

# State of the Society

**Brenda Finucane, MS, CGC**  
**NSGC President, 2012**

# Our Mission and Vision

- Mission

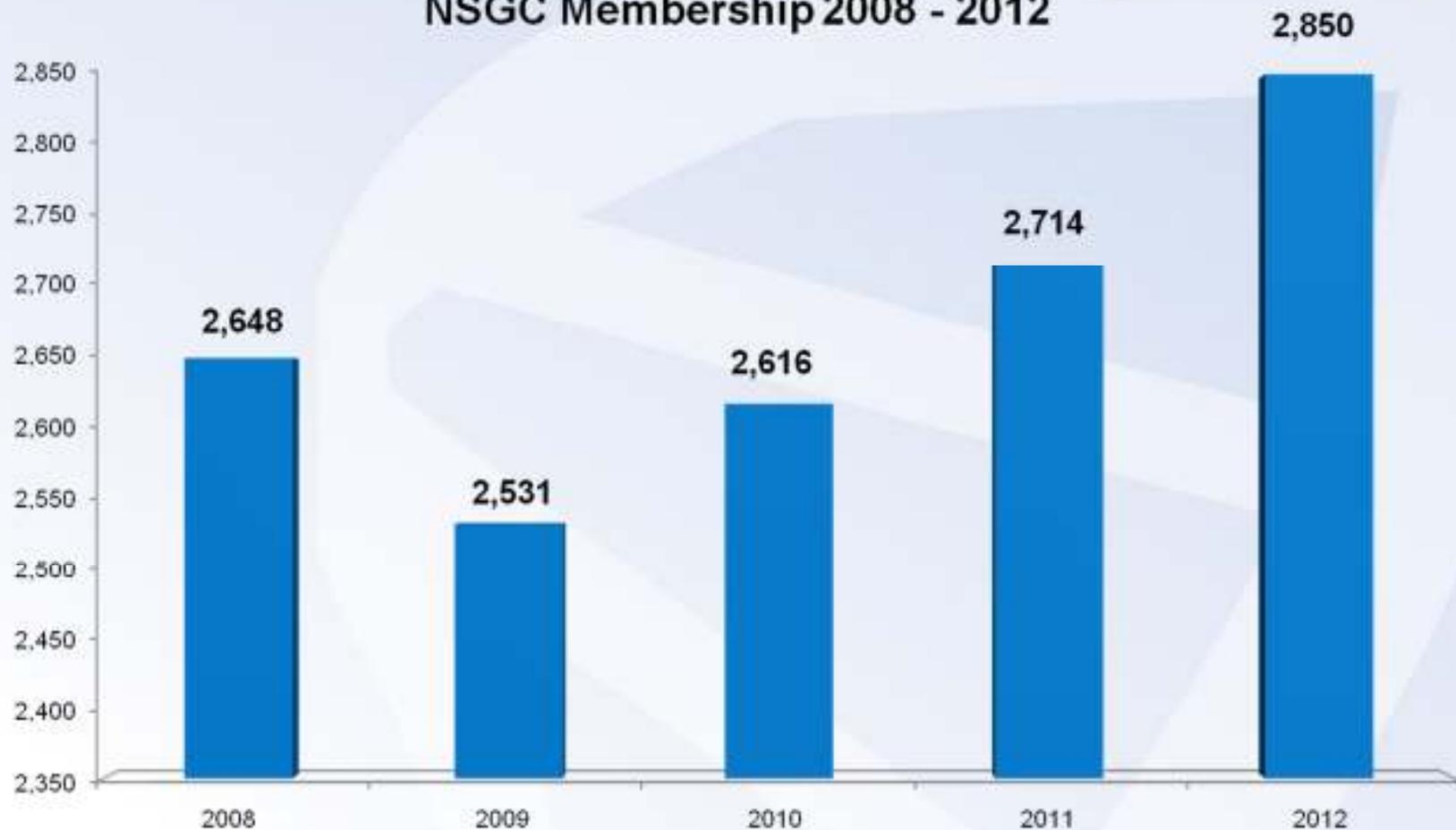
- > The National Society of Genetic Counselors advances the various roles of genetic counselors in health care by fostering education, research, and public policy to ensure the availability of quality genetic services.

