PUBLIC HEALTH DIVISION
Screenwise
Kate Brown, Governor

Oregon Health Authority

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NAME
ADDRESS1
ADDRESS2
CITY, ST ZIP

DATE

Regarding: Hereditary Breast and Ovarian Cancer Syndrome (HBOC) Survey and Resources

Dear «FirstName»,

Please help ScreenWise, an Oregon Health Authority program, by taking the enclosed survey. Your participation will help ScreenWise learn if and how Oregonian cancer survivors:

- Use cancer genetic services, such as genetic counseling and testing.
- Talk about genetic services with their providers.

Survey questions concern Hereditary Breast and Ovarian Cancer (HBOC) syndrome. More information about this project is included in the enclosed Hereditary Cancer Awareness Project fact sheet. More information about HBOC and related resources are included in the enclosed Frequently Asked Questions document. Cancer and its hereditary risk (risks that are passed from parents to children) are hard topics. There is no requirement to complete this survey. If you would like to talk to us about our work, our contact information is at the end of this letter.

Please return the finished survey by **Monday, April 30, 2018**. All answers will be kept private and confidential. Survey answers will not be connected to your health care in any way.

There are three ways to take this survey:

1. By mail: Please return your survey in the postage paid envelope enclosed.
2. Online: https://www.surveymonkey.com/r/5SP9F3L
3. Phone: Call ScreenWise at 971-673-0273 to schedule a time to complete the survey with a ScreenWise staff member.

Thank you for taking the time to help us learn more about the use of and communication about HBOC genetic services in Oregon. Please let us know if you have questions or comments about this project.

Sincerely,

Summer Lee Cox

Summer Lee Cox, MPH
ScreenWise genetics coordinator
971-673-0273
summer.l.cox@dhsoha.state.or.us

Jasmin Griggs

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ScreenWise genetics program analyst
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ScreenWise website: http://www.healthoregon.org/screenwise
Genetic conditions website: http://www.healthoregon.org/genetics

Your Hereditary Breast and Ovarian Cancer Syndrome Survey

Thank you for taking our survey!

We are on a quest for answers. By taking this survey you will help us learn more about people at risk for Hereditary Breast and Ovarian Cancer. Your input will also help us to know the best ways to talk about genetic services.

Don’t worry, we will protect your privacy. We will not publish any information that identifies you.

You can get this document in other languages, large print, braille or a format you prefer. Contact ScreenWise genetics team at 971-673-0273 or email **Summer.L.Cox@dhsoha.state.or.us**. We accept all relay calls or you can dial 711.

Hereditary Breast and Ovarian Cancer Syndrome Survey

Why did I get this survey?

ScreenWise, an Oregon Health Authority program, created this survey. Your answers will help us to:

- Learn if and how people get cancer genetic services in Oregon.
- Learn how people at risk of having hereditary breast and ovarian cancer (HBOC) make health care and lifestyle choices.
- Teach others about hereditary cancer.
- Make it easier for people at risk of having HBOC to see a genetic specialist.
- Advise people at risk of having HBOC to see a genetic specialist.

We will put a summary of the results for this survey online (**http://www.healthoregon.org/genetics**) by Sept. 28, 2018. This summary will not include any personal information.

How can I complete the survey?

- **By mail:** Fill out this survey and send it to us in the postage paid envelope included with this survey
- **Online:** Take the survey at **http://www.surveymonkey.com/r/5SP9F3L**
- **By phone:** Call the ScreenWise team at 971-673-0273 to set up a time to do so

How long will it take?

This survey will take about 20 minutes. Some people will take more time, others less.

When will I need to return it?

Please return the finished survey by ***Monday, Apr. 30, 2018.***

How do I state that I am willing to take the survey?

Read the **statement of informed consent** on the next page. If, after reading the informed consent, you are willing to complete the survey check that you agree. If you are not willing to complete it, you don't need to do anything.

Statement of informed consent

In this survey, you will say if you have had cancer genetic services. If you have, you will answer questions about your experiences with health care providers* and these services. If you have not, you will answer questions about deciding not to have these services.

You do not need to take this survey if you do not want to take it. **Deciding not to take this survey will not affect your health care.** You may skip questions that you do not want to answer. Taking this survey should not harm you in any way.

Your survey responses will remain private. Only our team will see the responses. The public will see pooled survey results. Therefore, the public cannot link responses directly to you.

What you tell us will help us make our program material better. It will also make it easier for people to use cancer genetic services.

At the end of the survey, we ask you if you are willing to take a short follow-up survey in six months. If you are willing to take the second survey, you will provide your contact information. We keep this separate from your survey answers.

If you have questions about this survey, please contact Summer Lee Cox, ScreenWise genetics coordinator. You can call her at 971-673-0273 or email **summer.l.cox@dhsoha.state.or.us.**

Do you agree to take this survey?

