NSGC
State of the Society
Erica Ramos, MS, CGC
President
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 At-a-Glance

- 4,000+ members
- 22 Special Interest Groups (SIGs)
- Official liaison relationships with over 25 organizations
- 1,000+ member volunteers
- Countless opportunities to get involved
Membership and Conference Growth

NSGC Membership 2014-2018

Annual Conference Registration 2014-2018

2014 (New Orleans) 2015 (Pittsburgh) 2016 (Seattle) 2017 (Columbus) 2018 (Atlanta)*
NSGC 5-Year Financial Trends

- Unrestricted Net Assets (Reserves)
- Operating + Strategic Expenses
- Operating + Strategic Revenue
- Fees to SmithBucklin
2016 – 2018 Strategic Plan

What did we accomplish?
Strategic Initiative 1

Drive the integration of genetic counselors throughout the healthcare delivery system to improve access to cost-effective, high-quality genetic and genomic services for healthcare consumers.
Federal Advocacy

- We have a bill!

- Investment in online grassroots support tool
  - YOU have sent 1,200+ emails to Congress to date
  - Watch for more information on targeted grassroots efforts

- Attend PI Panel tomorrow to learn more about how you can contribute to our strategy
Federal Advocacy Resources
State Licensure

- 25 states with licensure
  - Seven new states passed bills from 2016 – 2018
  - Another 22 states in process

- Ongoing investment in licensure grant awards
  - Increased funding in 2017 and 2018; maintaining in 2019
  - Canadian provincial efforts eligible to apply
Genetic Counselor Outcomes

• Outcomes Task Force now permanent Outcomes Committee

• Working to establish process and outcome measures for genetic counseling performed by genetic counselors

• Priority areas:
  – Access
  – Quality
  – Cost

• Working with National Quality Foundation to validate and gain endorsement for existing measures
Strategic Initiative 2

Direct the evolution and adaptation of the genetic counselor workforce.
Diverse Educational Offerings
Evolving to Support Our Members

• Professional Status Survey
  – Moving to annual survey
  – Abbreviated survey in odd years with four reports:
    • Executive summary
    • Demographics & methodology
    • Work environment
    • Salary & benefits
New Publisher: John Wiley & Sons
   - Upgraded journal website
   - Virtual issues in areas of specialization
   - Mobile app

New contract offers strategic support for journal and Society
Efficiency Toolkit

- Designed to guide teams toward improved efficiency and service delivery
- Resources to support:
  - Identifying process redundancies
  - Streamlining administrative steps
  - Enabling team members to work at top of their scope
Service Delivery Models

- Working with a statistician to analyze results from the 2017 SDM focus groups
- Comparing with 2010 SDM focus group results
- Analysis to be published in 2019
Genetic Counselor Workforce Initiatives

Does a genetic counselor workforce shortage exist?

The statement likely traces back 20 years ago and focused on genetics specialists—not genetic counselors specifically. While the shortage statement has been widely repeated in the press, NSGC data does not indicate a significant shortage at the current time.

The Facts

In early 2016, the NSGC commissioned Dobson | Daniels & Associates, LLC to conduct a workforce supply and demand study of United States-based certified genetic counselors over the next decade (2017-2026).

Since this study was published, the genetic counseling profession has experienced significant growth, outpacing the assumptions of the study. There are 4,026 certified genetic counselors (CGCs) today, and there will be over 4,900 by the end of the year.

Since 1990, the last 25 years, the profession will have undergone significant growth—over 1,000 (581 to 4,026).

The profession has grown by over 100% in the last 10 years and is expected to grow another 100% in the next 10 years. In five years, there should be over 5,800 CGCs, and in 10 years, there are likely to be over 7,000. Significant growth is being driven by the creation of additional training programs and the expansion of current programs.

The shortage "myth" is overstated, and in the coming months and years, it will be completely incorrect.

Wait Times to See a Genetic Counselor

The wait times to see genetic counselors vary by specialty. As the NSGC Professional Status Survey asks genetic counselors for their next available appointment, patients who can be flexible with their schedules and CPT codes are able to be accommodated quickly. Approximately 65% of clinical CGCs have a third patient appointment available within a week. Close to 90% of CGCs specializing in oncology report they can see a new patient within 3 days, most in the same day.

However, wait times are most significant in pediatrics as shown below. While the situations vary, those patients...
Strategic Initiative 3

Ensure NSGC will meet the increasing and dynamic consumer demand for genetic counselors’ services.
Timely information for consumers
Highlighting the scope of our profession
Communications Highlights
2018 Year to Date
2018 Media Placements
As of October 2018, our public relations efforts have resulted in:

502
Total media placements

889 MM
Audience reach of placements
Media Placements
Expert Alert: Marketing of 23andMe Genetic Testing for BRCA Mutations

**Business Insider**

Genetic experts have a message for anyone thinking of taking 23andMe's new breast cancer test

**The Atlanta Journal-Constitution**

FDA approves first-ever at-home breast cancer risk test

**CNN**

FDA approval of self testing for breast cancer genes comes with cautions

**USA Today**

When it comes to home cancer tests, think before you spit
NSGC Digital Brand Ambassadors #NSGCGenePool
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PhD in #HealthComm, #professor, #researcher, #BRCA2 #FORCE #HBOC hereditarycancer #PtExp #bcsm
NSGC Blog

