

# State of the Society

**Jennifer Hoskovec, MS, CGC  
NSGC President, 2014**

# Our Mission and Vision

## ■ Mission

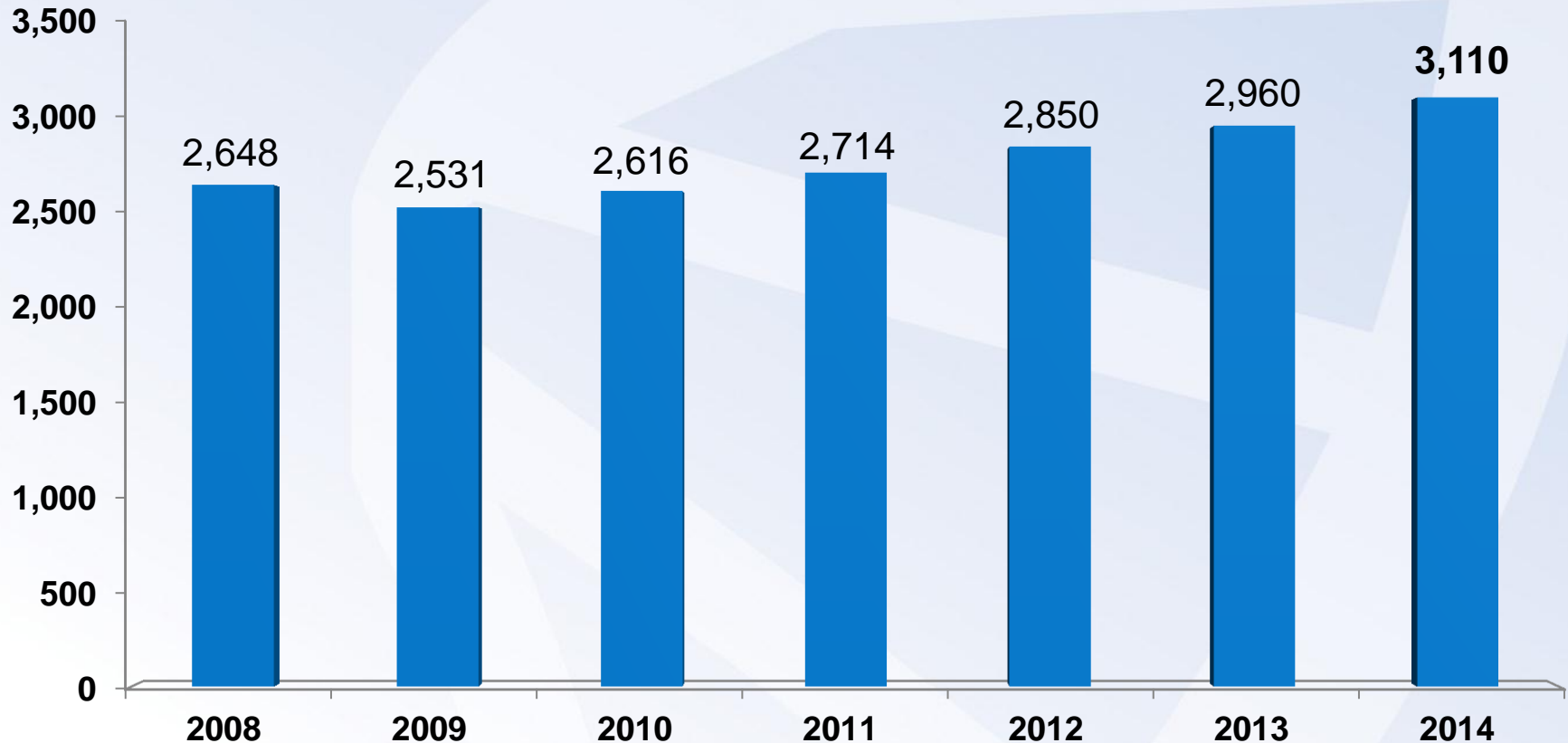
- The National Society of Genetic Counselors advances the various roles of genetic counselors in health care by fostering education, research, and public policy to ensure the availability of quality genetic services.

## ■ Vision

- Integrating genetics and genomics to improve health for all

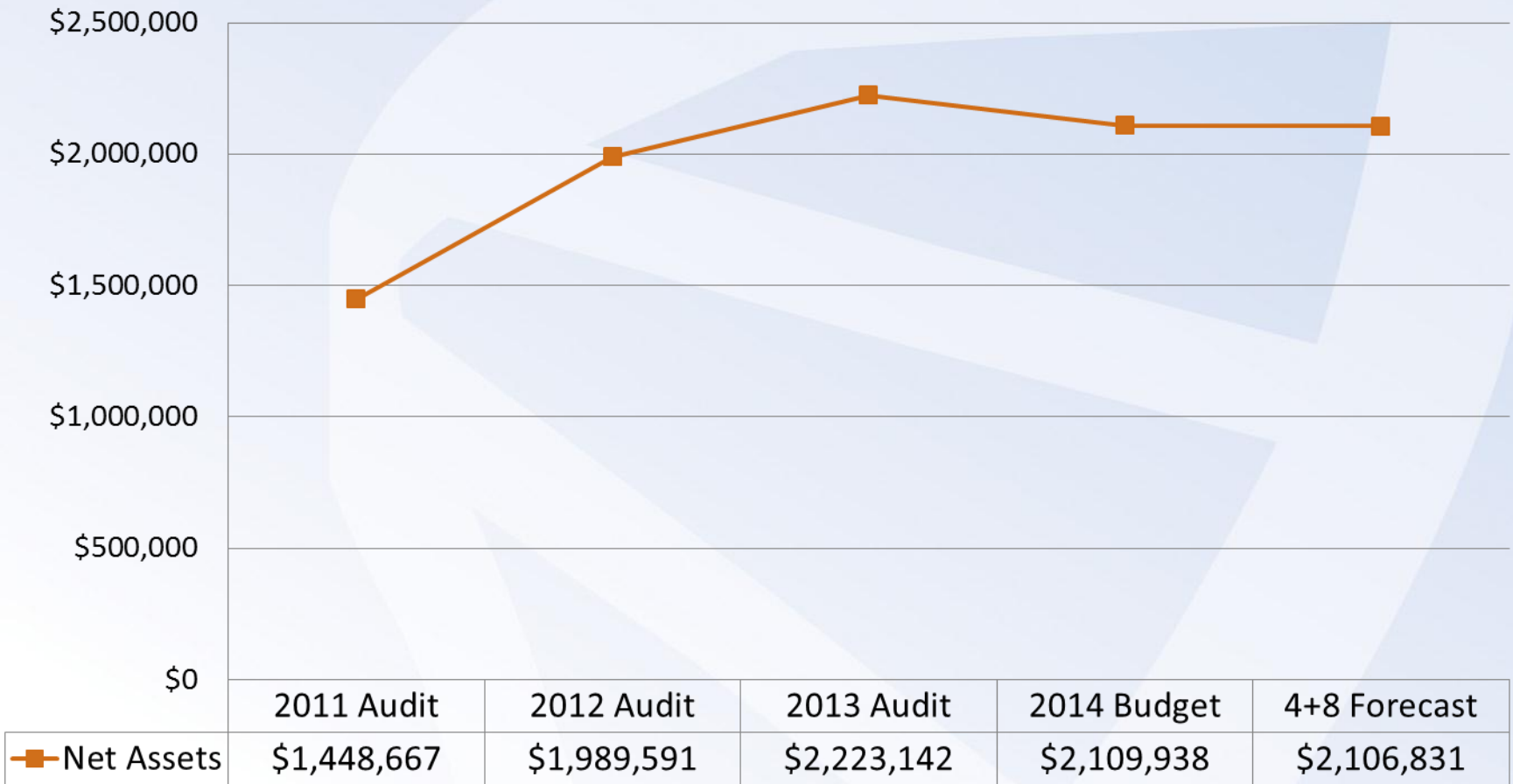
# NSGC Membership: 3,110 and Growing!

