Overview of Education Initiatives for Health Professionals
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MR. McINERNEY: Good morning. Thank you for the opportunity to address this group for the second time. I'm very grateful for that. I'm additionally grateful for your willingness to revisit this entire issue of education for health professionals.

I am the director of the National Coalition for Health Professional Education, which is known as NCHPEG, happily enough, so I don't have to repeat the full name too often. We work on genetics education for health professionals full-time. This is what we are devoted to: educating a broad range of health professionals. I have been doing this now for about eight years.

What I would like to do today is share with you some of my perspectives. I don't think I will cover all of those issues that were part of our assignment in 15 minutes, but I would like to give you some sense of the challenges and opportunities that I have been encountering and NCHPEG has been encountering and those many people who work with us have been encountering over the last seven or eight years as we have worked to integrate genetics into education and practice.

I would like to review some data about genetics education and genetics knowledge among health professionals, and then I would like to review with you just one of NCHPEG's many programs very briefly to give you some sense of how we are trying to address what we see as some of the particular barriers and opportunities that arise for us as a genetics community.

Now, I'm not sure you can read this from the back of the room. Can you? I will read it. It is really too much text for one slide, but I will read it to you anyway. Actually, I think I lost some of it.

It begins with a rhetorical question about what practicing physicians should know: "How much genetics knowledge should primary physicians have?" I hasten to point out that we can really extend this beyond physicians.

We will pick it up here now. Should they be able to diagnose, treat, and counsel about genetic diseases. Will it suffice for them to check the literature. I'm skipping ahead. Optimal knowledge must lie between these extremes because a primary physician should have enough knowledge to recognize a problem as genetic and should have enough familiarity with genetic principles to be able to use the literature wisely or to consult with a geneticist intelligently.

Now, that is, I think, quite a reasonable statement. It is a nice summary of some of the questions and problems we face right now. One of the difficulties for us is it was also an apt statement of the problem back in 1979 when this statement appeared in a book edited by Ian Porter and Ernie Hook on service and education in medical genetics. So we are still struggling with some of the same kinds of issues.

This slide is simply to illustrate some of the major challenges to genetics education that we have encountered over the last seven or eight years as we have tried to bring genetics education into curricula for various health professionals. None of these is a startling new piece of information for any of you, but some of them are, I think, more problematic than others because they are, in a very large sense, systemic issues.

It is very important for us to understand that when you encounter any educational system you are encountering a complex ecosystem. As the great ecologist Garrett Harden once said, in a

complex ecosystem it is impossible to do just one thing because no matter what you do reverberates throughout the rest of the system.

So, especially for those of you who teach in schools of medicine or in schools that prepare other health professionals, none of these things, as I say, is startlingly new for you.

But I will tell you that one of the issues that has come up over and over again is this issue here: a disconnect between basic sciences and clinical experiences during training. I'm going to talk a little bit more in a minute about the way genetics content is distributed, particularly in medical education, undergraduate medical education that is, before graduate training.

But one of the things we keep hearing here is that if students do encounter the basic science of genetics in the first one or two years of medical school for example, when they get to their clinical rotations they very rarely encounter people who are teaching in those rotations who understand genetics sufficiently well enough to elaborate and bring forward the genetics principles that they have learned in their first two years.

That, I say again, is not simply the case with medical education. We hear this for preparation of all health professionals. There is this separation between the basic science and clinical practice, and it reverberates into practice, as you will see in just a moment.

I'm not going to talk about all of these issues. I will say here that there are some courses -- and you will see in a minute when I show you some data -- where the instructors or the institutions claim that they are integrating genetics across the curriculum. For example, they say, "We don't have a genetics course but it is in biochemistry." I always recall the statement that Bruce Korf made some time ago, maybe even to this group, that often the genetics is so well integrated as to be invisible. So that is an issue.

These challenges then reverberate from education into practice. We will hear more about workplace issues I'm sure from some of our colleagues, but we do have a dearth of genetics professionals. There, of course, is a lack of knowledge about genetics among primary care providers. We still encounter misconceptions, some of them quite startling, for example about the deterministic nature of genetics and that if it is genetic we can't do anything about it anyway so why should we really bother learning about it. We hear that on occasion, happily not too often.

