

**SACGHS testimony**  
**June 15, 2004**

Good morning. I am Kelly Ormond, president-elect of the National Society of Genetic Counselors. As you are aware, NSGC represents over 2,000 member genetic counselors practicing in a variety of medical specialties and including academia, research, and biotechnology companies. NSGC is the leading voice, authority and advocate for the genetic counseling profession.

NSGC thanks SACGHS for taking our prior testimonies and support materials into account when developing the draft resolutions and reports. NSGC feels, with one exception that we will discuss today, that the vision report and included issue briefs accurately reflect our understanding of the issues. We urge SACGHS to continue to address these issues as proposed.

Today, NSGC would like to address three areas: the draft resolution on Direct to Consumer Advertising, the draft report on Coverage and Reimbursement of Genetic Services and our concern regarding the draft resolution on Genetic Education and Training of Healthcare Providers.

First, with regards to direct to consumer (DTC) marketing, the NSGC Code of Ethics states that genetic counselors will strive to enable clients to make informed decisions by providing necessary facts regarding genetic testing. As discussed in the issue brief and SACGHS's draft resolution on Direct to Consumer Marketing, many consumers view DTC marketing as providing them with additional information and options regarding their genetic healthcare, but we must be cautious about DTC efforts that provide misleading or inaccurate information. NSGC supports an individual's right to full disclosure of all appropriate medical information regarding genetic testing, and that genetic counseling services by a board certified/board eligible genetics professional should be an essential component of any genetic testing program that is marketed directly to consumers.

Second, NSGC agrees with SACGHS' statements in the Draft Coverage and Reimbursement report that genetic counselor billing is limited by the current lack of CPT codes for genetic counseling, and by the lack of inclusion of genetic counselors as non-physician Medicare providers. While we recognize the challenges in doing so, NSGC encourages SACGHS and the Secretary's office to consider ways to address these two issues. We also ask SACGHS promote the development of federal funding to support evidenced based studies of both genetic technologies and clinical genetic services. As was discussed yesterday, this data can be used in discussions with purchasers of benefit packages, such as employers, to support the inclusion of genetic services and testing as a reimbursable option within health plans. NSGC has prioritized issues of billing and reimbursement as one of our three primary foci in our recent strategic plan, and are also working on addressing these issues.

Finally and most importantly, NSGC would like to address the draft resolution and issue briefs on genetics education and training of health care providers. First, we applaud SACGHS's efforts to actively consider issues that impact the genetics workforce in healthcare, and to recognize the educational efforts which are already occurring. Our greatest concern, which was not the focus of yesterday's round table discussion, is that this draft resolution does not address the need for additional training of genetic specialists.

NSGC strongly believes that the provision of quality genetic medicine requires the involvement of healthcare providers of all specialties. Members of NSGC and other professional genetics organizations have been instrumental in developing and implementing educational initiatives for other healthcare providers, and we expect that they will remain the driving force towards a broader genetics competence in medicine.

While NSGC does not wish to promote the concept that only genetics professionals can address these issues in health care, it is clear that any future delivery models for genetic services will **require** the input of individuals with specialty training in genetics and genomics. The NCHPEG competencies state, "*Each health care professional should at a minimum be able to: (1) Appreciate limitations of his or her genetic expertise. (2) Understand the social and psychological implications of genetic services and (3) Know how and when to make a referral to a genetics professional.*" (NCHPEG, 2000). These competencies make it clear that non-genetics healthcare professionals should not be expected to provide comprehensive clinical genetic care, but rather to work in conjunction with genetic specialists. When one adds to this the fact that most health care providers are not comfortable with genetic information, particularly in the areas of ordering and interpreting genetic tests, and that fewer health care providers see the immediate clinical relevance of genetic testing and related technologies, it becomes clear that if consumers of genetic services are to obtain high quality healthcare, we must ensure that specialists are available to support the primary caregivers and referring specialists.

To echo the statements made yesterday by the American Board of Genetic Counseling, "*the recommendations to ensure that genetics education and training of all health care professionals is adequate will only be successful if there is an adequate genetics workforce to implement these recommendations.*" It is also clear that the current number of certified genetics providers needs to be expanded. Additionally, if we are to address the issues in health disparities raised by Healthy People 2010, SACGHS must also consider the limited cultural and ethnic diversity in genetic professionals, and that most of these genetic specialists currently work at academic medical centers, often limited in their ability to provide outreach to underserved regions or populations. Furthermore, there continue to be multiple impediments to increasing the training pipeline for both medical geneticists and genetic counselors. An infusion of federal funding would increase the number of quality genetic counseling training programs in a short time frame.

Genetics professionals, with their experience across various areas of medical specialization and ability to translate complicated genetic information into non-medical

terms, are the ideal professionals to help bridge these training gaps. As NSGC testified at prior SACGHS meetings, to meet the increasing needs of genetic medicine, a two pronged approach is necessary. First, we must increase the number and diversity of practicing genetic specialists trained in the United States. Second, as SACGHS has recommended in the draft resolution, we must increase the knowledge of health care professionals such that they can perform basic components of genetic medicine and develop knowledge of general genetic concepts and referral resources. To reach the goals of an educated health care provider population, we must actively work to reduce the barriers to training genetic specialists at the same time we are working to increase the genetics competence of non-specialists.

In conclusion, NSGC urges this committee to actively address the education and training needs for both specialist and non-specialist genetics training to ensure a competent genetics workforce in the future. NSGC is willing to work with SACGHS to develop an issue brief and draft resolution reflecting this approach.

Thank You.