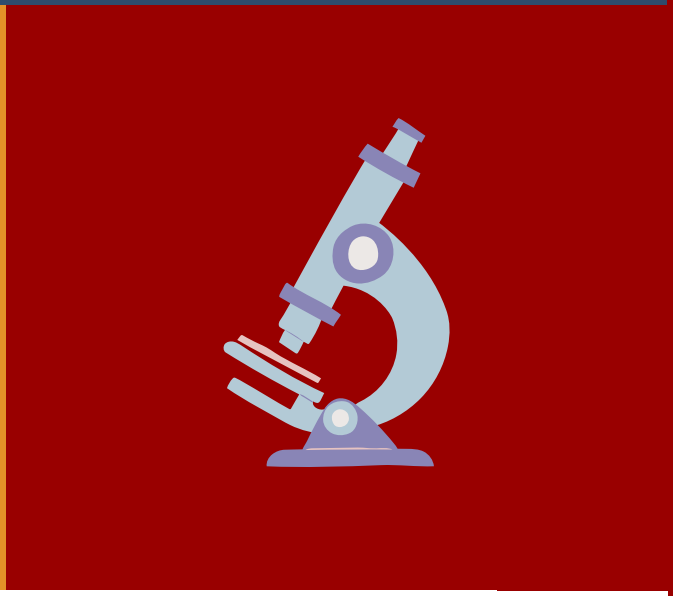
Community Genetic Navigation
Engagement Specialists
CoGENES Training Program

Colorectal Cancer and Genetic Testing Handbook



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Colorectal Cancer and Genetic Testing Handbook

This handbook was developed by the following individuals:

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Introduction:

This handbook is designed to provide an overview of colorectal cancer and cancer genetics. The pages can be used as a handbook or individually as handouts. Each page provides a summary of the following topics using graphics and language that is easy to understand.

Topics

Overview of colorectal cancer

Genetic inheritance

Mutation inheritance

Inherited colorectal cancer

Tumor mutations

Genetic tests for inherited cancer

Tumor mutation genetic testing

Cancer genetic risk

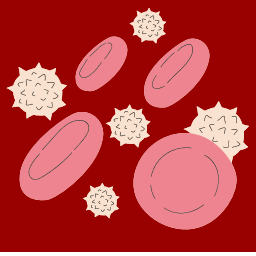
Genetic counseling

Supporting cancer patients

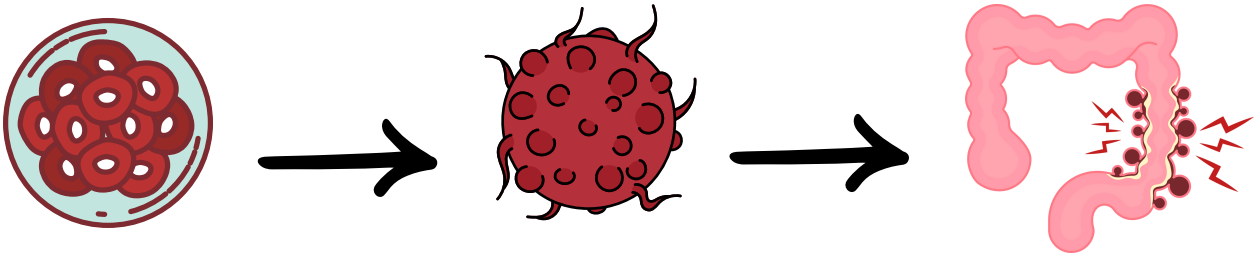
Navigating healthcare

Colorectal Cancer Facts

The body is made of **cells**.

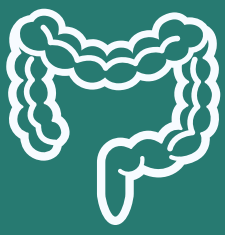


Cells divide to keep our body working, they know when to start and when to stop.



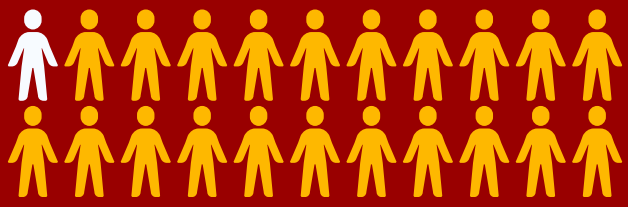
Sometimes cells are altered and can grow out of control.
If this is left alone, it can form a mass of cells called a **tumor.**

In Hispanic/Latino communities, colorectal cancer is the #2 most common cancer in men, and #3 most common in women

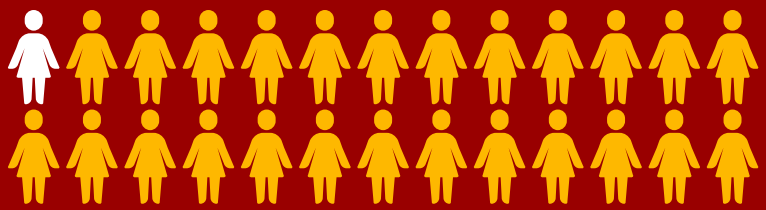


What are the chances of getting colorectal cancer in our lifetime?

