





Colorado Ovarian Cancer RESOURCE GUIDE

3rd Edition

Presented by

CO colorado ovarian Ca cancer alliance www.colo-ovariancancer.org



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The information presented in this guide is not intended in any way to be a substitute for medical advice or professional counseling. Please always include your health care providers in any decisions you make regarding changes in nutrition, exercise routine, and before you include complementary, alternative or integrative care into your treatment regimen.

Sources are cited for information, and the descriptions of services are from the websites of those businesses or nonprofits included herein.





Genetic Considerations

Genetics of Cancer

★ Your genetic makeup may have an effect on treatment options available to you for ovarian cancer. And, understanding hereditary cancer can help increase awareness of risk factors in your family.

Definition: Gene

from National Institutes of Health (NIH)

"Gene: The functional and physical unit of heredity passed from parent to offspring. Genes are pieces of DNA, and most genes contain the information for making a specific protein."

<u>www.cancer.gov/publications/dictionaries/cancer-</u> <u>terms?search=gene</u>

Definition: Gene Mutation

from Genetics Home Reference, National Library of Medicine (NLM), National Institutes of Health (NIH)

"A gene mutation is a permanent alteration in the DNA sequence that makes up a gene, such that the sequence differs from what is found in most people. Mutations range in size; they can affect anywhere from a single DNA building block (base pair) to a large segment of a chromosome that includes multiple genes.

Gene mutations can be classified in two major ways:

- Hereditary mutations are inherited from a parent and are present throughout a person's life in virtually every cell in the body. These mutations are also called germline mutations because they are present in the parent's egg or sperm cells, which are also called germ cells. When an egg and a sperm cell unite, the resulting fertilized egg cell receives DNA from both parents. If this DNA has a mutation, the child that grows from the fertilized egg will have the mutation in each of his or her cells.
- Acquired (or somatic) mutations occur at some time during a person's life and are present only in certain cells, not in every cell in the body. These changes can be caused by environmental factors such as ultraviolet radiation from the sun, or can occur if a mistake is made as DNA copies itself during cell division. Acquired mutations in somatic cells (cells other than sperm and egg cells) cannot be passed on to the next generation."

<u>https://ghr.nlm.nih.gov/handbook/mutationsand-</u> <u>disorders/genemutation</u>

Yrom Cleveland Clinic Genomic Medicine Institute Overview

"Cancer arises from the uncontrolled growth of cells. Cells are the units that make up our tissues and organs (for example, our skin, lungs and brain), which in turn make up our entire body. When cells are doing their job well, they know when to grow and when to stop growing. Cells contain genes. Genes are the instructions that tell cells how to function properly, like when to grow and when to stop growing. Cancer is caused by harmful changes in genes, called mutations. These mutations cause the cell to grow without control, and eventually become a cancer.

Sporadic Cancer

Most cancers are sporadic – they are not inherited and cannot be passed to your children. Because cancer is common, some families may have a few members affected with sporadic cancers just by chance. Sporadic cancers may be the result of environmental exposures. Sporadic cancer may also be due to mutations that occur in genes by chance when a cell divides. Since these mutations occur only in the cancer cells, they cannot be passed on.

Familial Risk

Sometimes cancers cluster in families. In these cases, more cancers are occurring than would be expected by chance, yet they do not appear to be clearly hereditary (able to be passed on within the family). It is possible that interactions are occurring between genes and the environment or among several genes that contribute to the development of these cancers. This type of moderately increased cancer risk can be called a "familial" risk.

Hereditary Cancer

About 5-10% of cancers are believed to be hereditary. Hereditary susceptibility to cancer can be inherited and passed on within a family. Individuals who inherit a mutation in a cancer susceptibility gene have a much greater chance for developing cancer. However, not everyone with a cancer susceptibility gene mutation will develop cancer.

Cancer susceptibility gene mutations can be inherited from, and passed on to, men as well as women. Almost all genes come in pairs. One gene copy of each pair is inherited from the father and the other gene copy is inherited from the mother. Therefore, if a parent has a gene mutation associated with cancer susceptibility, each of his/her children has a 50% (1 in 2) chance of inheriting the gene mutation. Each child also has a 50% chance of inheriting the working copy of the gene, in which case his/her cancer risk would be no higher than that of the general population.

