2016 NSGC Annual Business Meeting

November 9, 2016

Jehannine Austin, PhD, CGC NSGC President Laura Conway, PhD, CGC NSGC Secretary/Treasurer



Overview

- Welcome
- Volunteer Recognition
- 2016 Highlights and Accomplishments
- NSGC Growth
- NSGC Financial Update
- NSGC Publications Update
- Incoming Board Members
- Q & A



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.



2016 Board of Directors



Jehannine Austin
President



Mary Freivogel President Elect



Laura Conway Secretary/Treasurer



Monica Marvin
Secretary/Treasurer Elect



Joy Larsen Haidle Immediate Past President



2016 Board of Directors



Carrie Blout
Director at Large



MaryAnn Campion
Director at Large



Katie Dunn
Director at Large



Erynn GordonDirector at Large



Kaylene ReadyDirector at Large



Sara RiordanDirector at Large



Dan RicondaDirector at Large



Meghan Carey
Executive
Director



2016 Committee Chairs and Vice Chairs

Access and Service Delivery Committee Colleen Campbell, Chair Sara Gilvary, Vice Chair





Education Committee
Emily Edelman, Chair
Colleen Caleshu, Vice Chair





Marketing & Communications
Workgroup
Dena Goldberg, Chair





2016 Committee Chairs and Vice Chairs

Membership Committee Shar Munshi, Chair Katie Spoonamore, Vice Chair

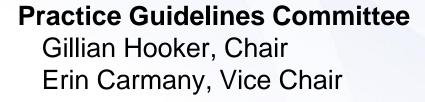




Public Policy Committee
Andy Faucett, Chair
Blair Stevens, Vice Chair













2016 Special Interest Group (SIG) Chairs

ART/Infertility	Andria Besser	Alyssa Snider
Cardiovascular Genetics	Sara Fitzgerald-Butt	Brittney Murray
Cystic Fibrosis	Matthew Pastore	Barbara Karczeski
Education	Shraddha Gaonkar	Carrie Guy
Familial Cancer Risk	Flora Poleshchuck	Victoria Raymond
Genomic Technologies	Kim Banks	Kelly Farwell Hagman
Health IT	Megan Frone	Willonie Mendonca
Industry	Darci Sternen	Kate Wilson
International	Yue Guan	Jennifer Fitzpatrick
Late Career	Bonnie Baty	TBD
Management & Leadership	Leah Williams	Leslie Bucheit
Management & Leadership Metabolism/LSD	Leah Williams Katharine Stoate	Leslie Bucheit Lauren McNair Baggett
<u>.</u>		
Metabolism/LSD	Katharine Stoate	Lauren McNair Baggett
Metabolism/LSD Neurogenetics	Katharine Stoate Amanda Bergner	Lauren McNair Baggett Jennifer Roggenbuck
Metabolism/LSD Neurogenetics Pediatric	Katharine Stoate Amanda Bergner Afifa Irani	Lauren McNair Baggett Jennifer Roggenbuck Rebecca Okashah
Metabolism/LSD Neurogenetics Pediatric Personalized Medicine	Katharine Stoate Amanda Bergner Afifa Irani Sarah Kalia	Lauren McNair Baggett Jennifer Roggenbuck Rebecca Okashah Shana White
Metabolism/LSD Neurogenetics Pediatric Personalized Medicine Prenatal	Katharine Stoate Amanda Bergner Afifa Irani Sarah Kalia Shannon Wieloch	Lauren McNair Baggett Jennifer Roggenbuck Rebecca Okashah Shana White Cori Feist
Metabolism/LSD Neurogenetics Pediatric Personalized Medicine Prenatal Psychiatric Disorders	Katharine Stoate Amanda Bergner Afifa Irani Sarah Kalia Shannon Wieloch Carmela Thompson	Lauren McNair Baggett Jennifer Roggenbuck Rebecca Okashah Shana White Cori Feist Hannah White
Metabolism/LSD Neurogenetics Pediatric Personalized Medicine Prenatal Psychiatric Disorders Public Health	Katharine Stoate Amanda Bergner Afifa Irani Sarah Kalia Shannon Wieloch Carmela Thompson Amy Gaviglio	Lauren McNair Baggett Jennifer Roggenbuck Rebecca Okashah Shana White Cori Feist Hannah White Andrea Durst

