# State of the Society Address

# Elizabeth Kearney, MS, MBA, CGC 2010 NSGC President





#### **NSGC** 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.



#### NSGC's strategic objectives



# Thought Leadership

# Growth

- Reimbursement
  Federal & state
  Insurance companies
  Service delivery
  Marketing/branding
- •Outreach
- •Publications
- •Educating members

•Increase revenue









**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

Attend the

Professional

more!

**Issues Panel** 

Saturday to learn

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



## SIG activities and contributions

- Educational contributions
  - > late-breaking sessions
  - > AEC topics
  - > Preconference symposia
  - online conference sessions

Genetic Sales Counselors

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

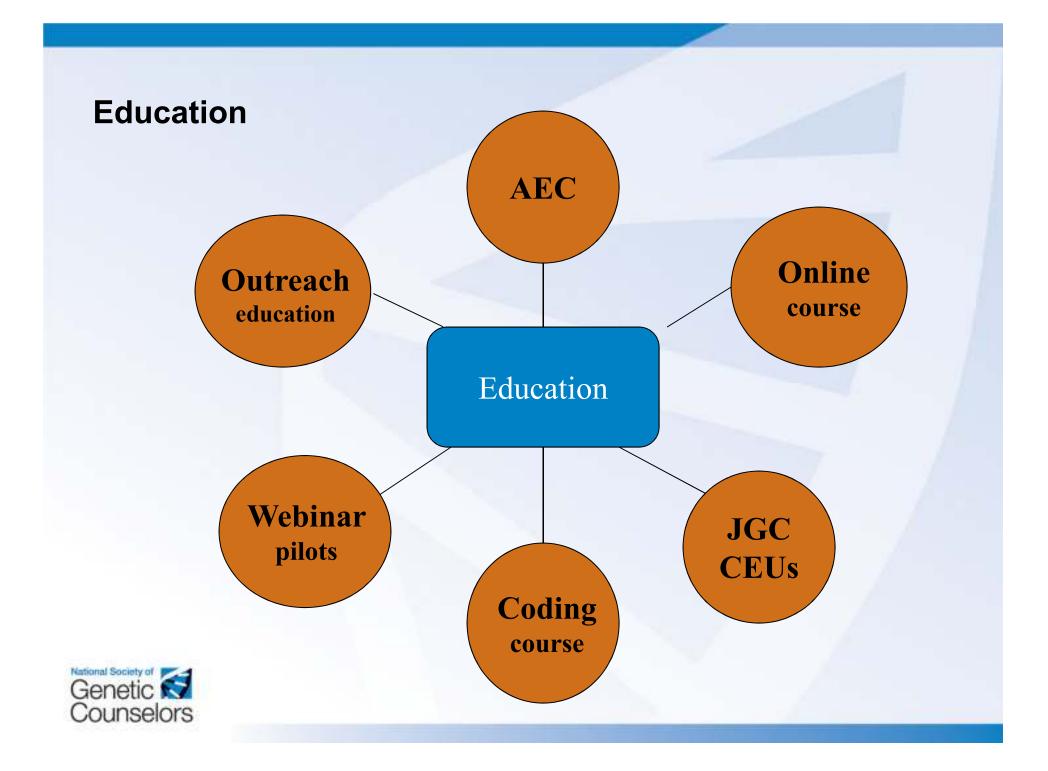
- Publications
  - > Practice Guidelines –
  - Postmortem banking (CV)
  - Prenatal Screening & CGH
  - Lynch syndrome & HBOC
  - Alzheimer (neuro)
  - Fabry disease (Metabolic)
  - Other
     Psychiatric, ART,
     Cancer,
     Prenatal, PH

Member benefits

Thought

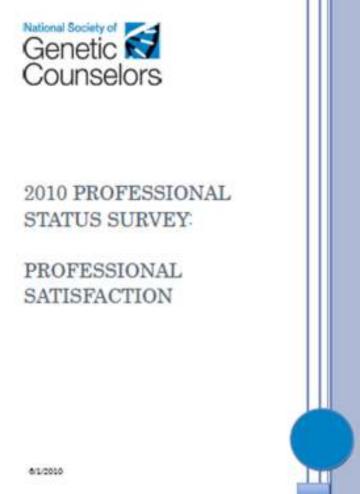
leadership

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

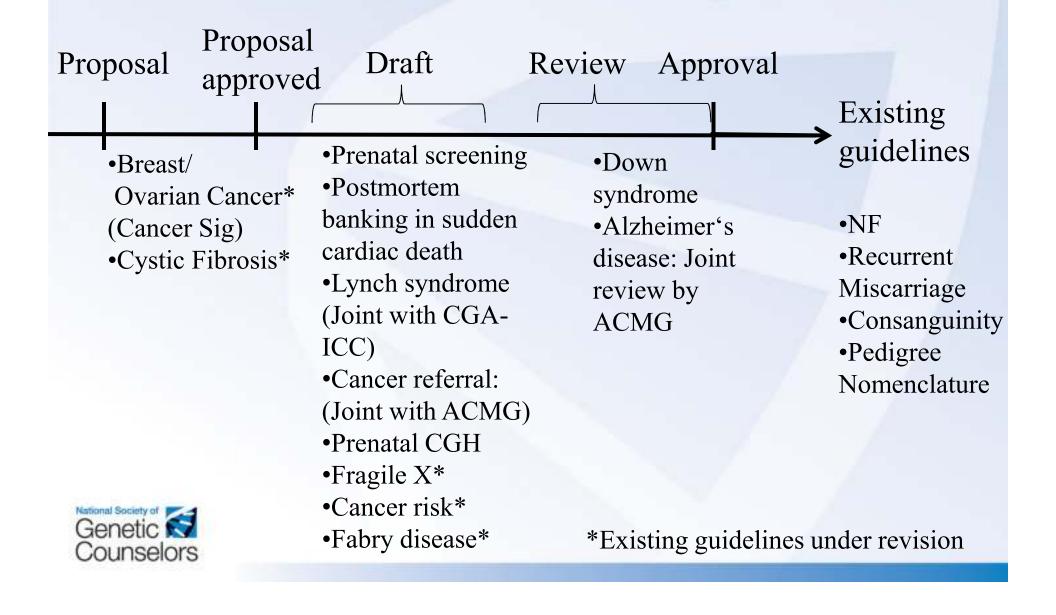


# Membership programs

- 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 Genetic Counselors



### **Practice Guidelines**



# **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

