

GENETICS

Genetic services are underutilized, and only a small proportion of Oregonians who are appropriate for cancer genetic testing are actually being tested.

KEY ISSUES

About 5%-10% of cancers are inherited, meaning that a single gene change (mutation) contributed to the cancer and is passed down from parents to offspring.

Genetic counseling is appropriate for high risk individuals, and genetic testing may be advised. The information from the test can be used to prevent the occurrence or reoccurrence of the disease. Increased screening, lifestyle changes, medication, and surgery are examples of risk reduction measures that may be appropriate for those at increased risk.

Signs of Inherited Cancer

Not everyone with a mutation will develop cancer, but those who carry the mutation are at increased risk of developing certain cancers. The following **red flags** indicate that genetic services (counseling and testing) may be appropriate:

- ✓ Early age of onset of cancer;
- ✓ Multiple cancers in one individual;
- ✓ Family members with the same or related cancers; or
- ✓ Family members with rare cancers.

CURRENT EFFORTS

The Oregon Genetic Program's mission is to promote the health, well-being, and quality of life of Oregonians using up-to-date knowledge of genomics. Since 2000, the program has addressed emerging issues in genetics and public health—including ethical, legal and social issues.

Oregon Genetics Program Priorities

- Reduce morbidity and mortality from genetic conditions.
- Educate the public and health care providers about how genomics influences health, and empower the public and providers to make informed decisions about the use of genomics in health care.
- Promote a supportive policy environment for genomics and health.
- Increase Oregon public health genomics capacity.

ACCOMPLISHMENTS

- Collected population data on family history, use of genetic services, and health outcomes.
- Evaluated disparities in Oregonians' access to genetic services for breast, colorectal, and ovarian cancer.
- Promoted policies that improved access to and coverage of genetic services.
- Evaluated disparities in Oregonians' access to genetic services for breast, colorectal, and ovarian cancer.
- Educated health care providers and the public about prevention, early identification, enhanced screening, treatment, and referral for genetic services.
- Safeguarded the public from detrimental use of genomic information.

Learning about one's genetic risk for developing cancer is frightening, and it's not information that everyone wants. But it allowed me to have surgery and prevent the cancers that I feared would eventually claim my life. –NANCY PROUSER, LAKE OSWEGO

OPPORTUNITIES

Benefits of Genetic Counseling and Testing

While genetic testing can help inform important healthcare decisions, it is crucial to ensure that patients are seen by a genetics specialist, so that appropriate counseling and testing are conducted:

- ✓ Medical decisions: Genetic test results can provide information about the chances of developing cancer and guide appropriate screening and risk reduction methods.
- ✓ Information for family members: Results of genetic testing can give information about cancer risk for other members of the family.
- ✓ Emotional well-being: Results of genetic testing can reduce anxiety by helping individuals to understand their risk for heritable cancers and give them an opportunity to take steps that will reduce their risk.



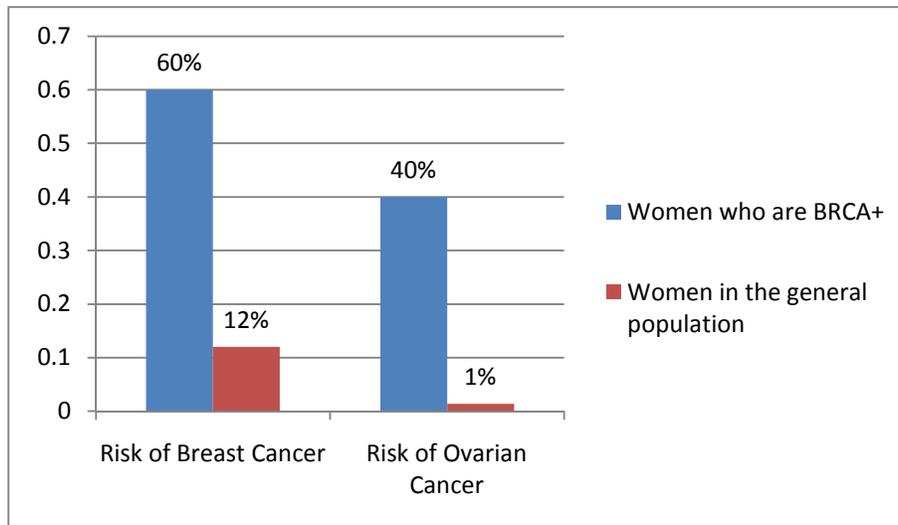
CHALLENGES

- Genetic services are underutilized, and only a small proportion of Oregonians who are appropriate for cancer genetic testing are actually being tested.
- In Oregon, cancer genetic services are located primarily in Portland and Eugene. Communities outside of those metropolitan areas are especially underserved.
- Most insurance companies cover genetic testing for high risk individuals. However, procedures recommended as a result of the test (e.g., increased screening, medication, prophylactic surgery) are inconsistently covered.

