

NSGC 2019 Annual Business Meeting

Amy Sturm, MS, LGC, President Carrie Atzinger, MS, CGC, Secretary/Treasurer



Agenda for Today

- Welcome and Introductions
- 2018 2019 Financial Update
- 2019 Year in Review
 - Strategic Investments
 - Operational Investments
- 2020 Strategic Plan Implementation
- Communications and Publications Update
- 2019 Nominations and Election Update
- Question & Answer Session



Our Mission and Vision

- Mission
 - The National Society of Genetic Counselors advances the various roles of genetic counselors in health care by fostering education, research and public policy to ensure the availability of quality genetic services.
- Vision
 - Integrating genetics and genomics to improve health for all.



NSGC At-a-Glance

- 4,000+ members
- 21 Special Interest Groups (SIGs)
- Official liaison relationships with over 25 organizations
- 1,000+ member volunteers
- Countless opportunities to get involved!



How do We Work?



NSGC's volunteer Committees, Task Forces, Advisory Groups and Working Groups provide the power for meeting our strategic goals



2019 Board of Directors



Amy Sturm President



Gillian Hooker
President Elect



Carrie Atzinger Secretary/Treasurer



Scott Weissman Secretary/Treasurer Elect



Erica Ramos Immediate Past President



Deepti Babu Director at Large



Shannan Dixon Director at Large



Colleen Schmitt Director at Large



Heather Shappell
Director at Large



Blair Stevens
Director at Large



Elizabeth Varga Director at Large



Heather ZierhutDirector at Large



Incoming 2020 Board Members



2020 President Elect



Colleen Campbell 2020 Secretary/Treasurer Elect



Michelle Fox 2020 Director at Large



Sara Pirzadeh-Miller 2020 Director at Large



Shivani Nazareth 2020 Director at Large



Access and Service Delivery

- Jodie Vento, Chair
- Deanna Erwin, Vice Chair

Education

- Carrie Guy, Chair
- Taylor Berninger, Vice Chair











Marketing and Communications Workgroup

- Rebekah Moore, Chair
- Rachel Shapira, Vice Chair

Membership

- Katie Bergstrom, Chair
- Christie Hoell, Vice Chair











Outcomes

- Megan Cho, Chair
- Stephanie Cohen, Vice Chair





Public Policy

- Leila Jamal, Chair
- Cori Feist, Vice Chair







Practice Guidelines

- Sarah Kalia, Chair
- Cindy James, Vice Chair







2019 SIG Leaders

SIG

ART/Infertility

Cancer

Cardiovascular Genetics

Cystic Fibrosis

Education

Genomic Technologies

Health IT

Industry

International

Late Career

Leadership Management

Metabolism/LSD

Neurogenetics

Pediatric

Precision Medicine

Prenatal

Psychiatric Disorders

Public Health

Research

Student / New Member

Co-Chair

Alleigh Hebner

Megan Frone

Allison Cirino

Kim Foil

Megan Tucker

Zoe Powis

Caiqian Cropper

Lauren Ryan

Yue Guan

Bonnie Baty

Leah Williams

Meghan Strenk Krista Qualmann

Audra Bettinelli

Marci Schwartz

Christina Dupre

Emily Morris

Becca Vanderwall

Julia Wynn

Tia Moscarello

Co-Chair

Gena Shepherd

Sarah Bannon

Katherine Agre Anna Essendrup

Nikkola Carmichael

Kimberly Banks

Lola Shukla

Melanie Hardy

Arpita Neogi

Ginny (Virginia) Corson

Leslie Bucheit

Elizabeth Smith

Catherine Schultz

Jessica Kianmahd Tara Schmidlen

Katie Sagaser

Kennedy Borle

Andrea Durst

Courtney Berrios
Sarah Mazzola

Co-Chair

Paulina Nassab

Kara Bui



Diversity & Inclusion Task Force



Kaitlyn Brown



Kara Bui



Aishwarya Arjunan Co-chair



Julia Platt Co-chair



Nadine Channaoui



Mitch Cunningham



Priscila Delgado Hodges



Tracey Grant



Ambreen Khan





Bruce R. Haas



Hebbah Sayed-Ahmad



Nicole Thompson



Chani Wiesman



Kami Wolfe Schneider



NSGCares Task Force

- Jay Flanagan, Co-chair
- Sarah Noblin, Co-chair
- Kaitlyn Amos
- Melanie Baxter
- Beth Denne
- Sam Hyde
- Amy Swanson
- Kathleen Valverde





