



Patient

FREQUENTLY ASKED QUESTIONS

Hereditary Breast and Ovarian Cancer Syndrome

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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.

* HBOC related conditions include:

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

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.

* 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-DEJALO-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.

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