

GEORGETOWN UNIVERSITY
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CENTER FOR BIOETHICS

INTERVIEW WITH DR. JAMES McCONNELL
IN REGARDS TO THE HUMAN GENOME PROJECT

- - -

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1 was so struck by it--I was absolutely dumbfounded--and I
2 was excited beyond belief. Of course. Of course it's time
3 that that can be done, that we're at that stage. And the
4 curious thing is my thoughts were "why hadn't we done it?
5 Why are we just now reaching this and why is it so
6 precipitous and why is it bursting on the scene?" It seems
7 to me that we should have, heard of it quietly through some
8 other route than to have it appear almost as a full-blown
9 idea whose time had come.

10 Those first conversations were not direct--they were
11 almost indirect conversations--with a variety of people who
12 were at the lab. I was listening in on them. Not that they
13 were secret. I don't mean that. But they were talking
14 among themselves and then I later spoke with Mark about
15 it.

16 But the next occasion when I heard it was when Senator
17 Domenici called together a group of individuals from the
18 national labs, from MIT, the Chancellor of MIT, the
19 Executive V.P of AT&T, his staff, me, Martha Buddecke, a
20 former politician--even yet he's a politician--who was
21 defeated for the Republican nomination for the Senate in
22 California, Zschau, I believe his name was.

23 DR. COOKE-DEEGAN: Ed Zschau?

24 DR. McCONNELL: Ed Zschau. Thank you. And Barber
25 Conable was the other person that I remember was there.

1 All of the presidents of the national labs in New
2 Mexico were there and one or two former presidents and one
3 or two additional people were there whose names and
4 positions escape me just now.

5 But the other person that was there that was
6 significant was former Director the NIH who was out at
7 Howard Hughes and actually was in the process of being
8 moved out Howard Hughes at the time—

9 DR. COOKE-DEEGAN: Don Fredrickson?

10 DR. McCONNELL: --Don Fredrickson. He and I happened to
11 be sitting next to one another at lunch, and I don't know
12 who it was--I think it was he who mentioned it--yes, it was
13 he who mentioned it and brought it up. And I said, "Tell me
14 more about it." And when he did it hit me again forcefully
15 and that's when I realized that this was an idea that I
16 should latch onto as well, not only one whose time has
17 come, but to hear his excitement and his enthusiasm for it
18 was contagious. And in fact we discussed it that afternoon
19 at Senator Domenici's ongoing conference, which started
20 around 9:00 and went until 3:00 or 3:30, or so.

21 At the finish of the conference at which I made a
22 presentation and Dr. Fredrickson made a presentation about
23 the Genome--mine was about something else; it was about
24 tech transfer--Senator Domenici said, "I don't want to keep
25 meeting and I don't want to be burdened with a lot of

1 detail, but I want four of you to meet to decide what
2 should be done about the ideas that have been proposed here
3 today." And it was I, Martha Buddecke, a former assistant
4 of his in Washington who is now at New Mexico in charge of
5 development for the state, Paul Gilman, his legislative
6 assistant, and a former legislative assistant who was in a
7 law office in Chicago and I've forgotten his name now.
8 Martha Buddecke would certainly know it.

9 DR. COOKE-DEEGAN: It wasn't Steve Bell, was it?

10 DR. McCONNELL: Yes, it was Steve Bell.

11 DR. COOKE-DEEGAN: Steve Bell?

12 DR. McCONNELL: Right. And Steve Bell. And he said,
13 "The four of you meet over the weekend and bring me the
14 recommendations on Monday."

15 I happened to be staying there on the weekend anyway,
16 as did Martha, so we met, absent Paul and Steve, on
17 Saturday afternoon after the meeting and then we met again
18 Sunday afternoon later, or Sunday evening, and then Monday
19 morning, and we proposed four things:

20 One was legislation supporting the superconducting
21 supercollider, support for the Sematech program, support
22 for a Human Genome Program, and then I proposed the idea
23 that there be created four Centers of Entrepreneurship near
24 the national labs where someone could come and learn the
25 techniques and

1 technology of being an entrepreneur. If they came with
2 their own idea and project, well and good; if they didn't,
3 there was certainly an abundance of opportunities for them
4 in the national lab, whether it was Oak Ridge, Lawrence
5 Livermore, Lawrence Berkeley, Argonne, the one up in Idaho,
6 the one in Washington. Any of those could have supplied
7 them with several ideas to choose among. And the thought
8 was that if we encouraged people to come and use those
9 ideas for tech transfer and assisted them, they would be
10 more apt to be successful. They could stay long enough-- By
11 the way, these schools of entrepreneurship would be funded
12 at the rate of \$5 million a year and would be attached to a
13 college or university that was nearby, and one could obtain
14 a Master's, if that's what they wanted, or if they wanted
15 just to come to learn how to write a business plan, a
16 prospectus, understand how to hire/fire, create stock,
17 obtain financing, patent law, whatever it was that they
18 needed to know, this would be available to them.

