**PROF. MEILAENDER:** I don't think that's true, Carl. We have in the past agreed on reports, some major portions of which simply sorted out disagreements in important ways which doesn't seem to me to be an unimportant thing to do. We have produced a long report, even at last end of sort of a highly philosophical report, the "Beyond Therapy" one that had nary a recommendation in it. I don't think we wasted our time in doing that and I have some reason to think that at least some people profited from it.

So it seems to me that the great virtue of this topic, though we — I mean certainly we're not going to solve every issue that it brings up is that it combines the opportunity for maybe some focused recommendations on certain policy questions. It has policy implications. It combines that with the opportunity, indeed, it almost compels one in thinking it through to think more deeply and richly about important anthropological questions in bioethics. Those are the richest topics, I think, the ones that force you into those deeper issues while also connecting to real policy issues that people are actually worrying about and arguing about.
This seems to me to be that kind of topic. It seems to me we've done sufficient work on it that we're in a position to say something useful, something useful perhaps with uncertain recommendations and something useful just in terms of sorting through and enriching understanding about it, and so I think it would be a mistake not to take what we've done and try to turn it into such a report and I think we could do something rather comparable to some of the things we've done in the past.

**CHAIRMAN PELLEGRINO:** Thank you. Further comments along this line?

I'd like your opinions. Dr. George?

**PROF. GEORGE:** Carl, I was wondering what you made of Gil's response. Would that kind of report that laid out the best arguments on the competing sides reflecting the spectrum of views on the Council which undoubtedly will reflect, come close to reflecting the diversity of views and society more broadly, do you agree that that would be useful or do you not think it would be?

**PROF. SCHNEIDER:** I think the question is not so much whether it could be of some use, but whether it is the best use of the resources that we have and I don't know, as I looked back over my life as a scholar in bioethics reading Presidential Commission reports, it's not clear to me that that kind of report is the kind that does the — that makes the best use of the resources of a body like this.

**CHAIRMAN PELLEGRINO:** Other comments?

**PROF. LAWLER:** I don't want to repeat what Gil said and I hardly ever agree with him 100 percent, but this time I think I do. This is an issue of pressing relevance for reasons Dan pointed out. There really probably is no way of adequately addressing the shortage, the alleged crisis, the scarcity short of turning to markets. So we have this pressing health need.

Our understanding of freedom is pointing everything in the market direction. And so I think the default position in the history of our country, as things go as the way things have so often gone within a certain amount of time, a decade or so, we may well have a market in organs and many members of this Council are against this, but in fact, the natural drift, I think, really is towards that. So it's an issue of pressing relevance which highlights competing human goods and calls, as Diana pointed out for example, forces us to think about what about our nation's devotion to health, what about the principle of consent in forming the national character.

And when we talk about dignity, are we talking about anything at all?

Carl made an excellent point, Dan too, that people on dialysis probably don't like to talk about dignity much, when would they work it in? So I think it's an issue of pressing bioethical relevance and that causes us to reflect deeply about who we are, so I think it's a tremendous issue.

**PROF. SCHNEIDER:** We may disagree about the current situation. I think the idea of a market solution to this is a complete nonstarter in terms of national politics.

As I recall, when Congress actually had a chance to address this, they were unanimous, close to unanimous in rejecting anything like — anything like a real market and I don't see anybody here who is in favor of that. I know of nobody in my personal circle is interested in that. I know of a few scholars who I think do not command the real attention of the American body politic.

**CHAIRMAN PELLEGRINO:** Further comments, questions?

**DR. FOSTER:** I guess in that response, since you're pretty — I mean one of the problems I've learned, you're pretty wishy-washy and don't make your opinion known very well, but I think I understand your opinion here. Are you going to — if you say well, okay, I don't know what the life of this Council is going to be, we don't know anything else about that, but are you going to mention tomorrow or now a subject that you think that the very talented staff that we have, which all of us agree that these papers are wonderfully done and we're proud of them and so forth, that you would see as an alternative that might be unlike other Presidential Council reports that more than a few people would pay attention to — do you want to —

It's one thing to say for us well, this is a bad idea to do that, but it might be helpful for us to hear what the — what an alternative idea or ideas would be to let us consider that.

