

Memo

To: NACHGR
From: Sara Riordan, MS, CGC, 2021 President
Date: May 10, 2021
Re: National Society of Genetic Counselors Activity Update

Following are key highlights of National Society of Genetic Counselors (NSGC) strategic initiatives and other key activities through early May 2021. If you have questions about information not included in this report, please do not hesitate to contact me at genomegrl@gmail.com. Additionally, we continue to welcome the opportunity for conversation around the RFAs for the Genetic Counseling R01 and R25 grants to support genetic counseling research, the Human Genetics and Genomics Workforce Diversity Initiative, as well as additional conversation around how NSGC can support the NHGRI strategic plan.

NSGC Membership

- As of April 30, 2021 NSGC had 4,173 members;
- Members are still renewing and joining for the 2021 membership year.

Board of Directors

- The NSGC Board of Directors held a virtual board meeting February 22-24, 2021.
- The NSGC Board will be meeting in person July 13-15, 2021.
- The NSGC 2019 – 2021 strategic plan is available on the [NSGC website](#). Strategic planning for the 2022-2025 cycle will take place during the July Board meeting.

Research

- NSGC has identified research as one of the four strategic areas of focus in our 2019-2021 strategic plan.
- NSGC's top research priorities have been outlined in: [Advancing the genetic counseling profession through research: Identification of priorities by the National Society of Genetic Counselors research task force](#).
- Our Research, Quality and Outcomes Committee is developing recommendations for an infrastructure to advance and support patient outcomes research by and about genetic counselors.

Diversity, Equity and Inclusion

- Diversity, equity and inclusion is another of the four strategic areas of focus in our 2019-2021 strategic plan.
- In mid-2020, NSGC engaged the health equity firm, the Exeter Group to conduct an organizational DEI assessment. The Exeter Group DEI Assessment and Recommendations were released April 28, 2021 and are open for comment by NSGC member and non-member genetic counselors and other stakeholders. The report and comment form are available [here](#).

- Following the close of the open comment period, NSGC will develop an organizational justice, equity, diversity and inclusion (J.E.D.I.) action plan that will be integrated in the next NSGC strategic plan.
- We would welcome a dialogue with NHGRI, ASHG and other organizations as we develop our action plan to ensure our organizational efforts align with, and contribute to increasing diversity and inclusion in the broader genetics and genomics workforce and extend the reach of genetics and genomics into underserved patient populations.

Education and Publications

- NSGC is approved as a provider of Continuing Education Units (CEUs) for genetic counselors. Please contact [Jennifer Aron](#), NSGC Continuing Education Coordinator, with any questions.
- The 2020 NSGC Annual Conference was held November 18-22, 2020. Due to the ongoing impact of the COVID-19 pandemic, the conference was held in a virtual format. Information is available on the [NSGC website](#)
- The 2021 NSGC Annual Conference will be held September 22-26, 2021 in New Orleans, Louisiana. Due to the ongoing impact of the COVID-19 pandemic, the conference will be held in a hybrid format with sessions available both in-person and online. Information is available on the [NSGC website](#).
- NSGC has many online educational opportunities available for additional continuing education. These cover a variety of topics such as family history, coding and billing and cultural competence. Additional information on these and other courses is available to the public on the [NSGC Online Education Center](#).
- Recently released online courses include:
 - *Pathways to Parenthood: an Overview for Genetic Counselors*
 - *Credentialing: How and Why?*
 - *Polygenic Risk Scores in Clinical Practice*
 - *Genetic Counseling and Huntington Disease*
 - *The Formation of Implicit Biases and Practical Strategies to Address Them*
 - *Integrating Pharmacogenomic Testing into Clinical Practice*
- Recordings of all sessions from the 2019 and 2020 Annual Conferences are [available online](#).

