I HAVE A FAMILY HISTORY OF OVARIAN CANCER.

WHAT DOES IT MEAN FOR ME?

> Sabrina, woman with ovarian cancer, and her daughter Adeena.

OVARIAN CANCER AUSTRALIA

WHO IS THIS FACT SHEET FOR?

This fact sheet is for anyone who has a biological family member who has had an ovarian cancer diagnosis. It provides information on how this may impact their risk of developing cancer and where they can seek further information and guidance.

WHAT IS FAMILIAL OR HEREDITARY CANCER?

Hereditary cancer is cancer that runs in families. Another term you may hear is family (or familial) cancer. This may also be referred to as having a family history of cancer.

Hereditary cancer may run in a family because of an inherited gene variant. If you inherit a gene variant that causes hereditary cancer, it means you are at greater risk of developing the types of cancer linked to that gene.

Approximately 20% of all ovarian cancers are caused by a gene variant that has been inherited from a biological parent.

WHAT ARE GENE VARIANTS?

Genes are made up of DNA and act as chemical instructions that tell our body's cells what to do (for example, how we grow, look, and how our body works). It is estimated humans all have the same set of about 25,000 genes. We all inherit two sets of these genes—one from each of our parents.

All of these genes have normal jobs to do in the body, but sometimes genes change and stop working as they should. Scientists call these changes variants, alterations, or mutations. Cancer develops because of genetic changes in cells that cause abnormal growth.

Most cancers are caused by genetic changes as a result of damage to our DNA that happen in a single cell over our lifetime. Genetic changes that happen as a cancer develops are called somatic variants and do not run in families.

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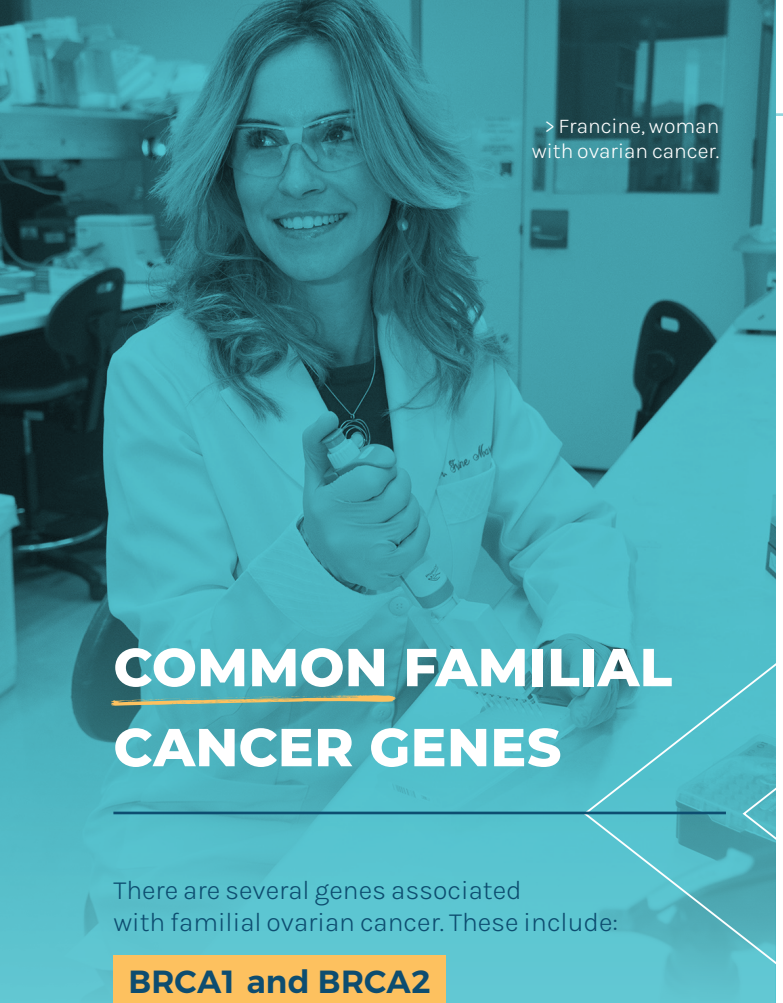
Changes to your DNA that you inherit from either one of your parents are called germline variants, which do run in families. Having a germline gene variant doesn't mean that someone will get cancer. It just means that they may have a higher risk than someone without an inherited gene variant. Inherited genetic changes that cause cancer are rare.



> Francine, woman with ovarian cancer.

COMMON FAMILIAL CANCER GENES

There are several genes associated with familial ovarian cancer. These include:

BRCA1 and BRCA2

Germline variants in these genes cause most cases of hereditary ovarian cancer. They are also linked to breast cancer (which is what the acronyms stand for, BReast CAncer), and can increase the risk of some other cancers. BRCA1 and BRCA2 mutations are more common in individuals of Ashkenazi Jewish descent.

