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

*Membership as of August 31, 2014*
NSGC Continues to Grow…

Net Asset Trend

<table>
<thead>
<tr>
<th></th>
<th>2011 Audit</th>
<th>2012 Audit</th>
<th>2013 Audit</th>
<th>2014 Budget</th>
<th>4+8 Forecast</th>
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<tbody>
<tr>
<td>Net Assets</td>
<td>$1,448,667</td>
<td>$1,989,591</td>
<td>$2,223,142</td>
<td>$2,109,938</td>
<td>$2,106,831</td>
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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
<table>
<thead>
<tr>
<th>Special Interest Group (SIG)</th>
<th>Chairs 1</th>
<th>Chairs 2</th>
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</thead>
<tbody>
<tr>
<td>ART/Infertility</td>
<td>Lauren Isley</td>
<td>Andria Besser</td>
</tr>
<tr>
<td>Cardiovascular Genetics</td>
<td>Colleen Caleshu</td>
<td>Sara Cherny</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>Renee Temme</td>
<td>Karen Siklosi Raraigh</td>
</tr>
<tr>
<td>Education</td>
<td>Shraddha Gaonkar</td>
<td>Kate Shane-Carson</td>
</tr>
<tr>
<td>Familial Cancer Risk</td>
<td>Sara Knapke</td>
<td>Sara Pirzadeh-Miller</td>
</tr>
<tr>
<td>Health IT</td>
<td>Heather Fecteau</td>
<td>Megan Doerr</td>
</tr>
<tr>
<td>Industry</td>
<td>Kathleen O'Conon</td>
<td>Lily Servais</td>
</tr>
<tr>
<td>International</td>
<td>Rawan Awwad</td>
<td>Angela Arnold</td>
</tr>
<tr>
<td>Metabolism/LSD</td>
<td>Jennifer Sullivan</td>
<td>Amy White</td>
</tr>
<tr>
<td>Neurogenetics</td>
<td>Lauren Hache</td>
<td>Shawna Feely</td>
</tr>
<tr>
<td>Pediatric &amp; Clinical Genetics</td>
<td>Marianna Raia (Horz)</td>
<td>Kimberly Lewis</td>
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<tr>
<td>Personalized Medicine</td>
<td>Liz Varga</td>
<td>Megan Grove</td>
</tr>
<tr>
<td>Prenatal</td>
<td>Blair Stevens</td>
<td>Andrea Harbison</td>
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<tr>
<td>Psychiatric Disorders</td>
<td>Heather Andrighetti</td>
<td>Edith Kolozsi</td>
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<tr>
<td>Public Health</td>
<td>Kate Reed</td>
<td>Amy Gaviglio</td>
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<tr>
<td>Research</td>
<td>Sharon Aufox</td>
<td>Gillian Hooker</td>
</tr>
<tr>
<td>Student / New GC</td>
<td>Katie Bergstrom</td>
<td>Elysia Pagano Davis</td>
</tr>
</tbody>
</table>
NSGC’s 2014 - 2016 Strategic Objectives

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

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

Growth
- 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:

<table>
<thead>
<tr>
<th>California</th>
<th>Massachusetts</th>
<th>North Dakota</th>
<th>South Dakota</th>
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</thead>
<tbody>
<tr>
<td>Delaware</td>
<td>Nebraska</td>
<td>Ohio</td>
<td>Tennessee</td>
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<tr>
<td>Illinios</td>
<td>New Jersey</td>
<td>Oklahoma</td>
<td>Utah</td>
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<tr>
<td>Indiana</td>
<td>New Mexico</td>
<td>Pennsylvania</td>
<td>Washington</td>
</tr>
</tbody>
</table>

> 3 states in rulemaking:

| Hawaii     | New Hampshire | Virginia     |

> 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

- 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
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
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

- Spokesperson Quoted: 93%
- NSGC Mention: 86%
- Website Mention: 14%
- Key Messages: 100%

Percent of Total Placements
Percentage of Placements

- Prenatal: 25%
- Incidental findings: 4%
- DTC testing: 4%
- Oncology: 13%
- Insurance: 21%
- Genetic testing: 4%
- Genetic counseling profession: 29%
NSGC Media Coverage Highlights

“Angelina Jolie Effect” Draws Attention to Genetic Counselor Model

Tips for Navigating Prenatal Genetic Testing

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

Genetic cancer screening moves beyond single-gene tests

Chromosomal Microarrays Flesh out Prenatal Ultrasound

Study a Hot Concentration Today for a Future Health Care Job

Dads
The conversation we’re not having about dads’ biological clocks
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.
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

Number of Likes and Followers

<table>
<thead>
<tr>
<th>Month</th>
<th>Twitter</th>
<th>Facebook</th>
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<tbody>
<tr>
<td>Jan.</td>
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<td>1500</td>
</tr>
<tr>
<td>Feb.</td>
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<td>March</td>
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</tr>
<tr>
<td>Aug.</td>
<td>2000</td>
<td>2400</td>
</tr>
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NSGC Social Media Highlights

Genetic Counselors @GeneticCouns

Congrats to all the spring #GeneticCounseling graduates!

9:46 AM - 9 May 2014

Genetic Counselors @GeneticCouns

#GeneticCounselors listed #2 of “5 Emerging Careers to Watch” buzz.mw/b0dzsf via @wallstCS

9:47 AM - 9 May 2014

Wall St. Cheat Sheet

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

Genetic Counselors @GeneticCouns

A new @NEJM study out today ties a new gene (PALB2) to major breast cancer risk via @AP @MMarchioneAP buzz.mw/bcqu8f

11:19 AM - 9 May 2014

National Society of Genetic Counselors

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/bjxwbyj

National Society of Genetic Counselors

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/bajxkic
Growth of our profession is critical

Growth

- Workforce working group
- Collaboration with NSGC, ABGC, ACGC, 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
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%)

| 2 best abstracts | 48 concurrent papers | 252 posters |

- 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 1st 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**
  - 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**
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…

Get involved - start or join a SIG
NSGC Collaborations and Liaisons

AMA Health Care Professional Advisory Committee
ACMG
MDA Coalition
National Advisory Council for Human Genome Research
ACOG
National Colorectal Cancer Round Table
AONN
National Newborn Screening and Genetic Resource Center
NBS Connect

AGCPD
Discretionary Advisory Committee on Heritable Disorders in Newborns and Children

ABGC
HRSA

TRIG

NHGRI
National Institutes of Health, National Human Genome Research Institute

NCHPEG
National Accreditation Program for Breast Centers

IOM

PQF

ACGC
American College of Surgeons Commission on Cancer

ASCO

SMFM

ACCC

CAGC

FH foundation

American College of Surgeons Commission on Cancer

Institute for Genetics in Primary Care

MDA Coalition
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!