19 DR. COOKE-DEEGAN: Jack, when you first heard about the
20 project from Mark Bitensky at Los Alamos it was '86, they
21 would have just been--they would have gone through their
22 first conference on that in March of that year--what were
23 the components of what was being called the Genome Project?
24 Was it the sequencing? Was it the technologies? Was it the
25 gene mapping? What was it that they were talking

1 about and what was it that kind of caught your attention?

2 DR. McCONNELL: Well, it was mapping, as I recall. It
3 was an indirect comment in a conversation that I had with
4 him about some other work that he was doing that was in the
5 field of diabetes that he and I both had an interest in,
6 and I was decrying the fact that here was a disease that we
7 had made very little headway in over the centuries, and in
8 fact it was not very different--we didn't treat it very
9 differently--now than we did 40 years ago and yet
10 technology must have been--must be around--for achieving
11 better results than we have that could be applied to this
12 disease. And he said, "Well, there will be. In fact, there
13 is a project now in discussion about the possibility of
14 mapping--making a map--of the gene," and, as I recall, he
15 did say "sequencing." But the essence of it that I took
16 away, because I didn't know enough about it to probe him
17 very much, was that they were going to make a map and
18 hopefully put in proper sequence the DNA.

19 I'm pretty sure that he knew much more about it than
20 he told me, and I expect that's part of the culture of the
21 national labs; they don't tell you everything that they
22 know.

23 DR. COOKE-DEEGAN: You might go back and explain a
24 little bit about how it was that you were involved with Pete
25 Domenici's interests in tech transfer. You might just give

1 a little bit of history there because I think that would be
2 interesting.

3 DR. McCONNELL: Pete called--Pete's office--called,
4 someone in his office, called me and asked me if I would
5 come out to New Mexico for a meeting in July, which I
6 believe was July of '85--maybe it was '84--to review a plan
7 that he had to transfer information and technology out of
8 the national labs into private industry. At the time I had
9 no idea who he was, what state he was from, or how he got
10 my name, and I was basically engaged in doing other things
11 and told him I didn't think I was the one. And frankly, in
12 fact, that was an honest comment. I wasn't being modest
13 about it. I just didn't think I knew enough about the
14 national labs.

15 They persisted and he made one or two other calls,
16 wrote a letter to the Chairman of the Board, who passed it
17 down and asked me if there was some reason I couldn't help
18 him. He asked me if I could and, if not, to let him know
19 why I wasn't in a position to. And with that, Martha
20 Buddecke called me and said she'd like to stop by and see
21 me. And she brought a fellow with her named Charles
22 something or other who was on assignment to the Senator
23 from TRW. And they came and visited me. And their thought
24 was to develop the technology that was in magnetic resonance
25 imaging that existed in the labs and then patent and license

1 that onward.

2 Well, I knew--and I'll be honest about and not modest
3 either--I knew much more about that than they did, because
4 I created the research team that did the work that resulted
5 in the first commercial MRI system in the United States.
6 And then we brought Technicare and, having gone through
7 that experience and knowing how much we were spending on
8 research and how little we were getting for it at this
9 point in time, because we were on the upward slope of the
10 S-curve at that point in time, it was just not profitable
11 to think that anyone could do a lot more about it because
12 the energy source--the energy--had been explored well
13 enough that was being used in MRI to tell you you're at the
14 theoretical--you're darned close--to the theoretical
15 limits. I was comfortable telling them that that was a bad
16 tree to go hunting up. But I said, "There are other things
17 out there at the national labs that I expect you have,"
18 and that was the only hook that they needed. That's all
19 they need. They said, "Well, come out and see for
20 yourself."