**PROF. SCHNEIDER:** Now or then?

**DR. FOSTER:** The answer is I certainly do have alternatives, and I'm happy to tell you about them now or tomorrow.
CHAIRMAN PELLEGRINO: I think you might save it until tomorrow for context of the other subjects. There’s certainly to be a question of priority.

Other questions on this?

DR. FOSTER: Well, Mr. Chairman, I move we adjourn.

PROF. GEORGE: Before doing that can I just put one clarification on to the record of something I said earlier. I’d like to clarify, in fact, in light of a question that Dan Foster raised in a private discussion, a point in my remarks this morning about Ginger’s paper? In seeking a justification for living organ donation that does not relax the traditional principles of medical ethics, I’m not promoting — certainly don’t mean to be interpreted as promoting a search for clever rationalizations for something many of us would favor, but actually might believe isn’t right.

I think we need to try our best to get to the truth of the matter, that is, whether the activities in question can be morally justified and if so, how they can be justified and then to bring our practices and policies in line with it. I think I was speaking in such a way as to leave Dan and perhaps others to suppose that I might just be looking for a way to rationalize something that I deep down knew couldn’t be justified.

I suspect that the practice in question can be justified. I just don't know what the justification is and I wanted to invite and did invite other members of the Council and I renew that invitation now to think about ways that living organ donation can be justified. And by that, I don’t mean again rationalized. I mean shown to be what I believe it to be, but don’t quite know how to show to be at least right now morally justified.

CHAIRMAN PELLEGRINO: Motion was made. We don’t go on motions, Dan, but I think we’ll take it as a motion. Let us be adjourned and gather together tomorrow morning.

(Whereupon, at 5:06 p.m., the Council meeting was adjourned, to reconvene tomorrow, Friday, September 8, 2006.)
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.
FLOYD E. BLOOM, M.D.

COUNCIL MEMBER

Floyd E. Bloom was until March 2005, Chairman of the Department of Neuropharmacology at the Scripps Research Institute. He is currently professor emeritus in the Molecular and Integrative Neuroscience Department at TSRI, and the founding CEO and board chairman of Neurome, Inc. He previously was Director of Behavioral Neurobiology at the Salk Institute and Chief of the Laboratory of Neuropharmacology of NIMH.

He has received numerous awards, including the Pasarow Award in Neuropsychiatry and the Hermann van Helmholtz Award, the Sarnat Award for Mental Health Research, as well as a number of honorary degrees from major universities. He was the editor-in-chief of Science magazine from 1995 to 2000.

Dr. Bloom was born in Minneapolis, Minn., in 1936. He attended Southern Methodist University in Dallas, Texas, where he received an AB degree cum laude and then an MD degree, cum laude from Washington University in St. Louis, Mo.

He is a member of the National Academy of Science (1977), The Institute of Medicine (1982), The American Philosophical Society (1989) and the Royal Swedish Academy of Science (1989).

Dr. Bloom has authored or co-authored a total of 32 books and monographs, 415 original research articles, 256 solicited articles and reviews, 59 editorials, and more than 300 abstracts.
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 world-wide 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.
NICHOLAS N. EBERSTADT,
PH.D.

COUNCIL MEMBER

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.

<< previous :: Return to Council Member List :: next >>
Daniel Foster, M.D.

COUNCIL MEMBER

Daniel Foster, M.D. John Denis McGarry, Ph.D. Distinguished Chair in Diabetes and Metabolic Research, University of Texas Southwestern Medical School. Dr. Foster, whose research is in intermediary metabolism, has received the Banting Medal, the Joslin Medal, the Tinsley R. Harrison Medal and the Robert H. Williams Distinguished Chair of Medicine Award for his work. He is a member of the Institute of Medicine of the National Academy of Sciences and is a Fellow of the American Academy of Arts and Sciences. He was chairman of the Department of Internal Medicine at UT Southwestern for 16 years.
ROBERT P. GEORGE, J.D, D.PHIL.

COUNCIL MEMBER

Robert P. George is McCormick Professor of Jurisprudence and Director of the James Madison Program in American Ideals and Institutions at Princeton University.


In 2008, Professor George received the Presidential Citizens Medal at a ceremony in the Oval Office of the White House. He is a winner the Bradley Prize for Intellectual and Civic Achievement; the Sidney Hook Memorial Award of the National Association of Scholars; and the Philip Merrill Award for Outstanding Contributions to the Liberal Arts of the American Council of Trustees and Alumni.