1 in 22 men



1 in 26 women



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Detection of Colorectal Cancer

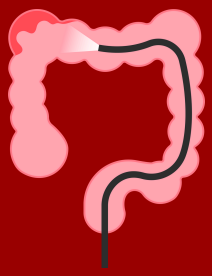
Colorectal cancer can be detected early through screening which is recommended after age 45

Stool Test (Fit Test)

- Detects blood in stools, which may indicate the presence of a tumor.
- A positive test has to be followed by a colonoscopy.
- **This test should be done every 1-2 years.**

Colonoscopy

- A small camera is inserted into the colon to see if anything is abnormal.
- Abnormal growths can be removed or a small piece can be taken for diagnosis.
- **This test should be done every 10 years.**



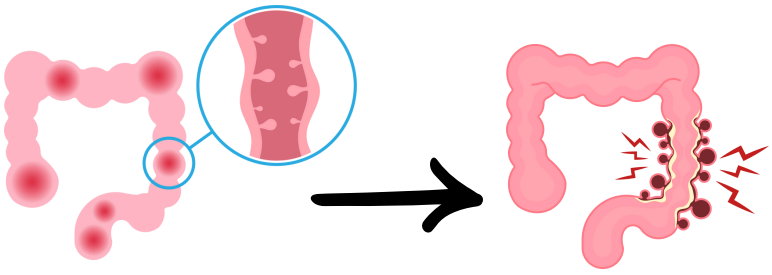
Symptoms of Colorectal Cancer

- Changes in bowel habits (diarrhea or constipation that do not go away).
- Blood in or on your stool.
- Abdominal pain, aches, or cramps that don't go away.
- Unexplained weight loss.

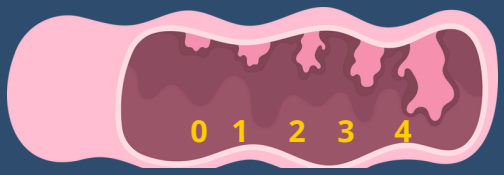
If these symptoms happen, get screened and talk to a doctor!

Polyp

Polyps are benign growths in the colorectum, they are not cancer. However, if left alone for a long time, they can become malignant **tumors**.



Looking under a microscope doctors can classify tumors from 1 to 4 depending on how advanced they are.



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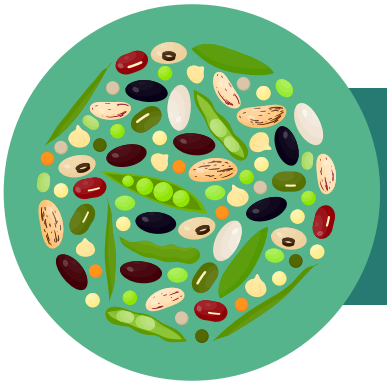
Healthy diet to reduce the risk of colorectal cancer

Fruits & Vegetables

5 servings of fruits and non-starchy vegetables per day.



Whole Grains & Legumes

Add whole grains & legumes to your diet (beans, lentils, oats, barley, brown rice).

Fiber

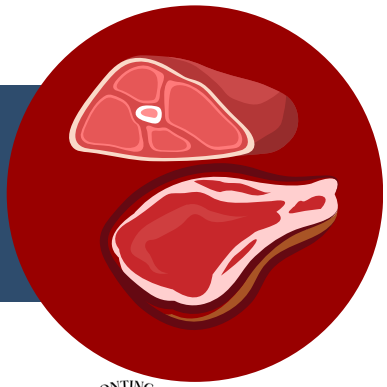
Consume at least 30 grams of fiber per day (fruits, vegetables, grains, cereals, legumes).

Avoid Processed Meats

Avoid processed meats like sausages, ham, bacon, hot dogs, salami & other deli meats.

Reduce Red Meat

Reduce consumption of red meat like beef, pork, lamb. Up to 3 small portions per week.