## NSGC Membership 2008 - 2014



# NSGC Continues to Grow...

## Net Asset Trend



# 2014 Board of Directors

## **President**

Jen Hoskovec

## **President Elect**

Joy Larsen Haidle

## **Immediate Past President**

Becky Nagy

## **Secretary/Treasurer**

Bronson Riley

## **Secretary/Treasurer Elect**

Sandra Darilek

## **Directors at Large**

Carrie Atzinger

Samantha Baxter

Amy Cronister

Erica Ramos

Leigha Senter

Quinn Stein

Amy Sturm

## **Executive Director**

Meghan Carey

# 2014 Committee Chairs & Vice Chairs

## **Marketing & Communications Workgroup**

Shar Munshi, Chair

## **Education Committee**

Renee Chard, Chair

Heather MacLeod, Vice Chair

## **Access and Service Delivery Committee**

Heather Zierhut, Chair

Kate Wilson, Vice Chair

## **Membership Committee**

Kaylene Ready, Chair

Holly Zimmerman, Vice Chair

## **Public Policy Committee**

Carrie Blout, Chair

Shanna Gustafson, Vice Chair

## **Practice Guidelines Committee**

Christina Palmer, Chair

Deepti Babu, Vice Chair

# 2014 Special Interest Group (SIG) Chairs

<b>ART/Infertility</b>	Lauren Isley	Andria Besser
<b>Cardiovascular Genetics</b>	Colleen Caleshu	Sara Cherny
<b>Cystic Fibrosis</b>	Renee Temme	Karen Siklosi Raraigh
<b>Education</b>	Shraddha Gaonkar	Kate Shane-Carson
<b>Familial Cancer Risk</b>	Sara Knapke	Sara Pirzadeh-Miller
<b>Health IT</b>	Heather Fecteau	Megan Doerr
<b>Industry</b>	Kathleen O'Connor	Lily Servais
<b>International</b>	Rawan Awwad	Angela Arnold
<b>Metabolism/LSD</b>	Jennifer Sullivan	Amy White
<b>Neurogenetics</b>	Lauren Hache	Shawna Feely
<b>Pediatric &amp; Clinical Genetics</b>	Marianna Raia (Horz)	Kimberly Lewis
<b>Personalized Medicine</b>	Liz Varga	Megan Grove
<b>Prenatal</b>	Blair Stevens	Andrea Harbison
<b>Psychiatric Disorders</b>	Heather Andrighetti	Edith Kolozsi
<b>Public Health</b>	Kate Reed	Amy Gaviglio
<b>Research</b>	Sharon Aufox	Gillian Hooker
<b>Student / New GC</b>	Katie Bergstrom	Elysia Pagano Davis

# NSGC's 2014 - 2016 Strategic Objectives



- Payer recognition of GCs
  - Cost effective
  - Cost saving
- Reimbursement
- Licensure
- Coalition-building
- Promoting value to other Providers

- GC Value
  - Evidence-based research and recommendations
  - Marketing
- Member Value
  - Education
  - Professional development

- Workforce growth
- Specialization
- Technology to build capacity and efficiency
- Collaborate with ABGC, ACGC & AGCPD
- Collaborate with other provider groups



# How do we improve access to genetic counselors and services?

## Access

- Reimbursement / Payer recognition
  - Federal
  - Third party
- Licensure
- Demonstrating and promoting value
  - Cost effective
  - Cost saving