- Vision

- > Integrating genetics and genomics to improve health for all

# NSGC Continues to Grow

NSGC Membership 2008 - 2012



# NSGC Continues to Grow

Operating Revenue 2008 – 2013 (projected)



# NSGC's 2012-2014 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

- Educating our workforce
- Service Delivery Models
- New practice settings
- Collaboration with ABGC & AGCPD
- Collaborative Genetic Services Summit

## 2012 Committee Chairs and Vice Chairs

### Communications Committee

Kimberly Barr, Chair

Sara Riordan, Vice Chair

### Education Committee

Leigha Senter, Chair

Kelly Jackson, Vice Chair

### Access and Service Delivery Committee

Shanna Gustafson, Chair

Stephanie Cohen, Vice Chair

### Membership Committee

Bronson Riley, Chair

Kami Wolfe Schneider, Vice Chair

### Public Policy Committee

Flavia Facio, Chair

Jill Stopfer, Vice Chair

### Practice Guidelines

Margo Grady, Co-Chair

Adam Buchanan, Co-Chair

# Access and Service Delivery Committee

## ■ Payer Subcommittee

- > Builds on the work done in 2011
  - > Data to support that GCs result in cost savings
    - ✓ Require GC before covering certain genetic tests and after testing
    - ✓ Reimburse CGCs for genetic counseling services
    - ✓ Recognize GCs as preferred providers of genetic counseling
  - > 2012: outreach to five national payers and regional or smaller payers in states with licensure
  - > Meetings will continue into 2013.
- 
- Data from Subcommittee is also supporting our Federal effort

### Case Example 1: Wrong genetic test is ordered

Boy is diagnosed with an inherited cardiac disease, and is found to carry a genetic mutation.

To assess risk for brother, physician orders full gene sequencing (\$5000), rather than targeted testing for the familial mutation (~\$500).

Genetic counselors would have enabled more targeted and less expensive genetic testing.



### Studies support physician demand for Genetic Counselors

- 71% of physicians rated their knowledge of genetics and genetic testing as poor and almost all would refer to a genetic counselor.

*Mt. Sinai J of Med* 2001; 67(2): 144-51.

- Surveyed physicians rated genetic counseling information as important on genetic test reports.

*Genetics in Medicine* 2003; 5(3): 166-71.



### Studies support consumer demand for Genetic Counselors

- Some women undergoing prophylactic surgery believed their risk for breast cancer to be higher than it actually was. Authors concluded that women should receive genetic counseling prior to the decision about prophylactic surgery.

*J Natl Cancer Inst* 2002; 94(20): 1564-9.



# Access and Service Delivery Committee

- Service Delivery Models Task Force
  - > Survey of SDMs utilized by NSGC members:
    - Identification and evaluation of SDMs
    - GCs incorporate non-traditional SDMs to address growing demand
    - Further exploration of SDMs to increase access and efficiency
  - > Publication in JOGC
  - > Second publication under review by JOGC.

# Practice Guidelines Committee

- Four new guidelines completed since Nov 2011
  - > Cancer Risk Assessment
  - > Lynch syndrome
  - > Genetic Counseling and Testing for *FMR1* Mutations
  - > Fabry Disease
- > Six (6) additional guidelines in development or revision

# State Licensure

- State Licensure Progress

- > 11 currently issuing licenses: CA, DE, IL, IN, MA, NM, OK, SD, TN, UT, WA
- > 4 in rulemaking: HI and NJ, OH, PA
- > 3 with bills introduced: NY, RI, TX
- > 13 with bills in preparation: CT, FL, ID, KS, MD, MI, MN, MS, NE, NH, OR, WI, VA

A total of 31 states at some point in the process

# Federal Efforts

- > Pursuing Medicare legislation to recognize GCs as independent HCPs
- > Met with members of Congress and committees of jurisdiction
- > Actively in discussion about bill sponsorship
  - > Seeking sponsor that is likely to be re-elected
  - > Seeking private “score” to prove cost neutrality or savings
  - > Introduction before year end

# Public Policy Committee

- New Position Statements in 2012

- > Non-Invasive Prenatal Testing
- > Blood Spot Storage and Use
- > Newborn Screening

- > Others in revision or development:

- Stem Cell (under review)
- Family History in the Electronic Health Record (under review)
- Testing Minors for Adult-Onset Conditions (in process)



