

***Ethics, Genetic Technologies, and Social Responsibility
in the Twenty-first Century***

A Panel Discussion Held on March 14, 2001 at the Townsend Center for the Humanities,
University of California, Berkeley ##¹

Sponsored by:

Program in the History of the Biological Sciences & Biotechnology, The Bancroft Library
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Weiner: I want to welcome you all here on a great day. On the East Coast if a day like this occurred in March, I would not be indoors. I guess you're either used to it or you are very interested in the topic, as we all are. I was going to invite David Farrell, who's not here at the moment, to welcome you on behalf of the sponsoring groups. Sally Hughes, could you tell who's sponsoring all of this?²

Hughes: The Program in the History of the Biological Sciences & Biotechnology of The Bancroft Library, the Office for History of Science and Technology, and the Townsend Center for the Humanities.

Weiner: I want to let you know why we're here. We're going to look, through presentations and discussions, at what's been learned about the ethical and social dimensions of the genetic technologies that have been applied in the last few decades. So that would lead to the next question--what can we learn from all of these experiences to aid us in decision making about current emerging and proposed genetic technologies? And then, what is the social responsibility of scientists and citizens in the decisions that must be made about priorities, choices, and limits to genetic technologies?

¹This symbol indicates that a tape or tape segment has begun or ended.

²Transcript was lightly edited by the presenters.

There will be three presentations, allowing lots of time for discussion-- discussion with full participation of all of you. After each presentation, we'll take a few minutes for quick comments and perhaps questions of clarification, but then we'll have time at the end for full discussion. Our speakers today are well equipped to do this. They are individuals who have been studying these issues past and present and are in active analysis of them and of policy relating to them.

Since I'm speaking first I'll introduce myself. I'm Charlie Weiner. I'm here this semester as a visiting professor based in the ESPM department. I was invited to come to do two courses--one on bioethics, an undergraduate class, and they'll be here at 4:00. They'd better be here. [laughter] I told them it was a field trip, and that they should take their lunches and get permission from their parents and definitely be here. And the other class is "Bioethics and Society"--it's a graduate seminar. And how many of the students from that class are here? Okay, we're taking attendance on that. And it has been really fun to do these classes.

I've spent several decades, as a historian of science, documenting the development of genetic engineering and biotechnology. Ordinarily I'm based at MIT. I'm professor emeritus there now, which gave me the freedom to do this trip for the semester. And I've been focusing on issues of social responsibility in science, on the ethical implications of genetics, of patenting, academic-industry connections, things that are very present in our lives now and that have an important historical dimension.

Diane Beeson is the chair of the Department of Sociology and Social Services at Cal-State Hayward. Her main research interest for nearly three decades has been in genetic testing and new reproductive technologies, and her most recent publications deal with responses to genetic testing among families at risk for cystic fibrosis and sickle cell disease.

Paul Billings is a medical geneticist, a physician, and a scientist. He is executive vice-president and chief scientific and medical officer of GeneSage, Inc., and the editor of *Gene Letter*, a very interesting online publication dealing with many of these contemporary issues. For years he has been studying and analyzing the social implications of genetic testing, among other things. His book, *DNA on Trial: Genetic Identification and Criminal Justice* is one example of his interests.

Marcy Darnovsky is research director for the Exploratory Initiative on the New Human Genetic Technologies,¹ a public interest group reaching out nationally, though based primarily in San Francisco at the moment. She teaches "Biotechnology in the Public Interest" at Cal State-Sonoma, and her recent publications have covered social movements, the politics of technology, human germline intervention, and reproductive cloning.

¹Now called the Center for Genetics and Society.

I'll moderate the discussion. Let me first give some background to the issues.

As a historian of recent science and technology, I've noted, as you all have, the enormous transformation of genetic sciences and the social context for them in the past twenty-five years. That period started off with the development of the recombinant DNA techniques, which made possible manipulation of genes and opened the door for genetic engineering, providing new power to understand genetic conditions, to understand disease, to do a lot of other things that we'll talk about.

Another important historical development that has transformed genetics is the commercialization of academic research in the field. The contemporary and future policy issues are important to consider. There has been a rapid and pervasive commercialization of genetic research in the universities, with industry alliances developing from the late seventies and taking off in the early eighties. This is a two-decade-long story.

I'm going to focus on the events that have to do with the ethical and the social responsibility issues. You could list all of the scientific understanding that's come from the genetic technologies. That's something that I'm ignoring here in order to lay out the background for what we want to talk about. The other issue is the crash program funded very heavily by the government to map and sequence the human genome.

There are many claims made regarding the benefits to be gained and almost a changing of our language, which is a kind of a new genespeak, a new geneticspeak language, with statements such as, "We used to believe our fate was in the stars, but now we know that our fate is in our genes." James Watson is the author of that. Another example is the book of life imagery used by the Human Genome Project.

There has been a real change in language and thinking as well. Genomic medicine is a new term that flows out of this, and the term revolution is used a great deal. There has been a geneticizing of illness and of problems in society. Everything is linked to genetics in this kind of a discourse. And of course recently there was great jubilation among many about the completion of this important stage in the Human Genome Project and media focus on battles which stem from the commercialization of the project.

Another set of issues has to do with current applications and proposals for the use of new genetic knowledge--questions that I'm sure will come up on the panel. How do you decide? What limits do you put on it? Should the commercialization of genetics determine what these applications are? For example, gene therapy, which should more correctly be called gene transfer experiments on human subjects. And under that category, germline modification--meaning inheritable genetic modification in humans, or what many people are promoting as enhancement

interventions--not for medical purposes, but to make designer babies, and so forth. And human cloning certainly fits into that.

The other important development is the change in ethics and the way it's looked at, the way it's organized. So I'm going to say something about each of these things.

In the mid 1970s when the new recombinant DNA techniques were developed, there was great excitement among the molecular biologists who were involved. But amid that excitement there was concern that the techniques might involve certain hazards to laboratory workers and people outside the laboratory, primarily health problems. But in some cases there was environmental concern as well.

Scientists in the field were very eager to proceed with their research, but they recognized that those problems needed to be addressed. Their aim was to reassure the public that scientists on their own could, in a system of self-regulation, develop these techniques and apply them in the laboratories. The issue was defined as a technical problem to be solved by technical means. Twenty-six years ago, a conference was held just down the road near Monterey at the Asilomar conference grounds, where the people in the field assembled to consider what the potential hazards might be, and how they could be avoided or minimized or controlled.

They developed a framework under which--a framework of self-regulation--through their funding agency the National Institutes of Health--which would allow the work to go forward under safety guidelines. The focus at Asilomar in 1975 was on the safety of newly developed technical tools for genetic engineering. The focus was on the means and not on the ends.

And that raises an interesting question about when is the appropriate time to consider the consequences of new technologies. Biologists themselves had been deeply concerned about the ethical limits to genetic engineering in the 1960s before it was possible to manipulate genes, before the recombinant DNA techniques were available. But that was put aside, and by a few years later when the technique became available, when the future arrived, the emphasis was on the technical problems and not on the consequences.

I'll give you an example of the spirit of that period. In his opening remarks at the 1975 Asilomar conference, David Baltimore expressed the views of the organizers about the limited focus of the meeting--and here I'll quote him:

"There are two issues which are peripheral to this meeting, and which could confuse it in a number of ways. One of these is the utilization of this technology in what has been called gene therapy or genetic engineering, which leads one into complicated questions of what's right and what's wrong-

-of complicated questions of political motivations, and which I do not think this is the time to discuss. And secondly an issue which is very serious and which many of us care about and have cared about for a long time, which is the possibility to utilize such technology in biological warfare. And again although I think it's obvious that recombinant DNA is possibly the most potent potential technology in biological warfare, this meeting is not designed to deal with that question. The issue that does bring us here is that a new technique of molecular biology appears to have allowed us to outdo the standard events of evolution by making combinations of genes, which could be immediate natural history. These pose special potential hazards while they offer enormous benefits."

There was a similar instance years earlier where the important moral consequences of new technologies were recognized, but they were deferred, and I'll give you a brief example of that. This was with J. Robert Oppenheimer, the physicist who led the atomic bomb project at Los Alamos. In 1954 when his advice was no longer what the leading military people wanted to hear--he was the head of the advisory committee to the Atomic Energy Commission in the post-war period--they had a hearing on his suitability and his loyalty and so forth. He was interrogated by the AEC personnel security board to determine why the scientific advisory committee he headed had initially opposed the launching of a crash program to develop a hydrogen bomb. And then the advisory committee later endorsed it. Of special interest to Oppenheimer's interrogators was that the advisory committee also had expressed moral qualms about the weapons when they first considered it, but made no mention of them later when they endorsed the crash program.

Here's Oppenheimer's response to the queries on that question:

"My feeling about development became quite different when the practicabilities became clear. When I saw how to do it, it was clear to me that one had to at least make the thing. Then the only problem was what one would do about them when one had them. The program we had in 1949 was a tortured thing that you could well argue did not make a great deal of technical sense. It was therefore possible to argue also that you did not want it even if you could have it. The program in 1951 was technically so sweet that you could not argue about that. It was purely the military, the political, and the humane problem of what you were going to do about it once you had it."

So there's the separation of the scientific from the ethical issues and the deferring of the ethical issues because of the lure of the technology and the intellectual excitement. Bombs are quite different than research intended to improve health and to help human beings. But it's a type of thinking that's very important regarding when is the appropriate time to deal with these issues.

Let me jump to the commercialization issue. The guidelines that were established by the scientists themselves were gradually downgraded in the absence of demonstrated risk. At the same time, the commercialization of the field and the involvement of academics in biotechnology companies was occurring at a rapid rate. The patent for the recombinant DNA technique was filed for by Stanford University and the University of California on behalf of two of the scientists [Herbert W. Boyer and Stanley N. Cohen] that developed the technique. The patent was granted in 1980 after the Supreme Court decided to allow the patenting of human-made organisms.

Biologists and the universities became involved in what soon became almost a complete commercialization of the work, starting very rapidly in the early 1980s. Academic biologists, most of whom were never before involved with industry, became consultants, advisors, founders, equity holders, and contractees of new biotechnology firms or new divisions of multinational corporations. We know about the current disputes that are prominent in the scientific and in the public media over patents on DNA sequences, human cells, tissues, body parts, and experimental processes and products.