## Access and Service Delivery Committee

- Payer and coding sub-committees
- State licensure sub-committee
- GR staff

## Public Policy Committee

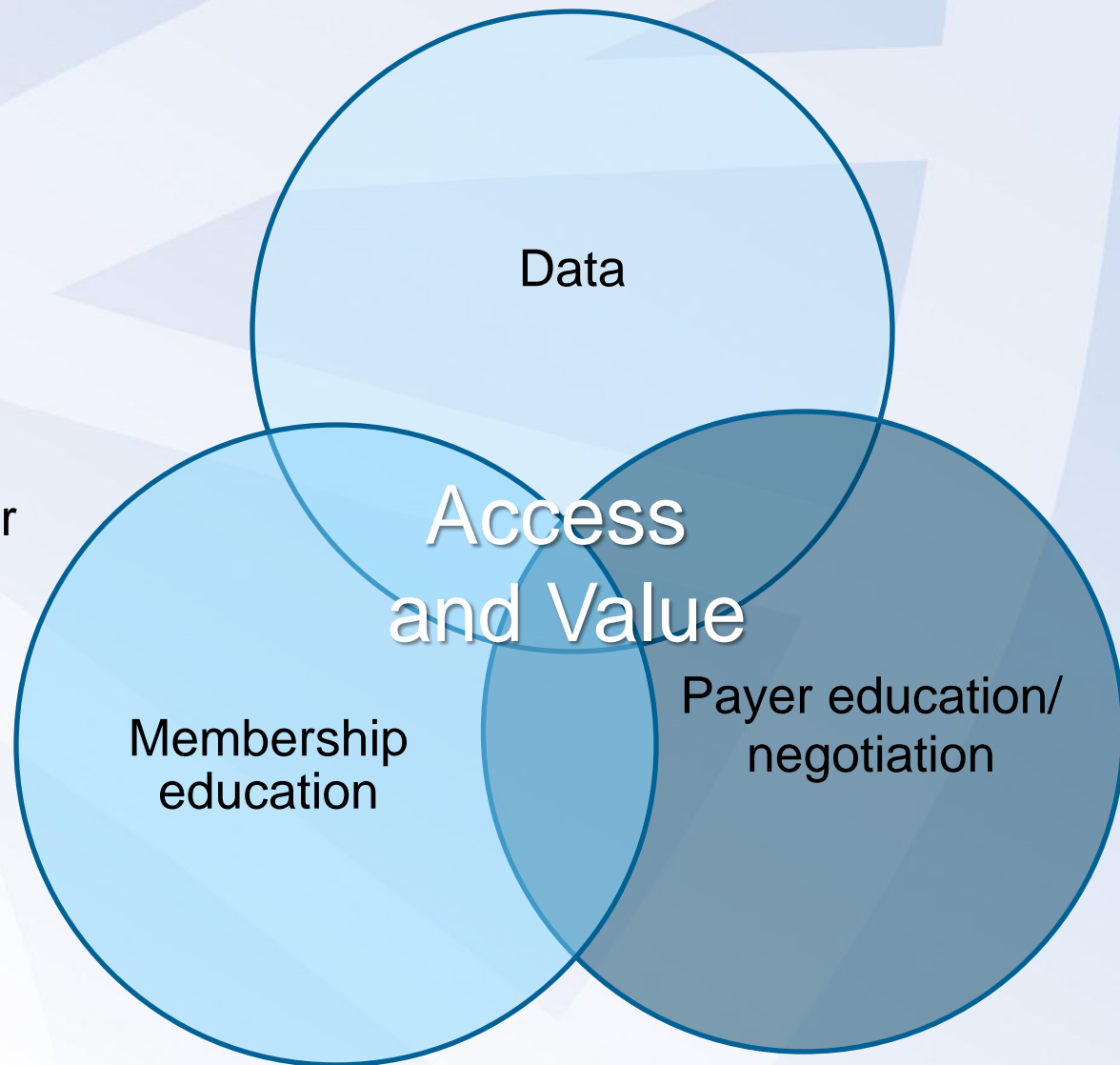
- Demonstration of expertise/unique voice
- Grass roots efforts for Federal bill

## Members

- Data showing value, cost effectiveness
- State licensure and local advocacy
- Payer negotiations

# Access and Service Delivery Committee

- Provide support for coding questions from members
- Developed Payer Presentation
- Completing draft payer model policy for genetic counseling
- Helped develop content for Business Foundations Courses



# State Licensure

## > 16 states currently issuing licenses:

• California	• Massachusetts	• North Dakota	• South Dakota
• Delaware	• Nebraska	• Ohio	• Tennessee
• Illinois	• New Jersey	• Oklahoma	• Utah
• Indiana	• New Mexico	• Pennsylvania	• Washington

## > 3 states in rulemaking:

• Hawaii	• New Hampshire	• Virginia
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## > Over 20 additional states have bills introduced or in preparation

# Federal efforts – 2014

- A bill that would recognize genetic counselors as independent healthcare practitioners under Medicare
- Allow GCs to be reimbursed for services
  - > Bill would not prevent other practitioners from providing genetic services within their scope of practice
  - > Communicating with physician organizations to ensure clarity around bill intent
- Attempted to attach bill to the SGR fix
  - > 2013 cost study demonstrated significant savings to Medicare
  - > Long wait for CBO score
  - > Last minute bill passed another patch

# Federal efforts – next steps

- Numerous hill visits over the past 12 months – gained the attention of new offices as a result of efforts around SGR fix
- Bill language has been drafted
- Working with sponsors to introduce stand-alone bill in upcoming month
  - > Will enable us to move forward with obtaining CBO score
  - > Build on existing support from members of Congress
- Will be positioned to serve as a cost offset to next attempt at SGR fix, or other opportunity

# Federal efforts – what can you do?

- Licensure is critical
  - > Licensure sub-committee within Access and Service Delivery committee
    - Contact John Richardson [jrichardson@nsgc.org](mailto:jrichardson@nsgc.org)
- Have discussions with local payers –
  - > Business Foundations courses provide how-to information for developing your arguments
- Collect data on GC value and cost-savings
- Payer sub-committee maintains bibliography and data
  - > Contact Monica Marvin [monicama@med.umich.edu](mailto:monicama@med.umich.edu)

# What value do genetic counselors provide?

## Value

- Evidence-based research
  - Outcome Measures
- Evidence-based recommendations
  - Publications
  - Practice Guidelines
- Position Statements
- Public Relations

## Access and Service Delivery Committee

- Define quality outcomes through genetic counseling research

## Practice Guidelines Committee and PPC

- Demonstration of expertise
  - Practice guidelines and position statements

## Members

- Research/data
- PG submissions
- Provide member feedback on PS

## Marketing, communications and PR

- Increase visibility of GCs

# Access and Service Delivery Committee

- Developing outcome measures
  - > Delphi Study conducted during 2014 (partially funded by AHSPA) focused on measurable outcomes for genetic counseling
  - > Currently prioritizing identified patient-centered outcomes
  - > Publication in draft form
- Next area of focus:
  - > Identify/create mechanisms to measure outcomes
  - > Educate the profession to promote utilization in genetic counseling research



# Public Policy Committee

- Position Statements published in 2014:
  - > Genetic Testing and Adoption
  - > Human Cloning by Somatic Cell Nuclear Transfer (SCNT) for Reproductive or Therapeutic Purposes
- Others in revision or development:
  - > Prenatal Testing for Adult-Onset Conditions
  - > Data Sharing
  - > Regulation of Genetic Testing (revision)
  - > Gene Patenting (revision)
  - Family Health History
- White papers
  - > Incidental findings
  - > DTC



# Practice Guidelines

- Practice Guidelines Committee working to implement new criteria required by National Guidelines Clearinghouse (NGC)
  - > NGC now requiring a more extensive understanding of evidence-based review, grading, recommendations and outcomes research
  - > Expertise did not exist fully within NSGC membership
- NSGC guideline development/revision process needs to be updated to ensure compliance and continued inclusion of our guidelines in NGC

# Practice Guidelines

- PGC chairs attended New York Academy of Medicine's TEACH workshop in August 2014 to gain knowledge and expertise
  - > Revising practice guidelines development process to reflect new criteria
  - > Incorporating new knowledge into updated guideline development manual for authors and committee members
- The PGC has taken a leadership role in identifying this issue and developing a proactive strategy for NSGC to ensure our guidelines remain relevant

# Marketing and Communications Workgroup and Expert media panel

- Marketing and Communications Workgroup
  - > Provided feedback and recommendations around the three public-facing sections of NSGC website
  - > Reviewed non-specialty specific resources within “Tools for Your Practice” section of the website
  - > Developing a social media “how-to” handout/webinar that will become part of the member GC self-marketing kit
- Expert media panel
  - > Four members completed media training with NSGC PR firm, PCI
  - > Media requests in the areas of cancer genetics, personalized medicine, genomics, Alzheimer’s, NIPT and many other topics



# PUBLIC RELATIONS CAMPAIGN RESULTS JANUARY - AUGUST 2014



**Public Communications Inc.**  
serving clients since 1962

# 2014 NSGC PR Objectives

- ❑ **Objective:** Secure **40 original** media placements
  - ✓ **Status:** We are **60 percent to goal** with 24/40 original placements.
  
