## *Educational Programs for Health Professionals: Addressing the Gaps*

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Our next speaker is Joe McInerney from NCHPEG, the National Coalition for Health Professional Education in Genetics.

MR. McINERNEY: Thank you very much, Dr. McCabe, and thanks to the committee for paying so much attention to this important issue.

I'm going to do essentially what Dr. Boughman did, and that is just hit some of the highlights here. There is no way we can cover all of the information that we have available to us about the status of education. I'm certainly not going to talk about K-12 education, although I would be happy to respond to questions about that during the discussion session because I have spent a fair amount of time doing that. I will talk primarily about what we're doing with non-physician health care professionals, but let me just tell you a little bit about NCHPEG first.

I think many of you already are familiar with us. At this point, we have 127 member organizations and the real benefit of NCHPEG is that it's an extraordinarily eclectic collection. We have all of the professional societies in human genetics, many of the medical societies that are related to genetics directly, and even those that seem only tangentially involved, at least on the surface, and we also have many of the allied health professions, and we also have groups such as the National Association of Catholic Chaplains and the Association of Professional Chaplains, all of these organizations recognizing the importance of genetics for their constituents, but what that allows us to do when we decide to take on a project is bring the genetics expertise to bear in the context of the advice and counsel from the members of other professional societies.

Now, I use this slide a lot from Drs. Hayflick and Eiff because I think it does a nice job of encapsulating the gaps and the challenges, and I've highlighted in yellow here what I see as the significant challenges and gaps. This notion of specific content is an echo of what we've heard several times already. It is quite clear as I travel around, which I do a lot, and talk to a lot of different health professionals that what you've heard already is absolutely true. People want to know what do I do now? Don't tell me what the Genome Project is going to do for me 10 years from now. The technology is very cool. The science is cool. I admit that. It resonates in my heart of hearts as a biologist, perhaps, but what do I do differently tomorrow when I go into the clinic? So that is an absolutely important challenge.

But the broader-based educational challenge, and this perhaps is the difference between education and training, is to change the way people think in what is referred to here as the "'usual' cognitive strategies." I would assert to you that if in fact genetics is going to become the substrate for the practice of medicine and for the maintenance of health in the future, we do have to change the way people think. It's what people such as Barton Childs have called "health care through a genetic lens."

Now, perhaps the most significant thing we've done to date to try to address this gap is to provide some "Core Competencies in Genetics," and I think most of you are familiar with these already. They've been out now since January of 2001. We've distributed about 2,000 copies of them. We recently did an evaluation of the effectiveness of the core competencies, and I'll be happy to share some of that evaluation data with you.

For those of you who have not seen these, I brought about 50 copies. They're on one of the tables outside.

You can pick them up if you wish.

Now, I won't assert that all the educational efforts that are underway now have been influenced by the NCHPEG core competencies, but certainly many of them have, and I just put this list up to give you some indication of the range of organizations that are involved in the development of educational programs in genetics. We've heard a number of these discussed already today and I won't go through examples of each of these because I will necessarily have to offend some organization or individual by leaving a program out.

But I will tell you that one of the things that comes through here -- and I don't know yet whether this is a good or bad thing -- is that there's no coordination. People are developing educational materials for specific health care professionals, but I will tell you that there's no coordination. There's no direction that says this is what ought to be included in terms of content or in terms of clinical objectives or in terms of a basic definition of genetic literacy, and I will tell you very straightforwardly that almost none of this, so far as I have seen, takes place in the context of a response to the question Dr. Willard asked before, and that is what do we want to be like 10 years from now? Those kinds of questions to me are not at the forefront of the development of these programs.

Again, I don't know whether it's a good thing or a bad thing that there is no coordination. I don't know whether centralization in this place is a good thing or whether decentralization is a good thing. I do know that the decentralization is a good thing to the extent to which it allows the individual disciplines to specify the way genetics plays out for them and is relevant in their own practices, but whether we need some overarching mechanism that specifies what the basic content should be is another issue.

So I'm just going to give you some very quick examples of some of the programs that already have been developed, and I will apologize. Some of these did not copy well from the web.

This is a program for speech and language individuals, speech and language professionals, speech and language therapists. This is "Genetic Syndromes in Communication Disorders." This is a program developed by the American Occupational Therapy Association, one of NCHPEG's members.

This, of course, many of you have already seen from HRSA and a number of other organizations, "The Report of the Expert Panel on Genetics and Nursing: Implications for Education and Practice."

This is a special issue of Family Therapy magazine produced by the American Association for Marriage and Family Therapy, a NCHPEG organization. Again, an indication of how eclectic our membership is, marriage and family therapists clearly seeing the need for genetics education for their membership.

