Overview of Education Initiatives for Health Professionals
Q&A

DR. McGRATH: Thank you. I think your perspective of being on the roundtable before in 2003 was really valuable. Thanks for starting us off with that data.

We have a minute or two for some questions.

DR. KHOURY: Thank you very much for this wonderful work that NCHPEG is doing. I would like to pick up the theme of stop using the words "genetic disorder" and "genetic disease." [I will] ask you to guide us a little bit about NCHPEG's activities over the last few years in this context particularly because I heard you a couple of times say genetic information has intrinsic value for us as geneticists. We have to provide guidance.

People sitting on the other side in the context outside genetic diseases for which genetic information has intrinsic value, they don't know whether it has intrinsic value, let's say for pharmacogenomics or for the treatment of Disease XYZ. They don't know whether it has intrinsic value or not.

The question that I want to ask NCHPEG [is], has NCHPEG picked up the concept of evidence-based medicine and working with the primary care providers and the evidence-based communities to see which type of genetic information -- outside of genetic diseases, which we all know we need to diagnose, treat, counsel, et cetera -- needs to actually be moved into mainstream?

The average practitioners are still asking all of us "What should I do now?" So in the absence of evidence-based guidelines to guide them to do this, they may not think that genetic information has intrinsic value. Help us go through this.

DR. JOHNSON: Thanks, Muin. That is a very interesting question. I will have to say we probably haven't addressed the concept of evidence-based medicine as carefully as we should have in most of our programs, or at least in some of our programs.

We do work with our colleagues in the provider community to try to identify those cases and those instances in the clinical setting that are most important and germane to them, and they actually try to help us to frame the discussion about what kinds of evidence will resonate with their providers.

In a more concrete sense, we have, in conjunction with Genetic Alliance, been working on, actually, a CDC-funded project called Access to Credible Genetics information. I don't have the acronym quite right.

But the issue here was for us to try to apply the principles of evidence-based medicine to the selection of genetics information that providers and patients can use to make informed decisions to improve health care. We found that there was not an easy one-to-one correspondence between the types of evidence that AHRQ requires, for example, and the types of information we want to present to providers and to individuals so they can make decisions.

So we have actually developed a separate toolkit and metric to help individuals, providers and patients alike, judge the completeness and the accuracy of the information that is available to them both in an educational setting and from the literature.

I don't know if that helps answer your question or not.

DR. McGRATH: Thank you.