- ❑ **Objective:** NSGC.org is mentioned in **29 percent** of NSGC media placements
  - ✓ **Status:** To date the website is mentioned in **14 percent of our placements.**
  
- ❑ **Objective:** Publish 12 blog posts developed by NSGC's Expert Media Panel for the NSGC blog
  - ✓ **Status:** To date we've published **eight blog posts.**

# PR Objectives

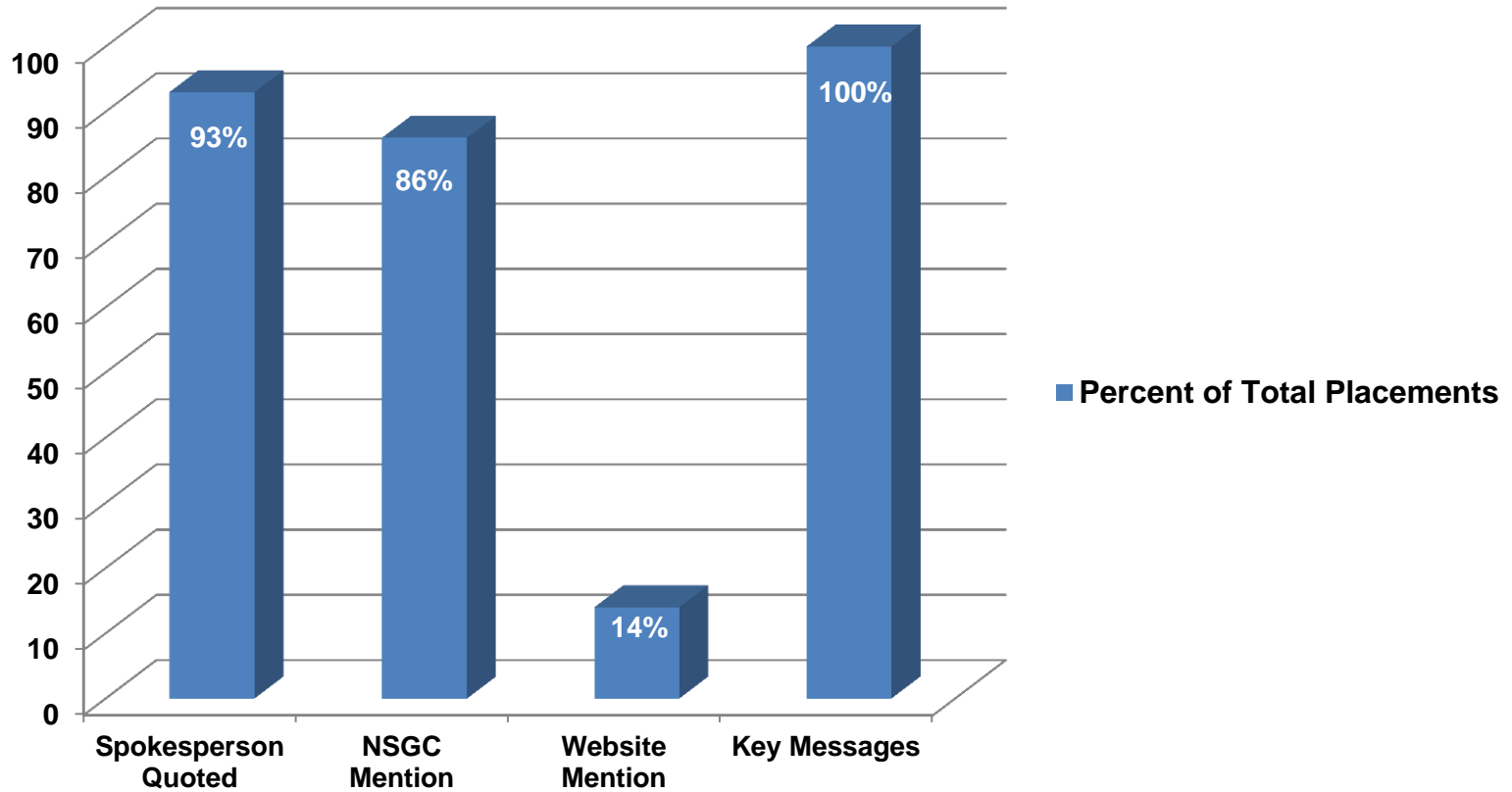
- ❑ **Objective:** Increase Facebook likes **35 percent to 2,000 fans**, and increase Twitter followers **43 percent to 1,500 followers**
  - ✓ **Status:** We've surpassed our Twitter goal with **1,600+ followers!** Facebook is close to goal with **1,800+ fans**.
  
- ✓ **Objective:** Secure at least one article in a payer/provider trade publication
  - ❑ **Status:** While we've secured trade coverage in outlets such as *Modern Healthcare*, we are still working to secure a payer- focused story.