Thank you to NSGC Executive Office Staff

Executive Director	Government Relations & Advocacy
Meghan Carey	John Richardson
Membership and Operations	Molly Giammarco
Kathryn Whitmer	Marketing and Communications
Eunice Hahn	Jennifer Kasowicz
Education	Hannah Jaracz
Katie Strang	Emily Krutz
Molly McGinnis	Internet and Technology Services
Erika Bruning	Scott Beitzel
Accounting	Hardeek Patel
Alexia Malamis	Events and Tradeshow
Jared Dechowitz	Catherine Perkins
Creative Services and Design	Ricci McDonald
Steve Biernacki	Kate Schulze
Kara Cooke	Rebecca Baker
	Jenny Worcester

Thank you to NSGC Executive Office Staff



Thank you to all of NSGC's 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!

Please check our Member News section for ways you can get involved with NSGC.



2016 HIGHLIGHTS & ACCOMPLISHMENTS



Rolling Strategic Plan

- Annual review of landscape by Board; full review of strategic initiatives every 3 years
- Align each 3-year strategic plan to support longer-term goals
- Plan adjustments and edits to ensure we are proactive and relevant
- We need member support for this process you are our best resource
 - —Engage with committees, subcommittees and workgroups
 - —Participate in SIGs
 - —Contact your leaders with emerging information



From Strategy to Action

Strategic Plan of Work Charges Action

NSGC's volunteer Committees, Task Forces and Working Groups are the power behind achieving our strategic goals



2016 Committees: Major Accomplishments*

Access and Service Delivery Committee

- Expanded payer resources available to membership
- Provided feedback to Cigna on its genetic counseling preauthorization forms (recommendations implemented by Cigna)
- Oversaw and received approval for application for NSGC's representative to the American Medical Association's Health Care Professional Advisory Committee
- •Created a licensure resource page for membership that includes letter templates, lobbying information, maps, and strategic resources
- Minnesota obtained licensure for genetic counselors
- •Overseeing NSGC's efficiency efforts and in the process of developing a long-term project plan that includes courses, webinars, and other member resources
- Provided licensure grants to Minnesota, New York, and the Quebec Association of Genetic Counsellors

Education Committee

- Increased coordination with SIGs regarding educational topics
- Launched an entirely redesigned New Online Learning Center
- Initiated an AEC Strategic Planning Meeting to review the future AEC conference model
- Developed and released new educational product surveys
- Developed six webinars on professional issues topics
- Rolled out a new online course structure in 2016 in response to the education needs assessment
- •Developed and released four new online courses on member-requested topics:
 - Variant Interpretation in the Era of WGS/WES
 - What the Specialized Genetic Counselor Needs to Know about Other Areas of Genomic Medicine
 - > Revisiting Research: Improving Your Skills to Integrate Research into Your Role
 - Psychosocial Counseling Skills
- Reviewed 200 Category 2 applications and 150 Category 1 applications
- Selected lineup of sessions for the 2016 AEC from a record-breaking 99 session proposals
- Reviewed 481 abstract submissions for the AEC (record-breaking)
- Selected ten journal articles for the Journal of Genetic Counseling CEU program and developed quizzes for each article

Marketing and Communications Workgroup

- Reviewed and helped select the new NSGC website design
- Provided input on organization of the NSGC website members-only pages
- Reviewed the design and content of the new NSGC patient website
- Developed the glossary of terms for the patient website
- Reviewed graphics and messaging related to NSGC online courses and member webinar series

Membership Committee

- Completed the 2016 PSS
- Largest historical response rate (n=2,205, 54% response rate)
 - Created PSS FAQ to be able to share statistical significant data with membership in streamlined way
 - Identified salary, specialty-specific significant findings
- Administered the lapsed member survey highest year of member retention
- Reformatted Leadership Awards resulting in 30 more nominations than last year
- Collaborated with Perspectives in Genetic Counseling to create new "Diversity Dialogue" column
- •Increased visibility of Mentor Program and implemented updates to Mentor Program website which resulted in more sign-ups and matches

