

## GENETICS EDUCATION AND TRAINING TASK FORCE

### Update on Data Gathering

**Barbara Burns McGrath, R.N., Ph.D.**

[PowerPoint presentation.]

DR. McGRATH: What I'm going to do today is give an update on the Task Force and provide some preliminary data. I actually thought that we were going to win the wow factor with this because we have a little bit of data. I know in a lot of these meetings we have no data, just ideas. This afternoon there has been so much data coming your way that it is not such a big deal anymore.

The purpose of the session is to update you. We are about halfway through on this task force, I would say. We are finishing our data gathering, so it is a good time to see if anybody in the room has suggestions for whether you think we are heading in the right direction. We are not going to completely change direction, but we welcome suggestions for new areas to look at and emphasizes.

A little bit of background, particularly for the new members. This issue of genetics education and training has been high on the priority list of SACGHS since its inception. In 2004, there was a similar task force that

was formed. They had a roundtable. Rather than a large report, they got away with just a letter and a series of recommendations to the Secretary of HHS.

We looked at those again around 2007 and, as a group, decided that it was time to look at it again. Things had changed enough. We decided that the issues merited forming another task force to look at this. So we have been around for a couple of years.

In the meantime, we had a Cathy/Kathy switch. Cathy Fomous was the staff person initially, and Kathy Camp now is the staff person assigned to this, so there have been some changes.

The Committee talked about what should the scope of this task force be. Like a lot of things with SACGHS, it is really a hydra. There are so many different ways you could look at genetics education and training.

We talked about K-12 education. We talked about emerging groups that haven't been addressed who have needs, like laboratorians, hospital administrators, or speech pathologists. There is no end to the boundaries of where you could think about who might benefit from greater genetics education and training, if that is your ilk.

We did decide to limit our scope to three groups. We were guided by the principle of point of care, trying to think of limiting it along those lines. We decided to focus on healthcare professionals and practitioners and their needs, public health providers, and then consumers and patients, including the public.

Underlying all of this is a hope that the results of this report will be recommendations to the Secretary of HHS and that our recommendations will be measurable and actionable. We are trying to focus on that angle. They are actually under the purview of HHS, trying to keep a focus on what is the role of the federal government in this area and trying to avoid getting too broad.

We are hoping to have a forward-looking document, not just looking at education tools that are in place now or education needs that are current but also look forward a little bit to what might be coming down the pike. Those are our hopes.

Those three scope areas were formed into workgroups, and I'm going to be reporting the data from those workgroups on their behalf. I think there are representatives of each workgroup still in the room, so we

will lean on them.

The first one is the Healthcare Professionals Group, led by Greg Feero. He has a nice group of people there that he works with. They are approaching their goal of trying to assess the training needs of health professionals by using a survey-based design. They are using two surveys. The first one is looking at professional organizations. They have done some survey on that. The next one is to use the same survey that was used in 2004 and try to compare some data with that. I will talk about that in a second.

Before I go further on that, all of the groups are doing review of literature of the areas that they are dealing with, with the goal of not to replicate existing efforts. We are trying to move forward rather than replicate what others are doing.

We have some of the results of those surveys. The first one, which is the one with professional organizations, identified 57 in those kinds of categories. Twenty-nine were general professional -- and these are professional organizations like AMA or American Academy of Family Physicians -- some of the genetics specialty ones,

ones devoted to professional education with an eye toward certification, and then looking at three advisory committees.

The return rate today is 58 percent, but one survey came in this morning. We expect that there might be more coming in, so that response rate of 58 percent is likely to go up. Not surprisingly, from genetics specialty groups there was 100 percent response. The general professional ones were pretty good. The educational committees had a pretty low response rate. I won't go into why.

Preliminary data. Of those groups that you saw, half of them actually have something dedicated to genetics, which means half don't.

The question was, what do you identify as your organizational barriers to providing education to your constituents, and those are the ones that they identified. [Indicates slide.]

This slide shows in broad relief the ones that stand out as competing priorities. These are priorities that the organizations have for providing it. You can imagine what some of those might be.

One thought we have is that if there was increased clinical utility demonstrated for genetics and genetics testing that the numbers of competing priorities might go down a little bit and it would rise as a priority issue. There are lots of other reasons to explain that one.

The second survey is the one looking at federal activities. Again, we are trying to compare has anything changed since the report of 2004. This is a smaller sample, for many reasons. One would be able to compare five of the agencies to that. The data analysis is just underway on that. We don't have a lot to say on that, but again, we are trying to see if there is any way to measure change over time with this.