New companies are continuing to form around the developing technologies, in agricultural biotechnology, pharmacology, gene sequencing, genetic testing, DNA profiling, and human gene therapy or human gene transfer. And universities are enthusiastically setting up companies and cutting multi-million-dollar deals with industry. So that's an important change to be considered when we talk about the issues in the rest of the program.

And then I want to talk about what I call "the ethics thing." I don't know if you remember the previous President Bush was criticized for not talking about "the vision thing" and not having a vision. He referred to it as "the vision thing." Well, I call this "the ethics thing."

In 1989 there were two scientists in Sweden who had helped develop a code of ethics for scientists in their research. One of the things they said in their comment on that code was, "The existence of ethical discussions and rules may be used to legitimate activities rather than to change them." This warning has special relevance to the current approach to ethics in the Human Genome Project, and in discussions about human gene transfer, stem cell research, human cloning, and xenotransplantation, among other issues.

I think most of you are aware that the Human Genome Project from the start allocated part of its budget to ethical, legal, and social issues. It was a fragment of their large budget, but for people concerned with such issues, it was a pretty significant amount of money--about 3 percent of their budget, which went up later to about 5 percent. The announcement was that the project was making an effort to identify the ethical/legal/social issues in advance, preparing society to deal with the

non-beneficial uses of the vast amount of genetic information the project would inevitably produce. The project's scientific goal and its policies were treated as a done deal, as inevitable.

Then the question was, what do you do with the information once you have it? Some of our commentators today have had grants from that project, and I believe they didn't take the money and run. I believe that they are going to tell us what they did with it.

Voice: They spent it. [laughter]

Weiner: This effort was compartmentalized and was separated in large part from the policies of the project itself, once again separating the technical from the ethical and deferring the ethical issues, defining them as a societal and not a scientific concern. James Watson, the first director of the genome project, is quoted by Lori Andrews in her book, *The Clone Age*, as referring to the ethical component of it as "a shield for the scientists so they could do their work unimpeded." George Annas, noted bioethicist and lawyer, observed in 1989 that "ethics is generally taken seriously by physicians and scientists only when it either fosters their agenda or does not interfere with it. If it cautions a slower pace or a more deliberate consideration of science's darker side, it's dismissed as fearful of the future, anti-intellectual, or simply uninformed." I'd like to believe that that's not true. I'd like to believe at least that there are exceptions, and there is some evidence, but it's an important observation.

And now a word about the new role played by a new professional group known as the bioethicists. The approach that is usually taken is based in biomedical ethics and physician-patient relationships, autonomy of the patient, and informed consent. The question is, is that approach adequate for the kinds of issues that we're facing today?

Bioethicists are involved at every level. They are on local committees at universities and national boards, and industry is setting up their ethics boards on these issues. So they are prominent, they're everywhere, and they're quoted on every major issue, and there are some deep-thinking people there.

My impression is that the focus is not on the deeper question of whether to do something, but on how to do it. The focus of many leading scientists and bioethicists is not about drawing the line, but about shifting the line. For example, from somatic cell interventions in humans to germline interventions. From germline to its components--medical and enhancement. And the germline taboo is giving way to campaigns for gaining public acceptance, otherwise known as marketing. The role of bioethics is compartmentalized and very often is there to take the pressure off: we've got people over there to think about this, and we've run it by the

bioethicists, and they're endorsing it, or they're saying they're going to work out a proper framework, and so forth.

A question to consider is, what is the role of the public in making decisions on these events and these developments? Are the bioethicists the surrogates for public participation? Is that the appropriate approach? How should citizens make decisions about these issues?

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Weiner: Diane Beeson, whom I briefly introduced, is going to get a longer introduction now. She specializes in medical sociology. She was a postdoctoral fellow at UCSF's Institute for Health Policy Studies and a visiting scholar at Stanford University's Center for Genomics, Ethics, and Society. She consulted there on the development of policy recommendations for genetic testing for breast cancer.

Her main research interest has been in genetic testing and new reproductive technologies, and her articles deal with these issues in the *Journal of Medical Genetics*, *Journal of Genetic Counseling*. Her recent studies, as I mentioned before, are on responses to genetic testing among families at risk for cystic fibrosis and sickle cell disease. Diane will speak for twenty-five minutes and then we'll have some time for comments.

Beeson: Twenty-five minutes. That's better than I expected. I'm delighted to be here. I'm delighted to see so many people interested in discussing genetics and social responsibility. Much of what genetic research promises us has yet to come to fruition.

Prenatal diagnosis, on the other hand, is one form of genetic technology that has been around for a little while. When I use the term prenatal diagnosis, I'm going to be mostly referring to amniocentesis and chorionic villus sampling [CVS], but some of what I say is also relevant to maternal serum alpha fetoprotein [AFP] screening and ultrasound. Do you know what amniocentesis and CVS are? Maybe I'd better tell you.

Amniocentesis is the most widely used form of prenatal diagnosis that's really invasive, except for maternal blood testing. It involves taking a long thin needle and sticking it through the pregnant woman's abdomen into the amniotic sac and taking out some of the amniotic fluid so that it can be analyzed chromosomally, genetically, and biochemically. It can tell us a lot about the fetus.

CVS is done transabdominally or transcervically, so it can be done through the vagina. It's also done with a long needle. It's a little more dangerous than amnio, but it can be done earlier--about ten weeks. Amniocentesis you don't usually do until about fourteen, sixteen weeks, and it takes longer to get the results.

So those are the kinds of procedures that I'm referring to when I talk about prenatal diagnosis. With these techniques, we use the euphemism of prevention, or some people use that term. These are preventive techniques, they say. But I think it's important to make it clear at the outset that what they prevent is not any disability or any condition. They prevent the birth of persons with particular conditions that are being selected for.

So prenatal diagnosis is a technique to determine which fetuses will be admitted to the human race. This is why Rayna Rapp has referred to couples who undergo prenatal diagnosis as moral pioneers. A more traditional name for such practices is eugenics. What I'd like to do now is give you some of my conclusions about what we can learn from over a quarter of a century of this form of moral pioneering.

Let me just say another word about my background. I think my interest in this was driven by my concern about what is required in our society of mothers of disabled children. I began researching this at the same time I began thinking about becoming a mother myself, and I was interested in what kind of a commitment I was making when I became a mother. And then I became interested in the extent to which technofixes might provide an adequate response to the problem of disability in our society.

Over the years I conducted a number of studies, first to get access to medical settings and prenatal detection clinics. I studied things like stress levels, which rise sharply immediately prior to prenatal testing and then again just before results are ready as women go through these procedures. Then I studied decision making, and more recently I've studied the diffusion of the technology and resistance to it, which has become more interesting to me.

Today I'm going to tell you what may be three of the most problematic social issues at work with prenatal diagnosis that might be relevant for some of the genetic technologies on the horizon. The first point I want to make is that I think it's pretty clear that the use of prenatal diagnosis has increased social inequities. And I should point out that in 1981 President Reagan placed restrictions on the use of federal funds for collecting health statistics that make it very difficult for us to really measure some of the health problems that we have in this country.

There's an organization called the Council of Regional Networks [CORN], which is composed of genetic service providers who have attempted to take up some of the slack. But CORN found that only New York and California are providing genetic counseling and other genetic services for low-income and minority populations in any significant degree.

What we have here is very, very expensive procedures that are available in the context of first trimester prenatal care. Now nearly 20 percent of the people in

this country don't get first trimester prenatal care. They get delayed or no prenatal care. And among these there are twice as many African Americans and twice as many Hispanics. There are studies that show that well over two-thirds of low-income women experience problems getting prenatal care--problems finding MDs who accept Medicaid, problems with transportation and childcare needed to get to these appointments.

Thirty-six states cover some of the costs of amniocentesis, but few also cover the cost of subsequent abortions. By the early nineties, only five states explicitly covered selective abortions under Medicaid for fetuses diagnosed as having grave conditions. And only six states conducted aggressive outreach informing poor women that prenatal care was available under Medicaid. So what's really happening with prenatal diagnosis is that we're redistributing congenital disabilities by social class.

Take for example, Down's syndrome. That's the most commonly diagnosed prenatal condition, and over 90 percent of identified cases are being aborted. So increasingly Down's syndrome is becoming a condition of poor people, and these children are getting harder to raise because there are fewer people who now specialize in that condition and know how to provide relevant support for families. The maternal serum AFP programs were developed primarily to prevent neural tube defects such as anencephaly and spina bifida.

I think it's really interesting that shortly after we got all these programs up and running, we began to read and hear more about the fact, more acknowledgment of the fact that the primary cause of neural tube defects is malnutrition. It's a B vitamin deficiency--folic acid. And we also know that 70 percent of the women in our society who are of childbearing age are not getting enough whole grains and enough green vegetables in their diet, so they are at risk for neural tube defects.

Instead of addressing the problem of malnutrition, we have this huge technological program, so now most women do get maternal serum screening at about sixteen to eighteen weeks of pregnancy. They get their blood drawn, and then what happens is a large number of them--I think it's 10 percent--show abnormal levels, and most of these--90 percent of the people who get these high levels--are what we call false positives. There's really nothing wrong at all, but these women then really go through emotional traumas, and they end up getting ultrasound to check the dates and maybe amnios and other tests to rule out Down's syndrome and neural tube defects. Recently the program has been expanded so they can detect more than just the neural tube defects, which are the folic acid deficiencies, but it has made prenatal diagnosis and even amnios much more widespread.

Another thing that is happening still--I'm trying to support my point that prenatal diagnosis increases social inequities--it's pretty clear that we're diverting vast amounts of medical expertise and training into endeavors that have little to do

with treatment or medical care; they have to do with this testing. Some interesting research has come out by Marteau and Drake out of England that shows in three countries that both health professionals and lay people are increasingly making negative judgments about women's roles in the birth of children with disabilities, so it's becoming more and more socially unacceptable to have a disabled child.

The second point I want to make is that prenatal diagnosis has been deployed with inadequate regard for the social, psychological, and emotional processes implicit in the relationship between a mother and her fetus, and in the process of forming a family. There's a lot of research on this, but it really doesn't enter the public policy discourse. Let's face it: I think most of us recognize on some level that most of the pain and suffering in our society today, the violence, is a function of a lack of compassion and sensitivity. Teenagers shooting their peers don't do so because of their genes. They do it because of the quality of their interactions with their own family members and with other people. Basically they are suffering from a lack of emotional nurturance, and we fail to recognize that the process of becoming human or making a baby is not only a biological process, it's a social process.