# Media Coverage by the Numbers

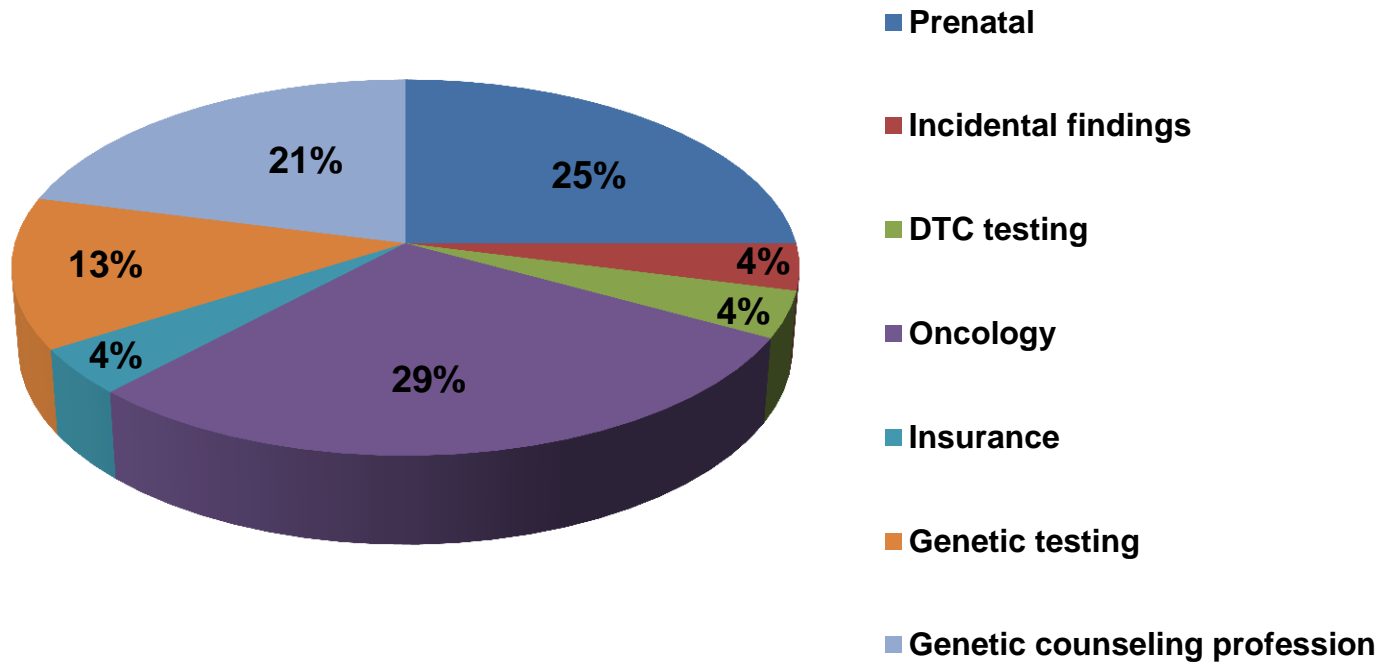
In 2014 to date, we secured a total of **24** original media placements reaching an estimated audience of **nearly 12 million.**



# Media Coverage Breakdown by Metrics



# Percentage of Placements



# NSGC Media Coverage Highlights

**Oncology  
NURSING  
NEWS®**

*Bringing the Oncology Nursing  
Community Together*

**“Angelina Jolie Effect” Draws Attention to Genetic  
Counselor Model**

**W I R E D**

**GO AHEAD AND ASK  
OTHERS FOR THEIR  
DNA RESULTS**

**ObGyn.net**

**Tips for Navigating  
Prenatal Genetic Testing**

**Modern  
Healthcare**

**Genetic cancer screening moves beyond single-  
gene tests**

**TIME**

**Healthy-Obesity Gene Found—But Genes Aren’t  
Everything**

**Medscape**

**Chromosomal Microarrays  
Flesh out Prenatal Ultrasound**

**U.S. News & WORLD REPORT**

**Study a Hot Concentration Today for a  
Future Health Care Job**

**TODAY Moms**

**Dads**

**The conversation we're not having  
about dads' biological clocks**

# NSGC Blog

In 2014, NSGC and PCI launched the NSGC blog featuring patient-focused content produced by the Expert Media Panel. To date, eight posts have published on a variety of topics from undiagnosed diseases to Alzheimer's disease, prenatal testing and the genetic counseling profession.



## [Understanding the Role of the Genetic Counselor](#)

Blog: [NSGC Blog](#) | By: Joy Larsen Haidle | Released: August 26, 2014, 6:58 am

Sharing family stories can do more than bring relatives closer together. When the stories are about health, they can help family members make the right medical decisions.

Genetic counselors play a key role in helping patients and their families get the care that's right for them. Genetic counse

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

Keywords: Announcements | Blogs |



## [Genetic Testing for Alzheimer's Disease: Is it Worth it?](#)

Blog: [NSGC Blog](#) | By: Susan Estabrooks Hahn | Released: August 18, 2014, 7:10 am

Alzheimer's disease, the most common form of dementia, is a growing global health problem. It is seen in all populations and its prevalence is rising. About five million Americans currently have this devastating disease, and the number is expected to increase to more than 13 million by 2050. It's al

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

Keywords: Announcements | Blogs |



## [Solving the Mysteries of Undiagnosed Diseases](#)

Blog: [NSGC Blog](#) | By: Erica Ramos, MS, CGC | Released: August 6, 2014, 6:00 am

In my last blog post, I talked about the value that the \$1,000 genome is expected to bring to healthcare. But that doesn't mean that we have not already seen great benefits from the introduction of whole exome and whole genome sequencing in the clinic. For patients who have spent months – even year

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

Keywords: Announcements | Blogs |



## [Is Mental Illness Inherited? How Family History and Environment Impact Mental Health](#)

Blog: [NSGC Blog](#) | By: Jehannah C. Austin | Released: May 20, 2014, 5:53 am

As a genetic counselor working exclusively with people with psychiatric disorders and their families, I help my patients better understand what we know from research about the causes of mental illness. More importantly – I support them through processing what this better understanding means for them

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

Keywords: Announcements | Blogs |



## [Angelina Jolie Effect: One Year Later](#)

Blog: [NSGC Blog](#) | By: Joy Larsen Haidle | Released: May 14, 2014, 8:51 am

One year ago today, Angelina Jolie bravely shared her deeply personal connection to breast cancer, including losing her mother, discovering she is a carrier of the BRCA1 mutation, and – most poignantly – her decision to undergo a bilateral mastectomy to reduce her risk of developing breast cancer.