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Healthy Lifestyle to Reduce the Risk of Colorectal Cancer

At least 20 minutes of moderate physical activity per day

Walking

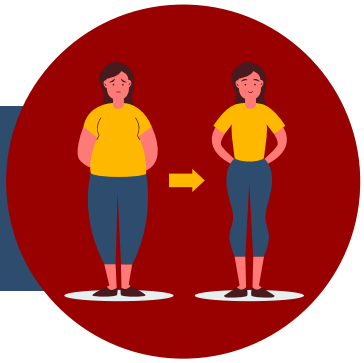
Playing a sport

Doing house chores

Gardening

Limit alcohol consumption (Beer, wine, liquor)

Keep or seek a healthy weight throughout your life.



Get screened for colorectal cancer starting at age 45.

Avoid tobacco products such as cigarettes and electric cigarettes.

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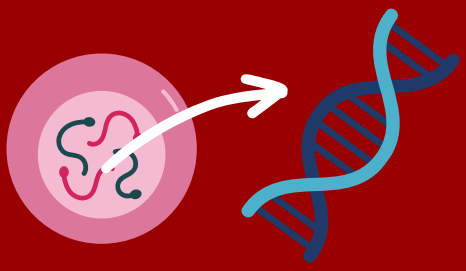
Genetic Inheritance

Genetics is the study of how living things, including people receive traits from previous generations.

DNA

DNA is the molecule in our cells that carries our biological information.



GENE

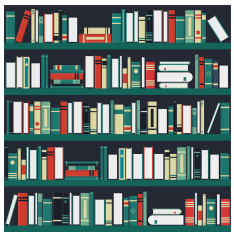
Genes are pieces of the DNA that hold instructions for how the body works.

CHROMOSOMES

DNA in the cells is organized into **chromosomes.** Each chromosome is made up of many different genes.

Genes are Like a Recipe

Genes contain the instructions to keep our body working, just like a recipe has the instructions on how to make a dish.



Chromosomes are Like a Recipe Book

Chromosomes are made up of many genes. The same way that recipes are organized into a recipe book. All the chromosomes together in a cell make up our DNA (genetic) library.

Mutations

- Mutations are mistakes that happen in our DNA.
- Similar to what happens with mistakes in a cooking recipe, some errors may be more serious than others!

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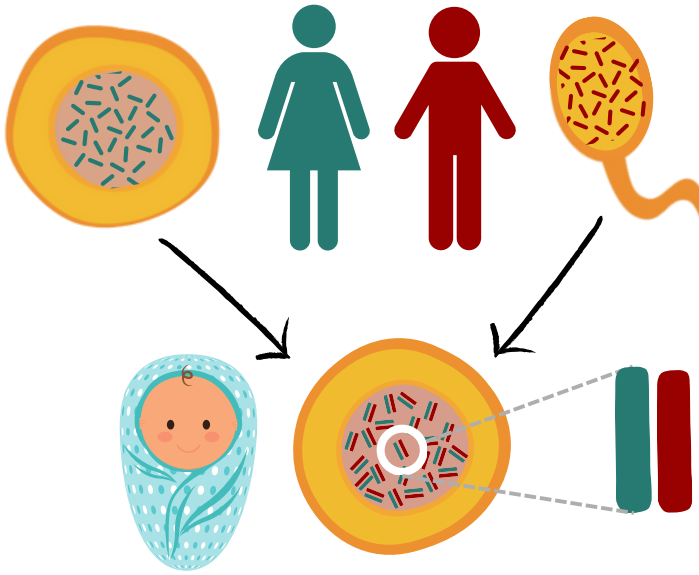
Genetic Inheritance

Heredity or genetic inheritance is the passing of characteristics from parent to child.

Half of our chromosomes come from our father and half from our mother. Together they make 23 pairs of chromosomes.

Egg
Female sex cell with 23 chromosomes.



Sperm
Male sex cell with 23 chromosomes.

Baby with all cells having 46 chromosomes in 23 pairs: One from mom, one from dad.

Mutations

- Mutations are mistakes in our DNA.
- They can happen in any cell of the body, including our sex cells, like sperm or egg.
- Only mutations that occur in our sex cells can be passed to our children.

When cells divide, mutations can be passed to new cells.

