Hereditary Cancer and Genetic Testing After a Cancer Diagnosis

Procedures, Infusions, Tests

Information to help patients and families understand genetic testing for hereditary cancer

Hereditary Cancer Clinic

Alberta Health Services

CancerControl Alberta

Your cancer care team offered you a test to check for hereditary cancer. Read more about hereditary cancer and genetic testing in this booklet:

A Hereditary Cancer

What is hereditary cancer?

Hereditary cancer can happen when we have a change (or mutation) in a gene that protects us from cancer. The mutation stops the gene from working the way it should and increases our risk of getting some kinds of cancer in our lifetime.

A mother or father can pass a gene mutation to their child before birth. When the gene mutation is passed on in this way the gene mutation is said to be inherited. If this happens, the child also inherits an increased risk of developing cancer in their life time. Gene mutations rarely increase risk of cancer in children, and mostly increase cancer risk in adults.

Hereditary cancer is not common. About 3 out of 20 (15%) people with cancer have hereditary cancer.

A cancer may be hereditary if:

- The cancer is diagnosed in someone who is younger than 50
- The cancer type is rare (for example: “triple negative” breast cancer, ovarian cancer, or breast cancer in a man)
- Close relatives in one side of a family are diagnosed with the same type of cancer
- Certain cancer types are all diagnosed in one person, or on one side, of a family (for example: breast and ovarian cancer; colon and uterine cancer)

Why does finding out if I have hereditary cancer matter?

Your cancer care team thinks you may have hereditary cancer. Finding a genetic cause of cancer may:

- Help guide your treatment
- Tell you if you are at increased risk for other cancers
- Help identify the best cancer screening and prevention options for you and your family

Do I have to have genetic testing?

No. Your cancer care team may have offered you genetic testing but **it is your decision whether to have the test**. Your decision will not change your relationship with your cancer care team.

If you still have questions after talking with your cancer care team and reading this booklet, you can:

- Review the online video www.cancercontrolalberta.ca
  Click 'Patients & Families' > 'In Treatment' > 'Procedures, Infusions, Tests'
- Ask to speak with a genetic counsellor
- Talk to your regular doctor or a trusted family member or friend about any concerns you have

My notes:

B Genetic Testing

What is genetic testing?

Genetic testing is best done with a blood sample. Genes are made of DNA. DNA is removed from the blood. Special machines are used to check the DNA for mutations related to hereditary cancer.

The test checks many genes linked to hereditary cancers including ovarian, breast, and colon cancers.

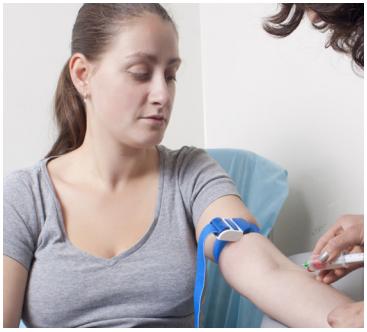
Scientists continue to learn about hereditary cancer. New genes may be added to genetic testing in the future.

The test may include these genes:

ATM, BRCA1, BRCA2, BRIP1, CDH1, CHEK2, EPCAM, MLH1, MSH2, MSH6, NBN, PALB2, PMS2, PTEN, RAD51C, RAD51D, STK11, TP53

Check with your care team.

Where do I get a genetic test?



You can have this blood test at any Alberta Public Laboratories site. Take the lab requisition your cancer care team gave you to the lab. You do not need to do anything special to get ready for the test.

Find an Alberta Public Laboratories site near you by:

- Asking your healthcare team
- Visiting www.ahs.ca
  Search for lab services, then look in the 'Hospitals & Facilities' tab

How will I get my test result?

Usually, the person who ordered the genetic test will:

- Tell you your test result
- Talk with you about what the result means for you and your family

Your result will usually be ready 4 to 8 months after you have your blood drawn.

The Hereditary Cancer Clinic Hub will follow-up with you about your genetic test result. You may also be offered an appointment with a genetic counsellor.

Private genetic testing is available if you pay for it. If you decide to get tested privately, make these plans with your cancer care team's help. Not all labs offer the same services. It is important to pick a lab that offers high quality testing, results, and genetic counselling.

What could my test result be?

There are 3 possible test results. These are:

No pathogenic variant detected (often called a 'negative' result)

This is the most common test result. A 'negative' result means no mutations were found in the genes tested.

If you have a family history of cancer there is still a chance that your cancer is hereditary. Please discuss your family history of cancer with your care team. Further genetic review may be right for you and your family.

Of all the people tested **about 13 out of 20** people (65%) will have a 'negative' result

Pathogenic variant detected (often called a 'positive' result)

Of all the people tested **about 3 out of 20** people (15%) will have a 'positive' result

A 'positive' result means a mutation was found in one or more of the genes tested. When a genetic mutation is found you may be told you have a 'hereditary cancer syndrome'.