Their next steps are to, of course, encourage the return of samples and do that comparative analysis and the complete data analysis. There are other reports coming out looking at genetics education and training from federal groups. We want to synthesize those reports so that they fit together nicely rather than duplicating or being really disparate. There are efforts to talk about synthesis.

Another goal is to have their report articulate

personalized medicine initiatives. We want to ensure that some of the things that come out with that make sense in terms of this report. That is that group.

The second group is the Public Health Providers Group, led by Joseph Telfair and his group of nice people. Their goals are similar. Their approach is to start with the notion of competencies. They have had the herculean task of gathering public health competencies around genetics and genomics from the various organizations. I think they started off with something like 100. They are working to whittle those down to a concrete set of 12 that at this point seem to be the core ones.

That set of 12 will inform the development of a survey to then be administered to the right people to see if they are achieving the competencies. If so, we want to know where they get the education. If not, we want to know where they wish they would.

These are examples of the kind of competencies they are talking about. These are four of the twelve -- I will just let you read them for a second -- looking at up-to-date scientific knowledge and behavior, opportunities to integrate into healthcare practice, of course the ELSI

issues, and then how to implement research. It clearly covers the whole public health arena.

That part is finished. The next part will be developing the survey. It will be an online survey to be distributed. They are at that point, so the survey should go out pretty soon. Then there will be data analysis of that.

The last group is the Consumer and Patient Workgroup, led by Vince Bonham, who is not here right now. He is in Africa. Sarah Harding will be here tomorrow, and she is filling in for him.

This is their group. We are proud to add a new member. Gwen Darien has agreed to join us, so that will be an excellent group of nice people.

Their goal is to provide recommendations that address the needs of consumers and patients. Their approach is to start with qualitative interviews. They conducted five paired semi-structured interviews with professionals in the following areas to get the landscape of identified areas of genetic needs for patients and consumers.

The data is just being analyzed, but some early

thoughts are that, not surprisingly, consumers get information from providers and the media. Interestingly, they feel government does have a role to play in this in terms of guidance.

Those interviewed people suggested that the need that they see for consumers coming up the pike is greater understanding of multiple risk factors and how genetics plays with that. Obviously, that is important, along with the role of the environment.

Other needs are for some discernment about the expertise among healthcare providers, who you go to for what sorts of issues, and some helpful tools. We talked about that with DTC this afternoon. We need some tools to evaluate this.

Some of the barriers that those professionals and advocacy groups identified for consumers were just general poor health literacy, a notion of genetic determinism or fatalism -- why learn about this when there is nothing you can do about it? -- and then fear of discrimination continuing even past the GINA era.

What they will do with those themes is to turn this into a survey, which is happening right now, and then

to distribute these to larger community-based organizations. The hope is for an N of about 100 of these, so a pretty good size for this kind of project.

Our group met this morning before orientation for this meeting, and one thing we talked about is the challenges of addressing the issues identified by the general public. So far, we are focusing on consumers and patients, meaning people that have some reason to be interested in genetics. We know the general public perhaps has a different orientation to this. The challenge of who is the general public and how to access attitudes from them, we don't have an answer to. We are going to talk about that further. There is a desire to see that we integrate that with this report.

I'm hearing some more about integrating some things about informed consent and research with genetics. We will talk about that.

Here is a scary slide. This is the timeline. We are working now on collecting the data and writing the background. That will go on until summer.

Our next step will be to develop some draft initial recommendations that we will present to the whole

Committee at the June meeting. These will be recommendations based on analysis of the data I just presented. In that meeting we will come to some agreement about the draft recommendations. That will go into a draft of the report, which will be written over the summer and sent to you at the end of summer for your end-of-summer reading. Get your novels done early because you will get this report at the end of the summer.

We will present that draft report in the October meeting, and then it will go out for public comment over the holiday in November. The final report is anticipated to be ready for publication and submission to the Secretary next year, probably in mid 2010.

We are pretty much on track, but I think the heavy lifting is yet to come in terms of the writing.

I would like to stop talking and see if people think from that brief review that we are on the right track. Are there things you would like to add or minimize? I will very much refer to the rest of the people on the workgroups because there is definitely a shared governance committee.

## **Committee Discussion**

DR. TEUTSCH: Thank you, Barbara. Any comments from the group? Any thoughts for Barbara? Gurvaneet, we can count on you.

DR. RANDHAWA: I think this is just great work.

DR. FROSST: I second that.

DR. TEUTSCH: Any thoughts for this committee before we turn them loose again? I know they have been working hard.

DR. McGRATH: We can take written comments, too, if you are more awake. You can send Emails.