It starts with a social relationship between a woman and her fetus, and prenatal diagnosis wreaks emotional havoc on this process. It treats the female body as a machine and invades it in ways that are physically so dangerous that hundreds, if not thousands, of healthy, wanted fetuses are destroyed every year. That's one in 200 for amnio, and three times that for CVS. Placing a long needle into the amniotic sac violates every protective impulse a mother has. This procedure combined with the very strong message that this fetus may not be acceptable to this society places women on an emotional roller coaster that increases stress levels dramatically and requires emotional numbing and detachment from the pregnancy until at least the test results are reported. And this is more often than not halfway through the pregnancy.

So what's going on is we're transforming the process of building families from primarily affective processes into essentially instrumental-rational processes that disregard relationship-building and really, I think, challenge some of the most essential assumptions about what it means to be a member of a family--what level of support and commitment that merits.

Interestingly, we have an appalling shortage of genetic counselors, people who help women and their partners figure out how to negotiate all of the decisions they have to make here. I understand that right here on this campus there was a wonderful genetic counseling program that really tried to grapple with some of these more profound issues. Admissions have just been suspended in that program. There are only about a thousand genetic counselors in the country, which indicates the importance we place on the emotional parts of dealing with genetic testing.

The third point I want to make is that individual decisions to use genetic technologies--to determine who will be born--reflect social context or social conditions far more than they reflect the objective nature of any condition being selected for. Prenatal diagnosis operates under the imprimatur of science. That is, what we're doing here is scientific, objective. But what I'm arguing here is that the individual decisions about using these technologies really reflect social context or social conditions, not any objective nature of the condition being selected for. And I will give you some examples.

What I'm saying is that these technologies are being used to express political and social prejudices. Perhaps the most powerful evidence I have for this argument is that worldwide the most common use for prenatal diagnosis, more than any other use, more than all the other uses combined, is what? It's for female feticide. That's what it's being used for throughout the world on an incredibly widespread basis, and it's being used so widely that it has had an alarming impact on the sex ratios in many countries--China, India, Korea, a lot of Asian countries.

Let's look at the case of India. India is not really one culture. It is many cultures. There's one state in India, Karala, which is the only state where female fetuses are not systematically aborted at a steady rate. And Karala is unique in several interesting ways. Why is it they're not aborting female fetuses? Well, they do have a historic absence of sex bias. They have very good reception to contraception. They have the highest level of female literacy anywhere in India. But perhaps most important of all, they have matrilineal inheritance. Under these social conditions, it's just fine to have a female child. But not anywhere else in India. So in Karala we don't see prenatal diagnosis having any impact on the sex ratio.

This is something that became very obvious in the study that I did with Troy Duster out of UC Berkeley's Institute for the Study of Social Change. This was an ELSI-funded study where we interviewed over 400 members of families that were at risk for genetic diseases, and primarily the diseases were cystic fibrosis and sickle cell disease. These are single-gene disorders, considered to be highly lethal.

It turns out that, in general, the more you know about sickle cell or cystic fibrosis, the less interested you are in prenatal diagnosis. The people that we interviewed in these high-risk families--because we were looking at the diffusion, decision making, how people responded to this--were overwhelmingly pro-choice. It's not that they are opposed to abortion. They really affirm, especially the African-Americans, the right of women to choose whether or not to terminate a pregnancy. But what they cannot understand and do not accept is that you would make such a decision on the basis of the characteristics of an individual fetus. Certainly not sickle cell or cystic fibrosis. Because people who know people with those conditions find it very difficult to reduce the meaning of that person's existence to their genetic condition. The average life expectancy for cystic fibrosis is thirty. It's much higher in Denmark; it's over forty now, but they're probably putting more

resources into treatment than we are. And people can live into old age with sickle cell.

The other disturbing thing about prenatal diagnosis is that none of these tests for cystic fibrosis, sickle cell, or even Down's syndrome will tell you anything about the severity of the condition. You can have cystic fibrosis and have no symptoms that are apparent, and in some people their only symptom is infertility. But that's not the kind of subtle decision that prenatal diagnosis enables you to make.

I want to give you another example of how the social context determines the use of these technologies. It's not the condition itself. There's nothing inherent in the condition that makes people want to apply genetic fixes. It's the social arrangements, the distribution of power and resources. Twenty-five years ago, when I was at UCSF, they had just begun to figure out how to do fetal blood testing. That was the first time they could detect the hemoglobinopathies, like sickle cell disease and thalassemia. For a long time it was very obvious that virtually no African-Americans would come for this procedure. They weren't interested; they weren't buying it; they weren't taking it. At the same time there would be Greek families that had spent their fortunes, their family savings, everything, who came from another part of the world to try to detect and abort fetuses with some pretty similar conditions.

When we began studying families at risk for sickle cell disease here in the Bay Area and in other parts of the country, we discovered that there are a number of interesting and important reasons why prenatal diagnosis doesn't have a great appeal among African-Americans. First of all, there's a mistrust of medicine among African Americans that has some pretty deep roots. Of course there's the Tuskegee study, but most African Americans have much more personal examples of how someone they love has been sterilized without permission, or other abuses. And the worst thing that can happen to you if you're a young woman who's African American in the context of the drug war is to be labeled as at-risk. Lisa Handwerker has done some very nice work--she's here in Berkeley--about the consequences of being labeled at-risk and what risk means to minorities. For one thing it usually evokes a fear that your child will be taken away from you. But when you start talking the language of risk around the pregnancies with young African Americans, they don't want to hear about it, and they get as far away as they can. Also, as I mentioned there's an intense aversion to selective abortion.

People will say, "Look, if a person can't have a child, if they're not ready to have a child, that's fine, I support their choice. But to abort a child because it's not perfectly healthy--I'm not that kind of a person." That's what they would usually say to us, something to that effect. I remember interviewing one woman who really wanted the testing. As I said, the testing is more attractive, at least with these conditions, the more distance you have from the condition. This may not be true with every condition. So the more abstract the fear is--like Down's syndrome used

to terrify me, until I met lots of happy families raising kids with Down's syndrome and having very rich and meaningful lives. Most African Americans cannot accept the idea that you would choose not to have a child because that particular child would not be healthy or would not be perfect.

In addition to this aversion to selective abortion is the perceived irrelevance of the genetic threat. When you tell people who face an array of social problems what their risks are, often if both parents are carriers, the chances that their child will have sickle cell disease is 25 percent. Well, we had many young women say, "Gee, 25 percent, that's really great odds; that's pretty good." When the chances of them getting through the month with enough to eat are maybe less than 50/50--and the chance of a lot of other dangers they face is much greater.

Those are just some examples of how the context shapes how people look at these things. Policy makers tend to individualize the decision making, but there's a substantial body of research that shows that social organization can really override culture. It can override culture in creating demand for genetic services. So social organization overrides culture. That is, even in situations where the culture seems incompatible, if the services are provided sensitively enough, people may be interested in these services, but social organization is the key. I just want you to keep that in mind whatever issue we're talking about.

I want to conclude by saying that I think if you look at the diffusion of prenatal diagnosis, you see that it has encouraged many people to buy into the illusion of human perfectability. But if there is such a thing as human perfectability, I think a lot more recognize that it's not to be found in our physical characteristics. For me the disability rights movement has been the main source of my own growing recognition that prenatal diagnosis is often a destructive and alienating response to human problems. I've found as I've gone out into communities and talked to people to see that many, many people don't buy the idea that genetic reductionism or biological determinism can provide any answers. Instead, I see that they're working actively on building social systems at all levels that are nurturing, compassionate, and inclusive. I think that's what we have to do. It's a much better alternative. Thank you. [applause]

Weiner: We'll ask for comments, questions. Tell who you are and where you're from.

Burak: I'm Geoff Burak. I'm on the faculty here at the School of Public Health. I take your point in particular about the disability rights traditional critique of prenatal diagnosis. I think there's a great deal of merit to that. But one concern that always arises in that discussion is that when your examples are chosen from conditions such as sickle cell and cystic fibrosis, where the manifestation of the disease is variable, there's a substantial chance for most children born with that disease for not only a good quality of life but a long life, that you're biasing the discussion in one direction. And then of course the counterexamples that are always raised are such

things as Tay-Sachs that are uniformly fatal and cause a great deal of suffering not only for the child but for the family. I wonder if you could comment on how consideration of those conditions affects what you have to say about prenatal diagnosis.

Beeson: I think you're right that it does make a difference what the condition is. Tay-Sachs is probably the most challenging example you could give to the kinds of arguments that I made. But I would argue that even with Tay-Sachs disease, the meaning of the experience is not inherent in the condition. It's the way we respond to it. I have actually had the experience of talking to mothers of children with Tay-Sachs disease who are opposed to prenatal diagnosis. Now they have more courage than I do; I have to admit that. The thing that makes these kinds of tragedies in human life so painful is that they isolate and divide us. They can bring us together and they can unite us. I'm just suggesting that probably even with diseases like Tay-Sachs there are more constructive approaches than prenatal diagnosis and selective abortion.

Tay-Sachs disease is very interesting because within the Jewish community there have been some great constructive uses of genetic testing, especially around the Orthodox Jewish community, Dor Yeshorim. They rely heavily on preconception testing, carrier testing, because they don't like prenatal diagnosis either, because they don't like selective abortion even for Tay-Sachs. So they rely on carrier testing, then they don't tell individuals what their results are. Because they have a lot of arranged marriages in this community, before the match is made, the DNA samples of the parties are examined. They test for a number of mutations, but carriers of recessive mutations are not stigmatized, because they are rarely informed that they are carriers. If both are carriers, they or their families are simply told this is not a good match. In this way, they are avoiding Tay-Sachs disease without resorting to prenatal diagnosis and selective abortion, or even labeling individuals as carriers. Of course, their situation is unique, and their solution won't work for most of us. So you are right to point out that the threat of Tay-Sachs disease makes it particularly difficult to reject prenatal diagnosis. I don't have simple answers to this problem. I think we need to make many changes in the way we offer care and support to parents who bear children with disorders. But we must also recognize that prenatal diagnosis carries with it negative consequences of its own, both for individuals and for our culture.

