



**BC Cancer Agency**

CARE + RESEARCH

*An agency of the Provincial Health Services Authority*

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**Hereditary Cancer Program**

# Understanding Hereditary Breast & Ovarian Cancer – the BRCA genes





## Hereditary Cancer Program

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### Introduction

The purpose of this booklet is to review the information about hereditary breast and ovarian cancer as discussed in a genetic counselling session. You may also wish to use this booklet to help you share information with other family members.

This booklet was prepared by staff of the Hereditary Cancer Program, based on information that was current at the time of printing.

Words that may be new to you are highlighted and are defined in the Glossary on page 28.

#### Acknowledgments

*We are grateful to the many people who provided such valuable feedback as this booklet developed, and to the BC Cancer Agency Multimedia Services Department for design, layout and illustration.*

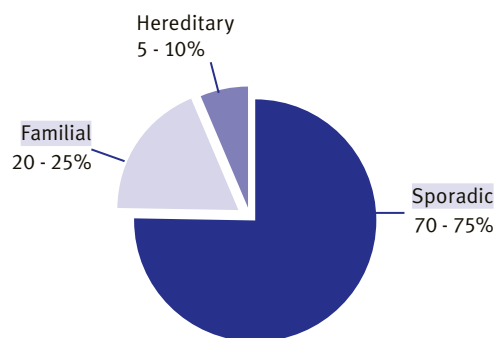
## How are cancer & genes related?

Each **gene** has a specific function in the body. Some genes control cell division. When **mutations** occur in these genes, a cell may begin to divide without control. Cells that divide when they are not supposed to may eventually become a cancer. See Appendix on page 30 for more information about genes, **chromosomes** and **DNA**.

## All cancer is genetic, most is not hereditary

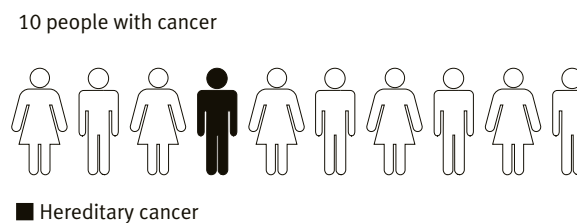
All cancers are the result of gene mutations. Mutations may be caused by aging, exposure to chemicals, radiation, hormones or other factors in the body and the environment. Over time, a number of mutations may occur in a single cell, allowing it to divide and grow in a way that becomes a cancer. This usually takes many years, and explains why most cancers occur at a later age in life. Because people are not born with these **acquired gene mutations**, they cannot pass them on to their children.

A small number of cancers are hereditary. This means that they are related to a specific gene mutation that is passed down (inherited) in a family. A person who is born with a mutation has it in every cell in his/her body, including some of the eggs or sperm. This means it *may* be passed down to the next generation. Individuals who inherit such gene mutations have a higher risk of developing certain forms of cancer compared to the general population. **Inherited gene mutations** help to explain why in some families, we see more people than expected with certain kinds of cancer.



## What is known about hereditary cancer?

About 5-10% of all cancer cases (less than 1 in 10) are thought to be due to an inherited gene mutation. That means that **most cancer is not hereditary**.



Research has found some of the genes that help to explain specific patterns of hereditary cancer. Other genes will be identified in the future.



## Is my family at risk?

The history of cancer in your close relatives is a clue to the chances of hereditary breast/ovarian cancer. **Close relatives** include your: children, brothers, sisters, parents, aunts, uncles, grandchildren, and grandparents, **on one side of the family**. History of cancer in cousins and more distant relatives may also be important.

An inherited mutation in the *BRCA1* or *BRCA2* genes is more likely if **at least 1 of the following features** can be confirmed in your family:

- A woman with breast cancer diagnosed at age 35 or younger
- A woman with ovarian cancer
- A woman with breast cancer and ovarian cancer
- A woman with 2 or more separate breast cancers, if the 1st diagnosis was at age 50 or younger
- A man with breast cancer and a close relative with breast cancer or ovarian cancer
- A woman with breast cancer and a close relative with ovarian cancer
- 2 closely related women with breast cancer, both diagnosed at age 50 or younger
- 3 closely related women with breast cancer, at least one of whom was diagnosed at age 50 or younger
- Ashkenazi (European) Jewish heritage and some family history of breast cancer or ovarian cancer

### Notes:

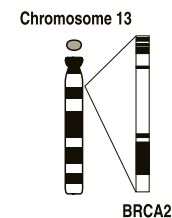
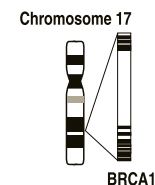
**Breast cancer** – does not include LCIS (lobular carcinoma in situ)

**Ovarian cancer** – includes fallopian tube and primary **peritoneal cancers**.

Pathology reports are needed to confirm the type of ovarian cancer because some of the less common types are not associated with inherited *BRCA1/2* mutations.

## The *BRCA1* and *BRCA2* genes

*BRCA* is an abbreviation for **breast cancer**. *BRCA1* and *BRCA2* were the first two genes discovered to be responsible for some hereditary breast cancer and some hereditary ovarian cancer.