NSGC Pathways to Genetic Counselors Task Force

- Jehannine Austin, Chair
- Barb Biesecker
- Emily Edelman
- Adam Buchanan
- Cathy Wicklund
- Melanie Myers
- Altovise Ewing

- Stephanie Cohen
- Debbie Cragun
- Kiley Johnson
- Maggie Miller
- Randa Newman
- Hetal Vig



NSGC Research Task Force

- Leigha Senter, Chair
- Megan Cho
- Jill Dolinsky
- Stephanie Harris
- Erin Linnenbringer
- Ian MacFarlane
- Vivian Pan
- John Quillin
- Julia Wynn



Thank You to All of Our Dedicated Volunteers!

We could not do it without you!

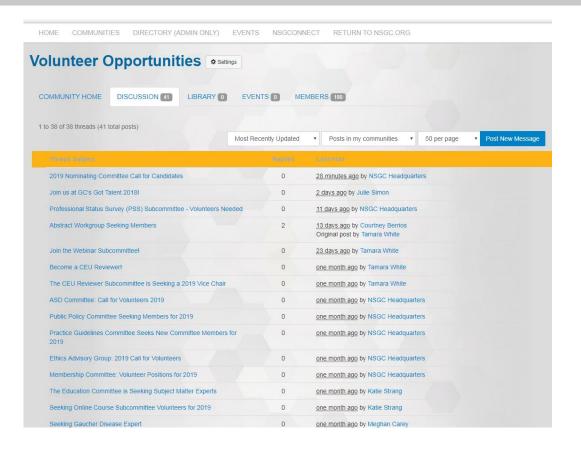
- Committees
- Task Forces
- SIGs
- Workgroups
- Subcommittees
- Ethics Advisory Group
- Annual Conference/Abstracts
- JEMF
- AHSPA

- Rollnick
- Liaisons
- Journal of Genetic Counseling
- Perspectives
- Various projects
- Many individual contributors!



Get Involved!

All are welcome - we need you!





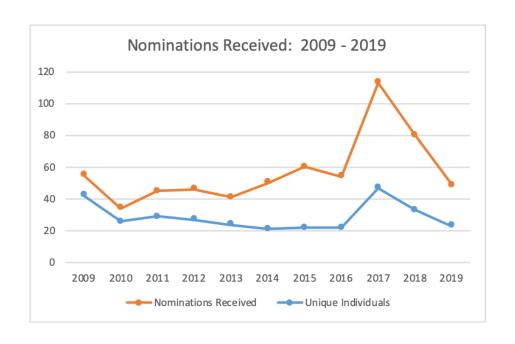
2019 Nominations and Election Update

Building our leadership pipeline



Nominations and Elections Process

- Call for Nominations opened in January 2019
- Members submitted 49 nominations (23 unique individuals)
- Nominees assessed using a combination of quantitative and qualitative measures
 - Statement from nominator
 - Written application and CV
 - Interview

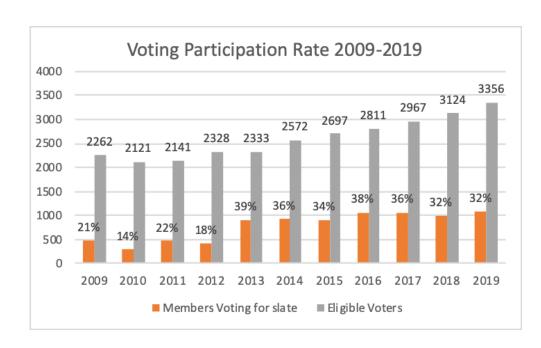




Election Results

- Diverse slate presented (specialization, work setting, years of experience, gender)
- 32% of eligible voters participated

