

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.

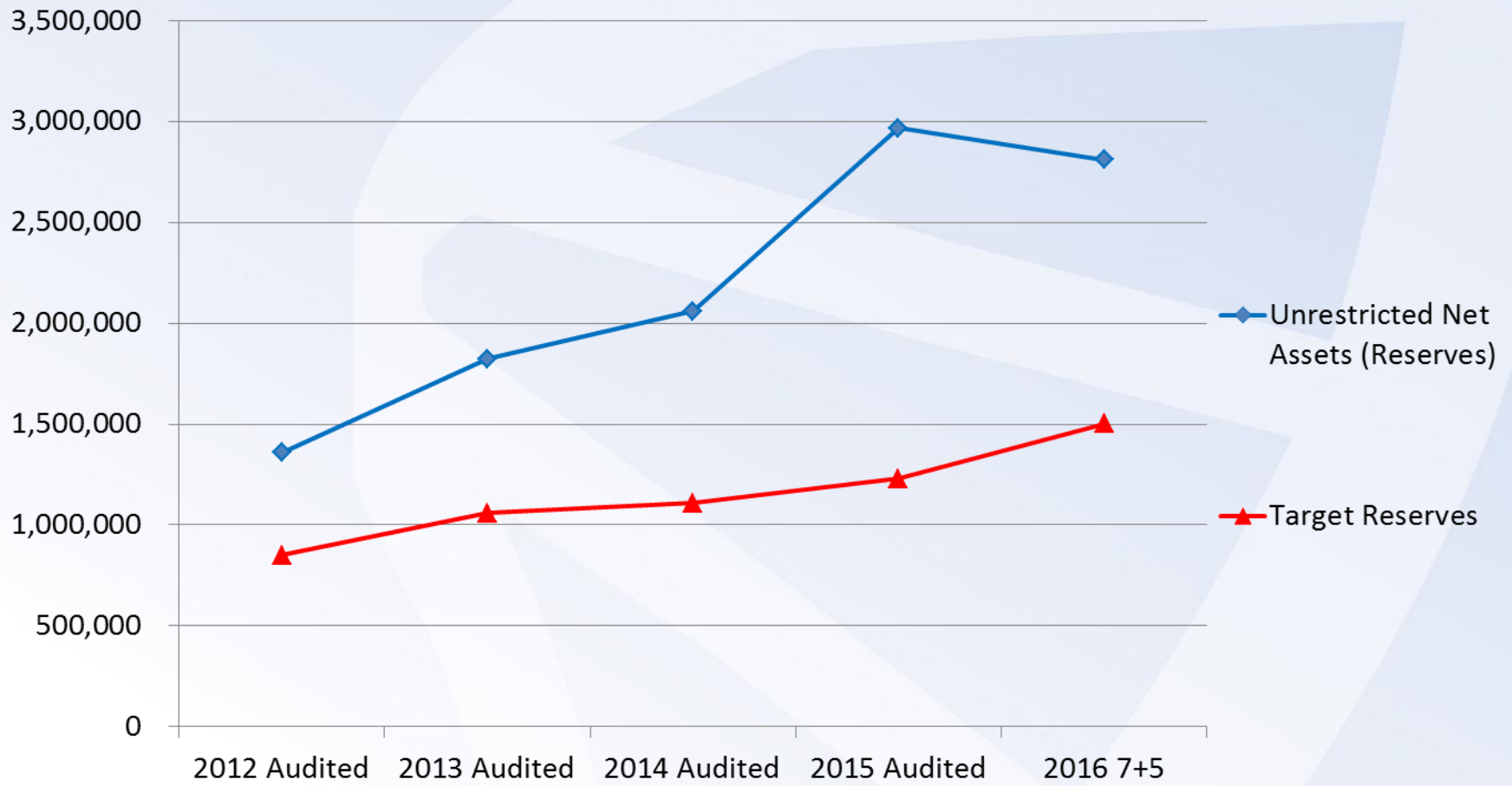
■ Vision

- Integrating genetics and genomics to improve health for all.

NSGC Membership: 3,584 and Growing!



NSGC Continues to Grow...



2016 Board of Directors



Jehannine Austin
President



Mary Freivogel
President Elect



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Monica Marvin
Secretary/Treasurer Elect



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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

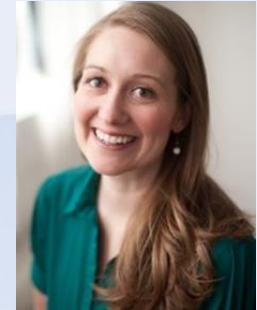
Dena Goldberg, Chair



2016 Committee Chairs and Vice Chairs

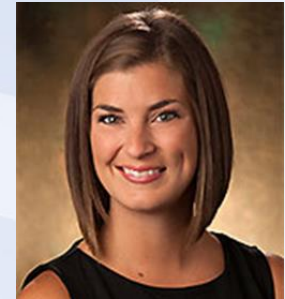
Membership Committee

Shar Munshi, Chair
Katie Spoonamore, Vice Chair



Public Policy Committee

Andy Faucett, Chair
Blair Stevens, Vice Chair



Practice Guidelines Committee

Gillian Hooker, Chair
Erin Carmany, Vice Chair



2016 Special Interest Group (SIG) Chairs

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

Thank you to NSGC Executive Office Staff

Executive Director	Government Relations & Advocacy
Meghan Carey	John Richardson
Membership and Operations	Molly Giammarco
Kathryn Schafer	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
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Creative Services and Design	Ricci McDonald
Steve Biernacki	Olivia Diehl
Kara Cooke	Kate Schulze
	Rebecca Baker
	Jenny Worcester

