

**Remarks of New SACGHS Chair**  
*Reed Tuckson, M.D.*

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I just want to give a couple of seconds to see if, even though he's going to be with us in deliberations for quite a while, but Ed did such a terrific job. As somebody who was on the first committee and watched this transition, I just marvel at what he was able to achieve as our leader both on the first and now this committee.

But, Ed, would you like to say a couple of comments, please?

DR. McCABE: Well, thank you.

It's been truly an honor to serve on the Secretary's Advisory Committee on Genetic Testing, and then the Secretary's Advisory Committee on Genetics, Health, and Society. One of the things that you will find, Reed, is that you have fantastic staff with Sarah in charge, and you will be wise to listen to what Sarah tells you. If you follow Sarah's directions, you will look extremely good. If I've had any success, that's been the secret to it.

(Laughter.)

DR. McCABE: But also, the committee members are just fantastic on both of those committees. From some experiences on the first committee, I learned that you always had my back, and I hope that I can do equally as well for you. Thank you.

(Applause.)

DR. TUCKSON: Well, we have a lot to do, and thank God for each one of you. It's going to be very interesting to watch as so many of you are going to have a chance to really produce and showcase the work that you've been doing as committee chairs of these subcommittees and so forth. I'm just amazed, as I read through all of this material again, at how hard each one of you are working on this committee's behalf. We owe you a grade of thanks.

The public was made aware of this meeting through notices in the Federal Register, as well as announcements on the SACGHS website and listserv. I will tell you that as I've come to review a little bit about how do you evaluate the quality of advisory committees to the government, I am reminded as I have looked through some of those criteria that the number-one way in which these committees demonstrate their value to the nation is through its ability to reach out to the public. So I'm very pleased, and I think we're even going to try to do some other things which we can talk about later in terms of redoubling our efforts to have all of our work into the hands of the public that is most interested in this and those who ought to be more interested in what we're doing. So this meeting was made available through those notices.

We were rechartered again through August of 2006, so you're stuck.

(Laughter.)

DR. TUCKSON: The following ex officio agency representatives, we want to thank all of them that are here, but I want to make particular note that we are joined today also by Ms. Cari Dominguez, chair of the Equal Employment Opportunity Commission. She will be serving as the EEOC's ex officio.

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Chair Dominguez, we're very, very pleased that you are taking the time. It really shows how important the issues are that you're here about, I know most that are of interest to you, how important it is to our country. So thank you for joining us.

Mr. Richard Campanelli, director of the HHS Office for Civil Rights, is also expected with us today, and that is also worthy of note.

Dr. Francis Chesley, director of AHRQ's Office of Extramural Research, Education, and Priority Populations, has been appointed to serve as AHRQ's new ex officio. Thank you very much, Dr. Chesley, for joining and serving.

We're glad for all of our other ex officios who have been maintaining their commitment to this committee.

Chris Hook and Joan Reede will not be attending. Hunt Willard will be joining us tomorrow. So we thank them for that.

One of the most important things, at least to me coming on, and I'm sure to you, was that given that we are advisory to the Secretary of Health, does the Secretary of Health and does his office care about what we are doing. I wanted you to know that I did put in a call to that office and spoke with, as the news would say, an unnamed senior official.

(Laughter.)

DR. TUCKSON: I was encouraged that the unnamed senior official was well aware of what we are doing. I was insistent and assured that within a couple of days of my conversation the Secretary would be briefed about the fact that the new incoming chairman of the committee wanted to be sure that it was important to him and that he was paying attention to what we are doing.

So I will just simply leave it there and say that I think it is important because you all are working so hard on this committee that you've got to know that it's not just being filed on a shelf somewhere, that this is important that it's getting done, and I'm going to take my responsibility, as Ed hands the baton off to me, to really ensure that that is happening. So I will give you an update on that, on the Secretary's conversation, the next time that we meet.

Let me say that the status of the committee's work product since June, what has been going on, we have the resolution on genetics education and training of health professionals. That copy is available at the desk. It was transmitted to the Secretary in August. The roadmap for the integration of genetics and genomics in society, the study priorities of the Secretary's advisory committee, will be transmitted to the Secretary very shortly, and that will happen really in the next matter of days and weeks.

The letter to the Secretary on direct-to-consumer marketing of genetic tests and technologies is in the final stages of review by our committee and will be transmitted to the Secretary soon. It's in the table folder, and there is still time, if you have any last, last, last minute, short, brief, non-controversial comments.

Sarah is kicking me under the table as I say that.

Finally, a very brief overview of the agenda. Of course, first we will start out with learning about

important HHS initiatives to promote family history-taking. We will then dive very deeply into the issue of genetic discrimination and information about the nature, magnitude and scope of the discrimination problem in society. We will move to completing our deliberations and finalizing our recommendations on coverage and reimbursement. Then finally, we'll begin planning future work on two high-priority issues, large population studies and pharmacogenomics.

Public comments are scheduled for today and tomorrow. So far we have about seven or so who have registered to provide comments. Any others who may be interested should sign up at the registration desk. Again, this is a relentlessly public experience. So if you have comments, we welcome you to do that.

With that, let me turn over to the czar, the general, Sarah Carr, who will take care of some very important technical stuff.

MS. CARR: Thank you, Reed.

As you know, the members of this committee are appointed as special government employees in order to serve, and at each meeting I always remind you about the rules of conduct that apply to government employees and to you. These rules are in a document called "Standards of Ethical Conduct for Employees of the Executive Branch," and each one of you got a copy of this document, and I know you've reviewed it very carefully.

I'm just going to highlight two of the rules today. One is about conflicts of interest, and the other is about lobbying.

Conflicts of interest. Before every meeting, you provide us with information about your personal, professional, and financial interests, and this is information that we use to determine whether you have any real, potential, or apparent conflicts of interest that could compromise your ability to be objective in giving advice during the committee meetings. While we waive conflicts of interest for general matters because we believe your ability to be objective will not be affected by your interests in such matters, we also rely to a great degree on you to be attentive during our meetings to the possibility that an issue will arise that could affect or appear to affect your interests in a specific way.

In addition, we have provided each of you with a list of your financial interests and covered relationships that would pose a conflict for you if they became a focal point of the committee deliberations. If this happens, we ask you to recuse yourself and leave the room.

Lobbying. Government employees are prohibited from lobbying, and thus we may not lobby, not as individuals and not as a committee. If you lobby in your professional capacity or as a private citizen, it is important that you keep that activity separate from your activities associated with this committee. Just keep in mind that we are advisory to the Secretary of Health and Human Services. We don't advise Congress. Thank you for being so attentive to the rules of conduct. We appreciate your conscientiousness very much.

DR. TUCKSON: Terrific. Well, to kick us off on our first session on the importance of family history in health, to get that started, I'm going to introduce Francis Collins. We have to be concerned that Francis flew on the redeye all night, so we're in great danger that he will fall off at any moment. So, Ellen and Daniel, if you'll keep an eye on him, we'll all appreciate it.