By marking “Accept,” you are stating that you are willingly taking this survey.

☐ **Accept**

IF you do NOT consent, please do NOT fill-out or return this survey.

How do I state my answers in the survey?

Check the box that matches closest to how you want to answer.

What if I don’t understand some terms used?

There is a glossary on the last page which describes some of the terms.

*See glossary

Questions about changes you may make.

Indicate whether you agree or disagree with the following statements	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
1. I learned something new about Hereditary Breast and Ovarian Cancer (HBOC) syndrome from the ScreenWise letter.					
2. I believe the information that ScreenWise sent is useful to me and my close blood relatives.					
3. Now that I have read the information, I will take action by:					
a. Talking with my health care provider*.					
b. Visiting with a board-certified cancer genetics specialist.					
c. Talking with my close blood relatives about our risk of cancer and how to stay healthy.					
d. Making changes to reduce my risk of getting cancer (*such as exercising more or drinking less alcohol*).					
e. Making changes to find cancer earlier (*such as getting screening tests like mammograms and MRIs, as often as my health care provider recommends*).					

Questions about visits with health care providers*.

4. Sometimes you bring up health concerns with your provider. Sometimes your provider brings up the topic. If you have talked about HBOC at a health care visit, who first brought up the topic?

- ☐ I brought it up, or a friend or family member with me brought it up
- ☐ My health care provider* brought it up
- ☐ I have talked with a health care provider* about HBOC, but I don't remember who brought it up
- ☐ I have never talked with a health care provider* about HBOC

5. Have you ever had genetic counseling* about your cancer diagnosis?

☐ Yes ☐ No — **If no, please skip to Question 9**

*See glossary

6. Why did you have genetic counseling*? (*Check all that apply*)

- ☐ My health care provider* recommended it
- ☐ I have had cancer
- ☐ I had cancer at an early age or I have had a certain type of cancer
- ☐ One of my blood relatives has had cancer
- ☐ One of my blood relatives has a BRCA1 or BRCA2 gene change (*mutation*) or other mutation
- ☐ To help make health care decisions
- ☐ To know my risk of having another cancer
- ☐ To know my blood relatives' risk of having cancer
- ☐ Other. Please list:

7. Did your health insurance cover the cost of your genetic counseling*?

- ☐ Yes, all
- ☐ Yes, part
- ☐ I chose to pay myself and not use my insurance
- ☐ No, none
- ☐ I did not have health insurance when I had genetic counseling*
- ☐ I don't know

8. After you had your genetic counseling*, did you make any of the following changes? (*Check all that apply*)

- ☐ Ate healthier
- ☐ Exercised more
- ☐ Lost weight on purpose
- ☐ Drank less alcohol (if you drank alcohol before the counseling)
- ☐ Stopped using tobacco or used less (*if you used tobacco before the counseling*)
- ☐ Started breastfeeding
- ☐ Took cancer screening tests more often or had more types of cancer screening tests (*like mammograms or MRIs*)
- ☐ Took cancer risk-reducing medication
- ☐ Stopped taking estrogen or progesterone
- ☐ Had risk-reducing surgery (*i.e., removed breast tissue, ovaries or fallopian tubes*)
- ☐ Other. Please list:
- ☐ None of the above

*See glossary

If you answered questions 6, 7 and 8, DO NOT answer question 9.

9. If you have NOT had genetic counseling*, please tell us why you have NOT had these services. (*Check all that apply*)

- ☐ Did not know it existed
- ☐ Issues with health insurance (*no coverage or out-of-pocket cost is too high*)
- ☐ Lack of child care or other support
- ☐ Lack of transportation (*or the clinic is too far away*)
- ☐ My health care provider* told me not to go
- ☐ No one ever recommended it
- ☐ Not enough time, or I am too busy
- ☐ Poor health or disability makes it hard to make appointments
- ☐ Too nervous (*i.e., I don't want to know my risk of hereditary cancer*)

Questions about genetic testing* for HBOC.

10. Have you ever had a genetic test* to figure out if you are at higher risk of having breast or ovarian cancer? This would likely be or include a BRCA test.