But there are still misconceptions that genetics is associated primarily with rare single-gene disorders and chromosomal anomalies that are circumscribed by two disciplines, primarily pediatrics and obstetrics. We have to work very hard, I think, to counter that perception.

You will hear more later, I'm sure, about inadequate family histories, and lack of referral guidelines is simply, in some sense, a catch-all phrase to say that we do not have enough clinical guidelines related to genetics in general to raise the level of importance of genetics for primary care providers and others who are providing services that we would like to see integrate genetics.

Now, the response we hear most often, and I hear this over and over again when I go out to talk to health professionals about genetics, and particularly if we talk about what is happening at the cutting edge of genetics, is: "That's great stuff, but I want to know what I have to do now." Those of you who are in practice know better than I that time is a significant issue. If we can't give providers something to do that is quite concrete and that is likely to improve patient outcome, it is very difficult for them to think about integrating it into practice.

If we say to them, five years from now we are going to be able to do X, Y, and Z, they say, "Great. Come see me in five years."

Now, this is a bit of a tongue-in-cheek comment from Charlie Epstein when he gave his presidential address at the American College of Medical Genetics, but I think it is important for us to pay attention to this because we as a genetics community believe that genetic information has value in and of itself. But the transmission of that information takes time and somebody has to pay for that somewhere along the way. So this is another issue that keeps coming up again and again.

Genetics is not a discipline that does a lot of stuff. It doesn't order, at this point at least, a lot of tests or a lot of procedures. Still, the information has great value, but how does it get reimbursed.

Now, Ms. Aspinall, who is at the table with us and a colleague from Harvard Medical School, published this paper recently in the Harvard Business Review. The assertion here is that physician behavior is one of four particular barriers that stand in the way of the realization of the promise of personalized medicine. One finds in the paper this assertion: "Most medical schools have yet to fully incorporate genetics and genomics into their curricula."

Let's take a look and see what we know about that and whether in fact we can demonstrate that with some data. In fact, I think this paper is included in your packet. There is a paper that appeared in Academic Medicine back in May by Virginia Thurston and her colleagues at the University of Indiana School of Medicine. They sent a survey to this group, as you see, of 149 U.S. and Canadian medical course directors, and they had a pretty good response rate as of June 2005. I will just review very quickly with you some of these data.

Seventy-seven percent, as you can see, reported that they teach medical genetics in the first year. Only 47 percent incorporate it in the third or fourth year. This harkens back to my previous comment about the separation of genetics from the basic science years and the clinical years, and it is going to come up again, for example right here.

Now, this seems to be a reasonable amount of hours of instruction devoted to genetics. It depends on how one defines it. Eighty-six percent, and we will talk a little bit more about this in a minute, say they cover primarily general concepts, but only 11 percent say they address practical applications of genetics.

Of course, to me, this illustrates the problem all over again that when the students are getting into their clinical years there aren't people who can elaborate the genetics perspectives that they have been introduced to during their first two years, or in whatever the training course is for the health profession in question.

Forty-six percent report a stand-alone course, and 54 percent say they integrate medical genetics into another course. I just told you a little bit about my perspectives on that.

Now, these are some additional data of the most commonly taught topics. This is a very interesting paper, by the way. There are, I think, a lot more analyses that Dr. Thurston and her colleagues can do. There are some data in there about whether these courses are being taught by individuals who are board-certified in genetics or not. What I think the authors are about to do is take a look at some comparisons with respect to the course content to see if there are significant differences in the course content based on the certification of the individuals.

But you see the topics that are covered. I thought this was pretty interesting, that 91.3 percent address multifactorial inheritance, given our increasing concern about common complex disease.

I should point out that the data about the lack of understanding of genetics and the lack of preparation of professionals in genetics, those data come not only from analyses within the healthcare community itself by other health professionals but also from the public at large.