Public Policy Committee

- "Submitted comments on behalf of NSGC re: the National Human Genome Research Institute's RFI for Clinical Sequencing Exploratory Research (late December 2015)
- Submitted comments on behalf of NSGC re: the FDA's Premarket Carrier Screening Exemptions (late December 2015)
- •Drafted NSGC's response to the EEOC/GINA proposed rule change (Workplace wellness programs)
- Drafted NSGC's comments to HHS' proposed rule change to the Common Rule
- •Presented member webinar on gene editing: The Germline Debate: Can We, Should We, and Will We Use Genetic Engineering to Alter the DNA of our Children?"
- Published white paper in JOGC on Prenatal Testing for Adult-Onset Conditions.
- Position Statements in progress
 - cfDNA Gene Editing
 - Testing Minors for Adult-Onset Conditions
 - Regulation of Genetic Testing
 - Senetic Testing
 - Workplace Wellness (early stages)
- Drafting NSGC's comments on the FDA's Guidances on NGS (Due October 1)

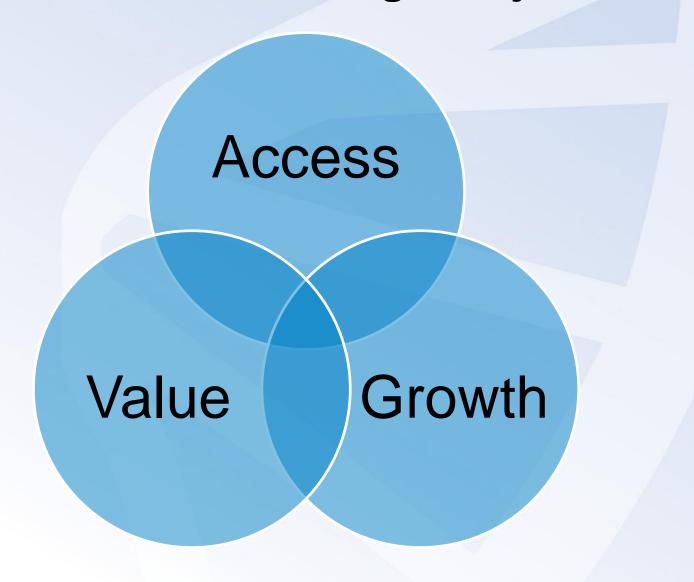
Practice Guidelines Committee

- •Implemented NSGC's evidence-based practice guideline process that includes systematic review and meets the National Guidelines Clearinghouse esteemed criteria.
- Developed Practice Resource option for documents and topics that have value for the genetic counselor and genetics community
- •In the process of working through seven member-submitted practice guideline proposals.
- Committee member invited to speak, and gave three presentations on NSGC's new Practice Guideline process, during ACMG's recent meeting



*as of September 9, 2016

NSGC's 2016 – 2018 Strategic Objectives





WORKFORCE DEVELOPMENT COLLABORATIVE EFFORTS



Workforce

- Workforce Working Group:
 - > ABGC
 - > ACGC
 - > AGCPD
 - > ASHG
 - > NSGC
- Commissioned and contributed to workforce analysis
- Results available on the NSGC website in the member section in the coming month



Workforce Analysis

- Focus on one subset of profession direct patient care CGCs
- Neither model accounts for large-scale external factors such as:
 - > Addition of significant new genetic tests, pharmaceuticals or technology
 - > Changes in reimbursement from public and private payers
 - > Regulatory changes
 - > Other factors unknown at this time



Workforce Analysis

Study assessed supply and demand for direct patient care CGCs over ten years (2016-2026):

- Scenario 1 (1 direct patient care CGC per 100K popul'n):
 - > Between 2023 and 2024 the number of direct patient care genetic counselors will satisfy a one FTE per 100,000 population demand
- Scenario 2 (1 direct patient care CGC per 75k popul'n):
 - Supply does not satisfy demand within the ten-year projection window; equilibrium would not be reached until between 2029 and 2030



Workforce Analysis – Next Steps

- Strategic Planning
 - > Incorporate ongoing activities/projects into plan
 - Convene stakeholders to discuss results, gaps in data, potential short and long-term approaches
- Continued Data Collection
 - > Revise professional status survey to sharpen questions concerning CGC practice
 - > Let NSGC know if you are collecting data
- Assessment of other segments of the workforce such as industry, education, etc...