2019 Voter Breakdown	%	#
Approve	95.6%	1,037
Abstain	4.1%	44
Write-in	0.3%	4
TOTAL Votes Cast		1,085





2018 – 2019 NSGC Financial Report

Maintaining our foundation; accelerating our progress

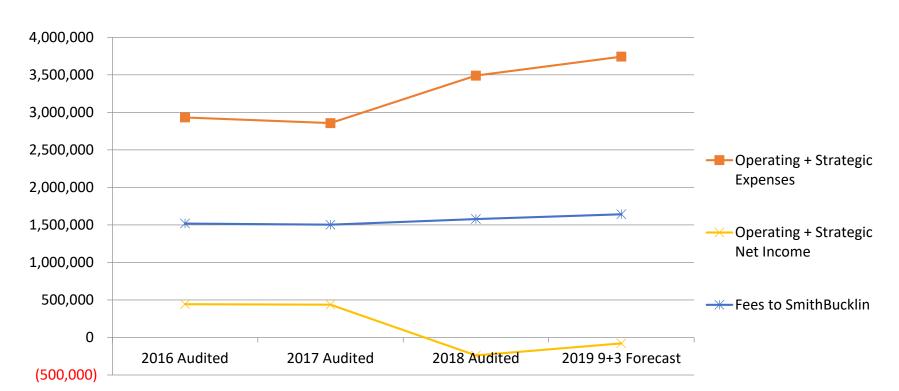


Membership Growth



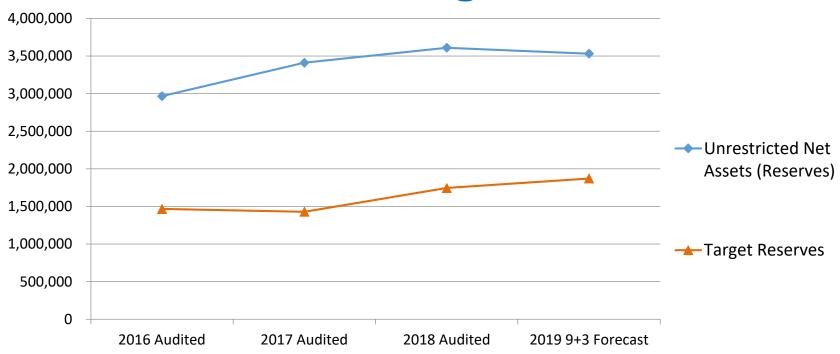


NSGC 5-Year Financial Trends





Resources for Strategic Investment





Assets as of Year End 2018

Cash Assets

NSGC liquid assets: \$2,599,231

NSGC investments: \$1,518,259

TOTAL Unrestricted Assets: \$3,501,949

Budgeted Revenue: \$3,114,443

Year-end Actual Revenue: \$3,283,069

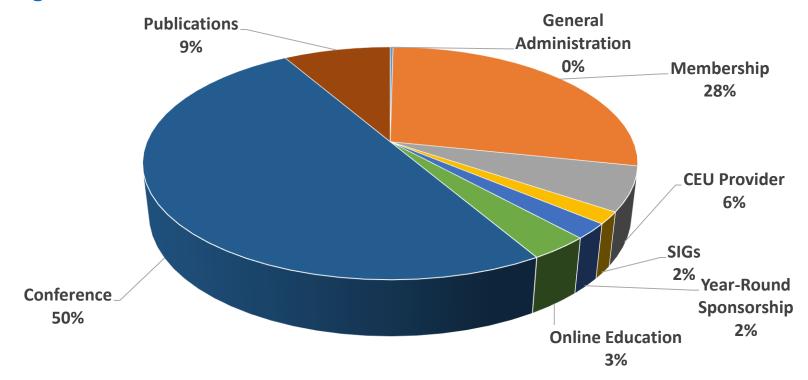
Budgeted Expenses: \$3,514,330

Year-end Actual Expenses: \$3,613,712

2018 Budgeted Net Revenue: (\$399,887) 2018 Year-end Actual Net Revenue: (\$330,643)

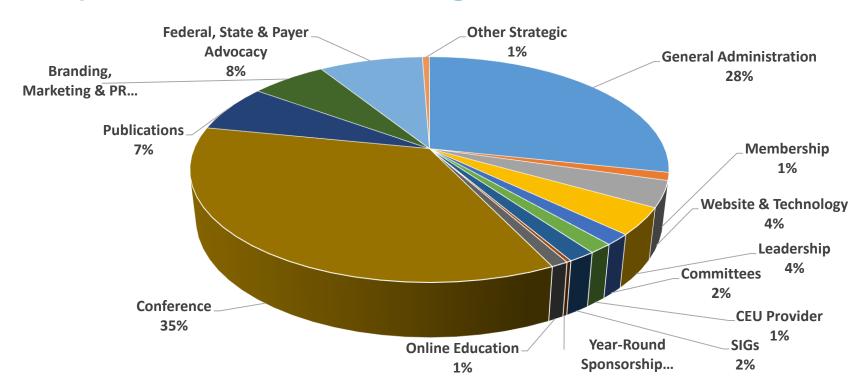


Major Sources of Revenue: FY 2018





Major Expense Categories: FY 2018





Financial Goals in 2020

- Maintain a healthy financial base
- Ensure operational support for our growing membership
- Invest in our strategic plan to benefit our profession
- Remain conscious of the total amount of money we spend in any given period of time
- Explore additional partnerships and sources of revenue



Where do we stand today?

2019 Forecast

Budgeted Revenue: \$3,588,466

9+3 Forecast for Revenue: \$3,660,890

Budgeted Expenses: \$3,822,321

9+3 Forecast for Expenses: \$3,743,216

2019 Budgeted Net Revenue: (\$193,321) planned investment

2019 9+3 Forecasted Net Revenue: (\$78,326) planned investment



2019 Year in Review: Strategic Initiatives

Advancing our profession



