

Who should get genetic counseling and testing?
EVERY woman who has or has had ovarian cancer.



Ovarian Cancer Research and News Hereditary Ovarian Cancer

Genetic Counseling and Testing: What it means for YOU

Lecture Series: Hereditary Ovarian Cancer

Join us on **Tuesday, July 27th** for a talk on Hereditary Ovarian Cancer with COCA Board Member and Genetic Counselor Lisa Mullineaux. Lisa was the first cancer genetic counselor in Colorado and has been working as a clinical cancer genetic counselor for the last 20 years.

This lecture discusses hereditary genetics and how they may affect your treatment as well as how hereditary markers may impact other family members.



Afternoon lecture: 1:00 pm

Ross-University Hills Branch Library- Large Meeting Room
4310 E. Amherst Ave. (just one block east of Colorado Blvd.)
Denver, CO 80222

Evening lecture: 6:00 pm

Jefferson County Public Library - Lakewood Room
10200 W. 20th Avenue. Lakewood, CO 80215

There is no need to register or RSVP.

This lecture is intended for informational purposes only. COCA does NOT provide medical advice nor endorse any particular provider of medical services.

Did you know?

Ovarian cancer does not have to run in your family
to have a hereditary marker.

Why Undergo Genetic Counseling and Testing?

Possessing genetic information empowers you and your healthcare professional with knowledge to help assess your risk of developing disease, **helps guide treatment decisions and can help assess your risk of disease progression and recurrence.**

Who should receive Genetic Counseling and Testing?

The simple answer to this is...

every woman who has or has had ovarian cancer.



According to the Society of Gynecologic Oncologists (SGO):

"Nearly one-third of women with hereditary ovarian carcinoma have no close relatives with cancer, and 35% of women with hereditary ovarian carcinoma are older than 60 years at diagnosis. **Therefore, all women diagnosed with ovarian, fallopian tube or peritoneal carcinoma, regardless of age or family history, should receive genetic counseling and be offered genetic testing.** Careful pre- and post-test counseling is essential to understanding genetic testing options and results. Genetic counseling and testing can be conducted by genetic counselors, as well as other knowledgeable medical professionals.

Identification of hereditary cancer susceptibility allows for **identification of cancer risk in other organs.** Additionally, genetic results are valuable to **inform other family members about their cancer risk, allowing personalized prevention to high risk individuals, including more intensive screening and risk-reducing surgery.** Family members found not to carry the mutation may also receive reassurance and avoid unnecessary screening and interventions.

New therapies such as PARP inhibitors are currently being tested for the treatment of ovarian carcinoma associated with mutations in *BRCA1* and *BRCA2*. The Society of Gynecologic Oncology (SGO) encourages the medical community to offer genetic counseling and testing to all women with ovarian, fallopian tube and peritoneal carcinoma."

You can read their full statement here:

[SGO Clinical Practice Statement: Genetic Testing for Ovarian Cancer](#)

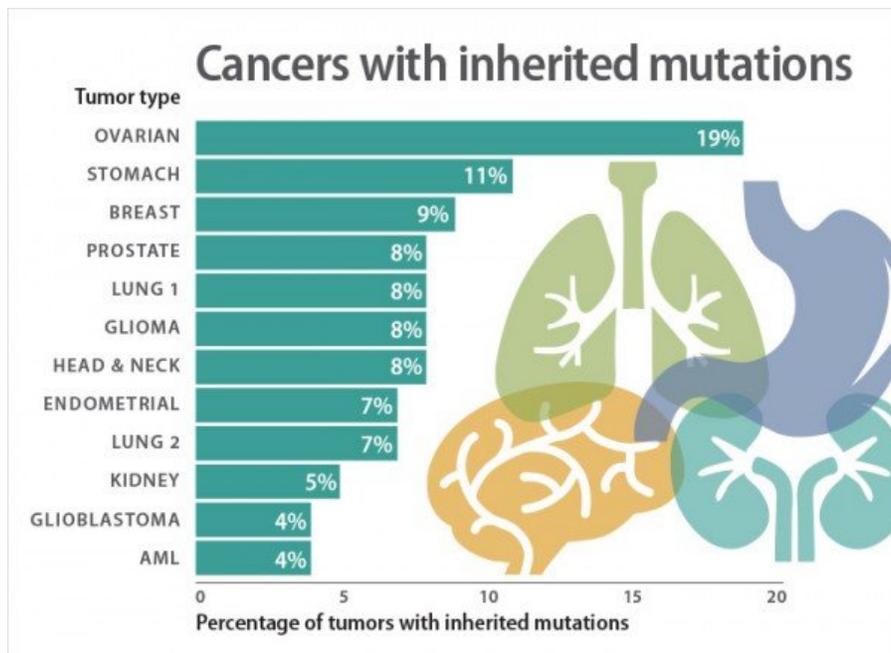


Chart Source: <https://www.sciencedaily.com/releases/2015/12/151222084730.htm>

Were you tested prior to 2012?

