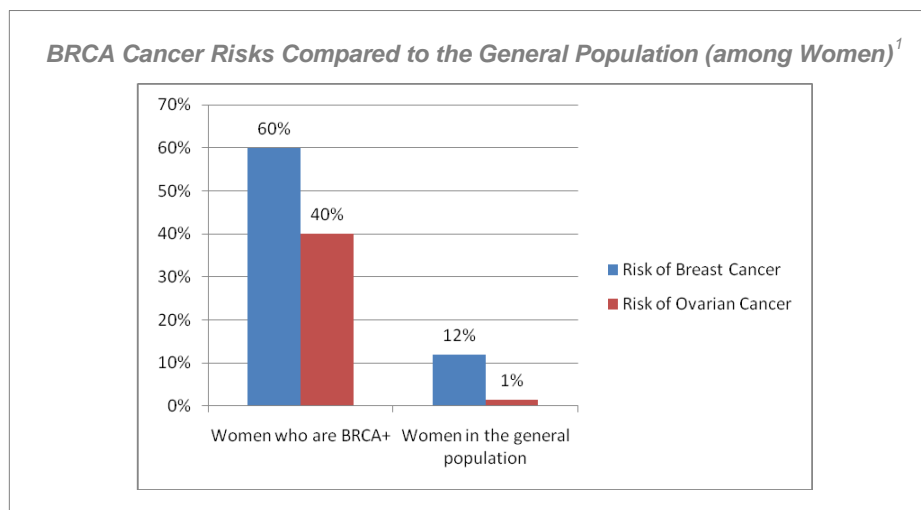




September 6, 2013

Dear xxx:

The Oregon Genetics Program is collaborating with the Oregon State Cancer Registry (OSCaR) to identify and educate individuals at high risk of hereditary breast and ovarian cancer syndrome (HBOC). As you may know, HBOC accounts for ~5–10% of all breast cancers and ~10% of ovarian cancers. Two-thirds of these HBOC cancers are due to mutations in the *BRCA1* and *BRCA2* genes. **Having a *BRCA* mutation greatly increases the chance of developing breast, ovarian and other cancers.**



Through OSCaR data from 2009 through 2011, we have identified health care providers who care for patients at increased risk for HBOC. We identified patients using the following criteria:²

- Breast cancer diagnosed \leq age 50
- Ovarian cancer at any age
- Male with breast cancer
- Triple negative breast cancer

Other risk factors for HBOC include: a significant family history, multiple primary cancers, and Ashkenazi Jewish descent.

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 A significant family history, multiple HBOC-related primary cancers, and being of Ashkenazi Jewish descent are other risk factors for HBOC. See the National Comprehensive Cancer Network (NCCN) for a detailed list of risk factors for HBOC: <http://www.nccn.org/index.asp> (You will need to set up a free account and log in.)

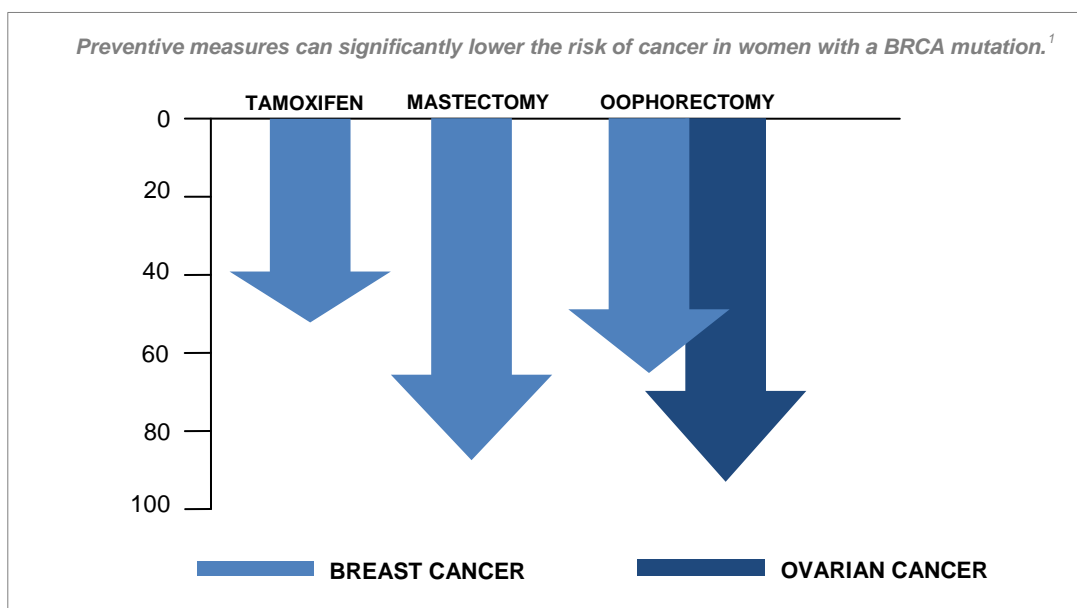
According to OSCaR data, you have recently seen patients who may benefit from a referral to a board-certified genetics specialist for a formal cancer genetic risk assessment.