Everyone is born with two copies of *BRCA1* and two copies of *BRCA2*, one copy of each gene from their mother and one copy of each gene from their father. These genes are found in every cell of the body, but are most important in breast cells and ovary cells. Because *BRCA1* and *BRCA2* work in the same way, **we will refer to them as *BRCA* genes in most of this booklet. Where there are specific differences, the genes will be described separately.**

A *BRCA* gene is the “code” to make a *BRCA* protein. This protein’s function is to control the division of cells in the breasts and ovaries. The protein acts like a traffic signal; it allows breast cells to divide during puberty (green light), and stops them from dividing at other times (red light).

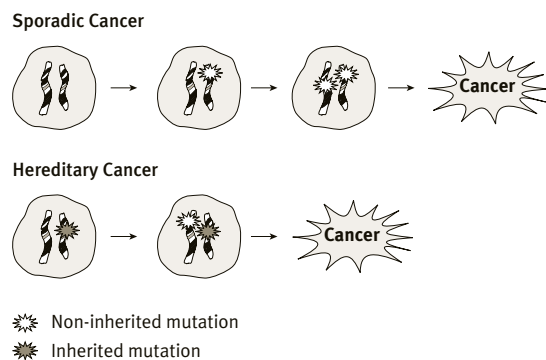
## What happens if there is a mutation in a *BRCA* gene?

Because we have two copies of every gene, a mutation in one copy of a *BRCA* gene in a breast or ovary cell does not cause a problem; the other copy can still produce the protein to control cell growth. A mutation must occur in both copies of the same *BRCA* gene in the same cell for the control to be lost and a cancer to develop.

## What happens if a person inherits a *BRCA* gene mutation?

This person is born with a mutation in one copy of a *BRCA* gene and this mutation is present in every cell of the body. The other copy of that gene is normal and is able to “do its job”. This person is a *BRCA* gene mutation **carrier**.

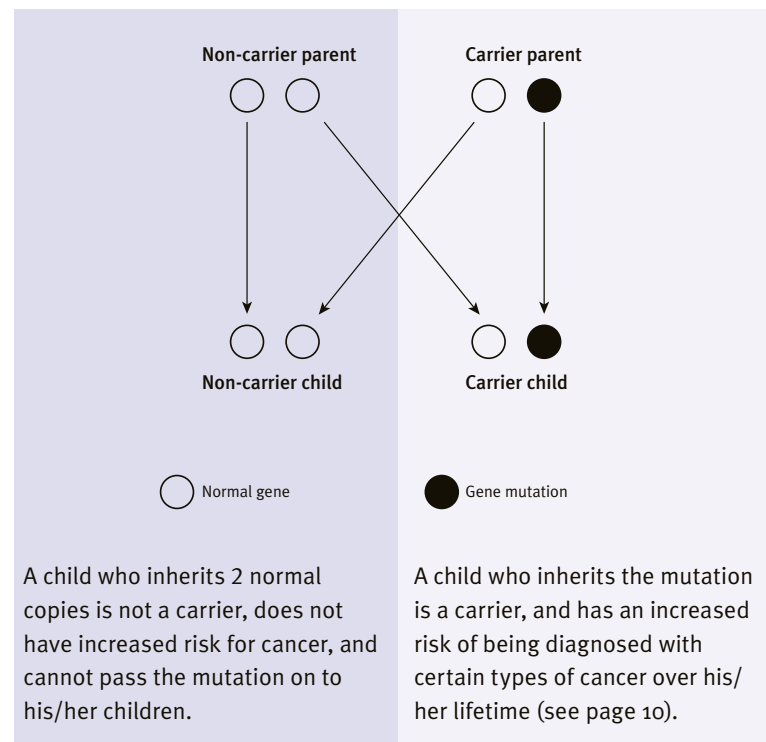
As a person ages, DNA mutations occur by chance, in different genes, in different cells. A woman who is born with 2 normal copies of the *BRCA* genes in every cell has to acquire a mutation in both copies of the same *BRCA* gene in the same breast or ovary cell for a cancer to develop. This is what happens in sporadic cancer.



If a mutation occurs by chance in the normal copy of a *BRCA* gene in a breast or ovary cell when a woman is a *BRCA* mutation carrier, the cell no longer has a working copy of that gene. The normal *BRCA* protein will not be made and a cancer may develop. That helps to explain why a woman who inherits a *BRCA* gene mutation is much more likely to be diagnosed with breast cancer or ovarian cancer than is a non-carrier. Hereditary cancer is also more likely to be at a younger age than the same kind of cancer in the general population. And there is a greater chance of having more than one separate cancer diagnosis (e.g. a new cancer in each breast).

## What are the risks for the children of a *BRCA* gene mutation carrier?

Remember that we inherit one copy of each of our genes from each parent, and we pass on one copy of each of our genes to our children. This means that every time a carrier has a child, either the normal copy of the gene or the gene with the mutation can be passed on. As shown below, each child has a 50/50 chance to inherit the gene mutation.



The way we inherit genes explains why it is important to look at the history of cancer on both sides of a family. A woman can inherit an increased risk of breast cancer or ovarian cancer from her father (if he is a *BRCA* gene mutation carrier) in the same way that she can inherit it from her mother. This has not been well understood until recently.

