

*Overview of Efforts by Organizations and Professional Societies to Address Genetics  
Workforce, Education, and Training Issues*

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Dr. Boughman.

DR. BOUGHMAN: Thank you, and I'd like to take this opportunity to thank the committee for letting us bring some of this information to you. You all have in your packets the written materials. I'm going to hit some of the highlights and give you some framework this afternoon.

Actually, I put the slide up here with the American Society of Human Genetics logo on it to remind you that today I am not speaking for the American Society of Human Genetics in this context. I'm speaking as a member of the genetics community and having been involved in genetics education in many aspects for a long time and having chaired the previous work group for SACGT.

I want to remind you of the stakeholders and that Dr. Fong's very nice pyramid in fact could be superimposed on this. What I'm going to do actually, I'm going to speak about genetic specialist positions and just a moment about public education, but in fact allow the other speakers to focus on those areas.

What I would like to do is talk to you and remind you yesterday afternoon that one of the comments that was made late in the afternoon talked about the responsibility or whose job is it? Who is ultimately responsible for various aspects? Yesterday's focus was on oversight. Today, I'd like to put that framework around education, if you will.

In general education, of course, we have all of the school boards and all of the curricula.

Let's move on to undergraduate education, which can, of course, be extremely variable, but the American Society of Human Genetics Information and Education Committee has done one survey and is getting ready to do another survey on undergraduate courses around the country and their content. The bottom line there is that the content is not sufficient, especially on the basic concepts of genetics that can be applicable to real-life situations, and in fact there's been one paper published that you have the reference to and there will be another paper talking about suggestions for content there.

When we move in the undergraduate to medical school, in the premed requirements, we're now talking about the AAMC, the Association of American Medical Colleges. It is interesting that medical students who have been surveyed rank genetics as the third most important content area, yet no medical school in the country requires genetics as an undergraduate course for entry to medical school. However, there are some other interesting requirements still out there for us. This is a question that has been raised with the AAMC and they are looking at it, but change is sometimes difficult.

The medical school curriculum themselves, once again the AAMC and various other accrediting agencies who will look at the medical school curriculum. However, we have other groups who have been involved in the development of those, and we'll get to that in just a moment.

Postgraduate programs or residencies. Now we start really getting into alphabet soup. We have the ACGME, the graduate medical education accreditation organization, residency review committees for every specialty, and the American Board of Medical Specialties, which incorporates all of the major

boards for all of the specialties and that serves as the umbrella for each one of those organizations.

For continuing medical education, we have the American Board of Medical Specialties, working through the individual boards, and in our case that would be the American College of Medical Genetics.

For geneticists themselves, both M.D. and Ph.D., their training, the content of their training, the accreditation of their programs, and their certification comes from the American Board of Medical Genetics. For counselors, that is the American Board of Genetic Counseling.

For health professions in general, I'm not going to go into that area. Joe McInerney will be covering some of these things, but from a slightly different angle in a little while.

Now, let's talk about the activities themselves. In the medical school curriculum, the American Association of Medical Colleges looks at those general curricula, but it is the Association of Professors in Human and Medical Genetics, a subgroup of geneticists, that have worked very hard over the last few years to in fact develop curricular content for medical schools that now has been adopted by the AAMC and in fact is out there and being integrated into many of the medical schools around the country. Constantly under change as we move to a problem-based learning curriculum, we have to make a variety of changes, but at least the curricular elements are there.

Then when we get to national board examinations, we bring in another organization, the National Board of Medical Examiners. Now, as geneticists, we have to deal with another organization to get ourselves appointed to the right exam-writing committees to make sure that we test on genetics in order to affirm that genetics was important in the curriculum in the first place, because the dean of a medical school, wanting to know whether his or her medical school is meeting the guidelines, will look at the results of the national board exams.

So now, over the last few years, in fact we now have genetics as a subset. You can actually look for genetics as a group of questions. This has been a hard-fought battle, but we're getting there.

In residencies, once again, the ACGME, the accrediting body, and the residency review committees are the ones that work on the residency curriculum, and this is not only in the didactic curriculum, but in the practice curriculum itself, how in fact the topics are woven into the various residencies, and I'll make a few more comments about that a little bit later.

Continuing medical education, which has been, in theory for a very long time, a very important concept. Now, it's written in stone because via the American Board of Medical Specialties and the individual boards who certify individuals, certifications are now time-limited. So people in fact, to continue to be board-certified, have to demonstrate competency in a variety of areas.

This is a window of opportunity for genetics, as I see it, because in fact genetics is one of those areas that all of the practicing physicians out there who are garnering board certification in their own specialty, we can in fact provide them with the elements to teach and examine on genetics in a variety of specialties. This is referred to as maintenance of certification and is a very important item on the docket of the American Board of Medical Specialties.

We've talked about the number of individuals certified and so on, with clinical geneticists being 1,075. Please notice over the last few years the numbers are dropping in the number of board-certified clinical geneticists.

If we look around the room and count the number of board-certified clinical geneticists who have been in

the room in the last two days, I would suggest that nearly 1 percent of those qualified have been here. Ergo, they are not seeing patients at this point in time. They are not teaching medical students. They are not teaching other places. It is this cadre of people that are responsible for doing all of these tasks.

Now that the American Board of Medical Genetics actually has a residency in genetics -- it's not just a fellowship on top of other residencies, and I'll talk about that option in just a second -- there are 175 slots available for medical genetic residents around the county.