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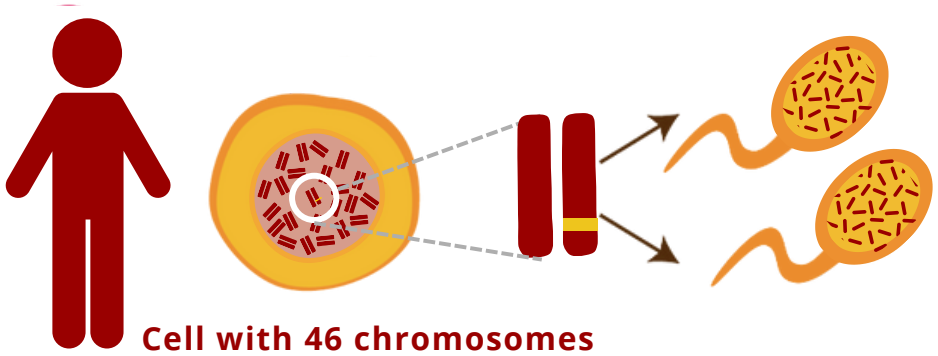
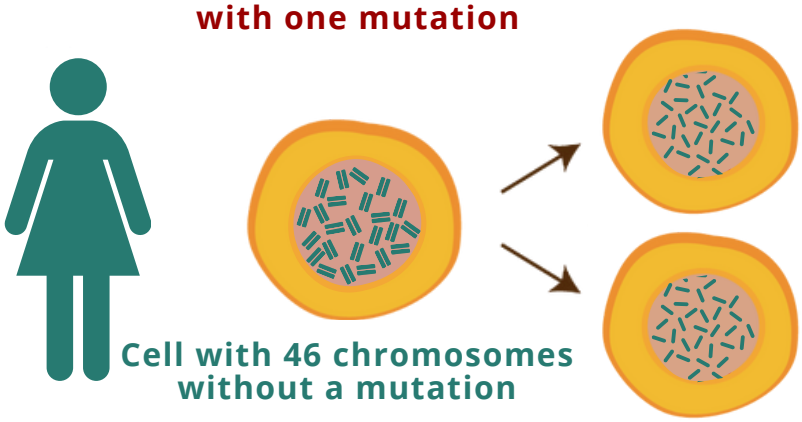
Mutation Inheritance

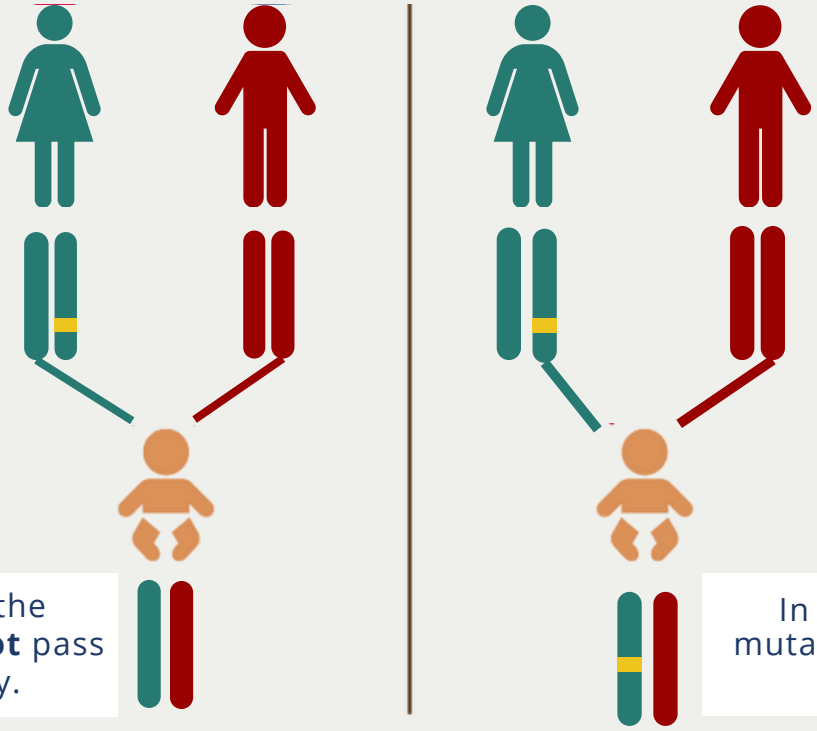
Mutations are not always passed to the next generation



Cell with 46 chromosomes with one mutation



Cell with 46 chromosomes without a mutation



In this case the mutation did **not** pass to the baby.

In this case the mutation did pass to the baby.

Blood relatives like siblings, parents, children, uncles, aunts and cousins, of a person with a mutation in a cancer risk gene might share the same gene mutation.

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Inherited Colorectal Cancer

Up to 1 out of 10 people develop colorectal cancer because of inherited mutations.

