Presidential Commission
*for the* Study of Bioethical Issues

# TRANSCRIPT
# Opening Remarks

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**DR. GUTMANN:**

Good morning, everybody. I'm Amy Gutmann and I'm President of the University of Pennsylvania and Chair of the Presidential Commission for the study of Bioethical Issues.

On behalf of myself and my Vice Chair Jim Wagner, who is President of Emory University, I would like to welcome you to Day 1 of our fourth meeting. Please note the presence of our designated federal officer, our Commission Executive Director Valerie Bonham.

Val, would you stand up so people can recognize you? Great.

It's good to be back in the nation's capital. We had our first meeting here, our second meeting in Philadelphia, and our third meeting in Atlanta.

This meeting is going to begin our study of several important issues. Today's subjects are the uses of genetics and neuroscience for research, diagnosis, risk identification, and prevention. Also the accompanying risks that accompany those uses; the invasion of privacy, lack of adequate counseling, insufficient information. You'll hear more about both the potentials and the risks of these sciences throughout the day.

For our first study on synthetic biology, the Commission adopted a deliberative and open-to-the-public approach to decision making. This approach does justice to the complexity of today's bioethical issues, it creates dialogue among experts and members of the public, and it raises the profile of issues that are of public importance and public concern.

Our Commission will use the same approach as we begin work on our new topic: genetics and neuroimaging. Genetic and neuroimaging tests are currently at the forefront of research to identify and treat disease.

Genetic tests including whole genome sequencing now may offer relatively detailed insight into a variety of human traits and conditions. Those traits and conditions are both physical and behavioral.

Neuroimaging is a newer science. It, too, may ultimately reveal detailed behavioral and personality insights and expand our understanding of brain order and disorder.

The tests that we are going to speak about will have, and do have, the potential to reveal unprecedented depths of information about individuals and perhaps also about their families and communities.

In today's meeting we will explore the science of genetics and neuroimaging. We will also consider the social and ethical concerns that advances in these fields raise and how best to address them. Ultimately the Commission will try not only to explain in a publicly accessible way what these sciences are now doing, but more importantly and more specific to our mission, we will try to recommend how we can look forward to a way of doing genetics and neuro testing that serves the public's interest, maximizing the benefits, minimizing the harm, treating people with respect as subjects, not just objects of science.

Before we begin, I would like to say a few words about public comments. We'll offer an opportunity at the end of each session, time permitting, for public comment relating to the specific content of that session.

Since there's been considerable public interest overall in the topics we're discussing at this meeting, we have also reserved 45 minutes at the end of tomorrow's session, which ends before lunch time tomorrow, for general public comments.

I want to get started but before we get started with the first session, I would like to ask our Vice Chair Jim Wagner to say a few words of welcome.

**DR. WAGNER:**

Well thank you, Amy. Welcome to all. Welcome to the visitors today.

Welcome to the Commissioners. Thank you, Amy, for all the work you've done since last time we were together; the rolling out of the synthetic biology report and the several groups that wanted to hear from you personally. I only had to fill in for you once and my impression was just as yours has been, that it was a well-received report that will be of value.

We need to do the same in our future projects. As our Chairman has mentioned, we are looking at genetic and neurological testing. These are emerging technologies in these areas that provide opportunity for discovery, for diagnosis, for predispositional studies, forensics prediction, prevention, etc. It's a pretty broad scope. We will learn more this morning specifically about the current state of the art.

But who knows what the future arts will be in this area, where technology will go. One can imagine future technologies that go beyond genetic testing. Perhaps epigenetic mappings of some sort.

We can certainly imagine quite easily higher resolution imaging technologies, higher spatial resolution, higher time resolution, and even

chemical species resolution. In other words, we can see the potential for growth in technologies beyond these two.
But all of them have in common overlapping, anyway, sets of ethical issues related if nothing else to the burden of this and how we manage and steward this new kind of knowledge ethically.

To the Commission, part of our work today we want to lead to a definition of the scope of what we want to do in this area.
Welcome, Francis. Good to have you here, Dr. Collins.

We want to work toward a definition of scope, as Amy says, how best to address these issues. For example, do we imagine that our energies are best spent to help shape and address ethical consideration for today and tomorrow by examining applications or a range of applications to which these and other technologies would be relevant?

Or do we believe that by focusing deeply on a technology and the several issues to which it applies we stand a better chance of constructively bounding our work and providing a template for approaching ethical issues that will come with new and advanced technologies? All of this, of course, we hope leads us to another report that people will find to be of value in shaping and guiding public policy.

Like the rest of the Commissioners I look forward to learning a great deal today and I look forward to some conversation along the lines we just discussed. With that, we will turn it back to our Chair and to our just-in-time visitor.

**DR. GUTMANN:**

Thanks. Before I introduce our first speaker, I just want to give you some sense of how today will go. We will have a series of panels on specific issues of genetics and neuro testing and neuroscience. Not just neuro testing and genetics but the science as well as the application.

At the end of the day before we adjourn, I'm going to ask all of the presenters from the day to join me for a round table and ask them if we are as a Commission to take up one issue, or make one contribution on any of the many subtopics that are discussed today, what do you recommend that to be? We will then also open it up for the Commission members to ask themselves the same question.

Just keep that in mind that the issues we're talking about today are extremely far-ranging. This is not a single topic but many topics. I think we need before we drill down in any specific way to see the landscape here. I'm pleased to say -- we all should be pleased to say that the landscape is very broad.

These sciences have made tremendous progress over the last decade and even more so if you look over decades of time. If you've gotten to the place I've been, decades seem like a short period of time now.