That number that I have there of 95 is an error. It is only 78 out of the 175 slots that are filled. There were many more applicants than those 78. They simply do not have the funding to fund those residency slots because from the hospital's perspective, they get so many dollars for residency slots and in order for genetics, a new residency, to get a slot, another residency slot has to be taken away from some other specialty. So from the training point of view, the mechanism and the process is there. The funding is not.

You'll hear more about the counselors again in just a moment.

We're trying. We're trying very hard in the genetics community. We have been working very diligently with a broad range of specialties on RRC, with the residency review committees, on their curriculum, and in fact in the American Board of Medical Specialties board programs, through geneticists being members of these other boards, we now have developed approved genetics curricular elements in pediatrics residencies, in internal medicine residencies, in neurology, in family practice, and in OB/GYN. So now any resident going through any accredited residency program would have those elements in their training process.

In addition, we have worked on formal combined residency programs. Right now, there is a medical genetics and pediatrics combined residency program, a medical genetics and internal medicine combined residency program, and a medical genetics and pathology special training in molecular genetics that has been approved by both boards and approved by the American Board of Medical Specialties. We are now working with psychiatry and neurology, the American Board of Obstetrics and Gynecology for general OB/GYN, as well as a way to integrate the maternal/fetal medicine program in genetics, and the American Board of Family Practice has approached the American Board of Medical Genetics.

I talked to you already about maintenance of certification. I will remind you that it is board-specific. So of the 24 boards out there, the geneticist will have to work with the members of each one of those boards to include the materials, to make programs available to them, and then to assist them in figuring out ways to develop the competencies.

This is where one of the really important transitions comes in. I've talked about the American Board of Medical Genetics, but the American College of Medical Genetics is the group that not only helps develop many of these curricular materials, but in fact produces guidelines, practice guidelines, that puts the genetic example into the practice situation of the individual who needs to practice that.

For example, the American College of Medical Genetics and the American College of Obstetrics and Gynecology with the CF testing. It is when that material comes into the OB/GYN's office and they see how it is supposed to work for a patient, if there then is a knowledge gap that he or she has, they can figure out a way to fill that knowledge gap.

But unfortunately, the idea of build it and they will come or put it on the web and they will learn it is not going to work in many situations. I commend the AMA and I use the AMA website for a lot of different kinds of things. It is really extremely well-done, but we're talking about those doctors out there that only have 10 minutes per patient as it is, and it is a challenge to find time to utilize those.

The ABMS now has a committee on the management of maintenance of certification, the maintenance certification police, as some of us are fondly calling it. In fact, right now, from the genetics community, we have nominated one of the public members to be a member from the Genetic Alliance, who in fact I think will have a lot to say about maintenance of certification in all specialties in the way genetics fits into the pediatrician, the OB/GYN, the family practitioner.

We need teaching models. There are a lot of curricular guidelines and elements out there. I suggested the professors group before and you'll hear more about NCHPEG. Professional guidelines. The American Society of Human Genetics and the College continuously are developing guidelines. Programming for the specialties, as I suggested, and faculty development, geneticists with individuals in other groups like the Genetics in Primary Care model.

I talked to you already about the undergraduate and medical school requirements and it's heartening to realize that genetics is rated as the third most important subject, but one of the challenges once again we have in the medical schools is often genetics is taught as a basic science. When you in fact ask medical students if they want to specialize in biochemistry or physiology, they'll probably say no as well. They are not yet seeing -- in the time, genetics is not yet into the fabric of practice.

We also need to deal with patient and consumer education, obviously, both with informational materials at the time of service and many of the websites that are being developed now, and groups such as the Genetic Alliance, the GeneTests, and the National Library of Medicine. Their new Genetics Home Reference is a great website.

We're working with teacher training with the National Association of Biology Teachers and the National Science Teachers Association, giving lectures and workshops at every annual meeting that they have, providing materials to the teachers from the NHGRI website and the American Society of Human Genetics and NCHPEG.

We have a mentor network set up with over 700 genetics volunteers available around the country for any science teacher or student to get on the website and find a geneticist in their area who is willing to come and talk to a classroom, work on a project, and so on. We have more work to do there.

I left the media slide blank because at this point I don't think we've begun to tap the resources that the media might provide us, and I would suggest to you that that is an area that does need to be looked at.

In the written materials, I suggested ways of addressing each one of these. I'm not going to do that orally here. We can do this during the discussion, but I would suggest to you that we do have big barriers, and one is the perceived lack of necessity or relevance that the everyday practitioner out there -- once again, what do you want me to do as a physical therapist or a family practitioner? What am I supposed to do differently?

We need to shift our focus from rare disorders to the common ones. We have the challenge of, once again, the overcrowded curricula and the complexities of the probabilistic material that we're trying to get across.

We have a lot of gaps left to fill. We aren't teaching enough concepts in college and probably not in high school or junior high school yet. Right now, we're facing a declining specialist pool. We don't have enough training faculty out there in all of the disciplines who are excited enough about and know enough about genetics to train other faculty to train the students to provide the service.

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TRANSCRIPT

There is a tremendous gap, of course, in understanding genetics and common disorders, and while my bottom line here is that we are improving -- I've tried to show you the way that we're working every day to increase the amount of genetics information that is out there at all these levels -- remember the curve of genetic knowledge that is coming out, and in fact one of the other speakers talked about this gap, and as the genetic knowledge goes up and we're working so hard to make this curve up, the gap still gets bigger.

So with that, I will sit down and we can continue the discussion a little later.

Thank you.

DR. McCABE: Thank you very much.