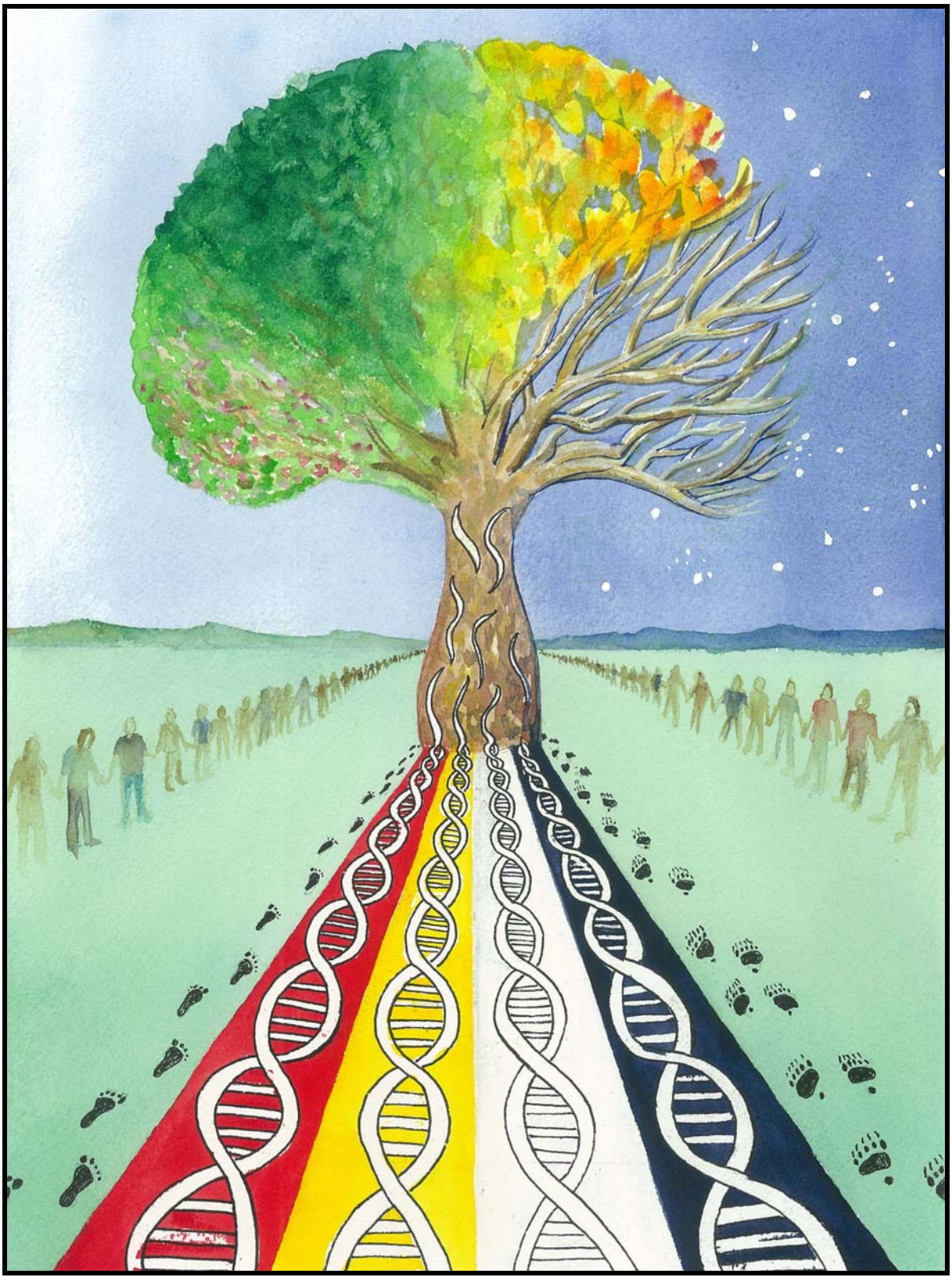


Cancer and Our Genes

Artist Statement
Cancer and Our Genes

The tree symbolizes all of the cycles of life, infant, child-spring-new beginnings, adolescence-young adulthood, summer/ adulthood-middle age, autumn/ elder hood, winter. Within the tree trunks going down to the roots are the connections to our DNA. There are 4 roots of DNA in the 4 sacred colors which also represent different ages and times as well as directions and races. They all come together to create the tree of life.

And as dawn goes into night we travel together as one people, stretching back to ancient times. I put the lines of people standing to represent all of the collective strength and experiences within humanity as well as to represent our ability to continue and persevere through lifetimes, whether that be persevering and triumphing over disease or other obstacles.