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

Keywords: Announcements | Blogs |



## [Questions Expectant Mothers Should Ask Before Prenatal Screening](#)

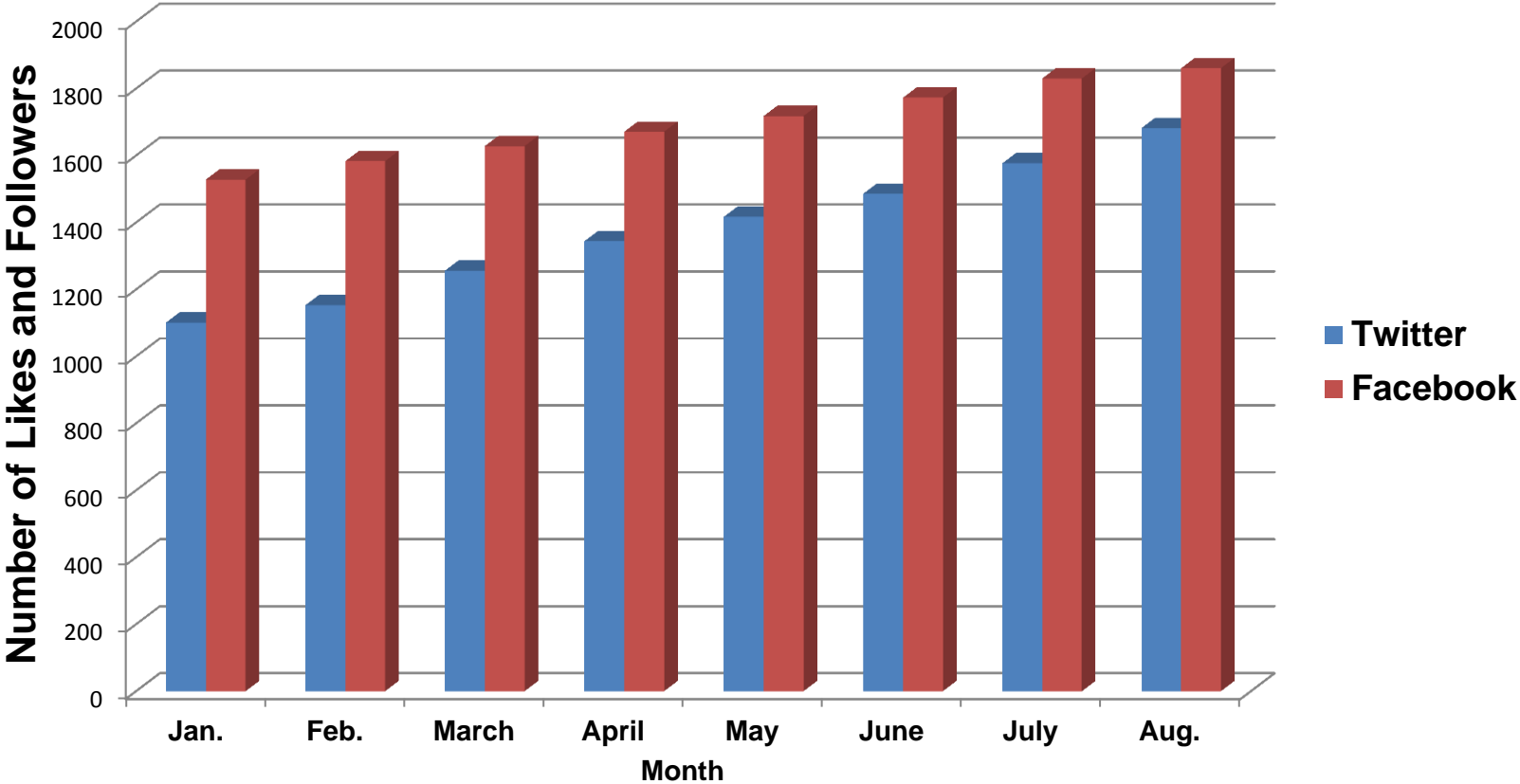
Blog: [NSGC Blog](#) | By: Jennifer Malone Hoskovec | Released: April 15, 2014, 11:49 am

Most expectant moms are faced with a barrage of tests throughout pregnancy to monitor their own health and the health of their baby. This includes prenatal screening, such as non-invasive prenatal testing (NIPT), which has advanced rapidly over the last few years. Now, expectant mothers can take a s

# Social Media by the Numbers

In 2014, we grew NSGC's Twitter followers by **61 percent** over 2013 numbers and Facebook likes grew **26 percent** with a combined online audience of **more than 3,500** members, consumers and media.

# NSGC Facebook and Twitter Growth in 2014



# NSGC Social Media Highlights



Congrats to all the spring #GeneticCounseling graduates!

Reply Retweet Favorite More

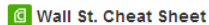
RETWEETS 12 FAVORITES 9

9:46 AM - 9 May 2014



#GeneticCounselors listed #2 of "5 Emerging Careers to Watch" buzz.mw/b0dzs\_f via @wallstCS

Reply Retweet Favorite More



Looking for Something New? 5 Emerging Careers to Watch  
Choosing a career that you love is important, but unfortunately there's little guarantee that you will pick a job field that has staying power.



View on web

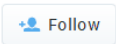
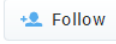
RETWEETS 10 FAVORITES 4



A new @NEJM study out today ties a new gene (PALB2) to major breast cancer risk via @AP @MMarchioneAP buzz.mw/bcqu8\_f

Reply Retweet Favorite More

RETWEETS 14 FAVORITES 3



**National Society of Genetic Counselors**  
We are excited to announce our new NSGC blog that will provide consumers easy-to-understand information about hot topics in genetic testing - and how genetic counselors empower patients to make informed health decisions. First up: President Jen Hoskovec provides Questions Expectant Mothers Should Ask Before Prenatal Screening [http://buzz.mw/bpx50\\_j](http://buzz.mw/bpx50_j)

Debra Lochner Doyle, Rawan I. Awwad, Christy Koellner and 72 others like this.  
18 shares

Album: Timeline Photos  
Shared with: Public

Open Photo Viewer

**National Society of Genetic Counselors**  
April 10



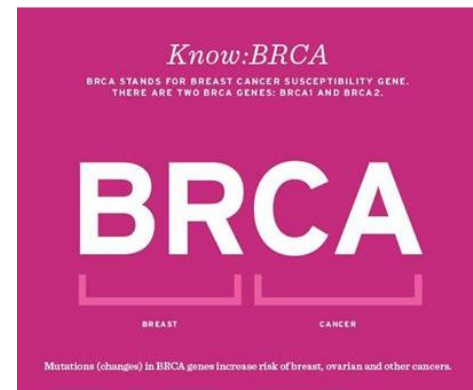
Today is #WorldCancerDay and one of the day's goals is to improve general knowledge around cancer and dispel myths about the disease. Here's information about how genetic counselors help families understand their genetic health. Members - Please share with your networks to spread the word! [http://buzz.mw/b5wbv\\_j](http://buzz.mw/b5wbv_j)



Like · Comment · Share 31

Debra Lochner Doyle, Lacey Benoit, Cathy Schmearek Lawson and 6 others like this.

The CDC's #KnowBRCA education initiative aims to promote awareness about hereditary breast and ovarian cancer, particularly among those at higher risk. As genetic counselors, we help patients understand their risk. [http://buzz.mw/bp3rk\\_j](http://buzz.mw/bp3rk_j)



Like · Comment · Share 15

Lacey Benoit, Linda Nichols, Emily Hurford and 34 others like this.

