

Progress in Integrating Genetics into Primary Care
Norman Kahn, Jr., M.D.

DR. McGRATH: That was nice. Getting back to it, the next speaker is Norman Kahn, who is with the American Academy of Family Physicians. Thank you.

DR. KAHN: I appreciate very much being here. I'm going to try to represent the position of medical education in this. The reason that I'm sitting here is that I have two video clips. They don't transfer on a thumb drive, so we are going to do our best with the video clips.

There have been a lot of revolutions in health care: antibiotics, aseptic techniques, surgical anesthesia, imaging. If you are part of these, you recognize the kind of revolution that takes place when these come into practice. Immunization, sewage disposal, water purity. The real question is whether or not genomics is going to turn out to be at the same level of revolutionary in the practice of medicine.

Francis Collins' great quote: "Virtually all diseases, except maybe trauma, have a genetic component." I think we all recognize that. As Joe McInerney has pointed out, I don't think that that concept has been integrated well into medical education yet.

I'm going to tell you about two projects, and I'm going to hint at a third one, and illustrate them with a couple of video clips. At the end, I'm going to do a little needs assessment for you to help guide your next steps.

The first project I'm going to talk about was called Genetics in Primary Care. This project started in 1998. Remember the genome was only sequenced in 2003, so this was really a prescient project. We very much appreciate the agencies that you see on the screen for their foresight in being able to recognize that it was going to be necessary to begin to educate medical faculty about genetics so that they could incorporate genetics into medical education. The goal, again, was to get it into undergraduate and graduate primary care education.

Now, the next two slides are probably the two most important slides of this presentation. The most important concept that we learn from the GPC project was the concept of primary care through a genetics lens and then genetics through a primary care lens.

When we brought the primary care community -- family medicine, pediatrics, internal medicine, to some extent OB/GYN -- [together] with the genetics community -- medical genetics, genetics counselors, Genetic Alliance, et cetera -- we discovered that there were two different languages, two different cultures, two different perspectives. Each of them was ignorant of the other's perspective. Recognizing the two perspectives was absolutely critical. Otherwise we would not be able to communicate with one another.

The concept of primary care through a genetic lens: as a primary care physician, I need to expand my differential diagnosis to include genetic conditions. I need to use an appropriate family history to identify genetic conditions. I may or may not be able to do a three-generation pedigree, but I certainly need to do an appropriate family history. I need to recognize the importance of non-directive counseling, which is the hallmark of genetic counseling, which is not the hallmark of primary care counseling, as we will see in just a moment. I particularly need to recognize the ethical, legal, and social issues raised by genetic diagnosis.

SACGHS Meeting Transcript
November 20, 2007

Now, the genetics community recognized that they needed to see genetics through a primary care lens. If the genetics community is going to contribute to genetics in primary care, then the genetics community learned that they needed to evaluate the utility of genetic information in terms of health outcomes.

The genetics community's basic premise is that all information is valid and valuable. What the primary care community contributed was that it needs to be evaluated. The utility needs to be evaluated in terms of health outcomes.

They need respect for patient preference. The patient is not ready for all information, doesn't prefer to make all decisions themselves.

Protect patients from media hype, and use the potential of longitudinal care. We learned that the genetics community's usual encounter is an hour in a consultation with a patient, whereas the primary care community is seeing people for 15 minutes on a weekly basis, on a monthly basis. People get ready for new information. Those two concepts became very important as we played out the relationships.

There were 19 teams. I think you all have a handout, so I'm not going to go through each of these teams. We put them up there in case you know people at these particular groups. You can talk with them about their experiences.

This was the GPC curriculum. There were seven topics that were recognized in primary care as having a genetic component. Now, what is interesting is, with the possible exception of hemochromatosis, in the primary care community, as Joe pointed out, we wouldn't consider these genetic disorders. Breast cancer is not considered a genetic disorder, nor is colorectal cancer.

Thinking genetically allows us to recognize the family history component, distinguish among the different types of colorectal cancer for example, see which are genetic and which are not. But the concept of patient acceptance is enhanced by not referring to these as genetic disorders.

There were several complementary tools. There is a curriculum. I'm going to give you the website for that curriculum. You can still get to it. We talked about evidence-based medicine even back then, between 1998 and 2003, and particularly cultural competency.

Here are the websites that you can go to. One of them is a federal website at the Maternal and Child Health Bureau. The other is the Genes R Us website, and you have these handouts.

After 2003 then, having focused on undergraduate and graduate medical education, we decided to focus on practicing clinicians and produced a program called Annual Clinical Focus, which means we spent the whole year of 2005 focusing on genomics and educating primary care clinicians at the practice level.

These are the supporters. These are the folks who paid for this particular endeavor, which we are extremely appreciative of. Again, additional supporters. One of the things that is interesting here is that there aren't very many pharmaceutical companies in the support here. Pharmaceutical companies love to support continuing education for physicians, but they weren't ready to support education in genetics. Very interesting.