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

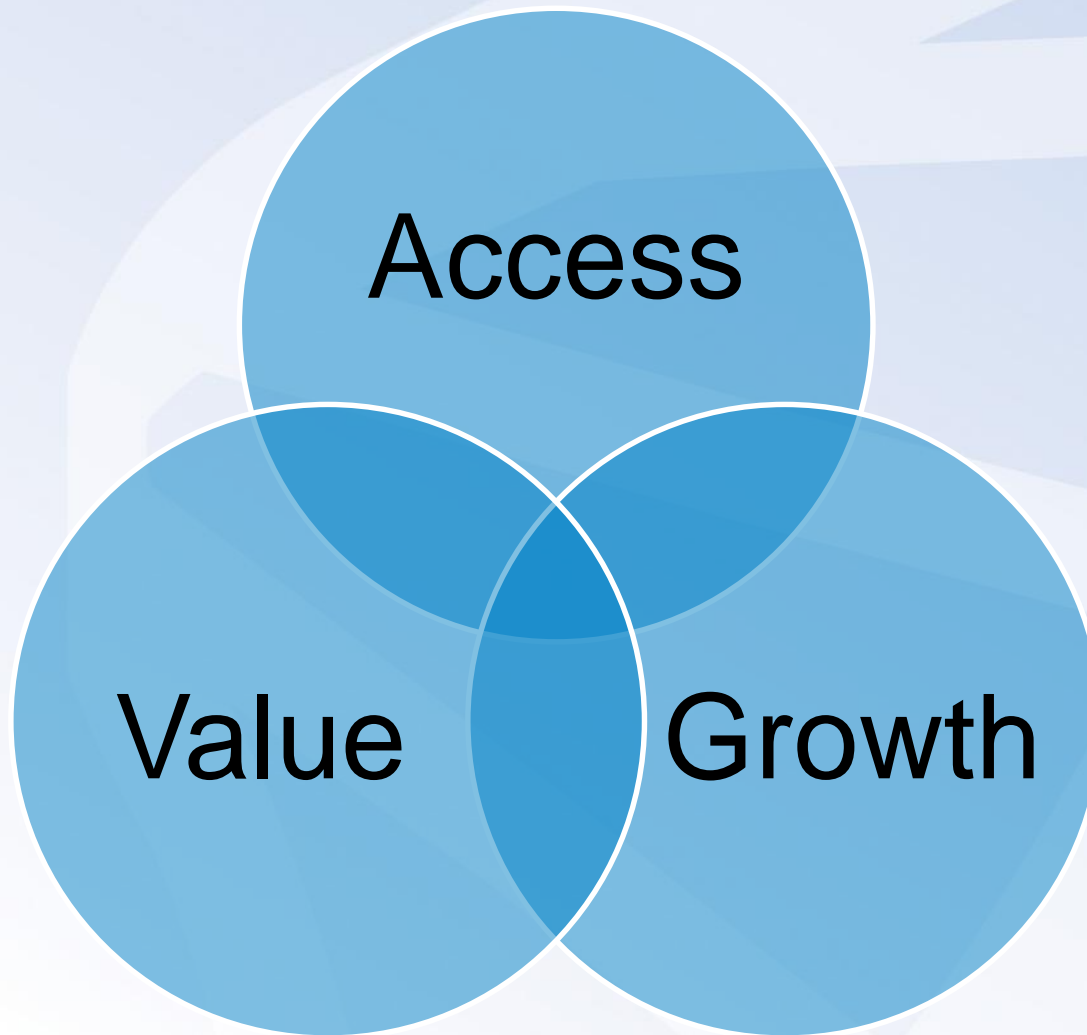
Public Policy Committee

- 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 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
 - > Genetic Testing
 - > Workplace Wellness (early stages)
- Drafting NSGC's comments on the FDA's Guidances on NGS (Due October 1)

