

State of the Society

**Rebecca Nagy, MS, LGC
NSGC President, 2013**

Robert G. Resta, MS LCGC
Natalie Weissberger Paul
National Achievement Award



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

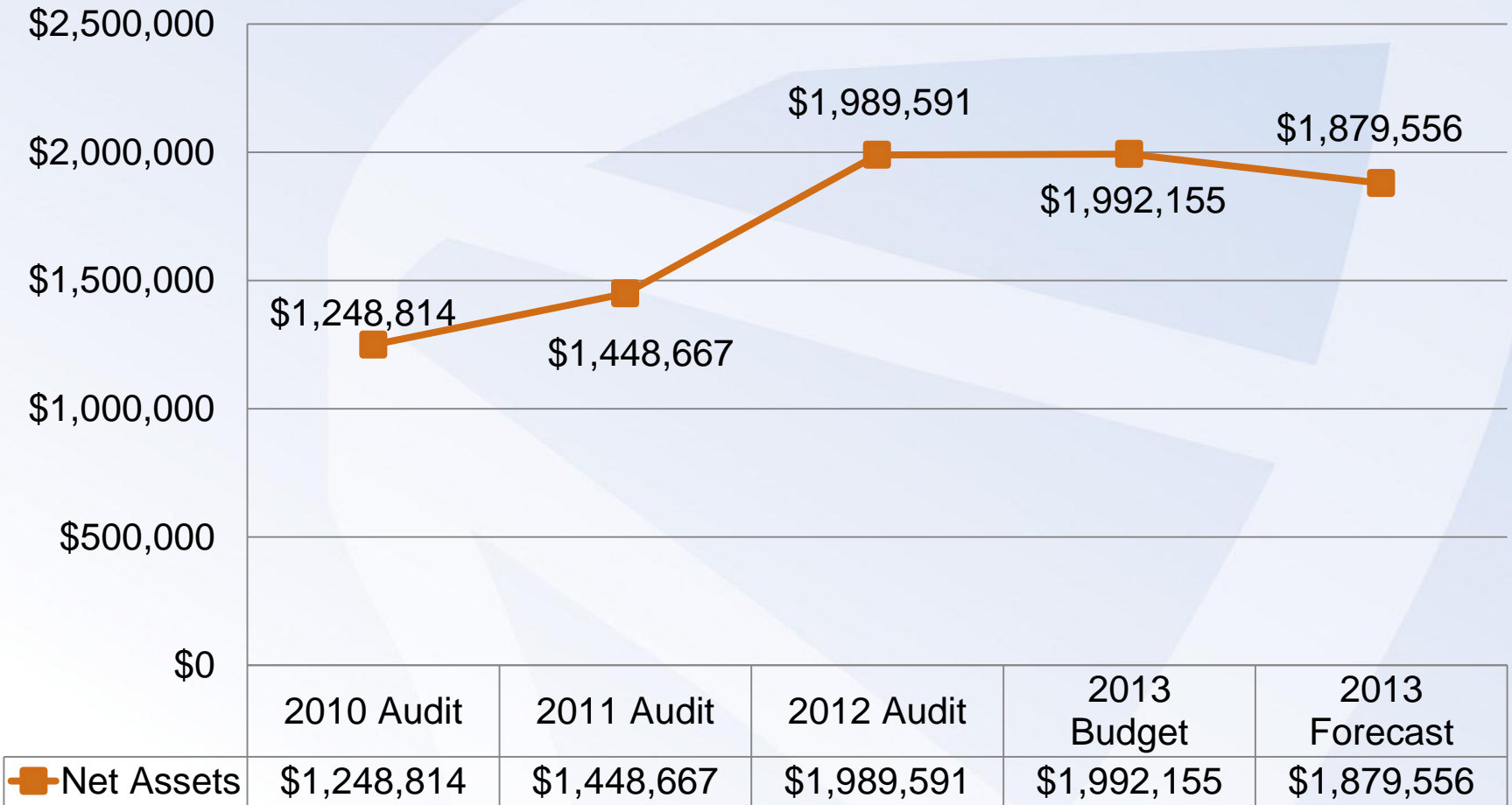
NSGC Continues to Grow

NSGC Membership 2008 - 2013



NSGC Continues to Grow

Net Asset Trend



2013 Committee Chairs and Vice Chairs

Education Committee

Kelly Jackson, Chair

Renee Chard, Vice Chair

Public Policy Committee

Jill Stopfer, Chair

Carrie Blout, Vice Chair

Access and Service Delivery Committee

Stephanie Cohen, Chair

Heather Zierhut, Vice Chair

Practice Guidelines Committee

Adam Buchanan, Chair

Christina Palmer, Vice Chair

Membership Committee

Kami Wolfe Schneider, Chair

Kaylene Ready, Vice Chair

Marketing & Communications Workgroup

Sara Riordan, Chair

2013 Board-appointed Task Force

Conflict of Interest Task Force

Cheryl Harper, Chair

Join a committee!

- All committee meetings are being held today
- Check your program
- Find a committee that fits your skills and interests or join a new committee that will expand your knowledge base and experiences
- Information in your program and NSGC AEC app

NSGC's 2013-2014 Strategic Objectives



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

- Evidence-based research
 - Outcome Measures
- Evidence-based recommendations
 - Publications
 - Practice Guidelines
- Position Statements
- Marketing & Branding

- Workforce growth working group
- Collaboration with ACGC, ABGC & AGCPD
- New practice settings

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

Public Policy Committee

- Demonstration of NSGC's unique voice
- Grass roots efforts for Federal bill

Access and Service Delivery Committee

- Payer sub-committee
- State licensure sub-committee
- GR staff

Members

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

Public Policy Committee

■ New Position Statements in 2013

- > Family Health history in the EHR
- > Testing Minors for Adult-Onset conditions
- > Incidental findings in Genetic Testing

■ White papers

- > NIPT
- > Stem cell research
- > Newborn screening

■ Others in revision or development:

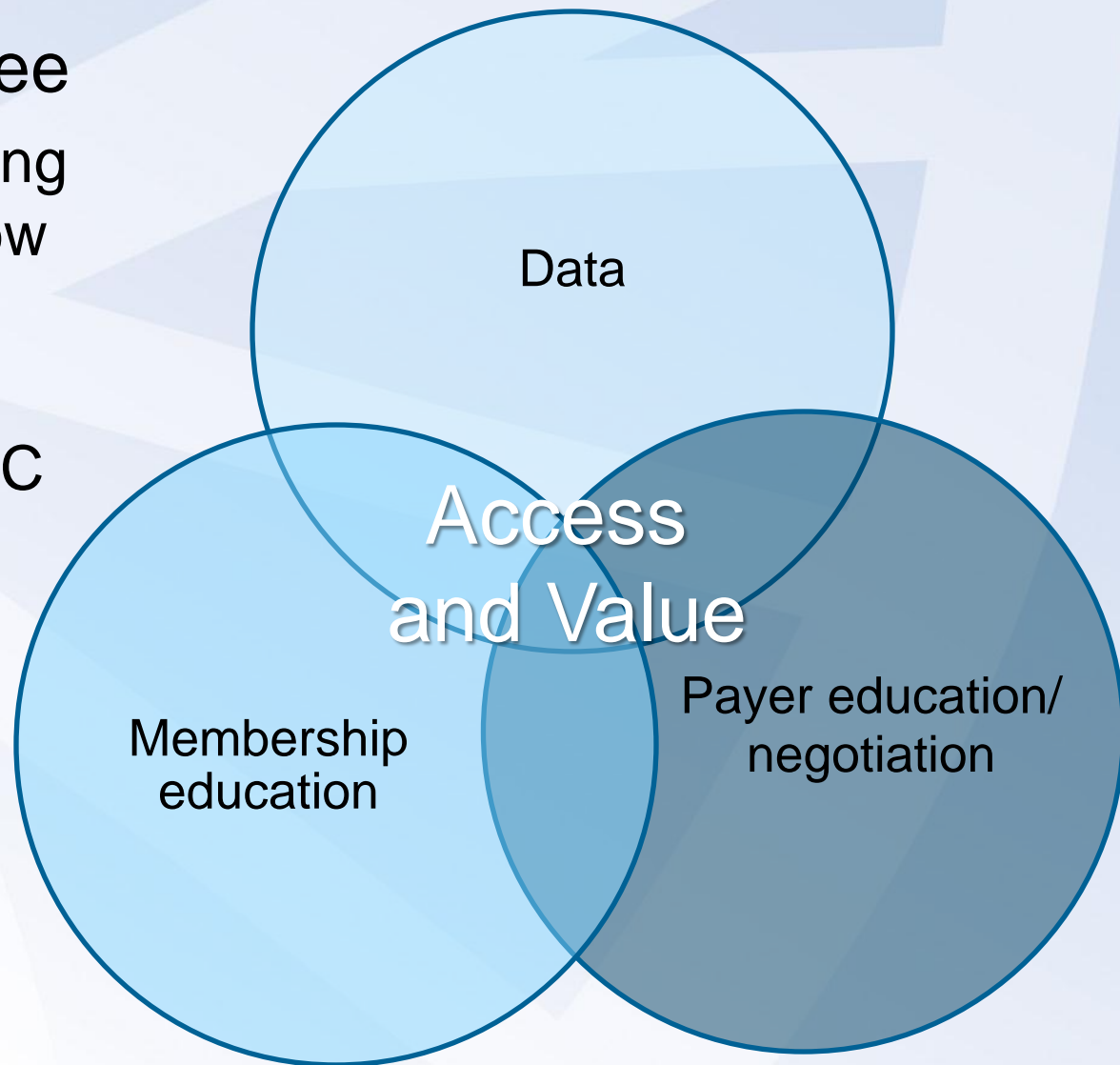
- > Adoption revision
- > Fetal Tissue research revision
- > SCNT/Cloning revision

**Grass roots advocacy
around bill**



Access and Service Delivery Committee

- Payer Subcommittee
 - > Focused on collecting existing data to show GC value
 - > Promote new research/data on GC value
 - > Payer outreach
 - > Membership education



Payer Sub-committee

- Data collected by subcommittee is directly supporting our Federal effort
 - > NSGC hired an external firm to conduct cost study and results were highly favorable
 - > Cost study currently being used in Hill visits
- Member resource
 - > Establishing an evidence base that can be used with various stakeholders
 - > Bibliography

PROFESSIONAL ISSUES PANEL FRIDAY AT 10:30am

Payers recognizing value of GCs

- Cigna and InformedDNA
- Requires genetic counseling by a certified GC or medical geneticist for several conditions
- Allows GC (in-person and telephone) to bill and be reimbursed for services using 96040
- Not a perfect policy
 - > Cigna has been made aware of our concerns; dialog ongoing
 - > Experiences with Cigna program will be used in future payer discussions

State Licensure

■ State Licensure Progress

- > 11 currently issuing licenses: CA, DE, IL, IN, MA, NE, NM, OH, OK, PA, SD, TN, UT, WA
- > 4 in rulemaking: HI, ND, NH, NJ
- > 21 with bills introduced or in preparation: CO, CT, DC, FL, GA, ID, IA, KS, KY, MD, MI, MN, MO, MS, NY, OR, RI, SC, TX, VA, WI

Federal efforts - background

- A bill that would recognize genetic counselors as independent healthcare practitioners under Medicare
 - > Private payers tend to follow Medicare policy
- Allow GCs to be reimbursed for services

Federal efforts - background

- Current financial climate provides opportunity to introduce bill
- Attach bill to the SGR fix
 - > Have to wait for this to be opened up for adjustment
- Evidence that genetic counselors are cost effective and save healthcare dollars
- Genetic counselors also provide value and high quality healthcare services

Federal efforts - Progress

- Cost study showing significant savings to Medicare if GCs were recognized providers
- Numerous hill visits over the past 6 months
- Senator Carper (D-DE) current champion of the bill
 - > Bill language has been drafted
 - > Co-sponsors

Federal efforts – what can you do?

- Licensure is critical
 - > Licensure sub-committee within ASD committee
 - Contact John Richardson jrichardson@nsgc.org
- Discussions with local payers
- Data on GC value and cost-savings
- Payer sub-committee can help
 - > Contact Joy Larsen Haidle joy.larsen.haidle@northmemorial.com or
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
- Marketing & Branding

Access and Service Delivery Committee

- Outcomes research
- Service delivery model papers

Practice Guidelines Committee and PPC

- Demonstration of expertise
 - Practice guidelines and position statements

Marketing, communications and PR

- Increase visibility of GCs

Members

- Research/data
- Outcomes focus groups
- PG submissions, member feedback on PS

Access and Service Delivery Committee

- Outcome measures
 - > Working to identify patient-centered outcomes measures in genetic counseling
 - > Identify and prioritize these measures
 - > Educate the profession to promote utilization in genetic counseling research
- Focus groups at the AEC
- Thanks to those who participated!