☐ Yes ☐ No — **If no, please skip to Question 18**

11. How did you get your genetic test*?

- ☐ My health care provider* or genetic counselor arranged it
- ☐ I ordered it directly from a company (*e.g. 23andMe, Gene By Gene, MyMedLab, Color*)
- ☐ I don't know
- ☐ Other. Please list:

12. Why did you have your genetic test*? (*Check all that apply*)

- ☐ My health care provider* recommended it
- ☐ I had cancer at an early age or I have had a certain type of cancer
- ☐ I have had cancer
- ☐ One of my blood relatives has had cancer
- ☐ One of my blood relatives has a BRCA1 or BRCA2 gene change (*mutation*) or other mutation
- ☐ To help make health care decisions
- ☐ To know my risk of having another cancer
- ☐ To know my blood relatives' risk of having cancer
- ☐ Other. Please list:

*See glossary

13. Did your health insurance cover the cost of your genetic test*?

- ☐ Yes, all
- ☐ Yes, part
- ☐ I chose to pay myself and not use my insurance
- ☐ No, none
- ☐ I did not have health insurance when I got the genetic test*
- ☐ I don't know

14. Please select your genetic test* result. (*Check all that apply*)

- ☐ At least one gene had a harmful mutation
- ☐ No harmful mutation was found in any of the genes that were tested
- ☐ At least one gene had an uncertain change (*sometimes called variants of uncertain significance* (VUS))
- ☐ I don't know

15. What does your test result mean?

- ☐ I have a higher risk of having breast or ovarian cancer than most people
- ☐ I have the same risk of having breast or ovarian cancer as most people
- ☐ I am not at risk of having breast or ovarian cancer
- ☐ Other. Please list:
- ☐ I don't know

16. Did you talk with a health care provider* about your genetic test* results?

☐ Yes ☐ No ☐ I don't know

17. After you had your genetic test*, did you make any of the following changes? (*Check all that apply*)

- ☐ Ate healthier
- ☐ Exercised more
- ☐ Lost weight on purpose
- ☐ Drank less alcohol (*if you drank alcohol before the counseling*)
- ☐ Stopped using tobacco or used less (*if you used tobacco before the counseling*)
- ☐ Took cancer screening tests more often or had more types of cancer screening tests (*like mammograms or MRIs*)
- ☐ Took cancer risk reducing medication
- ☐ Stopped taking estrogen or progesterone
- ☐ Had risk reducing surgery (*i.e., removed breast tissue, ovaries or fallopian tubes*)
- ☐ Other. Please list:
- ☐ None of the above

*See glossary

Genetic privacy and anti-discrimination laws.

Genetic Information Nondiscrimination Act (GINA)

A federal law that makes it illegal for the following to discriminate against an individual based on their genetic information, including family history:

- Health insurance companies
- Group health plans
- Employers of more than 15 employees

Oregon Genetic Privacy Laws (OGPLs)

State laws that help protect your genetic information. These laws also look to prevent the misuse of genetic information. It is:

- Illegal for an employer to obtain or use your genetic information to discriminate against you as an employee of a prospective employer.
- Illegal for health insurance companies to use your genetic information to price or decline individual policies.
- Required for health care providers to give clients an opportunity to request that their biological sample(s) and health information not be used for anonymous or coded genetic research.

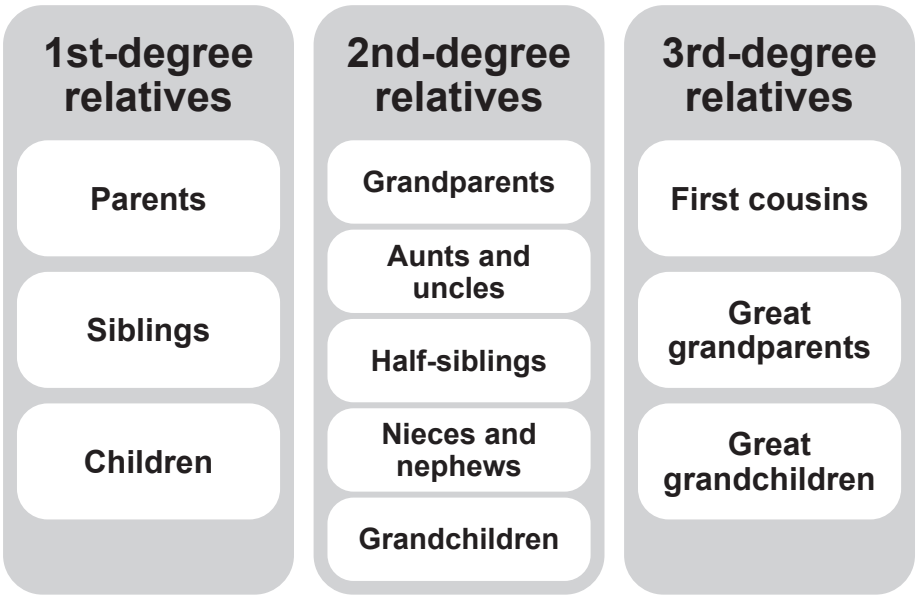
If you answered questions 11 through 16, DO NOT answer question 18.