This didn't copy very well at all, but this is a publication from Mr. Rackover's group. Again, a special issue devoted to the importance of genetics for physician assistants.

Now, it is important to have commitment from the top, and this is a statement from the House of Delegates of the American Physical Therapy Association. I'll just leave it up for a second, but I will tell you that that's not enough, simply having commitment from the top. This is a nice statement, but so far as I've been able to tell, nothing much has happened yet in terms of influencing the curriculum and the training of physical therapists since this document was produced or this statement was produced.

Roughly the same thing is the case for radiologic technologists. These are from the current curriculum guidelines for the American Society of Radiological Technologists, and you see just two objectives here.

Now, again, it's not clear how these are likely to play out in the curriculum. I don't really know what

these mean. Certainly, there's no national curriculum, so far as I'm aware of, for radiologic technologists, although they do have to pass a certifying exam, but I think these kinds of guidelines get played out in different ways in different institutions.

Perhaps the discipline that's further ahead than any of the others is nursing. You've heard a lot about nurses already, but just let me share with you some of what has been happening in nursing in terms of trying to bring some structure to genetics education and training of nursing professionals.

This began with this statement in 1998 by ISONG and the American Nurses Association, and we heard a little bit about this earlier today.

I thank Josh Carlson from the University of Washington's Public Health Genetics Program for providing these data. He did this as part of a master's thesis.

There are in fact a number of different genetics credentials within nursing. We heard about advance practice nurses this morning. There is also a genetics clinical nurse for those trained at the bachelor's level, and perhaps Dr. Feetham can correct me if I'm wrong, but I think this credential is actually provided by the Genetic Nursing Credentialing Commission, which is a subsidiary of ISONG. So you see, they are bringing some structure to the credentialing process here, which I think is missing in some of the other organizations.

There are actually certifications in a nursing specialty where there is a genetic component in certification or core competencies. There are 11 separate credentials here and these credentials are provided by the individual professional societies.

Of course, a lot of different graduate programs or certificate programs that emphasize genetics. Short courses, for example. We heard about the GIFT program already.

So nursing is really I think quite far along as compared to some of the other disciplines.

Social work is also coming along, and the National Association of Social Workers has developed a set of standards for integration of genetics into social work practice, and you can see the broad range of issues with which they are concerned.

Now, this is just a list of organizations that are asking for help or professions that are asking for help, and I won't touch on each of these.

I did just want to mention international groups. Some of you may have received this publication within the last few days from the U.K. It's called "Addressing Genetics and Delivering Health." I was happy to see NCHPEG cited in here. The folks who worked on this document came to the NCHPEG annual meeting last year, and I'm hopeful that we will be able to continue to collaborate with Dr. Burton and her colleagues on the development of educational programs for health professionals here and in the U.K.

There also will be a meeting in Santiago, Chile, in late November where we will begin to take a look at genetics education for health professionals in Latin America, focusing first on Chile and Costa Rica.

But again, we have requests from a fairly broad range of individuals and professions, and these are some of the things they request. Now, I should jump right down to the fourth bullet and tell you that in most cases, and this again reflects what Dr. Boughman was talking about, it is very unlikely that in most of these professions we're going to get a new course devoted to genetics. The task will be to supplement the curriculum in some way, to integrate genetics into the curriculum. Often, that requires that you have to

leave something out and that's, of course, very difficult because each professor has his or her own favorite topic and you step on turf toes.

Some practical constraints. Of course, we've already heard some of these constraints alluded to before. Individuals are being trained at different levels. There are vagaries in state-by-state regulation of practice.

Scope of practice is a big issue. For example, when I talk to the radiation technologists, they were extremely interested in genetics, but a number of them said to me, well, it's hard for us to imagine how we can even integrate genetics into our interaction with patients because their work is very circumscribed by scope-of-practice regulations in their own states. They often don't even get to talk with the patient.

Now, I just wanted to finish up talking with you about some new NCHPEG programs, some things we are trying to do to fill some of these gaps.

Many of you likely already have received this CD-ROM we developed on psychiatric genetics. We distributed this free of charge to all members of the National Society of Genetic Counselors and about another 3,000 copies to other health professionals. That was funded by the ELSI program at the Department of Energy. We have a follow-up grant to that where we're focusing on genetics and common chronic disease, and the target audiences here are primary care providers and public health professionals.

Another program for which we are seeking funding at the moment is a program to try to train obstetric and neonatal nurses about the cystic fibrosis guidelines developed by the American College of Medical Genetics and ACOG.

Now, just a word about this program that we're doing on common chronic disease for public health professionals and primary care providers. This has been a real struggle to find case study vehicles that are relevant to both groups, and we have another meeting of the advisory committee coming up and then the writing team coming back in January to help us with this.