Practice Guidelines Committee

- Five new/revised guidelines completed since Nov 2012
 - > HBOC published (accepted by NGC)
 - > Cystic Fibrosis published
 - > Fabry published (accepted by NGC)
 - > Prenatal Screening published (accepted by NGC)
 - > Fragile X (accepted by NGC)
- Committee's COI policy revised

Practice Guidelines Committee

■ Ongoing projects:

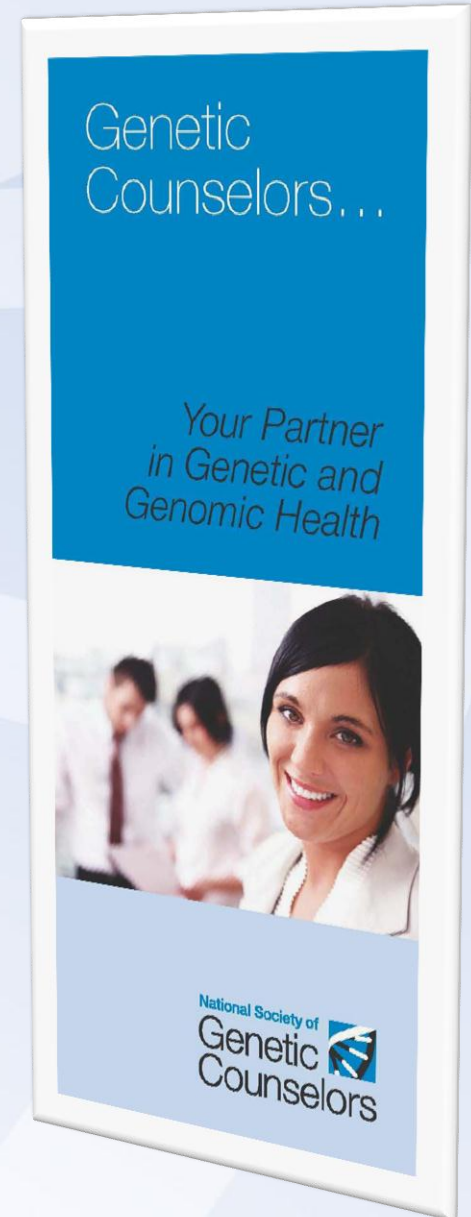
- > Five guidelines in review/revision process
- > NSGC invited to join joint carrier screening guidelines
- > Overseeing expert review/endorsement process for the American Academy of Neurology's FSHD guideline
- > Joint Cancer Referral guideline with ACMG almost ready for Committee review
- > National Guideline Clearinghouse revised criteria – working on background documents, author and member education initiatives, and revising Committee's guideline proposal form

Marketing and Communications Workgroup and Expert media panel

- Marketing and Communications workgroup
 - > Assisted with roll-out of new NSGC emails and member updates
 - > Will be involved in testing website after launch
- 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

Self-Marketing Toolkits – YOU are our profession’s best marketing asset!

- Establish yourself as a knowledgeable resource & increase referrals
- Variety of tips and templates to market self to physicians, primary healthcare providers
 - > Educate physicians about benefits of partnering with a genetic counselor
 - > Specialty-specific inserts now available to customize for use in different settings
- Access toolkit online under NSGC “Member Center” using member login



