



Presidential Commission
for the Study of Bioethical Issues

TRANSCRIPT

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DR. GUTMANN: First of all, welcome, everybody and good morning.

I am Amy Gutmann and I am Chair of the Presidential Commission for the Study of Bioethics, and I am also President of the University of Pennsylvania, and on behalf of myself and our terrific Vice Chair, Jim Wagner, who is President of Emory University, I'd like to welcome you to the first day of our deliberations, and I also am delighted that we're in San Francisco, and I have to give a very special thanks to Dr. Stephen Hauser, for enabling us to be at the UCSF Campus.

This is our eighth meeting of our Commission and before we begin, and I introduce where we are now with the Commission's deliberations and where we expect to go, I want to recognize the presence of our Designated Federal Official, who is also our Executive Director, Val Bonham. Val, will you stand up, please? Thank you.

So, let me begin just by a very quick recap of where the Commission has come from, and this is by way of also thanking the Commission for very hard and good work.

The past year and a half, we have produced three reports.

These include the first report, which was entitled "New Directions on Emerging Field of Synthetic Biology" and our second report, which was entitled "Ethically Impossible," which was the result of the investigation of what happened in Guatemala between 1946 and 1948, a dark chapter in the history of the U.S. public health services STD research.

In December, the Commission produced its most recent and third report, entitled "Moral Science," which was an outgrowth of having looked historically at some of the things that had gone wrong in U.S. Federal sponsored research, and really an attempt, I think a successful attempt, to focus on ensuring that human subjects would be protected from here on, in federally sponsored research, and indeed, the Commission found that nothing such as what happened in Guatemala could happen today in federally sponsored research, but the Commission also made some, indeed, 14 recommendations, for how human subjects could be protected better, moving forward.

I think as a Commission, we're all proud of those accomplishments, but we're also hard at work to do several new reports.

And so, turning now to the future, we have a very exciting and very full year ahead of us.

We begin today, focusing on genome sequencing and tomorrow, we're going to begin also looking at another report that we will do down the road, which is called tentatively, "Neuroscience and the Self," both of which are topics for this meeting.

I want to also remind our Commission Members and everybody here today, that we have yet a third report, that we've been asked to do by Secretary of Health and Human Services, Kathleen Sebelius, which is a report on the development of medical counter-measures for children.

And this issue gained significant public interest last fall, when another Federal Advisory Committee recommended pediatric testing of the anthrax vaccine.

So, we have been asked by Secretary Sebelius to look in depth at the issues, the ethical issues surrounding testing children for vaccines.

We will also do that at our next meeting, which is in May. We will take on that issue.

So, today, we're going to focus on our genetics project. We're going to focus on issues related to genome

sequencing and privacy and access to the data available, as the result of whole genome sequencing and its use in research and clinical care.

Before we get started and before I ask Jim if he'd like to make some introductory comments, there are two things that I would like to do.

One is how we're going to take comments from the audience, because we welcome comments from the public.

At the registration table out front -- where is the registration table?

Right out there, or if you ask any staff member, there are cards, there are comment cards, and all we do is ask that you write your comments down on the card, hand the card to any staff member, who are wearing badges saying "staff."

Will the staff members please stand up, so I can also thank you? Those are our staff members.

The staff will -- if you give the cards to the staff, the staff will give the cards to Jim or me, and we will read your questions and I hope, answer them.

One other thing I want to do is ask members of the Commission to go around the table and introduce

themselves, and why don't we start with Dr. Sulmasy?

DR. SULMASY: Dan Sulmasy from the University of Chicago, Department of Medicine and Divinity School.

MS. ALI: Hi, I am Lonnie Ali, wife of Muhammad Ali. I'm a care giver and Parkinson's advocate for research.

COLONEL MICHAEL: Nelson Michael from the Walter Reed Army Institute of Research.

DR. ATKINSON: Barbara Atkinson from the University of Kansas Medical Center.

DR. HAUSER: Steve Hauser from the University of California, San Francisco.

DR. GRADY: Christine Grady from the NIH Clinical Center.

DR. KUCHERLAPATI: Raju Kucherlapati from Harvard Medical School.

DR. FARAHANY: Nita Farahany from Vanderbilt Law School and Philosophy Department.

DR. GARZA: Good morning, Alex Garza from the Department of Homeland Security.

DR. GUTMANN: Jim, why don't you say a few words? Thank you.

DR. WAGNER: Well, Commission, it's good to be

with you again. Amy, thank you very much for the introduction.

We miss, of course, Anita and John with us, and hope they'll be joining us in our deliberation soon.

Over these next couple of days, we'll be looking at promising advances in science and technology of genetics genomics, today, and tomorrow, neuroscience.

Both are areas that are realizing great potential to address disease and even better inform us about what it means to be human.

But they carry, like all advances, they carry with them, certain responsibilities and attendant concerns about ethical use, in particular, we'll be learning a little bit about privacy issues that are a little more expanded, I would say, than conventional privacy issues about how it is one draws the lines around information to keep it private, because for the first time, as it seems to me, these privacy issues about bio-chemical and behavioral processes or involving questions actually involve fundamental questions about what it means to be a person.

So, I think we're in for some very interesting presentation and conversation this morning.