Please consider sharing this information with your patients and, if appropriate, refer them to genetic services. We have also sent an informational letter to patients who were added to OSCaR from 2009 through 2011 and presented with one or more of the four risk factors listed on the first page. Some of these patients may want to discuss this information.

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

High-risk patients and their family members can benefit from:

- Early identification of cancers through enhanced surveillance measures
- Reduction in risk of developing cancer through prophylactic measures



The following clinics currently offer cancer genetic counseling by board-certified genetics specialists:

PORTLAND

- Compass Oncology, Genetic Risk Evaluation and Testing Program, 503-297-7403
- Kaiser Permanente NW, Genetics Department (Kaiser members only), 503-331-6593 or 1-800-813-2000, Ext. 16-6593

¹ InheritedRisk.Com. Taking Action to Prevent Cancer. [Cited 2012 May 22]; Available from: <http://www.inheritedrisk.com/taking-action/>

- Legacy, Comprehensive Cancer Center, 503-413-6534 or 1-800-220-4937, Ext. 6534
- Oregon Health & Science University, Clinical Cancer Genetics, 503-494-2446
- Providence, Cancer Risk Assessment and Prevention Program, 503-215-7901

EUGENE/SPRINGFIELD

- Women's Care, Center for Genetics and Maternal-Fetal Medicine, 541-349-7600 or 1-800-970-7419

Coverage of Genetic Counseling and Genetic Testing for Unaffected Women:

Insurance companies that fall under the Affordable Care Act (ACA) are required to cover, at **no cost to the patient, genetic counseling** for women whose family history is associated with an increased risk for deleterious mutations in *BRCA1* or *BRCA2* genes. In addition, the insurance companies are required to cover, at **no cost to the patient, genetic testing** if appropriate. This is in accordance with the United States Preventive Services Taskforce (USPSTF) grade B recommendation that women whose family history is associated with an increased risk for deleterious mutations in *BRCA1* or *BRCA2* genes be referred for genetic counseling and evaluation for *BRCA* testing.

Financial assistance is available to help cover the cost of genetic testing for men and those who are uninsured, have an insurance plan that does not fall under the ACA, or do not fulfill the criteria in the USPSTF recommendations:

- Cancer1Source offers financial assistance for underinsured patients:
www.cancer1source.org
- Myriad offers financial help for uninsured patients:
www.myriadtests.com/index.php?page_id=51&usetemplate=pathome&usetype=1

We would appreciate your feedback on this letter!
Please visit www.surveymonkey.com/s/OGP1 to fill out
a 1-minute survey.

If you have any questions, please feel free to contact the Oregon Genetics Program.