18. If you have NOT had cancer genetic testing* to figure out if you are at higher risk of having breast or ovarian cancer, please tell us why you have NOT had testing*. (*Check all that apply*)

- ☐ Did not know it existed
- ☐ Issues with health insurance (*no coverage or out-of-pocket cost is too high*)
- ☐ Lack of child care or other support
- ☐ Lack of transportation (*or the clinic is too far away*)
- ☐ My health care provider* told me not to go
- ☐ No one ever recommended it
- ☐ Not enough time, or I am too busy
- ☐ Poor health or disability makes it hard to make appointments
- ☐ Too nervous (*i.e., I don't want to know my risk of hereditary cancer*)
- ☐ Worried genetic information could be used against me by an employer or health insurance company
- ☐ Wanted to talk with a genetic counselor first
- ☐ Other. Please list:

*See glossary

For question 19, please use this chart:



19. Please select the following statements that apply to your family (*first-, second- or third-degree blood relatives*) history of cancer. (*Check all that apply*)

- ☐ I have **one or more FEMALE** blood relatives who had or have **breast cancer** at or **before age 50**
- ☐ I have **one or more** first-, second- or third-degree **MALE** blood relatives who had or have **breast cancer at any age**
- ☐ I have one or more first-, second- or third-degree blood relatives who had or have **ovarian cancer at any age**
- ☐ I have two or more first-, second- or third-degree **FEMALE** blood relatives who had or have **breast cancer at any age**
- ☐ I have two or more first-, second- or third-degree blood relatives who had or have **pancreatic cancer at any age**
- ☐ **None** of these statements apply to my close blood relatives
- ☐ **I do not know** my family history of cancer

20. Please select the following statements that apply to your cancer diagnosis. (*Check all that apply*)

- ☐ I was diagnosed with **female breast cancer at or before the age 50**
- ☐ I was diagnosed with **male breast cancer**
- ☐ I was diagnosed with **triple negative breast cancer at or before the age 60**
- ☐ I was diagnosed with **ovarian cancer**
- ☐ I was diagnosed with both **breast and pancreatic cancer**
- ☐ Other. Please list:

Questions that will help us look at differences in health and health care between different people.

21. What is your race/ethnicity? (*Check all that apply*)

- ☐ American Indian/Alaska Native
- ☐ Ashkenazi Jewish
- ☐ Asian
- ☐ Black/African American
- ☐ Hispanic/Latino/a
- ☐ Native Hawaiian/Pacific Islander
- ☐ White/Caucasian
- ☐ Other. Please list:
- ☐ Don't know
- ☐ Prefer not to answer

22. Do you identify as being lesbian, gay, bisexual, transgender or queer/questioning (LGBTQ)?

- ☐ Yes
- ☐ No
- ☐ I don't know
- ☐ Prefer not to answer

23. What is your highest level of school attended?

- ☐ Grade school (*Grades 1-8*)
- ☐ Some high school
- ☐ High school diploma or GED
- ☐ Some college
- ☐ College degree or higher
- ☐ Prefer not to answer

24. What zip code do you live in?

25. If you live in Oregon, what county do you live in?

26. What can we do to improve the information packet we sent or this survey?

_____

_____

_____

_____

_____

The next page is the last page!

Last question!

27. May we send you a very short follow-up survey in six to nine months?

The follow-up survey will take about five minutes to complete. Some people will take more time, others less.

When you return this survey, we will separate this page from the rest of your survey answers. A code is used to connect your answers from this survey to your answers in the follow-up survey. Only one member of our team will have access to the code. We will keep your information private and confidential.

If we can send you a follow-up survey, please give your contact information below.
If you do not want to do the follow-up survey, do not fill out your contact.

Name: _____

Phone number: _____

Email address: _____

Mailing address: _____

City: _____ **State:** _____ **ZIP:** _____

Note:

Please make sure to read the information on page 3 and check the box that confirms your willingness to take the survey. If you do not check the box, we cannot use your survey.

That is all of our survey questions. Thank you so much for completing the survey!

We will put a summary of the results for this project on the Hereditary Cancer Awareness Project webpage. You will be able to go to **http://www.healthoregon.org/genetics** by Sept. 28, 2018, for the results. This summary will not include any personal information.This survey was approved by the Public Health Division in the Oregon Health Authority. It is Institutional Review Board exempt. If you have questions, please contact the ScreenWise genetics team:

- Summer Lee Cox, ScreenWise genetics coordinator, 971-673-0273; **Summer.L.Cox@dhsoha.state.or.us**, and
- Jasmin Griggs, ScreenWise program analyst, 971-673-0206; **Jasmin.A.Griggs@dhsoha.state.or.us**

ScreenWise website: **http://www.healthoregon.org/screenwise**
More information about hereditary cancer: **http://www.healthoregon.org/genetics**