Features suggesting hereditary cancer include:

• early ages of cancer diagnoses (i.e. breast cancer before age 50)

• two or more relatives with the same type of cancer, on the same side of the family

- several generations affected by cancer
- multiple primary cancers in one individual (including breast and ovarian cancer or bilateral breast cancer)
- male breast cancer

• clustering of cancers which are known to be genetically related (such as breast and ovarian cancer, or colon and uter-ine cancer)

• the presence of certain features which are known to be associated with hereditary cancer (such as moles and melanoma, or polyps and colon cancer)."

<u>https://my.clevelandclinic.org/ccf/media/Files/genomics/Hereditary%20Cancer_Background%20Information.pdf?la=en</u>

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Inherited Ovarian Cancer Risk Factors



HEREDITARY BREAST AND OVARIAN CANCER SYNDROME (HBOC)

from National Cancer Institute (NCI)

"An inherited disorder in which the risk of breast cancer (especially before the age of 50) and ovarian cancer is higher than normal. Most cases of HBOC syndrome are caused by certain mutations (changes) in the BRCA1 or the BRCA2 gene. People with HBOC syndrome may also have an increased risk of other types of cancer, including pancreatic cancer, prostate cancer, and melanoma. Also called hereditary breast and ovarian cancer syndrome."

www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=751863

LYNCH SYNDROME

from Genetics Home Reference, National Library of Medicine (NLM), National Institutes of Health (NIH)

"Lynch syndrome, often called hereditary nonpolyposis colorectal cancer (HNPCC), is an inherited disorder that increases the risk of many types of cancer, particularly cancers of the colon (large intestine) and rectum, which are collectively referred to as colorectal cancer. People with Lynch syndrome also have an increased risk of cancers of the stomach, small intestine, liver, gallbladder ducts, upper urinary tract, brain, and skin. Additionally, women with this disorder have a high risk of cancer of the ovaries and lining of the uterus (the endometrium)."

https://ghr.nlm.nih.gov/condition/lynch-syndrome

JEWISH WOMEN

"One in 40 Ashkenazi (Eastern European) Jews carries a BRCA gene mutation, nearly 10 times the rate of the general population, making Jewish families significantly more susceptible to hereditary breast cancer and ovarian cancer. If you have a strong family history of cancer, have considered genetic counseling, or have opted for genetic testing, [Sharsharet] can help." "...Recent studies show that Sephardic Jewish (Jews from Spain, Portugal, or the Middle East) women may also be genetically predisposed to hereditary breast cancer and ovarian cancer." See Sharsharet below for more information.

<u>www.sharsheret.org/how-we-help/women-all-ages/at-risk-brca-positive</u> <u>www.sharsheret.org/how-we-help/women-all-ages/at-risk-or-brca-sephardic</u>

HISPANAS AND THE SAN LUIS VALLEY

"Hispanic women are at higher risk for ovarian cancer due to the migration of the BRCA gene mutation through the Jewish population into the Spanish and Mexican populations during the 1600s. Especially at risk are women in the San Luis Valley of Colorado where influences of colonial Spain are evident and the BRCA gene mutations were established." See article in Smithsonian magazine and book by Jeff Wheelwright for more information. <u>http://jeffwheelwright.com/book.htm</u> www.smithsonianmag.com/science-nature/the-secret-jews-of-san-luis-valley-11765512/

HEREDITARY CANCER QUIZ

This online brief questionnaire will help you determine whether you should be further evaluated for either Hereditary Breast and Ovarian Cancer syndrome or Lynch syndrome. On average, the quiz takes less than 1 minute to complete. See: <u>www.hereditarycancerquiz.com/?utm_source=google&utm_medium=cpc&gclid=CISv552crLwCFY1cM</u> <u>godo28Aow</u>

Sharsheret – Support for Jewish Women Living with Ovarian Cancer "Whether you are living with early or later stage ovarian cancer, we provide specialized support for Jewish women and families. Connect to our ovarian cancer community in the way that feels most comfortable to you." <u>www.sharsheret.org/how-we-help/women-all-ages/living-ovarian-cancer</u>
FORCE - Facing Our Risk of Cancer Empowered "FORCE is the only national nonprofit organization devoted to hereditary breast and ovarian cancer. Our mission includes support, education, advocacy, awareness, and research specific to hereditary breast and ovarian cancer. Our programs serve anyone with a BRCA mutation or a family history of cancer." <u>www.facingourrisk.org</u>
Dr. Jaime Arruda, M.D. - <i>University of Colorado, Aurora, CO 80045</i> 303.724.2066 Dr. Arruda works with BRCA-positive patients to determine the best tracking and prevention options going forward. <u>https://cancer.coloradowomenshealth.com/about/doctors/jaime-arruda-md/</u>

Genetic Counseling

★ It is recommended that you speak with a trained Genetic Counselor to determine the need for and direction of genetic testing.