Ensuring delivery of high value genetic services



National Society of Genetic Counselors 2019-2021 Strategic Plan



SERVICE DELIVERY

Deliver the highest-value genetic services to meet specific consumer needs





Increasing Awareness and Access

- Pathways to Genetic Counselors Task Force
- Goals:
 - Develop a broad tool to increase the frequency and consistency with which individuals who will derive greatest benefit from speaking to a genetic counselor are identified
 - Promote increased and appropriate access to genetic counselors across specialties, settings, and communities



Expanding our Outreach and Impact

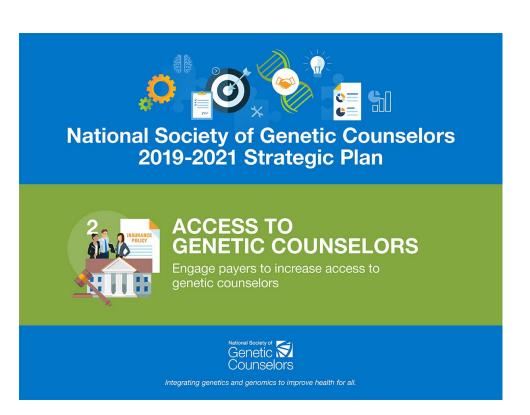
- Academy of Oncology Nurse & Patient Navigators
- ABGC
- ACGC
- ACOG Committee on Genetics
- American Council of Life Insurers
- ACMG
- AGCPD
- All of Us
- American College of Surgeons Commission on Cancer
- American Heart Association
- American Society of Breast Surgeons
- ASCO CancerLInQ
- ASHG
- Association of Community Cancer Centers
- Basser Center for BRCA
- BCBSA Evidence Street
- CAGC
- CDC
- Community Oncology Alliance

- EveryLife Foundation
- FORCE
- Genetic Alliance
- Government Accountability Office
- Hastings Center
- Heart Rhythm Society
- HRSA Advisory Committee on Heritable Disorders in Newborns and Children
- Huntington Disease Society of America
- Imerman Angels
- LUNGevity
- National Academies of Sciences Roundaable on Genomics and Precision Health
- National Accreditation Program for Breast Centers
- National Advisory Council for Human Genome Research
- National Colorectal Cancer Roundtable