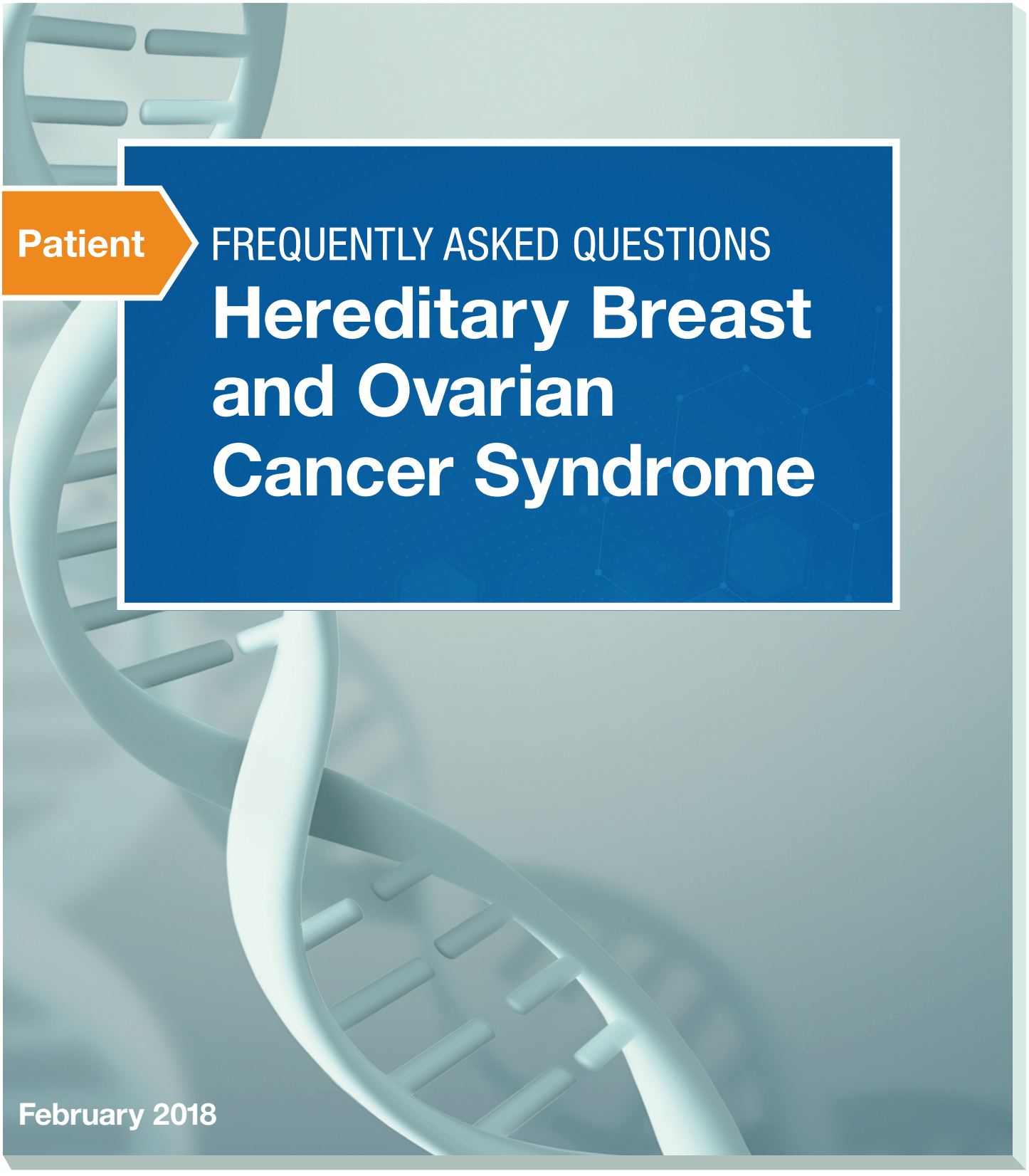
You can get this document in other languages, large print, braille or a format you prefer. Contact ScreenWise genetics team at 971-673-0273 or email **Summer.L.Cox@dhsoha.state.or.us**. We accept all relay calls or you can dial 711.

Glossary

Genetic counseling: When you talk with a board-certified genetic specialist about your risk for HBOC and HBOC-related cancers. The visit lasts an hour or longer. You talk about your health history and your blood relatives' health history. You also talk about if you want to have genetic testing.

Genetic test or testing: Use of saliva or blood to figure out a person's genetic risk for breast or ovarian cancer. The most common genetic test for breast and ovarian cancer risk is a "BRCA" test.

Health care provider: The person you see for medical care, such as a doctor, nurse, nurse practitioner or physician assistant.