Majority of colorectal cancer is sporadic

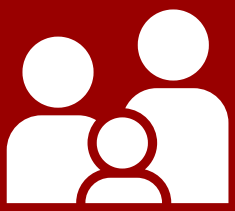
Majority of colorectal cancer happens without a family history or inherited mutation. Inherited cancers are rare.

Why is knowing if a cancer is inherited important?

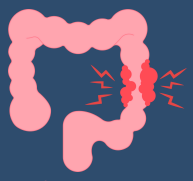
- Can help with choices about cancer treatments.
- May help prevent cancer in family members.

When can inherited colorectal cancer occur?

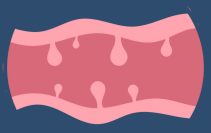
- Usually happens at younger ages.
- In families, including distant relatives like cousins, with other related cancers.
- When someone has 20 or more polyps, benign growths in the colon or rectum.



Hereditary Colorectal Cancer Syndromes



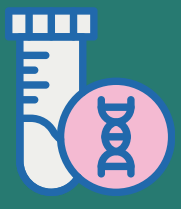
Lynch syndrome
Hereditary colorectal cancer that occurs without polyps.



Familial adenomatous polyposis syndrome
Hereditary colorectal cancer that occurs with many polyps.

How do Genetic Tests Help?

A genetic test can help understand if an inherited mutation was part of why the cancer developed.



Individuals with hereditary colorectal cancer more likely to develop more than one type of cancer, and so do their family members.

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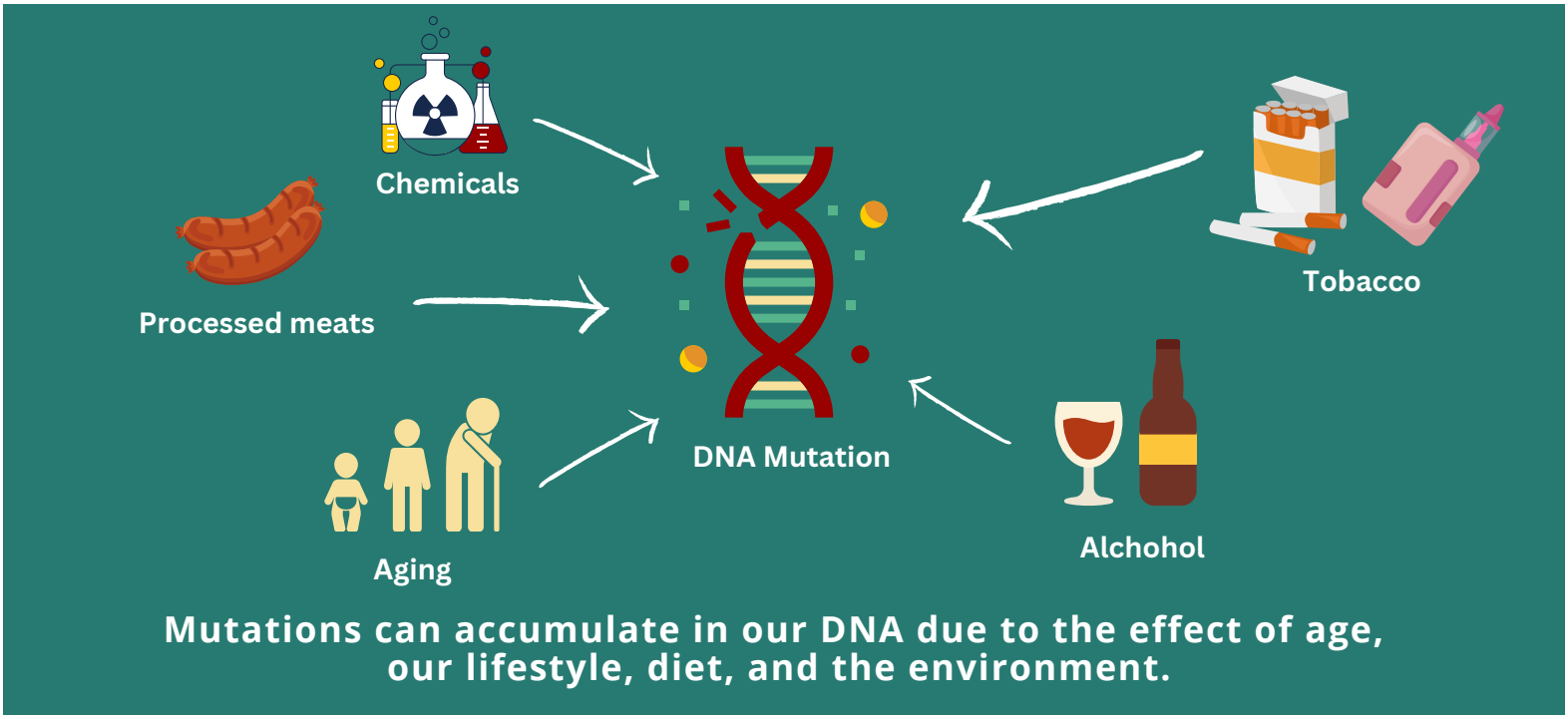
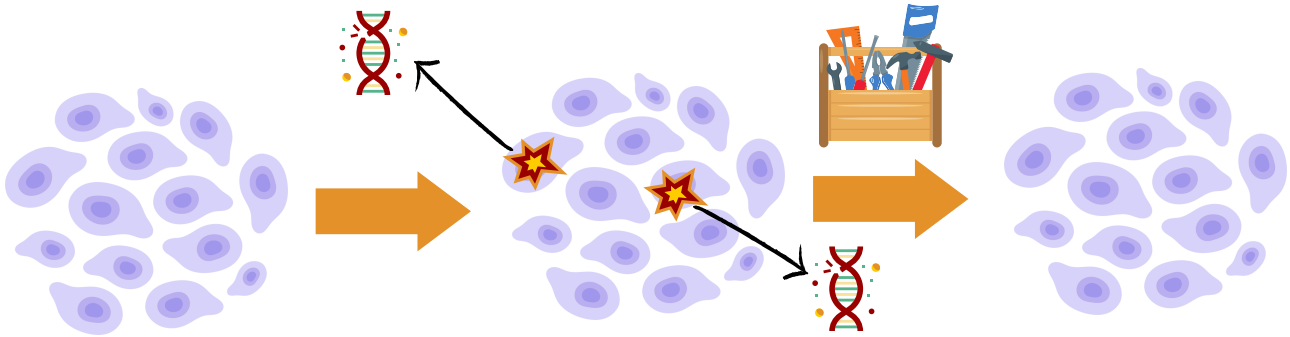
Tumor Mutations