NSGC Collaborations and Liaisons

AMA Health Care Professional
Advisory Committee

National Accreditation Program
for Breast Centers

AGCPD

IOM

MDA Coalition

ABGC

HRSA

TRIG

Discretionary Advisory Committee on Heritable
Disorders in Newborns and Children

National Advisory Council for
Human Genome Research

ACOG

NHGRI

NCHPEG

ACMG

AONN

ACGC

SMFM

National Newborn Screening
and Genetic Resource Center

ASCO

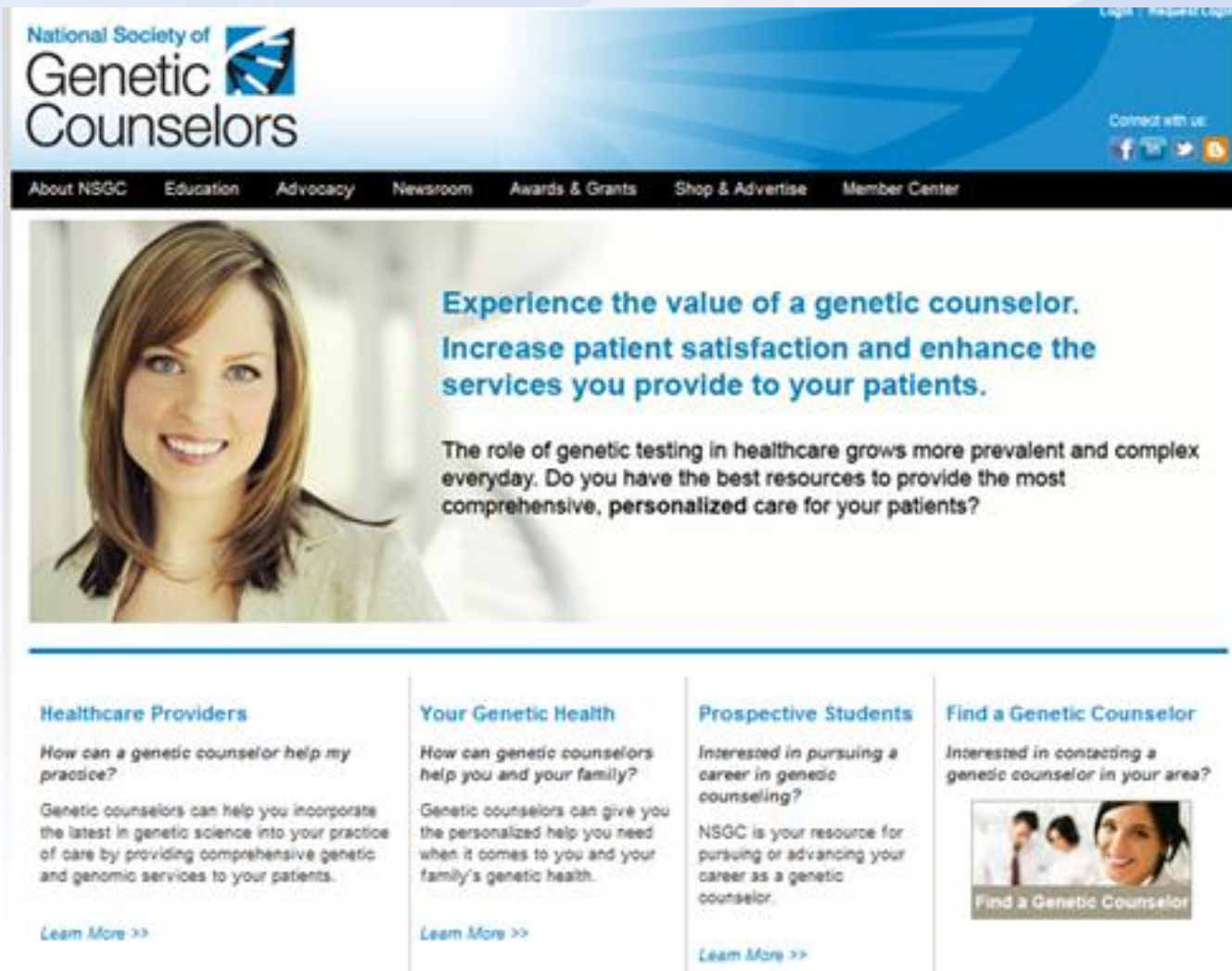
ACCC

American College of
Surgeons Commission
on Cancer

CAGC

NBS Connect


NSGC has a new Web site!



The screenshot shows the NSGC website homepage. At the top left is the logo for the National Society of Genetic Counselors, which includes the text "National Society of Genetic Counselors" and a stylized DNA helix icon. To the right of the logo is a "Login / Register/Logout" link. Below the logo is a navigation bar with links for "About NSGC", "Education", "Advocacy", "Newsroom", "Awards & Grants", "Shop & Advertise", and "Member Center". On the right side of the navigation bar are social media icons for Facebook, Twitter, and LinkedIn, with the text "Connect with us:" above them.

The main content area features a large image of a smiling woman on the left. To the right of the image is the text: "Experience the value of a genetic counselor. Increase patient satisfaction and enhance the services you provide to your patients." Below this is a paragraph: "The role of genetic testing in healthcare grows more prevalent and complex everyday. Do you have the best resources to provide the most comprehensive, personalized care for your patients?"

Below the main content area are four columns of text, each with a "Learn More >>" link:

- Healthcare Providers**
How can a genetic counselor help my practice?
Genetic counselors can help you incorporate the latest in genetic science into your practice of care by providing comprehensive genetic and genomic services to your patients.
[Learn More >>](#)
- Your Genetic Health**
How can genetic counselors help you and your family?
Genetic counselors can give you the personalized help you need when it comes to you and your family's genetic health.
[Learn More >>](#)
- Prospective Students**
Interested in pursuing a career in genetic counseling?
NSGC is your resource for pursuing or advancing your career as a genetic counselor.
[Learn More >>](#)
- Find a Genetic Counselor**
Interested in contacting a genetic counselor in your area?

[Find a Genetic Counselor](#)

With a new Member Center!

Counselors

Connect with us:



About NSGC

Education

Advocacy

Newsroom

Awards & Grants

Shop & Advertise

Member Center

Quick Links

- [Update My Profile](#)
- [My Discussion Forums](#)
- [My SIGs](#)
- [My Online Courses](#)
- [My NSGC Documents](#)
- [NSGC Blogs](#)
- [Member Directory](#)

NSGC Announcements

Welcome to NSGC's New Website!

Check out all the new benefits NSGC's website has to offer! Visit NSGC's new blog pages and be sure to personalize your profile page by updating your profile picture and information. Begin networking and subscribe to your favorite Discussion Forums!

Member Benefits & Resource Center

Access the [Member Benefits & Resource Center](#) for more of NSGC's member-only benefits, including Tools for Your Practice, Job Connection, information about Liability Insurance, NSGC's Mentor Program and JEMF. Find helpful resources for all members, including information for Students and Program Directors and more!



[Should You Get Tested for the Breast Cancer Gene?](#)

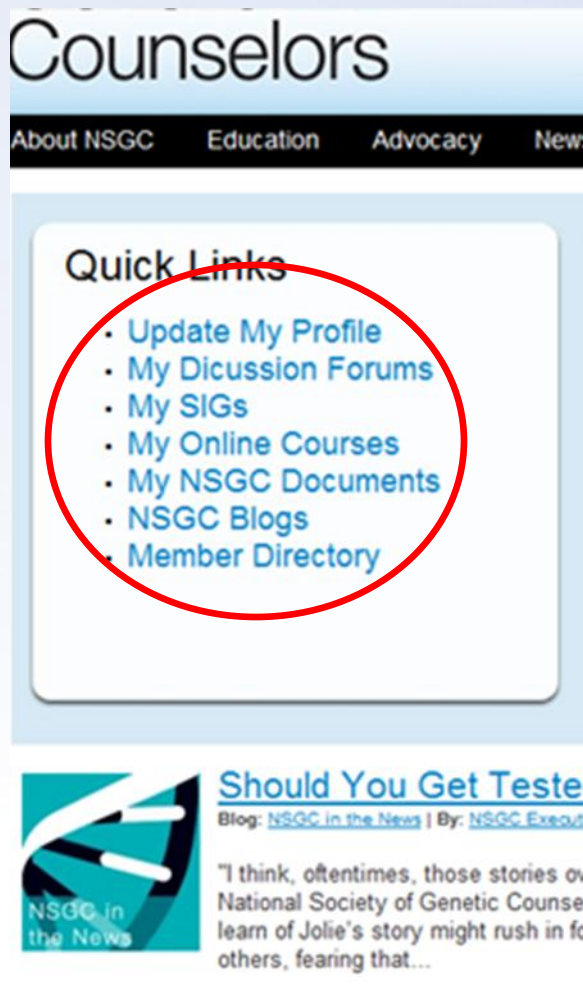
Blog: [NSGC in the News](#) | By: [NSGC Executive Office](#) | Released: Oct 03, 2013 04:10 PM

"I think, oftentimes, those stories oversimplify the matter," Rebecca Nagy, president of the National Society of Genetic Counselors, told Yahoo Shine. For example, she said, women who learn of Jolie's story might rush in for genetic testing even though they are not at risk—while others, fearing that...

Favorite Forums

- [Cancer SIG Discussion](#)
- [Edit Your Favorites](#)

Easy access to your favorites




Counselors

About NSGC Education Advocacy News

Quick Links

- [Update My Profile](#)
- [My Discussion Forums](#)
- [My SIGs](#)
- [My Online Courses](#)
- [My NSGC Documents](#)
- [NSGC Blogs](#)
- [Member Directory](#)

 **Should You Get Tested?**
Blog: [NSGC in the News](#) | By: [NSGC Executive](#)

"I think, oftentimes, those stories on National Society of Genetic Counselors learn of Jolie's story might rush in for others, fearing that..."