21 So, I read the proposal, and I'll be honest about it,
22 it wasn't a well written proposal. I don't know who put it
23 together. And they sent it to me and to--after I agreed to
24 go--they sent it to me and the Vice President of
25 Westinghouse and I forgot who the other fellow was.

1 DR. COOKE-DEEGAN: This was a proposal from the
2 national labs to do tech transfer arrangements?

3 DR. McCONNELL: It was a proposal by
4 Senator Domenici to form something called Riotech, which
5 was an acronym for the Rio Grande Technology Foundation,
6 which would stand as an independent non-profit organization
7 funded by private industry to help get access to the technology
8 and to move it into their own companies or to other companies.

9 And I took the proposal apart and put it back together
10 the way I thought it might work, and the fellow from
11 Westinghouse--and this sounds immodest and critical and I
12 don't want it to necessarily sound that way--was more
13 telling Pete, "Yes, that's a great idea, and it'll fly, and
14 you're doing a good job in Washington, and keep it up." But
15 the proposal would never have gotten where it was trying to
16 go, and we reworked it at the office and then Pete said,
17 "Well, I guess I've found my president." And he didn't ask
18 me, he appointed me, President of the Formation Committee
19 of the Rio Grande Technology Foundation and wrote the
20 Chairman of the Board to say how pleased he was that I'd
21 agreed to serve. And I had very little to say about it. I
22 knew that I had fallen into the hands of a master politician.
23 And I thoroughly enjoyed that because it was fun scratching
24 around in the archives there to find out what they had. And
25 it was amazing how much they had which applied to the

1 pharmaceutical and biotech industries. It was absolutely
2 amazing. I didn't think they'd have much of anything,
3 because most of it, I thought, would be coming out of
4 physics and engineering. But they had an enormous amount
5 and a lot of very talented people.

6 And we got a fellow to come in then to head it up,
7 after we got it organized, and that worked quite well. That
8 really worked quite well for a while. But he headed it off
9 in the direction of a Department of Manufacturing at the
10 University of New Mexico, and that was not what we were
11 organized for, and it sort of drifted, and I think it may
12 not even be in existence now.

13 DR. COOKE-DEEGAN: Why don't you go into a little after
14 you and Martha and--I presume you and Martha presented the
15 ideas--what then later became S. 1480? What was the process
16 that went on from there?

17 DR. McCONNELL: Martha and I presented them to Paul
18 that morning and he thought that they were good ideas and
19 indeed he improved on them, and we took them to Pete at
20 noontime. And it was amazing to me. I thought there'd be
21 more discussion about it. He approved them enthusiastically
22 at noontime, and there wasn't anything much more to it than
23 that. He asked us some very insightful questions about the
24 impact of it and why and the funding and who would be
25 involved and whether or not it would advance industry and

1 manufacturing and production in the United States and that
2 sort of thing, and then he said that this was something he
3 would pursue.

4 And Paul and I consulted then on several occasions
5 after that about S. 14--

6 DR. COOKE-DEEGAN:--80

7 DR. McCONNELL:--S. 1480. Paul did most of the writing,
8 and I was down on two or three occasions. Indeed, I had
9 Wally Gilbert and Ham Smith from--Wally Gilbert from
10 Harvard and Ham Smith from Johns Hopkins--to come over and
11 visit with Senator Domenici to confirm that their
12 impression was that indeed this idea did have value. And
13 then a fellow named Anderson-- What's his name?

14 DR. COOKE-DEEGAN: French Anderson or Norm
15 Anderson?

16 DR. McCONNELL: Norm Anderson. Norm Anderson came over
17 and made some comments which were helpful, I think, and
18 this was after--this was--as we were into the construction
19 of S. 1480, and Pete was really quite taken with this idea
20 of being the first on to present legislation which could
21 lead to a Genome Program. He was confident they would get
22 Sematech and he felt they'd get the superconducting
23 supercollider project passed. He was less confident about
24 the Genome, and I think he just mollified me with the
25 activity--the enterprise--on entrepreneurship at

1 the colleges. It originally had all four of those in it,
2 but in the conference with Congress, with the Congressional
3 side, with the House, that was dropped after a Senate
4 hearing that we had. And I don't know if that damaged it. I
5 think that idea was damaged in concert with the House.

