PUBLIC HEALTH DIVISION
Screenwise
Kate Brown, Governor

Oregon Health Authority

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FIRSTNAME MIDDLENAME LASTNAME
BUSINESS
ADDRESS1
CITY STATE ZIP

March 9, 2018

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

Dear Firstname Lastname,

Please help ScreenWise, an Oregon Health Authority program, by taking the enclosed survey. Your answers will help us to improve the information that we share with Oregon health care providers. We are hopeful that it will also help save lives.

Please complete the survey by Monday, Apr. 30, 2018. If you do so, you will receive a $15 Amazon gift card as a thank you for your prompt reply.

There are three ways to take this survey:

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

You received this letter because according to Oregon State Cancer Registry (OSCaR) data from 2012-2014, you have seen patients with any of the following:

- Breast cancer (DCIS or invasive) diagnosed before age 50
- Triple negative breast cancer before age 60
- Male breast cancer at any age
- Ovarian cancer at any age
- Pancreatic cancer and breast cancer at any age

These patients may be at high risk of having HBOC. They may benefit from a formal cancer genetic risk assessment for HBOC syndrome by a genetic specialist. We have also sent an informational packet to these patients about HBOC. Some patients may want to discuss this information with you.

Continued on back

Background information about HBOC and board-certified cancer genetic specialists in Oregon is enclosed. When appropriate, please consider referring your patients to genetic counseling for cancer genetic risk assessment.

We will put a summary of the results for this project on the Hereditary Cancer Awareness Project webpage at **http://www.healthoregon.org/genetics** by Sept. 28, 2018.

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.

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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**

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.

Oregon Health Authority

Hereditary Breast and Ovarian Cancer Syndrome Health Care Provider Survey

Thank you for taking our survey!

Hereditary Breast and Ovarian Cancer Syndrome Healthcare Provider Survey

Why did I get this survey?

ScreenWise, an Oregon Health Authority program, created this survey. Your answers will help us to tailor education materials for health care providers who diagnose and care for patients with hereditary cancer.

How can I complete the survey?

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

How long will it take?

The survey will take about 5 minutes. Some people take more time, others less.

When do I need to return it?

Please return the finished survey by **Monday, Apr. 30, 2018**. If you do so, you will receive an electronic $15 Amazon gift card as a thank you for your prompt reply. Please provide your email address below if you are completing the survey and would like to receive the gift card.

Email:

When do I get to see the findings of this project?

We will put a summary of the results for this project on the Hereditary Cancer Awareness Project webpage at **http://www.healthoregon.org/genetics** by Sept. 28, 2018.

1. Please indicate your practice specialty. (*Check all that apply*)

- ☐ Colorectal surgery
- ☐ Family medicine
- ☐ Gastroenterology
- ☐ General surgery
- ☐ General practice
- ☐ Internal medicine
- ☐ Medical genetics
- ☐ Obstetrics and gynecology
- ☐ Gynecologic oncologist
- ☐ Oncology
- ☐ Other(s) (*please name*):

2. What medical credential(s) do you have? (*Check all that apply*)

- ☐ DO
- ☐ MD
- ☐ ND
- ☐ NP
- ☐ PA
- ☐ Other (*please name*):

3. Indicate whether you agree or disagree with the following statements

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
a. I learned something new in the packet about Hereditary Breast and Ovarian Cancer (HBOC) syndrome.					
b. I will change my clinical practice based on the information I learned from the packet.					
c. I believe this information will be useful for other health care providers.					

4. What was the most helpful information in the packet?

5. What other information would have been helpful?

6. What feedback or comments do you have for us?

That is all of our survey questions. Thanks so much for your help!

