

MEMO

To: NACHGR

From: Meghan Carey, Executive Director

Date: February 6, 2024

Subject: NSGC Activity Update

Following are key highlights of National Society of Genetic Counselors (NSGC) strategic initiatives and other key activities through early September 2023. If you have questions about information not included in this report, please do not hesitate to contact me at mcarey@nsgc.org. Additionally, we continue to welcome the opportunity for conversation around opportunities for RFAs for Genetic Counseling R01 and R25 grants, the Human Genetics and Genomics Workforce Diversity Initiative, as well as additional conversation around how NSGC can support the NHGRI strategic plan.

Research

- 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 has developed and is implementing an infrastructure to advance and support the research capability of genetic counselors and to support research on the practice of genetic counseling, especially outcomes research.
- . research by and about genetic counselors.
- Number of NIH-funded NSGC members and mechanisms they are funded by (PIs and Co-PIs)
 -
- NSGC's current research initiatives are outlined below:
 - Jane Engelberg Memorial Fellowship (JEMF)
 - The Jane Engelberg Memorial Fellowship (JEMF), established in 1991 as a highly prestigious award of the National Society of Genetic Counselors, is an ongoing tribute to Jane Engelberg in the form of a \$90,000 annual grant that funds scholarly investigation, promotes professional development and improves the practice of genetic counseling.
 - JEMF-funded research in progress:
 - "Increasing Access to Genetic Counselors in the Inpatient Setting Through a Novel Service Delivery Method," Emily Brown, MGC, CGC, Principal Investigator
 - "An Exploration of Genetic Counselors' Professional Identity," Lisa Schwartz, EdD, MS, CGC, Principal Investigator
 - "Genetic Counseling Service Delivery and Outcomes in Diverse and Underserved Populations," Sara Pirzadeh-Miller, MS, CGC, Principal Investigator
 - JEMF Student Awards
 - The JEMF Student Research Award is intended for students who are enrolled in an ACGC-accredited genetic counseling training program. These funds should be used to support research done while the applicants are enrolled in their training program.
 - Audrey Heimler Special Project Fund Award
 - The Audrey Heimler Special Projects Award (AHSPA) is an annual \$10,000 grant that funds a project or research focusing on the future of the genetic counseling profession and/or the provision of genetic services.
 - NSGC Special Interest Group Research Grant Awards
 - The SIG Grant Awards are supported and funded by NSGC to seed research by members of NSGC's Special Interest Groups in specific areas of specialization.
 - \$20,000 total available annually; \$250-\$2,500 per grant
- NSGC publications during last reporting period:

- “Genetic Counseling for the Dystrophinopathies—Practice Resource of the National Society of Genetic Counselors” was approved by the NSGC Board of Directors and will be published in the *Journal of Genetic Counseling*
- NSGC collaborative statements during last reporting period:
 - The NSGC Board of Directors approved an Affirmation of Value for the publication “[Evidence-based consensus guidelines for ALS genetic testing and counseling](#)”

NSGC Membership

- As of the end of 2023, NSGC had 4,951 members. Membership renewal for 2024 is ongoing.

Board of Directors

- The next in person meeting of the Board is scheduled for May 7-8, 2024, in Washington, D.C.
- The NSGC 2022-2024 strategic plan is available on the [NSGC website](#) and outlines the Society’s strategic priorities over the next three years
- Strategic planning for 2025-2027 will take place in May 2024, and preliminary planning activity has started.

Justice, Equity, Diversity, and Inclusion

- Justice, equity, diversity, and inclusion (J.E.D.I.) is one of NSGC four pillars in our 2022-2024 strategic plan.
- The NSGC J.E.D.I. Action Plan is available [here](#). Work is underway and progress updates are provided biannually via the NSGC website.
- We continue dialogue with 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 support extending the reach of genetics and genomics into underserved patient populations.
- We would welcome a dialogue with NHGRI to align and collaborate with other genetics workforce diversity initiatives as our efforts move forward.

Education

- The 2023 NSGC Annual Conference was held October 17-21, 2023, in Chicago, Illinois. Sessions were also offered virtually in order to increase accessibility for all interested attendees.
- The 2024 Annual Conference will be held September 17-21 in New Orleans, Louisiana.

Liaison Activities

- Rachel Mills represents NSGC on the Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC-PEG).
- Leila Jamal serves as NSGC’s representative to the National Advisory Council for Human Genome Research (NACHGR).
- NSGC Past President Angie Trepanier and Meg Doerr represent NSGC on the GenomeEd (formerly G2C2) Committee.
- Cate Walsh Vockley represents NSGC on the HRSA Advisory Committee on Heritable Disorders in Newborns and Children Subcommittee (ACHDNC).
- 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.
- Barbara Bernhardt is serving as the NSGC liaison to the “value of genetic diagnosis” committee led by Marc Williams from ACMG.
- Past President Cathy Wicklund represents NSGC on the National Academies of Medicine Roundtable on Genomics and Precision Health.
- Kimberly Barr serves as NSGC liaison to the ACMG Practice Guidelines Committee.
- Maria Baker is serving as liaison to the American College of Surgeons Commission on Cancer (CoC).
- Christie Jett is NSGC’s representative to the National Accreditation Program for Breast Centers (NAPBC).
- Brian Reys is NSGC’s representative to the AMA CPT/Health Care Professional Advisory Committee Council.
- Alix D’Angelo represents NSGC on 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.

- Nicole Blum represents NSGC as a member of the American Association of Oncology Nurse Navigators (AONN+) Genetics and Genomics Committee.
- NSGC Past President Karin Dent represents NSGC as a member of the Genetics in Primary Care Institute, an initiative of the American Academy of Pediatrics.
- Heather Hampel represents NSGC as a member of the National Colorectal Cancer Roundtable (NCCRT).
- Allison Cirino represents NSGC as liaison to the Functional Genomics and Translational Biology (FGTB) Council of the American Heart Association.
- Kelly Knickelbein represents 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.
- NSGC Executive Director, Meghan Carey, serves as liaison to the Association of Professors of Human and Medical Genetics (APHMG).
- Ashley Svenson represents NSGC on CARA, a coalition supporting reproductive healthcare options led by the Society of Maternal and Fetal Medicine.

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*. 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](#): AL, AK, CA, CT, DE, FL, GA, ID, IL, IN, IA, KY, LA, MA, MI, MN, MT, NE, NH, NJ, NM, ND, OH, OK, OR, PA, RI, SD, TN, UT, VA, WA, WI
 - [Passed bills/in rulemaking](#): HI, MD
 - Most remaining states have bills introduced or in preparation