

NSGC 2018 Annual Business Meeting

*Erica Ramos, MS, CGC, President
Shannan Dixon, MS, CGC, Secretary/Treasurer
Meghan Carey, Executive Director*

Agenda for Today

- Welcome and Introductions
- 2017 – 2018 Financial Update
- 2018 Year in Review
 - Strategic Investments
 - Operational Investments
- 2019 Planned Initiatives and Investments
- Communications and Publications Update
- 2018 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
- 22 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 and Working Groups provide the power for meeting our strategic goals

2018 Board of Directors



Erica Ramos
President



Amy Sturm
President
Elect



Shannan Dixon
Secretary/Treasurer



Carrie Atzinger
Secretary/Treasurer
Elect



Mary Freivogel
Immediate Past
President



Deepti Babu
Director at
Large



Curtis Coughlin, III
Director at Large



Emily Edelman
Director at Large



Jason Flanagan
Director at Large



Gillian Hooker
Director at Large



Sarah Noblin
Director at Large



Elizabeth Varga
Director at Large

Incoming 2019 Board Members



MaryAnn Campion
2019 President Elect



Scott Weissman
2019
Secretary/Treasurer
Elect



Colleen Schmitt
2019 Director at
Large



Heather Shappell
2019 Director at
Large



Blair Stevens
2019 Director at
Large



Heather Zierhut
2019 Director at
Large

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!

HOME COMMUNITIES DIRECTORY (ADMIN ONLY) EVENTS NSGCCONNECT RETURN TO NSGC.ORG

Volunteer Opportunities Settings

COMMUNITY HOME DISCUSSION **41** LIBRARY **0** EVENTS **0** MEMBERS **190**

1 to 38 of 38 threads (41 total posts)

Most Recently Updated Posts in my communities 50 per page [Post New Message](#)

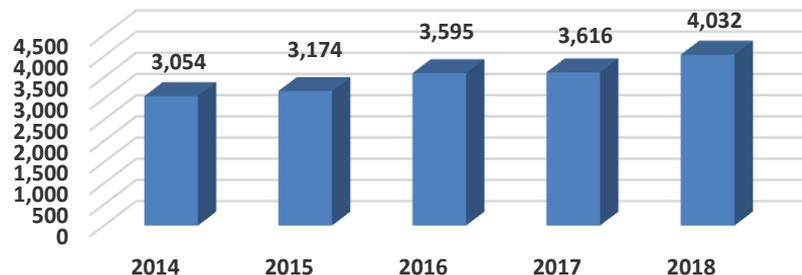
Thread Subject	Replies	Last Post
2019 Nominating Committee Call for Candidates	0	28 minutes ago by NSGC Headquarters
Join us at GC's Got Talent 2018!	0	2 days ago by Julie Simon
Professional Status Survey (PSS) Subcommittee - Volunteers Needed	0	11 days ago by NSGC Headquarters
Abstract Workgroup Seeking Members	2	13 days ago by Courtney Berrios Original post by Tamara White
Join the Webinar Subcommittee!	0	23 days ago by Tamara White
Become a CEU Reviewer!	0	one month ago by Tamara White
The CEU Reviewer Subcommittee is Seeking a 2019 Vice Chair	0	one month ago by Tamara White
ASD Committee: Call for Volunteers 2019	0	one month ago by NSGC Headquarters
Public Policy Committee Seeking Members for 2019	0	one month ago by NSGC Headquarters
Practice Guidelines Committee Seeks New Committee Members for 2019	0	one month ago by NSGC Headquarters
Ethics Advisory Group: 2019 Call for Volunteers	0	one month ago by NSGC Headquarters
Membership Committee: Volunteer Positions for 2019	0	one month ago by NSGC Headquarters
The Education Committee is Seeking Subject Matter Experts	0	one month ago by Katie Strang
Seeking Online Course Subcommittee Volunteers for 2019	0	one month ago by Katie Strang
Seeking Gaucher Disease Expert	0	one month ago by Meghan Carey

2017 – 2018 NSGC Financial Report

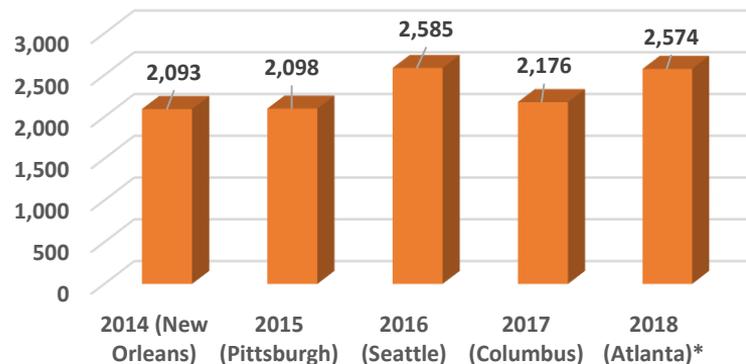
*Preserving our foundation; investing in our
members*