Liaison Activities

- NSGC Past President Joy Larsen Haidle is serving as NSGC's representative on the American Society of Clinical Oncology's (ASCO) CancerLinQ Oncology Leadership Council.
- Leigha Senter is representing NSGC on an Academy of Oncology Nurse & Patient Navigator (AONN+) task force to develop educational materials around genetic risk assessment for patient navigators.
- Stephanie Cohen and NSGC Past President Mary Freivogel are representing NSGC on a task force coordinated by the National Coalition of Breast Centers (NCBC) focused on a certificate program for breast cancer risk assessment.
- Jennifer Hoskovec represents NSGC as liaison to the American College of Obstetricians and Gynecologists (ACOG) Committee on Genetics.
- Rachel Mills is representing NSGC on the Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC).

- Barbara Bernhardt is serving as the NSGC liaison to the “value of genetic diagnosis” committee led by Marc Williams from ACMG.
- Cate Walsh Vockley represents NSGC on the HRSA Advisory Committee on Heritable Disorders in Newborns and Children Subcommittee (ACHDNC).
- Past President Cathy Wicklund represents NSGC on the National Academies of Medicine Roundtable on Genomics and Precision Health.
- Ashley Parrot is representing NSGC as liaison to the ACMG Practice Guidelines Committee.
- Maria Baker is serving as liaison to the American College of Surgeons Commission on Cancer (CoC).
- Megan Frone is representing NSGC to the National Accreditation Program for Breast Centers (NAPBC).
- Karen Lewis represents NSGC on the AMA CPT/Health Care Professional Advisory Committee Council.
- Rhonda Schonberg is NSGC’s representative to the National Advisory Council for Human Genome Research (NACHGR).
- Alix D’Angelo is representing NSGC as a member of the Training Residents in Genetics (TRIG) Committee. The TRIG committee is comprised of representatives from pathology and genetics organizations and is focused on ensuring genetics is included in future training of pathology residents.
- Kristin Vogel Postula is representing NSGC as a member of the American Association of Oncology Nurse Navigators (AONN+) Advisory Committee.
- NSGC Past President Karin Dent is representing NSGC as a member of the Genetics in Primary Care Institute, an initiative of the American Academy of Pediatrics.
- Heather Hampel is representing NSGC as a member of the National Colorectal Cancer Roundtable (NCCRT).
- Sarah Kalia is serving as NSGC’s representative to the ACMG Incidental Findings Working Group.
- Allison Cirino is representing NSGC as liaison to the Functional Genomics and Translational Biology (FGTB) Council of the American Heart Association.
- NSGC Past President Angie Trepanier and Meg Doerr represent NSGC on the G2C2 Committee.
- Anna Dennis is representing NSGC on the Northwest Regional Newborn Screening Advisory Board.
- Kelly Knickelbein is representing NSGC on the Cancer Precision Medicine Commons, the follow-up project to the Consistent Testing Terminology Working Group coordinated by LUNGevery and involving other patient advocacy groups, societies and industry.
- Karen Wain is serving as NSGC representative to the Association for Molecular Pathology Clinical Whole Exome Sequencing for Inherited Conditions as a First-Line Test: Spectrum of Applications and Standards

Government Relations and Advocacy

- Several NSGC position statements are in development or revision. All NSGC position statements are available on the [NSGC website](#).
- NSGC is pursuing legislation that will recognize genetic counselors as Medicare providers, the *Access to Genetic Counselor Services Act*. This act, has been introduced in both the House of Representatives and Senate in the 117th Congress, as H.R. 2144 and S. 1425, respectively.
 - Organizations interested in supporting this legislation can learn more [here](#).

- NSGC is providing ongoing guidance to states pursuing licensure and writing licensure rules and regulations:
 - [Issuing licenses](#): AK, CA, CT, DE, GA, ID, IL, IN, IA, KY, LA, MA, MN, NE, NH, NJ, NM, ND, OH, OK, PA, SD, TN, UT, VA, WA
 - [Passed bills/in rulemaking](#): AL, HI, MI
 - ~20 additional states have bills introduced or in preparation