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Weiner: Any other comments? Well, let's get on with our next speaker. Paul Billings is an MD and a PhD. He's a visiting professor here in anthropology. He's executive vice-president, chief scientific medical officer, and co-founder of GeneSage, which is a new company "that seeks to translate the promise of progress in human genetics into solutions for healthcare providers and consumers." And he's also editor-in-chief of GeneSage's *GeneLetter*, which you can get at www.geneletter.com.

Prior to joining GeneSage, Dr. Billings was deputy network director and chief medical officer of the Heart of Texas Veterans Healthcare System. He's an expert in clinical genetics, the genetics of common diseases, and the impact of genetic technology on society. He's been a member of the faculties at Harvard Medical School, UCSF, Stanford, and as I mentioned he's currently visiting professor here. He's done a lot of advising to the National Institutes of Health, their joint task force with DOE on genetic information and insurance. He's been a technical advisor to the National Association of Insurance Commissioners and to the NIH Recombinant DNA Advisory Committee. He has testified on many occasions to Congress. I could go on, but the credentials are there. He's going to talk about anything he wants to. [laughter]

Billings: Thank you very much. I'm very happy to see members of my class on genomics and identity, a seminar I'm teaching this semester here. I think I'm the closest thing to a practicing scientist and genetic medicine provider on the panel. My comments are going to be directed at the medicalization of genomic information.

I thought I should preface my remarks by talking about what I get asked about when I go around the country to talk about the sequencing of the human genome, which is probably in some ways the biggest public relations event for science since we put somebody on the moon. We had a Rose Garden thing in June with President Clinton, Craig Venter, and Francis Collins. It was on the front of every newspaper. In fact, it was on the business page, the sports page, the social page, and the front page of virtually every newspaper in the country.

And then two weeks ago we had the publication of the sequence of the human genome, both in *Science* and in *Nature*. It commandeered the two major publications in the scientific discipline. I think it's only responsible of me as a physician-scientist to put my own spin on the many spins that have been given this data. So here's my spin.

First, the sequence of the human genome is not complete. We have a working draft of the sequence with lots of problematic areas in the sequence, areas that have not been refined. The utility of that sequence for researchers of whatever their discipline is relatively minimal at this point. I'm not saying it's zero, but if you're expecting to have your healthcare modified very soon by information in that sequence, I think you should relive that expectation.

The sequence has taught us that there is no blueprint of human development and human life hidden in the DNA sequence. I think that that's very important because that metaphor dominated the first few years of the Human Genome Project. We were going to find the blueprint for human life in the genome. It's not there. Craig Venter actually has led the reshaping of the language around that.

Second, and this arises from the fact that we only have thirty or thirty-five thousand genes, and we don't know exactly how many genes there are. There are probably going to be more genes discovered as we refine the sequence a bit more. But it is very clear that the number of genes in our genome is not substantially different than many plants, many animals. Though you may be absolutely sure that you are more complex than your pet poodle, at least when counting the numbers of genes in your genome, there is no justification for that supposition on your part.

Third, if we were to take a picture of this group here today, though we may believe that we are very unique in our own way and very different from one another, most of that difference is not reflected in the sequence of the human genome. We are about 99.9 percent identical. In fact, I believe it was Craig Venter--it might have been Francis Collins--has been going around saying we're basically all identical twins. Now those of you who are diehard reductionists and determinists will of course say that in that 0.1 percent lies the essence of what makes you you and me me, and so forth and so on, but you cannot count on that.

Finally, and I actually think this is the most interesting, a lot of what I've just told you is either self-evident or had been foretold by other data as we've been heading toward the sequence of the human genome. I think one of the most interesting findings is that the genome and the nucleus that contains the genome, at least one of the genomes--(there's another genome in the mitochondria)--the genome is an organelle; it is not just an inert piece of chemistry. Dick Lewontin was always so fond of saying that DNA is one of the most inert chemicals that he's ever run across. The genome has jumping sequences. There are sequences that clearly have moved around, much as Barbara McClintock described in plants many years ago. This movement is likely responsive to environmental factors. So lo and behold, the environment is important, and of course we knew that. So that's my spin on the information in the genome, and I'm sure there are people here who would be happy to debate me about some of that. But nonetheless, I think that's really some of the most important take-home messages.

Now let me turn to the medicalization of the human genome. Despite the fact that we have known for a very long time from twin studies and adoption studies and lots of other models for assessing this, that the genetic and genomic-- The terms *genomic* and *genetic* are often interchanged. *Gnomic* is a more comprehensive assessment of the genetic component of something. There is technology that now allows you to assess multiple parts of the genetic component at the same time. Genetics has a history of single gene, of Mendelian factor analysis. And so, though *gnomic* and *genetic* are not entirely interchangeable, I sometimes slip back and forth in that language.

We've known for a long time that virtually all medical conditions, and in fact all human variance, are not particularly genetic. Most of the important medical targets only have 50 percent of their variability or so explained by 1, 10, 100, all the

genes in the human genome, which means the other 50 percent or more has to be environmentally mediated. When you look at disorders like cancer and heart disease, 80 percent of the variance in the population around those kinds of traits is environmentally mediated and not genetic. Yet the genome project was sold around the fact that it was going to provide primarily health benefits. The fact is that there are no "disease" genes. As we search through the sequence that we've just developed, we don't find disease genes.

There are genes, there are sequences, and whether those genes actually cause or participate in abnormal pathology, and whether that pathology then results in the disease, have to do with a whole bunch of other complexities, both biological, social, economic and otherwise, which are not reflected in the genome, and which may be in fact far more modifiable in the long run than any technology to analyze or change the genome.

So the genome is not inherently medical. Medicalizing it clearly has been done, and that has been done, as I will suggest in my comments about the Human Genome Project, for purely political reasons, and to some extent socio-political and other reasons as well. But by medicalizing the genome, you are bringing it into a different kind of tradition, so you have to think about what's happened in medicine over the last let's say fifty years. And many, many wonderful things have happened.

For instance, we are much more concerned about caring for individuals and particularly ameliorating the suffering of dying individuals. And I'm speaking now primarily in my experience of medicine in the United States, western medicine. Let's leave out other traditions of medicine in the third world for now. We're better at alleviating suffering. We're more concerned about that. We train physicians better about that.

There has been some attention to the issues of paternalism in medicine, which didn't occur before. And there is a growing interest in evidence as a basis for medicine. Now that's partly in response to an economic situation, which is that it's costing so much to provide medicine in the United States. So evidence is in some sense being offered as a gatekeeper for change in medicine. But nonetheless, it's basically a good trend to be interested in data and evidence.

There is another trend, of course, that has been going on in medicine, which is the corporatization of medicine, the third parties, in a variety of ways, intervening in what was a long and fairly well worked out relationship with many variations in different cultures between people suffering and people who are thought to be experts in suffering--that is the physicians or healthcare providers. Now, by medicalizing genomics in the United States, you are also fitting it into what is in fact an obviously broken healthcare financing system.

There were many predictable outcomes, some of which I've been involved in studying. Many other people and Diane and Marcy have been involved in it in other ways as well: discriminatory uses of genetic information arising out of primarily healthcare settings, discrimination in getting healthcare financing in employment, and so forth, has been demonstrated. Privacy violations often related to issues around discrimination have been demonstrated, and inequitable access to the products of increasing information in genomics and genetic medicine. Maldistribution of this information is clearly apparent and will cause rather predictable problems because of its maldistribution.

My comments about the Human Genome Project are partly drawn from the work of some historians. I would refer anyone who's interested in it to the work of Bob Cook-Deegan, who's very much an insider in documenting much of the history of the Human Genome Project. I've been struck by the portrayal recently of the public Human Genome Project, which was initially funded--was it 1990 or 1989? I think the legislation was passed in '88; it was funded in '89. Jim Watson was the first director and established it as an office within the NIH. It is now a separate institute [National Human Genome Research Institute] and Francis Collins is the director. It has a large intramural staff as well as a big extramural portfolio funding scientists around the country.

It has recently been portrayed that the public Human Genome Project, funded to the tune of about 250 million dollars a year, is in some ways different and distinct from the corporate genome project, which came rather late in the game by Celera Genomics, a company founded by a former NIH scientist, Craig Venter, and funded by PerkinElmer, a large instrumentation manufacturer which makes and sells instruments to the government and to the private sector as well. These are two very distinctly different entities--different cultures, different attitudes. The focus has been around the privacy issue. That is, the argument has been that Celera has wanted to retain some of the information or some control over the information that it was going to publish about the human genome, because in fact its business model is dependent on that fact.

But I think that that obfuscates the similarities between the corporate and private genome projects more than it really represents true differences. For as you remember, the Human Genome Project came out for a couple of reasons. One is that Wally Gilbert wanted to do the genome project at Biogen, the company that he had founded in the eighties, and he wanted to sell back the information to the scientific community. And the scientific community didn't particularly like that model, or it didn't really want one company to have entire control of it.

A second reason for the founding of the Human Genome Project had to do with University of California politics. Bob Sinsheimer, who was at that time the dean [chancellor] of the University of California, Santa Cruz, wanted to establish

genetics in a bigger way, wanted to get a lot of funding, both private and federal funding for his development of the departments at UC Santa Cruz.

And finally the Department of Energy was at a point in its funding cycles where it had developed an enormous amount of data capacity and an enormous amount of expertise for doing large scientific projects, but there wasn't as much money in the pipeline for defense-related work as before. So there was a need for a new set of projects. These, amongst other factors, and this is obviously selective, coalesced in the federal genome project which is shared between the NIH and the Department of Energy.

The point I really wanted to make was that the scientists who are part of the federal Human Genome Project are in many ways indistinguishable from the scientists who work on the Celera project. Most of them are consultants, participants, some of them are even founders of their own biotechnology companies and have very important corporate ties. The government itself, of course, is a very significant holder of DNA-related patents. Because of the vagaries of the Bayh-Dole Act, much of that information may end up in private hands and actually contribute to the one big problem with the patenting, which is the continued increase in the cost of delivering healthcare in the United States.

Indeed, many of the shining examples of the public role in medical genetics and genetics now are not really that shining. For instance, the one that's touted a lot is the SNP [pronounced snip] Consortium, which was a public/private organization, lots of drug companies took part. The Human Genome Project was an active participant in the SNP Consortium, and they have brought out for public consumption lots of information, lots of data about the genome.