- National Consortium of Breast Centers
- National Down Syndrome Society
- NHGRI
- Lettercase
- Personalized Medicine Coalition
- Prenatal Genetic Testing Consortium
- Society of Gynecologic Oncology







Expanding access to our services



116TH CONGRESS 1ST SESSION

H. R. 3235

To amend title XVIII of the Social Security Act to provide for expanded coverage of services furnished by genetic counselors under part B of the Medicare program, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

June 12, 2019

Mr. Loebsack (for himself and Mr. Kelly of Pennsylvania) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To amend title XVIII of the Social Security Act to provide for expanded coverage of services furnished by genetic counselors under part B of the Medicare program, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Access to Genetic Counselor Services Act of 2019".

SEC. 2. MEDICARE COVERAGE OF GENETIC COUNSELING SERVICES.

- (a) IN GENERAL .- Section 1861 of the Social Security Act (42 U.S.C. 1395x) is amended-
 - (1) in subsection (s)(2)—
 - (A) by striking "and" at the end of subparagraph (GG);
 - (B) by adding "and" at the end of subparagraph (HH); and
 - (C) by adding at the end the following new subparagraph:
 - "(II) covered genetic counseling services (as defined in subsection (kkk)(1));"; and
 - (2) by adding at the end the following new subsection:

"Covered Genetic Counseling Services





Advocacy in Action

Sponsors and Co-sponsors

Sponsors: Representatives Loebsack (IA-D) and Kelly (PA-R)

Co-sponsors as of November 30:

- Rep. Brian Fitzpatrick PA-R
- Rep. Dave Joyce OH-R
- Rep. Pete King NY-R
- Rep. Zoe Lofgren CA-D
- Rep. David Price NC-D
- Rep. Harley Rouda CA-D
- Rep. Terri Sewell AL-D
- Rep. Steve Stivers OH-R
- Rep. Eric Swalwell CA-D

Op-Ed Published in The Hill



Genetic counselors save health care dollars when involved in the testing process

BY AMY STURM, OPINION CONTRIBUTOR — 10/15/19 05:30 PM EDT
THE VIEWS EXPRESSED BY CONTRIBUTORS ARE THEIR OWN AND NOT THE VIEW OF THE HILL

6 COMMENTS

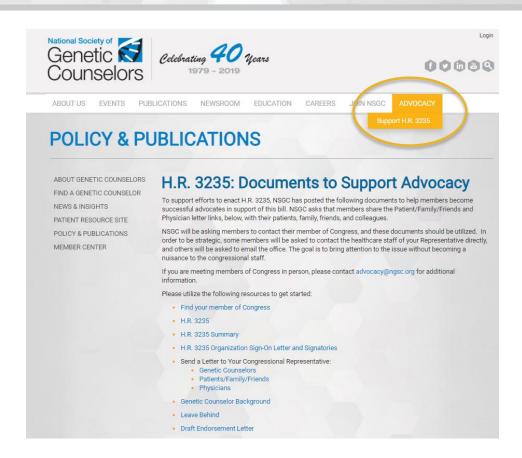
Over 230 organizations have signed our letter of support!

Day on the Hill with ABGC





How can you help?





State Licensure

- 29 states with licensure
 - Four new states passed bills since last Annual Conference
 - Most other states in process
- Ongoing investment in licensure grant awards
 - Maintaining funding level of \$80K to support ongoing success
 - Canadian provincial efforts eligible to apply



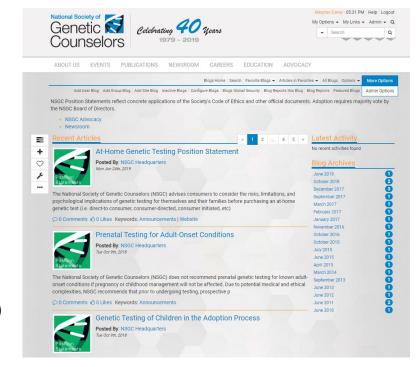
States Issuing Licenses for Genetic Counselors



Position Statements

Public voice of NSGC

- Incorporates your voice
- Used with media, payers, policymakers, general public
- Updated in 2019:
 - At Home Genetic Testing
 - Secondary/Incidental Findings (coming soon)





Expanding NSGC's research capacity and impact





RESEARCH

Accelerate research to expand the evidence base for genetic counselor services and value-based care



Integrating genetics and genomics to improve health for all.