A graduate of Swarthmore College and Harvard Law School, Professor George earned a doctorate in philosophy of law from Oxford University. He was elected to Phi Beta Kappa at Swarthmore, and received a Knox Fellowship from Harvard for graduate study in law and philosophy at Oxford. He holds honorary doctorates of law, letters, science, ethics, civil law, humane letters, and juridical science.

Professor George is a member of UNESCO’s World Commission on the Ethics of Scientific Knowledge and Technology. From 1993-98, he served as a presidential appointee to the United States Commission on Civil Rights. He is also a former Judicial Fellow at the Supreme Court of the United States, where he received the 1990 Justice Tom C. Clark Award. He is the recipient of a Silver Gavel Award of the American Bar Association, the Paul Bator Award of the Federalist Society for Law and Public Policy. In 2007 he gave the John Dewey Lecture in Philosophy of Law at Harvard. In 2008 he gave the Judge Guido Calabresi Lecture at Yale and the Sir Malcolm Knox Lecture at the University of St. Andrews in Scotland.

Professor George is a member of the Council on Foreign Relations, and serves as Of Counsel to the law firm of Robinson & McElwee.

<< previous :: Return to Council Member List :: next >>
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.

<< previous :: Return to Council Member List :: next >>
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, conservatism, 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.

Dr. Lawler recently edited a book on Tocqueville and American political life today and the fifth edition of *American Political Rhetoric*. He wrote an introduction to the new Sheed and Ward edition of John Courtney Murray’s *We Hold These Truths*, and book chapters on religion and the American founding, Locke and American greatness, Flannery O’Connor, and *Casablanca*. 
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.

<< previous :: Return to Council Member List :: next >>
DIANA J. SCHAUB, PH.D.

COUNCIL MEMBER

Diana J. Schaub is a professor and chairwoman of the department of political science at Loyola College in Maryland. From 1994 to 1995 she was the postdoctoral fellow of the Program on Constitutional Government at Harvard University. In 2001, she was the recipient of the Richard M. Weaver Prize for Scholarly Letters. Ms. Schaub has taught at the University of Michigan at Dearborn and served as assistant editor of the National Interest. She has her A.B. from Kenyon College, where she was elected to Phi Beta Kappa, and an M.A. and Ph.D. from the University of Chicago. She is the author of Erotic Liberalism: Women and Revolution in Montesquieu's "Persian Letters" (1995), along with a number of book chapters and articles in the fields of political philosophy and American political thought. Ms. Schaub's work also appears in the New Criterion, the Public Interest, and The American Enterprise.
CARL E. SCHNEIDER, J.D.

COUNCIL MEMBER

Carl E. Schneider is the Chauncey Stillman Professor of Ethics, Morality, and the Practice of Law, and is Professor of Internal Medicine at the University of Michigan. He was educated at Harvard College and the University of Michigan Law School, where he was editor-in-chief of the Michigan Law Review. He served as law clerk to Judge Carl McGowan of the United States Court of Appeals for the District of Columbia Circuit and to Justice Potter Stewart of the United States Supreme Court. He became a member of the University of Michigan Law School faculty in 1981 and of the Medical School faculty in 1998.

Professor Schneider has written extensively on bioethical issues, the law of bioethics, family law, constitutional law, professional training, and professional ethics. He is the author of The Practice of Autonomy: Patients, Doctors, and Medical Decisions (Oxford University Press, 1998), a study of the way the authority to make medical decisions is and should be allocated between doctors and patients, and is the co-author of The Law of Bioethics: Individual Autonomy and Social Regulation (West, 2003, 2006), a law school casebook. His family law casebook, An Invitation to Family Law (West), is entering its third edition. He is currently writing a book on the law regulating medical decisions of all kinds – especially contemporary and prospective decisions and decisions by competent patients and for incompetent patients. He is also engaged in research on consumer-directed health care, research supported by a Robert Wood Johnson Investigator's Award.

Professor Schneider has lectured, taught, and published in several countries. He has been a visiting professor at Cambridge University, the University of Tokyo, and Kyoto University, has taught for many years in Germany, and was a visiting professor at the United States Air Force Academy in the winter of 2007.