BRCA testing has implications for people with a cancer diagnosis:

- Access to clinical trials (ie-PARP inhibitors)
- Implications for blood relatives’ cancer risk
- Follow-up and preventive cancer for new primary cancer

Breast:
- Surgical decisions

Ovarian:
- Survival may be improved

Prostate:
- Some evidence of more aggressive cancer/poorer survival (BRCA 2)
HBOC Previvors

✧ Survivor of a Predisposition to Cancer = “Unaffected Carriers”
✧ Finding support can be challenging -> marginalized group
✧ Some commonalities with survivors
   ✧ Many of the medical interventions are similar
   ✧ Yet concerns sometimes minimized “At least you don’t have cancer”
✧ Since no manifest disease, concerns are sometimes misunderstood or criticized by others as “over-reaction”
✧ Health/psychosocial concerns are different from survivors and average-risk people
   ✧ Trade-offs of risk-management
     ✧ Risk reduction vs. surveillance
     ✧ Oophorectomy vs. early menopause
   ✧ Hereditary aspects impact family planning and family dynamics
“I need a label! What am I? I lost my mom at a young age to cancer. I lost my breasts to cancer risk. I sacrificed my fertility to prevent cancer. But I don’t have cancer.”

“I may not HAVE cancer, but I KNOW cancer.”

“I know I am at high risk & have been advised to remove my ovaries by age 35. That’s not ok with this unmarried woman with no kids…& it shouldn’t have to be.”

“…it’s tempting to keep my ovaries, because undergoing surgical menopause during my sexual peak feels like another cruel, cruel hand dealt to the BRCA patient…”
Importance of Genetic Counseling

Credible information is critical for decision-making
Genetic Counseling for Informed Decision-Making

✧ Genetic testing for cancer is best done in consultation with a qualified genetics expert
✧ Counseling before genetic testing
  ✧ Identification of hereditary cancer pattern
  ✧ Identification of appropriate tests to be offered
  ✧ Appropriate family members who might consider testing
  ✧ Discussion of benefits, risks, and limitations of testing
  ✧ Assistance with insurance reimbursement for testing
✧ Counseling after testing
  ✧ Interpretation of test results
  ✧ Cancer risk assessment based on test results, personal and family health history
  ✧ Discussion of risk management options that takes into account test results, age, disease risks, priorities and preferences
"I was tested by my breast surgeon. He said I was brca 2+. I had my ovaries out. My siblings were tested and told by same doctor they were brca2+. My niece in another city was referred to a genetic counselor who told her WE ARE NOT POSITIVE! So I saw a geneticist who said I wasn’t positive, we have a “variant of unknown significance” and I didn’t need surgery. I had my ovaries out and was planning to cut off my breasts and I am not positive? Please............help!"
Genetic Counseling for Informed Decision-Making

✧ Genetics is a rapidly evolving area of medicine
✧ People make life-altering decisions based on results of risk-assessment and genetic testing
  ✧ Requires up-to-date, evidence-based information on which to base clinical decisions
✧ Genetic counseling is available in person, via telemedicine, and via telephone
  ✧ Most people in the US will have access to qualified experts through one of these venues
✧ People have expectation and right to receive standard-of-care
Advocacy and Policy

Improving access to services
Genetic Discrimination

- Genetic Information Nondiscrimination Act (GINA)
  - Passed in 2008 and fully effective in 2009
  - Prohibits discrimination in health insurance and employment based on a genetic predisposition to disease
  - Doesn’t apply to manifest disease
- Affordable Care Act
  - Prohibits health insurances from using pre-existing conditions to deny coverage or determine benefits
USPSTF and PPACA

✧ Under the PPACA preventive services receiving a letter grade of B or higher from the USPSTF must be covered by insurance companies without any cost-sharing
✧ USPSTF guidelines have now become more important with regards to access to care
✧ April 2013 – USPSTF issued new guidelines for genetic counseling and testing for BRCA
✧ FORCE expressed concerns about these guidelines to and the gaps in coverage and care to USPSTF and AHRQ
Current Gaps in Required Coverage for Preventive Services

✧ Genetic counseling and testing for survivors
✧ Screening and surgery for high-risk women
✧ Most insurances will pay but deductible and co-pay apply
✧ Likely will require legislative action to change
✧ Medicare and BRCA testing women without cancer
✧ Coverage of genetic counseling and testing in men
✧ Pending results of IMPACT study or other evidence-based data on outcomes
✧ Coverage of genetic counseling and testing for Lynch and other syndromes
✧ Legislative action or introduction as topic for USPSTF review
Research

Informing health care decisions through PCOR
What is PCORnet?

✧ Funded through the Affordable Care Act, The National Patient-Centered Clinical Research Network (PCORnet) is a national platform for conducting large-scale patient-centered outcomes research

✧ Goal is to collect and connect personal health data and outcomes from 70 million Americans to conduct representative, large-scale research studies

✧ Hereditary Breast and Ovarian Cancer (HBOC) – through the ABOUT Network – is 1 of 18 conditions focused on in Phase I
ABOUT Patient-Powered Research Network

✧ 1 of 18 Patient-Powered Research Networks in PCORnet
✧ Research is designed and conducted by people from within the HBOC community led by FORCE
✧ Turns patient real-world experiences, decision-making, and questions related to HBOC into relevant and scientifically rigorous research
✧ Long term follow-up of outcomes for people affected by HBOC
FORCE Empowers Patients Through our Programs

- Helpline
- Conference
- Brochures
- Newsletter
- Mastectomy Photo Gallery
- Webinars
- Information
- Local Support
- Research Advocate Training
- Research
- Advocacy
Connect With Us

✧ Website: www.FacingOurRisk.Org
✧ Helpline 866-288-RISK (7475)
✧ Get Social: Facebook, You Tube, Twitter, and Pinterest (FacingOurRisk)
✧ Email: info@facingourrisk.org