Patient

FREQUENTLY ASKED QUESTIONS

Hereditary Breast and Ovarian Cancer Syndrome

February 2018

PUBLIC HEALTH
Screenwise

Oregon Health Authority

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What is hereditary breast and ovarian cancer (HBOC) syndrome?

HBOC stands for hereditary breast and ovarian cancer syndrome. Having HBOC does not mean that you have cancer, or that you will get cancer. Having HBOC means that you may have an increased risk for certain types of cancer. It also means that some of these cancers may run in your family, passing from generation to generation.

- Women with HBOC are more likely to develop cancers, such as breast and ovarian cancer, than women without HBOC.
- Men with HBOC are more likely to develop cancers, such as breast and prostate cancer, than men without HBOC.

NOTE:

HBOC can pass from either parent.
Therefore, it is important to know as much as you can about your family health history on both sides. If you can't know all of your family health history, your personal history can still help.

Why is it important to know if my cancer was hereditary?

NOTE:

If you have HBOC, you and your family can take steps to:

1: Understand your risk for developing other cancers.

2: Lower your risk of getting cancer.

3: Increase the chance that any cancer is caught early.

Changing behaviors around the following, can reduce your risk of cancer as well as many other chronic diseases:


Alcohol consumption


Diet


Physical activity

If you get the right health tests you can catch cancer and other health conditions early. If you think HBOC runs in your family you should:


Talk with your doctor.


Talk with your family.


Consider talking with a genetic specialist.

How do I find out if I have a hereditary cancer syndrome?

If you or a close blood relative* has one or more of the types of cancer listed on the next page, HBOC may run in your family.

NOTE: **Having a conversation with a board-certified genetic specialist can be a great help.**

A genetic specialist is trained to talk with people about genetic and non-genetic risk and can identify:

- What types of cancer tests are right for you and how often to get them
- Activities that may help lower your chance of developing a new cancer
- If genetic testing may be a good choice for you and your family

Genetic testing can help people make health care decisions and life choices. However, it is important to see a board-certified genetic specialist for genetic counseling **before** deciding to get genetic testing or not. This ensures that you make a fully informed choice. Genetic specialists are specially trained to order the right tests and interpret the results correctly.

A board-certified genetic specialist can be any of these
Certified genetic counselor (CGC)
Advanced practice nurse in genetics (APNG)
Geneticist (MD or PhD)

NOTE: **If you have had only BRCA† genes tested in the past, you may want to discuss panel testing with a genetic specialist.**

* Close blood relatives include first, second, and third-degree relatives:
  - First-degree relatives: Parents, full siblings, or children.
  - Second-degree relatives: Grandparents, grandchildren, aunts, uncles, nephews, nieces or half-siblings.
  - Third-degree relatives: First cousins, great grandparents or great grandchildren.

† The BRCA genes can be tested to check for breast cancer risk. Please see page 8 for more information about BRCA genes.

Personal and family history of cancer can be a sign of HBOC.

If you have one or more of the below, it does not mean you have HBOC. However, we recommend talking to a genetic specialist. The genetic specialist can help identify steps to take to keep you and your family healthy.

Signs that you should talk to a genetic specialist
Invasive breast cancer diagnosed at age 50 or younger
Triple negative breast cancer diagnosed at age 60 or younger
Ovarian cancer (including fallopian tube and primary peritoneal) at any age
Ductal carcinoma in situ (DCIS) diagnosed at age 50 or younger
Two separate breast cancers in a single individual
Male breast cancer at any age
Breast cancer and pancreatic cancer at any age
Three or more HBOC related conditions* for you or any close blood relatives
Breast cancer at any age and one or more close blood relatives with breast cancer at age 50 or younger
Breast cancer at any age and one or more close blood relatives with ovarian cancer at any age
Breast cancer at any age and two or more close blood relatives with breast and/or pancreatic cancer at any age
Breast cancer at any age and from a population at increased risk (such as Ashkenazi Jewish)

NOTE: **For more information about hereditary cancer, visit the Oregon Health Authority, Public Health Division genetic conditions page: www.healthoregon.org/genetics.**

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* HBOC related conditions include:

- Breast cancer
- Brain cancer
- Endometrial cancer
- Melanoma
- Leukemia
- Hamartomatous polyps of gastrointestinal (GI) tract
- Pancreatic cancer
- Diffuse gastric
- Thyroid cancer
- Sarcoma
- Macrocephaly
- Colon cancer
- Prostate cancer (Gleason score > 7)
- Kidney cancer
- Adrenocortical carcinoma
- Dermatologic manifestations

Where can I find a board-certified cancer genetic specialist?

Call 211 to get the most current list of cancer genetic specialists near you. The 211info line can give you information about community resources or give you a referral. You can also connect through their website at **http://211info.org/contact**.