# NSGC Collaborations and Liaisons

AMA Health Care Professional  
Advisory Committee

National Accreditation Program  
for Breast Centers

AGCPD

ABGC

HRSA

IOM

MDA Coalition

National Advisory Council for  
Human Genome Research

Secretary's Advisory Committee on Heritable  
Disorders in Newborns and Children

ACOG

NHGRI

NCHPEG

ACMG

National Newborn Screening  
and Genetic Resource Center

ASCO

SMFM

ACCC

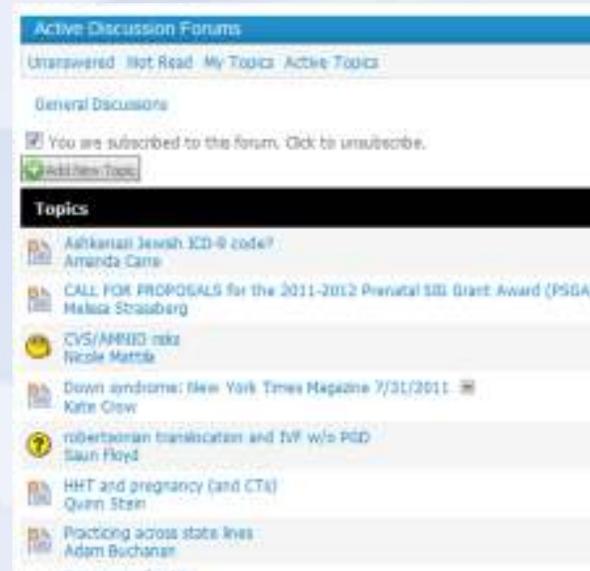
NBS Connect

American College of  
Surgeons Commission  
on Cancer

CAGC

# Communications Committee

- Reinforcing our brand
- Website
  - > Enhanced information for MD/HCPs
    - SIGs provided specialty-specific content
- Reviewed/Updating NSGC publications and products
  - > Revising out of date publications
  - > Moving many to online availability



# Communications Committee

- Self-Marketing Tool Kits
  - > Market yourself to physicians, primary HCPs
  - > Educate about value of partnering with a genetic counselor
  - > Soon to include specialty-specific inserts



# Education Committee

- Webinars
  - > Online, free, timely information
- Maintain and evaluate CEU opportunities
- Online Courses
  - > 2012: *Why choose just one gene? Large panel tests for genetic conditions*
  - > JOGC CEU Program
  - > Popular past online courses renewed for CEUs
  - > AEC Recordings

# Education Committee

- Annual Education Conference
  - > Another excellent program
  - > 2012 outreach event to high school / college students
  - > 2013 planning underway with expanded EBS schedule

# Membership Committee

- Successfully Redesigned Mentor Program
- Ongoing Student Programs
  - > Additional summer rotations / scholarships support student involvement and education
    - Cultural Competency Scholarship
    - Student Rotation programs
- Diversity Subcommittee



NSGC Mentor Program

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

# Membership Committee

- Leadership Development Task Force
  - > Leadership development program – piloted in 2011, enhanced in 2012
- Ongoing Evaluation of Nominations and Elections
  - > Recommended changes that were implemented in 2012
    - Remove President-Elect from Nominating Committee
    - Addition of another At-large member
- Continually working to ensure the value of NSGC membership
  - > New in 2013: increased emeritus benefits

# Task Forces

- Leadership Task Force

- > Launched redesigned Leadership Development Session in 2011; provided feedback for refinement of program in 2012
- > Evaluating the impact of NSGC leadership training
- > Making recommendations for leadership programming to support all members

- COI Task Force

- > Assessing NSGC's various COI policies, outlining guiding principles and identifying any gaps
- > Making recommendations to address gaps or strengthen current policies

# 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**

# 2012 Professional Status Survey

- Biannual survey of full members of NSGC
- First completed in 1980
- Earlier timeline
- Utilized by members and employers to:
  - > Provide comparison data for salaries and benefits
  - > Identify workforce issues facing the profession
  - > Gauge job and professional satisfaction in the community
- 2012 survey used by outside parties to set benchmarks:
  - > US Bureau of Labor Statistics
  - > US Department of Labor
  - > Online providers of employment data

# Changes for 2012

- First time all ABGC delegates invited to take survey
- Full reports available to non-members for purchase
- Executive summary available to public at no cost
- Greater differentiation for genetic counselors with multiple positions and/or working part time
- Inclusion of telemedicine and billing questions

