

**Role of Professional Societies**  
**Q&A**

---

DR. McGRATH: Thank you, Melissa. We have five minutes for questions until break. I know we are going to get back to some of the questions that you raised at the half hour, so we will start with Marc.

DR. KIRCHNER: Thank you for a very nice presentation. I'm sorry to hear that so many of the training programs are open. I guess the obvious question that that prompts is what are the job opportunities? You are the only geneticist at a fairly large center. Obviously there is not room for more or people have not hired one. I think that would drive, of course, the educational needs. Could you expand a little bit on that in terms of where are the job opportunities and is that something that can improve?

DR. FRIES: I believe that Judith is going to speak on workforce issues, and so it may be something that she would be able to defer that. I will let you comment in just a second, Judith.

I think the key point is that there are usually spaces available where people have the creativity to recognize the need. In genetics, we also have to market ourselves. It is not like they are limited, it is simply something that many people have not even recognized that there is a need for that.

Judith, do you want to speak to that?

MS. BENKENDORF: I don't have the statistics on unfilled positions, but I'm sure that is something we can get. I do want to comment about the residency slots. The 196 slots that are approved are not all funded slots. We do have, I think, 75 to 80 funded slots, and we can't even fill those. But what happens in hospitals is they say, "Fine. You want a genetics slot. We only can fund X residency slots, so we will take that funding away from pediatrics or surgery or another department," and that usually doesn't go over too well.

DR. FRIES: Yes.

DR. WILLIAMS: I think the other point that is missing here, and again I refer to your fifth slide, which is the colleges' positioning of medical genetics as ideal for students seeking an academic career.

Speaking as someone who is not an academic and has enjoyed my private genetics practice, there are a number of us out there. I think we may be the only specialty that has positioned ourselves as an academic career. I think most other specialties say you can do academics but there are plenty of opportunities in the private sector as well.

This was a point that I made to the organizers of Banbury I in the sense that there was no representation from the private sector there. I think that was addressed to some degree in Banbury II, but I think we really have to engage with the private sector because there is a lot more money, there are a lot more jobs, and there is a lot more need, quite honestly, in those settings. Then, as Peter pointed out, if those jobs become available, that will to some degree drive interest.

But as we have talked about in the context of healthcare systems and payers and that, once we can really consistently create the recognition that this is really needed out there for the patients that people are taking care of, then I think that will happen. Groups like Northern California Kaiser

that have really gotten this message and taken it forward for 30 years are very successful examples of that model.

DR. FRIES: I would agree with that. I would also comment that part of that was a brochure that we developed through the American College on Medical Genetics as a residency program emphasizing, with your comments, that it was an expanding role in the private sector.

Yes, sir.

DR. KHOURY: I would like to come back to your three Rs, Recognition, Referral, and Reimbursement, in light of the unfilled residency slots and in the light of the fact that there is really no marketing of genetics. Here we are in the 21st century and people are selling a whole genome on the street right now as we speak.

There is a major disconnect between the basic science and the marketing of that for the world of practice. This is, to me, a lack of translation in a major way. I wanted to get your thoughts on the idea that maybe we are only selling a very small part of what could be sold.

I'm a member of the College and all these societies, and we are selling genetic services. We are selling information to help families with genetic conditions. I'm not saying we should get away from that because there are a large fraction of individuals and families in the U.S. and everywhere that need those kinds of services. Individually conditions are rare. That is why for average practitioners the a priori probability of finding any particular syndrome or disease is fairly small.

But no one has positioned the medical genetics community so far and the various aspects of it to be the information translators for what genetic information means to the average person or the average encounter of patients with their physicians, whether it is drugs or not.

I want to come back to the concept of evidence-based medicine because that is what the average practitioners need, guidelines and criteria. As long as we in the genetics community keep selling the genetic services model, which applies to a fraction of genetic information, maybe we are missing a larger market out there, the market that allows us to interpret what decoded genetics is trying to do, and the genome profiles and all these combinations of genetic risk factors and pharmacogenomics.

I wanted to get your feel of what that means in a 21st century practice of genomic medicine versus the practice of medical genetics, which is what we all got trained in.

DR. FRIES: Clearly, our practice is going to be an evolution. For many of us, the practice initially started as a spinoff, perhaps of a subspecialty of what we did before: pediatrics, OB/GYN, internal medicine. But clearly, if we are going to make this a 21st century model, you have to work beyond that and you have to expand it.