6 DR. COOKE-DEEGAN: How deeply involved were you when
7 they tried to make s. 1480 part of the Trade Bill in
8 '87?

9 DR. McCONNELL: Well, I was not directly involved, but
10 I was in phone conversation with them probably once a week,
11 and that took many twists and turns, and it was difficult
12 for them to keep me up to date--I can understand that--
13 because they were investigating, maneuvering and
14 compromising as they do on Capitol Hill, and particularly
15 with the House and with the other people in the Senate, and
16 the ones that were involved with that were the former
17 Senator from Florida-- What's his name?

18 DR. COOKE-DEEGAN: McKay?

19 DR. McCONNELL: No.

20 DR. COOKE-DEEGAN: Claude Pepper?

21 DR. McCONNELL: No. No.

22 DR. COOKE-DEEGAN: Rogers?

23 DR. McCONNELL: No. He resigned last time and he's now
24 running for Governor down there.

25 DR. COOKE-DEEGAN: Oh, oh, oh, Lawton Chiles.

1 DR. McCONNELL: Yes, Lawton Chiles.

2 DR. COOKE-DEEGAN: So, yes, he was then in Congress
3 still.

4 DR. McCONNELL: Then in the Senate. And he became
5 involved in it and Senator Kennedy became involved in it.
6 And I was invited to visit with Senator Kennedy's staff,
7 and I found that very disappointing. That was not
8 encouraging because they asked me, "What are the weaknesses
9 in the program, and what are the weaknesses in this bill?"
10 And that's essentially the only question they wanted to
11 know, the only questions they wanted to know. I tried to
12 explain the program in some depth so that it would put it
13 in perspective, but they were more inclined to pursue the
14 negatives than the positives in the bill. And I don't know
15 whether they didn't agree with the project or whether their
16 noses were a bit out of joint that they weren't the first
17 ones to think of it, or whether Senator Kennedy, because of
18 his position in relationship to NIH, felt that it should
19 have come through him or should have been brought to his
20 office first I don't know, but I know that there was not a
21 very-- It was not a very inquiring group of people that
22 represented him. There was a fellow there from UCLA who was
23 on loan from the school there for a year, an African-
24 American, and I don't recall his name.

25 DR. COOKE-DEEGAN: It wasn't Stephen Keith?

1 DR. McCONNELL: No, I don't think so. No. That name
2 doesn't sound familiar. It might have been, but the name
3 just doesn't sound familiar. And a very nice young
4 physician from UCLA. But he was interested in the program,
5 but there was another person there on Senator Kennedy's
6 staff who was, well, he took almost an advocate's position,
7 almost as if it was trial, and he was questioning me about
8 why I did this or why I did that and why I didn't come to
9 him and why they just now learned about it. It was almost
10 embarrassing trying to tell them that, "Well, you should
11 have known about it yourself. You know, this is a year old
12 and it's been out, and the fact that you're just now
13 learning about it hasn't harmed anyone. You can join it
14 now. This is the first bill, and here you are, you can be a
15 part of it, and you're in the position to be a leader and
16 this helps your own area of interest, of NIH," and I was
17 trying to support it, but he was almost like a cross
18 examination, not a very pleasant experience all in all.

19 DR. COOKE-DEEGAN: Now, would that have been Stephen
20 Keith or Mona Sarfotie or David Nexon, or--

21 DR. McCONNELL: Is Stephen Keith an African-
22 American?

23 DR. COOKE-DEEGAN: Yes.

24 DR. McCONNELL: No, because the person--

25 DR. COOKE-DEEGAN: Stephen, it doesn't sound like

1 his personality.

2 DR. McCONNELL: No. This fellow was white and obviously
3 experienced in Washington. I mean, he had a sense of having
4 been there awhile.

5 DR. COOKE-DEEGAN: I don't know who did that
6 interview.

7 DR. McCONNELL: I don't know either. It was just not a
8 pleasant experience.

9 The fellow from UCLA was not acquainted with it and
10 took a back seat to the lawyer who was there and took his
11 lead from that. I must say--

12 DR. COOKE-DEEGAN: Oh, that person was a lawyer?

13 DR. McCONNELL: Yes, I think he was a lawyer.

14 DR. COOKE-DEEGAN: Oh, oh, oh, I'm blanking on that
15 name, but I do know who that was. Well, it doesn't matter.
16 I'll try to pick that up some other time.