These were the cooperating partners. You can see we did this with the nurse practitioners, pediatricians, physician assistants, medical geneticists, the internists, as well as family physicians, a variety of genetics groups, the Heart Association, the March of Dimes.

Here were the topics. You can see there is a lot of overlap in the topics. Family history was added in there. Bipolar disorder. I'm going to show you some usage data that I find particularly interesting.

First, I'm going to start with a video clip, if I can get the sound to work. We did test the video and I know the video works.

Just to give you a sense, there were eight programs with those eight particular topics. I say past tense because continuing education has a life span. It has an accreditation span of two years. Unfortunately, there are only two of them that remain on the Web. You can get to them if you get there before the end of November, when they expire. There are two remaining, and they are just at the homepage of the American Academy of Family Physicians, AAFP.org. Right there on the homepage you will find "Annual Clinical Focus" underlined, and you can get to these.

But let's see if we can get the video clip to work.

[Video presentation.]

DR. KAHN: I'm going to go on just in the interest of time. I think you get a feel for what we are trying to do with these programs. These are each 30-minute programs. We are trying to model. This in particular is a family physician, but we have a nurse practitioner on one, we have a physician assistant on one, we have a pediatrician on one. We are trying to model the interaction with the patient so that the practitioner gets a sense of what they can do now, today, in practice, not waiting for some new breakthrough.

We had hoped that the Web-based delivery would work. This is the usage data. When we talked to our partners, we had no way of knowing how many people would participate in this. If we got 5,000 visitors or users, we would be thrilled. As of today, we are over 30,000 unique visitors to this program. So we have far exceeded our expectations. My response to you is that this is a very good vehicle for educating clinicians in practice.

I'm just going to let you know that the residency training programs are also core curriculum for incorporating genomics into residency education. It is a particular reprint which I can get for you if you particularly need it.

Here is my needs assessment for you, as I conclude. Even though we did a five-year faculty development project and even though we spent an entire year with the entire primary care community, educating primary care clinicians, it isn't over. We still see that primary care clinicians need to see primary care through a genetics lens.

Primary care clinicians need to incorporate family history as a standard of practice in each patient's health record. Primary care clinicians need to be sensitive to the ethical, legal, and social issues in helping patients and families approach genetic testing.

Remember there are 2,000 certified medical geneticists and 2,000 genetic counselors in the United States. There are communities that don't have these professionals. A quarter of the U.S. population lives in communities of 10,000 or less. The only clinicians in those communities are

family physicians, osteopathic physicians, a few general surgeons, and some nurse practitioners and physician assistants.

Primary care clinicians need to know the evidence-based implications for genetic testing. A full disclosure: I serve on the Advisory Committee for Heritable Disorders and Genetic Diseases in Newborns and Children, which is dealing with implications of newborn screening and particularly the evidence-based implications for genetic testing in that realm.

Primary care clinicians need to be comfortable in interpreting and following up on genetic tests with patients and families. It is not going to be sufficient to say, "Oh, look. Your screening test revealed something. I will get you an appointment with a genetic counselor." That is going to be fine in a large, tertiary care center. It is not going to be fine in most community settings.

Primary care clinicians need to be comfortable managing chronic genetic-based illness using multidisciplinary teams and community resources.

Primary care clinicians need genetic decision support integrated into their electronic health records. You might be interested to know that the integration of electronic health records in the primary care community has really taken off, again much more quickly than some of us would have expected. In the family medicine community, the percentage of offices that are on electronic health records is close to 40 percent, with another 12 percent in the process of purchasing electronic health records. So the need for embedded decision support is right now.

I don't know how many of you have heard Dr. Collins' musical description of the current state of genetics education. I have Dr. Collins' permission to share it with you. In Francis' words, he says, "Oh, go ahead. My life is an open book anyway."

[Laughter.]

DR. KAHN: The Dr. Henley that he refers to is his medical school classmate Doug Henley, who is the CEO of the American Academy of Family Physicians. This was at the annual meeting of the society.

[Video presentation.]

[Applause.]

DR. KAHN: Just an interesting interlude.

DR. GUTTMACHER: Can I just give a little context for this? My major job as deputy director of the National Genome Research Institute is to try to keep Francis from doing this.

[Laughter.]

DR. GUTTMACHER: But I do have help in high places. As some of you know, a couple of weeks ago Francis was awarded the Presidential Medal of Freedom. Two or three weeks before that, he got called by the White House and told that he was going to be bestowed this medal and given directions about where to show up, how many guests he could bring, and that kind of thing. At the very end, the staffer said, "Oh, yes, Dr. Collins. There is one more item that I was specifically asked to tell you about." Francis said, "Yes, what's that?" He said, "No music."

SACGHS Meeting Transcript
November 20, 2007

[Laughter.]

DR. KAHN: As speakers are wont to do, Dr. Collins was gracious enough to receive individuals who come down to the stage and talk with him. My job was to guard his guitar because he has a very nice Martin guitar. Hordes of people came down to talk with him, and two people came straight for the guitar. They didn't care about Dr. Collins. They recognized the value of that guitar.