If you have any 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**

Provider

FREQUENTLY ASKED QUESTIONS

Hereditary Breast and Ovarian Cancer Syndrome

March 2018

PUBLIC HEALTH
ScreenWise

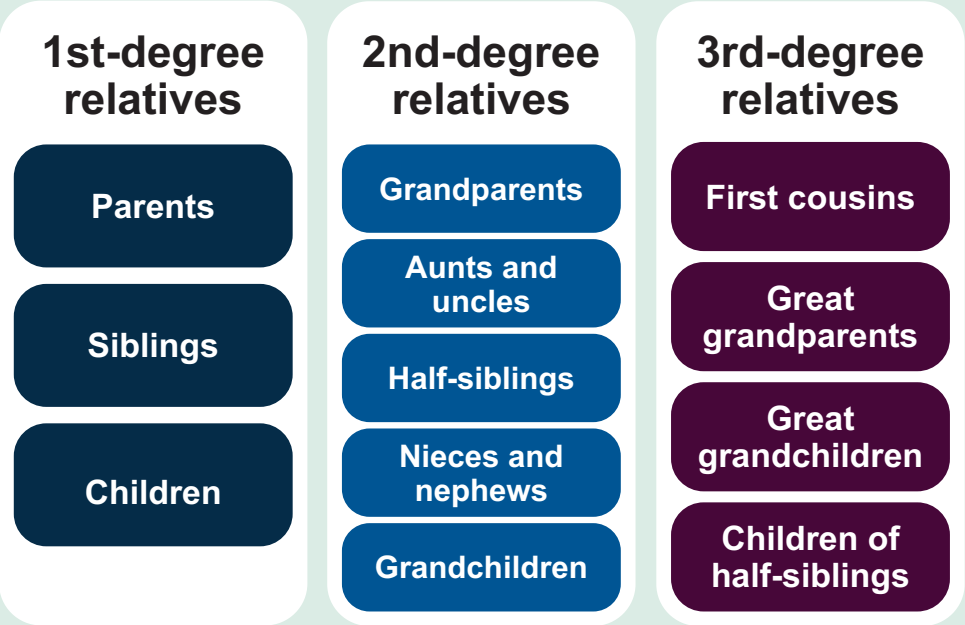
Oregon Health Authority

Table of contents

How do I gauge patients' personal and family histories of cancer and help save lives?

NOTE: **There are three key parts to collecting cancer family history:**

- Who had cancer?
  - » Relationship (e.g., patient, full or half sibling, aunt, etc.)
  - » Lineage (maternal or paternal side)
  - » Multiple generations (three generations are best)
- What was the location of the primary cancer and the age at diagnosis?
  - » Get as much information as possible about the cancer
- How and at what age did the relative die, if deceased?



Without any intervention, people with hereditary breast and ovarian cancer (HBOC) syndrome are at higher risk of developing early and aggressive cancers than people in the general population.

Other helpful information to get includes:

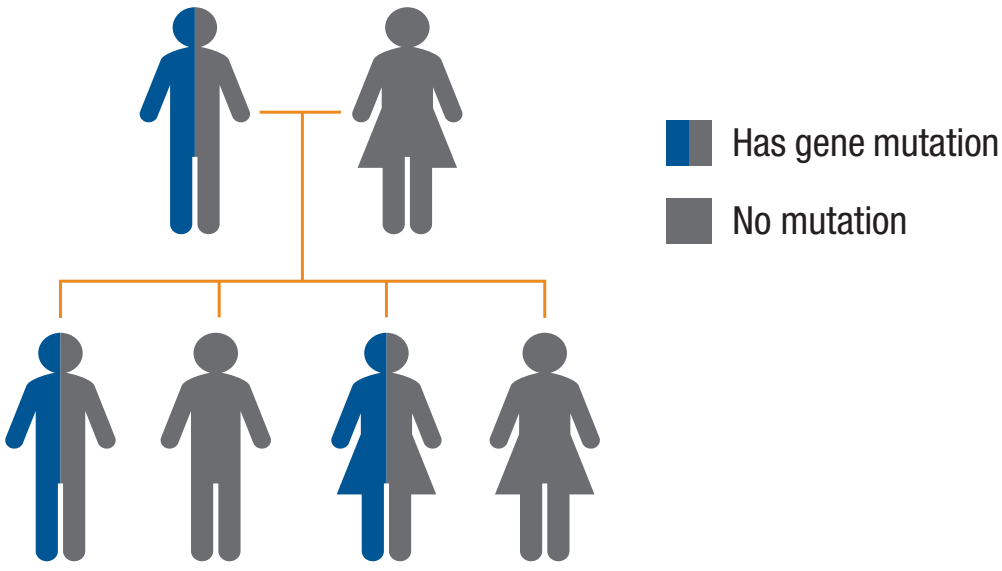
- Date and place of birth for all relatives
- Age at time of death for all deceased relatives
- Cause of death for all deceased relatives
- Ethnicity (some genetic diseases are more common in certain ethnic groups)
- Presence of chronic diseases and major medical conditions
- Information about habits, such as exercise, smoking, alcohol consumption and diet
- Information about jobs, such as farming or office work, and hobbies