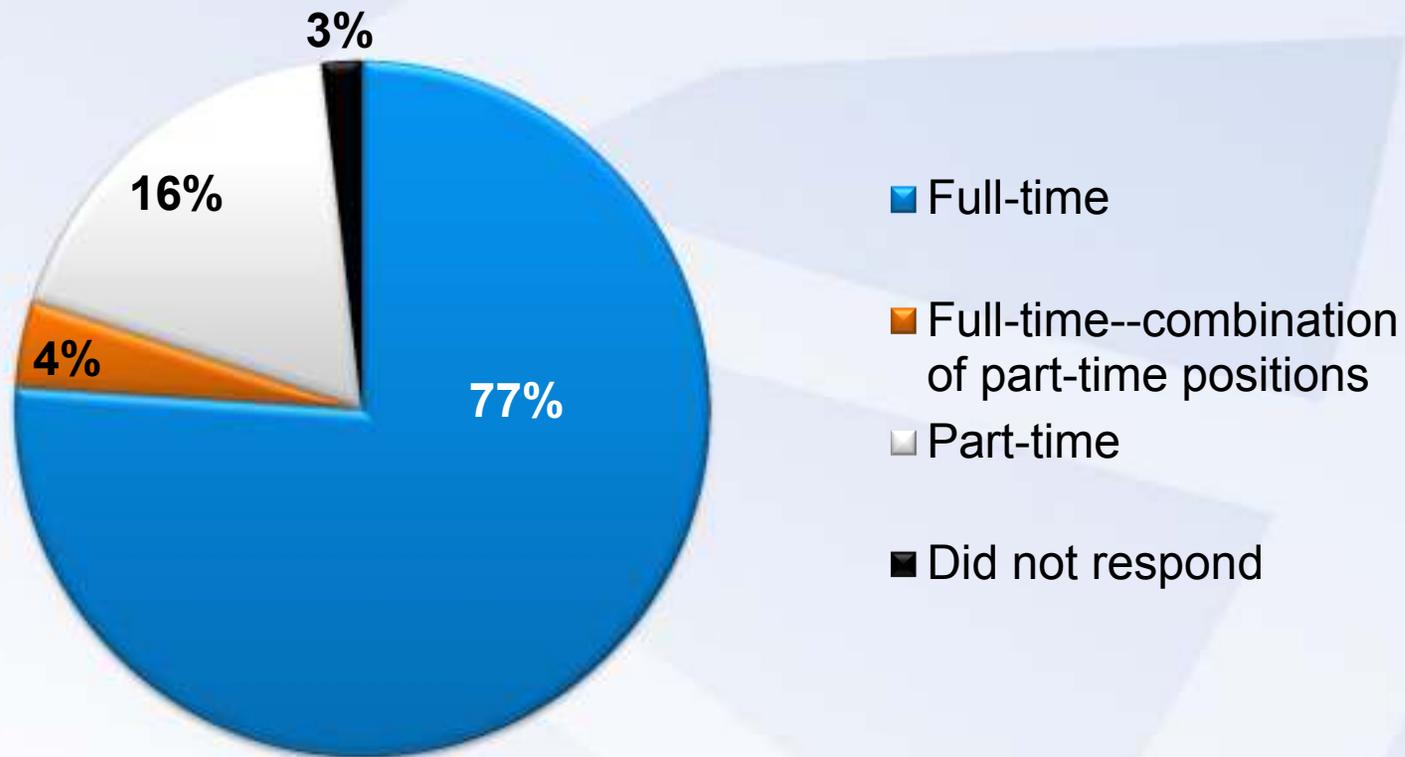
# 2012 PSS Overview

- 1,339 respondents (44% response rate)
  - > 200 more than 2010
  - > 956 (89%) were NSGC members; 116 (11%) non-NSGC members
  - > 303 New to PSS
- 80% provided salary information (1072/1339)
- 21% (N=281) used a previous PSS to help increase salary
  - > Of those, 67% were successful
- Demographics
  - > Over half now serving rural communities
  - > Majority in 29 to 39 age group
  - > 2% hold doctoral degree; 9% hold other advanced degrees including: MPH, BSN/RN, MBA, MSN, MSW/MSSW, JD and Med.