# Growth of our profession is critical

## Growth

- Workforce working group
- Collaboration with ACGC, ABGC & AGCPD
- Leadership development

## Workforce Working Group

- NSGC, ABGC, ACGC, AGCPD

## Members

- Start or support a GC training program
- High school and undergraduate outreach
- Promote profession locally



# NSGC workforce working group

- Small group of genetic counselors from the 4 US GC organizations
  - > ABGC, ACGC, AGCPD and NSGC
- Convened in late 2013
- Focused on collaborative efforts to grow and diversify the genetic counselor workforce

# Progress

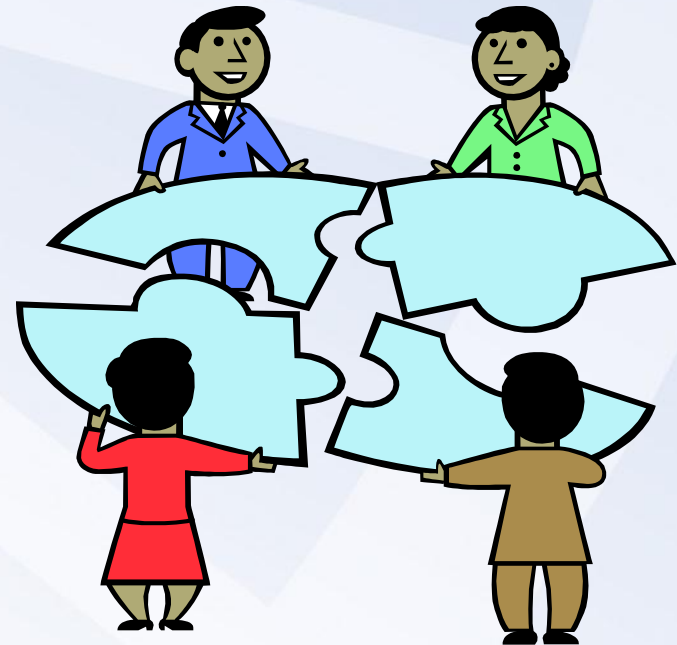
- Identify barriers and opportunities to growing the profession
- Identify smaller tasks and projects that each organization can focus on
  - Working group will drive and coordinate action within individual organizations
- Workforce analysis
- Strategic planning session in 2015 or 2016

# Workforce analysis

- Identify gaps in current knowledge, data
- Develop model(s) for GC workforce growth
- Hire external consultant
  - > They guide the process
  - > We provide context, data, direction, expertise

# Mapping out the future

- Extremely complex, but not insurmountable
- Identify barriers and opportunities for growth
- Many unknowns
  - > Need data
- Internal factors
- External factors
- Communication and collaboration are critical



# What member value does NSGC provide?

## Value

- Education
- Professional development
- Cultural competency
- Products and programs
- Specialty-specific networking

## Education Committee

- Professional Development
- Clinical knowledge development
- Continuing education

## Membership Committee

- Member benefits and services
- Networking
- Data supporting the profession

## Members

- Mentor a student member
- Volunteer to serve on the Nominating Committee
- Complete the PSS

# Addressing needs of our members

- In 2013, NSGC engaged a team of experts to assess needs of membership
- Rigorous process to understand what NSGC can provide to members that they are currently missing
- Invited over 1,500 members to focus groups and spoke with 45 members representing various
  - > Years of experience
  - > Practice Settings
  - > Work environments (single person to larger teams)

# What did we hear?

- After two rounds of concept testing with focus groups, narrowed down to two major areas of need:
  1. Insurance
  2. Billing, Coding and Credentialing
- Developed new, multifaceted course focused on business concepts impacting genetic counselors
  - > Didactic course content developed by Payer Subcommittee
  - > Ongoing webinar updates with course purchase
  - > Access to course-only discussion forums and experts



# BUSINESS FOUNDATIONS FOR GENETIC COUNSELORS:

Succeeding in Today's Healthcare Environment



## INSURANCE AND CREDENTIALING FOR GENETIC COUNSELORS:

What You Need to Know

[www.nsgc.org/businessfoundations](http://www.nsgc.org/businessfoundations)



## BILLING AND CODING FOR GENETIC COUNSELORS:

What You Need to Know

[www.nsgc.org/businessfoundations](http://www.nsgc.org/businessfoundations)

Take advantage of this new resource!

- Available as single courses, or as a full package
- Request funding from outside of education budgets
- Share with your medical staff and billing offices



# Education Committee

- Annual Education Conference

- > Another excellent program!

- > Outreach event

- > Abstracts

- 333 abstract submissions - 302 accepted (90.69%)

<b>2 best abstracts</b>	<b>48 concurrent papers</b>	<b>252 posters</b>
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- Abstract Task Force:

- ✓ promote high quality research

- ✓ showcase the breadth of genetic counseling research through concurrent papers and posters at the AEC

# Education Committee

- Six online webinars throughout the year
  - > 654 attendees to date
  - > Register for the October 1<sup>st</sup> webinar today!
- Maintain and evaluate CEU opportunities
- Online Courses
  - > Launched June 2014: “Incorporating Technology into Genetic Counseling Practice”
  - > JOGC CEU Program
  - > Popular past online courses renewed for CEUs
  - > AEC Recordings

# Membership Committee

## ■ Mentor Program



[www.nsgcmentor.org](http://www.nsgcmentor.org)

- > Next cycle starts in November/December
- > Be sure to sign up to be a mentee or mentor!

## ■ Ongoing Student Programs

- > Additional summer rotations / scholarships support student involvement and education

## ■ Identify at-large members for nominations committee



## NSGC 2014 Professional Status Survey

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

- PSS Subcommittee Chair – Shar Munshi
- 1,935 GCs completed surveys (54% response rate)
- The majority of GCs (89%) reported they are satisfied with their job
- 44% of GCs reported they have successfully used PSS data in salary negotiations with employers
- PSS data can also be used in conversations with employers around non-salary benefits, vacation, conference funding

