

# State of the Society

Karin M. Dent, MS, LCGC  
NSGC President, 2011

# 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

Executive Office

Board Directors

SIGs  
Management

Advisory Group  
Committees

Access and Service Delivery

Public Policy

Communications

Membership

Education

YOU!

Governance

Nominations

Finance

# Current Strategic Plan

## Access

- Reimbursement
  - Federal regulation
  - State licensure
  - Payers
- Service delivery
- Marketing & branding

## Leadership

- Collaborations
- Publications
- Leadership development
- Collaborative Services Summit

## Growth

- Member education
  - AEC
  - Webinars
  - Online course
- Revenue
- New Strategic Plan

# Access and Service Delivery Committee

## ■ Payer Task Force Module

- > Demonstrates GCs improve quality of care
  - Recognize GCs as preferred providers of gc
- > Stabilize and reduce costs
  - Reimburse CGCs for genetic counseling services
  - Require GC before covering certain genetic tests and after testing
- > Increase patient and provider satisfaction
- > Met with United Healthcare, April 2011
- > 2012: outreach to national (Aetna and Humana) and large regional payers, small payers in states with licensure
- > 2012: Payer Task Force » Payer Subcommittee

### 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.

## ■ Practice Guidelines Subcommittee

- > Practice Guidelines for Communicating a Prenatal or Postnatal Diagnosis of Down Syndrome, *Sheets K, et al., J Genet Couns 2011.*
- > Genetic Counseling and Testing for Alzheimer Disease: Joint Practice Guidelines of ACMG and NSGC, *Goldman JS, et al., Genet Med 2011.*
- > Cancer Risk Assessment, *in BoD review*
- > Lynch syndrome, *in expert review*
- > Genetic Counseling and Testing for FMR1 Gene Mutations, *open for member comment*
- > Fabry Disease, *open for member comment next week*
- > 7 additional guidelines in development or revision

Practice Guidelines subcommittee... new Committee in 2012!

## ■ 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

## ■ State Licensure

- > 11 currently issuing licenses: CA, DE, IL, IN, MA, NM, OK, SD, TN, UT, WA
  - > 2 in rulemaking: HI and NJ
  - > 5 with bills introduced: NY, OH, PA, RI, TX
  - > 13 with bills in preparation: CT, FL, ID, KS, MD, MI, MN, MS, NE, NH, OR, WI, VA
- > Total 31

Growth

Access



# Public Policy Committee



Leadership

## ■ Position Statements

- > Disability
- > Genetic Counselors in Healthcare Reform
- > Others in revision or development:
  - DTC (just approved)
  - Nondiscrimination (just approved)
  - Newborn Screening (in process)
  - Blood Spot Storage (in process)

## ■ Federal efforts

- > Pursuing Medicare legislation to recognize GCs as independent HCPs
- > Met with physician associations to move forward as a united front
- > Met with members of Congress and committees of jurisdiction

# NSGC Collaborations and Liaisons

AMA Health Care Professional  
Advisory Committee

National Accreditation Program  
for Breast Centers

AGCPD

ABGC

IOM

MDA Coalition

HRSA

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

National Advisory Council for  
Human Genome Research

NCHPEG

Leadership

ACOG

NHGRI

ASCO

ACMG

National Newborn Screening  
and Genetic Resource Center

SMFM

CAGC

Growth

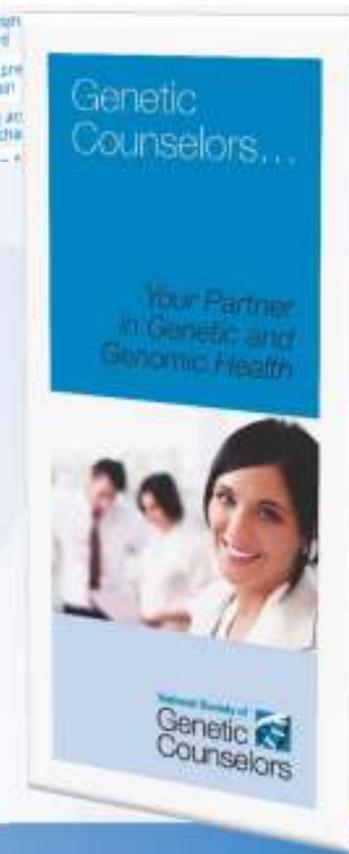
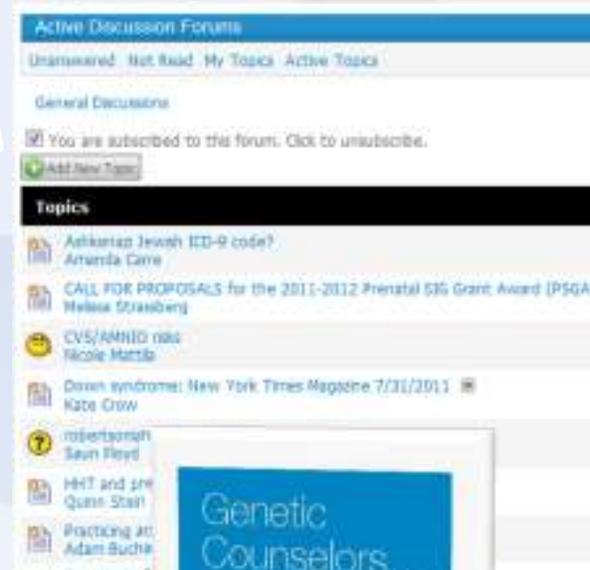
NBS Connect