NSGC CONSUMER OUTREACH EFFORTS



Media Relations Outcomes

Original placements to date in consumer media, national media and trade media

Total number

of media placements 234 MM reach of placements

Audience





Media Highlights

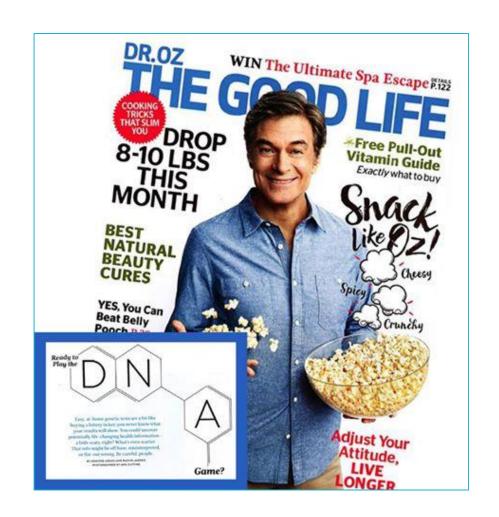
The Washington Post

Here's what men need to know about the Angelina Jolie 'breast-cancer gene'



STAT

Black women are less likely to have breasts and ovaries removed to prevent cancer





Media Highlights

GOOD HOUSEKEEPING

How a Genetic Test Changed My Life

As a teen, Lauren Holder learned that a cruel and fatal disease was stalking her family — and that she might have inherited the gene for it from her dad. Now 30, she shares her journey to discover the truth.



Should You Get Tested for the Breast Cancer Gene?





Genetic Tests May Not Change People's Unhealthy Ways

But DNA results could help spot at-risk individuals for screening and treatment, study authors say



Twitter Chats

Gynecologic Cancers/Cancer Risk



Rare Disease









Facebook Highlights









Twitter Highlights



Genetic Counselors @GeneticCouns · Apr 12

Our new #blog series "Dear Jeanie" is live! In today's post, GC Jeanie answers a question about #MTHFR: buzz.mw/b1jih | #GCchat

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Genetic Counselors @GeneticCouns - Apr 7

We're excited to announce NSGC is taking part in the @DNAday @reddit_AMA series. More info: buzz.mw/b1n1o I







Reddit Ask Me Anything



"It was a great experience to showcase our expertise in this really cool way!"

Reddit AMA outcomes at a glance:

10 million Impressions on Reddit

8,200 Pageviews on nsgc.org (60% daily increase on average)

266% Increase in impressions on Twitter posts about the AMA





Blog Highlights



Dear Jeanie: Half Sister Surprise

Posted By: Dear Jeanie Wed Aug 31st, 2016

Dear Jeanie,

My mom comes from a big Italian family and she had lots of cousins around growing up, but she and my dad moved to Texas after they got married and over the years she has lost touch with many of them. Dad died suddenly a few years ago



¿Qué esperar durante tu visita de consejería en genética?

Posted By: Ana Morales Thu May 19th, 2016

Si has recibido un referido para consejería en genética, es posible que te preguntes por qué. Es natural que no hayas oído hablar de la consejería en genética o que no sepas lo que es. Los consejeros en genét



Understanding Hereditary Cancer Syndromes and the Role of Certified Genetic Counselors

Posted By: Georgia Hurst Wed Jul 13th, 2016

After my brother was diagnosed with Lynch syndrome, I spoke with my doctor and he referred me to a certified genetic counselor. I immediately met with a genetic counselor and a geneticist and they took the time to explain the Lynch syndrome diagnosis.





Consumer Website:

www.aboutgeneticcounselors.com





NSGC GROWTH



NSGC Membership: 3,584 and Growing!





Very successful 35th AEC!