Membership and Conference Growth

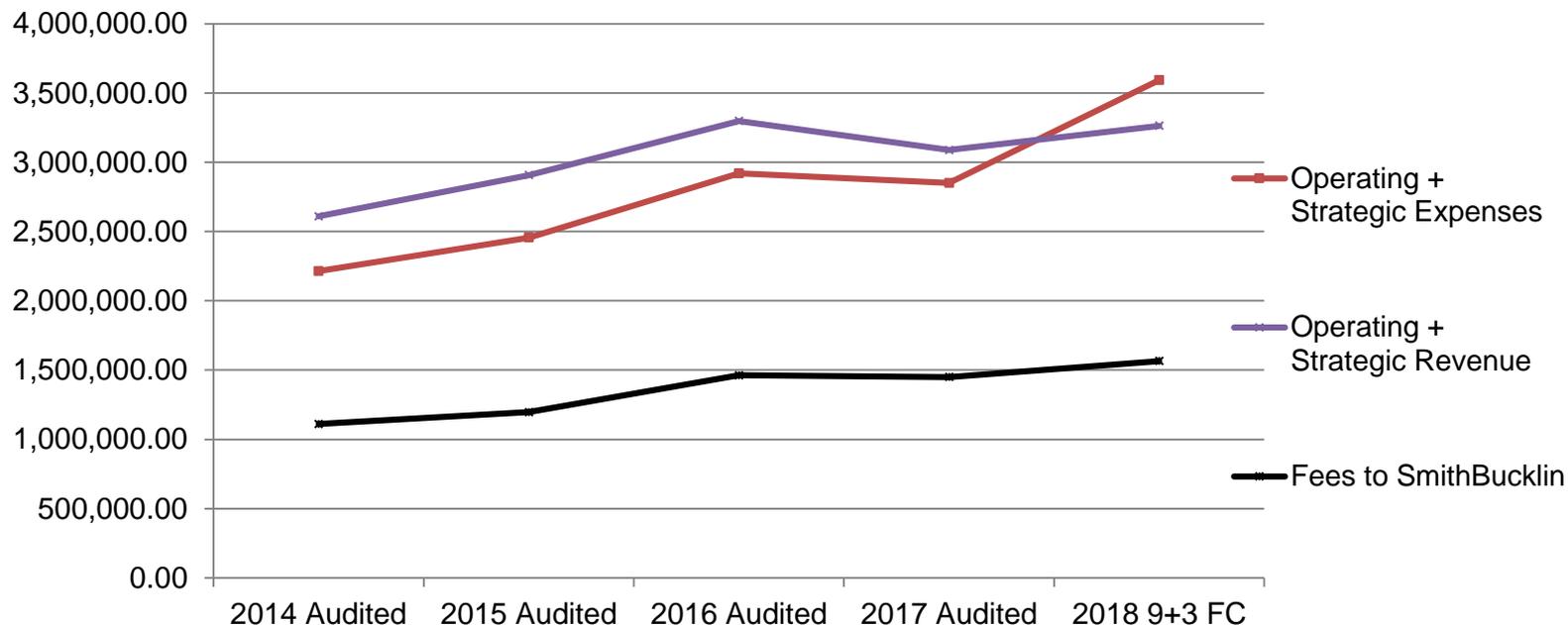
NSGC Membership 2014-2018



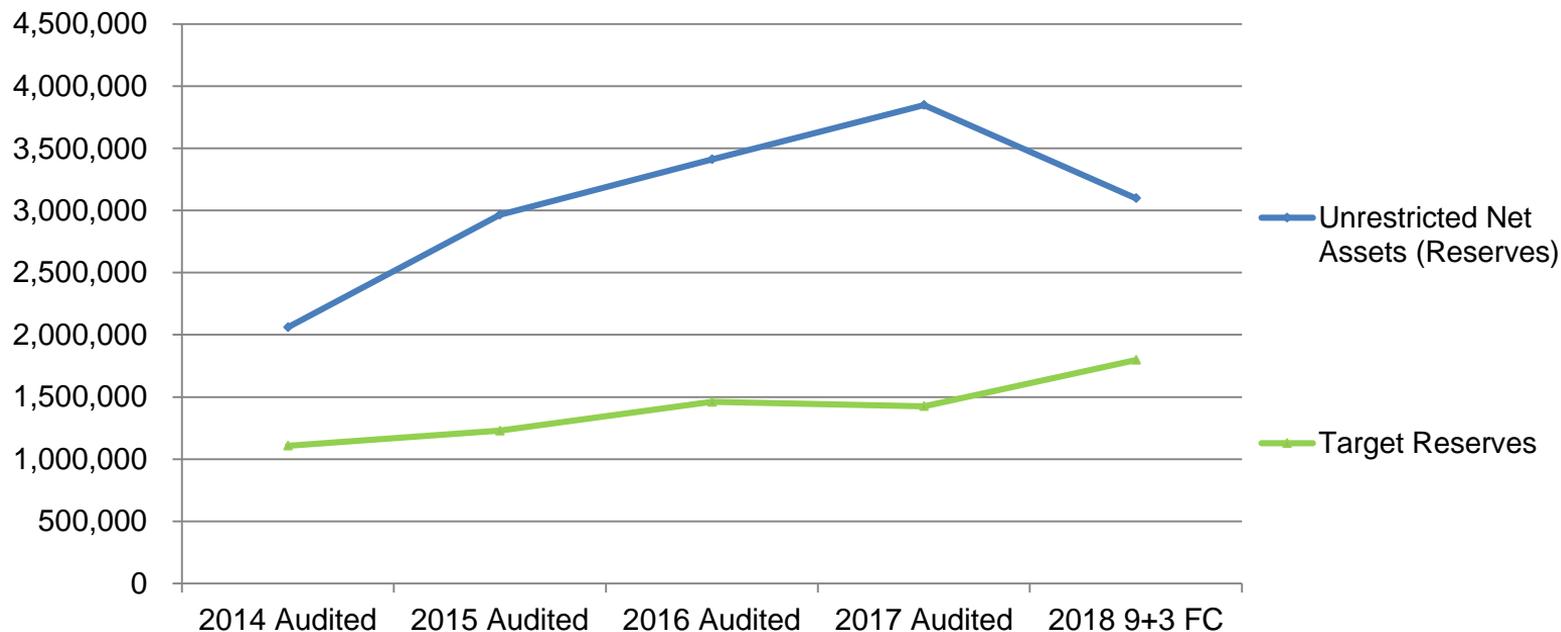
Annual Conference Registration 2014-2018