Who are Genetic Counselors?

(By the National Society of Genetic Counselors, Inc. 1983) "Genetic counselors are health professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. Most enter the field from a variety of disciplines, including biology, genetics, nursing, psychology, public health, and social work. Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They identify families at risk, investigate the problem present in the family, interpret information about the disorder, analyze inheritance patterns and risks of recurrence and review available options with the family. Genetic counselors also provide supportive counseling to families, serve as patient advocates and refer individuals and families to community or state support services. They serve as educators and resource people for other health care professionals and for the general public. Some counselors also work in administrative capacities. Many engage in research activities related to the field of medical genetics and genetic counseling."

<u>http://nsgc.org/p/cm/ld/fid=386</u>

Genetic Counseling and Test Results

from National Cancer Institute (NCI)

It is strongly recommended that a person who is considering genetic testing speak with a professional trained in genetics before deciding whether to be tested.... Genetic counseling can help people consider the risks, benefits, and limitations of genetic testing in their particular situation. Sometimes the genetic professional finds that testing is not needed. Genetic counseling includes a detailed review of the individual's personal and family medical history related to possible cancer risk. Counseling also includes discussions about such issues as: 1) Whether genetic testing is appropriate, which specific test(s) might be used, and the technical accuracy of the test(s); 2) The medical implications of a positive or a negative test result; 3) The possibility that a test result might not be informative—that is, that the information may not be useful in making health care decisions; 4) The psychological risks and benefits of learning one's genetic test results; 5) The risk of passing a genetic mutation (if one is present in a parent) to children."

<u>www.cancer.gov/about-cancer/causes-prevention/</u> <u>genetics/genetic-testing-fact-sheet</u>

Will Insurance Cover My Genetic Testing & Genetic Counseling?

"New Affordable Care Act guidance says women with ovarian cancer can receive free genetic counseling, testing."

"...The U.S. Department of Health and Human Services, Labor and Treasury issued new guidance to clarify services and coverage available under the Affordable Care Act. Before... only women with a family history of ovarian and breast cancer were eligible for genetic testing and counseling free from additional out-of-pocket expense... Guidance will now allow women diagnosed with ovarian cancer to also access this counseling and testing as part of their [insurance] coverage."

www.ovariancancer.org/2015/05/12/new-affordable-care-act-guidance-says-women-with-ovarian-cancer-can-receive-free-genetic-counselingtesting/

Privacy of Genetic Information

from National Cancer Institute (NCI)

"...People considering genetic testing must understand that their results may become known to other people or organizations that have legitimate, legal access to their medical records, such as their insurance company or employer, if their employer provides the patient's health insurance as a benefit. However, legal protections are in place to prevent genetic discrimination, which would occur if insurance companies or employers were to treat people differently because they have a gene mutation that increases their risk of a disease such as cancer or because they have a strong family history of a disease such as cancer. In 2008, the Genetic Information Nondiscrimination Act (GINA) became federal law for all U.S. residents. GINA prohibits discrimination based on genetic information in determining health insurance eligibility or rates and suitability for employment."

<u>www.cancer.gov/about-cancer/causes-prevention/</u> <u>genetics/genetic-testing-fact-sheet</u>

The Genetic Information Nondiscrimination Act of 2008 (GINA) GINA protects Americans from discrimination based on their genetic information in both health insurance (Title I) and employment (Title II).

"...In 2008 the Genetic Information Nondiscrimination Act was passed into law, prohibiting discrimination in the workplace and by health insurance issuers. In addition, there are other legal protections against genetic discrimination by employers, issuers of health insurance, and others." - *Courtesy: National Human Genome Research Institute* From: <u>www.genome.gov/10002077</u> Also see: <u>www.ginahelp.org</u>



Genetic Testing



What is Genetic Testing? *from Genetics Home Reference, National Library of Medicine (NLM), National Institutes of Health (NIH)*

"Genetic testing is a type of medical test that identifies changes in chromosomes, genes, or proteins. The results of a genetic test can confirm or rule out a suspected genetic condition or help determine a person's chance of developing or passing on a genetic disorder. More than 1,000 genetic tests are currently in use, and more are being developed.