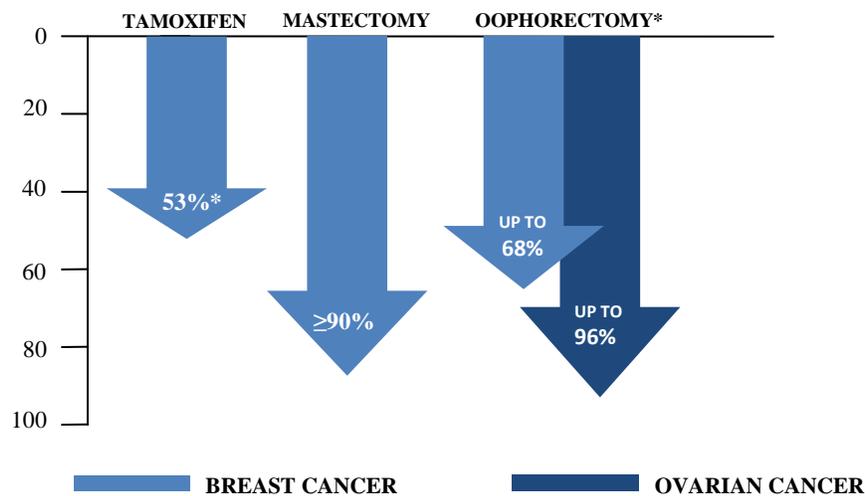
Cancer Risk Reduction

About 5% - 10% of breast cancer is inherited. Two thirds of these cancers are due to **BRCA genes (BREast CAncer genes)**. Having a mutation in one of the **BRCA 1&2** genes significantly increases the risk of developing breast and ovarian cancer. However, there are preventive measures that women with a BRCA mutation can take to lower their risk.

BRCA Cancer Risks Compared to the General Population (among Women)¹



Preventive measures, such as taking drugs or having prophylactic surgery, can significantly lower the risk of developing cancer in women with a BRCA mutation.²



*Oophorectomy = removal of the ovaries

¹ National Cancer Institute (NCI). *BRCA1 and BRCA2: Cancer Risk and Genetic Testing*. 05/29/2009 [cited 2012 February 14]; Available from: <http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA>.

² InheritedRisk.Com. Taking Action to Prevent Cancer. [Cited 2012 May 22]; Available from: <http://www.inheritedrisk.com/taking-action/>

Understanding one's genetic predisposition to cancer can empower individuals to make vital health care decisions that can lower their risk.

OBJECTIVE (ongoing)

Increase the proportion of Oregonians who receive appropriate genetic counseling and testing by a genetics specialist.

STRATEGIES

Education

- Educate health care providers about evidence-based cancer genetic risk assessment, and promote the use of cancer genetics practice guidelines.
- Inform the public about the relationship between genetics and cancer and the importance of family health history information.

Policy

- Promote reimbursement for appropriate cancer genetic services (including genetic counseling, and testing and follow-up care based on genetic test results).
- Promote capacity building of cancer genetic services to achieve equitable geographic, cultural, and socioeconomic access to services.
- Explore legislation for licensing certified genetic counselors, which would increase the number of trained genetic specialists in Oregon.

Surveillance

- Utilize population level data to assess family health history, use of genetic services, and health outcomes in Oregon.

Research

- Support efforts to evaluate the clinical validity and utility of cancer genetic tests.

RECOMMENDATIONS US Preventive Services Task Force (USPSTF)

- Women whose family history is associated with an increased risk for mutations in *BRCA1* or *BRCA2* genes should be referred for genetic counseling and evaluation for *BRCA* testing.

National Comprehensive Cancer Network (NCCN)

- Provides detailed recommendations for individuals at increased risk for hereditary cancers.*

* http://www.nccn.org/professionals/physician_gls/f_guidelines.asp

TARGETS FOR CHANGE Healthy People 2020 Objectives

- Increase the proportion of women with a family history of breast and/or ovarian cancer who receive genetic counseling
Baseline: 23.3% of women with a family history cancer received genetic counseling.*
Target: Increase 10% from baseline
- Increase the proportion of persons with newly diagnosed colorectal cancer who receive genetic testing to identify Lynch syndrome (or familial colorectal cancer syndromes).
Baseline: 55% of newly diagnosed colorectal cancer cases had MSI (microsatellite instability) testing.**
Target: Increase 10% from baseline

*National Health Interview Survey (NHIS) 2005

** Oregon State Cancer Registry (OSCaR) 2010