NOTE: **Be sure to ask your patients to update this information regularly.**

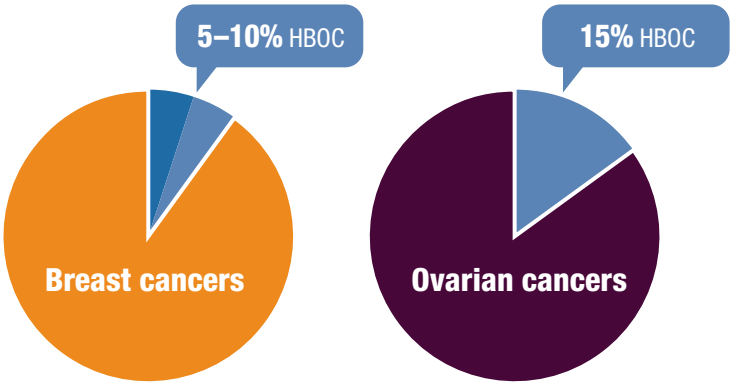
How are hereditary cancer syndromes inherited and what does it mean to have a harmful BRCA mutation?

Hereditary cancer syndromes generally follow an autosomal dominant inheritance pattern. This is where an affected individual has:

- One copy of a normal gene on a pair of autosomal chromosomes
- One copy of a gene with a harmful mutation
  - » The harmful mutation can be passed from mother or father. All 1st degree relatives of someone with a harmful mutation have a 50 percent chance of having the harmful mutation.



- Hereditary breast and ovarian cancer (HBOC) syndrome accounts for about 5–10 percent of all breast cancers. It also accounts for approximately 15 percent of ovarian cancers.
- Most cancers relating to HBOC are due to mutations in the BRCA1 (breast cancer 1) and BRCA2 (breast cancer 2) genes.



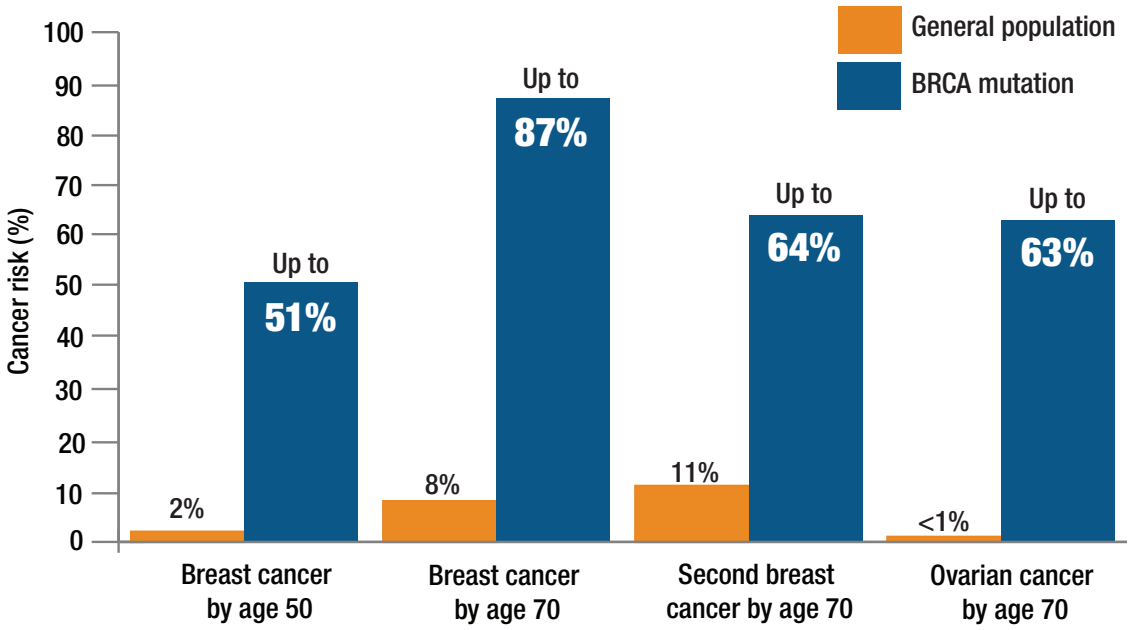
NOTE: **Having a harmful BReast CAncer (BRCA) mutation greatly increases the chance of developing breast, ovarian and other cancers.**