The clinics below offer cancer genetic counseling by genetic specialists. Counseling may occur in any of the following ways:

- Face-to-face
- In a clinic with a live video screen (like Skype)
- Over the phone

NOTE:

Let the genetics clinic know that you would like to talk about hereditary breast and ovarian cancer (HBOC) syndrome.

Be prepared to share your personal and family history of cancer.

If you do not live near a genetics clinic, call any clinic listed below. See if you can arrange a counseling session by phone, or from your home or a nearby health clinic.

Location	Institution	Genetic counseling providers	Phone number	Consultation type
Eastern Oregon (Boise, Idaho)	Saint Alphonsus "St. Al's" Cancer Care Center	St. Al's and Huntsman Cancer Institute	208-367-3131	Face-to-face (at St. Al's) Telephone (Huntsman Cancer Institute)
Eugene/ Springfield	Willamette Valley Cancer Institute and Research Center, (currently for established patients only)	Compass Oncology, Genetic Risk Evaluation and Testing (GREAT) program	503-297-7403	Live video screen
Medford	Asante Rogue Regional Medical Center's Infusion Services	OHSU, Knight Cancer Institute, Genetic Counseling and Risk Assessment	541-789-5006	Live video screen

Location	Institution	Genetic counseling providers	Phone number	Consultation type
Portland metropolitan area	Compass Oncology (Compass)	Compass, Genetic Risk Evaluation and Testing (GREAT) program	503-297-7403	Face-to-face
Portland metropolitan area	Kaiser Permanente Northwest (KPNW — Kaiser members only)	KPNW, Department of Medical Genetics	503-331-6593 or 1-800-813-2000 Ext. 16-6593	Face-to-face Telephone
Portland metropolitan area	Legacy Health, Good Samaritan Medical Center, Comprehensive Cancer Center	Legacy Genetic Services	503-413-6534 or 1-800-220-4937 Ext. 6534	Face-to-face
Portland metropolitan area	OHSU, Knight Cancer Institute (OHSU KCI)	OHSU KCI, Genetic Counseling and Risk Assessment	503-494-9300	Face-to-face
Portland metropolitan area	Providence Health and Services, Oregon and Southwest Washington (Providence)	Providence, Genetic Risk Clinic	503-215-7901	Face-to-face
Salem	Kaiser Permanente Northwest (KPNW — Kaiser members only)	KPNW, Department of Medical Genetics	503-331-6593 or 1-800-813-2000 Ext. 16-6593	Face-to-face Telephone

NOTE: **Visit the National Society of Genetic Counselors website at www.nsgc.org to:**

- Get more information about genetic counseling
- Find a genetic counselor near you

Will my health coverage pay for genetic counseling and testing?

Board-certified genetic specialists are experts that can help you figure out payments and deal with insurance issues. They can check what your insurance covers. They know how to help get you the right care that is affordable, no matter what your insurance is.

NOTE:

The Affordable Care Act (ACA) requires most insurance plans* to:

cover genetic counseling and testing at no cost†, for women with family health history associated with an increased risk for HBOC.

Oregon Health Plan:

- Covers cancer genetic counseling and testing for people with signs of HBOC.
- Services are covered according to the National Comprehensive Cancer Network Guidelines.

What are the BRCA genes?

BRCA stands for the genes linked to **BR**east **CA**ncer. There are two BRCA genes: BRCA1 and BRCA2. Normally, they help protect you from getting cancer.

NOTE:

When one or both of your BRCA genes change or mutate, cells are more likely to divide and change rapidly. That can lead to cancer.

There are tests that you can have to check the BRCA genes for breast cancer risk.

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* Please contact your insurer to find out what your plan covers.

† Your health insurance company may require in-network providers. They may also have other rules about how to access qualifying care. Please check with them for specific requirements.

What if I don't have coverage to pay for genetic counseling and testing?

Board-certified genetic specialists are experts at helping you get and pay for the care you need. There are also organizations that can help cover the cost of genetic counseling and testing, if you are uninsured or your insurance does not cover it.

NOTE:

Genetic specialists can find testing that is free, on a sliding scale or has a cost-cap. Many testing labs help people who are uninsured or who have high-deductible plans.

Patient Advocate Foundation has information, resources and assistance. They help support health care access and solve insurance issues (**http://www.patientadvocate.org**).

Genetic privacy and anti-discrimination laws.

Genetic Information Nondiscrimination Act (GINA)
A federal law that makes it illegal for the following to discriminate against an individual based on their genetic information, including family history:

- Health insurance companies
- Group health plans
- Employers of more than 15 employees

Oregon Genetic Privacy Laws (OGPLs)
State laws that help protect your genetic information. These laws also look to prevent the misuse of genetic information. It is:

- Illegal for an employer to obtain or use your genetic information to discriminate against you as an employee or prospective employee.
- Illegal for health insurance companies to use your genetic information to price or decline individual policies.
- Required for health care providers to give clients an opportunity to request that their biological sample(s) and health information not be used for anonymous or coded genetic research.