But there's another way of looking at this, which is that this was a strategy by those companies that were taking part in the SNP consortium to lessen the impact of the Celeras and Millenniums and others of the world. In fact, now companies like Merck are taking the information and patenting--having more defensible patents later on in the business cycle. And so it was really simply a different kind of collaboration in the academic/government/industrial complex.

Now finally let me just make a couple of comments about ELSI. As Charlie mentioned, ELSI is the ethical, legal, and social issues component of the Human Genome Project, represented from the beginning by 5% or so of the budget and has been enormously important for funding bioethicists in academic settings. It has created lots of university politics, which is a mixed blessing, I'm sure. I wonder what you would say if we went around here and asked what would you really want to get out of a bioethics analysis and function of a project like the Human Genome Project.

I've thought about this a bit, and I think we'd all like some sort of multidisciplinary review of the activities and concepts. We'd like some pluralistic discussion which brought in a range of voices. I think most of us would like some belief that this effort would go into some sort of control of application of the knowledge, and maybe we would even want it to influence the kinds of questions, what was to be addressed by the scientists, or at least influence their thinking about kinds of studies.

Well, that might be contrasted by another quote from Lori Andrews's book that was attributed to Jim Watson when he was talking about the ELSI working group, which is that he brought them together to talk, talk, and do nothing. There is a critique out there that says that in fact the ELSI structure and the bioethics discussion that it has fostered has really been more like corporate bioethics than it has been like effective control on the application of gnomonic knowledge and gnomonic science.

There is in fact no consensus on public policy which has been led by the bioethics community. They have been rather ineffective in engaging and dealing with many of the major players in genomics. In fact, one could argue that the public response to genetically modified food has been much more effective at catching the attention of some of the major players in the human genomics world than any of the great volume of work that the bioethicists have published. The very sad outcomes of the human gene therapy experiments at the University of Pennsylvania and newspaper coverage about work at the Fred Hutchinson Cancer Research Center—some of you may be aware that there's a series being published in the *Seattle Times* that started just yesterday of apparent scientific misconduct around stem cell use by Nobel laureates and a variety of other folks at the Fred Hutchinson center. The bioethics community has been rather ineffective at anticipating some of those problems.

So let me conclude then with just a couple of comments about what I've learned through all my experiences as an ELSI grantee and a provider of genetic information over the last decade or so of the Human Genome Project, and some of these other phenomena. One is, we have to end denial here. We are all going to be touched in one way or another by genomically informed biotechnologies, on our plates, in our food, in our healthcare environment, in our pocketbooks. And we ought to stop denying that that's going to happen. We ought to face that.

One way that I've been thinking about it--and I'm about to have another child, so maybe I'm thinking about this a little bit more--is that each generation is like a new species. Throughout human history, the differences between one generation and the next, and most of the differences between the species, have been culturally and environmentally determined. Now the last half of the 20th century showed us that atomic energy could annihilate the species, that we could create technology that could simply wipe us out, and that if we kept on being lousy stewards of the

environment that we might slowly wipe ourselves out. But basically these were environmental things that we were going to do to ourselves. Now we have the technology to actually alter the biology of the next generation. And I think we have to face the fact that that is a profound difference. That is a change.

Addressing those kinds of issues has to permeate the debate on human cloning, because to simply see this as irresponsible science because it's unsafe and requires a certain kind of human experimentation limits the profundity of what really is occurring.

The second thing that I think is very important, besides ending denial, is the fact that you need to question your information sources. There are enormous biases in the data and how it's spun, in the images that permeate textbooks. I once did a survey of images of genetic disorders in medical textbooks, and of course you always use the most archetypal case. But for most genetic disorders, the best pictures would be right out there, right?, because there are lots of genes involved in medical conditions out there, and they are absolutely indistinguishable from normal. So there are biases in images and biases in discourses. There are clearly groups that do not get their discourses into the databases as equally as others—the affected and disabled are one.

Third, I think we need to question the role of experts. I refer you to the work of Sheila Jasanoff and others about the role of expert scientists and their biases and their conflicts of interest in shaping the discussions and making decisions. I think we should not cede control of these very important decisions about technologies to the experts, however you might construct them.

And then finally I think we need to assert a new role for the community that extends past IRBs [Institutional Review Boards], human subjects committees, a sort of tokenism on the RAC [NIH Recombinant DNA Advisory Committee], and other kinds of organs of that sort. I think there's real movement here. For instance, the Internet and the linkage of the affected groups and the discussions that go on are part of an organic change. Information technology can democratize some of these discussions. The community needs more input into the targets of science, into its risk assessments, and of course into its applications. Thank you very much, Charlie, for inviting me. [applause]

Questioner: It seems to me that the topic of ethics requires a statement of should/should not and that predisposes some kind of a value system of the person who's making that determination. I have yet to hear any definition of your frame of reference, and by other bioethicists on: "Here is my value system, consequently here would be my ethic." What would be your value system?

Billings: Well, I don't think we should get into a big dispute about whether ethics has to come out of a value tradition or not. There is debate within the bioethics community about

that. There's this philosophical arm and then another might be called a utilitarian arm. The utilitarian people are more interested in practical issues of policy for the here and now, and the other in the principles of bioethics that have been well enumerated in a variety of ways or more out of a philosophical and value tradition. Those distinctions have a history, but most people play both sides, or at least try to play both sides. It's easier to get funded if you play both sides, amongst other reasons.

Questioner: So the emphasis is getting funded--

Billings: Well, that's part of it. We all have to make a living, and many of us need to demonstrate to our superiors that we can play in the current marketplace.

I think that you must be asking me in particular. I think that the dominant value of my view is my professional value, which is, do no harm. Being a medical geneticist and an expert in genetic medicine, if you will, I must not harm my patients. My interest in genetic discrimination came in part out of the fact that I was realizing that I was harming my patients, at least at that point in the history--that the cost benefit wasn't as clear cut as I had thought it was in terms of what people were getting out of coming to see me and getting genetic information. That's one thing. The other thing I would say is that I believe that information ought to be available to all those who want it, but it should not be used to hurt other people.

Questioner: Primum non nocere.

Billings: Right.

Evans: I'm Steve Evans. I'm the information services manager at the Ecology Center here in Berkeley, and I've been doing quite a bit of studying of these issues and actually have hosted a couple of seminars such as this one for visitors from departments of agriculture who have been doing work around genetics and food issues. When we had Professor Emeritus Richard Strohman in one of the panels, he was asked by one of these deputy ministers of agriculture who were very anxious to get this technology in and allay fears, "What are the risks of some sort of devastating consequence from some genetic experiment gone awry." And he had to quite honestly answer that he just didn't know. So in the face of that uncertainty, should not the precautionary principle rule?

Billings: Well, the discussion of the precautionary principle is a long one. It depends on what the target is. If you're talking about environmental releases of genetically modified things, that's one thing. If you are talking about individual human experimentation for people who are very ill and where the healthcare system has not been particularly effective to date in caring for them, I might argue slightly differently about the precautionary principle.

I have been encouraged that the discussion about what is required for the safe conduct of science, particularly science that does have a physical environmental rather than psychological environmental impact, has become more sophisticated. Because in fact, for both human experimentation and agricultural experimentation, our monitors, our abilities to assess what the impacts are are deficient and need the kind of investment and sophistication that we've been putting in the technology to make the alterations.

I'm frequently asked the question, What are the health impacts of genetically modified food? The answer is that I don't know. And the reason I don't know is because there aren't the tools to a) monitor it and b) to collect the data. There has been no interest paid, except in the post-introduction, in the classic tradition of the FDA where they introduce something into the medical establishment, or a company introduces something into the environment. They wait for a disaster or a series of disasters to happen and then they say, oh, well, let's not do that.

Evans: Well, they [FDA] are supposed to pre-test additives and so on.

Billings: I understand that. But I think you and I both know that the testing protocols and the evaluation of the data could be better and more sensitive.

Weiner: We're going to have a chance at the end of the next talk to have a general conversation on this. Let me introduce our next speaker, Dr. Marcy Darnovsky. She's research director for the Exploratory Initiative on the New Human Genetic Technologies. She teaches courses in the politics of science, technology, and the environment, including the course I mentioned before, Biotechnology and the Public Interest. She does this at the Hutchins School of Liberal Studies at Sonoma State.

She has served as editor of several journals, as co-editor of the volume *Cultural Politics and Social Movements*. She's written many academic and popular articles on social movements, the politics of technology, and media culture, and she's worked as an activist in a range of political movements. So you're going to bring us right into the present, I think.

Darnovsky: In lieu of a seventh inning stretch here, which I think we might need now, I'm going to ask for some shows of hands. I know that some of you are students of Charlie's and Paul's. So how many fall in that category? Oh my gosh! You can raise your hand more than once. How many of you are in the natural sciences? And how many social scientists and humanists do we have here? And how many are not presently affiliated with the university? And are there any other categories I should mention? You want to call out?

Weiner: None of the above.

Darnovsky: None of the above, right.

Let me ask you another question. How many people here have read some of the very recent media coverage about the efforts to clone a human being? Is everybody aware of that? And then how many people here could tell me some kind of reasonable definition of what germline genetic engineering is? Well, that helps me know what to talk to you about. What I want to discuss today are not quite the present applications of human genetic engineering, but some threatened near-term possible applications of human genetic engineering that I think pose questions of social responsibility that are paramount for us.

I think all of us in this room who have access to education and to the tools to become articulate citizens in whatever our roles as educators, as policy makers, and as citizens need to be very aware and very up-to-the-minute on the particular applications of genetic technology that I'm going to tell you about today, because it's moving very, very fast, and because there are some concerted efforts underway to put into play certain applications of human genetic engineering that have huge, and I believe horrific, consequences for all of us. The two technological applications that I'm speaking of are human reproductive cloning--producing a human being by means of cloning--and germline genetic engineering. I'm going to start by making a distinction and a definition here that I think will stand you in good stead as you read more and more in the media and in other places about what's coming down the line.

Germline refers to the germ cells. We're talking about sperm, eggs, and when we talk about germline genetic engineering also about early human embryos. What the particular application of germline genetic engineering means is that future children would be brought into the world after the manipulation of some of their genes for particular purposes, decided by the manipulators of those genes.