NSGC 5-Year Financial Trends



Resources for Strategic Investment



Cash Assets as of Year End 2017

- Cash Assets
 - NSGC liquid assets: \$2,721,874
 - NSGC Investments \$1,629,947

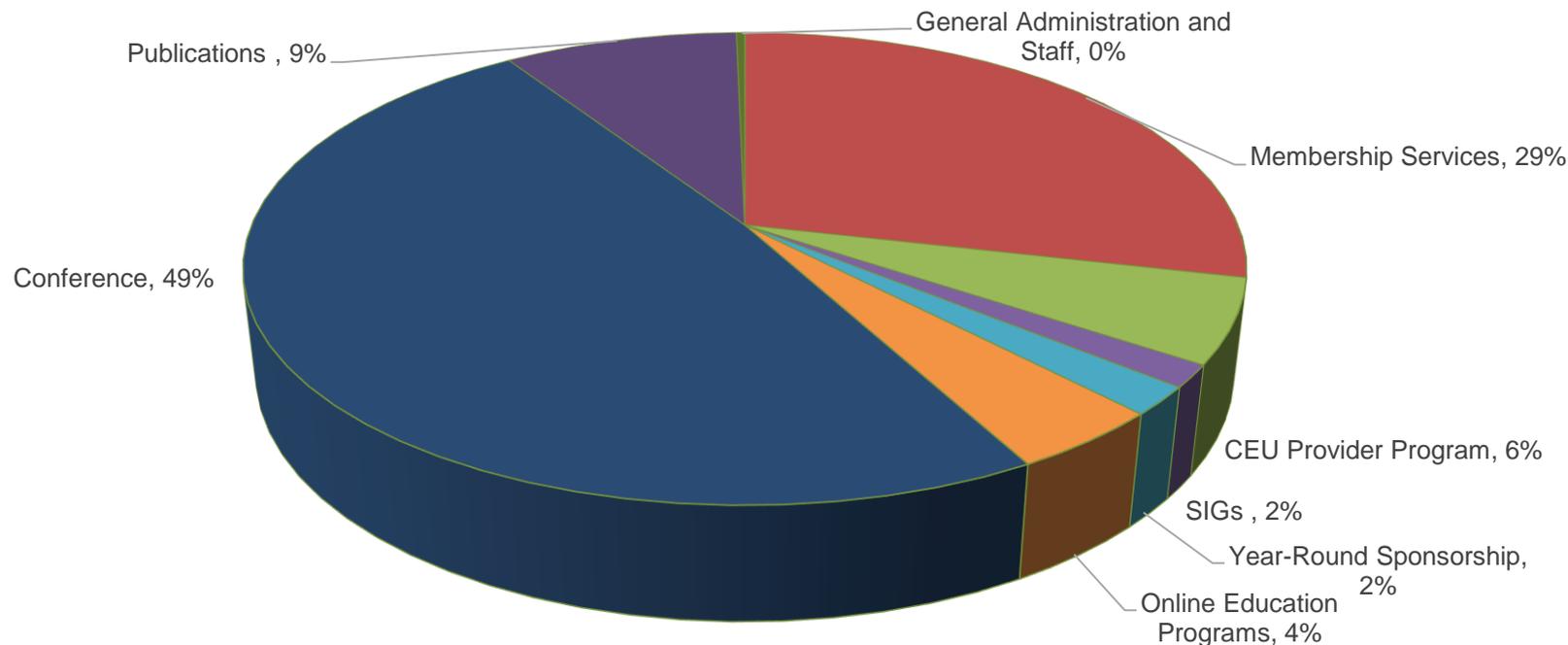
- Budgeted Revenue: \$3,100,132
- Year-end Actual Revenue: \$3,295,320

