

Oregon Genetics Program Public Health Division

John A. Kitzhaber, M.D., Governor



800 NE Oregon St., Suite 805 Portland, OR 97232 www.healthoregon.org/genetics

December 11, 2013

SHAROLYN BOWMAN

Dear SHAROLYN BOWMAN,

We are writing to you because we need your assistance with developing educational materials for Oregonians at risk of developing inherited cancers. We have included a \$2 bill in this envelope, as a thank you for completing a brief survey.

According to the Oregon State Cancer Registry (OSCaR) program, 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 <u>there are things you can do</u> to lower your chances of getting another cancer.

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 OSCaR program to identify and educate cancer survivors who may be at high risk of having hereditary breast and ovarian cancer syndrome (HBOC).

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, <u>preventive measures and screening tests</u> 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 OSCaR, you have had one or more of the following criteria, which increases the chance that you may have a change in one of your BRCA genes:

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

You and your family could benefit from genetic counseling:

If you meet one or more of the three criteria listed on the first page, 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 fainily.

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

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
- 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

Insurance Coverage of Genetic Counseling and Genetic Testing:

Insurance companies that fall under the Affordable Care Act (ACA) are required to cover **genetic counseling at no cost**, 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 **genetic testing at no cost**, 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 harmful mutations in *BRCA1* or *BRCA2* genes be referred for genetic counseling and evaluation for *BRCA* testing.

(303) 986-1439

BALL KENNAMER

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 do not fit 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

For more information about hereditary breast and ovarian cancer, visit: www.facingourrisk.org

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

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

We have enclosed a \$2 bill, as a token of our thanks for 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.

Sincerely,

411- (10-0213

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Summer Lee Cox, MPH

Rani George, MPI

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OREGON PUBLIC HEALTH DIVISION Health Promotion & Chronic Disease Prevention Section

John A. Kitzhaber, MD, Governor



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January 6, 2014

Sharolyn Bowman

Dear Sharolyn,

I am writing to follow-up on our telephone conversation last week during which you expressed concern regarding the reporting of your cancer case to the Oregon State Cancer Registry.

In this case, the Oregon State Cancer Registry was authorized to receive this diagnostic information under the requirements of Section 432.520 of the Oregon Revised Statutes, which states, "...any health care facility in which cancer patients are diagnosed or provided treatment for cancer shall report each case of cancer to the Department of Human Services...[and]...[a]ny practitioner diagnosing or providing treatment to cancer patients shall report each cancer case to the department..." Please be aware, however, that the information provided to the Cancer Registry is maintained according to strict confidentiality standards outlined in ORS 432.530 and Section 333-010-0050 of the Oregon Administrative Rules.

The Oregon State Cancer Registry (OSCaR) was established in 1996 for the purpose of collecting information on the incidence of cancer in the State of Oregon. The data compiled by OSCaR are used to support the evaluation of potential causes of cancer among Oregon residents. We are also involved in determining which populations are in need of cancer screening services and investigating suspected cancer clusters. Unfortunately, we are not permitted to delete reported cases from the registry database, as this would diminish the effectiveness and accuracy of Registry functions. I have, however, made a note in our records so you will not be contacted again by our office.

I hope this information addresses your concerns. Please feel free to contact me with any additional questions you may have about the Oregon State Cancer Registry.

Sincerely,

Jeff Spule, Research Coordinator Oregon State Cancer Registry

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Providence St. Vincent Cancer Röghtry clo 4865 MR (Jack St IN-6, Portland, OR 97213-2953 ph (593) 215-5014 fm (593) 315-6917

Jacoury 30, 2014

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The Providence Health System Regional Cancer Registry annually follows all patients diagnosed and/or treated for cancer and related diseases in its facilities as part of the requirements of the ACoS-approved cancer program. Plense complete the information requested below even if you are not following this patient for histor cancer diagnosed, Thank you for your prompt rapity. Your release of this information for purposes of this registry is HIPAA-approved and is required by ORS 432,500.

PROVIDENCE Health & Services

Name: DOB: DOB: Histology: Bouencer	Medical Rec #: ACC#: Dr: Data:
Date of Last Control:	
1. Date you last saw this patient:	j Day Year
2. Patient's Status at Last Follow-Up 1 Alive—no exidence of this cancer 2 Alive—this cancer present 2 Alive—other cancer present 2 Alive—other cancer present 2 Alive—cancer status unknown 2 Dead—no evidence of this cancer 2 Dead—this cancer present at Geath 2 Dead—this cancer present 2 Dead—cancer present, primary unknown 2 Dead—cancer present, primary unknown 2 Dead—presence of cancer unknown 2 Dead	3. Recurrence/New Primary Interpation No recurrence New primary Local recurrence Regional recurrence Distant recurrence Luchart distance free Luchartory evidence only Site:
Place of death: Date of death: Cause of death:	
4. What treatments has patient received beyond Initial first course? Date of new treatment:	[] none [] chernotherapy [] radiation agents [] other [] hormoné agents
Place of new Inestment	
 This patient is being followed by another physical 	sicjan?
Name of other physician;	· ····································
City/State and phone number	11