But we do believe, as it says here, that genetics does help us build bridges between population thinking, which is the purview of epidemiologists and public health people, and the primary care provider, and I borrowed this quote actually from Barton Childs at Johns Hopkins. "The epidemiologist asserts 'This is a risk factor,' and the geneticist says, 'For whom is it a risk factor?'" So we're trying to meld the two in this particular program.

A couple of other things. We actually have approached the notion of family history as the first genetic test and we think it is vital that all health care professionals be sensitive to the importance of family history in health care.

So under a five-year contract from HRSA and the Genome Institute and the Office of Rare Diseases, we are developing a number of programs, and this is one, a family history newsletter. We're doing three issues a year. They are appearing on the web, but we've also produced some hard copies. I brought about 50 copies of the summer issue. It's out on the table for those of you who want to take one home with you.

Now, I should tell you that the original charge to the Family History Working Group, which is chaired by Robin Bennett -- and I'll just digress to tell you that we really impose, is probably the right word, on the NCHPEG representatives to do a lot of work for us. They do an enormous amount of work as volunteers.

We're going to double your salary next year, Robin, actually.

(Laughter.)

MR. McINERNEY: We'll even triple it, if you like.

The original charge to us was to develop a generic family history tool, and for reasons that I won't go into now, that simply was not going to work. We didn't have the resources and there were a number of other issues, but what we did decide to do with the Family History Working Group was focus on the importance of family history itself and provide information about family history that we think health professionals can use.

Now, this is a project that actually began with Alan Guttmacher at the Genome Institute in 1999 and has moved over to NCHPEG, Genetics Resources on the Web, and we are hopeful that this will ameliorate some of the problems we heard about yesterday with respect to really egregiously erroneous information on the web.

This is a search engine that will search only the websites of the members of GROW. There are about 30 of them at the moment, including the American Society of Human Genetics, the Online Mendelian Inheritance in Man, GeneTests, the Genetic Alliance, and so on. Our intent here is to provide membership criteria that will serve as some certification that the information that you will access through this search engine is going to be reliable and accurate.

Certainly, the NCHPEG website is a resource that a lot of individuals use. We have lots of information on there, including a list of educational resources.

We also are undertaking a collection and review of genetics education programs. The reviews will be on the web. We've got an extensive list of materials submitted to us by a variety of individuals and agencies.

I should tell you that there's actually two pieces of this contract that I left out. One is our annual meeting, which will occur at the end of January in Bethesda, and the other is that each year we're developing a web-based program for a particular discipline or group of related disciplines. Actually, this year, the focus is on dentistry, and we actually have done this in response to requests from dental faculty and dental hygienists to try to improve the genetic literacy of the dental community.

Now, Dr. Boughman mentioned some work that the American Society of Human Genetics has been doing in undergraduate genetics, and I just wanted to mention this very briefly, if only to say that I think we need to keep in mind that genetics education for health professionals and genetics education for the public need to be conceptually congruent. We can't be teaching the public one thing and teaching health professionals another. That is not to say that the public needs to know all of the details of genetics that health professionals need to know, but we need to be approaching it from the same conceptual base and the same conceptual assumptions.

What we did in this paper was take a look at the genetics content of introductory biology courses for non-majors. This is a huge course. Many students who have only one science requirement, for example -- they are non-science majors -- they take biology. That's it. That's the last formal science they're going to take.

So we analyzed the content of genetics in these introductory biology programs and we made some recommendations about basic concepts in genetics for undergraduate non-majors. We specified concepts in these six areas. I'd be happy to provide a reprint of that paper if any of you here wish to see it. The next task, which we'll undertake at the Los Angeles meeting in a couple of weeks, is to look at the content of human genetics courses, elective courses, again for non-majors at the undergraduate level.

Now, this is probably as close to flat out heresy or blasphemy as one can get in this room, but this is my modest proposal. I use the phrase "modest proposal" in the way that Jonathan Swift used it in his essay on the amelioration of poverty in early 18th century Ireland. He used it to be a little -- well, more than a little provocative, but also to make a point.

What I'm proposing here is that if we really believe, as we've heard about 100 times in this room over the last two days, that genetics is really the substrate for the future of medicine, then we should stop talking about genetic disease and genetic disorders, and we should talk instead about the role that genes play in the expression of disease, in the variable expression of disease, in the onset of disease in individuals at particular times.

Now, again, this is a bit of hyperbole, I guess, but I think we send mixed messages, and I think what is says is it continues to reinforce the notion that there is genetics over here and that genetics doesn't necessarily have anything to do with everything else that is over here. So I would like us to really be consistent about promoting our assumption about genetics as the underlying substrate for health care.

Thank you very much.

DR. McCABE: Thank you very much.