- Budgeted Expenses: \$2,960,193
- Year-end Actual Expenses: \$2,857,083

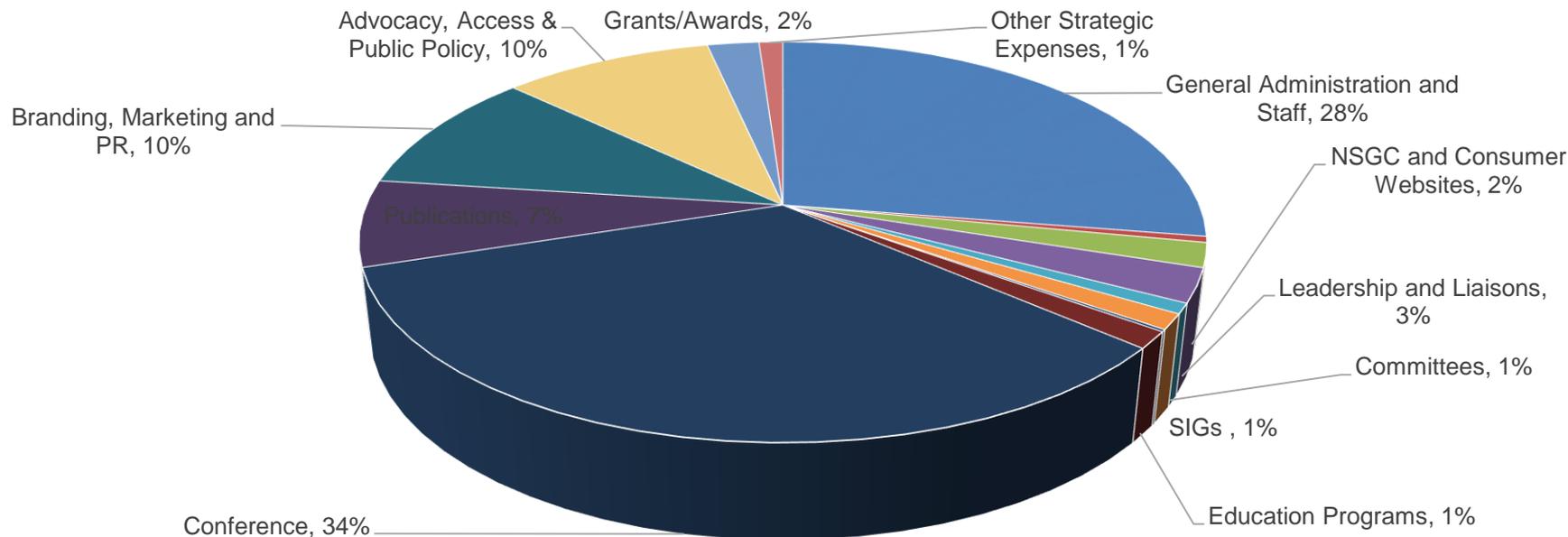
2017 Budgeted Net Revenue: (\$135,430)

2017 Year-end Actual Net Revenue: \$438,237

Major Sources of Revenue: FY 2017



Major Expense Categories: FY 2017



Financial Goals in 2018

- Maintain a healthy financial base
- Ensure operational support for our growing membership
- More aggressively invest in our strategic plan to benefit our members
- Every decision made on it's own merits – not evaluating one option over another
- Remain conscious of the total amount of money we spend in any given period of time

Where do we stand today?

- **2018 Forecast**

- Budgeted Revenue: \$3,114,443
- 9+3 Forecast for Revenue: \$3,208,069

- Budgeted Expenses: \$3,514,330
- 9+3 Forecast for Expenses: \$3,594,812

2018 Budgeted Net Revenue: (\$311,743) planned investment
2018 9+3 Forecasted Net Revenue: (\$399,887) planned investment

2018 Year in Review: Strategic Investments

Moving our profession forward

Federal Advocacy

- We have a bill!
- **Investment** in additional lobbying support: Capitol Counsel
- **Investment** in online grassroots support tool
 - YOU have sent just under 1,500 emails to Congress to date
- We will be contacting members to help with our targeted grassroots efforts
 - Patient advocacy organizations
 - Large health systems
 - Academic medical centers
 - Key legislators

115TH CONGRESS
2^D SESSION

H. R. 7083

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

OCTOBER 23, 2018

Mr. PAULSEN (for himself and Mr. LOEBSACK) 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

POLICY & PUBLICATIONS

ABOUT GENETIC COUNSELORS

FIND A GENETIC COUNSELOR

NEWS & INSIGHTS

PATIENT RESOURCE SITE

POLICY & PUBLICATIONS

MEMBER CENTER

H.R. 7083: Documents to Support Advocacy

To support efforts to enact H.R. 7083, NSGC has posted the following documents to help members become successful advocates in support of this bill. 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. In the coming weeks, NSGC will be implementing an online platform to make this easy and to aid you in becoming a great advocate for this important initiative.

If you are meeting members of Congress in person, please contact [John Richardson](#) for additional information.

Please download the following resources to get started:

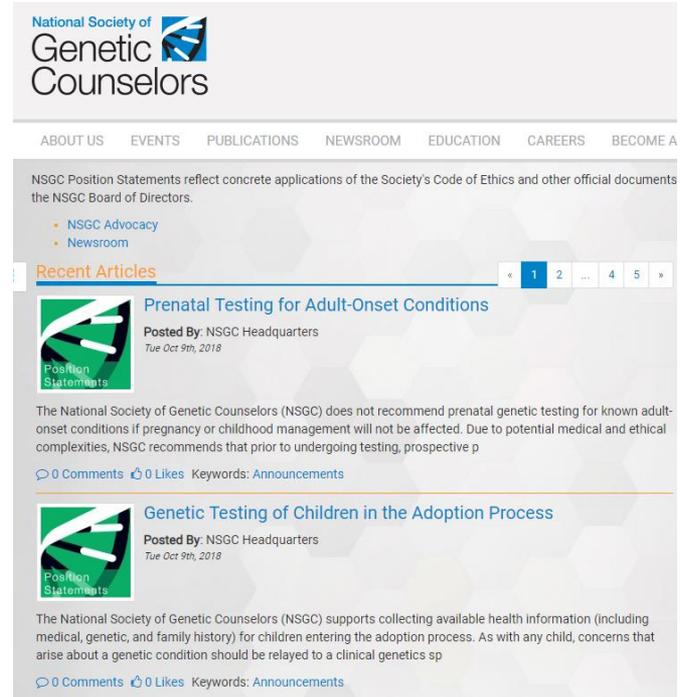
- [H.R. 7083 Text](#)
- [H.R. 7083 Summary](#)
- [Genetic Counselor Background](#)
- [Issue Brief](#)
- [Draft Email to Congressional Office](#)
 - Please copy advocacy@nsgc.org on your email.
- [Draft Endorsement Letter for patient Advocacy Organization](#)
- [Institutional Support Flowsheet](#)
- [Endorsement Form](#)

