

Welcome, Opening Remarks, and Induction of Members
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DR. ZERHOUNI: Well, if we can all be seated, we can start the proceedings. As you've guessed already, I am not Secretary Thompson. I'm Elias Zerhouni. I'm the Director of the National Institutes of Health, and I was asked actually to stand for the Secretary of Health, who really is sorry not to have been able to be here this morning to open the proceedings of this very important committee, the Secretary's Advisory Committee on Genetics, Health and Society.

Actually, I was very pleased when the Secretary asked me to stand in for him to launch the work of this committee. Last year, in the summer, we were reviewing committees and it was very clear to me at the time that the scope of the charter of this committee needed to be enlarged. Due to the progress in genomics and what was happening in the field of genetic research and the development of genetic technologies, we all thought that the Secretary needed a much broader scope of advice, and we're very pleased to have Dr. McCabe serve again as our chair and we're looking forward to your contributions in that regard.

On behalf of the Secretary, I want you to know that he supports genetic research and clearly embraces the plan that NIH has developed, in particular focused on the Human Genome Project and its consequences. As Francis and I talk about the future, we like to say that, in fact, 2003 is an important year because of the completion, full completion on April 14th of the human genome, 50 years after the discovery of the structure of DNA. My advice to him is to change the calendar for science and start with April 14 being Day 1 A.G., after genome, and anything before that was B.G.

Well, in fact, you are an important committee in this new era, and your advice and direction is going to be extremely critical. There isn't one aspect of what you're touching that will not affect both research and health care in this country for years and years to come. So it's important, I think, to understand and to realize that the Secretary, myself, all of us are really supportive of your efforts and look forward to your contributions.

I think, because of the longstanding commitment of the Secretary as a policy-maker and national leader to ensure that our laws and policies keep pace with scientific developments, it was not a surprise to me, in fact, that the Secretary took a personal interest in restructuring and rechartering this committee and expanding its charter once we advised him that it would be a good thing to do at this time. NIH is honored to be able to support the committee, to in fact assist the committee and be the lead agency in support of the activities of this committee. I know that the staff at NIH is really excited about being part of this and supportive of this.

So again, on behalf of NIH, on behalf of Secretary Thompson, I want to express our appreciation to each of you. Clearly, your work is not entirely related to just the Department of Health and Human Services or its agencies. You have to look at the broad scope of implications of the development of policies and issues in this area.

So again, I want to express my special appreciation to you, Dr. McCabe. It's clear that you've been a leader before and you'll be a leader again, and I know, based on all of the work that has been done already, there is a base here to build on and that the committee is going to be able to do so.

I don't want to make a long speech about the varied applications that are going to define the way we perform medicine that are arising from the Human Genome Project, but more importantly it's not just the Human Genome Project that we need to consider. It's all of the diagnostic technologies that are related to the downstream technologies that are emerging from rapid DNA sequencing, from DNA arrays, from proteomics. All of those technologies have an impact, I think, in our era.

There's no doubt that the issue of genetic discrimination is an important issue. As you know, the President has called for federal legislation to prevent the misuse of genetic information in health insurance and employment. We believe this is a core issue for the country. There's no progress possible unless we can provide assurances to individuals that their genetic information will never be misused against them. This is something that I think is making great progress. In Congress there is actually a bipartisan bill that is walking its way through the arcane process of becoming law, and I think the Genetic Information Non-Discrimination Act of 2003 will be a landmark if it goes through.

So clearly, our position is to be very supportive. Francis and the Genome Institute and I and many people have contributed in informing both the Senate and the House of the importance of this bill. It's been a long process, but I think we're there, and your support here would be very important.

So although we've made a lot of advances in terms of technology, as you know, from the very beginning, with the leadership of Dr. Watson, there was a commitment to spend 3 percent of the budget of the Human Genome Project on what we call ELSI issues. This is, in fact, something that needs to be expanded in its scope and depth, and the apex of that I think is your committee.

There's no doubt in our minds that without your work and the detail of the seven specific areas that your charter outlines -- one, the integration of genetic technologies into health care and public health; two, the clinical, ethical, legal, and societal implications of the new medical applications in the emerging technological approaches to clinical testing; three, the opportunities and gaps in research and data collection efforts -- we'd like you to focus on that.

What is missing in the portfolio of activities that we need to focus on today in this country that might actually influence our research portfolio and our stimulating the field towards directions that you may find are not explored at this point? The use of genetics in bioterrorism; the impact of patent policy and licensing practices on access to genetic technologies; the uses of genetic information in education, employment, insurance, including health, disability, long-term care and life; and the law. Obviously, the emerging scientific, ethical, legal, and social issues that are raised by these new technologies.

The public is really, I think, looking forward to an enlightened and informed debate. We sense that. Many, many constituencies will talk to us about their need for guidance and their need for clear policies, and I think it is the time to do so aggressively.

So we're just very confident that your work is going to be, A, very supported; B, very important; and three, needs to be wide-ranging. I think this is probably the challenge that you have to undertake.

I have the pleasure also to swear you in for this new job that you're undertaking for the country. So I'd like to have all the members stand up and be sworn in. Raise your right hand and repeat after me.

(Committee members sworn in.)

DR. ZERHOUNI: Thank you very much. You are now sworn in. To all of you, again thank you for the service you're about to render to the United States government and to the American people, and we look forward to learning of the outcome of your deliberations. Again, I wish you a thought-provoking and productive meeting.

I'll leave you now in the capable hands of our chair, Dr. McCabe.