The footprints alongside the roots of the tree, the left representing humanity and the journey through life, the right bear paw prints representing healing and quiet strength, needing to go within oneself to finding hidden strength and inner healing, it also represents the more “natural” healing an individual can access for treatment with Cancer.

Cassandra Leigh Darrough
Paiute-Shoshone
August 12, 2010

Section 3

Cancer & Our Genes

GOALS

Participants will learn about the role of genes in cancer. The importance of knowing a family cancer history is discussed. Reasons people may want, or choose not, to have gene testing will also be discussed.

OBJECTIVES

At the end of this section, each participant will be able to:

UNDERSTAND the relationship between cancer and genes

RECOGNIZE the differences among sporadic, familial, and hereditary cancers

DISCUSS why or why not people may choose to have gene testing

RECOGNIZE that cancer screening recommendations may be different for families with hereditary cancers

KNOW how to take a family cancer history

Table of Contents

Cancer & Our Genes

Check Your Understanding

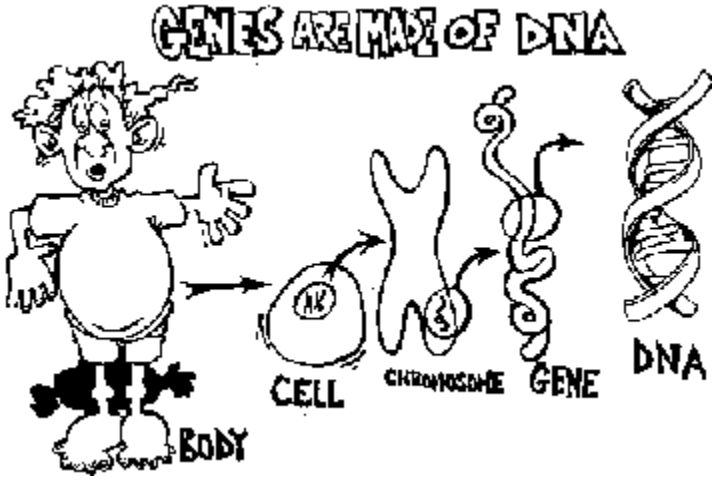
		TRUE	*FALSE*
1.	Genes carry the instructions for all of our body functions.		
2.	Cancers are the result of mutations in genes.		
3.	Most cancers are sporadic.		
4.	Hereditary cancer is very common.		
5.	The mother's cancer history is the most important.		
6.	People with hereditary cancer inherit a mutated gene from their parents.		
7.	Everybody over age 50 should have a gene test for cancer.		
8.	A negative gene test means you will not get cancer.		
9.	Inheriting a gene mutation means you will get cancer.		
10.	Counseling before and after gene testing is recommended.		

"Genetics" is the study of genes.

Genetics of Cancer

Many people have cancer in their family. Some families have more cancer than others and family members may want to know if they could get cancer too. This section will help you to talk with people about hereditary cancer.

What are genes and what do they do?



Our bodies are made up of trillions of cells. Within each cell are the 46 chromosomes that we inherit from our parents: 23 from our mother's egg and 23 from our father's sperm. Each chromosome is a double strand of DNA that contains chemical information. Genes are tiny segments of the DNA that carry instructions for making specific proteins that control cell function and growth. Each gene is one of a kind and is responsible for a very specific action. Different genes are turned on in different cells giving that cell type its special instructions.

Genes tell our body's cells how to grow, develop and function from the time of conception and continue until we die. We each have a unique set of genes inherited from our parents that give us our individual inherited traits, including physical characteristics, such as our hair color, eye color, etc.

Many factors from both within and outside our bodies can influence whether genes function properly or not. Outside factors such as exposure to tobacco, sun, chemicals, radiation, or environmental pollution can damage healthy gene function. Decreasing exposure to things that can cause harm to our cells and genes, as well as being physically active and eating in healthy ways will help our genes function normally.

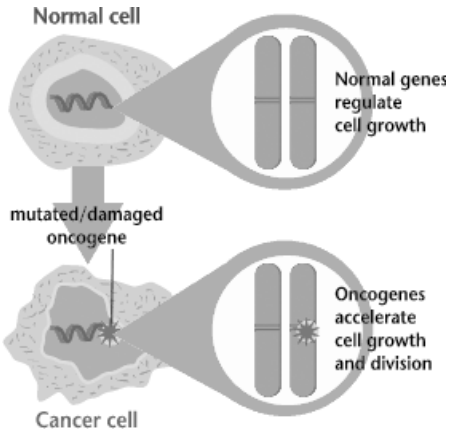
Why is cancer genetic?

All cancers are caused by changes in a person's genes. Changes in genes are called mutations. A mutation is a mistake or error in the chemical make-up of a gene. Gene mutations give cells the wrong instructions for what to do and how to function. Normally functioning cells grow and divide and know to stop growing.