- When working normally, BRCA genes are tumor suppressor genes. These genes make proteins involved in repairing DNA. This helps prevent cells from growing and dividing too quickly or in an uncontrolled manner.
- When the gene is **not** working effectively, people with a hereditary cancer syndrome often develop multiple cancers. They often develop these cancers at a younger age. In addition, they often have cancers that are aggressive.

NOTE: **HBOC related conditions include:**

- Breast cancer
- Brain cancer
- Endometrial cancer
- Melanoma
- Leukemia
- Hamartomatous polyps of gastrointestinal (GI) tract
- Pancreatic cancer
- Diffuse gastric cancer
- Thyroid cancer
- Sarcoma
- Macrocephaly
- Colon cancer
- Prostate cancer (Gleason score > 7)
- Kidney cancer
- Adrenocortical carcinoma
- Dermatologic manifestations (1)

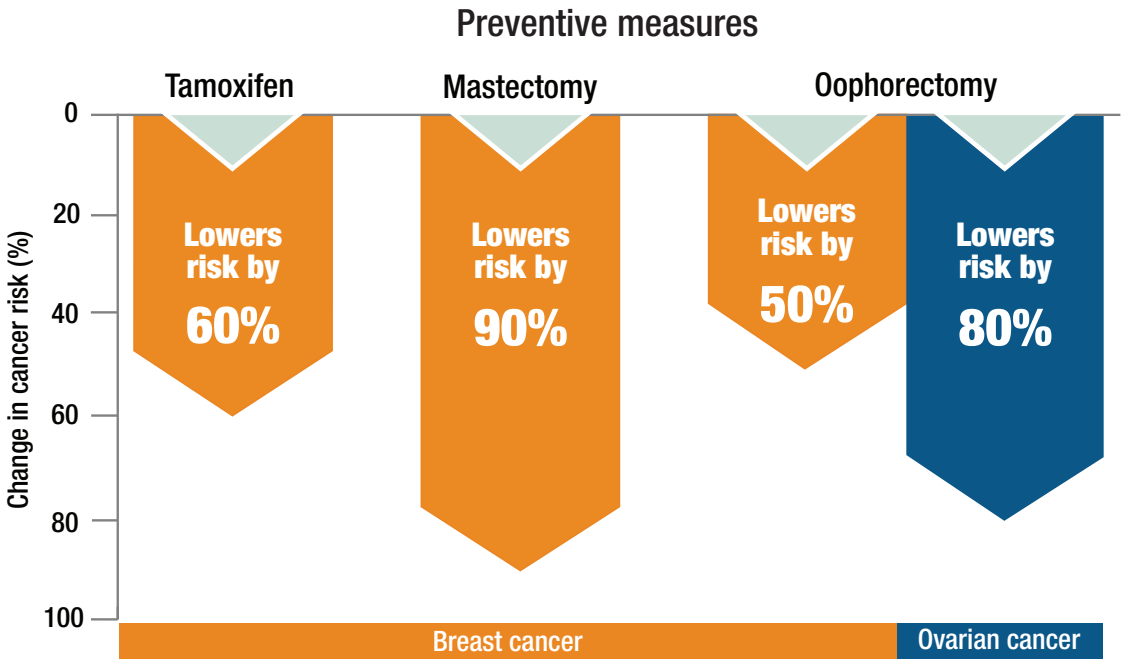
CHART 1 BRCA cancer risks compared to the general population (among women) (2)



Men with harmful BRCA mutations also have a higher risk of certain cancers.

Autosomal dominant mutations, such as the ones seen in BRCA, can be passed down from either side of the family.

CHART 2 Preventive measures can significantly lower the risk of cancer in women with a BRCA mutation (1)



How can I take action?