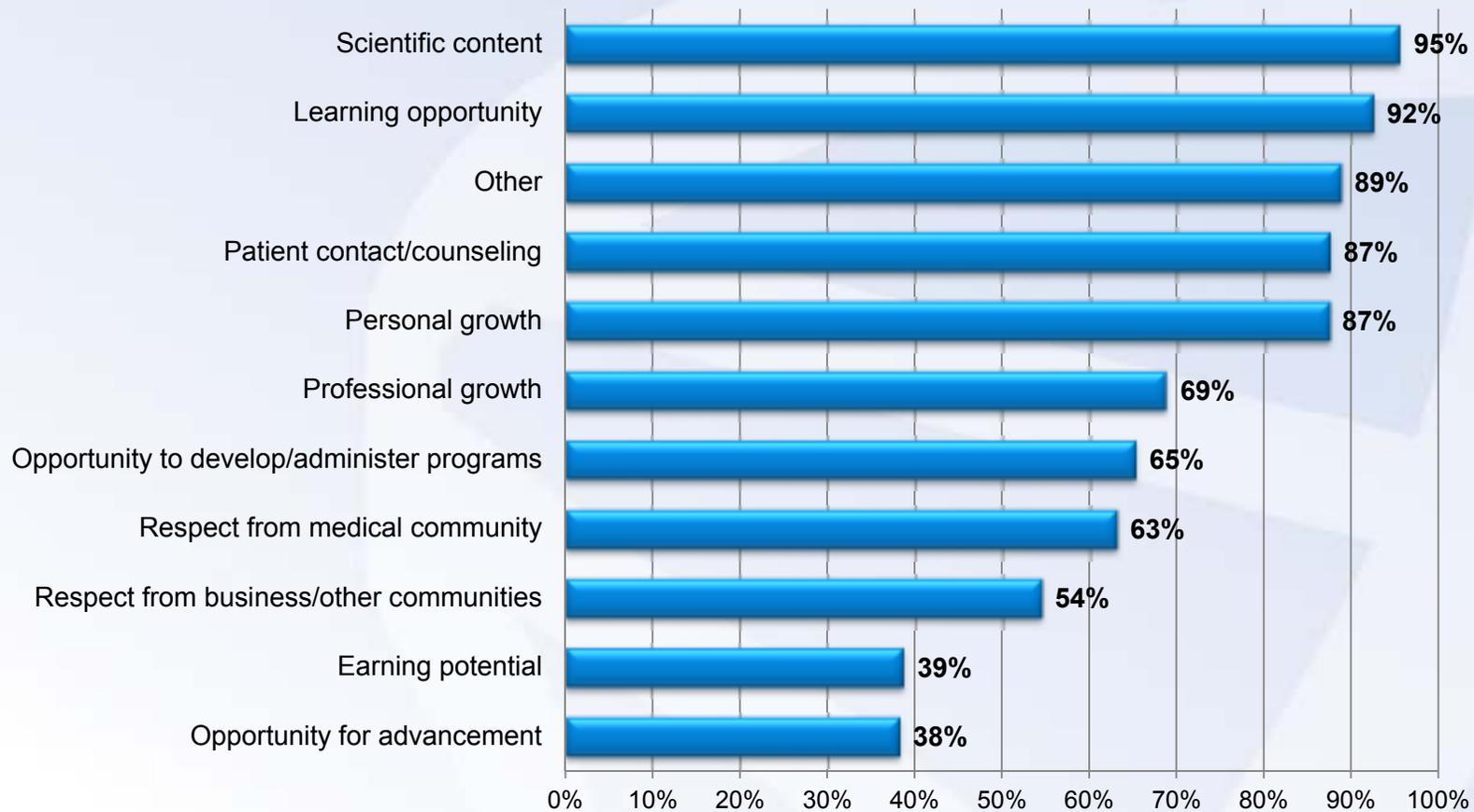
# Work Environment

- 83% of respondents are “clinical” genetic counselors
  - Over 1/3 of them work in a University Medical Center
- 17% are “non-clinical” genetic counselors
  - Over 1/3 work in a Diagnostic Laboratory – Commercial
- Information about patient volume, time spent for an average case, office staffing, MD supervision, reimbursement for services
- Since 2010, 57% of counselors reported an increase in patient volume, while 32% saw no change and 9% saw a decrease (averages at 8.6 new patients and 3 returning patients per week)
- 19% have faculty appointment

# Work Environment



# Professional Satisfaction: 2012 PSS



Overall, the majority of genetic counselors (91%) report they were satisfied with their job.

# Salary and Benefits

- Only  $N \geq 5$  is reportable
- Data reported in means, medians, as well as 25<sup>th</sup>, 75<sup>th</sup>, and 90<sup>th</sup> percentile
- Specific section detailing information from respondents who are employed part-time
- Segmented by “clinical” vs. “non-clinical” and by:
  - > Gender
  - > Region
  - > State/Province
  - > Years of Experience
  - > Region by Years of Experience
  - > Specialty Areas
  - > Certification Status
  - > Licensure
  - > Major Metropolitan Areas
  - > Specialty Areas by Years of Experience
  - > Work Setting
  - > Job Classification
  - > Earned Degrees
  - > Faculty Titles