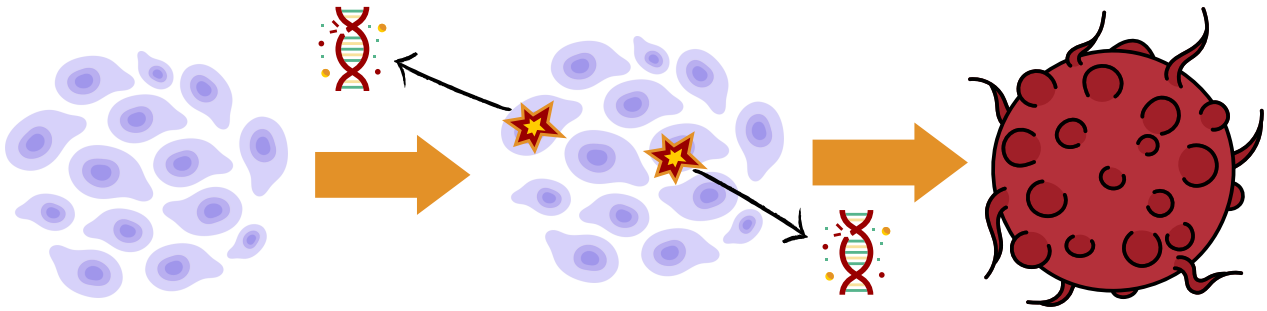
In addition to any mutations we may inherit from our parents, our cells also accumulate mutations through our life



Mutations can accumulate in our DNA due to the effect of age, our lifestyle, diet, and the environment.



Our cells have tools to fix errors and mutations in our DNA



Sometimes these tools fail and mutations accumulate. Over time if specific types of mutations accumulate, a tumor can develop.

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Genetic Tests for Inherited Cancer

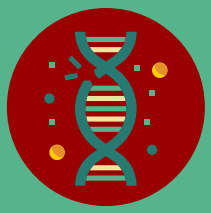
We can learn about mutations we carry in our blood, passed from our parents by doing genetic tests

DNA ANALYSIS

BLOOD OR SALIVA SAMPLE

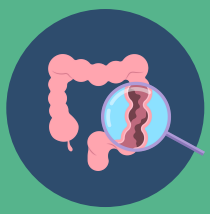
GENETIC TEST REPORT

Why are genetic tests for inherited cancers important?



They identify inherited mutations. Usually multiple genes are tested.

Those who have certain mutations may have a higher chance of developing cancer.