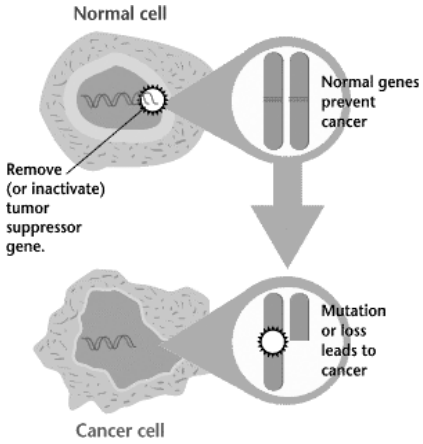
However, genes that control how cells normally grow and divide can malfunction. If this happens, the cell will divide endlessly and grow out of control. The type of gene that causes this to happen is called an **oncogene.** Genes come in pairs. If a damaged or abnormal oncogene is stronger than the healthy oncogene it will cause abnormal cell growth.

Some normal genes in cells are there to stop cells from multiplying or doubling. This prevents cancer from developing. **Tumor suppressor genes** work together in pairs to keep cancer from forming. If one isn't doing its job, the other gene will take over to keep the cell healthy. When both tumor suppressor genes are not working, cancers can form.

Oncogenes and tumor suppressor genes are only 2 of the types of genes involved in cancer.



"Oncogenes" *are damaged (mutated) genes that can cause a normal cell to become malignant or cancerous. When oncogenes are present in a cell, they tell the cell to continue to grow and divide, without stopping.*



"Tumor suppressor genes" *are normal genes that prevent cancer from developing. If both tumor suppressor genes are not working because of a mutation (damage), cancer can develop.*

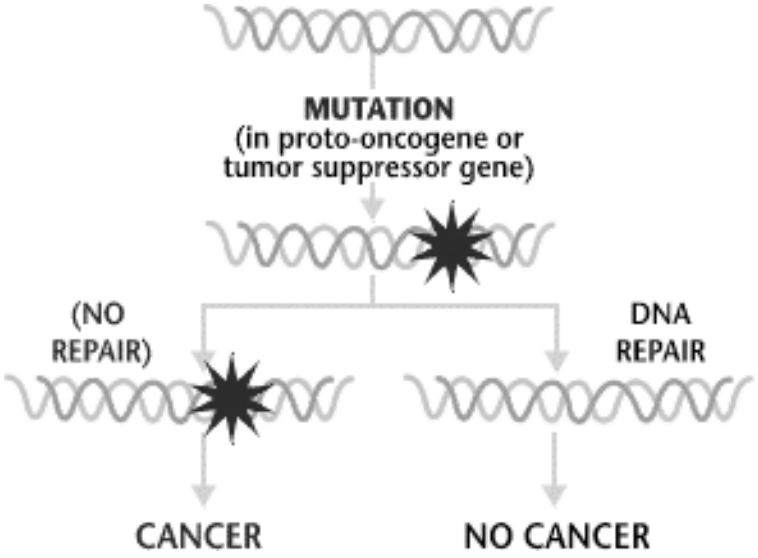
Genetics of Cancer

Oncogenes are like the accelerator pedal in a car, speeding up cell growth.

Tumor suppressor genes are like the brakes, telling the cell not to divide.

What is a mutation?

A mutation is a mistake or error in the chemical make up of a gene causing the gene to give the wrong instructions to the cell. It may be caused by damage from tobacco, alcohol, viruses, the sun, environmental pollution, or even random events within a cell. Mutations happen quite often and not all of them cause cancer. This is because we have genes in the DNA of our cells that have the job of fixing mutations. Mutations in the genes that prevent the cell from reproducing normally or that damage the DNA repair genes can cause cancer to grow. Generally, it takes many mutations and many years before a cancer starts to grow. However, if the first mutation happens in a gene that repairs or prevents mutations, then other mutations can happen quickly.

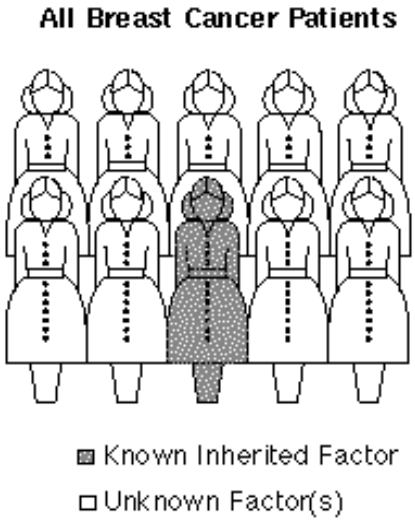


"DNA repair genes" *are special genes that protect us from cancer causing mutations. They repair errors that happen when cells copy their DNA just before they divide to make new cells. If DNA repair genes are absent or damaged, other mutations in the cell do not get repaired. If mutations in oncogenes (cancer causing genes) or tumor suppressor genes are not repaired, cancer can develop.*

