

Framing the Issues
Joann Boughman, Ph.D.
Vice President, American Society for Human Genetics

DR. McCABE: Well, in June, we talked about the importance of ensuring that our health professional workforce was well-prepared for genetic knowledge, services, and technologies, and there was concern expressed by our members about the role of genetics in health and disease, that as it increases and the technology advances, that the health professions may not be sufficiently well- prepared to integrate this information.

We decided it would be helpful to learn about federal and private sector activities in this area. HRSA, since they have a leading role within HHS in addressing workforce issues in the health professions, we asked Dr. Sam Shekar, HRSA's ex officio, to take the lead in compiling information on federal efforts.

Dr. Joann Boughman, executive vice president of the American Society of Human Genetics, who testified before our committee in June about the importance of preparing future genetics professionals, generously offered to take the lead in compiling information on various professional society activities. I should also note that Dr. Boughman served as chair of the SACGT Education Work Group, and she will be sharing some of that information.

In addition, we will also have the benefit of presentations from Dr. Judith Cooksey, who is principal investigator of a federally-funded genetics workforce study, and then after lunch we will hear from Joe McInerney, director of NCHPEG, the National Coalition for Health Professional Education in Genetics, and Robin Bennett, past president of the National Society of Genetic Counselors.

This series has been organized to give us a better overview of public and private sector efforts in these areas, and I'll thank in advance Drs. Willard and Tuckson for serving as facilitators. Thank you.

So with that, Dr. Boughman.

DR. BOUGHMAN: Thank you.

In the next few minutes, what I would like to do is frame some of the issues and, in just a few minutes, save you many hours of reinventing some of the wheels or rehashing again some of the issues that have been talked about for a great deal of time.

The challenge we have is enormous. Genetic knowledge and technologies, as we know, are moving very, very rapidly. We also know that the integration of genetics into health care and public health practice is actually driven by three main forces. First of all, these advances. Secondly, consumer and patient demand, but we always have to include cost considerations and the new emphasis on prevention.

These forces are what are driving the health care professionals to need to in fact be so well-educated, and in the webcast session that I watched yesterday -- all of you were in my office as well as here, two places at once, at least -- there was a question of is it adequate? The answer is no? Is it outrageously inadequate? Becoming so if we don't catch up quickly.

In fact, I'm going to come back later this afternoon and say that one of the aha moments that we had in the SACGT Education Work Group was when one of the private practitioners who is a family practitioner said, "Give me all the curriculum you want, but what I need to know is what should I be doing in my

office differently tomorrow."

It all comes down to that and until we can reach that bullet, then in fact we have more challenges before us because health professionals are the ultimate arbiters and we know that major gaps exist in health professionals' knowledge and education and training in genetics, and you'll see later today with some data that actually the age of the clinician is inversely correlated with the amount of genetic knowledge they have and use on a daily basis. There are gaps in knowledge, education, and training that will limit that integration into all aspects of health care as we know it.

We have several key stakeholders that we'll be hearing about in various aspects. I'll be talking about genetic specialists on the M.D. and Ph.D. side. We'll hear about genetic counselors. I will also be talking about other physicians, several of us will be mentioning other public health professionals, and then we will also hear about nurses and allied health professionals, always with the background of patients, consumers, and the general public as our ultimate stakeholders.

There have been several prior national efforts, and I'm sure you all have had materials given to you. I'm going to point out what I believe, after our years in SACGT and the Education Work Group, the real highlights were.

There was a National Academy of Sciences group in '75. The IOM had the "Assessing Genetic Risks" in '94. There was the Task Force on Genetic Testing in '97. IOM came back again and in fact had their issues on educating public health professionals in 2002, and then the SACGT Education Work Group in 2001 and 2002.

Even in 1975, the National Academy of Sciences group said medical school curricula and continuing education should emphasize genetics, that physician knowledge of genetics should increase orientation toward preventive medicine, and that schools of medicine and public health and allied health should be provided support for programs to set these standards and train personnel.

The Institute of Medicine -- I'm just going to highlight some of these -- they again said we needed to train more professionals and several of these other things.

