

national society
of genetic
counselors, inc.



To: National Advisory Council for Human Genome Research

From: Wendy R. Uhlmann, MS, CGC
National Society of Genetic Counselors Liaison to NACHGR

Date: February 6, 2005

Re: Report of Activities

The National Society of Genetic Counselors (NSGC) membership as of January 2005 is 2189. Kelly Ormond, MS, CGC is our current president (Oct 2004 – November 2005). Here is a summary of some of our activities:

➤ **Strategic Plan:**

NSGC is starting the second year of our 2004-2006 strategic plan. Our strategic plan focuses on three initiatives: genetic counseling service delivery models, visibility and billing and reimbursement issues. http://www.nsgc.org/about/strategic_plan.asp

➤ **Genetic Nondiscrimination:**

- NSGC collaborated with FORCE (Facing Our Risk of Cancer Empowered) to publish the patient brochure “Genetic Information, Privacy and Discrimination: What You Need to Know,” which can be downloaded at: http://www.nsgc.org/consumer/genetic_discrimination_resource.asp
- NSGC provided letters of support and text for the “Faces of Genetic Discrimination” project initiated by the Coalition for Genetic Fairness. <http://www.nationalpartnership.org/portals/p3/library/GeneticDiscrimination/FacesofGeneticDiscrimination.pdf>
- Multiple letters were sent to House Speaker Dennis Hastert and other congressional leaders regarding genetic nondiscrimination legislation.
- NSGC and individual genetic counselors provided testimony on genetic discrimination at the October 2004 SACGHS meeting.
- NSGC provided testimony at the NCOIL (National Conference of Insurance Legislators) conference in February and July 2004.
- NSGC is a founding member of the Coalition for Genetic Fairness and will continue to be active in coalitions supporting genetic nondiscrimination legislation in 2005.
- NSGC compiled resources on the issue of genetic discrimination which are posted at our website: http://www.nsgc.org/members/com_sub_activities/genetic_discrimination.asp.

➤ **Genetic Counseling Licensure:**

On September 29, 2004, Illinois became the third state to pass legislation for licensure of genetic counselors. California, which passed legislation in 2000, has not issued any licenses because the

the leading voice, authority and advocate for the genetic counseling profession

Executive Office Mailing Address: 233 Canterbury Drive • Wallingford PA 19086-6617

VoiceMail: 610-872-7608 • FAX#: 610-872-1192 • E-Mail: fyi@nsgc.org • www.nsgc.org

regulations required to initiate this licensure have not been promulgated. Utah, which passed legislation in 2001, has begun issuing licenses to genetic counselors. Florida introduced a bill to create the genetic counseling practice act in January 2004 which was not enacted. Licensure bills for genetic counselors are currently pending in New Jersey and New York. NSGC has established a small grant that genetic counselors can apply for to assist in state licensure efforts. Information about genetic counselor licensure bills can be found at the National Conference of State Legislatures website: <http://www.ncsl.org/programs/health/genetics/gencoun.htm>

➤ **Billing and Reimbursement:**

NSGC issued an RFP and selected Carolyn Watts, PhD, Professor of Health Services, from the University of Washington to perform a cost-benefit analysis of genetic counseling. The focus of this research is to gather quantitative data to address the issue of direct billing and reimbursement of genetic counseling by third party payers. NSGC provided testimony on reimbursement of genetic services to the SACGHS and will be providing invited testimony in February 2005. NSGC has made available to the public our “Primer on Billing and Reimbursement for Genetic Counselors.”

http://www.nsgc.org/members/tools/BR_PRIMER_10_03_BP.pdf

➤ **Position Statements and Practice Recommendations Adopted in 2004:**

- “Genetic Cancer Risk Assessment and Counseling: Recommendations of the National Society of Genetic Counselors” *Journal of Genetic Counseling* 13(2); 83-114, April 2004.

- Position statement on Somatic Cell Nuclear Transfer (SCNT) or Cloning for Therapeutic and Reproductive Purposes: <http://www.nsgc.org/about/position.asp#17>

- Cystic Fibrosis Carrier Screening Practice Recommendations. Will be published in the February 2005 issue of the *Journal of Genetic Counseling*.

All of NSGC’s position statements can be found at the above website address.

➤ **Professional Status Survey:**

Results from the 2004 Professional Status survey are available at the NSGC website. This biannual survey tracks the genetic counseling profession and includes data on work environments, job responsibilities, professional activities (teaching, research, publications), salaries, job benefits and other informative data. A 10-year retrospective analysis of past professional status surveys was also performed in 2004 and this data is posted at our website.

http://www.nsgc.org/careers/pss_index.asp

➤ **Genetics Education and Awareness Outreach Efforts:**

- NSGC collaborated with ASHG and the Genetic Alliance to develop a family history tool:

<http://www.nsgc.org/consumer/familytree/index.asp>

- NSGC participated in the October 2004 Banbury Summit Meeting on Training of Physicians in Medical Genetics.

- NSGC is supporting efforts for minority recruitment, which is being initiated by the Midwest Consortium of Genetic Counseling Programs.

- NSGC participated in a work group meeting at NHGRI to develop a career awareness DVD focusing on genomics professions.

➤ **Journal of Genetic Counseling:** Starting in January 2005, our journal is now Medline-indexed.