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 Zierhut
Director at Large
Incoming 2020 Board Members

Sara Riordan
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
2019 Committee Chairs

Access and Service Delivery
• Jodie Vento, Chair
• Deanna Erwin, Vice Chair

Education
• Carrie Guy, Chair
• Taylor Berninger, Vice Chair
2019 Committee Chairs

Marketing and Communications Workgroup
• Rebekah Moore, Chair
• Rachel Shapira, Vice Chair

Membership
• Katie Bergstrom, Chair
• Christie Hoell, Vice Chair
2019 Committee Chairs

Outcomes
• Megan Cho, Chair
• Stephanie Cohen, Vice Chair

Public Policy
• Leila Jamal, Chair
• Cori Feist, Vice Chair
2019 Committee Chairs

Practice Guidelines
• Sarah Kalia, Chair
• Cindy James, Vice Chair
<table>
<thead>
<tr>
<th>SIG</th>
<th>Co-Chair</th>
<th>Co-Chair</th>
<th>Co-Chair</th>
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<tbody>
<tr>
<td>ART/Infertility</td>
<td>Alleigh Hebner</td>
<td>Gena Shepherd</td>
<td>Paulina Nassab</td>
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<tr>
<td>Cancer</td>
<td>Megan Frone</td>
<td>Sarah Bannon</td>
<td>Kara Bui</td>
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<td>Cardiovascular Genetics</td>
<td>Allison Cirino</td>
<td>Katherine Agre</td>
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<td>Cystic Fibrosis</td>
<td>Kim Foil</td>
<td>Anna Essendrup</td>
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<td>Education</td>
<td>Megan Tucker</td>
<td>Nikkola Carmichael</td>
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<td>Genomic Technologies</td>
<td>Zoe Powis</td>
<td>Kimberly Banks</td>
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<td>Health IT</td>
<td>Caiqian Cropper</td>
<td>Lola Shukla</td>
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<td>Industry</td>
<td>Lauren Ryan</td>
<td>Melanie Hardy</td>
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<td>International</td>
<td>Yue Guan</td>
<td>Arpita Neogi</td>
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<td>Late Career</td>
<td>Bonnie Baty</td>
<td>Ginny (Virginia) Corson</td>
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<td>Leadership Management</td>
<td>Leah Williams</td>
<td>Leslie Bucheit</td>
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<td>Metabolism/LSD</td>
<td>Meghan Strenk</td>
<td>Elizabeth Smith</td>
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<td>Neurogenetics</td>
<td>Krista Qualmann</td>
<td>Catherine Schultz</td>
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<td>Pediatric</td>
<td>Audra Bettinelli</td>
<td>Jessica Kianmahd</td>
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<td>Precision Medicine</td>
<td>Marci Schwartz</td>
<td>Tara Schmidlen</td>
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<td>Prenatal</td>
<td>Christina Dupre</td>
<td>Katie Sagasner</td>
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<td>Psychiatric Disorders</td>
<td>Emily Morris</td>
<td>Kennedy Borle</td>
<td>Andrea Durst</td>
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<td>Public Health</td>
<td>Becca Vanderwall</td>
<td>Andrea Durst</td>
<td>Courtney Berrios</td>
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<td>Research</td>
<td>Julia Wynn</td>
<td>Sarah Mazzola</td>
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<tr>
<td>Student / New Member</td>
<td>Tia Moscarello</td>
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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
Kristal Platt
Bruce R. Haas
Hebah 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

<table>
<thead>
<tr>
<th>2019 Voter Breakdown</th>
<th>%</th>
<th>#</th>
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<tbody>
<tr>
<td>Approve</td>
<td>95.6%</td>
<td>1,037</td>
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<tr>
<td>Abstain</td>
<td>4.1%</td>
<td>44</td>
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<tr>
<td>Write-in</td>
<td>0.3%</td>
<td>4</td>
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<tr>
<td>TOTAL Votes Cast</td>
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<td>1,085</td>
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Voting Participation Rate 2009-2019
Membership Growth