Sincerely,

Summer Cox, MPH, and Rani George, MPH

Oregon Genetics Program, Public Health Division, Oregon Health Authority

971-673-0271

oregon.geneticsprogram@state.or.us

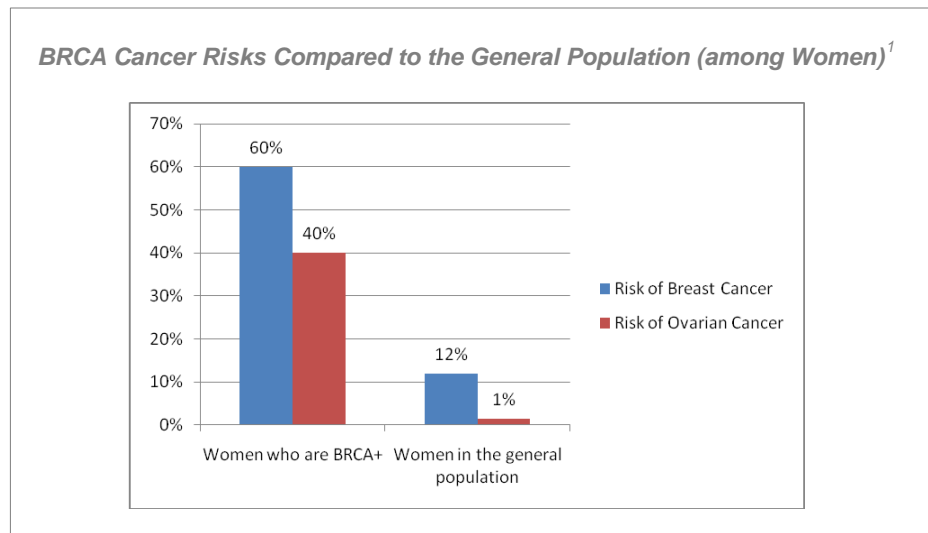




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As a clinician who cares for cancer patients, you may see individuals who are at high risk of having HBOC based on the following characteristics:²

- Breast cancer diagnosed \leq age 50
- Ovarian cancer at any age
- Males with breast cancer
- Significant family history
- Multiple primary cancers
- Triple negative breast cancer
- Ashkenazi Jewish descent

Patients at high risk for HBOC may benefit from a referral to a board-certified genetics specialist for a formal cancer genetic risk assessment. Please consider sharing this information with your patients and, if appropriate, refer them to genetic services.

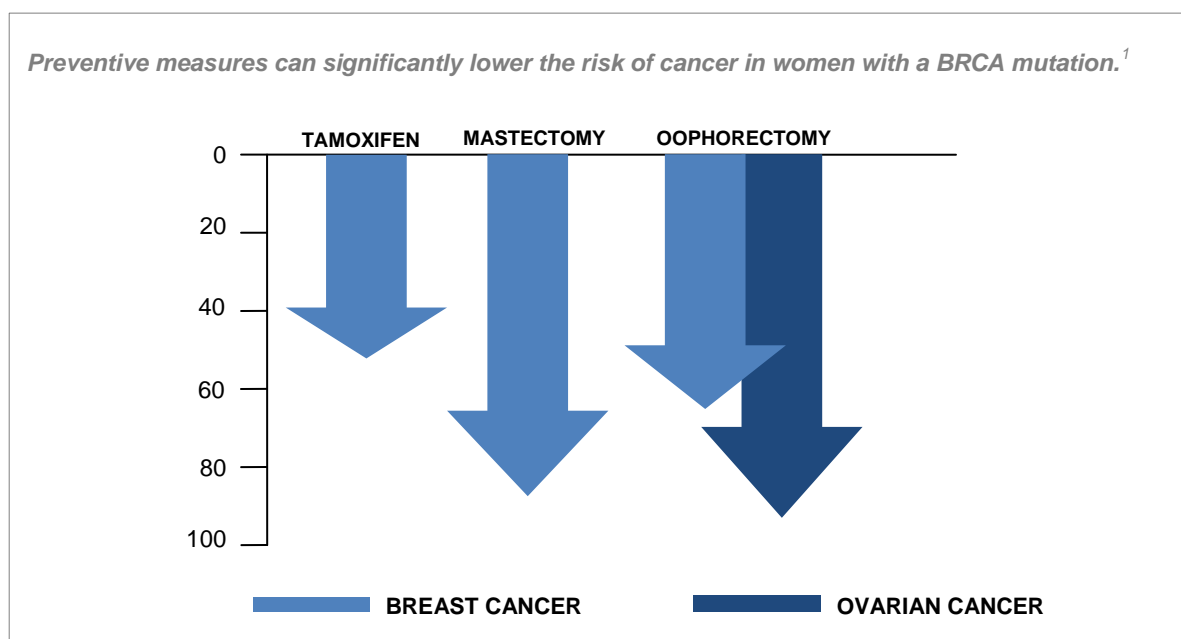
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While genetic testing can help inform important health care decisions, **it is crucial to ensure patients are seen by a genetics specialist, so that appropriate counseling and testing are conducted.**

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- Cancer1Source offers financial assistance for underinsured patients:
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September 6, 2013

Dear _____,

The Oregon Genetics Program promotes the health, well-being, and quality of life of Oregonians using up-to-date knowledge of genetics. The Oregon Genetics Program is working with the Oregon State Cancer Registry (OSCaR) to identify and educate cancer survivors who may be at high risk of having hereditary breast and ovarian cancer syndrome (HBOC).