What I have done in the materials that you have on the slides is try and indicate to you some of the progress that has been made and some of the groups that have been working on these issues. We have genetic counseling programs. We have ABMG, the American Board of Medical Genetics, training programs, and you'll hear later today about some of the programmatic efforts to teach the teachers, if you will.

It was also said in 1994 that we needed to maintain genetic counseling programs and also to develop programs for single-gene disorder educators and counselors, and we believe the shift has changed from that focus.

It also suggested that consideration of genetic counseling and education should be a part of the standard of care. This, of course, would fall into the area of professional guidelines, as well as changes in curriculum that we will talk about later today, too. Also, that CME programs should be expanded.

They went on to say that we should simply reform education, which is why the breadth of our challenge is so huge. However, that's what we're doing because we're not only talking about the science. We are talking about looking at medicine from a genetic point of view, including the ethical, legal, and social implications. That is an educational reform across the board. Progress is being made in many of these areas, and I've listed several of the groups that are at least chipping away at this challenge, and we'll hear

more about that later today as well.

We come again to CME programs for all professionals, not just the physicians. At that time, there was concern and there is continuing concern about recruiting more minorities, and there are federal programs that help us do that, and even in 1994, there was the admonition that we should develop and evaluate online systems of education, be they programs, full curricula, or simply websites themselves.

They went on to talk about genetics curricula that we'll talk more about later today, and to develop tools to enable professionals to acquire competence. We'll come back to this issue as well, but there are several organizations that in fact are providing some of those educational programs.

We need to strengthen genetics training programs in schools of nursing, social work, and public health, and in your handouts, for the members of the committee and others, in fact we believe that there are several of these groups that are working very hard toward this goal.

In 1997, that task force again talked about increasing genetics curricula in medical school and residency. There was a slight change here, though, to talk about enhancement of licensure and certification. This now involves the states, the boards, and professional licensure organizations, and we will in fact address that later today.

Also, they were very concerned about increasing the continuing medical education, both federally-supported programs and those based in the physician and other professional programs, and that it was incredibly important to develop the competence of physicians and laboratorians. We'll come back to this later, but this includes the maintenance of certification and in fact deeming what competence is in relationship to the individual professions as it relates to genetics. Of course, we also have CLIA and the accreditation of the laboratories and the laboratorians there.

The Institute of Medicine added that schools of public health should be teaching students to think genomically. Again, an admonition for reform in education to include the ethical, legal, and social issues, and the Institute of Medicine was the first national body to in fact affirm the NCHPEG and the CDC core competencies that in fact could be used to guide curricular development.

The Education Work Group of SACGT continued on in looking for more innovative approaches to integrating genetics into the continuing care because at this point, from the 1997 to the 2001 time frame, we are now moving from genetics as a group of rare disorders into the mainstream of all medicine, and our focus then was on integrating across all the traditional departments and disciplines.

We thought that federal funding could be directed to the training of genetic specialists and general genetics education for all professionals in a variety of ways, and we'll talk about a few of those initial suggestions this afternoon, and I hope that that spurs many more suggestions from the group around the table.

Our ultimate goal, restated from the Education Work Group, was an educated public. At least, a public educated enough to receive the information that they would be receiving from their physicians and other health care professionals.

We also tried to put some emphasis on creative, interactive, and accessible programs. The Internet is not what it was in 1997 and we need to be utilizing the technologies that we have.

SACGT also emphasized collaborations in outreach, and we'll have a few of those examples this afternoon, plus the web-based kinds of things that we could use the expertise of multiple groups to come

together to utilize the web as a resource for all of the groups, all of our stakeholders.

These are just a few of the highlights, but we've been at this for a very long time. There have been a lot of people thinking very hard about these things.

We are, though, in a new phase. We have the Internet, we have an awareness now that was not present five years ago, and we have an opportunity now to capitalize on that very basic information that we have. So this morning, we're going to have some discussions about workforce and some of the issues about workforce, and Dr. Shekar's going to share with us some of the many federal initiatives that there are out there. I think that by the end of the day, you will feel pleased that there are a lot of people working very hard, but you're also going to help us be able to find where the big gaps are and how we can muster more resources to help us do better.