NSGC Membership 2015-2019

<table>
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<tr>
<th>Year</th>
<th>Membership</th>
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<tbody>
<tr>
<td>2015</td>
<td>3,174</td>
</tr>
<tr>
<td>2016</td>
<td>3,595</td>
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<tr>
<td>2017</td>
<td>3,616</td>
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<tr>
<td>2018</td>
<td>3,931</td>
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<td>2019</td>
<td>4,070</td>
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NSGC 5-Year Financial Trends

- Operating + Strategic Expenses
- Operating + Strategic Net Income
- Fees to SmithBucklin
Resources for Strategic Investment

Unrestricted Net Assets (Reserves)

Target Reserves
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

- Conference: 50%
- Publications: 9%
- Membership: 28%
- CEU Provider: 6%
- SIGs: 2%
- Year-Round Sponsorship: 2%
- Online Education: 3%
Major Expense Categories: FY 2018

- General Administration: 28%
- Conference: 35%
- Online Education: 1%
- Federal, State & Payer Advocacy: 8%
- Publications: 7%
- Other Strategic: 1%
- Website & Technology: 4%
- Leadership: 4%
- Committees: 2%
- CEU Provider: 1%
- SIGs: 1%
- Year-Round Sponsorship...: 1%
- Branding, Marketing & PR...: 1%
- Membership: 1%
- Federal, State & Payer
- Advocacy: 8%
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
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 Roundtable 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
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 13, 2016

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. 1395a) is amended—

(1) in subsection (a)(2)—

(A) by striking “and” at the end of subparagraph (G); and

(B) by adding “and” at the end of subparagraph (H); and

(C) by adding at the end the following new subparagraph:

“(1) covered genetic counseling services (as defined in subsection (k)(4)(B));”.

(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

Over 230 organizations have signed our letter of support!

Op-Ed Published in The Hill

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

Day on the Hill with ABGC
How can you help?

H.R. 3235: Documents to Support Advocacy

To support efforts to enact H.R. 3235, NSGC has posted the following documents to help members become successful advocates in support of this bill. NSGC asks that members share the Patient/Family/Friends and Physician letter links, below, with their patients, family, friends, and colleagues.

NSGC will be asking members to contact their member of Congress, and these documents should be utilized. In order to be strategic, some members will be asked to contact the healthcare staff of your Representative directly, and others will be asked to email the office. The goal is to bring attention to the issue without becoming a nuisance to the congressional staff.

If you are meeting members of Congress in person, please contact advocacy@nggc.org for additional information.

Please utilize the following resources to get started:

- Find your member of Congress
- H.R. 3235
- H.R. 3235 Summary
- H.R. 3235 Organization Sign-On Letter and Signatories
- Send a Letter to Your Congressional Representative
  - Genetic Counselors
  - Patients/Family/Friends
  - Physicians
- Genetic Counselor Background
- Leave Behind
- Draft Endorsement Letter
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
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 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?
Building a diverse and inclusive community
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.
NSGCaress 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

<table>
<thead>
<tr>
<th>Annual PSS Survey and Reporting Schedule</th>
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<tr>
<td><strong>Full PSS Administered in Even Years</strong></td>
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<tr>
<td>Demographics / Methodology</td>
</tr>
<tr>
<td>Executive Summary</td>
</tr>
<tr>
<td>Work Environment</td>
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<tr>
<td>Salary and Benefits</td>
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<td>Service Delivery and Access</td>
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<tr>
<td>Profession Overview and Satisfaction</td>
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2019 Education by the Numbers

- 120+ contact hours of content produced through NSGC Education Committee
- 140 Category 1 CEU applications
- 272 Category 2 CEU applications
- 4 Online Courses with 14 hours of content
- 454 Abstracts
- 7 Webinars
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
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

- 2015 (Pittsburgh): 2,098
- 2016 (Seattle): 2,585
- 2017 (Columbus): 2,176
- 2018 (Atlanta): 2,358
- 2019 (Salt Lake City)*: 2,675

*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.

Value = \frac{Quality \cdot Safety}{Costs} = \frac{Patient\text{ experience} \cdot (Efficacy/Need)}{Costs \text{ incurred} - Costs \text{ avoided}}
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

The New York Times
Parade
Yahoo! Lifestyle
Mashable
Forbes
The Boston Globe
STAT
Cosmopolitan
The Wall Street Journal
The Washington Post
npr
Business Insider
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](http://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 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
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!