Sporadic, Familial, & Hereditary Cancer

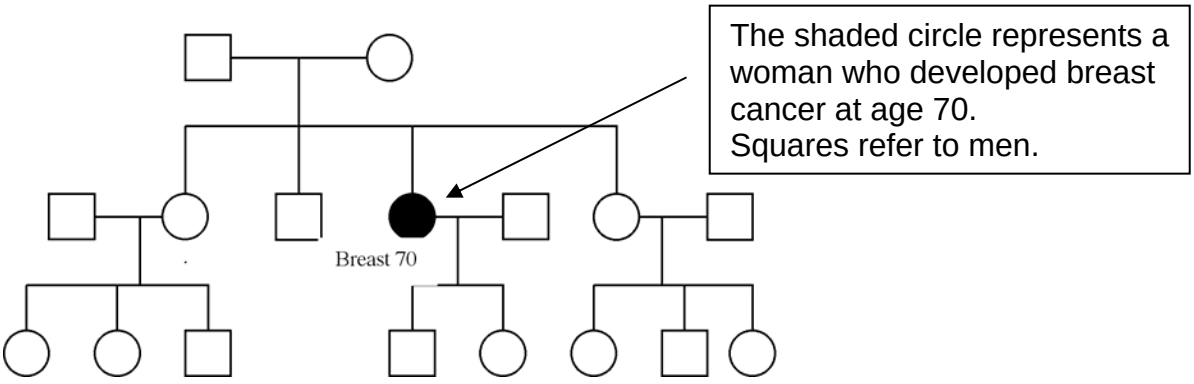
What is sporadic cancer?

Sporadic means that something happens by chance. Most cancers are sporadic and not due to an inherited cancer-causing gene. People who have sporadic cancer did not inherit cancer-causing mutations from their parents. Instead, certain cells in their body developed mutations that led to cancer. In sporadic cancer, ***only the tumor cells have the mutation; it is not found in every cell.*** A tumor is an abnormal mass of cells. Tumors can be benign (not cancer) or malignant (cancer).



The mutation is not present in other family members and is not passed generation to generation. Sporadic cancers can be any kind of cancer, and happen more often in older people. About 9 out of 10 people with cancer have a sporadic cancer.

Most cancers are sporadic and not due to an inherited cancer-causing gene. For example, only one woman in every ten women with breast cancer has an inherited cause.

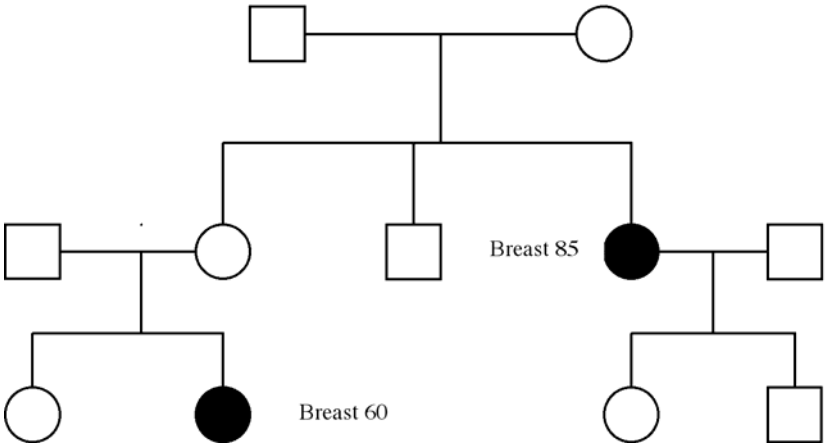


Sporadic Cancer = a single occurrence in a family
Sporadic cancers can be any kind of cancer and happen more often in older people. The cancer risk is not present in other family members and is not passed from generation to generation. Refer page 3-19 'Drawing a Family Tree'.

What is familial cancer?

Familial cancer means that cancer has happened in 2 or more blood relatives in the same family. They may be first degree relatives, such as a mother, father, daughter, son, sister, or brother, or more distant relatives such as a grandparent, aunt, uncle, niece, or nephew. There may be several different kinds of cancers within the family.

As families, we share many of our genes. We also share some of the same lifestyle characteristics like the food we eat, how much physical activity we get, our exposure to tobacco, and the environment we live in. Researchers are not sure how much of familial cancer is caused by inherited genes, and how much is caused by shared environment and by shared lifestyle. A person in a family with familial cancer has a slightly increased risk of developing cancer.