You can help save the lives of your patients at risk of developing hereditary cancers by:

- Using the family history information that your patients share and getting updates over time
- Making referrals to genetic counseling and working with board-certified genetic specialists
- Creating and implementing personalized cancer surveillance and risk reduction plans for your patients
- Helping your high-risk patients get enhanced screening according to guidelines
- Encouraging your patients to practice risk reduction through lifestyle behaviors, such as those listed in the "How patients can lower their risk" section

Any of the following meet criteria for referral to genetic counseling (1)
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)

Genetic counseling can help people make health care decisions and life choices

NOTE:

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

- Identify what types of cancer tests and screenings are right for the patient and how often to get them
- Identify activities that may help lower the patient's chance of developing a new cancer
- Ensure patients make fully informed choices
- Help identify if genetic testing may be a good choice for the patients and their family
- Ensure the right tests are ordered and the results interpreted correctly

Does health insurance pay for genetic counseling and testing?

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

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

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* Your patients will need to contact their insurers to find out what their plans cover.

† Your patients' health insurance companies may require in-network providers. They may also have other rules about how to access qualifying care. Please remind your patients to check with their insurance companies for specific requirements.

What if patients don't have health insurance to pay for genetic counseling and testing?

Board-certified genetic specialists are experts at helping patients get and pay for the care they need. Many testing labs help people who are uninsured or who have high-deductible plans.

There are also organizations that can help your patients cover the cost of genetic counseling and testing if they are uninsured or their insurance does not cover it. For example, Patient Advocate Foundation has information, resources and assistance. They help support health care access and solve insurance issues (**http://www.patientadvocate.org**).

Where are the board-certified cancer genetic specialists?

These clinics currently offer cancer genetic counseling by board-certified genetic specialists.

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
Portland metropolitan area	Compass Oncology (Compass)	Compass, Genetic Risk Evaluation and Testing (GREAT) program	503-297-7403	Face-to-face

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Location	Institution	Genetic counseling providers	Phone number	Consultation type
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

How can patients lower their risks?

Studies have shown that people can take action to catch cancer early. They can also lower their chances of getting cancer. These things are possible, even if they don't get genetic testing.

Lowering patient risks

More screenings

Patients may benefit from starting breast cancer testing in their 40s or earlier. Talk to patients who are at higher risk for breast or other cancers. (3)

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, a patient using a lot of energy can talk, but not sing. A patient using a lot of energy will not be able to say more than a few words without stopping for a breath. (4)

Weight control

A patient's healthiest waist size will measure between 50 percent and 40 percent of their height. For example, if a patient is 5-feet (60 inches) tall, their waist size is healthiest if it measures less than 30 inches and more than 24 inches. (5, 6)

Breastfeeding

A patient who has given birth can breastfeed to lower their risk of breast and ovarian cancer, if possible. (7)

Limit alcohol consumption

Consume less than one drink per day. (8)

Continued on next page

Lowering patient risks (continued)

Don't use tobacco

A patient who uses tobacco can call the Quit for Life® Program. There is telephone and web-based counseling to help the patient quit using tobacco and nicotine products. The phone line is open 24 hours a day, seven days a week. (9)

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

Tamoxifen and raloxifene are the only drugs that are approved in the United States to help lower the risk of breast cancer. However, for some patients, drugs called aromatase inhibitors might be an option as well. (10)

Not using estrogen or progesterone

These types of therapies can increase patients' risks for breast, ovarian and endometrial cancer. (11)

Risk reduction (prophylactic) surgery

Some preventive surgeries may be an option for some patients. (12)

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**.

Where can I learn more about HBOC?

There are many free and fee-based learning opportunities available, often with continuing medical education (CME) credits. Three examples of free opportunities with CMEs are:

- The Centers for Disease Control and Prevention (CDC) has a Bring Your Brave campaign. The goal is to educate young women and health care providers about early onset breast cancer and hereditary breast and ovarian cancer risk. To learn more, go to **https://www.cdc.gov/cancer/breast/young_women/bringyourbrave/health_care_provider_education/index.htm**.
- The Jackson Laboratory has genetics related course offerings with CME and continuing nursing education (CNE) credits for providers. Topics include hereditary cancer syndromes, family history collection, precision medicine and more. To learn more go to **https://learn.education.jax.org/browse/hpe**.
- The "HBOC: Is Your Patient at High Risk?" CME module was developed to help primary care providers identify, evaluate and manage patients at increased risk of HBOC. To learn more, go to **https://learn.education.jax.org/browse/hpe/cme/courses/hboc**.