17 DR. McCONNELL: In fact, he had all the demeanor and
18 manner of a lawyer.

19 DR. COOKE-DEEGAN: A prosecutor, it sounds like.

20 DR. McCONNELL: Yes, that's right, a prosecutor
21 possibly.

22 DR. COOKE-DEEGAN: Just a kind of overarching thing. In
23 your sense of looking back over the first 5 years

1 of the genome debate, what do you see as the most
2 significant events in the whole launching of the project?

3 DR. McCONNELL: Honestly, I could hardly believe that
4 NIH was a reluctant partner in this. I could hardly believe
5 that. I mean, how can the most exciting thing that's
6 happened in their lifetime and will happen in the future of
7 the institution be treated as a red-headed stepchild? I
8 mean, here is an institution that claims to be at the
9 very forefront of science and technology in the field of
10 medicine and biology and why weren't they leading it? That
11 was the thing that absolutely puzzled me, and still puzzles
12 me. I don't understand one that stands back from your
13 own field and says, "I'm not sure I want to be in it
14 because I didn't think of it," and that was almost the
15 attitude that came out of the group from NIH. Why they were
16 a reluctant rider on this bus surprises the dickens out of
17 me.

18 DR. COOKE-DEEGAN: So, did you have meetings with NIH
19 folks at some point along the way here?

20 DR. McCONNELL: No. I had meetings with-- I talked to
21 them on the phone. The fellow from the National Library and
22 a gal who heads up the library there and Jim Wyngaarden, I
23 spoke to him on two occasions I guess it was.

24 Who is it that's head of the Library now? It's a
25 gal.

1 DR. COOKE-DEEGAN: It wasn't the Library. Was it the
2 General Medical Sciences?

3 DR. McCONNELL: Maybe it was General Medical
4 Sciences.

5 DR. COOKE-DEEGAN: Ruth Kirschstein?

6 DR. McCONNELL: Ruth Kirschstein. I visited with her.
7 And then there was a fellow there who-- Oh gosh, what was
8 his name?

9 DR. COOKE-DEEGAN: The Library person?

10 DR. McCONNELL: Yes, the Library person.

11 DR. COOKE-DEEGAN: Was it Don Lindberg?

12 DR. McCONNELL: Yes. Yes, right. Don Lindberg. Right.
13 And we had two-- I never did visit with him. We had two
14 nice conversations on the phone. And I got the impression
15 that both of them felt threatened by it.

16 DR. COOKE-DEEGAN: Both of--

17 DR. McCONNELL: Both Kirschstein and Lindberg felt
18 threatened by it and neither wanted to have it and control,
19 or to destroy it. I've overstated it a bit, but those were
20 the impressions that one could get from our conversations.
21 And that's the first thing. And the second thing is that we
22 never really understood what this project was all about. In
23 essence it's a manufacturing process. The process of
24 creating a map and sequence of the genome, once the
25 technology is here, is a

1 manufacturing process. And why would the NIH worry about
2 someone-- Well, by the way, they did finally get on board,
3 but they got on board in the wrong way in my opinion. They
4 sucked it totally into their sphere and that's not where it
5 belongs. It needs-- This is a massive, multidimensional,
6 multi-institutional project the likes of which they have
7 never run, and I still think that my original impression
8 was correct, that it should have been run by someone or
9 some group that had managed multidisciplined and multi-
10 institutional programs, such as someone from the national
11 labs.

12 Now, they could assign that person to NIH, but that's
13 the kind of talent you need to run it. When you're
14 organizing a company, you don't bring a salesman in out of
15 the field and say, "Now, go do it," and yet, in many ways,
16 that's what we have done in the Genome Program. I don't
17 think--God bless him--but I don't think Watson has ever run
18 a multidiscipline program of this magnitude, nor has anyone
19 else in the field of medicine and biology. I think he's
20 extremely brilliant and it was a clever trick on the part--
21 not trick, I don't mean it that way--a clever maneuver on
22 the part of Wyndgaarden to bring him in and absorb his
23 reflected aura for himself and for the NIH, and to say,
24 "Here, this is our man, and now here let's go with it,
25 because we are the best ones to run it, "when, in point of

1 fact, I don't think that's true, because this is not a
2 program-- Particularly when you say that man will be
3 working part time. This is not a part-time project. It is
4 the largest thing, the most important thing, the most
5 creative, the most inventive, and I think in the total
6 scheme of it will have by far the biggest impact on
7 medicine and biology and on our society over the next 30-40
8 years that's coming down the pike. Oil shortage, Saddam,
9 another Hitler, the break-up of the Soviet empire
10 notwithstanding, this impacts every sector of our society
11 and we have not yet begun to even think about the result of
12 this impact on our society. We cannot be successful on the
13 timeframe that we want to be--(Tape ends mid-sentence.)