- 2,575 attendees!
- Over 400 abstracts presented
- Over 100 exhibitors
- Expanding our profession and our influence



Measuring our Growth



NSGC 2016 Professional Status Survey

Analysis of survey data from genetic counselors, which identifies new and emerging trends in the genetic counseling profession.



ACCESSIBILITY

Most genetic counselors report they can see new patients within one week, and 23 percent could see a new patient within 1-3 days.



55% of genetic counselors report that return patients can be seen within one week. Telegenetics (telephone counseling) can be available within a day for expedited cases where surgical decisions need to be made.*



The number of Certified Genetic Counselors (CGCs) continues to rise – there has been an **88 percent increase since 2006**.

There are more than 4,000 CGCs today.



CAREER PROFILE

Genetic counseling is a unique and specialized STEM (Science, Technology, Engineering and Math) career.

Nine out of 10 genetic counselors

reported that they were satisfied with their job.



\$0 \$81K \$250K

Genetic counselors are passionate about helping patients and medical professionals use genetic information to make decisions. The average salary for a full-time genetic counselor is **\$81,377**, **an 8 percent increase over 2014**. Salaries can range up to \$250,000.

The U.S. Bureau of Labor Statistics projects a growth rate of 29 percent for genetic counseling positions over the years 2014-2024.



WORK ENVIRONMENT

The largest specialty area for genetic counselors is **cancer genetics**, but genetic counselors work in a variety of areas.

SPECIALTY AREAS Prenata/ pediatric Cardiologu Neurogenetics Adult Metabolic Testing General Disease

EXPANSION IN SPECIALTIES BETWEEN 2014 AND 2016



GENETIC COUNSELORS WORK IN A VARIETY OF SETTINGS







Laboratories

Non-Profits & Government

NSGC & our profession's growth

 Providing a "home" or common base for us all based on our shared roots and values

 Acknowledge, support and celebrate the everdiversifying professional roles that genetic counselors hold



NSGC's Education Challenge

- Our challenge: meeting increasingly diverse needs
 - > NSGC Annual Conference
 - —Growth and change
 - —Highlighting research
 - —Building community
 - > New online courses
 - —shorter courses, more topics, lower price
 - > Professional Issues topics delivered through free webinars
 - > Specialty-specific webinars offered through SIGs





Nominations and Election Process & Results



NSGC Leadership: Nominations and Elections Process

Nominating Committee:

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



NSGC Leadership: Nominations and Elections Process

- Call for Nominations opened in January 2016:
 - > Members submitted 54 nominations
 - Nominations represented 22 individuals; 19 were willing to be considered
 - Nominees assessed using a combination of quantitative and qualitative measures
 - Quantitative measures assessed through application materials and CV: provide overall metrics for candidates, including years of experience, specialty area, work setting and genetic counseling experience
 - Qualitative measures assessed through interviews: provide assessment of leadership skills, strategic thinking and other personal and professional experience

NSGC Leadership: Nominations and Elections Results

- Membership identified strong pool of nominees
- Diverse slate presented (specialization, work setting, years of experience, gender)
- 38% of eligible voters participated
- Ballot approved by 94% of those voting
 - > 5% abstained from voting
 - > 1% submitted write-ins and/or did not approve the slate



Nominations: Future directions

- Continue to enhance feedback process to nominees
- Call for nominees opens in early 2017
- You can make a difference in the future of NSGC:
 - > Nominate a colleague
 - > Apply to serve on the Nominating Committee
 - > Nominate yourself!