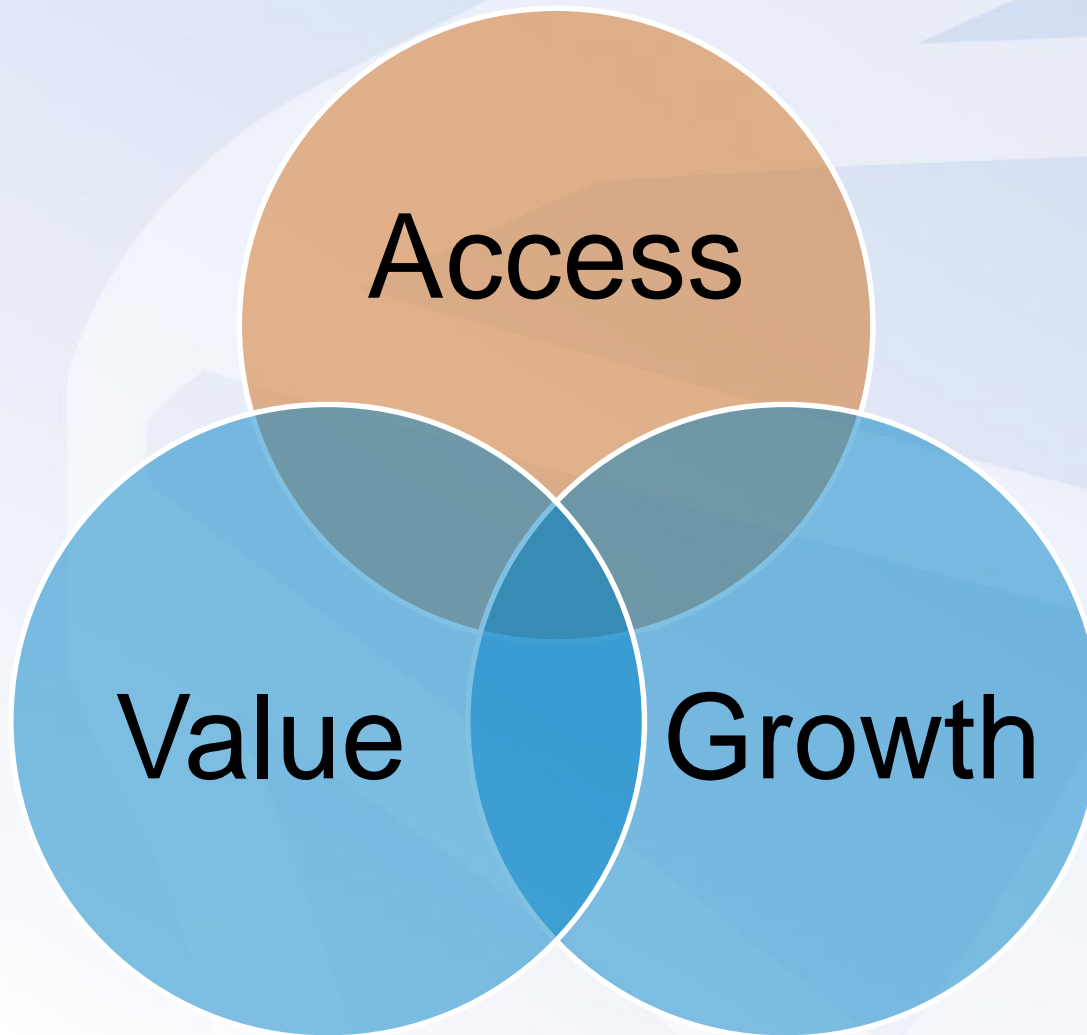
Practice Guidelines Committee

- 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

NSGC's 2016 – 2018 Strategic Objectives

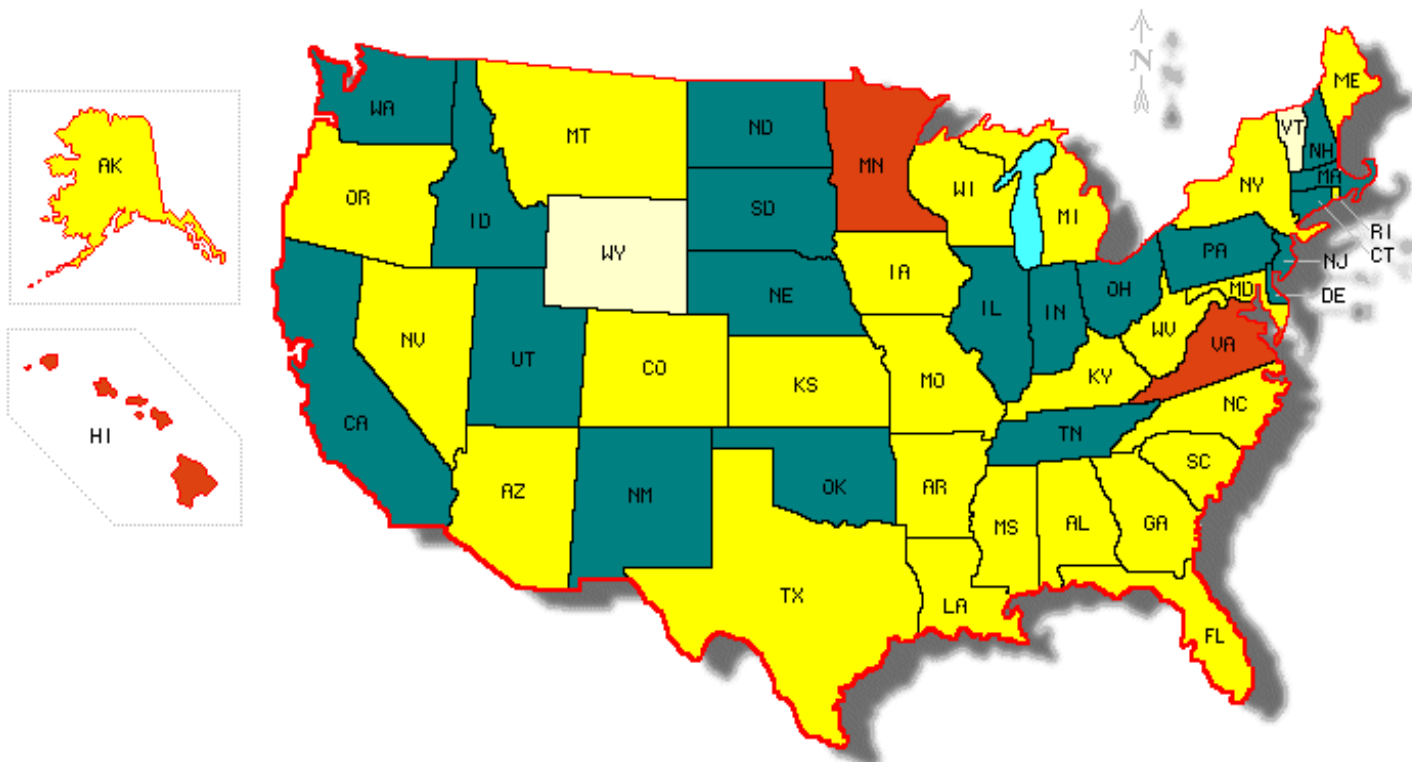


NSGC's 2016 – 2018 Strategic Objectives



State Licensure

- - States w/Licensure
- - States in Rulemaking
- - States in Progress



Working with Payers

- Issues around coverage, credentialing, enrollment, adequacy of GC networks
- Access:
 - > Building genetic counselor networks
 - > Streamlining enrollment

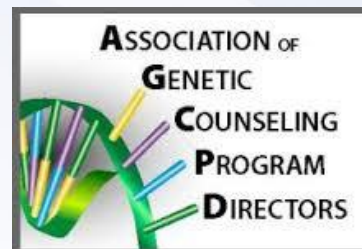
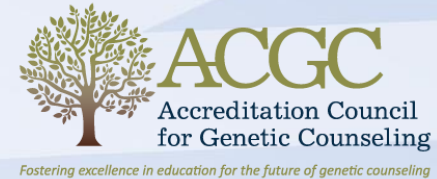


CMS Recognition

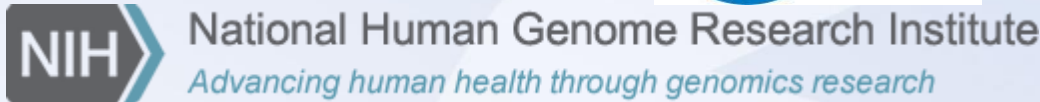


- Legislation drafted: to recognize certified genetic counselors as providers of Medicare
- Other organizations' support: secure
- Come to the Professional Issues Panel for more!