This knowledge can help take preventative steps, such as surgery or screening to reduce the chance of cancer.

What are the different types of blood test results?

Positive: A mutation was identified. It may explain why a person developed cancer and help understand if there is a risk for another cancer in the future.

Negative: No mutation was found. This means no inherited explanation for a cancer was identified. However, depending on the family history it may still be recommended to see a genetic counselor.

Variant of uncertain significance: A genetic difference has been identified that may or may not affect the gene. Most of these variants are normal differences among people. This result should not be used to direct medical management.

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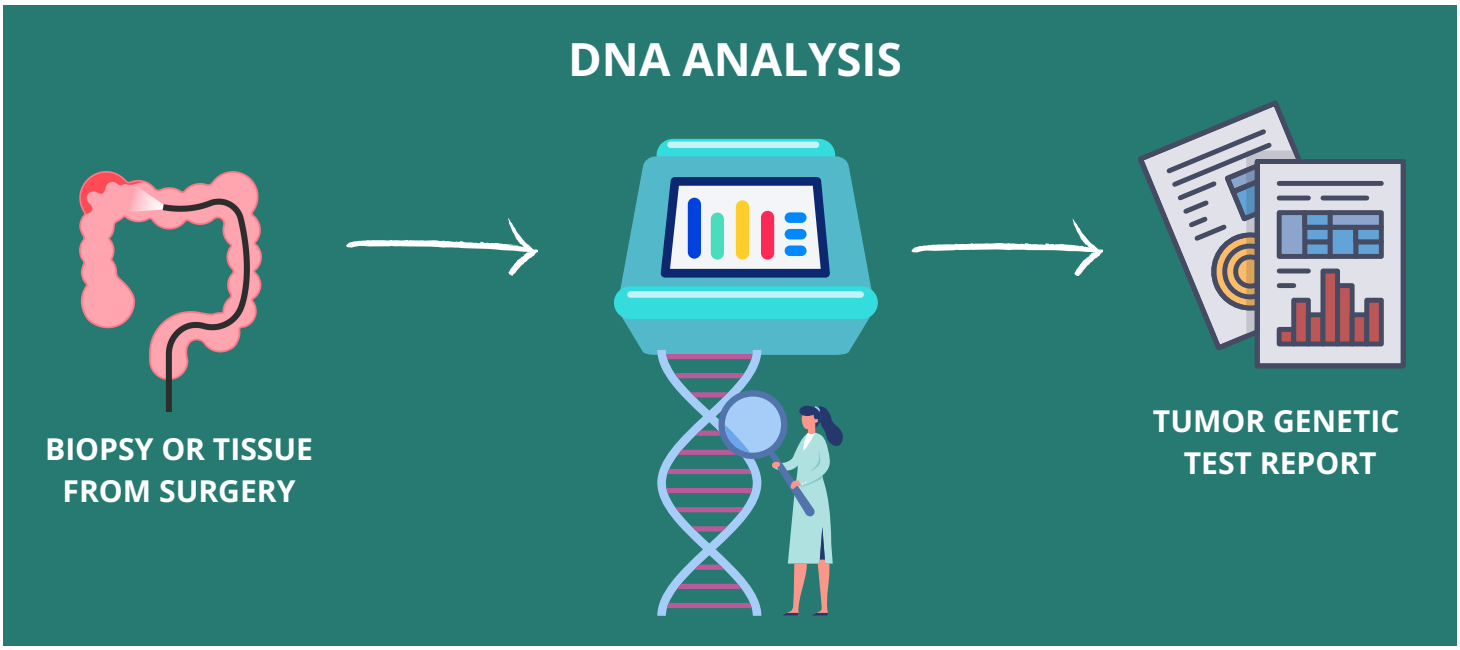
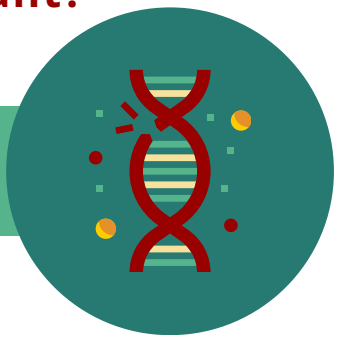
Tumor Mutation Genetic Testing

We can learn about mutations in a tumor by doing genetic tests in our DNA.



Why are tumor genetic tests important?

Genetic tests done in a tumor provide information about mutations present in tumor cells.



Some cancer medications work better when certain mutations are present.

Cancer doctors can use this information to decide what is the best treatment for that tumor.

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Cancer Genetic Risk

How do we know if there is risk of cancer in our family?

