

MEMO

To: NACHGR

From: Meghan Carey, Executive Director

Date: May 16, 2024

Subject: NSGC Activity Update

To follow are key highlights of National Society of Genetic Counselors (NSGC) strategic initiatives and other key activities through early May 2024. If you have questions about information not included in this report, please do not hesitate to contact NSGC 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.

NSGC Research

- NSGC Research, Quality and Outcomes (RQO) Committee: RQO issued an RFP in support of its 2024 Research Initiative around reproductive healthcare. An award will be made in July 2024.
- NSGC Research Grant Programs:
 - Jane Engelberg Memorial Fellowship (JEMF)
 - The JEMF provides support for research projects that drive innovation in the field of genetic counseling. The 2024 Full Member Award application has closed, and the JEMF advisory group will meet in June to select the winner.
 - 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. The application deadline is June 1, 2024.
 - Audrey Heimler Special Project Fund Award (AHSPA)
 - The Audrey Heimler Special Projects Award is an annual grant that funds a project or research focusing on the future of the genetic counseling profession and/or the provision of genetic services. The application deadline is May 13, 2024.
 - NSGC Special Interest Group (SIG) 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. For 2024, research awards have been made to the NSGC Cancer, Cardiology, Neurology, International, and Research Special Interest groups.

NSGC Journal of Genetic Counseling (JoGC)

- New Editorial Board: The JoGC editorial board has been refreshed with [new members from around the world](#), including the Philippines, Japan, India, Romania, Switzerland, Australia, South Africa, the UK, Canada, and the USA.
- The structure has also changed, with a focus on review for methodological rigor. Four deputy editors – two handling qualitative manuscripts, and two handling quantitative manuscripts – report to the Editor in Chief, together with two Directors of DEI integration, and four new editor-at-large positions for trainees.
- New Scope Statement: The editorial board updated the [scope statement for the JoGC](#), and is working on an updated DEI statement.
- New JoGC Podcast Series: JoGC has launched a [podcast series](#), "DNA Dialogues: conversations in genetic counseling research," with each episode focused on two recently published JoGC papers and in-depth conversations with the

authors.

- Special Issue on Research Methods: JoGC is currently launching a call, and soliciting papers for a special virtual issue of the journal on Research Methods in Genetic Counseling.
- Collaborative Nature Genetics/JAMA Paper: JoGC collaborated with other genetics journal editors on a co-authored paper published in Nature Genetics/JAMA about [genetic ancestry](#).
- CGA-IGC Collaboration: The JoGC is working with the Collaborative group of the Americas on inherited gastrointestinal cancer (CGA-IGC) on publishing a “best GC paper” simultaneously with their conference.
- English Language Assistance: JoGC is launching a volunteer led program to provide assistance to authors who cannot afford the publisher language editing services but need assistance with language and grammar.
- Notable Papers Published:
 - New practice resource: [Genetic counseling for the dystrophinopathies—Practice resource of the National Society of Genetic Counselors](#)
 - Paper on NIH funded Genetic Counseling research: [The State of National Institute of Health Awards for funding genetic counseling research, resources, and training over the past decade](#)
- NIH Funded Work Recently Published in JoGC:
 - [Research participants' perspectives about the return of uninformative genomic test results in a clinical research setting](#)
 - [Promoting the integration of genetic counseling education and research across the spectrum of learners at a large academic institution](#)
 - [Beyond multiple choice: Clinical simulation as a rigorous and inclusive method for assessing genetic counseling competencies](#)
 - [Applying the \$R = MC^2\$ implementation science heuristic to assess the impact of readiness on reach and implementation of a population-wide genomic screening program](#)
 - [Conducting inclusive research in genetics for transgender, gender-diverse, and sex-diverse individuals: Case analyses and recommendations from a clinical genomics study](#)
 - [Ciencia, Genética, y ¿Desinformación?: A content analysis of genetic testing coverage from US Spanish-language news media](#)
 - [The impact of cohort relationships on BIPOC genetic counseling students: Results from a longitudinal qualitative study](#)
 - [Young adults' reasoning for involving a parent in a genomic decision-making research study](#)
 - [Patient decisions regarding cancer gene panel testing: An exploratory study](#)
 - [Research participants' perspectives regarding the feedback of secondary findings—A cohort from the DDD-Africa study, South Africa](#)
 - [Measuring the therapeutic bond in genetic counseling: Testing measurement error in the bond subscale of the Working Alliance Inventory](#)
 - [Genetic counselors' and community clinicians' implementation and perceived barriers to informed consent during pre-test counseling for hereditary cancer risk](#)
 - [Is it time for a paradigm shift? Inclusion of APOE on genetic dyslipidemia panels](#)
 - [The lived experience of reconstructing identity in response to genetic risk of frontotemporal degeneration and amyotrophic lateral sclerosis](#)
 - [Families' experiences accessing care after genomic sequencing in the pediatric cancer context: “It's just been a big juggle”](#)
 - [Genetic counseling for congenital disorders of glycosylation \(CDG\)](#)
 - [Experiences of hereditary cancer care among transgender and gender diverse people: “It's gender. It's cancer risk...it's everything”](#)
 - [The emotional journey of adapting to prenatally identified trisomy X](#)
 - [An exploration of cultural competency training and genetic counselors' racial biases](#)

Justice, Equity, Diversity, and Inclusion

- NSGC has completed a J.E.D.I organizational assessment survey and stakeholder interviews to evaluate the progress of NSGC’s J.E.D.I efforts.

- NSGC continues to collaborate 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.
- NSGC would welcome a dialogue with NHGRI to align and collaborate with other genetics workforce diversity initiatives as our efforts move forward.

Education

- The [2024 NSGC Annual Conference](#) will be held September 17-21 in New Orleans, Louisiana.

Liaison Activities

- National Institute of Health 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 additionally participates in the following committees, councils, coalitions, and roundtables: American Society of Clinical Oncology's (ASCO) CancerLinQ Oncology Leadership Council, National Academies of Medicine Roundtable on Genomics and Precision Health, ACMG Practice Guidelines Committee, American College of Surgeons Commission on Cancer (CoC), National Accreditation Program for Breast Centers (NAPBC), AMA CPT/Health Care Professional Advisory Committee Council, Training Residents in Genetics (TRIG) Committee, the American Association of Oncology Nurse Navigators (AONN+) Genetics and Genomics Committee, American Academy of Pediatrics Genetics in Primary Care Institute, National Colorectal Cancer Roundtable (NCCRT), Functional Genomics and Translational Biology (FGTB) Council of the American Heart Association, Cancer Precision Medicine Commons, Association of Professors of Human and Medical Genetics (APHMG), and the Society of Maternal and Fetal Medicine's CARA coalition.

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, the *Access to Genetic Counselor Services Act*, that will recognize genetic counselors as Medicare providers. Organizations interested in supporting this legislation can learn more [here](#).
- NSGC is developing education materials and resources in support of a new CPT billing code.