2015 - 2016 Financial Report

Laura Conway, PhD, CGC NSGC Secretary/Treasurer



Financial Objectives in 2015

Maintain a healthy financial base



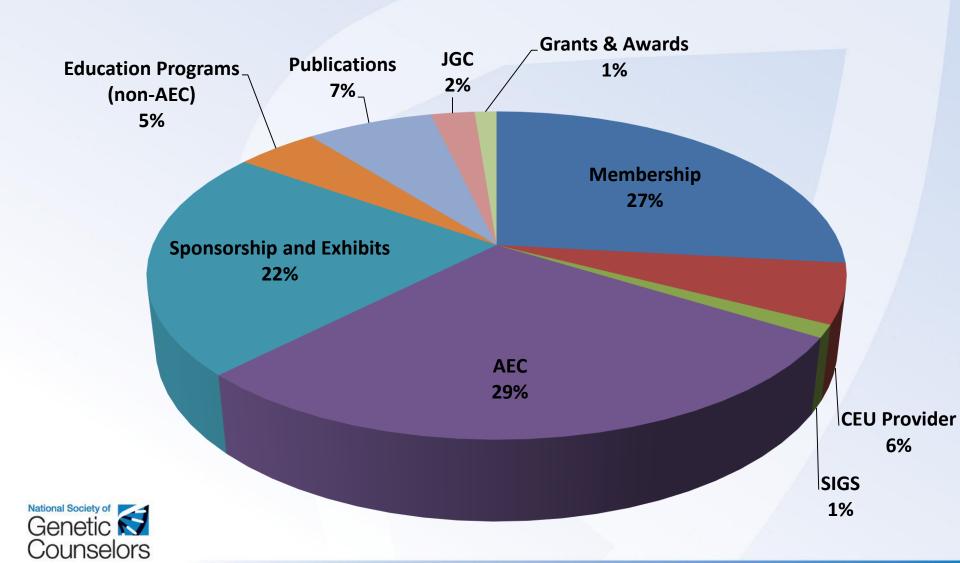
Invest in our members and the profession



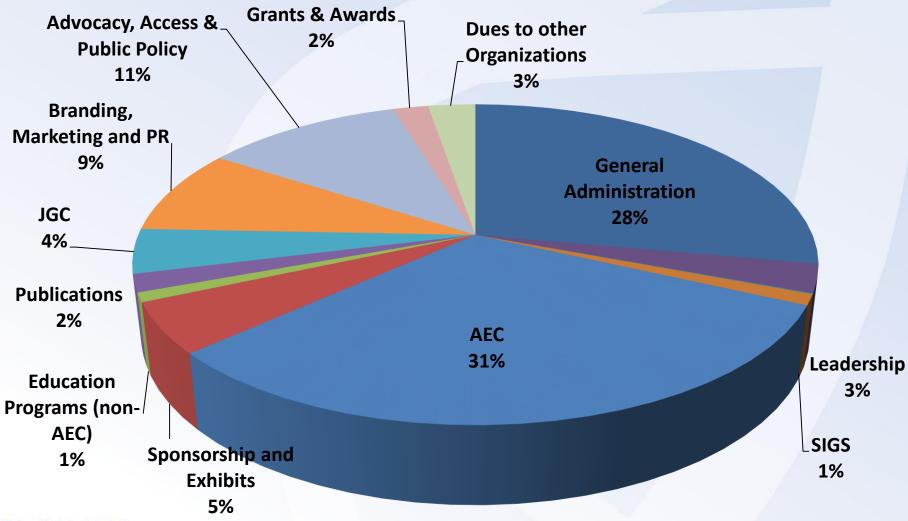
- Invest in tools and initiatives to promote awareness of genetic counselors
 - > Increased advocacy support
 - > Increased public relations support
 - > Developed new consumer education tools
 - > Funded workforce initiatives



Sources of Revenue: 2015 Year-end



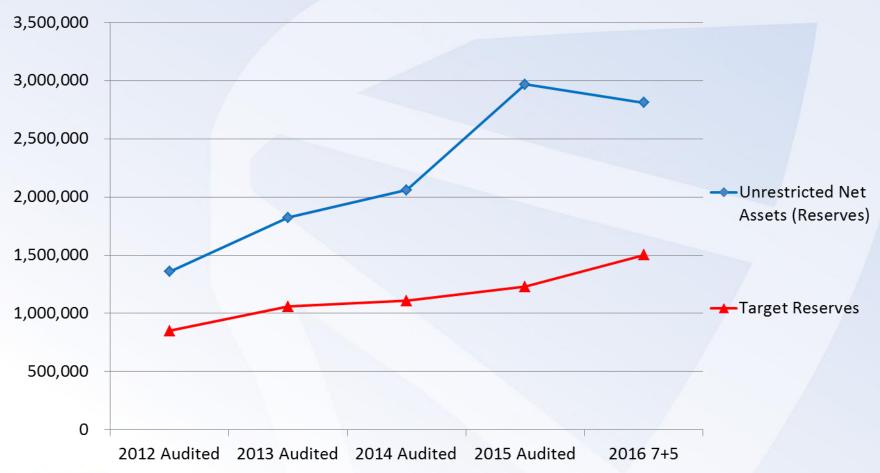
Expense Distribution: 2015 Year-end





*Note that general administration includes staff, legal fees, IT, website hosting, public relations, accounting, insurance, bank and credit card fees, office services and postage.