The At-Home Genetic Test

The Power of Cascade Testing and How Genetic Counselors Can Help

Five Things I Tell My Patients Considering Prenatal Genetic Testing
Social Media

13,479
COMBINED FACEBOOK/TWITTER AUDIENCE OF MEMBERS, MEDIA AND CONSUMER

20.5%
YEAR-OVER-YEAR INCREASE FROM THE THIRD QUARTER OF 2017
2019-2021 Strategic Plan

Where are we going next?
National Society of Genetic Counselors
2019-2021 Strategic Plan

1. SERVICE DELIVERY
2. ACCESS TO GENETIC COUNSELORS
3. RESEARCH
4. DIVERSITY AND INCLUSION
Goal 1: Service Delivery

- Identification of patients who may benefit most from genetic counseling
- Access and Service Delivery Committee to promote collaborative approaches to care to promote effective, efficient, value-based genetic services
Goal 2: Access

• Grassroots support for the federal bill led by the Public Policy Committee

• Ongoing support from Access and Service Delivery Committee
  – Rule-making for federal bill
  – State licensure
  – Payer efforts
Develop NSGC’s research agenda with input from the Outcomes Committee and Practice Guidelines Committee

Develop an infrastructure to support funding and ongoing management of research
Goal 4: Diversity & Inclusion

- Organizational structure to advance our approach to inclusion, diversity and community building; implemented in part through the Membership Committee and Education Committee

- Marketing and Communications Workgroup to support identification, guidance and development of resources and partnerships to facilitate member outreach to engage with diverse communities
NSGCommunities

- Easily view and build your NSGC contacts
- Establish your network
- One central location for all of your NSGC communities and connections
Get Involved!

All are welcome - we need you!
Supporting each other throughout our careers
Supporting and Building Our Community
Supporting Our NSGC Community

Rebuilding The Center Houston

Like so many in Houston, The Center has recently been devastated by Hurricane Harvey and we are calling on caring individuals to help rebuild this incredible organization.

Originally founded by parents of children with intellectual disabilities, The Center’s mission is to "promote the pursuit of choice, growth, and personal independence for adults with intellectual and developmental disabilities".

This special community provides over 450 adults with daily activities and educational opportunities - many of which are necessary so that their family members and caregivers can maintain employment. The Center also offers independent and assisted living, in addition to a highly-specialized dental clinic to further support the growth and independence of their residents.
• Join the registry today!
• There are two ways to join:
  – Text “Cure01” to 61474 for a link to join
  – Visit NSGC Central in the exhibit hall
Supporting the Genetics Community
Our Community in Action!
Coming next year...
2018 Outstanding Clinical Supervisors Award

- Clinical supervisors critically important to the growth of our profession
- As such, initiated a process to formally recognize their contributions annually
Selection Process

• Graduates from the class of 2018 submitted nominations
• Criteria
  – Supervision competencies demonstrated
  – Written statement
• Program directors from each program selected from nominations submitted by their graduates
• 35 awardees
• Represent a range of years of experience and practice areas
2018 Outstanding Clinical Supervisors

Priyanka Ahimaz
Long Island University

Mary Ahrens
University of Minnesota

Shabnam Asgari
Sarah Lawrence College

Sarah Bannon
University of Texas Houston

Janet Ober Berman
Arcadia University

Fallon Brewer
University of Alabama Birmingham

Colleen Caleshu
Stanford University

Whitney Dodge
Brandeis University

Sara Fernandes
Augustana-Sanford University

Stephanie Fox
McGill University
2018 Outstanding Clinical Supervisors

Kathryn Steinhaus  
French, UC-Irvine

Hayley Green  
Boston University

Melissa Hsu  
Northwestern University

Karen Huelsman  
University of Cincinnati

Logan B. Karns  
University of Michigan

Jill Kelsay  
University of Arkansas

Kaitlin Kerr  
Mount Sinai School of Medicine

Kayla King  
Virginia Commonwealth University

Sandy Linn  
University of Colorado
2018 Outstanding Clinical Supervisors

Nicole Martin
University of Toronto

Maureen May
University of Pittsburgh

Ryan Noss
Case Western Reserve

Suzanna Schott
UNC Greensboro

Jessica Scott
University of Maryland

Sally M. Shields
University of South Carolina

Nicola Cadenas Stewart
CSU Stanislau

Kali Swift
Indiana State University
2018 Outstanding Clinical Supervisors

Cheryl Portigal-Todd  
U of British Columbia

Kayla Treat  
Indiana University

Christie Turcott  
University of Wisconsin  
Madison

Joyce Turner  
JHU/NHGRI

Nancie Petrucelli Walden  
Wayne State University

Lauren A. Wallace  
University of Utah

Daniel Wiesman  
Emory University

Kristin Zajo  
The Ohio State University
In Memoriam- Aida Metzenberg
September 29, 1955- March 18, 2018
Journal of Genetic Counseling
2018 Best Trainee Paper Awards

All Trainee Category

Susan Christian


Krista Redlinger-Grosse

Journal of Genetic Counseling
2018 Best Trainee Paper Awards

Genetic Counseling Trainee Only Category

Anthony Chen

Daniella Kamara
thank you!