- Member profiles include new features for social networking
- One-click access to your SIGs, courses, document folders and blogs
- Opt to remain signed-in for quick access to members only content

NSGC updates in one place


- You choose your newsfeed/bulletin board:
 - > Member News
 - > Position statements
 - > Press Releases
 - > NSGC in the News
 - > *The Advocate* archives
- Follow any or all feeds

Blogs Home | Search | Favorite Blogs | Articles in Favorites | **All Blogs** | Options | Admin Options

Member News

Articles Actions ▾


Find the information you need about all NSGC happenings, announcements and updates in the Member News Blog.



[Accepting Proposals for State Licensure Grant Awards Through October 18, 2013](#)
Blog: [Member News](#) | By: [NSGC Executive Office](#) | Released: Oct 01, 2013 06:22 PM

NSGC's Licensure Subcommittee is now accepting Licensure Grant Award (LGA) proposals for Fall 2013. ...


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



[2011 AEC Recordings Eligible for CEUs until February 23, 2014](#)
Blog: [Member News](#) | By: [NSGC Executive Office](#) | Released: Oct 01, 2013 06:18 PM

After February 23, 2014, the 2011 AEC Recordings will no longer be accessible or available for CEUs....


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



[Journal of Genetic Counseling CEU Program Registration Closes November 18, 2013](#)

About this Blog

[Member News](#)
Member News



Recent Articles

- [Accepting Proposals for State Licensure Grant Awards Through October 18, 2013](#)
- [2011 AEC Recordings Eligible for CEUs until February 23, 2014](#)
- [Journal of Genetic Counseling CEU Program Registration Closes November 18, 2013](#)

Archives

- [October 2013 \(3\)](#)

Reorganized content

ADVOCACY

Looking For:

- NSGC Position Statements
- Federal Advocacy
- State Licensure for Genetic Counselors
- NSGC Practice Guidelines
- NSGC Liaison Resources
- Contact NSGC

NSGC ADVOCACY

NSGC sponsors a variety of strategic activities aimed at increasing patients' access to genetic counselors and

NSGC is currently engaged in the following advocacy activities:

[NSGC Position Statements](#)

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

[NSGC Public Policy Update](#)

The NSGC Public Policy Update provides you with the latest news and issues important to genetic counselors and members of the NSGC Public Policy Committee.

[Federal Advocacy](#)

NSGC's Federal advocacy efforts focus on improving access to quality genetic counseling services and ensuring the profession is a recognized and integral part of the healthcare system.

[State Licensure for Genetic Counselors](#)

NSGC has developed resources for state licensure that include draft sunrise applications and model legislative



- Quick links to related content appear on most pages
- Buttons provide access to major content areas

Updated Find A Counselor Search

Search for a Genetic Counselor:

Search For: Any criteria Exact criteria

State/Province: First Name:

OR

Near (Postal Code or City, State): Last Name:

Within: Types of Specialization:


Student Contact Welcome:

Sees Patients:

Telephone Counseling Service:

Board Certified:

Warning: only 20 results displayed.



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8618 Commonwealth Apt #245
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2 Karen Boyle Leydler
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Buena Park, CA, US 90621-1601
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3 Gail B. BARISEL-BOWERS
Genzyme Genetics
6530 Grand Maran Dr
Cypress, CA, US 90630-6447
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(714) 245-6252 (fax)
gail.barisel-bowers@genzyme.com

4 Forum Shan
University of California, Irvine
11544 153rd St
Anaheim, CA 92705

- Easier to use search interfaces on one screen
 - Location search
 - Name or area of specialization
- Location search returns contact information and maps location

Updated Discussion Forums

- Improved functionality based on your feedback:
 - > Reply right from your inbox like a listserv!
 - > Access past posts as with our current discussion forum
 - > Archives will be moved over for all forums

The screenshot shows the 'Forums & Discussions Home' page of the National Society of Genetic Counselors (NSGC). The page features a navigation bar with links for 'About NSGC', 'Education', 'Advocacy', 'Newsroom', 'Awards & Grants', and 'Shop & Advertise'. Below the navigation bar, there are links for 'Forums Home', 'Search', 'Favorite Topics', and 'Posts in Favori'. The main content area is titled 'Forums & Discussions Home' and includes a sub-header: 'A place for members, communities, and committees to have discussions online and Click a category or topic to below to start the conversation..'. The page displays a grid of forum categories, each with a folder icon and a link to 'View Topics'. The categories listed are: Committee/Task Force Files, AEC Resources, AGCPD (Program Directors), ART/Infertility SIG, Board of Directors, Cancer SIG, Cardiovascular Genetics SIG, Cystic Fibrosis SIG, Education SIG, Health IT SIG, and Industry SIG.

Launching soon!

- Watch your email for announcements on the launch date (mid-October)
- Visit the NSGC Booth in the Exhibitor Suite for a preview!



Public Communications Inc.