Resources for Strategic Investment





Cash Assets as of December 31, 2015

Cash Assets

> NSGC liquid assets: \$1,704,187

> NSGC Investments \$1,386,375

> JEMF: \$42,903

> Rollnick: \$72,431

> AHSPA \$20,139

Budgeted Revenue: \$2,321,510

Year-end Actual Revenue: \$2,741,025

Budgeted Expenses: \$2,434,714

Year-end Actual Expenses: \$2,321,333

2015 Budgeted Net Revenue: (\$113,204)

2015 Year-end Actual Net Revenue: \$419,691



Progress toward financial goals

- Ended 2015 with an overall surplus of \$423,751 after incorporating our restricted funds and any gains/losses from investments.
- Allowed us to make some significant strategic investments in 2015 and 2016 in public relations, advocacy, staff support for committees and workforce initiatives.
- We have not accessed our investment funds to cover any expenses since <u>2006</u> and we have not increased membership fees since <u>2011</u>.



Where do we stand today?

2016 Forecast

> Budgeted Revenue: \$2,764,965

> 7+5 Forecast for Revenue: \$3,017,175

> Budgeted Expenses: \$2,916,738

> 7+5 Forecast for Expenses: \$3,016,573

2016 Budgeted Net Revenue: (\$151,773)

2016 7+5 Forecast for Net Revenue: \$602



NSGC Publications Update

- >Journal of Genetic Counseling
- >Perspectives in Genetic Counseling
- >Position Statements
- >Practice Guidelines





Journal of Genetic Counseling



Bonnie LeRoy, MS, CGC Editor-in-Chief



Pat McCarthy Veach, PhD Assistant Editor





Journal of Genetic Counseling Associate Editors

Christina Palmer, PhD

Editor for COI papers



Ian MacFarlane, PhD
Stats expert extraordinaire!





Journal of Genetic Counseling Data September 15, 2015 through September 15, 2016

- Manuscript submission and processing has increased
 - > Over the above 12 months, JOGC editorial office received:
 - 269 <u>new</u> submissions; 22-23 new per month
 - We had about 14% increase in the number of new manuscripts received over the same time period last year.
- 102,010 Downloads in 2015.



Journal of Genetic Counseling highlights

- Impact Factor is currently 2.030
- 2016 AEC Abstracts: available online, to be published in Dec 2016 issue
- Special Issues
 - Professional Development guest edited by Krista Redlinger Grosse and Nancy Callanan: published in August of 2016.
 - Complex Counseling Issues guest edited by June Peters and Luba Djurdjinovic: in the final stages of preparation.
- NEW this year! Outstanding student publication award: Springer has provided funding to recognize up to 2 papers/year! The editorial board is developing a selection process for these awards. Winners will each receive a \$500 award.



Journal of Genetic Counseling

A call for papers is out for a Special Issue: *Technology and Genetic Counseling.*

If you have an appropriate manuscript, please participate in this issue.

(See website for JoGC for full description of call for papers).

If you are interested in serving as a reviewer, PLEASE contact Bonnie or Pat. Your expertise is important!

leroy001@umn.edu

veach001@umn.edu





Perspectives in Genetic Counseling



Kirsty McWalter, MS, CGC, Editor



Kristen Hanson, MS, CGC, Associate Editor



Perspectives in Genetic Counseling

Perspectives continues to be a highly valued member benefit

- Content solicitation strategy:
 - Maintains pipeline of thoughtful and interesting articles
 - Highlights a range of genetic counselor experiences
- New this year: PGC will introduced a Diversity column
 - Feedback on this new column has been very positive.
 - Alternates with the popular Global Genetics column.
- Kirsty and Kristen welcome contributions and suggestions from NSGC members!