**AVERAGE SALARY FOR FULL TIME WAS  
\$68,066**

**8% INCREASE VS. 2010**

# Acknowledgements

- Contact us with any questions regarding survey administration and results ([psscomments@nsgc.org](mailto:psscomments@nsgc.org))
- The PSS workgroup
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  - EMI - Online Research Solutions
- John Richardson and the Access and Service Delivery Committee

***Thank you to everyone who completed the survey!***

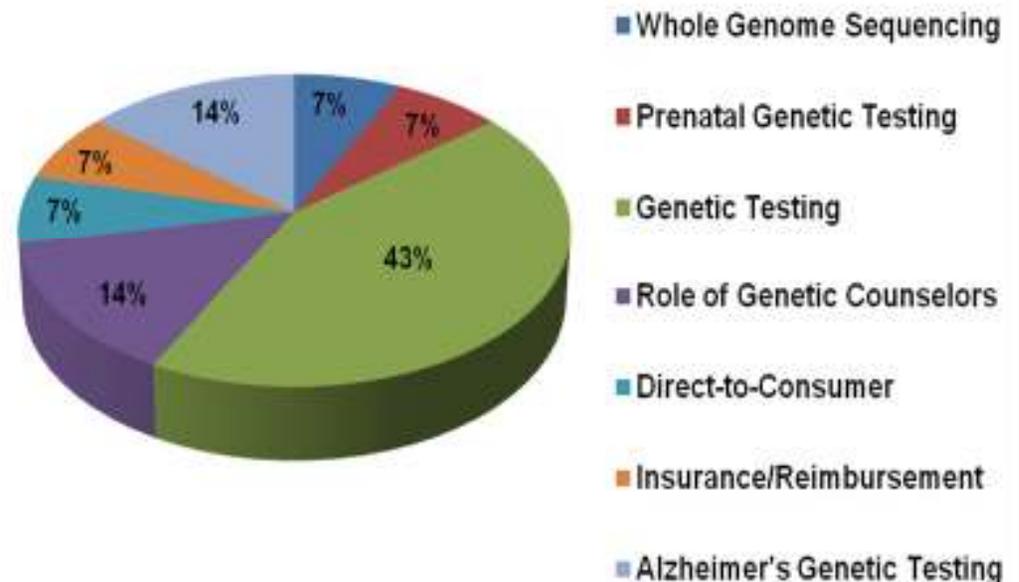
# Public Relations – 2012 Highlights

- To date in 2012, we have secured **52** media placements reaching an estimated audience of more than **17.5 million**.

Key placements include:

- *American Medical News*
- *Chicago Sun-Times*
- *Chicago Tribune*
- *Dallas Morning News*
- *Detroit Free Press*
- *Health Technology Trends*
- *New York Times*
- *San Francisco Chronicle*
- *USA Today*
- *Wall Street Journal*
- *Washington Post*
- *NYTimes.com*
- *TED.com*
- *WashingtonPost.com*
- *WSJ.com*

Percentage of Placements



# NSGC participation in GCADTF

The Genetic Counseling Advanced Degree Task Force (GCADTF) was formed by the professional organizations in genetic counseling (NSGC, ABGC, AGCPD, CAGC) to discuss whether the profession should adopt a clinical doctorate

- Activity began in March 2011 at ACMG meeting
- Monthly conference calls
- Webinar
- Resources available online
  - Webinar recording
  - Q&A
  - Bibliography

# GCADTF Process

- Investigate standards and considerations in transition to CD across other professions
  - > Educate GC community about potential move towards CD and experience of other professions
  - > Evaluate stakeholder opinions including GCs, employers, educational institutions, colleagues
  - > Convene summit of professional leadership organizations to exchange ideas and present findings
  - > Hold vote\* to determine whether profession will adopt a clinical doctorate\*\*

\* Voting bodies include: NSGC, AGCPD, CAGC, ABGC/ACGC, members at large (3)

\*\*Path to clinical doctorate (entry level vs. advance practice) TBD by GCADTF

# Collaborative Genetic Services Summit

Under NSGC's leadership, brought together primary care providers, genetics specialists and other key stakeholders

- > Held in November 2011
- > Goal: Develop a competency and evidence-based, collaborative model for integrating genetics and genomics into healthcare.
- > Outcome: Developing consensus model(s) in specific specialty areas for triaging genetic and genomic services that can be applied practically in the clinical setting to increase appropriate access.

# 2013 AEC

- **The Future is Now**
  - > Anaheim, CA
  - > Anaheim Convention Center
  - > October 9 – 12, 2013



**THANK YOU !**