I think part of that has to go with some of the issues on how insurers are going to support some of the evidence-based medicine as well. Insurers clearly are going to be looking and saying this is a justifiable point to do.

For example, I have one insurer that will not reimburse me as a complex consultation for my genetics consultation. They will only reimburse me for a moderate consultation. It depends. What do you call moderate, what do you call complex. If it takes me 90 minutes to get this information out, that is pretty complex. So some of it has to be driven.

As we said, it is the ecology of our entire changing time. You can't just change one thing, you have to change the whole process. But some of it is you have to make genetics sexy. Genetics is sexy. We deal with sex all the time, so you have to make it that way.

DR. TUCKSON: Please, my god.

[Laughter.]

DR. TUCKSON: Some of us aren't ready for this.

We are going to do this. We are going to do three quickies, real quick, and then we are going to take the break. So, no fooling around. One, two, three.

DR. WILLIAMS: This is just a follow-up to what Muin said. I think what we need to do is think systematically and look at what healthcare systems need and be the knowledge resource. Some of it is going to be direct hands-on patient care, but some of it is going to be being the intelligent filter of all the information that is coming forward. The economic argument that can be made to systems is that if you don't do this right, you are going to be spending money and valuable resources on things that really don't add value.

So we need to be thinking from a more systematic perspective, and that is something that payers want, too. But we have not been willing as a society in general to engage with those types of things. We have tended to remain in that economic model.

DR. TUCKSON: Andrea.

DR. FERREIRA-GONZALEZ: I was very pleased to see some of the improvements for the USMLE step one questions on the board specific for the genetics. My concern comes, and maybe we can discuss this later at the roundtable, for some movement that is going on through the USMLE to reorganize the curriculum for medical schools to place more emphasis on the clinical sciences and decrease some of the basic science. What is the impact going to be with all this movement down the road.

I don't know if you want to address this now or maybe discuss this later.

DR. TUCKSON: Why don't we tee it up for the discussion. Put it in your notes to make sure we come back to it. Daniel.

MAJ. WATTENDORF: The question I have is regarding this high-complexity visit with a clinical geneticist. In fact, I'm keying in on what Dr. Kahn said and something else that Dr. Khoury said. I think as personalized medicine moves forward, the clinical geneticist arena will expand beyond the high-complexity rare disease visit and really needs to hit the reimbursement for a predictive evaluation and predictive genetic testing, both testing which we don't get reimbursement for easily with CMS reimbursement right now.

The paradigm needs to shift from high complexity visits to within the 15-minute visit where a predictive evaluation of an individual's risk stratification is part of the clinical practice. I don't see the clinical genetics community really moving into that arena.

DR. TUCKSON: Great. We will get that on the discussion as well. That is an important observation. Lastly, Hunt.

SACGHS Meeting Transcript  
November 20, 2007

DR. WILLARD: Thank you, Reed. There is something symmetrical about this. I will make the same comment I made in 2003, the first time I spoke, and this is going to be my last word.

[Laughter.]

DR. WILLARD: Muin wants evidence-based medicine, but I think we ought to have some evidence-based education. The evidence says, and it has been saying this for 10 years, that medical genetics is not a growth industry as a medical specialty. The growth industry is in genetics and genomics and genomic medicine. There is great excitement. The consumers are there. All the other medical specialties recognize, to greater or lesser degrees, that they need to figure out how to get genetics and genomics into them.

But the specialty of medical genetics, where we are half-empty on the residency end, clearly that is not a growth industry. There are two competing messages. One is, and I think even in your own words you allude to this, there is the need to take care of the traditional business of medical genetics because, clearly, that is a need. There are genetic disorders, there are genetic syndromes, and those kids who become adults need care and there is a medical home for those.

But for all the other disorders that we don't want to call genetic disorders, to Joe's point, the medical community and consumers don't believe that those are in the purview of medical genetics. Those are in the purview of all the rest of medicine.

So evidence-based education would, I think, tell us to steer our educational efforts elsewhere and then separate that from the somewhat smaller but equally important task of refilling the boat of medical geneticists. We will need a relatively small number, but we need them to deal with "genetic syndromes" going forward.

DR. TUCKSON: Hunt is nothing if not consistent. Thank you for that.

We will stop. At 10:50 Angela will begin. So you have to hustle because Angela will start at 10:50.