State of the Society

Jehannine Austin, MSc, PhD, CGC, CCGC
NSGC President, 2016
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 Membership: 3,584 and Growing!

As of September 22, 2016

- 2012: 2,850
- 2013: 2,960
- 2014: 3,054
- 2015: 3,174
- 2016: 3,584

As of September 22, 2016
NSGC Continues to Grow…

![Graph showing growth in Unrestricted Net Assets (Reserves) and Target Reserves from 2012 to 2016.](image-url)
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 Gordon
Director at Large

Kaylene Ready
Director at Large

Sara Riordan
Director at Large

Dan Riconda
Director at Large

Meghan Carey
Executive Director

National Society of Genetic Counselors
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

Practice Guidelines Committee
Gillian Hooker, Chair
Erin Carmany, Vice Chair
## 2016 Special Interest Group (SIG) Chairs

<table>
<thead>
<tr>
<th>Category</th>
<th>Chair 1</th>
<th>Chair 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>ART/Infertility</td>
<td>Andria Besser</td>
<td>Alyssa Snider</td>
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<tr>
<td>Cardiovascular Genetics</td>
<td>Sara Fitzgerald-Butt</td>
<td>Britney Murray</td>
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<tr>
<td>Cystic Fibrosis</td>
<td>Matthew Pastore</td>
<td>Barbara Karczeski</td>
</tr>
<tr>
<td>Education</td>
<td>Shraddha Gaonkar</td>
<td>Carrie Guy</td>
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<tr>
<td>Familial Cancer Risk</td>
<td>Flora Poleshchuck</td>
<td>Victoria Raymond</td>
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<tr>
<td>Genomic Technologies</td>
<td>Kim Banks</td>
<td>Kelly Farwell Hagman</td>
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<tr>
<td>Health IT</td>
<td>Megan Frone</td>
<td>Willonie Mendonca</td>
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<tr>
<td>Industry</td>
<td>Darci Sternen</td>
<td>Kate Wilson</td>
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<tr>
<td>International</td>
<td>Yue Guan</td>
<td>Jennifer Fitzpatrick</td>
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<tr>
<td>Management &amp; Leadership</td>
<td>Leah Williams</td>
<td>Leslie Bucheit</td>
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<tr>
<td>Metabolism/LSD</td>
<td>Katharine Stoate</td>
<td>Lauren McNair Baggett</td>
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<tr>
<td>Neurogenetics</td>
<td>Amanda Bergner</td>
<td>Jennifer Roggenbuck</td>
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<td>Pediatric</td>
<td>Afifa Irani</td>
<td>Rebecca Okashah</td>
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<tr>
<td>Personalized Medicine</td>
<td>Sarah Kalia</td>
<td>Shana White</td>
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<tr>
<td>Prenatal</td>
<td>Shannon Wieloch</td>
<td>Cori Feist</td>
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<tr>
<td>Psychiatric Disorders</td>
<td>Carmela Thompson</td>
<td>Hannah White</td>
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<tr>
<td>Public Health</td>
<td>Amy Gaviglio</td>
<td>Andrea Durst</td>
</tr>
<tr>
<td>Research</td>
<td>Morgan Similuk</td>
<td>Gillian Hooker</td>
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<tr>
<td>Student / New GC</td>
<td>Kaitlin Allsbrook</td>
<td>Monica Helm</td>
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Thank you to NSGC Executive Office Staff

<table>
<thead>
<tr>
<th>Executive Director</th>
<th>Government Relations &amp; Advocacy</th>
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<tbody>
<tr>
<td>Meghan Carey</td>
<td>John Richardson</td>
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<tr>
<td><strong>Membership and Operations</strong></td>
<td><strong>Marketing and Communications</strong></td>
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<tr>
<td>Kathryn Schafer</td>
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<tr>
<td>Eunice Hahn</td>
<td>Jennifer Kasowicz</td>
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<tr>
<td><strong>Education</strong></td>
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<tr>
<td>Katie Strang</td>
<td>Hannah Jaracz</td>
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<td>Molly McGinnis</td>
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<td>Erika Bruning</td>
<td>Emily Krutz</td>
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<td><strong>Internet and Technology Services</strong></td>
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<tr>
<td>Alexia Malamis</td>
<td>Scott Beitzel</td>
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<td><strong>Events and Tradeshown</strong></td>
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<tr>
<td>Jared Dechowitz</td>
<td>Catherine Perkins</td>
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<tr>
<td><strong>Creative Services and Design</strong></td>
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<tr>
<td>Steve Biernacki</td>
<td>Olivia Diehl</td>
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<tr>
<td>Kara Cooke</td>
<td>Kate Schulze</td>
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<td>Rebecca Baker</td>
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<td></td>
<td>Jenny Worcester</td>
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</table>
Thank you to NSGC Executive Office Staff
2016
HIGHLIGHTS & ACCOMPLISHMENTS
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 JGOC on Prenatal Testing for Adult-Onset Conditions.
- Position Statements in progress
  - cfDNA Gene Editing
  - Testing Minors for Adult-Onset Conditions
  - Regulation of Genetic Testing
  - Genetic Testing
  - Workplace Wellness (early stages)
- Drafting NSGC’s comments on the FDA’s Guidelines 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
NSGC’s 2016 – 2018 Strategic Objectives