Perspectives in Genetic Counseling Readership Data

- Open rates continue to be strong in 2016 and average 36% with click-through rates around 31%
- In comparison, open rates for associations and healthcare organizations are 11-30% and click-through rates are 6-8% (Constant Contact FAQs, August 2015)

	Total Distribution	Opens	Open Rate	Click Throughs	Click Through Rate
Q1 2016	3,375	1,227	37%	424	35%
Q2 2016	3,124	1,026	34%	312	30%
Q3 2016	3,687	1,306	37%	346	27%



Perspectives in Genetic Counseling

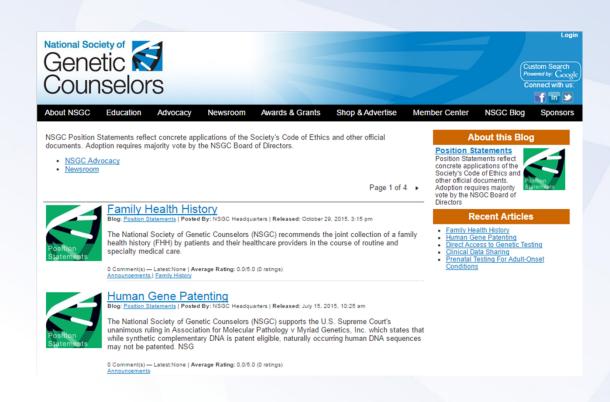
The *Perspectives* Committee continues to be a <u>very</u> dedicated group of volunteers – we thank them for their work!



Position Statements

- Public voice of NSGC on key issues
- Used with media, policymakers, payers







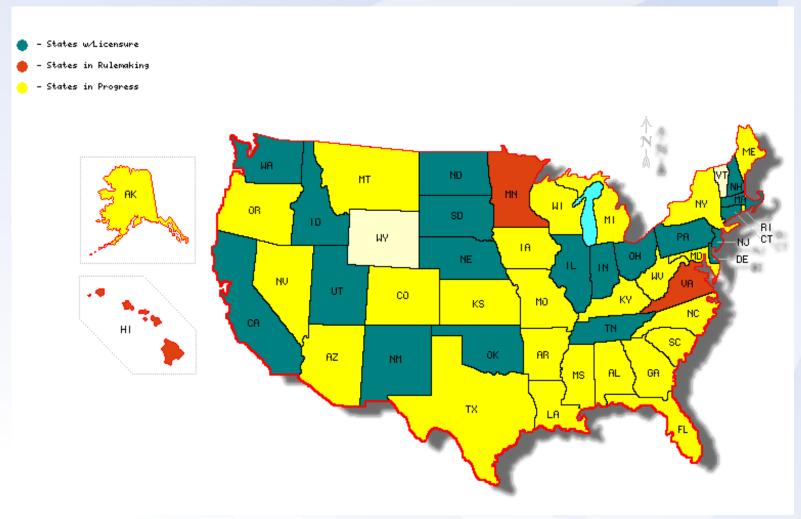
Practice Guidelines

- New rigorous process ahead of other organizations
 - > In line with National Guidelines Clearinghouse requirements
- Evidence-based best practice
- Setting standards for patient care



State Licensure







CMS Recognition



- Legislation drafted: to recognize certified genetic counselors as providers of Medicare
- Other organizations' support: secure
- Bill sponsor re-elected





Incoming 2017 NSGC Board Members



Erica Ramos
Incoming President Elect

National Society of

Genetic 🔊

Counselors



Shannan Delany Dixon Incoming Secretary/Treasurer



Curtis Coughlin, II
Incoming Director at
Large



Jason Flanagan Incoming Director at Large



Emily Edelman
Incoming Director at
Large



Sarah Noblin
Incoming Director at
Large

Question & Answer Session

Jehannine Austin, PhD, CGC 2016 NSGC President

Laura Conway, PhD, CGC

2016 NSGC Secretary/Treasurer

Meghan Carey

NSGC Executive Director



Thank you for your participation!