Federal Advocacy Resources

Position Statements

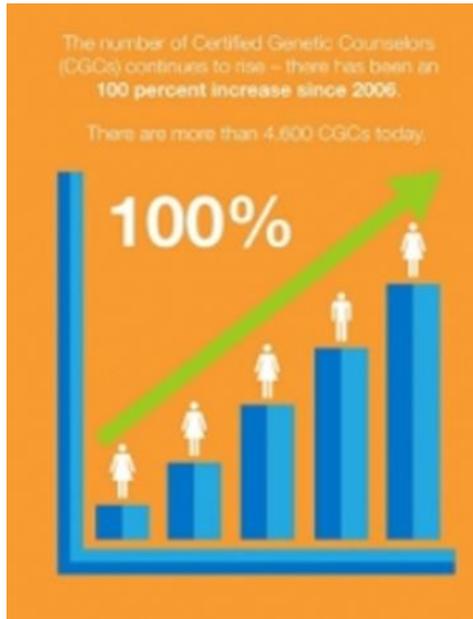
Public voice of NSGC

- Incorporates *your* voice
- Used with media, payers, policymakers, general public
- In 2018, **investment** in education for training programs on key policy issues



The screenshot displays the NSGC website's 'Recent Articles' section. At the top, the NSGC logo is visible. Below it is a navigation menu with links for ABOUT US, EVENTS, PUBLICATIONS, NEWSROOM, EDUCATION, CAREERS, and BECOME A. The main content area features a heading 'NSGC Position Statements reflect concrete applications of the Society's Code of Ethics and other official documents the NSGC Board of Directors.' followed by links to 'NSGC Advocacy' and 'Newsroom'. A 'Recent Articles' section shows a list of articles with a pagination control (1, 2, ..., 4, 5). The first article is 'Prenatal Testing for Adult-Onset Conditions', posted by NSGC Headquarters on October 9th, 2018. The article text states that NSGC does not recommend prenatal genetic testing for known adult-onset conditions if pregnancy or childhood management will not be affected. The second article is 'Genetic Testing of Children in the Adoption Process', also posted by NSGC Headquarters on October 9th, 2018. The article text states that NSGC supports collecting available health information for children entering the adoption process. Both articles include a '0 Comments' and '0 Likes' indicator and are categorized under 'Announcements'.

Workforce Development



- **Investment** in video for student recruitment
- First annual Clinical Supervisor Awards in collaboration with AGCPD
- Ongoing updates to workforce projections

Professional Status Survey



- **Investment** in survey revisions to support strategic use of data
- **Investment** in new reports and enhanced reporting format

Journal of Genetic Counseling

- **Investment** in RFP process for new publisher
- **Investment** in consultant support for RFP, publisher selection and transition
- Selection of strategic publishing partner to grow the journal in influence and impact
- Favorable financial package to support ongoing growth of journal and strategic initiatives


2018


2019

Wiley Online Library

Search 

Login / Register

Journal of
Genetic Counseling



Edited By: Christina Palmer
Impact factor: 1.698
Online ISSN: 1573-3599
© The National Society of Genetic Counselors



The *Journal of Genetic Counseling* will begin publishing with Wiley in 2019!

HOME

ABOUT

CONTRIBUTE

BROWSE



About the Journal

The *Journal of Genetic Counseling* (JOGC), published for the National Society of Genetic Counselors, is a timely, international forum addressing all aspects of the discipline and practice of genetic counseling. The journal focuses on the critical questions and problems that arise at the interface between rapidly advancing technological developments and the concerns of individuals and communities at genetic risk. The publication provides genetic counselors, other clinicians and health educators, laboratory geneticists, bioethicists, legal scholars, social scientists, and other researchers with a premier resource on genetic counseling topics in national, international, and cross-national contexts.

Featured



Announcing the 2018
Best Trainee Paper
Awardees!

To recognize and promote excellence in research and scholarship in our recent trainees, the *Journal of Genetic Counseling* is pleased to announce the **Best Trainee Paper Awards**. For more about the 2018 winners, click [here](#).

-  Submit an Article
-  Subscribe to this journal
-  Browse sample issue
-  Get Content alerts
-  Recommend to a librarian

National Society of
Genetic
Counselors

Published in partnership with the National Society of Genetic Counselors.

Tweets by @GeneticCouns

 Genetic Counselors @GeneticCouns
Genetic counselors are taking over Atlanta for #NSGC18! What are you looking forward to the most at this year's conference?