# PSS: External Value

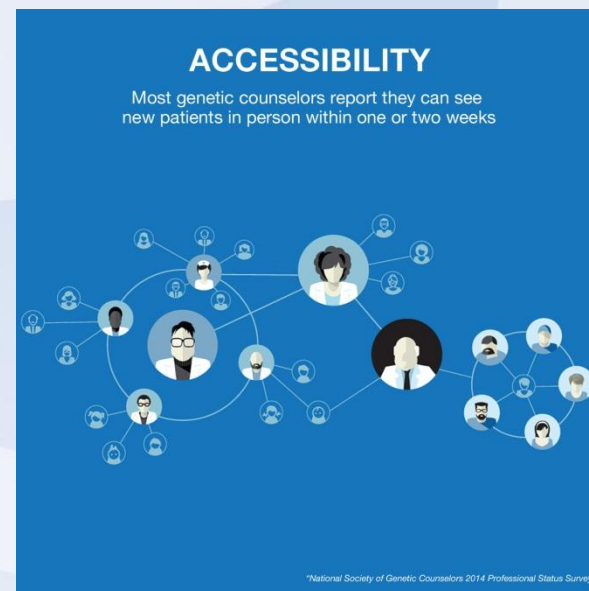
## ■ Visibility

### > Media Pitch

- Accessibility of GCs
- Diversity of GC roles
- Growing STEM Career

## ■ Recruitment

- > Genetic Counselor was named a “Hot Concentration” for a future job in healthcare in a 2014 article published by U.S. News and World Report. The article notes that the Bureau of Labor Statistics projects above-average growth for genetic counseling positions over the years 2012 - 2022.



# NSGC Publications

- *Journal of Genetic Counseling*
  - > Manuscript submission and processing has increased
  - > The Impact Factor has increased to 1.748
  - > The abstracts from this meeting will be in the Dec 2014 issue
- *Perspectives in Genetic Counseling*
  - > More of a focus on PGC Committee soliciting and writing content, particularly feature content
  - > Move to new interactive, online format has been well received
    - Under the new format, our open rates have increased and average 43% with click-through rates around 38%

# Special Interest Groups (SIGs)

- NSGC's SIGs are accomplishing so much:
  - > Providing education to the general NSGC membership
  - > Contributing to the NSGC Strategic Plan
  - > Collaborating with other SIGs and Committees
  - > Partnering with outside organizations around mutual goals
  - > Creating new publications and resources
  - > Proposing and writing practice guidelines
  - > Helping develop position statements
  - > Publishing in peer-reviewed and trade publications
  - > Proposing webinars and AEC sessions
  - > Providing grants and scholarships
  - > And so much more...

# NSGC Collaborations and Liaisons

AMA Health Care Professional  
Advisory Committee

National Accreditation Program  
for Breast Centers PQF

ACMG

AGCPD

IOM

MDA Coalition

TRIG

ABGC

HRSA

National Advisory Council for  
Human Genome Research

Discretionary Advisory Committee on Heritable  
Disorders in Newborns and Children

ACOG

NHGRI

NCHPEG

Genetics in  
Primary Care  
Institute

National Colorectal Cancer  
Round Table

AONN

ACGC

SMFM

National Newborn Screening  
and Genetic Resource Center

ASCO

ACCC

American College of  
Surgeons Commission  
on Cancer

CAGC

FH foundation

NBS Connect

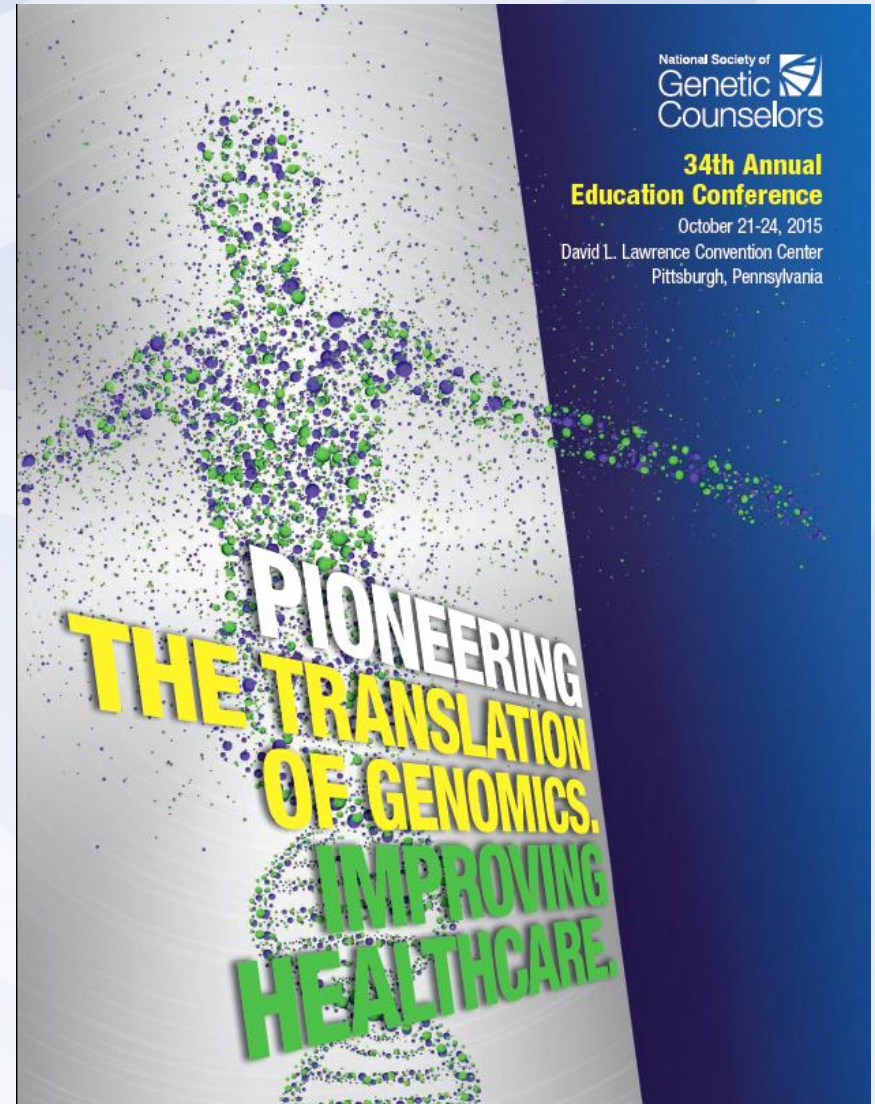


# Demonstrating our Expertise

- Banbury III
  - > “Genetics training in the genomics era”
  - > Hosted by ACMG
  - > Leadership from NSGC, ABGC, ACGC, AGCPD
- AMA House of Delegates
  - > ASCO Resolution in response to CIGNA
  - > Conversations with CoC, ACMG, ASBrS, SGO
  - > Testimony – June 2014, Chicago
  - > Outcome – continued conversations with the physician community around collaborative opportunities

# 2015 AEC

- Join us in Pittsburgh!



**THANK YOU !**