So it would be distinguished from the kind of human genetic engineering that is taking place today, which is sometimes called somatic genetic engineering. Somatic comes from the Greek word "soma"--body. Somatic engineering is what Charlie referred to as gene transfer experiments on human subjects, but people call it gene therapy. There are some hundreds of gene therapy, somatic genetic engineering trials ongoing, and Paul referred to the tragic case when a young man died as a result of participating in one of those gene transfer experiments.

This distinction between somatic genetic engineering and germline genetic engineering is really crucial because it means that if you're asked the question, "Are you for or against human genetic engineering?" The answer is, "Well, what do you mean--what kind?" "Are you for or against" is the wrong question. Because for all the problems that we can name that apply to somatic genetic engineering--the safety risks; the questions of efficacy, which are certainly important--it has got to work; the questions of access; and the questions about social decisions about allocating what are ultimately always going to be scarce medical resources--money and

medical talent-- In principle, I believe that somatic genetic engineering holds promise, and that if all these questions are answered in an affirmative way, I would feel that this type of human genetic engineering would be worthy of support.

By contrast, germline genetic engineering I think is a technology that needs to be taken off the table. It needs to be banned, and that's not something that I say or that I think one should say lightly. When you talk about introducing bans on particular technological applications, you have to have a really good reason for doing that. And I'm going to argue that this is one of the technologies that meets that standard. So somatic genetic engineering on the one hand, germline genetic engineering on the other hand--that distinction you need to remember.

When you talk about human cloning, an important distinction has to do with possible medical justification and benefit. The cloning of human embryos in order to derive stem cells that may some day be able to be used for therapeutic purposes is sometimes called embryo cloning. Producing a human being by means of cloning can be called reproductive cloning, and that's a very, very different thing. Technically it's very similar, because when you have perfected embryo cloning, all you need to do to turn it into reproductive cloning is to implant the cloned embryo into a woman's uterus. But the social meaning and the implications and the ethical meaning are very, very different.

So you can see that these are issues that require some kind of technological understanding to evaluate ethically and politically and socially. But you don't have to be a technical expert in order to reach value judgments about them. Just as Diane explained, prenatal screening takes its meaning from the social context and the social structures in which it is used, in which it's introduced.

We have to realize that the same is true of any technology, and at the same time that technologies aren't neutral. Many technologies have certain tendencies built into them. So certain kinds of energy production have built into them a tendency towards centralized systems of authority. Nuclear power, for example, requires protection against poisonous wastes over many, many years. In an analogous way, human germline engineering and human reproductive cloning have built into them the tendency to foster the kinds of control of some human beings over other human beings, that are objectionable and would be objectionable to most of us who believe in a longstanding tradition of human dignity and human equality that we can derive from many different value systems.

Now the recent media coverage of human cloning has something in common with the perhaps less spectacular coverage over the last few years of human germline engineering. I'm going to hold up two examples. In February [2001], this issue of *Wired* magazine came out, and it says on the front, "Someone Will Clone a Human in the Next Twelve Months." You see the cute Caucasian baby on the photocopy machine? "You again" is the name of the article. And then just a couple

of weeks later, *Time* magazine had another cute baby on its cover--"Human Cloning is Closer Than You Think." Now you look at these titles and you think, Oh, I guess that's going to happen. It's really on its way. It's practically a fait accompli. And that's been a theme of the media coverage of human cloning and human germline engineering.

The media coined the term "designer babies" to describe the babies that would be born after being genetically enhanced by the techniques of germline genetic engineering. And the articles--we've collected a lot of them--make a very strong case that there is a mantra of inevitability here. In fact, human cloning, as far as we know, has never been done, and human germline engineering has never been done. So we have an opportunity here to evaluate its social, political, and ethical implications in a real way, in a widely participatory way: Are these applications of these technologies that we should be favoring? Or are they applications that we need to resist, that we need to reject, that we need to take off the table?

Well, I want to tell you how I came across these questions, and I'm going to start with a quote that maybe some of you have heard before, from a scientist named Lee Silver. How many people here have read Lee Silver's book called *Remaking Eden*? A few of you. I came across this book in the course of teaching a class called Biotechnology in the Public Interest. I was following the issues of genetically modified food crops as they were emerging, first in Europe and then in the United States. I was also interested in what many people have seen as a resurgence of genetic and biological reductionism.

For example, I was teaching my students about the book *The Bell Curve* and the responses to it. The book argues that different racial groups have different intelligences and that African-Americans are less intelligent and Asian-Americans are more intelligent than Caucasians and so on. I picked up Silver's book, *Remaking Eden: Cloning and Beyond in a Brave New World*. It came out in 1997, just after the birth of the cloned sheep in Scotland. Lee Silver is a molecular geneticist at Princeton University, a prestigious institution of course. This, however, is a popular book, a key text in what I was soon to learn was a public campaign to make these technologies of human germline engineering and human reproductive cloning acceptable to the American public.

One of Lee Silver's techniques, which he relies on quite, often, is to spin out scenarios of what the future will look like if we accept these technologies. And he is very, very blunt. Here's some of what he says in his prologue: "The most striking difference" [between 2350 and now] "is that the extreme polarization of society that began during the 1980s has now reached its logical conclusion, with all people belonging to one of two classes. The people of one class are referred to as *Naturals*, while those in the second class are called the *Gene-enriched*, or simply the *GenRich*."

Skipping a few paragraphs: "The GenRich—who account for 10 percent of the American population--all carry synthetic genes. Genes that were created in the laboratory and did not exist within the human species until twenty-first century reproductive geneticists began to put them there. The GenRich are a modern-day hereditary class of genetic aristocrats." Skipping a few pages:

"All aspects of the economy, the media, the entertainment industry, and the knowledge industry are controlled by members of the GenRich class. GenRich parents can afford to send their children to private schools rich in the resources required for them to take advantage of their enhanced genetic potential. In contrast, Naturals work as low-paid service providers or as laborers." And on the following page:

"If the accumulation of genetic knowledge and advances in genetic enhancement technology continue at the present rate, then by the end of the third millennium, the GenRich class and the Natural class will become the GenRich humans and the Natural humans--entirely separate species with no ability to cross-breed, and with as much romantic interest in each other as a current human would have for a chimpanzee."

He ends his prologue saying, "There is no doubt about it. For better and worse, a new age is upon us. And whether we like it or not, the global marketplace will reign supreme."

So I read this book, and I was stunned. I told myself, okay, this guy sits in his mouse lab all day, and he comes home at night, he turns on the computer, and he indulges in mad scientist mode. I actually did manage to convince myself that I didn't really have to take this seriously as a political or social issue. But I soon learned to my dismay that I was wrong in that conclusion, that Lee Silver is part of a loose network of very influential scientists, that includes Nobel laureates, who just in the past several years have decided that they are going to begin what really amounts to a campaign of advocacy for these technologies of germline enhancement and reproductive cloning.

And they're taking this campaign on the road. They've been on national television repeatedly. They're at public and scientific conferences. They're writing in scientific and mainstream media journals, *Time* magazine and others, and their message is very consistent. Lee Silver is the most blatant in some ways, but I could read you lots of other quotes where you have prestigious people from prestigious institutions talking about breeding human beings and making your kid brighter than

any other kid on the block, and how parents are going to be held responsible if they don't make use of these technologies, and so on.

And it's not just in their pronouncements. They are working with institutions like the World Health Organization and others to form policy on these questions. In 1998 there was a public conference at UCLA that was called "Engineering the Human Germline" and about a thousand people attended. It was given front page coverage in the *New York Times* and the *Washington Post*, very approving coverage. And the organizers of the conference said that the purpose of it was to make these technologies acceptable to the American public.

So as I learned more about these things, I realized, okay, this isn't science fiction. We know about the successes of research with transgenic and cloned animals. It's one in several hundred successes, but nonetheless they have been able to produce these genetically engineered and cloned animals. As I learned about the institutional momentum, as I observed the building cultural momentum, I realized that it's not far off, not something that's fantasy or science fiction, that it's coming up pretty quickly, it's near term, and that it's an agenda; it's not just speculation. For some people this is, for whatever reason--and it's very interesting to speculate about why--an actual social and political agenda.

I looked around to see who was paying attention to this, who's working on this. Are there environmental groups that are interested in this? Are there bioethicists that are interested in this? And what I found a couple of years ago was that there is a discussion in the bioethics literature on these topics. As Charlie told you at the beginning, it seemed to me that the bioethicists were specializing in not drawing lines, or were shifting the line rather than helping us see where lines do need to be drawn. We can talk about some of the bioethicists who actively support these technologies.

There were a couple of groups (Paul's associated with one of them--the Council for Responsible Genetics in Cambridge), which have been tracking these issues for a long time. But among civil society organizations, public health, women's health, advocates for children's welfare, environmentalists, there was very little awareness about these issues, and certainly little among the public.

Where we are now is different than where we were a couple of years ago. Because of the headlines I think people are aware that human cloning could be close. And so what used to be filed in the "mad scientist" part of people's brains is slowly moving out of that category, and people are starting to take it seriously as a near-term prospect. But what I don't think has happened yet, and what I'm urging all of you and everyone else I talk to to do, is to really engage these technologies with your critical faculties of political, social, and ethical analysis. And to do it in a way that allows the possibility that this is something that might be a very urgent matter for all of us to act on.

Now, a lot of people are reluctant to oppose these technologies because they believe that there are medical benefits from germline engineering and reproductive cloning specifically. It would be a very different kind of political issue if those claims of medical benefits were true.

I don't have time to go through this argument in detail, but let me briefly explain why I don't think germline engineering can be justified medically. When the advocates of germline engineering talk about "germline therapy," what they usually mean is the prevention of serious gene-related conditions. The appeal to our sympathy for people who carry life-threatening genetic mutations and want to avoid passing them on to their children. But the claim that germline engineering is necessary to achieve that end is quite strained.

Those at risk of having a child with a serious genetic disease can already do that, using one of several screening and selection procedures. They can rely on prenatal screening and abortion, or use a more recently developed procedure called pre-implantation genetic diagnosis, or PGD. With PGD, embryos are created by IVF, and then screened for the genetic configuration in question. Only embryos not affected are transferred to a woman's uterus.

Diane has discussed the very serious ethical questions raised by these selection technologies. Who decides which traits or conditions should warrant intervention to keep a person from being born? Tay Sachs? Cystic fibrosis? Down's syndrome? Cleft palate? A propensity to obesity? to being gay? It's obvious that the line between therapy and enhancement is very blurry.