We can start by collecting information about who in our family has or had cancer, what type of cancer, and at what age they were diagnosed

When should I talk to a Genetic Counselor?

If you or any of your family members have had any of the following :

- Breast, colorectal, or uterine cancer at age 50 or younger
- Pancreatic or ovarian cancer at any age
- Male breast cancer at any age
- Two separate cancer diagnoses
- A type of breast cancer called “triple-negative breast cancer” at any age
- Prostate cancer at age 55 or younger or metastatic prostate cancer
- Tumor testing that shows a mutation in a gene associated with hereditary cancer.
- Eastern European Jewish ancestry and breast, ovarian or pancreatic cancer at any age.

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Genetic Counseling

Genetic Counselors

Genetic counselors are Healthcare professionals who specialize in genetics.

They can help you figure out if you and your family may have high risk for cancer and recommend you for genetic testing

What happens during a genetic counseling session?

The counselor helps review the family history to determine if there is high risk for cancer

The counselor provides education about genetics and cancer risk

If recommended, the counselor will help consent for genetic testing

The counselor will review results and explain options for follow-up to reduce personal risk as well as risk of family members

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Where Can You Find Genetic Counselors?

- Genetic counselors are available at many healthcare centers
- A primary care doctor may refer you due to personal or family history
- You can inquire about a referral from your primary care provider if you are concerned

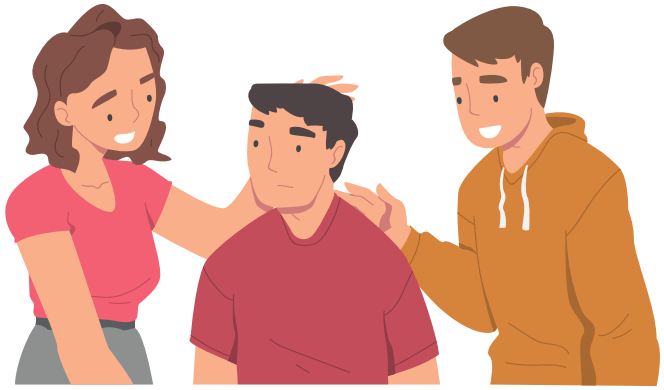
Here are some places to find genetic counselors		
National Society of Genetic Counselors	https://findageneticcounselor.nsgc.org/	(312) 321-6834
Virtual Genetic Counseling		
Informed DNA	https://informeddna.com/	(800) 975-4819
Genome Medical	https://www.genomemedical.com/	(877) 688-0992
Grey Genetics	https://www.greygenetics.com/	(516) 900-4363
Genetic Labs with Financial Assistance or Accepts Cash Payments		
Invitae Genetic Testing	https://www.invitae.com	(800) 436-3037
Ambry Genetics	https://www.ambrygen.com/	(949) 900-5500
Myriad	https://myriad.com/	(801) 584-3600
Integrated Genetics	https://www.labcorp.com/	(877) 821-7266
Quest Diagnostics	https://www.questdiagnostics.com/	(866) 697-8378
Color Health	https://www.color.com/	(844) 362-6567
Gene Dx	https://www.genedx.com/	(888) 729-1206

You can find resources for genetic testing and high risk cancers visiting this link
www.usccopecc.org/resources

Supporting Cancer Patients

HOW TO SUPPORT SOMEONE WITH COLORECTAL CANCER?

- Encourage them to talk about their feelings.
- Be positive, but don't be unrealistic
- Help connect them with resources
- Help them find a support group
- Take care of yourself so that you can take care of them.



For Resources on Colorectal Cancer and Cancer Genetics in English and Spanish visit our website or scan our QR code

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Navigating Healthcare

HOW TO GET THE HELP YOU NEED IF YOU OR A LOVED ONE ARE DIAGNOSED WITH CANCER

Understand your Insurance

Where can you seek care? What is your deductible?
If you don't have any talk to a social worker you may qualify for special plans.

Find a Colorectal Cancer Specialist

Check your insurance's website or ask your primary doctor for a recommendation.

Check with your insurance about pre-authorizations for treatment

If unclear, talk to a social worker at the clinic or hospital.

File Claims for your Payments

keep copies of all papers and bills, talk to the insurance if you have questions

If a Claim is Denied you can Appeal the Decision

Talk to the insurance company to find out the steps

Connect to Resources Available to you

this may include free transportation, insurance plans, help filing for disability

Contact Us

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Center for Optimizing Engagement
of Hispanic Colorectal Cancer
Patients in Cancer Genomic
Characterization Studies

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