

Draft Charge for the Education Task Force
Barbara Burns McGrath, R.N., Ph.D.

DR. TEUTSCH: We are recharged after our morning's exertions. Now we get to turn to, hopefully, some fun stuff. We have two items for this afternoon. One is to review the charge for the Genetics Education and Training Taskforce, and then we get to blue-sky what our future might look like.

First, I need to remind everyone that this is the taskforce that we got underway in November. Reed had given them some preliminary direction and charge, and the taskforce has been busy trying to sharpen up what they are going to do.

We owe a special debt of gratitude to Barbara Burns McGrath for a couple of things. One is, as you may or may not know, she had to do a lot of this work from the other side of the world, where she was, and then she has had a lot of things to deal with in the last week. So we are particularly grateful that she actually was able to find a few hours to come and be here not only for this morning's session but to be part of this discussion.

What we have asked Barbara to do is to go ahead and present the draft charge for the Genetics Education and Training Taskforce and then to lead us in a discussion. What we need to do, of course, is get to agreement. We will vote on the charge at the end.

You will find the materials in Tab 4 of your briefing books. We really appreciate, Barbara, all your extraordinary efforts to be here and to lead us through this discussion.

DR. McGRATH: Thanks, Steve. It makes me nervous to start another taskforce when we are just putting one to bed. As everyone keeps saying during breaks, let's use this one as a learning curve. So, we can learn from the Oversight Committee, for better or worse.

DR. TEUTSCH: You mean we get to do it again?

[Laughter.]

DR. McGRATH: I will give a little bit of an overview of what we are up to for about 20 minutes. Then we have, for about another half hour, some time to talk about what is going on with the Committee.

The title of it is an Education and Training Taskforce, and it is made up of several of us on the Committee here and several ex officio members. Our staff representative is Cathy Fomous, who has been very much involved in this.

The purpose for today is simply to give a bit of an update to all of you on what we have been doing over the last couple months. One thing we did was to create a draft charge. We will go over that. We would like some feedback on it because the goal for today is to reach consensus on a final version of that charge.

In terms of background about this committee, the history of the education and training interests with SACGHS goes back to its very beginning, when it was one of the priority areas. Following that, there was a meeting around 2003 that resulted in a resolution that was written in 2004. We have used that as our starting point. Then we met last year in November for the first time and had a session on that. The resolution that was written in 2004 was a great starting point.

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The whole thing is in your tab area as well. If you read it, you might come to the same conclusion that we did. It was fairly broad. Nothing to argue about in there. It was all logical recommendations that anyone might want to make. So it gives us a little bit of guidance, but we are hoping to move it forward.

Last fall, we did have what I thought was a pretty interesting session where we first identified some really interesting people in the community who know this area well. Ten folks were here and talked about education and training from each discipline's perspective. The areas that they covered were professional as well as education, diversity in the work place, family history, and emerging issues, as well as who the emerging stakeholders might be.

At the end of that meeting in November, there was a discussion. A vote was taken by the committee, first saying that the topic continues to be of interest and is consistent with our charter, and second, that these issues can best be addressed through a taskforce. So the taskforce was formed.

Between November and now, that task group has been meeting on Email and phone conferences, and our one order of activity was to develop a charge so we know what direction we should be heading. That is what we will be looking at.

I thought about whether reading all of this aloud would be a good idea, or have a little silent reading, but I'm afraid if we do silent reading it will get kind of dozy in here. So I will read the charge and then we can talk about it. I ask for comments to hold to the very end so you get the flavor of the whole draft. It is not that long. Then we will open it up to discussions to help us fine-tune it a little bit more.

The first thing is the need for the charge. "Advances in genetics and genomics are leading to a better understanding of disease processes and improved application of genetic testing to guide health decisions. With increased integration of genetics into other medical disciplines, however, health professionals with or without training or expertise in genetics are challenged to keep pace with this dynamic and rapidly evolving field.

"Education will have to address the growing importance of genetics in common disease, which likely will require more knowledge and understanding about risk assessment and communication.

"In addition, the accelerated growth of direct-to-consumer genetic services highlights the need for informed decision-making." That is the need.

"To realize the benefits of genetic technologies and protect against potential harms, the education of the healthcare professionals, the public health work force, and the general public is critical. For these reasons, the Secretary's Advisory Committee on Genetics, Health, and Society has formed a taskforce to build on the findings of the Committee's 2004 Resolution on Genetic Education and Training of Health Professionals."

The overall aim. "The taskforce is charged with developing a plan to identify the education and training needs of health professionals, lay health educators, and the general public in order to optimize the benefits of genetic and genomic services for all Americans. This plan will also outline the steps required to meet these needs and evaluate the efficacy of educational and training efforts. The plan includes, but is not limited to, the following activities."

So there are basically eight goals that we have created in this process.

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"No. 1, Assembling evidence to determine which recommendations from the 2004 Education Resolution were implemented and which ones require additional efforts;

"No. 2, Identifying the education and training needs specific to genetics and genomics for health professionals involved in providing care for individuals and for those involved in the development of guidelines, policies, and strategies for incorporating genetics and genomics into clinical care;

"No. 3, Identifying the education and training needs of lay health educators who are non-credentialed individuals from the local area trained to promote health and provide general health care services for a specific condition or program;

"No. 4, Identifying the education needs specific to genetics and genomics for medical directors, administrators, and policymakers in the public and private sectors to inform policy development, legislation, coverage and reimbursement decisions, and other issues that directly or indirectly impact the provision of genetic services;

"No. 5, Identifying the education needs of patients and consumers to assist them in informed decision-making about the use of genetic services and enhance their understanding and utilization of results and how these results impact decisions about prevention or treatment;

"No. 6, Identifying effective educational tools that can be incorporated into electronic health records, personal health records, and clinical decision support systems that would enhance the appropriate integration of genetic and genomic technologies throughout the healthcare system without adversely impacting privacy, access, and work flow. In addition, identify gaps where such tools do not currently exist and develop recommendations on how to address these gaps;

"No. 7, Assessing the use of evaluative research methods to determine the efficacy of genetics and genomics education and training; and

"No. 8, Promoting active involvement by health professional governing bodies that influence education and training (for example, residency review, National Board of Medical Examiners, and so forth) to be more proactive in their requirements for genetics in curricula, clinical training, and licensing and certification and continuing ed requirements."

So those are the goals that we created. The idea is that after we fine-tune these, perhaps make them more specific, that will give us some guidance about what other members to add to this taskforce. So we will be adding ad hoc members based on the goals that we end up deciding on today, and they could come from any of these sorts of organizations or other ones that we identify today.

So the next steps are to decide on the initial activities that we think are important for this taskforce to do; form workgroups, because there will be too many. We need to divide them up. Select ad hoc members as needed; and, the report on our progress at the July 2008 meeting.

I'm interested in hearing your thoughts on the scope of this taskforce. I think there is a danger of it getting too large so that we take on things that are perhaps handled in other groups or have been handled in other ways. So I would like to get some feedback on the scope.

My other plea is that I hope we end up with goals that are measurable so that at the end of the period of time the next task group that comes on education in five years' time will be able to look

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at our work and really have a clear sense of whether they were achieved or not, rather than just having them be pleasant suggestions.

Those are my two pleas. I'm asking for help to help us decide as a group where our scope should be, where we should draw the boundaries, and help us to make these more measurable.

That is all I needed to say now. I think we can open it up to suggestions and feedback.