NSGC 2013 PUBLIC RELATIONS CAMPAIGN RESULTS

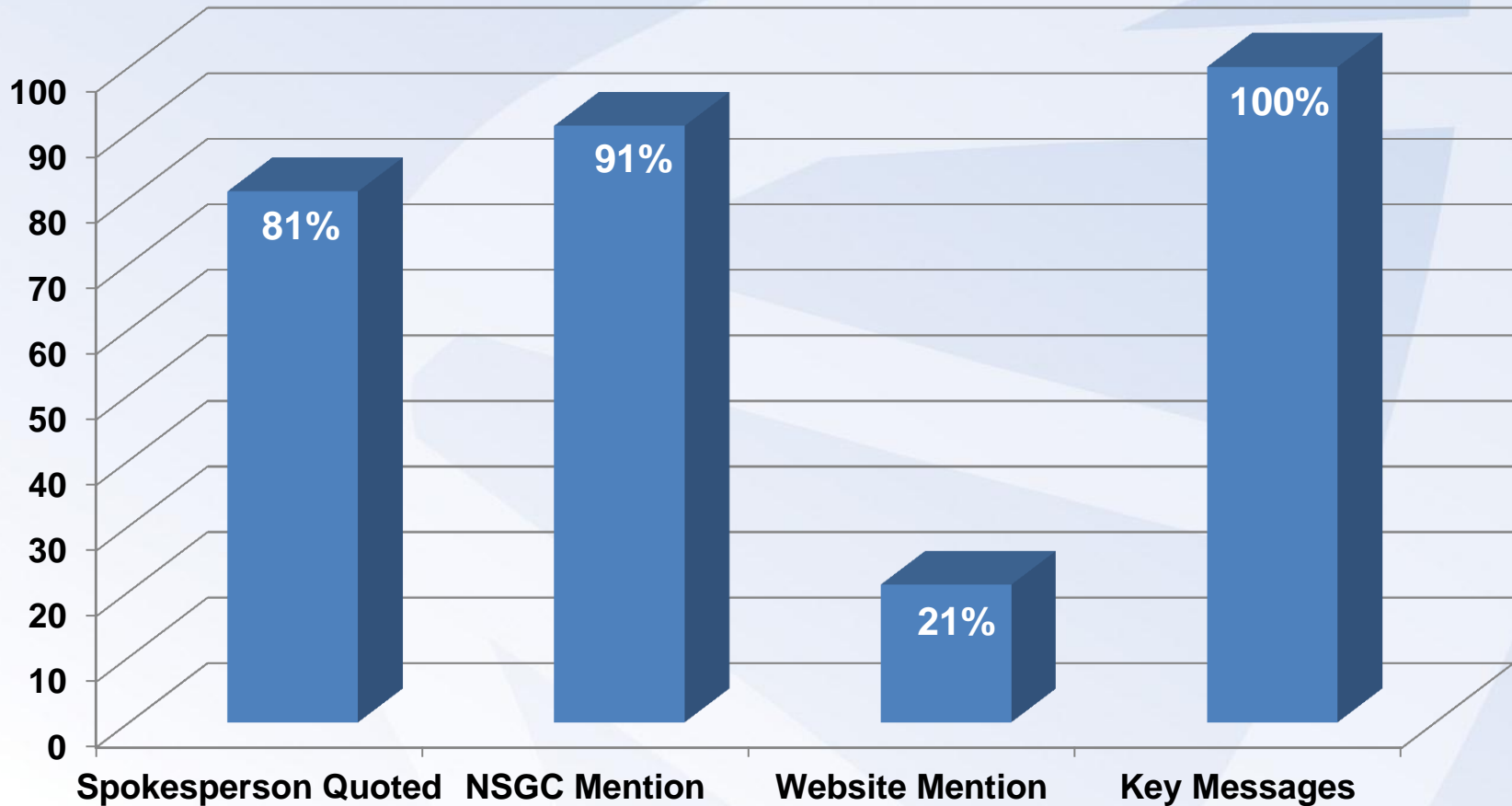


www.nsgc.org

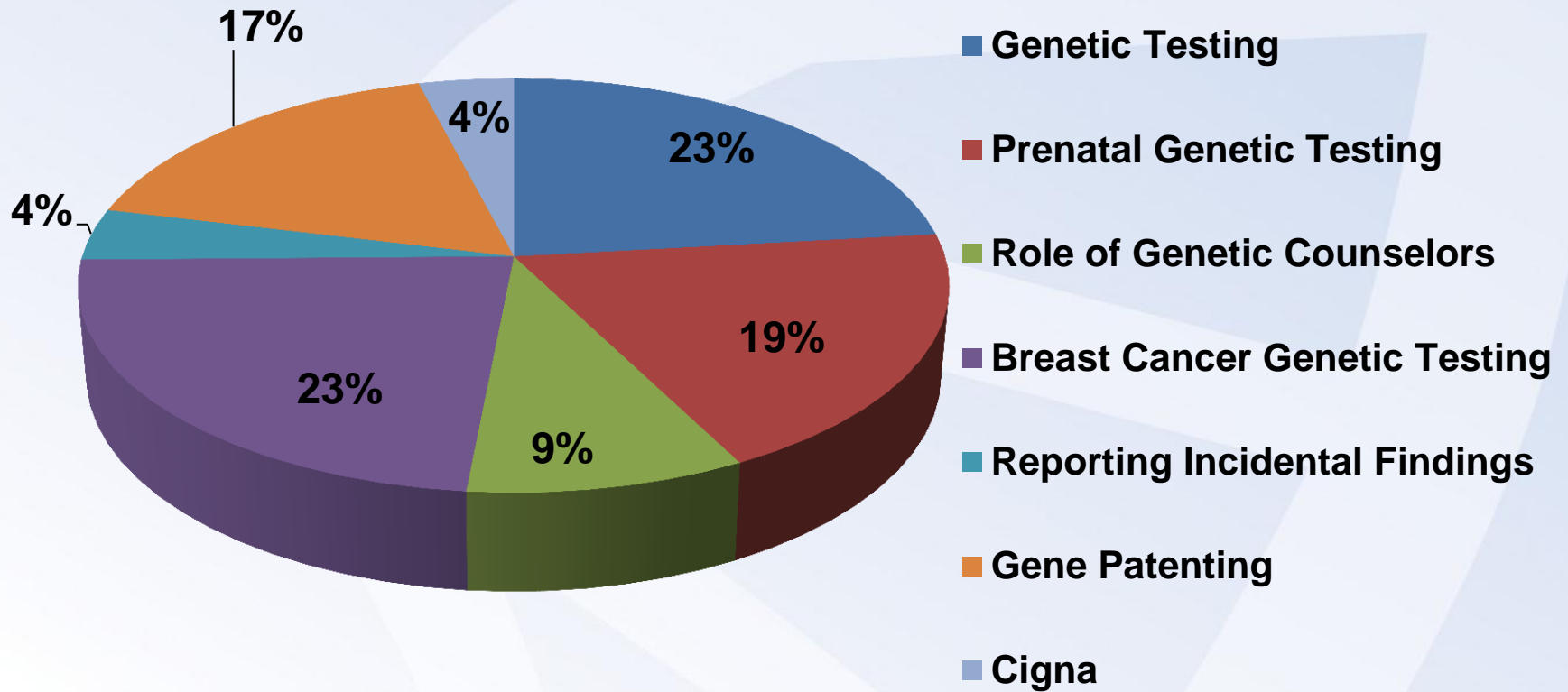
Media Coverage by the Numbers

- During 2013, we secured a total of **48** original media placements (**582** including pick-up) reaching an estimated audience of more than **68 million**.