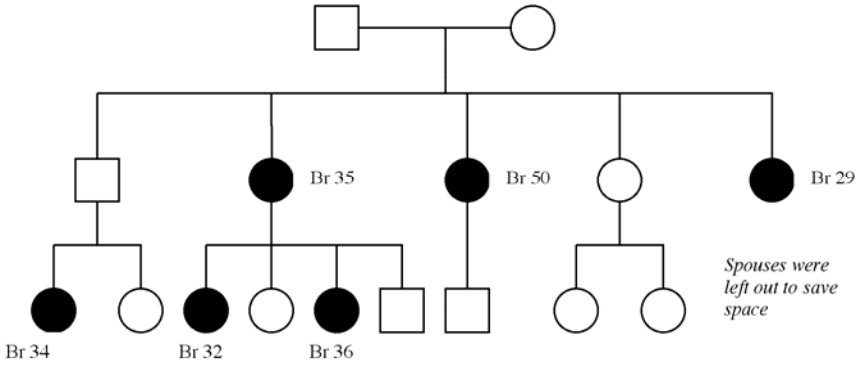
Familial Cancer

Familial cancers occur in 2 or more blood relatives. The onset of the cancers is generally later in life. In this diagram of a family tree, the 2 shaded circles represent the 2 women who developed breast cancer. One woman at age 85 and one woman at age 60. The square symbol is for men.

What is hereditary cancer?

People with hereditary cancer inherit a mutated gene from one of their parents. At time of conception, either their father or mother passes on a gene that already has a mutation and is not working. Every cell in the person's body contains the mutation. Cells of the ovaries and testes, which make eggs and sperm, contain the mutation and can pass the mutated gene to the next generation.

It generally takes more than one mutation to cause cancer. People who have inherited a mutation are one step closer to cancer than those who have not. For example, a child with an inherited mutation in a tumor suppressor gene will grow up with only one functioning tumor suppressor gene, instead of the two she or he would have normally. If the one working tumor suppressor gene gets damaged, say from tobacco use, then she or he is more likely to develop cancer and to develop it at a younger age. She or he also may pass this mutation on to her or his children. People who inherit a cancer-causing mutation are at higher risk to develop cancer, but that does not mean that **all** family members will develop cancer.



Hereditary Cancer

Hereditary cancer means there is an inherited cancer-causing mutation within a family. In this diagram of a family tree, each shaded circle represents a woman who has developed breast cancer. The number next to the circle is the age the woman developed breast cancer. The squares are symbols for men.

Hereditary cancer is not very common.
Only 5 to 10 people out of every 100 people who develop cancer, have a hereditary cancer. **Most cancers are sporadic** and not related to an inherited cancer-causing gene.

Clues to Hereditary Cancer

Here is a list of clues that could mean the cancer happened because of an inherited gene mutation. Not every family will have each of these clues.

- Several first degree relatives, such as a mother, father, son, daughter, sister, or brother, have the same type of cancer.
- The kind of cancer is an uncommon childhood cancer.
- Cancer happened in an adult at an earlier age than expected, less than age 40.
- A person developed cancer in both paired organs, both breasts developed cancer or both ovaries had cancer.
- A person developed more than one type of cancer, such as colon and breast cancer, or colon and prostate cancer.
- A man has breast cancer.
- More than one generation in a family was affected by cancer.

Where do I find the clues?

American Indian and Alaska Native people know the importance of preserving the past for the future. Ancestors passed on a rich heritage of hunting, fishing, food, dance, values, and GENES! The clues to hereditary cancer risk are in the family medical history. The more detailed information available, the more accurately hereditary cancer risk can be predicted. Getting a good family medical history takes time and may require some "detective" work. Here is the information you need to know:

- Who in the family has or has had cancer? Include the immediate family: mother, father, daughters, sons, sisters, brothers, grandparents, siblings, aunts, uncles, nieces, nephews, and cousins. Record three or four generations.
- Find out, if you can, exactly what kind of cancer family members had. Remember, the more details you know the better.
- If the cancer happened in paired organs, like breasts or kidneys, was it found in both breasts or both kidneys?

- Did anyone in the family have more than one kind of cancer? This information can be tricky to sort out. Cancer can spread to other parts of the body away from the primary site. When asked, people may remember that their relative had breast cancer and lung cancer, but really the breast cancer spread to the lungs. Try to find out if the first cancer spread to other organs or if it was truly a new cancer in a different organ.

- How old was the person when the cancer was found? If the relative is deceased, what was their age and cause of death?

- How old are family members who have not developed cancer?