14 [Begin side two]

15 DR. COOKE-DEEGAN: Okay.

16 DR. McCONNELL: I think he's working, I think Watson's
17 working, as hard as he can and done an extremely effective
18 job with the environment in which he's been placed. Now, if
19 I were he I would not have taken it under those terms. I
20 would have wanted a much more-- I would have wanted a
21 different set of parameters for it. And that's a pity
22 because I think we are not making anywhere near the
23 progress that we should in trying to move quickly with this
24 program, as quickly as those people who are ill deserve, or
25 would want us to, and indeed they deserve better

1 | than they're getting out of this.

2 | So, this program is not a program about science and
3 | it's not a program about mapping and sequencing. That's
4 | just a technology and a tool and a method to get there.
5 | It's a program about the possibility of creating, in the
6 | middle of this next century, a disease-free society. Now
7 | that's the magnitude of it, if we choose to. And here we
8 | are bound down with the discussions about the cost and its
9 | relative impact on small science when the whole damned
10 | thing only costs five and a half Stealth bombers. Now that
11 | is criminal for us to say we probably should not pursue
12 | this one--for scientists in the field to mount a program
13 | saying we probably should not pursue this--because you're
14 | interfering with our small science. Well, splendid. Go do
15 | your small science, and God bless you. I think you've made
16 | a fantastic record to date, but you have answered all the
17 | questions, all the great unanswered questions of medicine,
18 | you're going to answer using small science. We're now in a
19 | position to move into another plateau at which we'll be in
20 | a position to answer darned near any unanswered questions
21 | of medicine and some that haven't even been asked yet.

22 | And it's not their fault, it's the fault of Congress,
23 | to say that we--and indeed it's the fault of society, and
24 | maybe it is the fault of the scientists too-- to say that
25 | we think that another five and a half Stealth

1 bombers are more important than the Human Genome Program.
2 Now, that is criminal. That is criminal.

3 DR. COOKE-DEEGAN: Jack, in what way do you see this?
4 What do you see as being the benefits of this? What's the
5 vision that you're--

6 DR. McCONNELL: Well, first of all will come testing,
7 and that is a dilemma for sure, because do you test without
8 being able to treat? Do you want to know? Do you really
9 want to know what your genetic profile is? And if you do,
10 do you want others to know? We run the risk, moving forward
11 with this too fast in the testing, puts whole program at
12 risk because if we don't manage that well with the public
13 and let them know that this is just the first chapter, if
14 you will, of this book, they will say, "Hey, I have been
15 labeled, or my child has been labeled, as a genetically
16 flawed person and they won't allow him in the fast path in
17 school, or may not even allow him into college, period, or
18 not the colleges that we can afford to send the kid to."
19 And how does that account for slow starters? Or how does it
20 account for, shall we say, those with dyslexia? Will we say
21 everyone with dyslexia cannot get a college education? Then
22 how about Winston Churchill and Albert Einstein, and
23 Rockefeller, Governor Rockefeller?

24 Moving forward with this--I don't mean to say too
25 fast--but without alerting the public to what it means and

1 putting the whole program--sharing with them
2 the whole book, instead of just the first chapter of the
3 book, puts the whole darned book at risk. Will we say that
4 we will test them and allow their employers to know, or
5 will their employers demand to know? And then how does that
6 impact society in general, and how does that put us in
7 conflict with society in this program? Or how about-- Well,
8 how about insurance? I can guarantee you the insurance
9 companies are going to go after this like a chicken on a
10 june bug. They're going to demand to have these genetic
11 profiles and with it create what someone has called a
12 "biological underclass." I think it's a beautiful term. It
13 was in an article that I read somewhere.