Now, admittedly, this is a selected group. This is an analysis that we conducted in conjunction with our colleagues at Genetic Alliance. We had almost 6,000 responses to this survey of consumers' perceptions of the genetics knowledge of their providers. I will refer you to this paper. In general, the news was not very good. The consumers did not evaluate their providers very well with respect to their understanding of genetics.

Here are the central questions and challenges. There are embedded in here a number of opportunities, of course, but increasingly we struggle with these issues. Which content is appropriate and for whom.

There is a great deal of difference between "accurate" and "complete." Those of you who have developed educational materials know that we struggle with this issue all the time. We are not going to turn, and we don't hope to turn, all other health professionals into geneticists, so they will never have a complete understanding of genetics the way many of the people around this table have it.

But, what is the slice we have to take through that content, is it accurate, how do we ensure that it is accurate, how do we ensure that it is clinically relevant, and which clinical behaviors and attitudes do we want to change and can we.

Presumably, our educational programs are intended not only to increase knowledge but to change behavior. We want people to do something differently. What are those things we want them to do and how do we measure them.

I'm skipping ahead a little bit to how do we define and measure success, but equally as important is how do we get these materials to people and how do we get them used so that we don't end up with what I like to call "state-of-the-shelf" materials. There is lots of good stuff out there, but many times it sits unused. So, how do we improve implementation and use, and then how do we define and measure success. If we are trying to change clinical behavior, how do we measure that. If we are trying to assert that education will improve patient outcome, how do we measure that. Those are very complicated and costly tasks.

I will skip ahead fairly quickly here, but just to say that we have recently produced a third edition of our Core Competencies in Genetics, which we first presented to this group a very long time ago. Based on feedback from the community, we have pared those down considerably based on surveys and based on what people tell us is really important in teaching and practice. I have some handouts of that that I will be happy to send around.

Here is another program I wanted to tell you about that is one of our attempts to try to provide access to genetics content in a clinically relevant way. I should say, by the way, that we at NCHPEG don't believe we are providing the answer, the only solution. After eight years of doing this, I don't even know what all the questions are, much less the answers.

So this is one potential solution, and we call it Gene Facts. It derived from our observation. As I have said in other settings, this is a little bit more rigorously dichotomous than the reality displays.

But there are these open-source genetics databases that include these characteristics, and subscription databases that include these characteristics. Often the subscription databases are highly clinically relevant. The material is presented in ways that the providers can relate to, but it is often not very sound.

The genetics data, on the other hand, are generally very sound, but the providers can't access them; that is, conceptually or in terms of their practice. They can access them physically but not conceptually and practically.

So we are proposing a middle ground, a point-of-care decision support system where the material is written by primary care providers and geneticists working initially with content abstracted from gene reviews or created de novo from content that doesn't reside on gene reviews. It is our hope that we will be providing information that is clinically relevant and genetically sound.

I should point out that Dr. Khoury's group has provided us with some seed money to get this started and we have made a lot of progress on this. I won't share the template with you now, but I will be happy to send it to any of you who are interested.

Just to let you know, we do have a list of criteria for selection of the first 50 entries that we will put up on this system. I'm not going to go over those with you, but I do want you to know that we have thought about that very carefully.

This is something I shared with you the last time I spoke here three or four years ago. I think it is even more germane now. I think we make a mistake by talking to our non-genetics colleagues about genetic disease all the time because for them, in my view, that simply walls genetics off in ways that we don't want it walled off.

What I'm saying is, and I know it is almost heretical to say it to this group, I really would like us to stop talking about genetic disease as if there is genetic disease and non-genetic disease. I don't know what the easy locution is yet, but I would like it to express something such as the following: it is not whether the disease is genetic or not genetic, the question is what role is genetic variation playing in the onset and expression of disease now in this particular person. Sometimes it will be quite salient, sometimes the genetic contribution will not be quite so salient.

But I would like us to start thinking a little differently. If we want our colleagues in the other health professions to think genetically and think differently about genetics, I think we have to provide some guidance for them in doing so and not continue to convey the notion that there is this what I consider to be a false dichotomy of genetic and non-genetic disease.

I thank you for your patience, and I will stop there.