Key Metrics for Media Placements



Placements by Topic



NSGC Media Coverage Highlights



Doctors, patients praise Jolie's openness on surgery



*Do Right
by Your DNA*

Money

Cracking Open
Your Own Code

Parade

What's Lurking in
Your DNA? *And do you really
need to know?*

Los Angeles Times

Angelina Jolie mastectomy: A closer look at DNA,
breast cancer risk

PREGNANCY & newborn *Have you heard
about genetic
counseling?*

AP

National Society of
Genetic Counselors
**JOLIE ADMIRER FOR BRAVERY IN MASTECTOMY
REVELATION**

WebMD

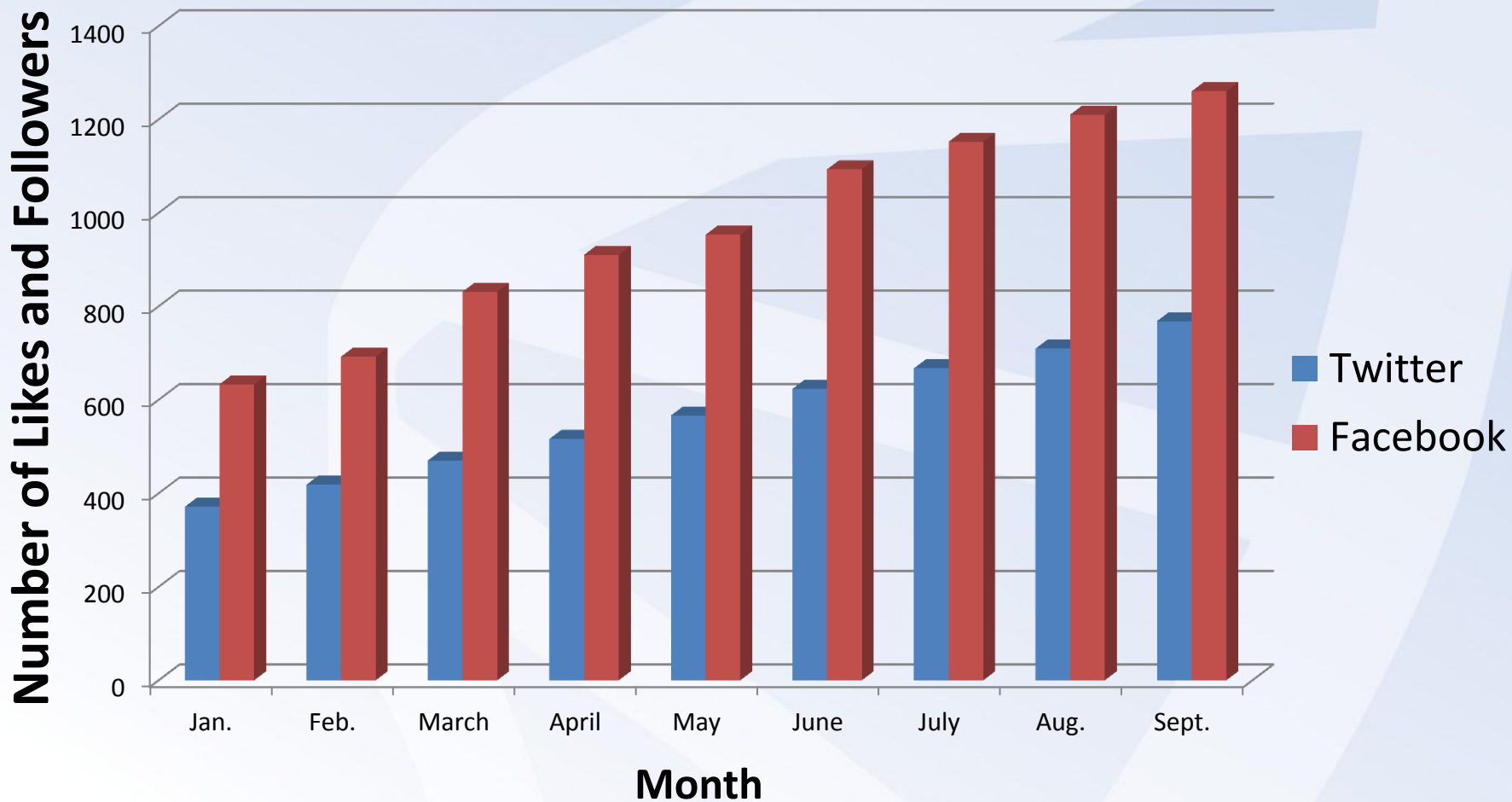
Supreme Court: Human Genes Can't Be Patented
Decision should have profound impact on medicine, gene-testing industry

Social Media by the Numbers

2013 was a year of growth!

- We grew NSGC's Twitter followers by **107 percent**
- **Nearly doubled** Facebook likes with an online audience of **more than 2,000** members, consumers and media.

NSGC Facebook and Twitter Growth in 2013



NSGC Social Media Highlights



Dr. Muin Khoury

@DrKhouryCDC

Follow

RT @GeneticCouns If you have questions about BRCA please talk to a genetic counselor! NSGC.org



Genetic Counselors

@GeneticCouns

Follow

NSGC's President talks about how DNA influences breast cancer risk and what women can do about it in @latimeshealth lat.ms/1o1IqL

Reply Retweet Favorite More

Los Angeles Times

Angelina Jolie mastectomy: A closer look at DNA, breast cancer risk

By opting for surgery to remove her breasts while they were still healthy, Angelina Jolie joined a growing number of women who have used genetic testing to take control of their health.



Genetic Counselors

@GeneticCouns

Follow

How can genes help diagnose #psychiatric disorders or predict early onset? Read how in @PsychTimes bit.ly/1oEQdD3



Genetic Counselors

@GeneticCouns

Follow

Our President explains what the @USSupremeCourt gene patent ruling means for BRCA1 BRCA2 tests in @medpagetoday bit.ly/162ZuTv

Reply Retweet Favorite More

MedPage Today

National Society of Genetic Counselors

July 12

Genetic counselors, particularly those who specialize in cardiovascular disease, are uniquely qualified to help surviving family members navigate the medical and psychosocial issues after a young sudden cardiac death attributable to genetic causes. GCs partnered with the National Association of Medical Examiners to develop a paper on how to assess and help these families: <http://bit.ly/11BM3qF>

At least



of young sudden cardiac deaths are linked to genetic causes

Like · Comment · Share

25 11

1,399 people saw this post

Boost Post

National Society of Genetic Counselors

February 27

NSGC's Find a Genetic Counselor tool is featured in March issue of O, The Oprah Magazine. <http://bit.ly/13k8mpX>

Like if you agree!

Until the majority of doctors catch up with the science, meeting with a genetic counselor or a clinician with training in the field is your safest option.



Like · Comment · Share

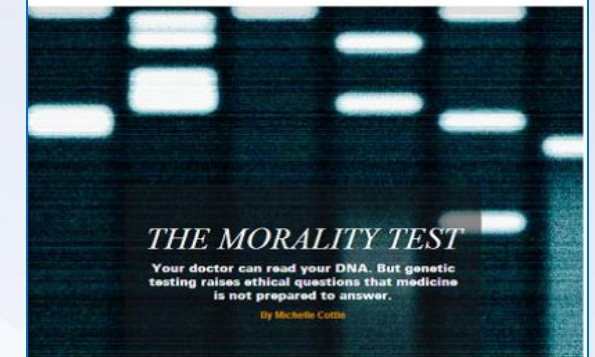
214 people like this.