We are writing because, according to OSCaR, you were diagnosed with cancer sometime in 2009 through 2011. **Did you know that as a cancer survivor with certain risk factors, you may have hereditary breast and ovarian cancer syndrome (HBOC)?** It is important to know your risk, because **there are things you can do** to lower your chances of getting another cancer.

Hereditary cancers occur because of a change in certain genes that normally protect the body from developing cancer. Having a change in one of the genes called *BRCA1* or *BRCA2* can increase your chance of developing a new cancer. These changes can be passed down from parents to children. There are, however, **preventive measures and screening tests that can help you stay healthy.**

If you are a woman with a gene change associated with breast and ovarian cancer, you are more likely to develop breast cancer and also more likely to develop ovarian cancer than a woman without the gene change.

Why are you telling me about the risk for having HBOC?

According to the Oregon State Cancer Registry, you have had one or more of the following, which increases the chance that you may have a change in one of your BRCA genes:

- Breast cancer diagnosed younger than age 50
- Ovarian cancer at any age
- Triple negative breast cancer

You and your family could benefit from genetic counseling:

If you meet one of the above criteria, your cancer may be hereditary. **You and your family could benefit from a referral to a board-certified genetics specialist for a formal cancer genetic risk assessment.** This assessment can help with:

- Using effective screening tests at a frequency determined specifically for you, such as mammography every year, for early identification of new cancers.
- Taking preventive steps to lower the chance of developing a new cancer.
- Determining whether genetic testing would be helpful to you and your family.

While genetic testing itself can help inform important health care decisions, **it is important that you are seen by a genetics specialist**, so that appropriate counseling and testing are conducted.

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Insurance Coverage of Genetic Counseling and Genetic Testing:

Insurance companies that fall under the Affordable Care Act (ACA) are required to cover, at **no cost, genetic counseling** for women whose family history is associated with an increased risk for harmful mutations in *BRCA1* or *BRCA2* genes. In addition, the insurance companies are required to cover, at **no cost, genetic testing** if appropriate.

This is in accordance to the United States Preventive Services Taskforce (USPSTF) grade B recommendation that women whose family history is associated with an increased risk for harmful mutations in *BRCA1* or *BRCA2* genes be referred for genetic counseling and evaluation for *BRCA* testing.

Financial assistance is available to help you cover the cost of genetic testing if you are uninsured, if you have an insurance plan that does not fall under the ACA, or if you don't fulfill the family history criteria in the USPSTF recommendations:

- Cancer1Source offers financial assistance for *underinsured* patients (for example, if you cannot pay your deductible or co-pay): www.cancer1source.org
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For more information about hereditary breast and ovarian cancer, visit: www.facingourrisk.org

For more information about the Oregon Genetics Program, visit:
www.healthoregon.org/genetics

We would like your feedback on the information in this letter!
Please visit www.surveymonkey.com/s/OregonGenetics to fill out a 15-minute survey

We have enclosed a \$2 bill, as a token of our thanks in filling out the survey – spend it or keep it as you see fit. This survey will be used to develop educational materials and help people in Oregon get genetics services.

If you have any questions, please feel free to contact the Oregon Genetics Program.

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We are writing because according to OSCaR, you were diagnosed with breast cancer sometime in 2009 through 2011. **Did you know that as a male diagnosed with breast cancer, your cancer may be inherited** (passed down from parents to children)? It is important to know your risk, because **there are things you can do** to lower your chances of getting another cancer.

Hereditary cancers occur because of a change in certain genes that normally protect the body from developing cancer. Having a change in a gene called *BRCA2* can increase a man's lifetime chance of developing prostate cancer and a second breast cancer. Also, such gene changes can be passed down from parents to children. There are, however, **preventive measures and screening tests that can help you and your family stay healthy.**

If you are a man with a gene change associated with breast cancer, you are more likely to develop another breast cancer and also more likely to develop prostate cancer than a man without the gene change.

You and your family could benefit from genetic counseling:

Because you've had breast cancer, your cancer may be hereditary. **You and your family could benefit from a referral to a board-certified genetics specialist for a formal cancer genetic risk assessment.** This assessment can help with:

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If you have any questions, please feel free to contact the Oregon Genetics Program.

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