Research Task Force Recommendations

- Research Framework & Research Agenda
- Develop NSGC Research Infrastructure
 - Advance the NSGC Research Agenda
 - Perform research into identified priority questions
 - Foster development of a research consortium that could collect standard data elements across genetic counseling specialties
 - Build research capacity among our membership
- Establish a Research Committee to steward the NSGC research strategy and agenda, and genetic counselor research



NSGC Research Framework

Access

What are the barriers to and facilitators of access to genetic counseling (GC) services?

GC Clients

What predicts access to and benefit from genetic counseling?

GC Process & Outcomes

What are the efficacious components and outcomes of genetic counseling services?

Value of GC Services

How do we define value for genetic counseling services?





National Society of Genetic Counselors 2019-2021 Strategic Plan



DIVERSITY & INCLUSION

Promote diversity and inclusion in the profession to expand access for all



Integrating genetics and genomics to improve health for all

Building a diverse and inclusive community











ABOUT US

PUBLICATION

NEWSROOM

DUCATION

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ABOUT NSGC

ABOUT GENETIC COUNSELORS

FIND A GENETIC COUNSELOR NEWS & INSIGHTS PATIENT RESOURCE SITE POLICY & PUBLICATIONS MEMBER CENTER

The Leading Voice for Genetic Counselors

Our Mission

The National Society of Genetic Counselors (NSGC) promotes the professional interests of genetic counselors and provides a network for professional communications. Access to continuing education opportunities, professional resources, advocacy and the discussion of all issues relevant to human genetics and the genetic counseling profession are an integral part of belonging to the NSGC.

- Mission: The National of the National of the National of the National of Senetic counselors in the National of Senetic Counselors in the Availability of quality genetic services.
- · Vision: Integrating genetics and genomics to improve health for all.

Our Future

View the 2019 - 2021 NSGC Strategic Plan.

Our Statement of Diversity, Equity and Inclusion

A guiding principle of the National Society of Genetic Counselors (NSGC) is to integrate genetics and genomics to improve healthcare. As a society, we can only meet this goal by promoting the active participation and leadership of people with diverse identities, perspectives, and backgrounds. Starting within our organization and extending into the larger healthcare system, we seek to empower our members to advocate for themselves, each other, and the diverse people we strive to serve.

History and Responsibility

We know that a diverse and inclusive organization does not build itself, but must be created through sustained effort by leadership, staff, and each individual member. We acknowledge the history of genetic differences being used and misused to justify stark injustices and reinforce social inequalities. Within the membership and leadership of NSGC, we do not yet have adequate representation or inclusion of minori identifies, a disparity that has influenced our policies and services. We are responsible for learning from the past in order to pursue equity in our profession.

Advocates for Underrepresented People

NSGC Statement of Diversity, Equity, and Inclusion





Vision Statement

NSGCares embodies a foundation of community and compassion that is inherent in the work and spirit of genetic counselors. NSGCares is committed to engaging NSGC members, genetic counselors and students in efforts to cultivate our inclusive community, support our colleagues, and connect with our patient and consumer networks.



NSGCares Structure and Framework

Annual Conference

- RARE Bears and onsite volunteer opportunities (such as a local partnership)
- Ambassador Program



Year-Round Activities

- Opportunities to assist following a request
- Provide recommendations on member-wide issues regarding the profession (e.g. burnout)
- Highlighting work members are doing in their local communities
- Promoting other NSGC activities that relate to community-building and/or supporting members



2019 Year in Review: Operational Investments

Support for our committees and membership



Practice Guidelines Support

Invested in methodologist support to accelerate development

Guidelines under Development

Telegenetics
Epilepsy
Hypertrophic Cardiomyopathy
Expanded Carrier Screening
Hereditary Cancer Risk
Monogenic Diabetes

Practice Resources in Process

HBOC retired guideline (soon to be published)
Lynch syndrome retired guideline
NF1 retired guideline