## What is the risk of cancer for a *BRCA* gene mutation carrier?

In this section, *BRCA1* and *BRCA2* will be described separately. The following table shows the chance that women and men who carry *BRCA1* or *BRCA2* gene mutations will develop specific types of cancer during their lifetime, compared to the general population. These estimates may change as new information becomes available.

Note: these figures are based on published data, obtained from research with high-risk families.

TYPE OF CANCER	RISK IN GENERAL POPULATION	<i>BRCA1</i> CARRIER	<i>BRCA2</i> CARRIER
breast cancer - women	11%	47-66%	40-57%
ovarian cancer	1-2%	35-46%	13- 23%
breast cancer - men	0.1%	up to 6%	6%
prostate cancer	12%	increased by approx 2-3 times	
pancreatic cancer	1%	slight increase	slight increase
other cancers	varies	—	slight increase

In this table, we see that women who carry a *BRCA* gene mutation do not have a 100% chance of developing breast cancer. This supports the idea that there are several steps, and probably several genes, involved in the process of a cancer developing. We do not yet know what all of those steps are, but **it is important to remember that not every mutation carrier will develop cancer.**

It is also important to understand that a woman who has already had breast cancer or ovarian cancer and carries a *BRCA* gene mutation has a significant risk to develop a new cancer.

The risk of other cancers is the subject of ongoing research and can be discussed in more detail with your genetic counsellor.

## What is genetic testing?

Genetic testing is done on a sample of blood or tissue to look for a mutation in a gene. For hereditary breast and ovarian cancer risk, a blood sample is tested to look for a mutation in the *BRCA1* or *BRCA2* genes. Finding a *BRCA* gene mutation may help to:

- inform family members about their own cancer risks
- explain the history of cancer in a family

Testing for hereditary cancer genes is not “just another blood test”. It is complex and there are many issues to consider.

Genetic testing is discussed in a genetic counselling appointment. You may also read the following pages to help you understand:

- who can have *BRCA* genetic testing
- how *BRCA* genetic testing is done
- the possible results of *BRCA* genetic testing
- some issues to consider
- some advantages and disadvantages of *BRCA* genetic testing

## Who can have genetic testing?

Testing for a mutation in *BRCA1* or *BRCA2* is available through the Hereditary Cancer Program when specific criteria are met. In addition to genetic counselling and informed consent, testing criteria include:

- a *BRCA1* or *BRCA2* mutation has been confirmed in a close relative (carrier test) OR
- a blood sample is provided by an eligible **index** case. Criteria for index *BRCA1/2* testing are listed on page 6.



## How is BRCA genetic testing done?

A series of complex tests are done on a blood sample in a specialized lab. The goal of these tests is to look for an inherited change (mutation) in the *BRCA1* or *BRCA2* genes. Thousands of different mutations have been found in these 2 very large genes. Some families have a mutation that has never been seen before.

The testing can be like trying to find “a needle in a haystack.” So the first *BRCA* test in a family should usually be done on the person with the highest chance of having a mutation. This is called an index test. If the index test finds a mutation, other members of a family may choose to have carrier testing.

Index test	Carrier test
<ul style="list-style-type: none"> <li>– the first gene test in the family</li> <li>– usually offered to a person who has had breast or ovarian cancer</li> <li>– complete testing of the <i>BRCA1</i> and <i>BRCA2</i> genes</li> <li>– results take many months</li> </ul>	<ul style="list-style-type: none"> <li>– offered when a gene mutation is already confirmed in the family</li> <li>– looks only for a specific mutation in <i>BRCA1</i> or <i>BRCA2</i></li> <li>– results usually take weeks</li> </ul>



## Results of BRCA genetic testing

You will be contacted when the testing is complete. You and your genetic counsellor will arrange to discuss the results when you are ready. Your *BRCA* testing results are only shared with other people on your request.

This section describes the possible results of index and carrier *BRCA* testing.

**Index test results:** There are 3 possible results from *BRCA* index testing. Each type of result is described below.

Uninformative	<ul style="list-style-type: none"> <li>• Most common <i>BRCA</i> index test result</li> <li>• No mutation is found in <i>BRCA1</i> or <i>BRCA2</i></li> <li>• Possible reasons:                             <ul style="list-style-type: none"> <li>- Your cancer was sporadic or familial, not hereditary (see page 4), OR</li> <li>- Your cancer was caused by a mutation in other gene(s) that have not yet been identified, OR</li> <li>- Your cancer is related to a <i>BRCA</i> gene mutation that cannot be found by current testing, OR</li> <li>- You do not have a <i>BRCA</i> gene mutation, but there may still be one in your family</li> </ul> </li> <li>• More testing may be offered to some families</li> <li>• Carrier testing is not possible for your relatives</li> </ul>
Variant of uncertain significance	<ul style="list-style-type: none"> <li>• 15-20% of <i>BRCA</i> index test results</li> <li>• There is a change in the gene, but its meaning is not known at this time</li> <li>• More testing may be offered to some families</li> <li>• Carrier testing is not possible for your relatives</li> </ul>
Positive	<ul style="list-style-type: none"> <li>• A mutation is found in <i>BRCA1</i> or <i>BRCA2</i> and is known to increase the risk for specific types of cancer</li> <li>• You may have higher risk for a new cancer diagnosis</li> <li>• Your sisters, brothers and children each have a 50/50 chance of having the same mutation</li> <li>• Carrier testing is possible for your relatives</li> </ul>