- **BRCA1** gene variants cause about a **40%** lifetime risk of developing ovarian cancer
- **BRCA2** gene variants cause about an **18%** lifetime risk of developing ovarian cancer

MLH1, MSH2, MSH6 and PMS2

Germline variants in these genes are responsible for a condition called Lynch syndrome, which causes hereditary bowel cancer. People with variants in these genes have about a **3 to 17%** lifetime risk of ovarian cancer.

RAD51C or RAD51D

Germline variants in these genes have about a **10%** lifetime risk of ovarian cancer.

PALB2

Germline variants in this gene have a **5%** risk of developing ovarian cancer over their lifetime.

MORE INFORMATION

You can read more about these gene variants at eviQ.

HOW DO I KNOW IF I SHOULD CONSIDER GENETIC TESTING, AND WHO SHOULD I SPEAK TO?

If you have a family history of ovarian, breast or other cancers, or if one of your relatives has a known germline variant, we recommend discussing this with your GP. Your GP will take a thorough look at your history and may refer you on to a familial cancer centre (FCC).

BEING TESTED FOR GENETIC CANCER RISK

Familial cancer centres or cancer genetic services provide genetic counselling, information on inheriting cancer, individual risk, screening, cancer prevention and genetic testing. Most are public clinics with no out-of-pocket cost. Some private genetic services offer genetic counselling and testing, but you are likely to have out-of-pocket expenses.

Genetic testing is usually done on a small blood or saliva sample. Making a choice about having a test can be confronting. However, it can help you clarify your risk of ovarian and other cancers, and can help you take steps to reduce your risk. If you decide to go ahead with genetic testing, it's important to speak with a health professional with experience in genetic testing.

"Once I knew Mum had the BRCA gene, I wanted to find out as soon as possible if I had it, even though I was afraid of what it could mean for me. But I needed to know so I could make informed decisions about how to decrease my risk."

Michelle

WHAT IS GENETIC COUNSELLING?

Genetic counselling is a communication process to help you understand, make decisions about, and adapt to what genetics means for your health. Genetic counselling can be important before genetic testing, after you get a result, or if you are unsure about, or do not wish to have genetic testing. Talking about genetics can bring up different emotions for different people.

Genetic counsellors are allied health professionals with specific skills, training, and certification in genetic counselling who can give you information and support. Genetic counselling is different from mental health counselling and may be part of the role of many different health professionals.

You can find more information about genetic counselling at the Centre for Genetics Education www.genetics.edu.au (search "genetic counselling").

You can find out more information about the qualification of genetic health professionals in Australia, and a list of public and private services is available through the Human Genetics Society of Australasia (HGSA) (www.hgsa.org.au).

WHAT YOUR RESULTS MEAN

If a hereditary gene variant is not found, it means your risk of developing ovarian and other cancers is likely to be the same as the general population.

If you're told you do have a hereditary gene variant, it's important to speak with healthcare providers who can explain how it will affect you, including screening and prevention for any future cancers. A genetic counsellor or someone from a family cancer centre should discuss your result with you. You may also be seen by a clinical geneticist, gynaecological oncologist, or other specialist doctor, or be referred to a specialist clinic, to discuss your risk of cancer and ways you can reduce it.

"Finding out my sister and I both had the BRCA2 gene fault made sense. Finally, there was a reason why both Mum and her sister had been diagnosed with and had passed with ovarian cancer. It is more important for us to know and take preventative steps than not to know at all!"

Karen

> Jo, woman with ovarian cancer and daughter Caitlyn.

> Vicki, a woman with ovarian cancer, and her daughter Angela.

REDUCING YOUR RISK OF CANCER

Although there is no effective screening test for ovarian cancer, there are options to reduce your risk.

To reduce the risk of developing ovarian and other cancers, there may be several options to consider, including:

- regular screening for other cancers
- risk-reducing surgery
- risk-reducing medication
- lifestyle choices

A specialist doctor or clinic can discuss the best approach with you, based on your general health, your family history, and your test results. They can also refer you to the right specialists for cancer screening and/or risk-reducing surgery.

You can find out more about reducing your risk of cancer by reading the 'Testing for ovarian cancer in women who do not have symptoms' fact sheet available from Cancer Australia (www.canceraustralia.gov.au)

WHAT ABOUT ELIGIBILITY FOR INSURANCE?

Genetic testing does not affect your eligibility for private health insurance in Australia.

It won't affect any life insurance policies you already have in place, but it may affect new applications or changes to current insurance policies. You may wish to discuss this with an insurance broker.

You can find more information by reading the fact sheet "Life insurance products and genetic testing in Australia" on the NSW Health Centre for Genetics website (www.genetics.edu.au).

MORE INFORMATION

Please call our helpline **1300 660 334** (Monday to Friday, 9am to 5pm AET) to speak to one of our ovarian cancer nurses, or email the support team at **support@ovariancancer.net.au**

Address 210 Lonsdale St, Melbourne VIC 3000
Phone 1300 660 334 | **Email** support@ovariancancer.net.au | **Web** www.ovariancancer.net.au

This resource has been reviewed by medical experts. Reviewed 10/22