This result may mean:

- Different cancer treatment is better for you
- You have a higher risk for another type of cancer
- Your relatives may have the same gene mutation and, if they do, they could be at higher risk of cancer

Variant of unknown or uncertain clinical significance (VUS) detected (often called an 'uncertain' result)

About 20% of genetic tests have a VUS or 'uncertain' result. A VUS is a gene change that is not well understood at this time. This means we don't know if the VUS is a mutation that increases your risk of cancer or just a genetic difference that does not increase your cancer risk.

Since the meaning of a VUS is not clear, genetic testing of family members for the same VUS is **not** recommended.

Of all the people tested **about 4 out of 20** people (20%) will have a VUS result

C What Are the Benefits and Risks of Genetic Testing?

Genetic testing has benefits and risks. Understanding them will help you decide if the test is right for you.

Mark the benefits and risks that are most important to you.

Possible Benefits	Possible Risks
☐ Getting a genetic explanation for your cancer	☐ Getting unclear answers about whether you or your family have a genetic risk for cancer
☐ Helping to identify the best cancer screening and prevention options for you and your family	☐ Upsetting family members who do not want to know about or discuss a genetic risk for cancer
☐ Helping confirm what cancer treatments are best for you (such as surgery, medication, clinical trials)	☐ Being recommended a cancer treatment medication that is not paid for by Alberta Health Insurance or your health insurance plan
☐ Learning if you have risks for any other hereditary cancer This can be a benefit or a risk depending on how you feel about the possibility of getting information like this	

In 2017, the Genetic Nondiscrimination Act (GNA) became law in Canada. This law protects people from insurance and employment problems based on genetic test results. But, there may be some issues that are not covered by this law.

Some people find making a decision about genetic testing or making sense of a result can be emotionally difficult. Psychosocial Oncology can offer counselling to patients and family members to help reduce emotional distress and explore coping techniques. No referral is needed.

For more information or for contact details, look in **Sources of Help**

D What Do I Do After I Get My Test Result?

☐ Ask your cancer care team questions, such as:

- Does my result impact my treatment plan? If so, how?
- What are my risks for other cancer and what can I do for cancer prevention?
- Does my test result impact my family? If so, how?

☐ Ask to speak to a genetic counsellor if you have unanswered questions.

☐ Share your results with your regular primary care doctor.

☐ Talk with your family about your test results.

You or your family may find it difficult to talk about the test results.

- Share your results with family in person, by phone, or in a letter.
- Talk to your cancer care team or a genetic counsellor If you need help finding ways to share this information and also protect everyone's privacy.

My notes:

E Where Can I Get More Information?

- CancerControl Alberta (ALBERTA) www.cancercontrolalberta.ca
  - Click 'Patients & Families' > 'In Treatment' > 'Procedures, Infusions, Tests'
  - Watch the Considering **Genetic Testing After a Cancer Diagnosis** Video
- MyHealth.Alberta (ALBERTA)
  - https://myhealth.alberta.ca/genetics/understanding-genetics
- Hereditary Cancer Clinic Hub (ALBERTA) - Toll-free 1-833-955-0505
- Canadian Cancer Society (CANADA)
  - www.cancer.ca/en/cancer-information/cancer-101/what-is-cancer/genes-and-cancer/
- Hereditary cancer advocacy groups:
  - Breast and Ovarian Cancer - HBOC Society of Alberta (ALBERTA) https://www.hbocsociety.org/
  - Lynch Syndrome- AliveAndKickn (USA) https://www.aliveandkickn.org/
  - Colon Cancer - Kintalk (USA) http://kintalk.org/
- Genetic Non-discrimination Act (GNA) information (CANADA) https://laws-lois.justice.gc.ca/eng/acts/G-2.5/index.html
- Canadian Association of Genetic Counsellors (CAGC) (CANADA) https://www.cagc-accg.ca/

References:

- GeneReviews®: https://www.ncbi.nlm.nih.gov/books/NBK1116/
- Alberta Public Laboratories NGS gene panel information sheets:
  - Expanded breast-ovarian panel: https://www.albertahealthservices.ca/assets/wf/lab/wf-lab-gls-br-ov-ngs-info-sheet.pdf
  - Lynch syndrome gene panel: https://www.albertahealthservices.ca/assets/wf/lab/wf-lab-gls-lynch-syndrome-ngs-panel-info-sheet.pdf
- American Society of Clinical Oncology (ASCO) Genetics Toolkit: https://www.asco.org/practice-guidelines/cancer-care-initiatives/genetics-toolkit

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