Annual Professional Status Survey

- Launched first annual survey in January 2019
- Transitioned the current PSS cycle to provide benefits for members and for NSGC's various policy and advocacy efforts
- In 2020 exploring additional report focused on professional diversity

Annual PSS Survey and Reporting Schedule	
Full PSS Administered in Even Years	Annual PSS Administered in Odd Years
Demographics / Methodology	Demographics / Methodology
Executive Summary	Executive Summary
Work Environment	Work Environment
Salary and Benefits	Salary and Benefits
Service Delivery and Access	
Profession Overview and Satisfaction	



2019 Education by the Numbers





Resources for your Practice

- SIGs up to 21 this year!
- Tools for Your Practice
 - Digital Tools for Genetics Professionals
 - Consumer-Driven Genetic Testing
 Primer Deck Resource
 - Professional Issues webinars
 - Model credentialing policies
 - Coding Corner



Tools for your Practice

PROFESSIONAL RESOURCES

promote your value as a genetic counselor.

Demonstrate and

Enhance your knowledge and utilize shared resources developed by NSGC and its members.

MEMBER CENTER





Engage with NSGConnect

Welcome! The NSGConnect program reflects NSGC's commitment to you and your professional development. This unique online networking and career development tool is designed to provide you with professional connections to enrich your career.

You can apply to the NSGConnect program in four simple steps:

1. Update Your Profile

Complete your NSGCommunities profile. Make sure your contact information is up to date, add a recent professional profile picture, expand on your bio and add your education and job history information. Having a complete and accurate profile is crucial to the success of selection and matching.

Profile complete? Return back to this page and move on to "Enroll as a Mentor or Mentee"

2. Enroll as a Mentor or Mentee

Are you looking to be a mentor or mentee? Perhaps both? Sign up using the forms below:

Enroll as a MENTOR Enroll as a MENTEE

Make selections for each section of the form to set your preferences. Please note that some fields are required for enrollment. The more information you provide, the easier it will be to make the best match. Keep in mind in order to request a mentor, you must be enrolled as a mentor to vou may be enrolled as a mentor to vou may be enrolled as a mentor. You may be enrolled as both an emptor and a mentee.

3. Search for Matches

Use the Mentor and Mentee Directories to find available mentors and/or mentees

Find a MENTOR
Find a MENTEE

4. Connect with Mentors or Mentees

Next click on the member's name that you're interested in establishing a mentor/mentee connection with. The link will bring you to their profile page. Look around. If you think it's a match, look under their profile image for the green (request as a mentor) or blue (request as a mentee) buttons, which when clicked will allow you to request your desired connection. If it's not a match, you can simply select the back button to refund to your previous search results.

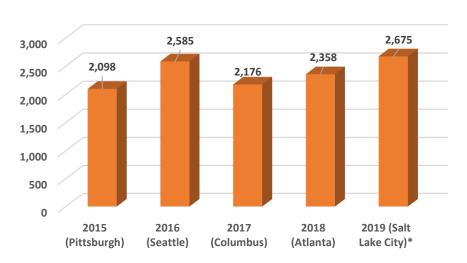
Supporting each other throughout our careers

- Not only for early career GCs
- Connect to share or learn about:
 - Mutual interests
 - New opportunities/challenges
 - Peer support
 - Areas of specialization
 - Specific questions/coaching
 - Discussion of issues



Conference Growth

Annual Conference Registration 2015-2019





*Final, unaudited registration count



2020 Strategic Plan Implementation

Investment in our future





What's coming in 2020?

Business Cases for Genetic Counselors

- Promote hiring, utilization, and retention of genetic counselors in diverse work settings
- Assess financial value proposition for including genetic counselors in patient care
- Provide business tools for you to use in your workplace to support hiring and resource allocation that will allow you to practice at the top of your scope





What's coming in 2020?