We need a broad and deep, thoughtful and thorough discussion of these questions. But in assessing germline engineering, the bottom line is that people with serious genetic conditions who want to bear children not affected by them can do so--without using germline engineering.

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Darnovsky: Reproductive cloning is often presented as just another infertility treatment. Here again, I think there's an argument that you can go through in some detail. But the key point is that there are very, very, very few couples in which neither member produces viable gametes--the man doesn't produce viable sperm, the woman doesn't produce viable eggs. Where one partner's gametes are inadequate, donor sperm and donor eggs can overcome infertility problems. Of course there's always adoption as well. So the arguments for reproductive cloning as fertility treatments are quite strained.

The bottom line is that there's no medical necessity for either human germline engineering or human cloning. The benefits are very, very few and far between, if they exist at all.

That's actually become an argument that the proponents of these technologies often don't deny. And so they've become, over the past few years, much more explicit about the fact that what they're really interested in is enhancement. They're really interested in producing improved babies, perfect babies. They talk about seizing control of human evolution. They talk about specific enhancements that they would like to see parents be able to provide for their children: They talk about greater height, increased muscle mass, improved memory, something they call "hyper-intelligence," and many other traits. They acknowledge that these will be expensive technologies that will be available only to the affluent, and that they are likely to lead to the kind of genetic castes that Lee Silver talks about.

There is a kind of advocacy that Lee Silver epitomizes that just kind of shrugs and says, well, we can't stop it; that says we should extend the free market to these new reproductive genetic technologies; that this should be up to parents; that it has nothing to do with the kind of eugenics we saw in this country in the early part of the century or in Nazi Germany because it's not coerced by the state. It's about voluntary parental choice. Even though they are quite blatant about saying, yes, we'll see the emergence of genetic castes, they disavow the characterization of their project as eugenics.

There is another group of people, professional bioethicists, who also acknowledge that these technologies threaten to produce genetic castes, but who believe that this should not be completely left to the market. They argue that the state will have to intervene to make sure that there is some kind of equitable access to these enhancement technologies. Some of them have gone to many hundreds of pages to propose models for how this might happen.

Perhaps my favorite one is this: We're not going to be able to prevent affluent people from accessing these technologies. But we can't allow the affluent to completely monopolize genetic enhancement, not only because it's unethical, but because it would certainly destabilize democracies if poor people came to see that we're going to inscribe inequity in the genome, and that they're never going to be able to have their children enhanced, have their memories improved or whatever, and we can't have this. It would close the "safety valve of upward mobility," and that would be dangerously destabilizing. So they came up with the idea of a genetic lottery. Those who can afford it go to the fertility clinics and select the enhancements that they want for their children; some of the poor folks will have access through genetic lotteries.

In my snider moments I call the first group "eugenicists with a shrug" and the second group "eugenicists for social responsibility." [laughter] I think their recommendations boil down to a very similar vision of the human future. I think it's one that is an abandonment of principles of equality and human dignity that go back to the Enlightenment and the French Revolution. This is not an issue that you have to be some kind of radical critic of the free market or capitalism to go along with.

I was interested to see just a few weeks ago that several very conservative commentators, including George Will and Dinesh D'Souza, have taken this issue up. Dinesh D'Souza has a very eloquent article in *The National Review* in which he says that the kind of control of some human beings over other human beings that we're talking about here is the kind of control that we last saw during slavery. He goes to great length about the Lincoln/Douglas debates and the need for something like the abolitionist movement to control these potentially disastrous technologies. They must be taken off the table.

I'm about out of time, but I want to address one last point. I'm speaking to you today much more as an advocate than as an academic. I think there is really important and interesting academic, conceptual, intellectual work to be done on many, many aspects of these issues, in the natural sciences, in the social sciences, in the humanities. There are debates raging among philosophers in Germany and France. There is a best-selling novel out in France called *Elementary Particles* that has sparked debate about these issues. There are certainly projects here to keep an army of graduate students in sociology and anthropology and public health busy for a long time.

I think there's also work for all of us as citizens and activists. Let me tell you just a word about the Exploratory Initiative on the New Human Genetic Technologies. What we've been doing over the past year, since we began, is talking to key figures in religious denominations and civil society organizations: environmentalists, women's health/reproductive rights groups, and others about these issues and about the need for some kind of response to them. We would like also to bring students into this effort, and first of all to help them study up on these issues, and to ask them if this is the kind of effort that makes sense to them. Because it is, we believe, a technology that will shape in dramatic ways the possibilities for our future. Toward that end we're having a meeting here on campus next Thursday.

A final comment is that over my lifetime there are a few other times when I have acted as an advocate on issues of the democratization of technology and science. For all that effort, I still don't know exactly what that means. But I know that technologies shape our lives just as much as do political candidates and policies. And I know that it's important that we find ways to intervene in the applications of technology to produce the kind of human future that we want.

As I've been working on this issue, I've talked with groups in living rooms and college classrooms and activist organizations and so on. What I wasn't prepared for and what's been gratifying in the context of a really horrifying prospect is that this conversation reaches people in a different way. It touches people deeply because it's about our children, and because it's about what it means to be human, and what kind of human future we want to work toward. It raises the questions: What does it mean to democratize technology? What does social responsibility around genetic science mean? The last two are interesting conceptual and

intellectual and political questions. The others are more ethical, value-oriented questions. That combination, in my experience, produces very thoughtful, very deep responses. That's something that for those of us taking on this issue will keep us going. Thank you. [applause]

Weiner: Thank you, Marcy. Thanks to the other panelists. It's time for everyone to talk-- specific comments on the last talk by Marcy Darnovsky, or comments on the issues in general, or ones that are relevant that we haven't discussed.

Questioner: There was a man in Germany sixty-nine years ago who would have loved to work with genetically altering fetuses. He was trying to breed a super race. I've got a theory that there's going to be another guy like Hitler coming around.

Darnovsky: That would of course be terrifying. But I don't think we need Hitler, and I don't want to have anyone think that I'm calling the people who advocate this Hitlers. I don't think they're Hitlers. They believe that they are bringing salvation to the human race. They believe that they are improving humanity. Daniel Koshland, who spoke at a symposium here on campus about two years ago, when this question came up, he said the reason that he supports human germline engineering is that we've created a society that is so technically complex, now we must use germline engineering to create human beings who are smart enough to manage the technically complex society. [laughter]

Charlie, you talk about technical sweetness. The advances in genetic science in the last fifty years have been so dizzying, stunning, that I think people who are at the center of the fray perhaps have lost their bearings on some of these large social issues. We don't need Hitlers in order to make these technologies very, very threatening.

Questioner: Of course not. But I'm just saying that if it falls into the wrong hands, or somebody is going to use it the wrong way--

Weiner: Well, that question was addressed by leading bioethicists. I can give you the names of several. Arthur Caplan, Glen McGhee have published statements about what's wrong with eugenics. Their argument is that the problem with the old eugenics, which means the Nazi eugenics or the eugenics in this country earlier on, is that it was state coercion. But the new eugenics would be voluntary choice. If you want to improve the life of your child and give your child every advantage, you send your child to a private school, ballet lessons, tennis, all those things that you want to give your child to have an advantage if you can afford it. So why not, if you can afford it, give your child better genes, so-called, or enhance that child in some way. And the next thing they say is that this is a question of autonomy, of personal choice. If you've got the money, you have the ability to do it. So that's how they address the issue. By the way, the people who have made these statements are very often the people who are on these various ethics boards considering these kinds of issues.

- Lomax: Geoff Lomax, School of Public Health. I think the upshot of the science is that there's very little credibility to these claims of human genetic engineering. I think the flipside of the coin on the human genome and the science is that it might be telling us in the near term the most relevant factors in terms of improving the condition of humans are the social and environmental determinants. Does the panel have any thoughts on the bright side? Maybe we can make progress on the other issues that we all care very much about.
- Billings: Spoken like a true public health advocate, Geoff.. [laughter] Well, there's a cynical view of the genetic manipulation phenomenon, which is that the GenRich will do it to themselves and kill themselves off by all the manipulation, and all us Naturals will stay behind and take care of the environmental things.
- Lomax: [unintelligible]
- Billings: Yes, exactly. And then they'll be tittering as the rich manipulate themselves into extinction. But I think that we should not ignore the fact that some progress in human genetic knowledge will in fact be useful in refining debates about environmental mediation of variance of traits, of human phenomena. The fact is that individual variation has been a confounder in environmental analysis for some time, and we'll be able to get some handle on that and so refine studies.
- There's a frustration, vexation that we've spent so much money on all these social programs, though in fact relatively we haven't spent that much money on these social programs, and we haven't really fixed anything. I think that that's a political argument more than based in fact, in that creativity and improvement in how we spend money for social and environmental mediation will, in effect, yield rather profound results in the next generation.
- Weiner: Diane.
- Beeson: Yes, I'd like to add one quick comment to that. I think you're on the right track and that we do have to be careful that we don't believe all the hype and give it too much legitimacy. The reason Europeans are so much more sophisticated and critical about all this, I think, is because they're more committed to some kind of democracy. I think one of the most important things we could do to stave off some of the worst offenses in this area is to fight for things like universal health care. To the extent that we can establish the principle that we share equally in the benefits of science, we have a much better chance of not letting this stuff run wild if they ever should do more than just produce a lot of hype.
- Darnovsky: Could I make a comment? It is really important not to believe some of the more grandiose claims of the advocates. At the same time I think it's really important to take seriously that they can cause a lot of damage both biologically and politically no matter what their eventual accomplishments. You only have to look back at the

pre-Third Reich eugenics movement that was very popular, both in this country and in England, to see that damage can be done in the name of eugenic and genetic science. There's a very important piece of conceptual work that needs to be done, looking at the analogies and differences between that early twentieth century eugenics movement and the current one, which we sometimes call "techno-eugenics." One of them is that scientists of both eras have been willing to go way out on limbs to make claims about the science of their times. Another is that both then and now there's no clear left/right political division on these issues. In the early part of the twentieth century, eugenics was promoted very strenuously by liberals as well as by social conservatives. We have a few very libertarian/left[ist] promoters of techno-eugenics now as well. So I think it important not to take the hype too seriously; also very important not to discount the damage that can be done.

Weiner: *Genetic Crossroads* is the online newsletter that Marcy edits. What's the site for that?