Several methods can be used for genetic testing:

- Molecular genetic tests (or gene tests) study single genes or short lengths of DNA to identify variations or mutations that lead to a genetic disorder.
- Chromosomal genetic tests analyze whole chromosomes or long lengths of DNA to see if there are large genetic changes, such as an extra copy of a chromosome, that cause a genetic condition.
- Biochemical genetic tests study the amount or activity level of proteins; abnormalities in either can indicate changes to the DNA that result in a genetic disorder.

Genetic testing is voluntary. Because testing has benefits as well as limitations and risks, the decision about whether to be tested is a personal and complex one. A geneticist or genetic counselor can help by providing information about the pros and cons of the test and discussing the social and emotional aspects of testing."

https://ghr.nlm.nih.gov/handbook/testing?show=all

Genetic Testing

from National Cancer Institute (NCI)

"Genetic testing looks for specific inherited changes (mutations) in a person's chromosomes, genes, or proteins. Genetic mutations can have harmful, beneficial, neutral (no effect), or uncertain effects on health. Mutations that are harmful may increase a person's chance, or risk, of developing a disease such as cancer. Overall, inherited mutations are thought to play a role in about 5 to 10 percent of all cancers.

Cancer can sometimes appear to "run in families" even if it is not caused by an inherited mutation. For example, a shared environment or lifestyle, such as tobacco use, can cause similar cancers to develop among family members. However, certain patterns—such as the types of cancer that develop, other non-cancer conditions that are seen, and the ages at which cancer typically develops—may suggest the presence of a hereditary cancer syndrome.

The genetic mutations that cause many of the known hereditary cancer syndromes have been identified, and genetic testing can confirm whether a condition is, indeed, the result of an inherited syndrome. Genetic testing is also done to determine whether family members without obvious illness have inherited the same mutation as a family member who is known to carry a cancer-associated mutation.

Inherited genetic mutations can increase a person's risk of developing cancer through a variety of mechanisms, depending on the function of the gene. Mutations in genes that control cell growth and the repair of damaged DNA are particularly likely to be associated with increased cancer risk. Genetic testing of tumor samples can also be performed..." <u>www.cancer.gov/about-cancer/causes-preven"tion/</u> <u>genetics/genetic-testing-fact-sheet#q1</u>

Statement On Risk Assessment For Inherited Gynecologic Cancer Predispositions

from Society of Gynecologic Oncology

Johnathan M. Lancaster, C.BethanPowell, Lee-may Chen, Debra L. Richardson, on behalf of the SGO Clinical Practice Committee: a. H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL, USA, b. Permanente Medical Group San Francisco, CA, USA, c. UCSF Helen Diller Family Comprehensive Cancer Center, San Francisco, CA, USA, d. The University of Texas Southwestern Medical Center, Dallas, TX, USA

"Women with germline mutations in the cancer susceptibility genes, BRCA1 or BRCA2, associated with Hereditary Breast & Ovarian Cancer syndrome, have up to an 85% lifetime risk of breast cancer and up to a 46% lifetime risk of ovarian, tubal, and peritoneal cancers. Similarly, women with mutations in the DNA mismatch repair genes, MLH1, MSH2, MSH6, or PMS2, associated with the Lynch/Hereditary Non-Polyposis Colorectal Cancer (HNPCC) syndrome, have up to a 40 - 60% lifetime risk of both endometrial and colorectal cancers as well as a 9-12% life-time risk of ovarian cancer. Mutations in other genes including TP53, PTEN, and STK11 are responsible for hereditary syndromes associated with gynecologic, breast, and other cancers. Evaluation of the likelihood of a patient having one of these gynecologic cancer predisposition syndromes enables physicians to provide individualized assessments of cancer risk, as well as the opportunity to provide tailored screening and prevention strategies such as surveillance, chemoprevention, and prophylactic surgery that may reduce the morbidity and mortality associated with these syndromes. Evaluation for the presence of a hereditary cancer syndrome is a process that includes assessment of clinical and tumor characteristics, education and counseling conducted by a provider with expertise in cancer genetics, and may include genetic testing after appropriate consent is obtained. This commentary provides guidance on identification of patients who may benefit from assessment for the presence of a hereditary breast and/or gynecologic cancer syndrome."