American College of  
Surgeons Commission  
on Cancer

# Communications Committee

- Reinforcing our brand
- Website
  - > Enhanced information for MD/HCPs
    - SIGs provided specialty-specific content
  - > Discussion Forums
    - Up to date technology, ability to expand
- Self-Marketing Tool Kits
  - > Market yourself to physicians, primary HCPs
  - > Educate about value of partnering with a genetic counselor
  - > See a preview at the NSGC booth
- Reviewing/Updating NSGC publications and products

Access



# Education Committee



Growth

- Webinars
  - > New this year
  - > Online, free, late-breaking
- Maintain and evaluate CEU opportunities
- On-line Courses
  - > 2011 Genomics and Personalized Medicine
- JoGC CEU Program
- Annual Education Conference
  - > Excellent program
  - > 2011 outreach event to high school / college students
  - > 2012 planning underway
- Outreach education

Leadership

# Membership Committee



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

- Redesigned Mentor Program
  - > Enhance networking opportunities for NSGC members
  - > 2 six month cycles of Match / Mentor phases completed
    - 240 members, half registered as mentors
    - 40 matches each cycle
- New Student Programs
  - > Additional summer rotations
    - Informed, St. Petersburg, FL. 2011 first year, great feedback.
    - Lineagen, Salt Lake City, UT. 2012 first year
  - > Cultural Competency Scholarship
- Leadership Development Task Force
  - > Leadership development program for GCs – pilot 2011

Leadership

## ■ Professional Status Survey, 2012

- > Establishes benchmarks for salaries and benefits
- > Identifies workforce issues facing the profession
- > Gauges job and professional satisfaction in the community
- > Administered biennially (2010)

### - New for 2012:

- ✓ New survey administrator
- ✓ Survey all genetic counselors (including non-members)
- ✓ Results available June 2012

Your participation is IMPORTANT!

# Special Interest Groups (SIGs)

- New SIGs this year
  - > Education
  - > Health Information Technology
- SIG Strategy (2010)
  - > Provide education to the general NSGC membership
  - > Contribute to the NSGC Strategic Plan
  - > Demonstrate value of SIG membership as a member benefit



Leadership

## Education

- AEC: EBS and Plenary sessions
- Pre-conference symposia
- Webinars
- Online courses

## Publication

- Practice Guidelines
- Multiple articles: Sci Transl Res, Ob/gyn and infertility nurses, Hem Onc Today, Comm Onc, DTC manuscript, etc.
- Book: “How to talk to families about genetic and psychiatric illness.” (Psych)

## Collaboration

- Expertise utilized by NSGC BoD: PM, Health IT, Prenatal
- Committees and fellow SIGs
- CV and N.A.M.E. survey
- Cancer SIG research consortium

## Member Benefit

- Case conferences
- Professional development at AEC
- Patient and GC resources: neuro resource referrals, peds family connection
- Needs assessment and mission evaluation
- Student awards and scholarships

# Public Relations – 2011 Highlights

- Statements and Press Releases
  - > NSGC applauds FDA for recognition of GCs in DTC testing, March 2011
  - > California licensure of GCs, July 2011
- Media Relations
  - > Alzheimer Joint Practice Guideline
    - Medscape.com
  - > JAMA, letter to the editor
  - > Multiple interviews with GCs with links to NSGC
    - Time, Nature, WebMD, ivillage.com, SELF, MedCityNews.com, etc.
- Reached >8 million audience members!
- 2012 Program Aims
  - > Promote GCs to MD/HCPs through physician organizations
  - > Support Federal advocacy efforts



# Collaborative Genetic Services Summit

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

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

# 2012 – 2014 Rolling Strategic Plan

## Access

- Payer recognition
- Cost-effective, efficient
- Licensure
- Reimbursement
- Promote value

## Value

- Evidence based research
  - Performance measures
  - Publications
- Marketing and Branding
- Collaborate with AGCPD

## Workforce

- Meet increasing demand
- Collaborations
- Service delivery models
- Evidence-based recommendations
- Revenue

# 2012 AEC

- Expanding the Spectrum of Genomic Health
- Boston, MA
- Hynes Convention Center
- October 24 – 27
  - > Wednesday – Saturday



# Celebrate Success...Commit to Our Future

- Volunteer!
  - > Committees, SIGs, Task Forces, Advisory Groups, Board of Directors, etc.
- Donate
  - > Audrey Heimler Special Project Award Fund
- Propose a Practice Guideline
- Market your Services
- Collaborate



**THANK YOU !**