Darnovsky: If you send an email to teel@adax.com, I'll put you on the subscription list for the newsletter.

Wofsy: Leon Wofsy, I'm emeritus in molecular biology.

I think it's very, very important not to be in denial about the developments that have taken place in genetics over the last couple of decades. In my opinion, these are amongst the most significant advances in science in human history, and they are, as Paul points out, going to have enormous implications for the future.

So far, the Human Genome Project has come up with something very different than was anticipated by a lot of genetic determinists. It has knocked for a loop notions that one-to-one relationships between genes and the characteristics of fruit flies would pertain in much the same way to defining humans.

One has to look at the politics of people who attempt to use genetics to advance theories of social behavior and justify discrimination. They don't have a basis in genetics, as *The Bell Curve* insisted. The more information that develops, the clearer it is that there is an intimate relationship at every level between genetics and environment and that both are very important. The more we know about both, the better off we'll be--with one proviso.

And that brings me to the question of ethics. I think in general that the notion that the bioethicists are going to straighten out science is cockeyed, because all disciplines operate under the same social pressures. What you get to, fundamentally, is the relationship between these technologies and what are the values and the priorities of society.

In my opinion, what is driving this terribly reactionary stuff about behavior based on genetics, and the like, is part and parcel of the biggest problem that faces society today. And that's the problem of corporate control, of corporate greed, from the patenting of genes to the business of trying to bar generic drugs for dealing with the AIDS epidemic. In my opinion, what's really at issue is putting control of human health and human destiny in the hands of the people, and against what is happening more and more, total corporate domination over basic human health needs and rights. They own your genes; they own and patent everything. The biggest ethical issue of all is not how one human being behaves, but how society handles the questions of human health, in the interest of people and against corporate privilege. [loud, sustained applause]

Weiner: Well, that's a reminder that before we leave this room, we ought to talk about the idea of social responsibility, what that means for scientists, for citizens, for individuals everywhere. Because we're not spectators. We're not just talking about this in some academic or political way, as it happens. The point of this discussion, and the point of anything at a university is to help people understand so that they learn on their own and participate. So it would be nice if some people could address in the discussion what you do. Do you get to vote on this, or what?

Questioner: There's a lot of discussion about the bigger picture and what effect this technology is going to have on society, and what effect the individual that's genetically modified is going to have on society. Have there been any discussions about how is the genetically engineered individual going to feel living in this society, not knowing what personal traits are bought and what is actually them?

Weiner: That's a good question. Marcy, I think you could address that.

Darnovsky: Well, I think your question contains its own answer. Think about what it would mean for parents to go and scrape together their money because what was really important to them was having a child with musical abilities. And the child comes along, grows up, and all she wants to do is paint. She doesn't want to play the piano. Do the parents sue the fertility clinic? [laughter] Seriously, what does that do to family relationships? What does it do to our relationship with our children?

I have a small child, and people told me before I had a child that one of the big challenges of being a parent is helping your child emerge as an autonomous being. How would that be affected by having a child who either had some genes transferred into him or her as an embryo, or a cloned child who was growing up with a genetic legacy that we've already seen in the world? What expectations? It's not as if unreasonable parental expectations don't exist, but I think if you inscribe it genetically that it would be greatly exacerbated.

A corollary of your question about what would be the effects on a so-called enhanced child or cloned child: What would be the effects, in a world where those

technologies became widespread, on children who were unenhanced--who are the Naturals? What would it mean to their concepts of themselves and their ideas about their future possibilities?

Handwerker: My name's Dan Handwerker, and I'm a grad student here. Diane Beeson talked about prenatal screening and how a primary motive now is for eliminating female fetuses. What about the useful aspects of fetal screening, such as ultrasound being used to detect heart disease in the fetus which can be operated on perinatally, or in PKU, phenylketonuria, where with early diagnosis you can treat the child early and help more. My question is, do you see a place for fetal screening at all, or do you only see the more negative aspects of it?

Beeson: I see an important place for prenatal screening and testing in a world where it's every person for themselves, and we don't care about the sick, and we don't support them, and we don't have any consciousness about how valuable the life of a person with a disability can be. Look, I don't know what I would do or even what I would want my daughter to do. I'm just tired of all of our brilliance and resources being put into putting us in really difficult positions with our choices.

Why don't we use some of our talent and some of our resources to create genuine options: where a pregnant woman would know that if she wanted to go through the pregnancy without the trauma of prenatal diagnosis, that whatever child she produced would still be loved and nurtured and be given the support that we can give it; where we spend all our scientific expertise on caring, on healing, on curing.

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Billings: I'd like to point out one other back door that's created by what you said, which is that there has been a trend over the last several decades to medicalize pregnancy. And therapeutic interventions late in gestation, while not overwhelmingly common, are attempted. Many of them actually fail, but they have been attempted for heart disease and a variety of other things when, on the whole, caring physicians thought that developmental harm would result if you didn't make the intervention until the baby was born.

So there has been a tendency to medicalize pregnancy, and this tendency has been going on earlier and earlier in pregnancy. Of course what this runs up against is the woman's right to choose and the issue of abortion, because if you define the fetus as an individual which requires medical treatment, it becomes harder and harder to then justify its termination in abortion.

Beeson: And you get an adversarial relationship set up between the fetus and the mother before the baby's even born.

- Billings: Medicalizing the fetus has actually been used by the germline gene therapists, particularly French Anderson, as a way of saying, Well, we're going to treat fetuses that need medical treatment earlier in development, and that treatment may inadvertently then cause a germline genetic change. But the ethical rubric that he uses is that of the fetus as a patient and the honor of medicine in its attempt to treat individuals as the avenue to germline genetic change.
- [Joe]: My name's Tommy [Joe]. There's a tribe whose genetic code is owned by a corporation. What are the implications of that? The implications are that yours and mine can also be owned by a corporation, and so anything we allow a corporation to do in relation to our genetics affects everyone.
- Weiner: Who wants to respond?
- Beeson: Well, you raised a point that follows up on Professor Wofsy's point: probably the most important thing any of us could do if we care about the issues that Marcy is raising is we've got to challenge corporate power in this society. One interesting idea is that corporations are defined legally as persons, with all the rights of human beings. Whoever thought that up? And why are we tolerating that? If we got rid of that, we'd be protected from a lot of the things you're worried about.
- Weiner: Let's see--other hands here?
- Thayer: I'm Dr. Michael Thayer from UCSF. One of the most profound aspects of the sciences is that they are universal, fungible. For instance, those fellows who want to do cloning are going to do it in a private setting in Italy. It's not really so much whether it's the corporate people who control or whether some dictator arises who controls or whether the government controls it. One of the most profound issues that needs to be addressed is the universality of this technology. The biotechnology industry uses very cheap labor because the amount of actual sophistication one needs to transfect *E. coli* and grow it in vats is no greater than in making beer. This isn't high-tech. Anyone can start doing this at any point, in any place, outside of this country, inside of this country, under any aegis, and I think that that needs to be really confronted.
- Beeson: The U.S. is holding the entire world back in terms of all kinds of international treaties about controlling this kind of stuff. It's true that we may not ever be able to control all of it, but look at the role that the U.S. plays in the United Nations, with all these environmental decisions--
- Thayer: Let me give an example. I did research in China. I went into the real hinterland where the standard of living is something like maybe twelfth century. They essentially don't know anything about hygiene. But they have ultrasound machines. And you know why.

Weiner: They want boys.

Thayer: That's right. The women get their ultrasound, and if it's a girl they get an abortion. That's what I'm talking about.

Darnovsky: I think this is a very important point. It's not going to be enough if we get the Institutional Review Boards to say no human germline and no cloning. It's not going to even be enough if we get federal legislation passed in this country, which we desperately need and we don't have.

This recurring theme of inevitability that the advocates keep repeating really flies in the face of the fact that there are already several dozen countries in the world that have outlawed human reproductive cloning. In Japan, if you try to clone a human being, you go to jail for ten years. In the United States, there are no federal laws against human cloning. You're not allowed to use federal monies if you're a researcher, but there are no laws. There are also many countries in the world that have outlawed human germline engineering. So policies can be put into place. As I described by explaining the distinctions to you, there are some pretty bright lines, technical lines, that can be drawn that distinguish the really horrific technological applications from those that are either worthy of support or at least less consequential.

We need those kind of laws. We need them in every country. We also need some global instruments, treaties, or bans. We don't want to put in place a system where there's eugenic tourism, where you can go to some island or onto some cruise ship to have your designer baby. We need bans on human reproductive cloning and germline engineering, and effective regulation for the acceptable genetic and reproductive technologies. That's a big project: putting in place a system that will let us reap the benefits, the real promises, of genetic knowledge without risking these horrible, horrible futures that we want to avoid.

In order to put these policies in place, we're going to need a social movement, and that's something that is already starting to bubble. I think we're at the very early stages of something that could easily be as big as the environmental movement or the women's rights movement. You point out that these are technologies that you can basically do in your bathtub like making beer. Yes, there may be some violations of the laws once we have put them in place. We have laws against a lot of things that we don't like. We have laws against murder. We have laws against incest. Now those laws get broken, but think what the world would be like if there were no laws against murder, and there were no laws against incest. It would be a very different world; similarly with these genetic technologies.

Weiner: Let me just read a news bulletin, which will show you the urgency of this. This is dated Saturday, March 10th, 2001 *L.A. Times*. The title of the article is, "Forum on Human Cloning Turns Raucous," by Richard Boudreaux. "Rome—In a scientific

forum punctuated by shouting matches, three doctors from the United States, Italy, and Israel told critics Friday that nothing can stop their plan to create cloned children and said that more than 600 infertile couples have already signed up with them. The would-be pioneers disclosed little new information about their semi-secret project, announced six weeks ago, and spurned the idea of submitting to ethical or scientific oversight by any government." [whistle from audience] It goes on.

There were stories on the wire services yesterday about responses in different countries, including China, to prevent this kind of thing. So it is urgent. There are ways to do it--some through international agreements. All of that is necessary to counter the argument of inevitability, because inevitability leads to acquiescence and passivity and discourages public participation and discourages scientists themselves from speaking out on these issues.

I feel that this is just the beginning of the kinds of discussions that we need to have, and I guess I'll consider that a way of wrapping this up because it's time that we do. [loud sustained applause]

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