Improving access through collaboration



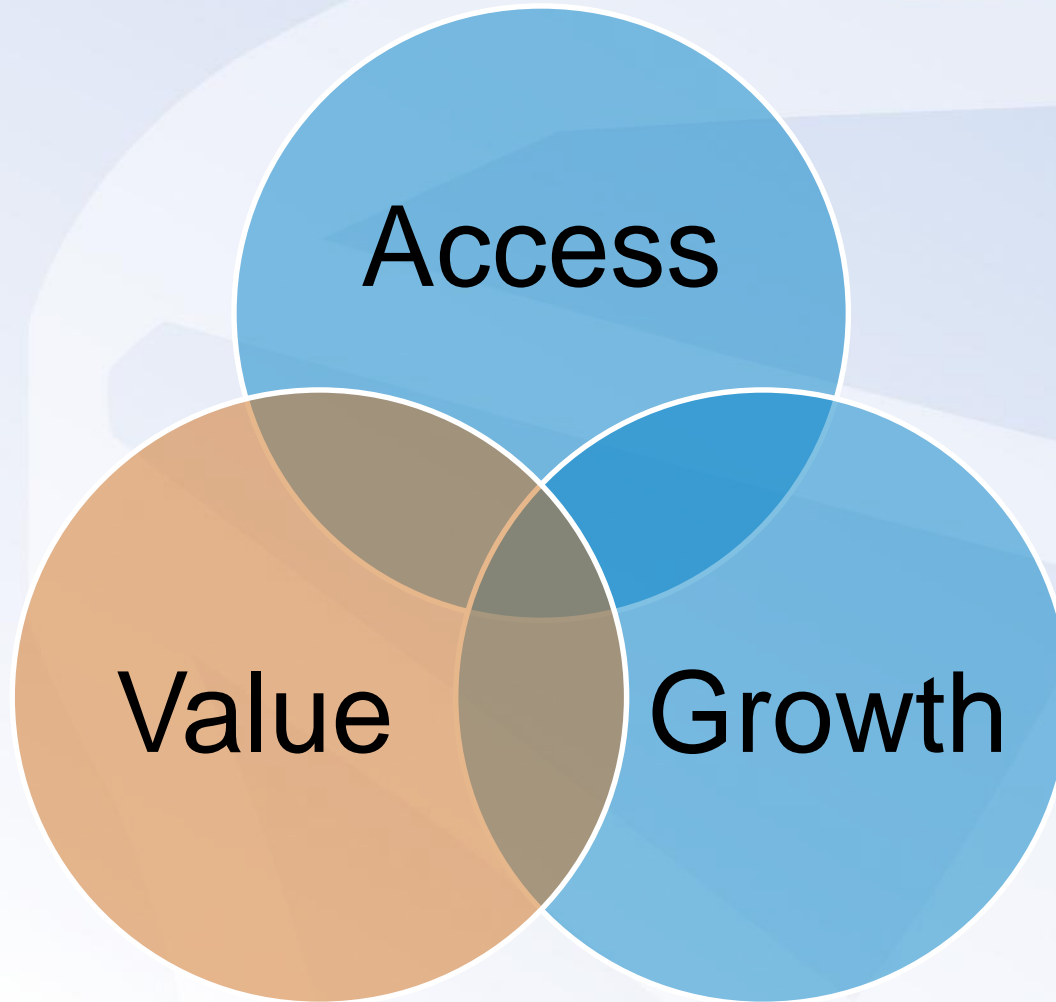
And the many liaisons who represent us



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



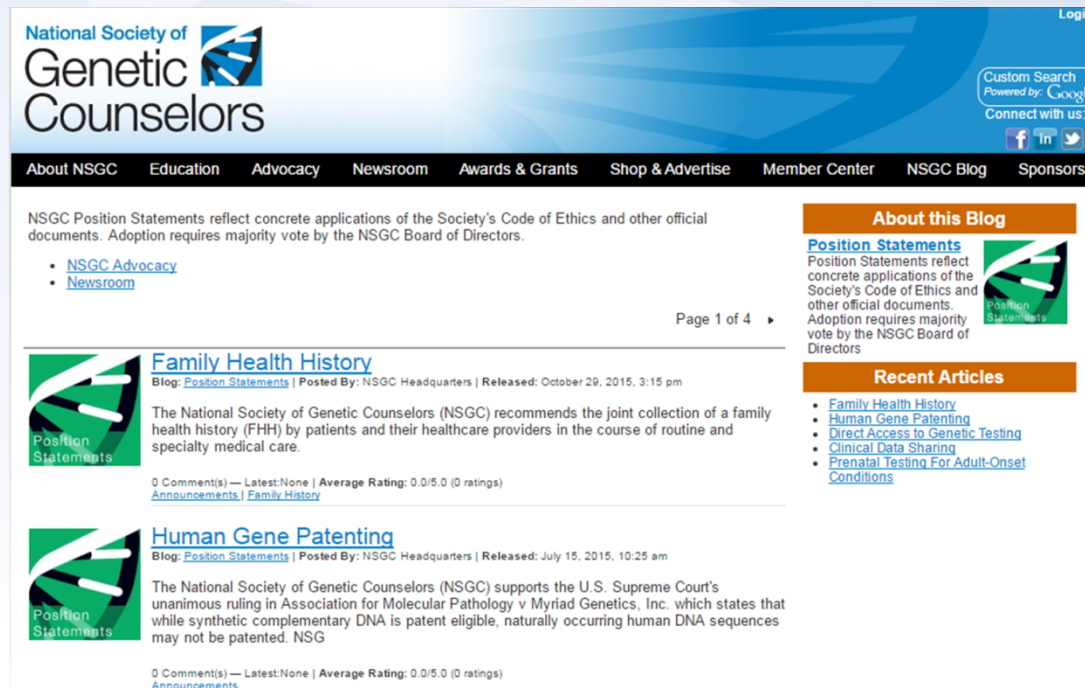
Differentiating Ourselves

- 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



The screenshot shows the NSGC website's Position Statements blog page. The header includes the NSGC logo, a search bar, and social media links. The main content area features a navigation menu and a list of position statements. The first statement is titled "Family Health History" and the second is "Human Gene Patenting". Both statements include a brief description, a date, and a rating.

National Society of Genetic Counselors

About NSGC Education Advocacy Newsroom Awards & Grants Shop & Advertise Member Center NSGC Blog Sponsors

NSGC Position Statements reflect concrete applications of the Society's Code of Ethics and other official documents. Adoption requires majority vote by the NSGC Board of Directors.

- [NSGC Advocacy](#)
- [Newsroom](#)

Page 1 of 4 ▶

Family Health History
Blog: [Position Statements](#) | Posted By: NSGC Headquarters | Released: October 29, 2015, 3:15 pm

The National Society of Genetic Counselors (NSGC) recommends the joint collection of a family health history (FHH) by patients and their healthcare providers in the course of routine and specialty medical care.

0 Comment(s) — Latest: None | Average Rating: 0.0/5.0 (0 ratings)
[Announcements](#) | [Family History](#)

Human Gene Patenting
Blog: [Position Statements](#) | Posted By: NSGC Headquarters | Released: July 15, 2015, 10:25 am

The National Society of Genetic Counselors (NSGC) supports the U.S. Supreme Court's unanimous ruling in *Association for Molecular Pathology v. Myriad Genetics, Inc.* which states that while synthetic complementary DNA is patent eligible, naturally occurring human DNA sequences may not be patented. NSG

0 Comment(s) — Latest: None | Average Rating: 0.0/5.0 (0 ratings)
[Announcements](#)

About this Blog
[Position Statements](#)
Position Statements reflect concrete applications of the Society's Code of Ethics and other official documents. Adoption requires majority vote by the NSGC Board of Directors.