Genetic privacy and anti-discrimination laws

State

Oregon Genetic Privacy Laws (OGPLs)

These state laws make it:

- 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.

Federal

Genetic Information Nondiscrimination Act (GINA)

This federal law makes it illegal for the following to discriminate against an individual based on that person's genetic information, including family history:

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

The Americans with Disabilities Act (ADA)
This federal law makes it illegal to discriminate in employment, public services, accommodations and communications against a person:

- Who is regarded as having a disability based on genetic information relating to illness, disease or other disorders
- With symptomatic genetic disabilities
- With a genetic predisposition

The Affordable Care Act (ACA)
This federal law establishes "guaranteed issue," meaning:

- Issuers offering insurance in either the group or individual market must provide coverage for all individuals who request it.
- Issuers of health insurance are prohibited from discriminating against patients with genetic diseases by refusing coverage because of pre-existing conditions.
- Certain health insurers may only vary premiums based on a few specified factors such as age or geographic area, thereby prohibiting the adjustment of premiums because of medical conditions, including genetic diseases.

Health Insurance Portability and Accountability Act (HIPAA)
This federal law is not specific to genetics; rather the law has sweeping regulations governing all personal health information. This law:

- Applies to employer-based and commercially issued group health insurance, and:
  - » Prohibits group health plans from using any health status-related factor, including genetic information, as a basis for denying or limiting eligibility for coverage or for increasing premiums
  - » Limits exclusions for preexisting conditions in group health plans to 12 months and prohibits such exclusions if the individual has been covered previously for that condition for 12 months or more
  - » States explicitly that genetic information, in the absence of a current diagnosis of illness, shall not be considered a preexisting condition.
- Protects medical records and other personal health information maintained by health care providers, hospitals, health plans, health insurers and health care clearinghouses, and:
  - » Limits the nonconsensual use and release of private health information
  - » Gives patients' rights to access their medical records and to know who else has accessed them
  - » Restricts most disclosure of health information to the minimum needed for the intended purpose of establishing criminal and civil sanctions for improper use or disclosure
  - » Establishes requirements for access to records by researchers and others.

Endnotes

1. National Comprehensive Cancer Network (NCCN). Clinical practice guidelines in oncology [Internet]. Genetic/Familial High-Risk Assessment: Breast and Ovarian. Version 1.2018. [cited 2018 Feb 5]. Available from: **www.nccn.org**.

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5. Centers for Disease Control and Prevention. Healthy weight, assessing your weight [Internet]. May 15, 2015 [cited 2017 Jul 18]. Available from: **https://www.cdc.gov/ healthyweight/assessing/index.html**.

6. Health-Calc. Waist to height ratio [Internet] [cited 2018 Feb 21]. Available from: **https://www.health-calc.com/body-composition/waist-to-height-ratio**.

7. Breastcancer.org. Breastfeeding history [Internet] [cited 2018 Feb 21]. Available from: **http://www.breastcancer.org/risk/factors/breastfeed_hist**.

8. Breastcancer.org. Drinking alcohol [Internet] [cited 2018 Feb 21]. **Available from: http://www.breastcancer.org/risk/factors/alcohol**.

9. Breastcancer.org. Smoking. [Internet] [cited 2018 Feb 21]. Available from: **http://www.breastcancer.org/risk/factors/smoking**.

10. American Cancer Society. Tamoxifen and raloxifene for lowering breast cancer risk [Internet] [cited 2018 Feb 21]. Available from: **https://www.cancer.org/cancer/breast-cancer/risk-and-prevention/tamoxifen-and-raloxifene-for-breast-cancer-prevention.html**.

11. American Cancer Society. Menopausal hormone therapy and cancer risk [Internet] [cited 2018 February 21]. Available from: **https://www.cancer.org/cancer/cancer-causes/medical-treatments/menopausal-hormone-replacement-therapy-and-cancer-risk.html**.

12. National Comprehensive Cancer Network (NCCN). Clinical practice guidelines in oncology [Internet]. Breast Cancer Risk Reduction. Version 1.2017. [cited 2016 Dec 16]. Available from: **www.nccn.org**.

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