Public Comments 10/19

There is a wonderful opportunity to hear from the public. There is a person named Andy Faucett who is going to present. We are very pleased to have the perspective of the American Board of Genetic Counseling once again.

Thank you for your earlier contribution to the meeting, Andy. Please, you have five minutes. We're very interested in what you have to say.

MR. FAUCETT: Thank you, Chairman Tuckson, and other members of the committee. I really enjoyed the opportunity this morning to answer your questions. I'll just start by saying that please feel free at any point to use the ABGC as a resource. We really want to make ourselves available.

The American Board of Genetic Counseling is a national accrediting and credentialing body for the profession of genetic counseling. The ABGC establishes minimum requirements for graduate programs in genetic counseling, and develops a criteria by which individuals become eligible to sit for the certification exam.

ABGC also recognizes the importance of demonstrating a lifelong commitment to maintaining the knowledge and skills necessary to provide genetic services, and as a result, oversees recertification of genetic counselors.

ABGC feels that resolution of the two issues discussed by this committee during this meeting, genetic discrimination and building and reimbursement, are critical to the continuation and growth of the field of genetic counseling. One of the primary goals of the process of credentialing and accreditation provided by ABGC is to protect the public by ensuring access to professionals appropriately trained in genetics.

Comments from presentations yesterday and from working genetic counselors imply that some individuals are fearful of genetic discrimination, and are afraid to seek the help of trained genetic professionals. Such individuals may feel they must seek genetic information from other health care providers, non-medical care givers, friends and family members.

In requesting answers to important questions about their risks to develop medical conditions with an inherited component, they often receive incomplete or incorrect information. This could potentially result in an individual not obtaining information about optimal health care interventions and prevention programs.

ABGC-accredited training programs universally include the topic of discrimination in their curriculums, and teach genetic counseling students how to discuss the advantages and disadvantages of obtaining genetic information. Legislation designed to reduce genetic discrimination and educational initiatives addressing the actual versus the procedural risk of genetic discrimination needs to be developed so that individuals may freely discuss their concerns about genetic conditions with professionals who can knowledgeably provide accurate information. The ABGC is willing to work with this committee and others to reach this goal.

ABGC also works to ensure that the field of genetic counseling remains a viable and attractive career. The difficulties with billing and reimbursement for genetic counseling services could impede the development of new genetic counseling programs, and interfere with the ability of institutions housing clinical genetics programs to support the activities of genetic counselors.

As discussed at the last meeting of this committee, efforts must be made to increase the number and size of training programs. University leaders will assess the viability of the profession, and the need for new programs and expansion of existing programs in genetic counseling before committing resources.

Lack of reimbursement for genetic services could result in a decrease in these services, affecting not only our patients and their families who are dependent on these services, but also decreasing the availability of clinical training sites for genetic counseling students.

Lastly, potential students may be hesitant to enter the field of genetic counseling because of the uncertainty of reimbursement for services. As this committee is well aware, the advances in genetics are forcing fundamental changes in the way health care providers practice medicine and think about health and disease.

Knowledge about genetics and its social and ethical implications is becoming increasingly essential for many health care professionals. Genetics health care professionals have been and will continue to be the ones who will train and educate other health care professionals about the many complexities of genetic medicine, including the potential for discrimination.

According to a professional status survey administered by the National Society of Genetic Counselors in 2002, a majority of genetic counselors are currently involved in the genetics education of physicians, medical students, and other health care professionals.

Many genetic counselors have developed and implemented innovative, educational models that facilitate the genetics education of other health care professionals and students. ABGC is committed to working with this committee to reduce the barriers of genetic discrimination and inadequate billing and reimbursement for genetic services, and encourage the public to seek information from trained genetic professionals.

As certified genetic professionals, we recognize the demand for genetic counseling services will continue to increase, and we would like to ensure that these services are provided by appropriately trained professionals.

ABGC supports this committee and its efforts to recognize those qualified to provide genetic counseling services, and hopes the committee will support the credentialing process already in place for genetic counselors, nurses in genetics, and others. Clinical genetics services must be recognized by the health care industry, and reimbursed appropriately, both so patients can receive quality genetic services, and genetic professionals can be trained.

There must be high standards for all genetics professionals, and competency must continue to be assured through accreditation of training programs and certification, and recertification of practicing genetic counselors.

Thank you.

DR. TUCKSON: Terrific. Thank you so much. As discussed earlier today, we really are looking forward to your report where you can sort of clarify the landscape for us around what is known and what is not known in the area of the certification and how that whole thing fits together with the reimbursement issue.

I think the more explicit, complete, and precise you can be, the better your efforts will be served, and the better our committee can do its job. So we really put a lot of faith in your report.

MR. FAUCETT: Thank you.

DR. LEONARD: Could you comment on the genetic counseling community view of how you see genetic counselors integrating into genomic medicine? Moving toward it being complex disease traits, and what implications that has for the workforce that would be needed, the genetic counseling workforce?

MR. FAUCETT: Well, I would have to say first that I don't think the community has reached a uniform decision about how that will move forward. But many of the models that have been talked about would use other individuals to help in the process. You may or may not have a genetic counselor who is looking at the more difficult cases or the more involved cases, kind of a triage-type effect.

But clearly the number of individuals that will be needed to help with those types of issues I think are very complex. My concern though is just because a test looks for five or six things at once and it would be complicated, that we would reduce the need for genetic counseling, where I actually think it might even be increased because of the complexity of the issues. Particularly if your real interest is to test for Disease 1, but they use tests for five diseases, and you have to find out about something you don't know much about.

So I think it is going to get more complex rather than less complex. But I do think we're going to have to look at models to involve multiple other individuals in the triage system.

DR. WINN-DEEN: I was wondering if you could comment on what impact it might have on the amount of time that a counselor spends with a patient if we actually had federal nondiscrimination legislation in effect and protecting individuals. Would this allow you to spend less time discussing those issues, and more time focusing on the real clinical issues?

MR. FAUCETT: Having done cancer counseling for a number of years, prenatal first, and then cancer, I would kind of agree with some of the comments yesterday, that the current section, about half of it is talking about the implications of the testing. A large part of that being the concern about how will it affect your health insurance, life insurance, and future medical care.

I think it could make a significant difference in the amount of time if you could be very reassuring to people that that was taken care of, and would make the process much more productive.

DR. TUCKSON: Any other questions? (No response.)

DR. TUCKSON: Thank you very much, Andy. We really appreciate it.

MR. FAUCETT: Thank you.