Recent Articles

- [Family Health History](#)
- [Human Gene Patenting](#)
- [Direct Access to Genetic Testing](#)
- [Clinical Data Sharing](#)
- [Prenatal Testing For Adult-Onset Conditions](#)

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





NSGC Communications Report

January – September 2016



**Public
Communications
Inc.**

Media Relations Outcomes

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

51

Total number
of media
placements

234 MM

Audience
reach of
placements

Media Highlights

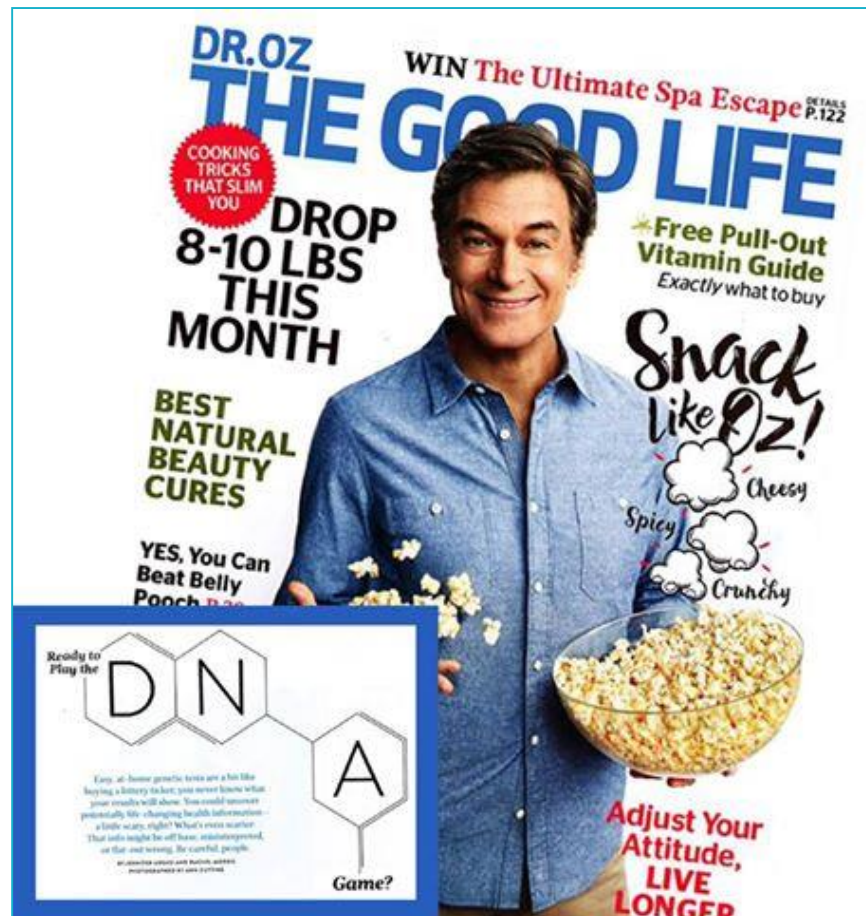
The Washington Post

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.

Health

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

You Retweeted

 **Joy Larsen Haidle** @JoyLarsenHaidle · Mar 9
T4 Find a Genetic Counselor near you at FindaGeneticCounselor.org
[#gynscsm](#) @GeneticCouns

10 retweets, 7 likes

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. [#gynscsm](#) @GeneticCouns

11 retweets, 7 likes


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. [#gynscsm](#)

9 retweets, 10 likes

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](#)

8 retweets, 8 likes

[View conversation](#)


 **Genetic Counselors** @GeneticCouns · Mar 1
T4: NSGC Expert @ERamosSD offers suggestions for connecting with families affected by [#rare diseases](#) buzz.mw/badjo_l [#abcdrbchat](#)

2 retweets, 3 likes

Facebook Highlights

National Society of Genetic Counselors
Published by Rachel Bowen [?] · April 1 · 🌐

U.S. News and World Report published a wonderful piece written by a clinical geneticist about the value of genetic counselors and how they are "unsung heroes" when it comes to helping patients understand genetic tests and results. <http://bit.ly/1M6i8DI>



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

HEALTH.USNEWS.COM

64,773 people reached Boost Post

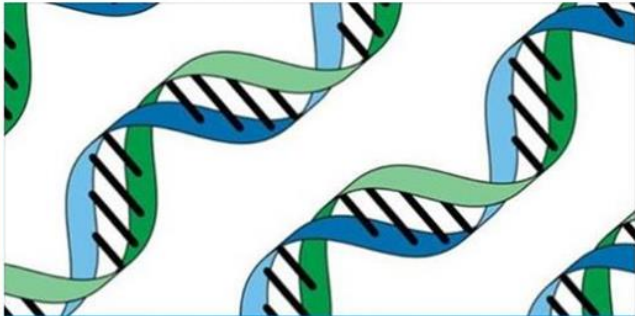
👍 Like 💬 Comment ➦ Share

👍 🗣️ Tamra Gibby Hill, Ege Sarikaya and 426 others Top Comments ▾

397 shares

National Society of Genetic Counselors
Published by Rachel Bowen [?] · April 13 · 🌐