K.C. Hauck Well heck, if Oprah says so....
March 1 at 2:38pm · Like · 1

National Society of Genetic Counselors

June 5

In a feature article out today, Newsweek analyzes the ethical questions behind genetic testing, as well as how GCs support physicians. NSGC's President explains "A basic tenet of genetics is that patients should have autonomy—meaning the right to choose what they do and do not want to know." <http://thebea.st/15AWIES>



Like · Comment · Share

20

Vivi Einy, Carol Hallett Laubitz, Debra Collins and 35 others like this.

Growth of our profession is critical

Growth

- Workforce growth working group
- Collaboration with ACGC, ABGC & AGCPD
- Diversity
- New practice settings

Access and Service Delivery Committee

- New working group in 2014

Collaborative partners

- Collaboration between all stakeholder organizations critical

Members

- Start a GC training program
- Highschool and undergraduate outreach
- Promote profession locally

Addressing Demand: Looking to the Future of the Profession

- Continued growth at current rate while expanding the number of training programs/graduates
- Define obstacles to the growth of the profession
- Determine how we can overcome obstacles
- Consider how to address immediate demands and access issues

**New workgroup to address these issues
beginning in 2014**

NSGC member benefits

- High quality educational programming
- Programs, products and services
 - > Ethics Advisory Group
 - > Grant awards
 - > Professional Status Survey
- Networking and expertise
 - > AEC, discussion forums, SIGs
- Professional growth and development
 - > Volunteer opportunities, mentorship

Education Committee

- Annual Education Conference
 - > Another excellent program!
 - > 2013 outreach event to college students
 - > 2014 planning underway
 - > Abstract sub-committee appointing a task force to look at AEC abstract review process

Education Committee

- Six online webinars
 - > Whole exome sequencing, Gene patenting, Intro to NSGC committees, CoC standards, Pharmacogenetics
 - > **1065** attendees
- Maintain and evaluate CEU opportunities
- Online Courses
 - > 2013: *Career advancement and Professional development*
 - > JOGC CEU Program
 - > Popular past online courses renewed for CEUs
 - > AEC Recordings

Membership Committee

- Successfully Redesigned Mentor Program

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

Professional Status Survey



- The 2014 PSS opens in January
 - > Important data for the genetic counseling community, so please participate!
 - > All full NSGC members and ABGC delegates will be eligible to complete the survey
- Remember that higher participation rates translate to better data for all of us; so please take a few minutes out of your day to help yourself as well as your profession!!

Task Forces

- COI Task Force

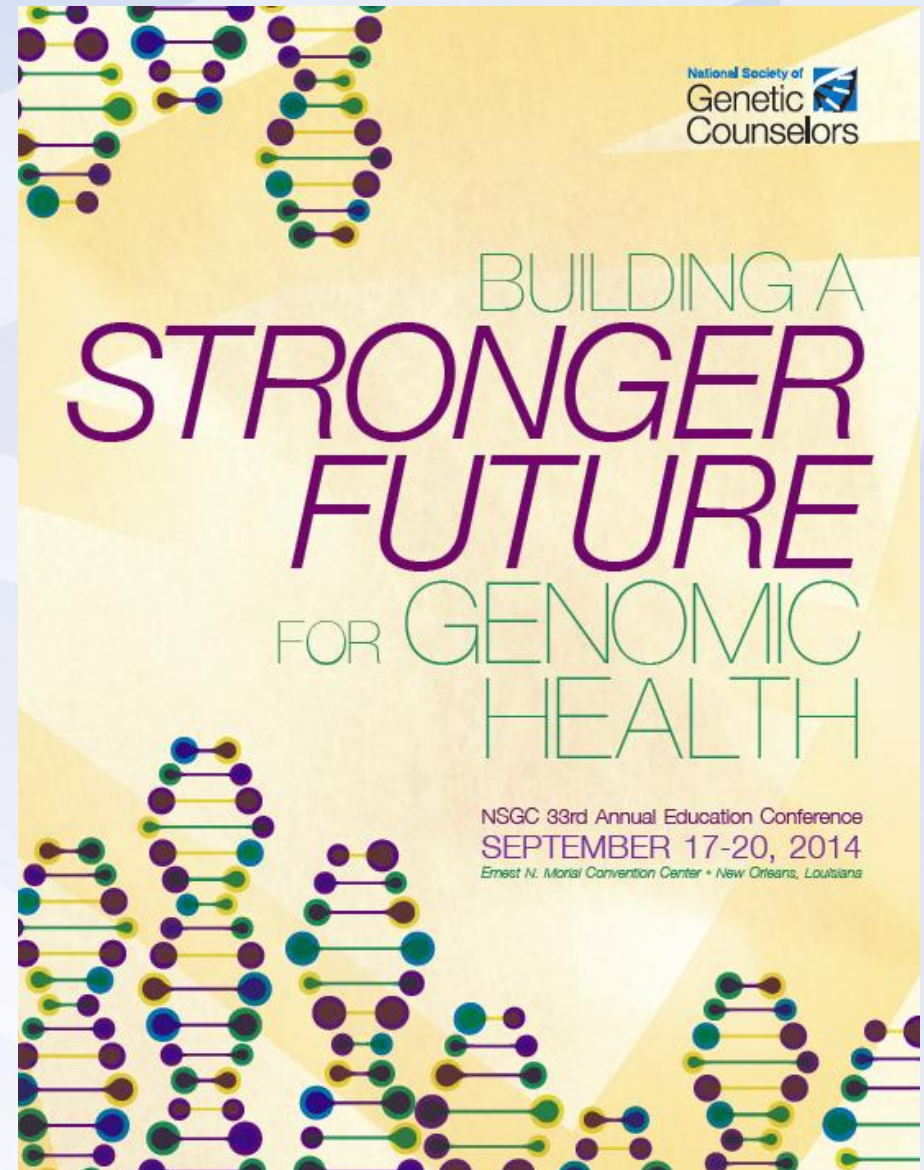
- > Reviewed and revised NSGC's various COI policies
- > Addressed gaps in the policies and aligned with IOM recommendations

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...

2014 AEC

- **Join us in New Orleans!**
 - > Ernest N. Morial Convention Center
 - > New Orleans Hilton
 - > September 17-20, 2014



THANK YOU !