**Carrier test results:** There are 2 possible results from *BRCA* carrier testing. They are described below.

Positive	Negative
<ul style="list-style-type: none"> <li>• You have the mutation</li> <li>• Your cancer risks are increased (see page 10)</li> <li>• Each of your children has a 50/50 chance to have the same mutation</li> </ul>	<ul style="list-style-type: none"> <li>• You do not have the mutation</li> <li>• Your cancer risks are not increased, but are the same as others of your age</li> <li>• Your children cannot inherit the mutation</li> </ul>

## Cancer screening

The goal of **cancer screening** is to find a cancer before there are any symptoms. Treatment is likely to be the most effective when cancer is found early. Your genetic counsellor will discuss current cancer screening advice based on your family history. Screening guidelines for people with a family history of breast cancer are provided below, and are based on published recommendations and expert opinions. References are available on request.

### ❑ If BRCA testing results are not available or are uninformative for your family:

#### Women

Breast cancer screening includes:

- Clinical breast exam every 6 months, by a trained healthcare professional
- **Mammogram** every 12 months, starting 5 -10 years younger than the youngest diagnosis of breast cancer in the family. Mammograms should not usually start until age 30.

Screening for other cancers is based on family history and current guidelines.

#### Men

Screening for prostate and other cancers as suggested for all men.

### ❑ If you know you do NOT have the BRCA gene mutation that is in your family:

#### Women and men

Follow cancer screening advice for the general population, unless your family history suggests otherwise.

### ❑ If you have a BRCA gene mutation (or have 50% chance of having the BRCA gene mutation in your family):

#### Women

Breast cancer screening includes:

- Clinical breast exam every 6 months, by a trained healthcare professional
- Mammogram every 12 months, starting at age 30
- Breast **MRI** every 12 months from age 25-65
- Other tests if recommended by a **radiologist**

Ovarian cancer screening is not recommended at this time. Current screening tests do not reliably detect ovarian cancer at an early stage.

Screening for other cancers is based on family history and current guidelines.

#### Men

Cancer screening includes:

- Clinical exam of the chest/breasts every 12 months by a trained healthcare professional
- Prostate cancer screening starting at age 40
- Screening for other cancers based on family history and current guidelines





## What about surgery to reduce cancer risks?

Women with a *BRCA* gene mutation may think about 2 types of surgery to reduce their cancer risks:

- salpingo-oophorectomy is surgery to remove the **ovaries** and **fallopian tubes**
- mastectomy is surgery to remove the **breasts**

Surgery that is done to try to prevent cancer is called **prophylactic** or risk-reducing. The tissue that is removed should be thoroughly examined by an expert **pathologist**. Sometimes a very early cancer is found, but this is not common.

Some general information about risk-reducing surgery is provided below. Ask your genetic counsellor or your doctor for more details if you are interested. You may also wish to speak to women who have had surgery to learn what it was like for them.

Some women choose to have surgery and some do not. Having surgery to reduce cancer risk is a very personal decision. It is important to take the time you need to make the decision that is right for you. You may want to discuss this topic with your doctor. You may also want to meet with a specialist who is an expert in this area.

### **Prophylactic salpingo-oophorectomy**

Surgery to remove the ovaries and fallopian tubes is recommended to women with a *BRCA* gene mutation because of the lack of good ovarian cancer screening tests. Research has found that this surgery reduces the chance of cancer in the ovaries and fallopian tubes by 80-85%. Having this surgery before menopause also appears to reduce breast cancer risk by up to 50%.

Women are strongly advised to consider having this surgery at age 35-40 or after childbearing is complete. It is important to know that the surgery will cause menopause to begin for a woman who is still having menstrual periods.

### **Prophylactic mastectomy**

Some women may think about having surgery to remove their healthy breasts to try to avoid ever having breast cancer. Research has found that having this surgery reduces the chance of breast cancer by about 90-95%.

Most women who choose this option also plan to have breast reconstruction. It is important to think about how this surgery might change how you feel about your body, how much you worry about cancer, and many other issues.

## What about using medications to reduce cancer risks?

For pre- or post-menopausal women with an increased risk of developing breast cancer due to a family history of breast cancer, their chance of developing breast cancer can be reduced by taking a tamoxifen tablet daily for 5 years. For post-menopausal women a similar benefit has also been seen with raloxifene and exemestane tablets. Before choosing to try tamoxifen, raloxifene or exemestane you should have a detailed discussion with your doctor about the potential benefits and side-effects for you specifically, and the availability and cost of these medications.

Tamoxifen and raloxifene are members of a drug class called Selective Estrogen Receptor Modulators (SERMs). They work by interfering with the effect of the female hormone, estrogen, on the breast. Tamoxifen has been used to treat breast cancer for many years and now it is also used in women at increased risk of breast cancer to decrease their chances of developing the disease.