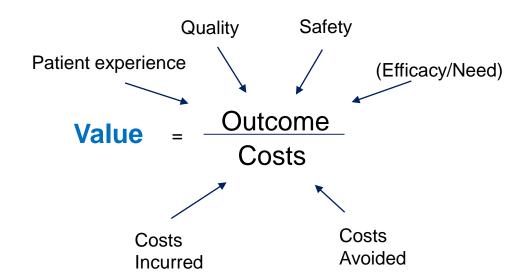
- Continue building co-sponsorship for H.R. 3235
- Request Congressional Budget Office (CBO) score
- Possible Senate companion bill
- Continued progress with state licensure
- Increased focus on payer outreach
 - Ongoing research into value
 - Professionally packaging our message
 - Proactive payer engagement





What's coming in 2020?

A thriving, growing, well-recognized profession whose value is proven.



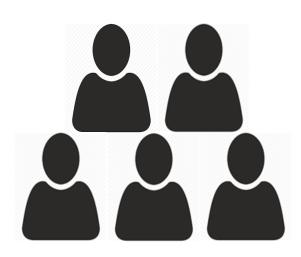


NSGC Research Consortium

Institutional



Individual



- Agree to collect a common set of PROMs
- Agree to document relevant details about counseling provided
- Agree to share data





What to expect in 2020?

- Establishment of a Diversity, Equity, and Inclusion (DEI) Advisory Group
- DEI consultant to work with Advisory Group and develop organizational plan
- Recommendations and preliminary implementation of Universal Design
- Establishment of regular communication about opportunities to be involved with NSGC DEI activities, as well as a place for member feedback
- Unconscious Bias online course (launched this week)
- Continued DEI content at our Annual Conference
- Increased programming and a formal process for requesting support through NSGCares



Communications and Publications Update

Public Relations and NSGC Publications

Media Placements





Genetic counselors save health care dollars when involved in the testing process













Mashable Forbes

The Boston Globe STAT

THE WALL STREET **JOURNAL**



The Washington Post





Medium



Social Media

20,616

Combined Facebook, Twitter and LinkedIn audience of members, media and consumers 53%

Year-over-year increase from the third quarter of 2018





How Do We Communicate With You?

Big picture issues:

- State of the Society
- Annual Business Meeting
- The Advocate

Ongoing Activity:

- Dates and Deadlines
- The Link
- The Source
- General Discussion Forum

Committee recruitment opportunities

Posted on www.nsgc.org and advertised in e-newsletters In 2020, process will be centralized and coordinated to ease in identifying opportunities to volunteer



Journal of Genetic Counseling



Christina Palmer, MS, PhD, CGC Editor-in-Chief



Robin Grubs, PhD, MS, CGC Associate Editor



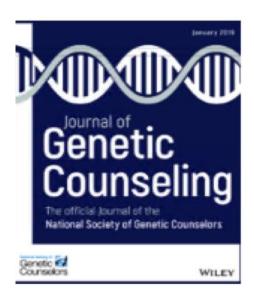




Journal of Genetic Counseling 2019

New Publisher – Wiley

- New Journal website
- New Issue Highlights section
- Enhanced promotion of publications
- New app for viewing journal content!





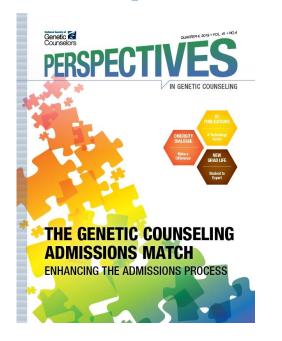
Journal of Genetic Counseling Special Issues

 Examining the Exome: guest edited by Allyn McConkie-Rosell, Robert Resta, and Jennifer Sullivan: Published April 2019

 Minority and Health Disparities in Research and Practice in Genetic Counseling and Genomic Medicine: guest edited by Vivian Ota Wang, Lila Aiyar, and Nadine Channaoui, anticipated publication early 2020



Perspectives in Genetic Counseling





Kristen Hanson, MS, CGC Editor



Shelly Cummings, MS, CGC Associate Editor



Happy Anniversary to us!







Question & Answer Session

Amy Sturm, MS, LGC 2019 NSGC President

Carrie Atzinger, MS, CGC 2019 NSGC Secretary/Treasurer

Meghan Carey
NSGC Executive Director



Thank you for your participation!