Our new blog series "Dear Jeanie" is live! The series uses fictional patient questions written by an NSGC expert based on her experiences as a genetic counselor. In the first post of the series, genetic counselor Jeanie answers a question about a mutation in MTHFR. <http://bit.ly/1WqHP4v>



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

18,852 people reached Boost Post

👍 Like 💬 Comment ➦ Share

👍 🗣️ Jenn Sloan, Carolyn Piccinin and 266 others Top Comments ▾

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_l #GCchat

14 17

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



10 38

 **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

National
DNA DAY AMA SERIES

"Ask Me Anything" (AMA) Series
On the reddit science community forum
"[r/Science](https://www.reddit.com/r/science/)"



Hosted by **ASHG**, **pgEd**, and **NHGRI**
Featuring prominent geneticists from a range of research areas.

April 18 - 22, April 25



14 14

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.

Your Communications Team



Wendi Koziol

SENIOR VICE PRESIDENT



Jennie Szink

SENIOR ACCOUNT EXECUTIVE



Rachel Bowen

ASSISTANT ACCOUNT EXECUTIVE

Consumer Website

Find a Genetic Counselor | Search this site

Brought to you by National Society of Genetic Counselors

Genetic Counselors

Personalized Care For Your Genetic Health

ABOUT GENETIC COUNSELORS GENETIC COUNSELING GENETIC TESTING GENETIC CONDITIONS FAQS + RESOURCES

What is a Genetic Counselor?
TELL ME MORE

How Do I Find a Genetic Counselor?
SEARCH HERE

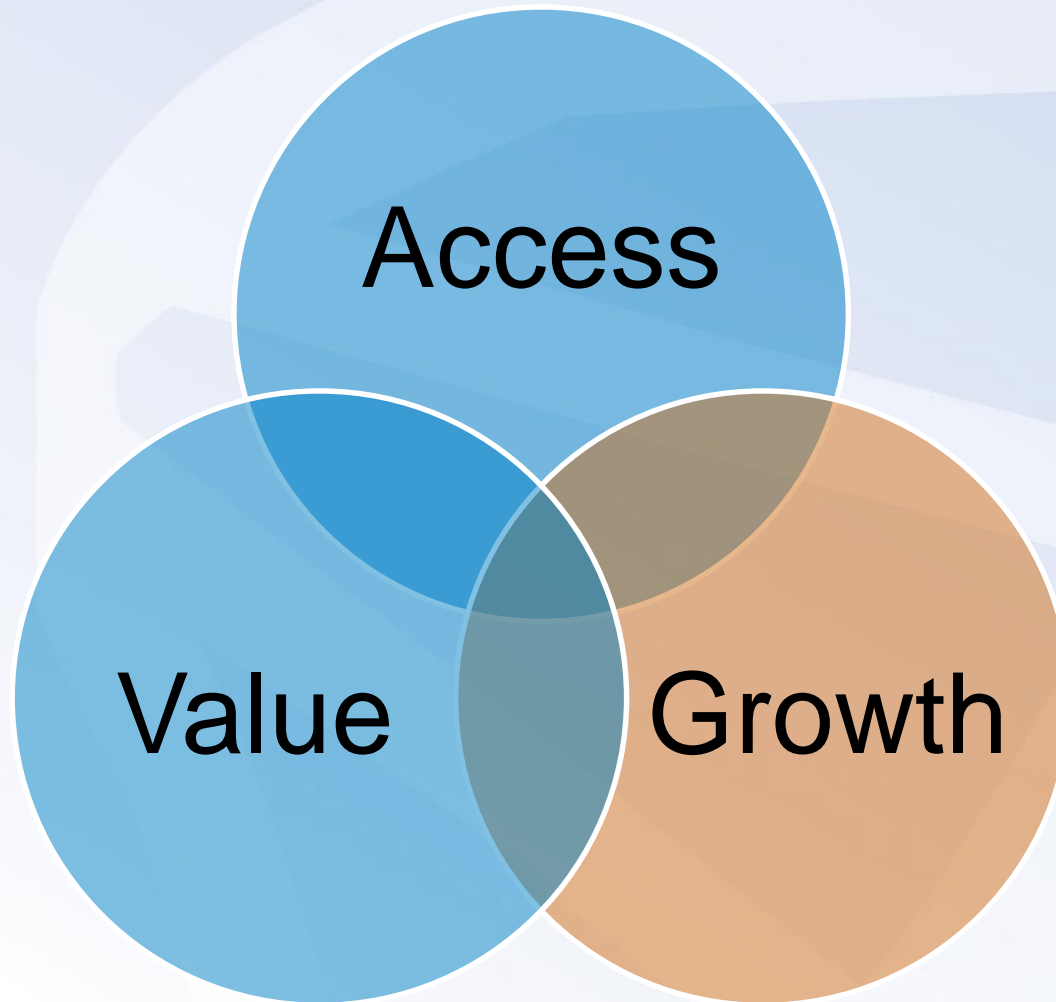
How Can a Genetic Counselor Help Me?
WE CAN HELP YOU

How Much Does Genetic Counseling Cost?
LEARN MORE

What Should I Expect when Seeing a Genetic Counselor?
LET US TELL YOU

Have More Questions about Genetic Counseling?
FAQS + RESOURCES

NSGC's 2016 – 2018 Strategic Objectives



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.