<u>www.sgo.org/wp-content/uploads/2012/11/SGO-</u> <u>Position-Statement-Genetics.pdf</u>

Definition: Germline Mutation

from National Cancer Institute (NCI)

"A gene change in a body's reproductive cell (egg or sperm) that becomes incorporated into the DNA of every cell in the body of the offspring. Germline mutations are passed on from parents to offspring. Also called hereditary mutation."

<u>www.cancer.gov/publications/dictionaries/</u> cancer-terms?cdrid=46384

Genetic Counselors in Colorado

GREATER METRO DENVER

University of Colorado -Hereditary Cancer Clinic Aurora 720.848.5944 <u>www.uchealth.org/Pages/Ser-</u> <u>vices/Genetic-Testing-and-Coun-</u> <u>seling.aspx</u>

Porter Adventist Hospital -Genetic Counseling

Denver 303.765.6500 www.porterhospital.org/poh/ specialties/genetic-counseling/ our-genetic-counselor/

St Anthony Hospital - Genetic Counseling

Denver 720.321.0400 <u>www.stanthonyhosp.org/sah/</u> <u>specialties/cancer/genetic-coun-</u> <u>seling/</u>

St Joseph's Hospital -Genetic Counseling

Denver 303.318.3478 http://www.saintjosephdenver. org/services-and-departments/ cancer-centers-of-colorado/ cancer-treatment-and-services/ genetic-counseling/

Swedish Medical Center - Genetic Counseling

Englewood 303.788.4668 <u>swedishhospital.prod.ehc.com/</u> <u>service/cancer-care-genetic-coun-</u> <u>seling</u>

Invision Sally Jobe - Genetic Counseling *Greenwood Village - Golden - Parker.*

720.493.3700 <u>www.riainvision.com/counsel-</u> <u>ing/genetic_counselor.aspx</u>

Littleton Adventist Hospital -Genetic Counseling

Littleton 303.734.2035 www.mylittletonhospital.org/ mlh/specialties/cancer-care/ genetic-counseling%281%29/ Lutheran Hospital -Genetic Counseling Wheat Ridge 303.425.8191 www.lutheranmedicalcenter.org/ services-and-departments/comprehensive-cancer-center/cancerscreenings/genetic-counseling/

Parker Adventist Hospital -Genetic Counseling Parker 303.269.4975 www.parkerhospital.org/pah/ specialties/genetic-counseling/

Good Samaritan Medical Center -Genetic Counseling Lafayette 303.673.1944 www.goodsamaritancolorado. org/services-and-departments/ cancer-centers-of-colorado/

Rocky Mountain Cancer Centers- Genetic Counseling 1.888.259.7622 <u>www.rockymountaincancer-</u> <u>centers.com/cancer-treatments/</u> <u>genetic-testing/</u>

Kaiser Permanente Insurance Group Genetic Counseling Englewoood, Lafayette. 303.788.1220

COLORADO SPRINGS Penrose Cancer Center - Genetic Counseling 719.776.5279 www.penrosecancercenter.org/ pcc/cancer-treatment/other-services/genetic-counseling

University of Colorado Health -Memorial Hospital Genetic Counseling 719.365.9867 www.uchealth.org/Pages/Services/Genetic-Testing-and-Counseling.aspx

PUEBLO St. Mary Corwin-Dorcy Cancer Center Hereditary Cancer Services 719.557.4252 <u>www.stmarycorwin.org/stc/</u> <u>specialties/cancer-center/genetic-</u> <u>counseling</u>

ASPEN

Aspen Valley Hospital (via partnership with Invision Sally Jobe) - Genetic Counseling 720.493.3226 www.aspenvalleyhospital.org

EDWARDS Shaw Regional Cancer Center – Genetic Counseling 970.569.7626 www.shawcancercenter.com/diagnostics-treatments/hereditarycancer-service.aspx

FRISCO St. Anthony Summit Medical Center Genetic Counseling 720.321.0400 www.summitmedicalcenter.org/ smc/specialties/breast-center/ genetic-counseling

GLENWOOD SPRINGS Valley View Hospital Calaway Young Cancer Center - Genetic Counseling 970.384.7570 www.vvh.org/calaway-youngcancer-center/treatment-healing/ genetic-counseling/

GRAND JUNCTION St. Mary's Hospital - The Regional Medical Center - Genetic Counseling 970.298.7956 www.stmarygi.org/services-and-

departments/cancer-care

NATIONAL - Genetic Counseling Services InformedDNA

Personalized Genetic Counseling by phone Toll Free: 1.800.975.4819 <u>www.informeddna.com/forpatients</u>