2018 Year in Review: Operational Investments

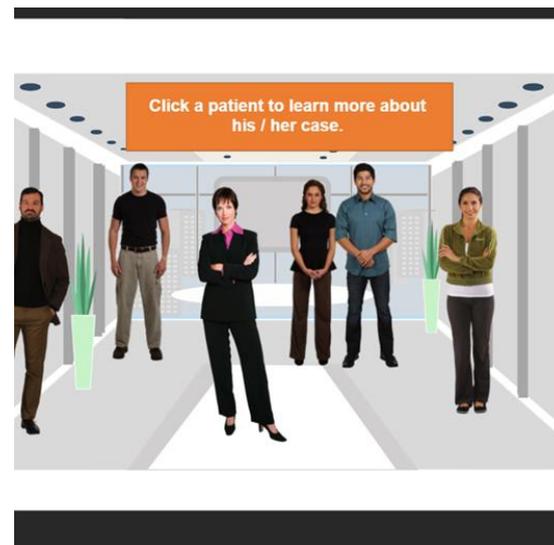
Support for our committees and membership

Education Initiatives

CEU Online Portal

The screenshot shows the National Society of Genetic Counselors CEU Online Portal. At the top left is the logo. Below it is a search bar with the text "Search" and a search icon. To the left of the search results is a sidebar with "Follow Your Results" and a list of "Locations" including Denver, Atlanta, Denver, Richmond, San Diego, St. Louis, and St. Petersburg. The main content area shows "Showing 1 to 10 of 18" results, including ASHG2018, ASRM 2018 Scientific Congress, 2018 Annual North American Cystic Fibrosis Conference, 2018 NSGC Annual Conference - Educational Breakout Sessions and Workshops, NSGC Annual Conference - Sponsored Sessions, 2018 LING Genetic Counseling Supervision Workshop, 2018 Genetic Counseling + Clinical Genomics Meeting, 2018 NSGC Annual Conference - Pre-Conference Symposia, 8th Annual Symposium on Lysosomal Storage Disorders, and VCU Health Clinical Genetics Weekly Educational Conference.

Interactive Online Courses



NSGCommunities

- Easily view and build your NSGC contacts
- Establish your network
- One central location for all of your NSGC communities and connections

The screenshot displays the NSGCommunities website interface. At the top, there is a navigation bar with links for 'Contact Us', 'Help/FAQs', and 'Terms and Conditions'. The main header features the NSGC logo and a search bar. Below the header, a navigation menu includes 'HOME', 'COMMUNITIES', 'EVENTS', 'NSGCONNECT', and 'RETURN TO NSGC.ORG'. The main content area shows a user profile for Erica Ramos, MS, LCGC, with a profile picture and a bio: 'Director and Head of Clinical & Business Development, Geisinger National Precision Health'. Below the profile are tabs for 'MY PROFILE', 'MY CONNECTIONS', 'MY CONTRIBUTIONS', and 'MY ACCOUNT'. A section titled 'People You May Know' lists three individuals: Gillian Hooker (Vice President of Clinical Development at Concert Genetics), Amy Sturm (Director of Cardiovascular Genomic Counseling at Geisinger), and Emily Edelman (Associate Director at The Jackson Laboratory). Each entry includes a 'Request Contact' button and an 'Ignore' button. A 'Contacts' section below lists three contacts: Diana (Moglia) Tully (Quest Diagnostics), Katie Bergstrom (Texas Children's Hospital), and Leslie Bucheit (Counsyl). Each contact entry includes a profile picture, name, organization, and buttons for 'Send Message' and 'Remove Contact'.



NSGConnect

PROFESSIONAL CONNECTIONS TO ENRICH YOUR CAREER

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 mentee, and in order to request a mentee, you must be enrolled as a mentor. You may be enrolled as both a mentor 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 return to your previous search results.

Coaching and Support throughout Your Career

- Flexible, peer mentoring, coaching and support program
- Designed for ALL members, regardless of career stage
- Type and duration of mentor relationship is up to you!

2019 Planned Initiatives and Investments

Funding our new strategic plan

Annual Professional Status Survey

- **Investing** in annual survey beginning in January 2019
- Transitioning the current PSS cycle to provide benefits for members and for NSGC's various policy and advocacy efforts:
 - Annual data collection for key professional issues
 - Annual data on the most dynamic and highly utilized workforce and access data
 - Annual salary data for use by NSGC members

Annual PSS Survey and Reporting Schedule	
<i>Full PSS Administered in Even Years</i>	<i>Annual PSS Administered in Odd Years</i>
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	

Practice Guidelines Support

- High-impact publications; robust development process
- **Investing** 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

Lynch syndrome retired guideline

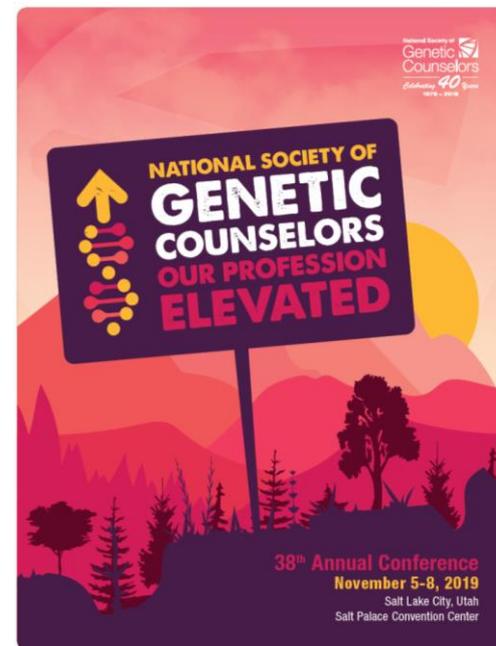
NF1 retired guideline

Value of Genetic Counselors

- **Investing** in support from a health economist
 - Assistance with endorsement by National Quality Forum genetic counseling performance measures
 - Develop business cases for utilizing genetic counselors in multiple settings
- Advocacy support from lobbying firm

Annual Conference Enhancements

- New post-conference sessions
- New session formats to address different learning styles
- Increased time and space for networking and individual meetings
- Community-building activities and opportunities for attendees to enhance your experience



NSGC turns 40!