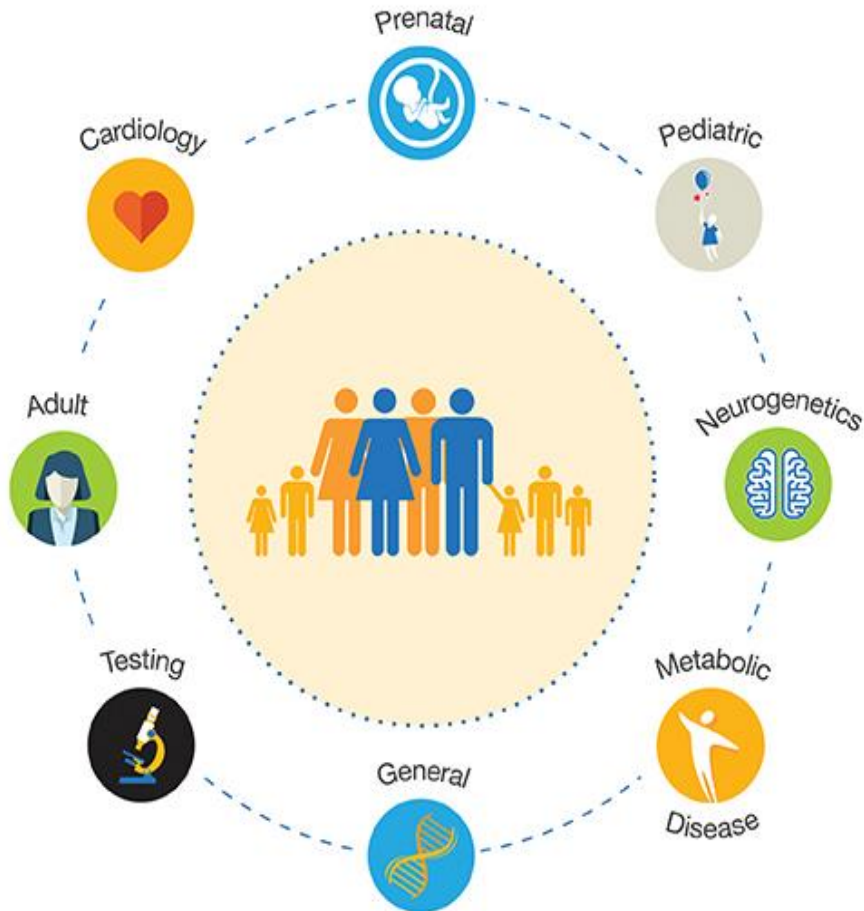
The U.S. Bureau of Labor Statistics projects a **growth rate of 29 percent** for genetic counseling positions over the years 2014-2024.



WORK ENVIRONMENT

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

SPECIALTY AREAS



EXPANSION IN SPECIALTIES BETWEEN 2014 AND 2016



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

SAVE THE DATE FOR NSGC's ONLINE BUSINESS MEETING

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!

National Society of
Genetic
Counselors

36th Annual Education Conference

September 13-16, 2017

Greater Columbus Convention Center
Columbus, OH

RESEARCH PSYCHOSOCIAL
PRENATAL COUNSELING/ULTRASOUND ANOMALIES POLICY DEVELOPMENT/
ADVOCACY TECHNOLOGY
PEDIATRICS EDUCATION
ACCESS & SERVICE DELIVERY PROFESSIONAL ISSUES
HEALTHCARE CONSULTING COUNSELING NEURO
FETAL INTERVENTION & THERAPY GENETIC & GENOMIC TESTING
FAMILIAL CANCER RISK COUNSELING GENETIC & GENOMIC TESTING
PSYCHIATRIC DISORDERS ASSISTED REPRODUCTIVE TECHNOLOGIES/INFERTILITY
PUBLIC HEALTH GENOMICS DIAGNOSTIC LABORATORIES METABOLIC
HEMATOLOGY GENETICS
CARDIOVASCULAR GENETICS PERINATAL PHARMACEUTICAL INDUSTRY PERSONALIZED
MARKETING/PRODUCT DEVELOPMENT PSYCHO SOCIAL SERVICE DELIVERY MANAGEMENT CASE MEDICINE
CLIENT-CENTERED COMPETENCIES PEDIGREES MODELS
INFORMATION ACTIVE DECISION-
LISTENING MAKING
CONTRACTING
DISEASE
RISK
MEDICAL
SKILLS
FAMILY
HISTORY

1971 ACGC
SARAH LAWRENCE COLLEGE HUMAN GENETICS
PUBLIC POLICY
1979 NATIONAL SOCIETY OF GENETIC COUNSELORS
FOSTER EDUCATION
1987 PERSPECTIVES
EDUCATION
TRAINING PROGRAMS JEMF ABGC RESEARCH ACCPD
GENOMICS TRAINING ACCPD EDUCATION

• GROWING OUR PROFESSION TO NEW HEIGHTS •

THANK YOU !