One American and three European research studies have examined the effectiveness of tamoxifen for the prevention of breast cancer. These studies included over 25,000 women, about half of whom received tamoxifen and half of whom received an inactive tablet (placebo).

The consistent evidence from all of these studies is that tamoxifen, taken daily for 5 years, prevents about 4 out of 10 breast cancers. The preventive effect of tamoxifen lasts for at least 10 years (i.e. for the 5 years while the tablet is taken and for at least 5 years after). You should ask your doctor or genetic counsellor to estimate your personal breast cancer risk and to explain how much your personal risk can be reduced by taking tamoxifen for 5 years. Tamoxifen has been shown to prevent hormonally responsive (that is, estrogen receptor positive) breast cancer but did not appear to prevent the development of estrogen receptor negative cancers.

Unfortunately very few women with BRCA1 or BRCA2 mutations participated in these large trials. Therefore, these trials did not provide useful information about whether tamoxifen is effective for these specific women. However, some other studies have suggested that tamoxifen may reduce breast cancer risk by a similar amount for women who carry mutations in BRCA1 or BRCA2, but this has not been tested in clinical trials. If you have a mutation in BRCA1 or BRCA2 you should discuss this further with your doctor.

Most women who take tamoxifen tolerate it well but some experience side-effects. In the trials described above about 1 in 10 women stopped tamoxifen due to side-effects. If side effects do occur they should be discussed with your doctor who will suggest ways in which they may be improved. Alternatively your doctor may suggest stopping the medication and reviewing your options for managing your breast cancer risk. Your doctor can provide you with a list of the most common or important side-effects.

## Taking care of your health

### **Listen to your body.**

Knowing your own body is important for any woman or man with a family history of breast or ovarian cancer. Recognizing symptoms and getting regular checkups may help to detect cancer early.

Be aware of your body and know what is normal for you. If you notice any unusual changes, tell your doctor about them. The sooner you report signs to your doctor, the sooner a problem can be dealt with.

**Breast health** starts with knowing your breasts, no matter what your age. Be aware of what is normal for your breasts, even if you are having regular screening tests. Some women and men find their own breast cancer through changes in the look and feel of their breasts. Many people find breast changes that turn out not to be cancer.

### Women should also be aware of **possible signs of ovarian cancer.**

Ovarian cancer may not cause any symptoms in its early stages. When symptoms do start, they are often vague and easily mistaken for more common illnesses.

- Ovarian cancer may cause:
- swelling or bloating of the abdomen
  - pelvic discomfort or heaviness
  - pain in the back or abdomen
  - fatigue
  - gas, nausea, indigestion
  - feeling full after a light meal
  - change in bowel habits
  - emptying your bladder frequently
  - irregular menstrual bleeding
  - weight loss or weight gain
  - pain with intercourse

Contact your doctor if you have 1 or more of these symptoms without another obvious cause, and they are getting worse, or last longer than 2 to 3 weeks. Often such symptoms are caused by other less serious health problems, not cancer. Your doctor can arrange the tests that are needed for a diagnosis.

## Issues to consider

There are many important issues related to *BRCA* genetic testing. This section includes some questions that other people have asked while deciding whether or not to have genetic testing. You may wish to discuss these topics with your genetic counsellor.

### What kind of information will genetic testing give me?

Genetic testing may help to clarify your risks for a new cancer diagnosis. The results cannot tell you if or when cancer will develop, or what type of cancer. Some people with a *BRCA* gene mutation never develop cancer, and some have several different cancers. Your genetic counsellor will discuss cancer screening based on the results of your genetic testing.

### When is the right time to have genetic testing?

Deciding to have genetic testing is a choice that only you can make. It must be the right decision for you, at the right time in your life. Think about how and when you would use the test results. Some people find this an easy choice, and others find that it is very hard to decide. Talking with a genetic counsellor, your doctor, and family members may help you to make a decision. Support from those who are close to you may be helpful before and after you receive genetic test results.

You may feel pressured to have genetic testing when:

- You feel it is your responsibility. Other family members may not be able to have genetic testing if you do not have the test first.
- Other members in the family have a gene mutation.
- Your spouse or other family members worry for you.

It can be extra hard to make a decision when you feel pressure like this. You can take as much time as you need to decide, and you may want to talk with your genetic counsellor.

### How might my genetic test result impact my family?

It is important to remember that we share our genes with our family members. Your genetic test result may provide information about your relatives' chance to also have a *BRCA* mutation. It may also impact their cancer screening advice and their cancer risks.

Family members may have very different feelings about genetic testing and cancer. It may be important to discuss your thoughts about genetic testing with key family members before your blood is tested. These are hard topics to discuss in some families. It may be stressful if family members do not agree with your decision about genetic testing. Sharing the results of genetic testing may also cause stress in families.

### What type of emotions might I feel?

Talking about your family history of cancer may bring up memories from many years ago. Thinking about genetic testing and getting your test results may lead to feelings of relief, anxiety, hope, confusion, guilt or worry. Sometimes these feelings are unexpected. It may not be possible to guess how a person is going to react to their genetic test result.