What can I do to lower my risk for getting breast cancer and other cancers?

Studies have shown that you can take action to **catch cancer early**. You can also **lower your chances of getting cancer**. These things are possible, even if you don't get genetic testing.

How to lower your risks

More screenings

You may benefit from starting breast cancer testing in your 40s or earlier. Talk to your doctor about this if you are a woman at higher risk for breast or other cancers.

Exercise

As an adult, it is healthiest to exercise in either of the following amounts each week, if possible

- Moderate energy – 150 minutes or more
- A lot of energy – 75 minutes or more
  - » In general, if you are using moderate energy you can talk, but not sing. If you are using a lot of energy, you will not be able to say more than a few words without stopping for a breath.

Weight control

Your healthiest waist size will measure between 50 percent and 40 percent of your height. For example, if you are 5-feet (60 inches) tall, your waist size is healthiest if it measures less than 30 inches and more than 24 inches.

Breastfeeding

If you have given birth, you can breastfeed to lower your risk of breast and ovarian cancer, if possible. It is best to supply all the milk your child needs by breastfeeding for six months or longer.

Limit alcohol consumption

As an adult, it is healthiest to consume less than one drink per day.

NOTE: **For more information about being and staying healthy,** visit the Oregon Health Authority, Public Health Division Healthy People and Families page at **http://oregon.gov/oha/ph/HealthyPeopleFamilies**.

Don't use tobacco

Call the Quit for Life® Program, if you do. There is telephone and web-based counseling to help you quit using tobacco and nicotine products. The phone line is open 24 hours a day, seven days a week.

English
1-800-QUIT-NOW
1-800-784-8669
quitnow.net/oregon
quitnow.net/oregonsp

Spanish
1-855-DEJELO-YA
1-855-335356-92
quitnow.net/oregonsp

TTY:
1-877-777-6534

Risk reduction (prophylactic) medication

Breast cancer risk reduction drugs may be an option for you. Please talk with your doctor.

Not using estrogen or progesterone

These types of therapies can increase your risk for breast cancer. Talk to your doctor before you stop taking any prescriptions.

Risk reduction (prophylactic) surgery

Some preventive surgeries may be an option for you. Please talk with your doctor.

You can get this document in other languages, large print, braille or a format you prefer. Contact Screenwise at 971-673-0581 or email ScreenWise.info@dhsoha.state.or.us. We accept all relay calls or you can dial 711.

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OHA 9292A (03/2018)

Hereditary Cancer Awareness Project Fact Sheet

Purpose:

1. Survey – To find out more from Oregon cancer survivors and clinicians:
    a. Their understanding of Hereditary Breast and Ovarian Cancer (HBOC) syndrome or Lynch Syndrome (LS)
    b. Their use of, or referrals to, resources
2. Educate – To inform Oregon cancer survivors and clinicians about HBOC or LS:
    a. Raise knowledge of resources
    b. Encourage life-saving conversations

Process: A letter, survey and other material sent to specific persons:

- Cancer survivors who fit cancer genetic services referral guidelines.
- Reporting clinicians of cancer survivors (when known).

Survey candidates: ScreenWise used the Oregon State Cancer Registry (OSCaR) to find certain cancer survivors and reporting clinicians. We looked for cancer survivors who may have been offered cancer genetic services to gauge if they have HBOC syndrome or LS. This does not mean the person has HBOC or LS. However, it does mean that some people with that cancer diagnosis might have HBOC or LS.

To learn more about HBOC or LS, the person may want to talk with their doctor or a board-certified genetic specialist. For example, they may want to talk to their certified genetic counselor (CGC) or a geneticist (MD or PhD). These specialists can explain the risk of HBOC related cancers to the person and their family.

Post survey: By Sept. 28, 2018, we will put a summary of the results for this project on the Hereditary Cancer Awareness Project webpage. You will be able to go to **http://www.healthoregon.org/genetics** for the results. This summary will not include any personal information.

Data source: The Oregon State Cancer Registry. For more information about OSCaR, go to **http://healthoregon.org/oscar**.

Administered by: The Oregon Health Authority's ScreenWise Program. Go to **http://www.healthoregon.org/screenwise** for more information about ScreenWise.

Funded by: Centers for Disease Control and Prevention (CDC), Division of Cancer Prevention and Control, cooperative agreement number DP005353-04.

You can get this document in other languages, large print, braille or a format you prefer. Contact ScreenWise genetics team at 971-673-0273 or email Summer.L.Cox@dhsoha.state.or.us. We accept all relay calls or you can dial 711.