14 DR. COOKE-DEEGAN: I think that's Dorothy Nelkin's
15 term.

16 DR. McCONNELL: Dorothy Nelkin. That's right. Dorothy
17 Nelkin's term. These are the things that bother me about
18 this. And it's our fault as much as anything. We're going
19 after it as if it's science. That's not all it is. It's
20 science. It's science as the driving force. But it's
21 science that is on the cutting edge of changing society,
22 and that touched every segment of our society. And we need
23 to get out in front with that as a scientific group and to
24 have conferences and invite people outside of science in to
25 listen to us and to tell them what we're up to and invited

1 them to go write articles about it. If enough are out
2 there, truth will come to the fore.

3 DR. COOKE-DEEGAN: So, this is Chapter One that you're
4 concerned about. It's the foreshadowing. What are the rest
5 of the chapters that you are thinking of? You referred to a
6 "disease-free society."

7 DR. McCONNELL: Okay. Well, as these things emerge we
8 will fight an uphill battle to finish this project until we
9 have the first major therapeutic success. And if that
10 occurs in some dramatic disease or in a family of one of
11 our top elected officials, then we're going to have easy
12 sailing for awhile. And that's the politics of science
13 again.

14 If we were to discover the treatment of alcoholism, I
15 mean the gene, and the therapy, the quick and easy therapy
16 for alcoholism with the problem having been pronounced now
17 in the wives of one our Presidents and another Presidential
18 candidate, can you imagine the dramatic impact on that? We
19 only need on big success really to capture the imagination
20 of the public as to what it means for them.

21 DR. COOKE-DEEGAN: What is your vision of the linkage
22 between the Genome Project and being able to solve problems
23 like that? What

1 are the scientific/medical steps that you're thinking of,
2 and how does the Genome Project fit into that?

3 DR. McCONNELL: Well, you need the basic dictionary of
4 information of the sequences and then, of course, you need
5 the protein that's excreted from it, and first, I think,
6 will come products developed by industry on their ability
7 to wither augment, or suppress, or alter the activity of
8 these proteins. And then I think fast after that, if a
9 pharmaceutical company is not geared in to move quickly
10 from there into gene therapy, I think they're going to lose
11 out. I fear greatly that a company like, oh, the larger
12 ones in the pharmaceutical industry, and multifaceted, such
13 as Johnson & Johnson, may become the General Motors of the
14 Genome Era. But some small company or some small country
15 will eat our lunch, will absolutely eat it, because J&J and
16 Bristol-Myers, Lilly, Upjohn, SmithKline until it was
17 absorbed, and others, have a policy of being fast seconds,
18 waiting until someone else has developed it and then coming
19 in afterwards and buying a license or buying a company.
20 That's not the way it's going to be in the future. Whoever
21 discovers the protein and how to deal with the protein from
22 a gene sequence and the disease entity that is the result
23 of that will own that disease forever.

24 Now you can say, "Well, there'll be enough single gene
25 or multi-genetic diseases around to suffice and they

1 won't all be taken," and that's true. But the major ones,
2 you can bet your bottom dollar, are going to be snapped up
3 right away. And I suspect, I suspect strongly, that the
4 reason the Japanese are not spending their money on the
5 Genome Program is they don't have to. It's of no moment to
6 them, and in many ways that may be why our own
7 pharmaceutical companies are not spending much effort in
8 involving themselves with it. That's not where it is. They
9 can wait until it's done and then move in. but that's
10 exactly what the Japanese are going to do. They're going to
11 wait until the gene sequence is darned near developed and
12 then move in on certain selected segments of it and own it.
13 I mean they'll absolutely own it then, from there on out.

14 DR. COOKE-DEEGAN: Do we need to stop?

15 MAY ELLEN McCONNELL: Well, it's nearly ten of, I
16 guess, and we're all here.

17 DR. COOKE-DEEGAN: Okay. Why don't you let me ask him
18 one final question and then we'll-- Actually I'll ask you
19 two final questions.

20 DR. McCONNELL: Okay.

21 DR. COOKE-DEEGAN: One is, briefly, what do you think
22 your personal role was in all of this? How did you fit into
23 the grand scheme of it?