- Celebrate at 2019 Annual Conference
- Timeline of our history
- Be part of our future



Research Agenda

- Identify NSGC research priorities
 - Develop operational infrastructure to support our research priorities

- Develop and pilot patient identification tool
 - Which patients will benefit from genetic counseling?



RESEARCH

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

Payer Advocacy

- Meeting of payer representatives to advocate for value of covering genetic counseling
- Ongoing advocacy around Medicare coverage for genetic counselors



ACCESS TO GENETIC COUNSELORS

Engage payers to increase access to genetic counselors

Additional Anticipated **Investments**

- Diversity & Inclusion initiatives
- NSGCares initiatives and community-building efforts

Communications and Publications Update

Public Relations and NSGC Publications

2018 Media Placements

As of October 2018, our public relations efforts have resulted in:

502

Total media placements

889 MM

Audience reach of placements

Social Media

13,479

COMBINED
FACEBOOK/TWITTER
AUDIENCE OF
MEMBERS, MEDIA
AND CONSUMER

20.5%

YEAR-OVER-YEAR
INCREASE FROM
THE THIRD
QUARTER OF 2017



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*
- Volunteer Opportunities
Discussion Forum
- General Discussion Forum

Journal of Genetic Counseling

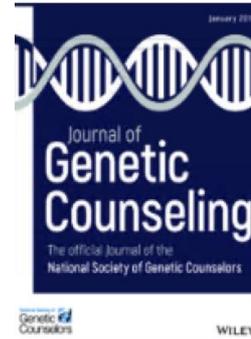
2018 New Editor in Chief

- *Christina Palmer*



2019 New Publisher

- *New: Journal website, cover design, Issue Highlights section, and enhanced promotion of publications*



Journal of Genetic Counseling



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

Melanie Myers, MS, PhD, CGC
Deputy Editor



Journal of Genetic Counseling

Associate Editors

Robin Grubs, PhD, MS, CGC

Associate Editor

Qualitative methods expert



Ian MacFarlane, PhD

Associate Editor

Statistics expert



Journal of Genetic Counseling

Section Editors

Genetic Counseling Theory, Methods, & Practice

Melody Menezes, GDipGenetic Couns, PhD

Kami Wolfe Schneider, MS, CGC

Heather Zierhut, MS, PhD, CGC

Public Health, Public Policy, and Access & Service Delivery

Adam Buchanan, MS, LGC

Myra Roche, MS, CGC

Education and Genetics Professional Workforce Issues

Angela Trepanier, MS, CGC

Ethical, Legal, and Social Issues

Laura Hercher, MS, CGC

Lisa Parker, PhD

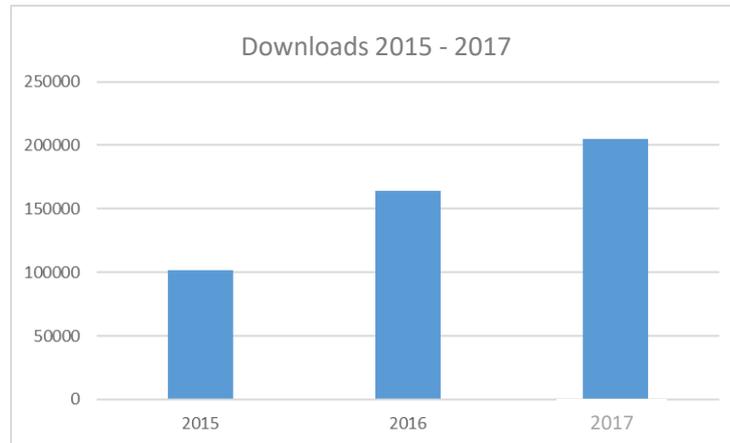
Risk Assessment

Toni Pollin, MS, PhD, CGC

Journal of Genetic Counseling Data

September 15, 2017 through September 15, 2018

- Manuscript submission and processing continues to increase
- Over the above 12 months, JOGC editorial office received:
 - 304 new submissions; ~25 new papers per month
 - 5.5% increase in the number of new manuscripts received over the same time period last year



2017 JOGC Highlights

- Impact Factor is currently **1.698**
- Special Issues
 - Technology in Genetic Counseling Practice: published in April of 2018.
 - Examining the Exome: guest edited by Allyn McConkie-Rossel, Robert Resta, and Jennifer Sullivan: plan to publish in 2019
- 2nd Annual JOGC Best Trainee Paper Award:
 - **Susan Christian** from the University of Alberta for her paper: *“Uptake of predictive genetic testing and cardiac evaluation for children at risk for an inherited arrhythmia or cardiomyopathy”*
 - **Krista Redlinger-Grosse** from University of Minnesota for her paper: *“Elaboration of the Reciprocal-Engagement Model of genetic counseling practice: A qualitative investigation of goals and strategies”*
 - **Anthony Chen** from the University of Minnesota for his paper: *“Seekers, finders, settlers, and stumblers: Identifying the career paths of males in the genetic counseling profession”*
 - **Daniella Kamara** from California State University-Stanislaus for her paper: *“Cancer counseling of low-income limited English proficient Latina women using medical interpreters: Implications for shared decision-making”*