- Having a gene with a mutation does not always mean someone will develop cancer, but that person can still pass a mutated gene to her or his children. A father who inherits a breast cancer gene from his mother has a 50% chance of passing it to his daughters or to his sons, who, in turn, can pass it on to their children. The daughters and sons who inherit the mutation will then be at a higher risk to develop breast cancer. A parent who carries a gene mutation also has a 50% chance of not passing it to her or his children. If the mutated gene is not passed on, then their child has the same cancer risk as other people without hereditary cancer in their family. Only genetic testing can determine whether a specific gene was passed on.

What is a hereditary cancer syndrome?

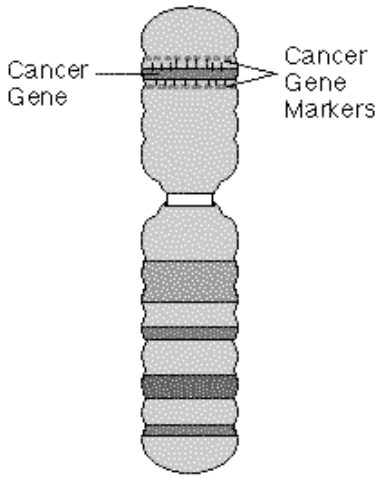
A syndrome is a set of symptoms or medical conditions that occur together. In genetics, it is a set of traits resulting from one gene. Sometimes an inherited mutated gene can cause more than one kind of cancer in a family. When this happens in a family on a regular basis, we call it a hereditary cancer syndrome, because the cancers come from the same inherited gene. Some cancer syndromes result in breast and/or ovarian cancer for a woman and prostate cancer for a man in the family. Another kind of gene causes a syndrome in which family members may have breast, thyroid, or colon cancer. Asking about ALL cancers in the family is very important. A complete family medical history is necessary to decide if a cancer is sporadic, familial, or hereditary, including a hereditary cancer syndrome. If a hereditary cancer is suspected, gene testing may be an option for the family.

Remember to ask about BOTH parents. The mother's AND father's cancer histories are important.

Gene Testing

Is gene testing for cancer available?

Researchers have identified many cancer-causing gene mutations and are continually identifying more. Gene tests are available to the public for only a few of these genes, and others are only available to research institutions. Commercially available tests for the public include those for inherited forms of breast and colon cancers.



For some inherited cancers, a special laboratory can examine the DNA (genetic material in chromosomes) for a particular gene mutation.

How is gene testing done?

A small sample of blood is sent to a special laboratory where they examine the DNA for a particular gene mutation. A positive gene test (the gene mutation is found) tells us that a person is at increased risk for cancer. It cannot tell whether or not the person will actually develop cancer.

First, they test blood from the person who has cancer to look for a gene mutation. Experts then try to decide if the mutation caused the person's cancer. The blood sample must be sent to whichever lab is an expert in testing that gene. Because some genes are very large, they may take longer to check. Results might take 3 weeks or 2-3 months, depending upon the individual gene.

If the lab finds a mutated gene, it is called a "positive result". They can then test other family members for the same mutation. If the other family members did not inherit the same gene mutation as the relative with the cancer, they have a "negative" result. A negative result does not mean they can never develop cancer. They have the same risk to develop cancer as other people in families without hereditary cancer.

If no mutation is found in the person with known cancer, this is also a "negative result". It could be that the gene mutation was not in the genes tested at the lab and a different gene has the mutation. It could be because the family has a mutation that the laboratory is not able to recognize yet (no test is currently available). When there is a "negative result", the people in the family are still at very high risk for cancer based upon their family history. The lab just didn't find the gene mutation causing that family's cancer.

Sometimes a laboratory finds a change in the gene that has not been seen before, but they aren't sure if it caused the person's cancer. This result is "uncertain" or "inconclusive", and can be very confusing and frustrating for the family. It is important for people to understand this uncertainty might happen, even though they are hoping for a clear answer. Since gene testing might not give a person a clear answer, it is important to talk about all the information so people can decide if they want the testing done.

STEPS IN GENE TESTING

Individual with cancer is tested

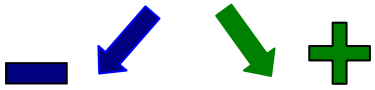
NEGATIVE FINDING

- Mutation not present.
- Mutation present but testing was not able to find.
- Gene testing of other family members not useful.

POSITIVE FINDING

(mutation present)

Other family members can be tested.



NEGATIVE

Hereditary cancer risk not increased.

POSITIVE

Hereditary cancer risk increased.

Who should consider gene testing?

Gene testing might be useful for someone who appears to have a hereditary cancer, and for individuals in a family that has a family medical history consistent with a hereditary cancer. Consider gene testing when the family has:

- Cancer in multiple generations.
- Multiple persons with the same cancer.
- Unusually young age of onset for a specific cancer, less than 40.
- Cancers in both paired organs.
- Cancers in two major body parts.