24 DR. McCONNELL: Well, it was a very minor role
25 actually. I am not a scientist in the sense that I think of

1 a scientist. I do have a bit of vision and I think I've
2 enjoyed some success with that over the decades, and I
3 think the biggest contribution I made was in convincing
4 Senator Domenici of the validity of this, the value of this
5 project for society. Now mind you, he was willing to listen
6 because early on in the '80s he used a term that I had
7 never heard before. He used a phrase which said-- When I
8 was asking him-- When I first went out to New Mexico I
9 said, "This is a beautiful little state. Why in the world
10 do you want to change it? I mean, you've got this beautiful
11 smog-free climate here in Albuquerque and here you are
12 trying to bring in more industry." And he says, "Jack, if
13 peace breaks out..."--and I was startled at that because this
14 was in the early '80s, and I said, "Who in the world ever
15 heard of a term like that, "if peace breaks out,"--he said,
16 "...we will be in a lot of trouble here, and I intend to have
17 our national labs in New Mexico poised to take full
18 advantage of whatever research and creative activities they
19 want to get into and should be involved in." And my ability
20 to convince him that this was one of those areas that would
21 have an enormous impact on society, and value, was a
22 contribution that I made. And in fact I think I still have
23 his easy confidence that he and I still share in this
24 program.

25 DR. COOKE-DEEGAN: Finally, do you think

1 the Genome Project is going to succeed?

2 DR. McCONNELL: Oh, absolutely. Absolutely. It's going
3 to succeed, whether we do it or not. But, you know, it's
4 almost-- It has a momentum of its own. It has a life of
5 its own. We can retard it, but I don't think we can
6 stop it. I mean, once this is out of the bag it's going to
7 succeed.

8 Science comes along not in a linear fashion; it comes
9 along in stair steps, and we have just moved up a major set
10 of stairs here to another level. And now that we have it in
11 sight--we may not be there yet, but we have it in sight and
12 we're putting that set of steps up there to it-- once
13 that's in sight someone is going to finish it whether we do
14 or not. I must say that I am not very-- I'm not overwhelmed
15 by how we have proceeded with it here in the United States.
16 I'm not proud of the way that we've almost under-funded it
17 and left it begging for funds, and I'm not very pleased
18 with how we seem to have allowed internecine battles to
19 develop in the scientific community where we're at odds
20 with our own scientific brothers about this project. We
21 haven't done a good job of telling them what it's all
22 about. We should have grabbed that initiative right at the
23 outset instead of having to react to it the way we've done,
24 and I don't think that we are an effective international
25 leader in this area. To me HUGO is a disaster, or close to

1 it, in terms of operation. It's a beautiful thought and
2 organization and structure, but as far as having any major
3 impact on the development of this they are a disaster. They
4 fell in the hands of UNESCO who are "johnny come latelies"
5 in the field of science and have their own agenda which is
6 obscure to me. I don't know what it is. And I'm not
7 comfortable with that close relationship with UNESCO. Their
8 agenda is different than I think this program should be and
9 no one yet has convinced me, or maybe understands, what
10 indeed UNESCO's agenda is here.

11 DR. COOKE-DEEGAN: And then a final question is when
12 you were thinking about whether this is going to succeed or
13 not and you said, "Of course it will, whether we do it or
14 not," how do you know? What does that success look like?
15 What is it? In what way is it going to succeed?

16 DR. McCONNELL: ...to succeed and it will create the
17 technology that will allow us to look at-- Well, we'll do
18 several things. As an endpoint we will have the gene
19 sequences by the end of this decade. That will be of value
20 to us and they'll appear in their own fashion and at their
21 own rate and pace. But what we will do, we will be able to
22 diagnose, or to predict, to diagnose, to treat, to cure,
23 and eliminate diseases that to date have not been-- that
24 we've not been able to manage even, or at least not manage
25 well.

1 We will change the way medicine is practiced, the way
2 the doctor looks at his patient, the way the patient looks
3 at his or her disease, the way health care is delivered. We
4 will change the statistics of longevity in our country and
5 indeed around the world. We will change the way we think
6 leisure, of retirement, of education, of aging. We will
7 alter the Social Security Program so that I think it's
8 going to startle a lot of folks, and we're certainly going
9 to upset the insurance industry. We're not even beginning
10 to look at all the issues that will emerge out of this
11 project that need to be thought of now and examined, as we
12 should have thought of--our brethren--who feel threatened
13 by this project in the scientific community.

14 DR. COOKE-DEEGAN: Okay. We'll stop there.

15 DR. McCONNELL: Yes Okay. Thank you, Bob, for this
16 opportunity.

17 DR. COOKE-DEEGAN: Well, it's great.

18 (whereupon, the interview concluded.)