- Access
- Value
- Growth
Working with Payers

- Issues around coverage, credentialing, enrollment, adequacy of GC networks

- Access:
  - Building genetic counselor networks
  - Streamlining enrollment
CMS Recognition

- Legislation drafted: to recognize certified genetic counselors as providers of Medicare
- Other organizations’ support: secure
- Come to the Professional Issues Panel for more!
Improving access through collaboration
And the many liaisons who represent us
Workforce

- Workforce Working Group commissioned and contributed to workforce analysis

- Results will be shared at the Professional Issues Panel - FRIDAY!
NSGC’s 2016 – 2018 Strategic Objectives

Access
Value
Growth
Differentiating Ourselves

- Impact and outcomes of genetic services performed by genetic counselors

  > Reporting standards for GC intervention research
  > Quality Measures
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
Publications

- **Journal of Genetic Counseling**
  - Public face of our profession
  - Enhancing our research base

- **Perspectives**
  - Information and idea sharing
  - Professional issues
<table>
<thead>
<tr>
<th>Media Relations Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Original placements to date in consumer media, national media and trade media</td>
</tr>
<tr>
<td>51 Total number of media placements</td>
</tr>
</tbody>
</table>
Media Highlights

The Washington Post

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

CNBC

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.

Health

Should You Get Tested for the Breast Cancer Gene?

HealthDay

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

You Retweeted
Joy Larsen Haidle @JoyLarsenHaidle · Mar 9
T4 Find a Genetic Counselor near you at FindaGeneticCounselor.org #gyncsm @GeneticCouns

You Retweeted
Joy Larsen Haidle @JoyLarsenHaidle · Mar 9
T3 A genetic counselor can help determine the best test based on your personal and family history. #gyncsm @GeneticCouns

You Retweeted
Mary Freivogel @MaryFreivogel · Mar 9
T1: GC helps patients make informed decisions to be proactive with their health and the health of their relatives. #gyncsm

Rare Disease

In reply to Dr. Richard Besser
Jehannine Austin @J9_Austin · Mar 1
Yes! There is a tool to locate a genetic counselor specialist in your area: findageneticcounselor.com @abcDrBChat #abcDRBchat #GCchat

Genetic Counselors @GeneticCouns · Mar 1
T4: NSGC Expert @ERamosSD offers suggestions for connecting with families affected by #rarediseases buzz.mw/badjo_1 #abcdrbchat
Facebook Highlights

The Value of Genetic Counselors
Growing field advises patients in many areas, like assessing risk related to a family history of cancer.

64,773 people reached
397 shares

Dear Jeanie:
What Should I Know About the Gene MTHFR?

18,852 people reached
140 shares
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_I #GCchat

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_l

Genetic Counselors @GeneticCouns · May 24
Congrats to all recent genetic counseling graduates! Welcome to the profession. #GCchat

National DNA DAY AMA SERIES
“Ask Me Anything” (AMA) Series
On the reddit science community forum “/r/Science”
Hosted by ASHG, pgEd, and NHGRI
Featuring prominent geneticists from a range of research areas.
April 18 – 22, April 25
Reddit Ask Me Anything

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

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

---

National Society of Genetic Counselors
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.
Your Communications Team

Wendi Koziol  
SENIOR VICE PRESIDENT

Jennie Szink  
SENIOR ACCOUNT EXECUTIVE

Rachel Bowen  
ASSISTANT ACCOUNT EXECUTIVE
Consumer Website

[Image of the Consumer Website for Genetic Counselors]
NSGC’s 2016 – 2018 Strategic Objectives

Access

Value

Growth
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.

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.

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.
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.

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.

WORK ENVIRONMENT

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

SPECIALTY AREAS

- Prenatal
- Pediatric
- Neurogenetics
- Metabolic
- Disease
- Adult
- Cardiology
- Testing
- General

EXPANSION IN SPECIALTIES BETWEEN 2014 AND 2016

- Cancer: 48%
- Prenatal: 43%
- Pediatrics: 25%
- Cardiology: 29%
- Adult: 35%
- Testing: 12%
- General: 5%

GENETIC COUNSELORS WORK IN A VARIETY OF SETTINGS

- Universities
- Hospitals
- 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 ever-diversifying professional roles that genetic counselors hold
Continuing Education

- Our challenge: increasingly diverse needs
- Conference
  > Growth and change
  > Highlighting research
  > Building community
- New online courses (shorter courses, more topics)
- Professional Issues topics delivered through free webinars
2016-2017
FUTURE PLANS
Future plans

- **Access:**
  - Federal bill introduction
  - Working with payers

- **Value**
  - Promotion/expansion of new website
  - Publishing practice guidelines and position statements
  - Finding new ways to meet the needs of our diversifying membership (e.g. enhancing mentorship program)

- **Growth**
  - Acting on the findings of the workforce study
Wednesday, November 9, 2016
10:00am - 11:00am Pacific
11:00am – 12:00pm Mountain
12:00pm – 1:00pm Central
1:00pm - 2:00pm Eastern

Contact nsgc@nsgc.org to register and receive your webinar access link
Incoming 2017 NSGC Board Members

Erica Ramos
Incoming President Elect

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
See you in Columbus!
THANK YOU!