It is important for a person to carefully consider all the reasons why and why not gene testing might be helpful before having a gene test.

Is gene testing helpful?

Some people say yes, that it is a relief to know if they have the mutation or not. If they are truly negative, they can have cancer-screening tests done on the schedule recommended for the general population. If they know they are positive, they may have more checkups, or decide to use medicines or surgery to help prevent the inherited cancer from developing. It is important to remember a positive test result does not mean cancer will develop for sure, and it does not tell you at what age cancer might develop.

Gene testing may help a person to:

- Make health care choices, such as more frequent screening exams, medicines to help prevent cancer, or surgery to remove organs that might develop cancer.
- Find out if she or he has or does not have a mutated gene.
- Understand her or his risk of developing cancer.
- Give family members useful information.
- Change her or his lifestyle to help prevent cancer such as increasing physical activity, eating a healthy diet, and stopping tobacco use.

A negative test result could make someone think they have no chance of developing cancer. They might think they do not need recommended health care screening exams, and this could be very harmful. It is important for people to understand that even though they had a negative gene test, they still have the same risk of developing cancer as the general population.

What are reasons people choose not to have gene testing?

There are many reasons why people choose to have or not have gene testing done. It is a very personal decision that varies from family to family and among people within a family at risk.

A person may not want to do gene testing because:

- They do not want to know if they have a higher risk of developing cancer.
- Gene testing is very expensive, and it is not always paid for by health care insurance.
- Currently, if a mutated gene is found it cannot be fixed.
- They may worry they have passed a cancer gene on to their children.
- They may become angry if they have a mutated gene and someone else in the family does not have the mutated gene. Other family members may feel guilty if they do not have the mutated gene.
- It can be frustrating if a gene test result is uncertain.
- They may have concerns about discrimination in the workplace or eligibility for health care insurance and life insurance.
- A positive test result in one family member affects other family members even if they decide not to be tested.

Each person must decide for herself or himself. To make this decision, a person needs information about gene testing and what it can and cannot offer. It is recommended that families and individuals seek assistance with this decision-making process from their health care provider and/or a genetic counselor. Some people learn more about gene testing and decide not to do it. Other people might want to have gene testing at first, but then change their minds, and do not want to know their test results.

Who are genetic counselors and what do they do?

Genetic counselors are people trained in the scientific, medical, and emotional aspects of inherited diseases. Cancer genetic counselors specialize in counseling and educating individuals and families with cancer or people who are at risk for hereditary cancer.

Genetic counselors help families to collect and interpret their family medical history. They assess the likelihood of hereditary cancer and make recommendations about gene testing. They explore the medical, emotional, and financial implications of cancer risk and gene testing.

Genetic counseling is recommended before and after gene testing. After a discussion with the genetic counselor and time to think, the individual makes the personal choice whether to have gene testing or not. The counselor can arrange gene testing if it is available, and explain the possibility of negative, positive or uncertain results. A counselor can help people cope with their feelings about cancer and testing and medical issues. They can also suggest ways for a person to decrease her or his risk of developing cancer by making healthy lifestyle choices and having recommended screening exams.

Reducing the Risk of Cancer

For people at high risk for hereditary cancer, depending upon their unique situation, there is a variety of screening and risk reduction options they should discuss with their health care provider:

- cancer screening exams
- diet, exercise, and lifestyle activities
- preventive surgeries
- cancer prevention medications

Finding and treating cancer early saves lives! Having a hereditary risk for cancer is all the more reason to have recommended screening exams for early detection. People at an increased risk for developing cancer may need to be screened more frequently or begin at a younger age.

Individuals at high hereditary risk for developing cancer may consider preventive surgery to remove the specific organ. Some women at high risk for hereditary breast or ovarian cancer may choose to have surgery to remove both breasts, or to have their ovaries taken out, before cancer has a chance to develop. Some people at high risk for colon cancer may choose to have their entire colon removed. These preventive surgeries will reduce the person's risk for cancer, but it is not 100% for sure the person will not develop cancer.

Remember --- A person's risk for developing cancer can be higher because of inherited genes, but it does not mean that he or she will develop cancer. All people can make lifestyle choices to help prevent cancer and live a healthier life.

Check Your Understanding answers: 1)T, 2)T, 3)T, 4)F, 5)F, 6)T, 7)F, 8)F, 9)F, 10)T

Family History Questions for Cancer

As part of a family medical history, ask:

Has anyone in your immediate family related by blood (mother, father, brother, sister, son, or daughter) had cancer?
Yes or No

If Yes, the answers to the following questions help to identify people that may be at risk for a hereditary cancer.