If you had genetic testing done **prior to 2012**, you should be tested again because the field of genetic testing has changed so dramatically in the past several years!

The Process: Starts With A Conversation

The process of genetic counseling and testing should start with a conversation with a Certified Genetic Counselor. While each appointment and conversation will vary, here is a list of the types of things that the counselor will cover with you.

- Introduction to Cancer Types: Hereditary, Familial, and Sporadic
- Personal and/or family history collection
- Discussion of gene mutations and their relevance to developing certain cancers
- Risk-reducing surgeries and preventative medication strategies that may reduce cancer risk
- Testing options
- Possible test results: Positive, Negative, Uncertain
- Family impact
- Test coverage
- Privacy issues
- Benefits and limitations of genetic testing
- Next steps and a management plan

(Courtesy of Myriad Genetics)

The Process: Testing

This is the simple part for you! Testing is done either with a saliva swab or blood test.

Then the sample is sent to a laboratory where technicians look for specific changes in chromosomes, DNA, or proteins, depending on the suspected disorder. The laboratory reports the test results in writing to a person's doctor or genetic counselor, or directly to the patient if requested.



From the date that a sample is taken, it may take a few weeks to several months to receive the test results. The doctor or genetic counselor who orders a particular test can provide specific information about the cost and time frame associated with that test.

Here's a great resource for information about the genetic testing process:

[Genetics Home Reference](#)



Learn About Genetics and Precision Medicine

According to the National Institutes of Health (NIH), precision medicine is "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person."

This approach will allow doctors and researchers to predict more accurately which treatment

and prevention strategies for a particular disease will work in which groups of people. It is in contrast to a "one-size-fits-all" approach, in which disease treatment and prevention strategies are developed for the average person, with less consideration for the differences between individuals.

If you would like to learn more about genetics in general, visit this informative site:

[Genetics Home Reference: Help Me Understand Genetics](#)

Insurance Coverage and Costs

In most cases, health insurance plans **will** cover the costs of genetic testing when it is recommended by a person's doctor or health care provider. Health insurance providers have different policies about which tests are covered, however. A person interested in submitting the costs of testing may wish to contact his or her insurance company beforehand to ask about coverage.

Some people may choose not to use their insurance to pay for testing because the results of a genetic test can affect a person's insurance coverage. Instead, they may opt to pay out-of-pocket for the test. People considering genetic testing may want to find out more about their state's privacy protection laws before they ask their insurance company to cover the costs.

The cost of genetic testing can range from under \$100 to more than \$2,000, depending on the nature and complexity of the test. The cost increases if more than one test is necessary or if multiple family members must be tested to obtain a meaningful result.

Here is some interesting information about coverage of genetic testing from the National Human Genome Research Institute:

<https://www.genome.gov/19016729/>

Privacy and Non-Discrimination

The Genetic Information Nondiscrimination Act of 2008 (GINA) is a federal law that protects individuals from genetic discrimination in health insurance and employment.

Genetic discrimination is the misuse of genetic information.

Insurers: GINA makes it against the law for health insurers to request, require, or use genetic information to make decisions about:

- Your eligibility for health insurance
- Your health insurance premium, contribution amounts, or coverage terms

This means it is against the law for your health insurer to use a genetic test result or family health history as a reason to deny you health insurance, or decide how much you pay for your health insurance.

In addition, GINA makes it against the law for your health insurer to:

- Consider family history or a genetic test result a pre-existing condition
- Ask or require that you have a genetic test
- Use any genetic information they do have to discriminate against you, even if they did not mean to collect it

Employers: GINA makes it against the law for employers to use your genetic information in the following ways:

- To make decisions about hiring, firing, promotion, pay, privileges or terms
- To limit, segregate, classify, or otherwise mistreat an employee

This means it is against the law for your employer to use family health history and genetic test results in making decisions about your employment.

It is also against the law for an employer to request, require, or purchase the genetic information of a potential or current employee, or his or her family members. There are a few exceptions to when an employer can legally have your genetic information. If an employer does have the genetic information of an employee, the employer must keep it confidential and in a separate medical file.

Visit GINA's website to learn more: [Genetic Information Nondiscrimination Act](#)

Resources

If you want to further explore the topic of genetics, genetic testing and counseling, check out these great resources:

Genetic Alliance has lots of online information and publications available on a wide range of topics:

<http://geneticalliance.org/publications>

Genetics Home Reference is a division of the US National Library of Medicine:

<https://ghr.nlm.nih.gov/primer>

Myriad Genetics' website has some great information about Hereditary Ovarian Cancer:

<https://www.myriad.com/patients-families/disease-info/ovarian-cancer/>

To find a Genetic Counselor near you, follow this link:

[Find A Genetic Counselor](#)



Knowledge is
Power

Colorado Ovarian Cancer Alliance
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www.Colo-OvarianCancer.org

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