Perspectives in Genetic Counseling



Kirsty McWalter, MS, CGC
Editor



Shelly Cummings, MS, CGC
Incoming Associate Editor



Kristen Hanson, MS, CGC
Associate Editor

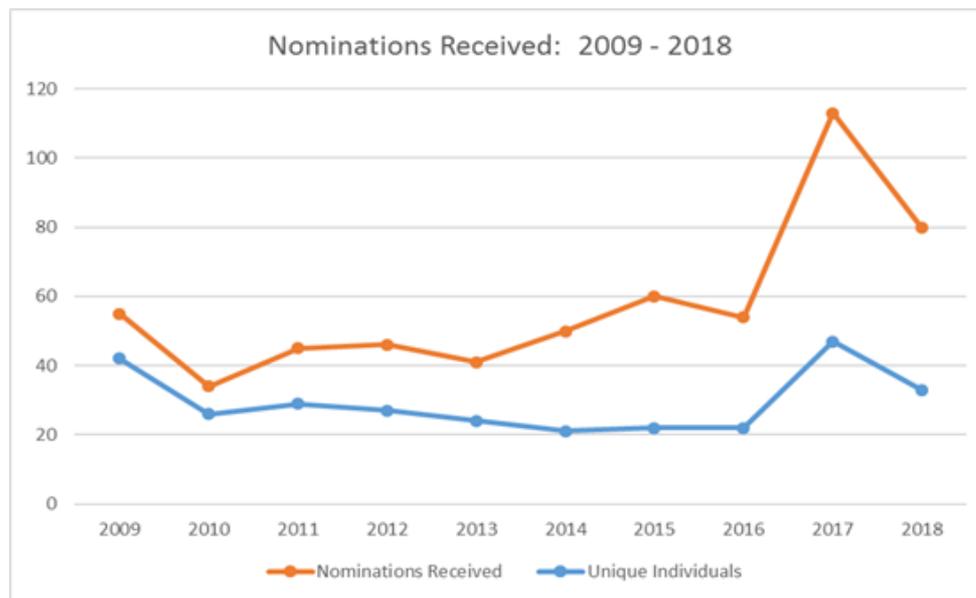
2018 Nominations and Election Update

NSGC Nominating Committee

- Four (4) at-large members selected by Membership Committee from individuals responding to an open call for applicants
- President, past president, two (2) non-officer board members

Nominations and Elections Process

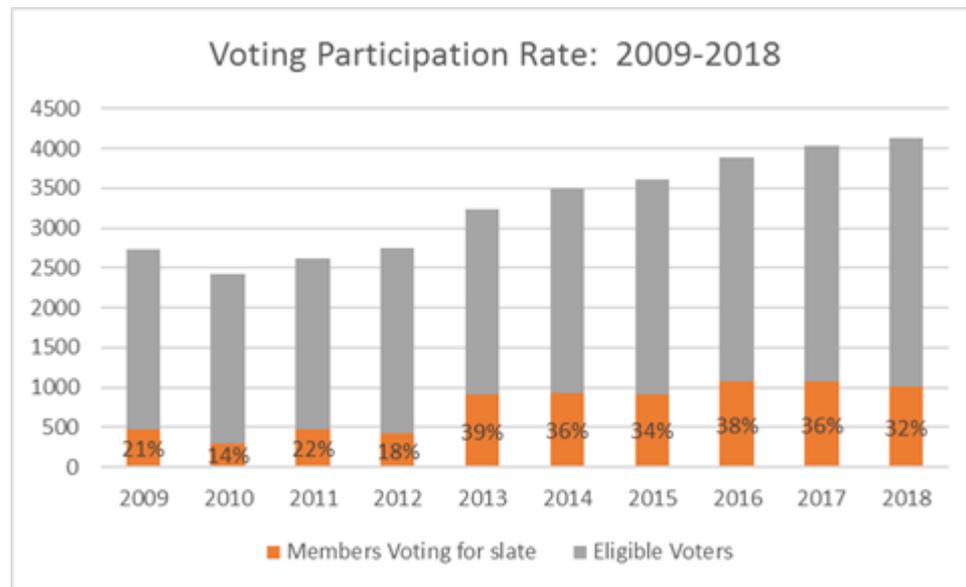
- Call for Nominations opened in January 2018
- Members submitted 80 nominations (31 unique individuals)
- Nominees assessed using a combination of quantitative and qualitative measures
 - Statement from nominator
 - Written application and CV
 - Interview



Election Results

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

2018 Voter Breakdown	%	#
Approve	97.2%	978
Abstain	2.4%	24
Write-in	0.4%	4
TOTAL Votes Cast		1006



Question & Answer Session

Erica Ramos, MS, CGC
2018 NSGC President

Shannan Dixon, MS, CGC
2018 NSGC Secretary/Treasurer

Meghan Carey
NSGC Executive Director

**Thank you for your
participation!**