

Memo

To: ACMG, ASHG, ABGC, AGCPD, APHMG, NACHGR, CAGC, Genetic Alliance, FORCE, ISONG

From: Elizabeth Kearney, 2010 President

Date: January 26, 2010

Re: NSGC Activity Update

Following are key highlights of NSGC strategic initiatives and other key activities through December 31, 2009. If you have questions about information not included in this report, please do not hesitate to contact me at 510-708-9805 or lizkearneygenetics@gmail.com.

NSGC Membership

- As of December 31, 2009 NSGC had 2,566 members in all categories, with 2,246 being practicing genetic counselors. Membership renewal for 2010 is ongoing.

Board of Directors

- The NSGC Board of Directors met November 11, 2009 in Atlanta, Georgia. During this meeting the Board conducted business and finalized the plan of work for 2010.
- The 2010-2012 NSGC Strategic Plan was approved in June 2009. The new plan is available at <http://www.nsgc.org/about/strategicPlan.cfm>

Education

- NSGC is approved as a provider of CEUs for genetic counselors by the International Association of Continuing Education and Training (IACET). Application information is available at <http://www.nsgc.org/CEU/index.cfm>. Please contact Meg Orsi at morsi@nsgc.org with any questions.
- NSGC held two regional conferences in April 2009. The first meeting was held in Chicago, IL, April 3-4. The second meeting was held in Washington, DC on April 17.
- NSGC's online course, "The Diverse Practice of Genetic Counseling" launched in June 2009. This course consists of 10 sessions on a variety of topics, allowing self-directed learning. Additional is available on the NSGC website at <http://www.nsgc.org/conferences/OnlineCourse2009/index.cfm>
- The NSGC Genetic Counseling Access and Service Delivery Committee launched an online Coding Course in September 2009. This course was specifically designed to be an educational tool for the complexities of compliant billing and coding of genetic services. More information will be available at <http://www.nsgc.org/conferences/CodingCourse2009.cfm>
- The 2009 AEC was held in Atlanta, Georgia, November 12-15, 2009 and provided a broad spectrum of educational content covering advances in genetics and genomics and various areas of

genetic counseling specialization. New in 2009, the AEC included a day of preconference symposia allowing for in-depth coverage of specific topics.

Liaison Activities

- NSGC liaison Renee Chard participated in the SMFM Nuchal Translucency Oversight Committee Meeting held January 29, 2009 in San Diego, CA.
- NSGC 2009 President Steven Keiles, Past President Angela Trepanier and President Elect Elizabeth Kearney attended the ACMG Annual Meeting held March 25-29, 2009 in Tampa, FL.
- NSGC Past President Angela Trepanier has continued to participate in follow-up activities related to the December 17-18, 2008 workshop, "Personal Genomics: Establishing the scientific foundation for using personal genome profiles for risk assessment, health promotion and disease." The meeting was co-sponsored by the NCI Division of Cancer Control and Population Sciences, the CDC National Office of Public Health Genomics, the NHGRI Social and Behavioral Research Branch, the NHGRI Office of Population Genomics, Division of Prevention and Population Sciences NHLBI and the NIH Office of Behavioral and Social Sciences Research. Workshop participants have continued to discuss next steps related to the meeting outcomes and plans for future workshops are in development.
- During 2009, NSGC was represented on Institute of Medicine Roundtable on Translating Genomic-Based Research for Health by past President, Cathy Wicklund.
- NSGC liaison Scott Weissman represented NSGC at the American College of Surgeons Commission on Cancer Conference held in Chicago, IL in May 2009 and provided recommendations on behalf of NSGC for inclusion of genetic counseling information in the revised Cancer program standards to be published in 2011.
- NSGC 2009 President Steve Keiles presented at the first annual Consumer Genetics Show in Boston, MA in June 2009 as part of the panel discussion, "Different Perspectives on DTC Genetic Counseling."
- Steve Keiles represented NSGC at the NIH State of the Science meeting regarding using Family history to improve health outcomes and contributed to the consensus statement developed by the panel.
- In June 2009, Steve Keiles participated in "Developing a Blueprint for Primary Care Physician Education in Genomic Medicine". This meeting was co-sponsored by the HRSA ACHDNC, CDC, HRSA, NCI, NHGRI, NHLBI, ORDR and NNSGRC to propose a 5 year blueprint for improving primary care clinician literacy in genetics and genomics.
- Steven Keiles and Elizabeth Kearney attended the Genetic Alliance Annual Conference and Genetics Day on the Hill in July 2009. Steve Keiles co-presented a session on establishing relationships with the media to benefit your organization with Alice Lara from Sudden Arrhythmia Death Syndromes (SADS).
- In August 2009, Steve Keiles served on the National Task Force for the Early Identification of Childhood Neuromuscular Disorders. This task force was cosponsored by Parent Project MD and the CDC and the major goal of the group is to decrease the time to appropriate referral and diagnosis for children with neuromuscular disorders.
- Steven Keiles represented NSGC at the conference, "Examining the Scientific Basis for Spinal Muscular Atrophy Carrier Screening" in September 2009 in Atlanta, GA. The meeting was cosponsored by The National Human Genome Research Institute, the Eunice Kennedy Shriver

National Institute of Child Health and Human Development, and the National Institute of Neurological Disorders and Stroke to inform the research agenda for the field.

- NSGC President Angela Trepanier was elected to the NCHPEG Board of Directors for a three-year term beginning in 2009. She serves as the NSGC representative to NCHPEG and represented NSGC at the NCHPEG Annual Meeting in September 2009.
- NSGC liaisons Cate Walsh Vockley and Michelle Fox attended the HRSA Advisory Committee on Heritable Disorders of Newborns and Children meeting in Bethesda, MD in September 2009. Ms. Vockley attended the Education and Training Subcommittee and Ms. Fox attended the Follow-up and Treatment Subcommittee. Both are working to identify opportunities for of genetic counselors to support the work of these subcommittees.
- NSGC liaison Cheryl Harper represented NSGC at the inaugural meeting of GAAPNet in Ann Arbor, MI in October 2009. Cheryl will continue her involvement with GAAPNet in 2010 through the Partners and Policy Work Group.
- Steve Keiles presented at the ISONG Annual Meeting in San Diego, CA in October 2009, discussing the NSGC strategic plan and potential NSGC and ISONG collaboration.
- Steve Keiles presented to the ACMG Board of Directors and discussed areas of collaboration between NSGC and ACMG at their October 2009 meeting in Honolulu, HI.

Government Relations and Advocacy

- NSGC has provided ongoing guidance to states pursuing licensure and writing licensure rules and regulations.
 - Issuing licenses: IL, MA, NM, OK, TN, UT
 - Passed bills/in rulemaking: CA, HI, IN, NJ, SD, WA
 - Bill introduced, held hearings: NY, PA, TX,
 - Preparing to introduce bills: CT, FL, KS, MD, MI, MN, NE, NH, OH, OR, RI, VA, WI
- The NSGC Public Policy Committee continues to maintain a blog, providing information on various policy issues. The blog may be viewed at <http://nsgcpolicy.blogspot.com/>