You may wish to discuss your feelings with people who have given you support in other difficult situations (e.g. therapist, religious leader, support group). Referral to the BC Cancer Agency's Patient and Family Counselling department is another option for support to address some of these feelings.

### Is *BRCA* testing offered to children?

No. *BRCA* genetic testing is offered to people aged 18 or older. This is because a *BRCA* test result will not change the medical care for children. Also, it is important that a person is able to decide about genetic testing for him/herself.

### Are genetic test results kept confidential?

Yes. Your *BRCA* test results are only shared with other people on your request.

### Will genetic testing affect my insurance?

In Canada, you will have the same public health insurance whatever the result of your genetic testing. If you know you have a gene mutation, you must disclose your result to private life and medical insurance companies if you are asked. It is possible that this information could impact your chances and/or the costs of getting new life insurance or extended health coverage. You may wish to review your insurance policies before you have any genetic testing done.

## What are some pros & cons of genetic testing?

The following table lists some of the possible advantages (pros) and disadvantages (cons) of genetic testing. You may find other advantages or disadvantages, which you can add to the table. This list may help you to think about which issues are most important to you.

PROS	CONS
<ul style="list-style-type: none"> <li>• results may help some people to make medical and lifestyle decisions</li> </ul>	<ul style="list-style-type: none"> <li>• there are no proven ways for mutation carriers to eliminate all cancer risk</li> </ul>
<ul style="list-style-type: none"> <li>• may provide helpful information for family members</li> </ul>	<ul style="list-style-type: none"> <li>• family members may have different ideas about genetic testing</li> </ul>
<ul style="list-style-type: none"> <li>• results may help some women make decisions about prophylactic surgery</li> </ul>	<ul style="list-style-type: none"> <li>• employers and insurance companies may treat you differently if they learn you are a mutation carrier</li> </ul>
<ul style="list-style-type: none"> <li>• results may reduce anxiety for some people</li> </ul>	<ul style="list-style-type: none"> <li>• results may increase anxiety for some people</li> </ul>
<ul style="list-style-type: none"> <li>• may help to explain why people in the family have had cancer</li> </ul>	<ul style="list-style-type: none"> <li>• a negative result may provide a false sense of security for some people</li> </ul>
<ul style="list-style-type: none"> <li>• may have an impact on family relationships</li> </ul>	<ul style="list-style-type: none"> <li>• may have an impact on family relationships</li> </ul>
<ul style="list-style-type: none"> <li>• may be able to be involved in research studies</li> </ul>	<ul style="list-style-type: none"> <li>• more research is needed to understand the long-term impact of genetic testing</li> </ul>
Other issues	

## How do I contact the Hereditary Cancer Program?

You can contact your genetic counsellor directly, at the number given to you during your appointment. People who are seeking general information about hereditary cancer can call the Hereditary Cancer Program (HCP) at: 604.877.6000 local 672325, or 1.800.663.3333, local 672325.

### Resources – People

HCP genetic counsellors are available to you, and can make referrals to other professionals as needed (social worker, counsellor, surgeon, genetics programs in other provinces, etc.) or arrange for family members to have genetic counselling.

Genetic counselling appointments are available in person in Vancouver, Victoria, Abbotsford, Surrey, Kelowna and Prince George. Genetic counselling by video-conference is also available to many locations in BC and the Yukon.

### Your genetic counsellor’s name:

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#### Genetic counsellors in Abbotsford:

604.851.4710 local 645236  
 1.877.547.3777 local 645236

#### Genetic counsellors in Vancouver:

604.877.6000 local 672198  
 1.800.663.3333 local 672198

The HCP has a list of people who have gone through genetic counselling and offered to be available to others who might want to talk to someone who has “been there”. Ask your genetic counsellor if you think you might find such a contact helpful.

## Peer Support Groups

### Facing Our Risk of Cancer Empowered (FORCE)

[www.facingourrisk.org](http://www.facingourrisk.org) 1.866.288.7475

- American non-profit organization founded in 1998
- Mission is to improve the lives of individuals and families affected by hereditary breast and ovarian cancer
- Resources include a toll-free peer support helpline, online message board and chat room, annual conference, newsletter, and other printed materials

### Hereditary Breast and Ovarian Cancer Society of Alberta (HBOC)

[www.hbocsociety.org](http://www.hbocsociety.org) 780.488.4262 or 1.866.786.4262

- Canadian charitable organization founded in 2002
- Goal is to advance the education of the public concerning hereditary breast and ovarian cancer and offer support to affected individuals and families by providing information, advice and peer support
- Resources include quarterly newsletter, workshops, peer support meetings

### Willow Breast Cancer Support Canada

[www.willow.org](http://www.willow.org) 1.888.778.3100

- Canadian community-based, survivor-driven information and support services to help those living with breast cancer
- New hereditary breast and ovarian cancer programs in 2010 include peer support and information packages

### Bright Pink

[www.bebrightpink.org](http://www.bebrightpink.org)

- American non-profit organization that provides education and support to young women who are at high risk for breast and ovarian cancer
- Goal is to enlighten and empower high-risk individuals to take control of their breast and ovarian health

