Memo

To: NACHGR

From: Sara Riordan, MS, CGC, 2021 President

Date: February 15, 2021

Re: National Society of Genetic Counselors Activity Update

On behalf of NSGC, we would like to recognize the RFAs for the Genetic Counseling R01 and R25 grants to support genetic counseling research. This is a major step in advancing the capacity of genetic counselors to engage deeply in research that will promote evidence-based practice in genetic counseling. NSGC is also enthusiastic about our participation in the Human Genetics and Genomics Workforce Diversity Initiative in partnership with NHGRI, ASHG and ACMG. We would welcome the opportunity to continue the conversation around each of these areas to identify how NSGC can support the NHGRI strategic plan.

Following are key highlights of National Society of Genetic Counselors (NSGC) strategic initiatives and other key activities through mid-February 2021. If you have questions about information not included in this report, please do not hesitate to contact me at genomegrl@gmail.com.

NSGC Membership

- As of December 31, 2020 NSGC had 4,072 members;
- Member are still renewing and joining for the 2021 membership year.

Board of Directors

- The NSGC Board of Directors held a virtual board meeting November 13, 2021.
- The NSGC Board will be meeting virtually February 22-24, 2021.
- The NSGC 2019 2021 strategic plan is available on the NSGC website.

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: <u>Advancing the genetic counseling profession</u> <u>through research: Identification of priorities by the National Society of Genetic Counselors research</u> <u>task force</u>.
- 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.

- NSGC has engaged the health equity firm, the Exeter Group to conduct an organizational DEI assessment. Final recommendations are expected in May 2021, with development of an organizational DEI action plan to follow.
- 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 extending 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.
- NSGC shifted our <u>2020 member Webinar Series</u> to address topics related to genetic counseling practice during the pandemic, as well as other professional issues impacting genetic counseling service delivery. Topics in 2021 will shift back to coverage of a broad range of professional and practice issues, including COVID-related issues.
- 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:
 - o Pathways to Parenthood: an Overview for Genetic Counselors
 - Credentialing: How and Why?
 - Polygenic Risk Scores in Clinical Practice
 - o Genetic Counseling and Huntington Disease
 - The Formation of Implicit Biases and Practical Strategies to Address Them
 - o Integrating Pharmacogenomic Testing into Clinical Practice
- Recordings of all sessions from the <u>2018</u> and <u>2019</u> Annual Conferences are available <u>online</u>.
- Recordings of sessions from the 2020 Annual Conference will be available in early March 2021.

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 an 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.
- Christie Jett and Rachel Shapira are representing NSGC on the Consistent Testing Terminology Working Group coordinated by LUNGevity 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, previously introduced in the House of

Representatives in the 116th Congress, is being prepared for reintroduction in both the House and Senate in the 117th Congress.

- o Organizations interested in supporting this legislation can learn more <u>here</u>.
- NSGC is providing ongoing guidance to states pursuing licensure and writing licensure rules and regulations:
 - <u>Issuing licenses</u>: 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
 - o Passed bills/in rulemaking: AL, HI, MI
 - ~20 additional states have bills introduced or in preparation