To learn more, Ask ...

1. In your mother's family or father's family, including yourself, have two people related by blood had the same type of cancer?
   Yes or No
2. Including yourself, has anyone in your family had cancer in matching organs (for example, cancer in both breasts, ovaries, kidney, eyes)?
   Yes or No
3. Including yourself, has anyone in your family had cancer at age 40 or younger?
   Yes or No
4. Including yourself, has anyone in your family had two different cancers that began in two different organs? Examples would be breast and ovarian cancer in the same person or colon and kidney in the same person.
   Yes or No

If the answer is "yes" to any of the questions 1 - 4, talk to your health care provider about getting a more complete family cancer history.

Drawing a Family Tree

A family tree or a family pedigree is a map of a family medical history. It is made using the information from family members, medical records, and death certificates. When you make a family tree, you can include all medical problems or focus on a specific medical or health concern such as cancer, heart disease, or diabetes. In this section, we are learning about cancer within a family.

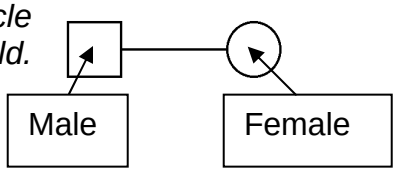
Start with a blank family pedigree (see page 3-22) and begin to fill in family members and whether or not they have cancer. If they have or had cancer include what type of cancer and how old they were when they were diagnosed. Include family members who have died, their cause of death and age.

Common symbols are:

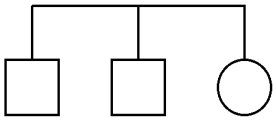
Squares mean males.

Circles mean females.

A square connected to a circle by a single line means they had a child.



Squares and circles hanging on a line mean brothers and sisters (siblings). (In this example there are two brothers and one sister.) Put the oldest at the left across to the youngest at the right.



Filled in squares and circles mean those family members have or had cancer. Put what kind of cancer(s) and how old they were when they were diagnosed with cancer.

A line through a square or circle means that family member died.

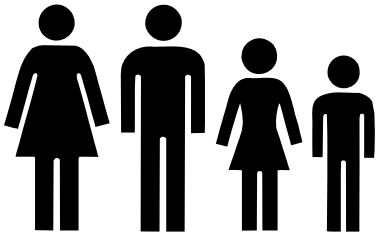
How to Draw a Family Tree or Family Pedigree

Clues to Hereditary Cancer in this Family

Refer to 3-21

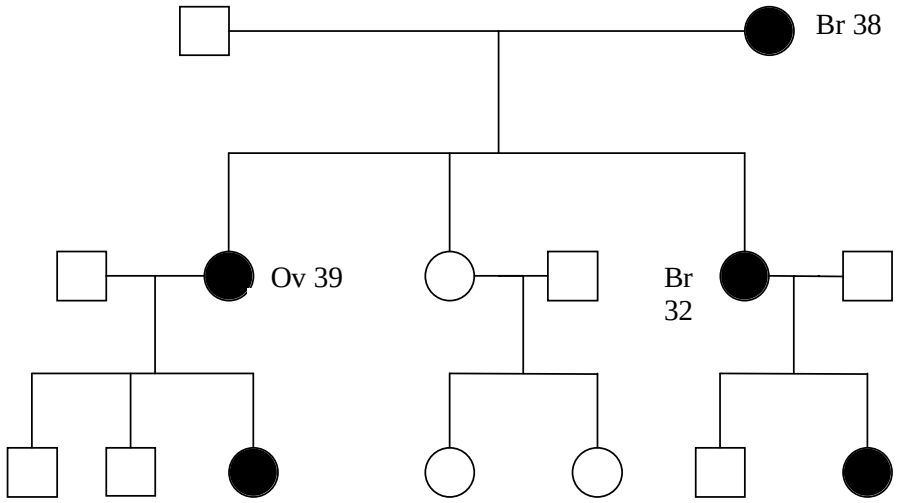
- Breast cancer is present in 3 generations without skipping a generation.
- Breast cancer occurs at a younger age than usual, less than age 40.
- Ovarian cancer is present in 2 generations without skipping a generation.
- Ovarian cancer occurs at a younger age than usual less than age 40.
- Breast and ovarian cancers occur in one individual.

For example, a family member was tested and found to have a gene mutation for breast cancer. Other family members may choose to be tested to determine their hereditary risk for developing cancer.



This family tree has clues that may mean there is a mutated gene causing hereditary cancer. What are the clues?

Example of a



= male = female = married

or = affected with cancer

= siblings (brother and sister)

Br = breast cancer Ov = ovarian cancer

Numbers = age at onset of cancer

Cancer & Our Genes

Example of a Family Pedigree