## Decision Guides

### Ovarian Risk-Reducing Surgery: A Decision-Making Resource

- Produced in 2006 by Fox Chase Cancer Center in Philadelphia
- Can be ordered by sending email to: [surgerybook@fccc.edu](mailto:surgerybook@fccc.edu)

### Prophylactic Mastectomy: A Decision-Making Guide for Women at High Risk for Breast Cancer

- Produced in 2002 by Hereditary Cancer Program (update is planned)
- Copies available from HCP on request

**Books** Copies may be available for loan from the HCP, the BCCA library, or public libraries

### Positive Results: Making the Best Decisions When You're at High Risk for Breast or Ovarian Cancer

Joi L. Morris & Ora K. Gordon, 2010, Prometheus Books

- Combination of a memoir and a reference book
- Presents complex information in a way that is easy to understand and to use

### Pretty is What Changes: Impossible Choices, The Breast Cancer Gene, and How I Defied My Destiny

Jessica Queller, 2009, Random House Publishing

- A memoir regarding the author's experience with a *BRCA* positive result

### Breast Cancer: Daughters Tell their Stories

Julianne S. Oktay, 2005, The Haworth Press

- Presents case studies of women whose mothers had breast cancer
- Stories were collected through a research study

### Mayo Clinic Guide to Women's Cancers

Lynn C. Hartmann & Charles L. Loprinzi (Eds.), 2005, Mayo Clinic

- Written for both lay people and health care professionals
- Comprehensive information about breast, ovarian, endometrial and cervical cancers

### Am I Next in Line?

Monique Achtman, 2004

- A personal account of the Canadian author's "journey of genetic discovery" related to her family history of breast and ovarian cancer
- Can be ordered online: [www.aminextinline.com](http://www.aminextinline.com)

## Videos

### **In The Family**

83 minute documentary, 2008, First Run Features

- American filmmaker Joanna Rudnick (age 31) explores *BRCA* genetic testing and her personal experience
- Available for loan from HCP

### **At My Mother's Breast**

55 minute film, 2005, National Film Board of Canada

- A 27-year-old Canadian woman shares her family's experience to illustrate how breast cancer changes mothers and daughters
- Available for loan from BCCA library

### **E3 - Eat Right - Exercise - Examine**

24 minute video produced in 2003

- Aimed at teenage girls and young women
- Available from BC/Yukon Chapter of Canadian Breast Cancer Foundation

### **Understanding Hereditary Breast and Ovarian Cancer**

15 minute video produced in 2001 by the Hereditary Cancer Program

- Covers some of the information in this booklet
- Copies available for loan from the HCP or BCCA library

### **Genetic Testing for Breast Cancer Risk: It's Your Choice**

14 minute video produced by the National Action Plan on Breast Cancer (U.S.)

- A balanced presentation of the complex nature of decision-making about genetic testing
- Copies are available for loan from the HCP

Note: The BC Cancer Agency's Library and Cancer Information Centres provide materials to people in British Columbia and the Yukon. You can visit the main library at 675 W 10th Ave in Vancouver or call 604-675-8001 (or 1-888-675-8001, local 8001) to request items. There is also a smaller library/cancer information centre within each cancer centre (Vancouver, Victoria, Surrey, Kelowna and Abbotsford).

## Websites

These are some suggestions to get you started. Most websites provide links to other related sites of interest.

### **Hereditary Cancer Program/Cancer Screening Programs**

[www.screeningbc.ca](http://www.screeningbc.ca)

- Hereditary tab links to information about the Hereditary Cancer Program, referrals, eligibility, and information for healthcare professionals
- Information about cancer screening recommendations for the general population

### **BC Cancer Agency**

[www.bccancer.bc.ca](http://www.bccancer.bc.ca)

- General information about cancer and its treatment

### **Canadian Cancer Society**

[www.cancer.ca](http://www.cancer.ca)

- General information about cancer and other resources
- Look in the Prevention section under Family Genetics for hereditary cancer information
- CCS also operates a national telephone information service (1.888.939.3333)

### **Abreast and the Rest**

[www.abreastandtherest.ca](http://www.abreastandtherest.ca)

- Canadian newsletter addressing breast cancer and gynecological cancers

### **Breast Cancer Now What**

[www.breastcancerwhat.ca](http://www.breastcancerwhat.ca)

- Developed by young women in BC, to address issues that are unique to young women with breast cancer
- Provides information, support, inspiration and a sense of community

### **Canadian Breast Cancer Foundation**

[www.cbcf.org](http://www.cbcf.org)

- National volunteer-based organization with regional offices that provide general information, fundraising events, and research



**Canadian Breast Cancer Network**

www.cbcn.ca

- A national survivor-driven network of groups and individuals to support people affected by breast cancer

**Ovarian Cancer Canada**

www.ovariancanada.org

- Registered Canadian charitable organization whose mission is to overcome ovarian cancer
- Focus is support for women living with the disease and their families, raising awareness in the general public and with health care professionals, and funding research

**National Cancer Institute (U.S.)**

www.cancer.gov

- Comprehensive source of cancer information for patients, health professionals & researchers

**National Library of Medicine (U.S.)**

www.nlm.nih.gov

- Medline/PubMed allows access to medical literature
- Includes a link to the National Cancer Institute website (see above)

