State of the Society Address

Elizabeth Kearney, MS, MBA, CGC
2010 NSGC President
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.
NSGC’s strategic objectives

**Access**
- Reimbursement
  - Federal & state
  - Insurance companies
- Service delivery
- Marketing/branding

**Thought Leadership**
- Outreach
- Publications
- Educating members

**Growth**
- Increase revenue
Experience the value of a genetic counselor. Increase patient satisfaction and enhance the services you provide to your patients.

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?

Learn More
New vision statement

*Integrating genetics and genomics to improve health for all*

-Announced April 16, 2010, DNA Day
Public Relations

- Walgreens’ announcement
  > NSGC press release distributed same day
  > NSGC mentioned in 47 stories
  > Your contact with local media – thank you!

- Year-to-date media placements
  > Total of 83 placements
  > Estimated audience of 105 million
Policy/Advocacy

- Position statements
  - Gene patenting
  - Reproductive freedom
  - In progress:
    - Genetic testing regulation
    - Update on DTC testing
    - Update on genetic non-discrimination

- Federal efforts
  - Testimony and comments to FDA re: genetic testing regulation
  - Input provided to NIH regarding plans for voluntary test registry
  - Comments provide to SACGHS on genetics education of providers and public
Collaborations - Ongoing

- Institute of Medicine (Cathy Wicklund)
- National Coalition for Healthcare Professional Education in Genetics (Angelia Trepanier)
- American Medical Association Health Care Professional Advisory Committee (Debra Doyle)
- American College of Surgeons Commission on Cancer (Scott Weissman)
- HRSA Advisory Committee on Heritable Disorders in Newborns and Children (Cate Walsh-Vockley)
- Evaluation of Genomic Applications in Practice and Prevention (Andy Faucett)
- Genomics Applications in Practice and Prevention Network (Cheryl Harper)
- Society of Maternal-Fetal Medicine Nuchal Translucency Oversight Committee (Renee Chard)
- Down Syndrome Consensus Group (Angela Trepanier and Cam Brasington)
- ACMG Program Committee (Jennifer Hoskovec)
Collaborations - New

- HRSA Advisory Committee on Heritable Disorders in Newborns and Children
  - Subcommittee on Follow up and Treatment (Michelle Fox)
  - Committee on Heritable Disorders in Newborns and Children Health Information Technology Workgroup (Lori Williamson)
- ACMG “value of genetic diagnosis” committee (Barbara Bernhardt)
- ACOG Committee on Genetics (Jill Stopfer)
- National Accreditation Program for Breast Centers (Scott Weissman)
- National Human Genome Research Institute Genetics and Genomics Competency Center (Leslie Cohen)
- Pathology associations (Brenda Finucane)
Access

- State licensure
  - Issuing licenses: IL, IN, MA, NM, OK, TN, UT
  - Passed bills/in rulemaking: CA, DE, HI, NJ, SD, WA
  - Bill introduced: FL, PA, TX, MI, MN, NY, WI, RI
  - Organizing: CT, ID, KS, NH, OH, OR, VA, NE, MS

- Third-Party payers
  - Payer task force established and begun work
  - Leverages knowledge from prior success
  - Support for individual members working with regional payers

- Service Delivery Models
  - Rigorous approach to assessing current delivery models

Attend the Professional Issues Panel Saturday to learn more!
SIG activities and contributions

- Educational contributions
  - late-breaking sessions
  - AEC topics
  - Pre-conference symposia
  - online conference sessions

- Collaborations
  - ACOG Committee on Genetics
  - National Accreditation Program for Breast Centers
  - Commission on Cancer
  - National Association of Medical Examiners conference

- Publications
  - Practice Guidelines – Postmortem banking (CV)
  - Prenatal Screening & CGH
  - Lynch syndrome & HBOC
  - Alzheimer (neuro)
  - Fabry disease (Metabolic)
  - Other Psychiatric, ART, Cancer, Prenatal, PH

- Member benefits
  - Awards (PH, research, psych, cancer, prenatal)
  - Literature review/journal club (PM, Neurogenetics)
  - Case conferences (CV)
Education

- Outreach education
- Online course
- Webinar pilots
- JGC CEUs
- Coding course
Membership programs

- 2010 Professional Status Survey
  > Now available online
  > Restructured reports to better meet various needs
    — Professional Satisfaction
    — Work Setting
    — Salary Survey

- Diversity committee
  > Focus groups here at AEC – tonight, 7:30-9pm
    Cumberland C & A
Practice Guidelines

Proposal
• Breast/Ovarian Cancer* (Cancer Sig)
• Cystic Fibrosis*

Proposal approved

Draft
• Prenatal screening
• Postmortem banking in sudden cardiac death
• Lynch syndrome (Joint with CGA-ICC)
• Cancer referral: (Joint with ACMG)
• Prenatal CGH
• Fragile X*
• Cancer risk*
• Fabry disease*

Review
• Down syndrome
• Alzheimer’s disease: Joint review by ACMG

Approval

Existing guidelines
• NF
• Recurrent Miscarriage
• Consanguinity
• Pedigree
• Nomenclature

*Existing guidelines under revision
Genetic Counseling Foundation (GCF)

- President Vivian Weinblatt
- Foundation allows for tax-deductible donations
  - Members
  - Other foundations
  - Corporations charitable giving
- Key project for 2011
  - Collaborative Genetic Services Summit
  - Question: What are the appropriate delivery models for genetic services in the future?
  - 60% funded and looking for more donors
- **Your help is needed – foundations need:**
  - High membership participation
  - Cover administrative costs

Donate at least $10 at the AEC and enter to win a prize!
Celebrating Success, Commitment to the Future

- Volunteer
- Donate to the GCF
- Participate in member surveys
- Propose a practice guideline
- Approach a payer
- Market your services
Integrating genetics and genomics to improve health for all