GENOMICS, ACRONYMS, AND UNDERSTANDING: TRANSLATING GENETICS RESEARCH FROM CANCER FAMILY REGISTRIES TO BEHAVIORAL MEDICINE

Sherri Sheinfeld Gorin (Chair), Deb Bowen on behalf of the Behavioral Working Group of the CGN, Louise Keogh, Jan Lowery, Dennis Ahnen, Kristi Graves, and Sheri Schully
• Genetics and genomics findings will create a positive impact on public health if genetic information is translated for disease prevention, early detection, and/or adoption of risk management behaviors.

• Family cancer registries, offering case ascertainment, collection of validated family histories, and follow-up data, provide unique opportunities for translational research from gene discovery to population health.
Registries are effective tools for population-based behavioral research (Bowen, 2011)

• Recruit diverse and large samples
• Offer participation in multiple studies
• Retain registry members for future (and longitudinal) studies
The aim of this symposium is:

• To examine studies that have translated the findings from family registries to: (1) empirically-based recommendations for cancer care, (2) assessing clinical outcomes, and/or (3) population-level impacts.
• We will highlight the contributions to behavioral medicine of two established international cancer genetics research consortia:
  • Colon Cancer Family Registry (CCFR)
  • Cancer Genetics Network (CGN)
THE COLON CANCER FAMILY REGISTRY (C-CFR)

• Begun in 1997 international consortium, funded by the NCI
• To support research on colorectal cancer etiology
• Six collaborating centers in the US, Canada and Australasia (in California, Hawaii, Minnesota, Ontario, Canada; Washington; Melbourne, Australia)
• Recruited 10,019 probands across all sites (2007)
• Family cancer registries, offering case ascertainment, collection of validated family histories, and follow-up data
• Translational Working Group (TrWG) has described sharing individual genetic test results (Keogh et al., in preparation)
Cancer Genetics Network
(Anton Culver 2008; Bowen, 2011)

- Begun in 2007, funded by NCI, with 8 US sites
- Resource to study the inherited predisposition to cancer
- Enrolled clinical and population-based samples:
  - 20,000 probands who can be re-contacted,
  - 16,000 families, and
  - 435,000 individual family members.
- Core dataset: socio-demographics, hx of cancer, surgeries, 4-generation cancer family pedigree, hx of tobacco use, interest in genetic counseling.
- Some data available on cancer-related outcomes, screening, counseling, and attitudes/beliefs.
- Limited biospecimens.
Recruitment and retention in the Cancer Genetics Network: Deb Bowen on behalf of the CGN

Disclosing Genetic Research Results: Experiences of the Colon Cancer Family: Louise Keogh, Douglass Fisher, Sheri Schully, Jan Lowery, Dennis Ahnen, Judi Maskiell, Noralane Lindor, John Hopper, Terrilea Burnett, Spring Holter, Sherri Sheinfeld Gorin, Mercy Laurino, Pam Sinicrope for the Colon Cancer Family Registry

Outcome analysis of the Family Health Promotion Project: An intervention to improve colonoscopy screening in families at high risk of colorectal cancer: Jan Lowery, Dennis Ahnen, Al Marcus, Nora Horick, Dianne Finkelstein
Lynch Syndrome: A Behavioral Perspective: Dennis J Ahnen MD, Jan Lowery PhD, Al Marcus PhD

A Pilot Study Investigating the Gene Disclosure Process to Colon Cancer Family Registry (CCFR) Participants: Pamela Sinicrope, Kristi Graves, Sandra Nigon, Mary Jane Espllen, Carrie Zabel, Susan Peterson, Jan Lowery, Sherri Sheinfeld Gorin, Pat Harmon, Ellen McGannon, Christi Patten, Noralane Lindor

How do individuals decide whether to accept or decline an offer of genetic testing for colorectal cancer? Louise Keogh, Belinda McClaren, Judith Maskiell, Heather Niven, Alison Rutstein, Louisa Flander, Clara Gaff, John Hopper, Mark Jenkins

Discussant: Sheri D. Schully, Ph.D.