**Myriad Genetic Laboratories (U.S.)**

www.bracnow.com

- Commercial genetic testing company in Utah



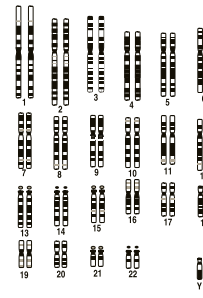
## Glossary

Acquired gene mutation	A change or alteration in a gene within a cell, that happens by chance during a person's life. Caused by aging, exposure to chemicals, radiation, hormones, other factors in the body and the environment.
<i>BRCA1</i>	The 1st gene found to be related to some hereditary breast and ovarian cancer. Discovered in 1994. Located on chromosome 17.
<i>BRCA2</i>	The 2nd gene found to be related to some hereditary breast and ovarian cancer. Discovered in 1995. Located on chromosome 13.
Cancer screening	Specific medical tests that are done to try to find a cancer at an early stage, when treatment can be most effective. Screening tests are done when there are no symptoms of cancer.
Carrier	A person who is born with an inherited gene mutation.
Chromosome	"Package" of DNA located within the nucleus of a cell. Normal human cell has 46 chromosomes (23 pairs). Genes are located on chromosomes. See Appendix on page 30
DNA	<b>DeoxyriboNucleic Acid.</b> Chemical substance that makes up genes. See Appendix on page 30
Familial cancer	Refers to cancers caused by a combination of multiple genetic and environmental factors. Also known as multifactorial.
Gene	Section of a chromosome, made up of a specific sequence of DNA. "Recipe" for a specific protein that has a specific function in the cell. See Appendix on page 30
Hereditary	A gene change that can be inherited.
Index	The person whose blood sample is tested first, to try to find a specific gene mutation in a family.
Inherited gene mutation	A change in a gene that is passed down from parent to child (i.e. it is present in every cell in the body at birth). See Hereditary.
Mammogram	An x-ray of the breast.
MRI	Magnetic Resonance Imaging. A medical test that uses powerful magnets and radio waves to create computer images of body tissues and organs. Does not use radiation.
Mutation	A change or alteration in a gene that may cause it not to function normally. Mutations may be inherited or acquired.
Pathologist	A doctor who identifies diseases by studying cells and tissues under a microscope.

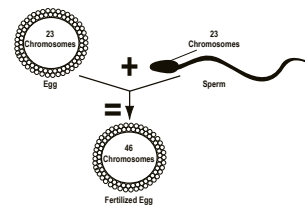
Peritoneal cancer	Cancer of the tissue that lines the abdominal wall and covers organs in the abdomen. Similar to ovarian cancer.
Prophylactic mastectomy	Surgery to remove healthy breast tissue, with the goal of avoiding breast cancer. Also called risk-reducing mastectomy.
Prophylactic salpingo-oophorectomy	Surgery to remove the ovaries and fallopian tubes, with the goal of avoiding cancer. May be referred to as a “total hysterectomy” if the uterus is also removed, but it’s more helpful to be specific about which organs were removed.
Radiologist	A doctor who specializes in creating and interpreting pictures of areas inside the body to diagnose diseases. The pictures are produced with x-rays, sound waves (ultrasound), or other types of energy.
Sporadic cancer	Cancer that happens “by chance” or randomly. The biggest risk factor for sporadic cancer is getting older. Other common risk factors include diet and lifestyle.
Variant	A change in a gene that is not yet understood, and may or may not have any impact on how the gene works.



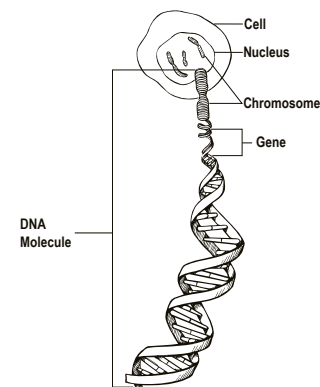
## Appendix: What are DNA, chromosomes & genes?



Every cell in the human body contains a chemical substance called **deoxyribonucleic acid (DNA)**. DNA is packaged into structures called **chromosomes**. Each human cell contains 23 pairs, or a total of 46 chromosomes. The 23rd pair of chromosomes determines our sex – females have 2 “X” chromosomes, and males have 1 “X” and 1 “Y” chromosome.



Chromosomes come in pairs because one set of 23 chromosomes comes from the mother in the egg and the other set comes from the father in the sperm. When a sperm and an egg unite, they form a new cell with 46 chromosomes. When this cell (the fertilized egg) divides, all 46 chromosomes are copied and passed on to every cell that eventually makes up a new human being.



Looking at a single chromosome, we see that its DNA is arranged in units called **genes**. Genes direct the growth, development and function of the human body; everything from eye colour, to height, to how often cells divide. We have approximately 25,000 different genes, each in a specific place on a specific chromosome. Since we have two copies of every chromosome, we also have two copies of every gene; one copy from each parent.

Sometimes a gene is changed in some way, so that it does not function properly. A change in a gene is called a **mutation**.



## BC Cancer Agency

CARE + RESEARCH

*An agency of the Provincial Health Services Authority*

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### Hereditary Cancer Program

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