Interpreting for Cancer Genetics

Cynthia E. Roat, MPH

National Consultant on Language Access in Health Care

Galen Joseph, PhD

Professor, University of California, San Francisco

Mari Gilmore, CGC

Licensed Certified Genetic Counselor

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Developed 2024, revised 2024

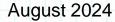
What is genetic counseling?

"Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease."

The National Society of Genetic Counselors www.nsgc.org

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What do genetic counselors do?





Assess Risk

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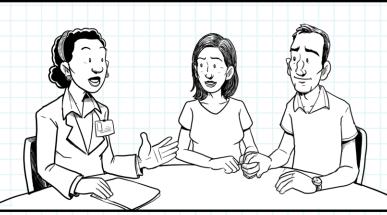
Educate



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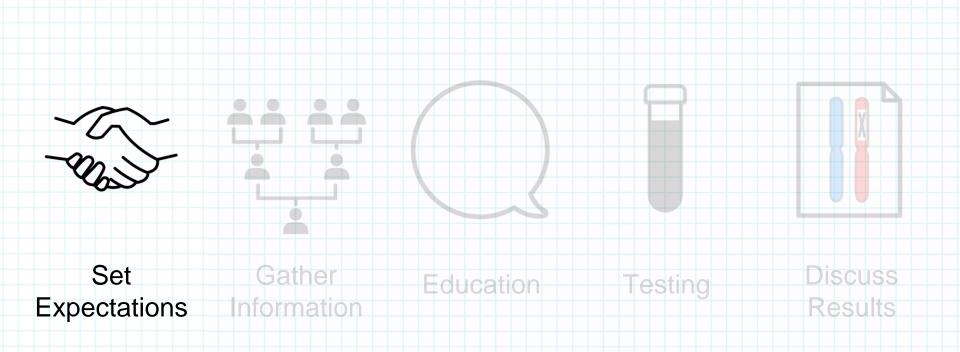


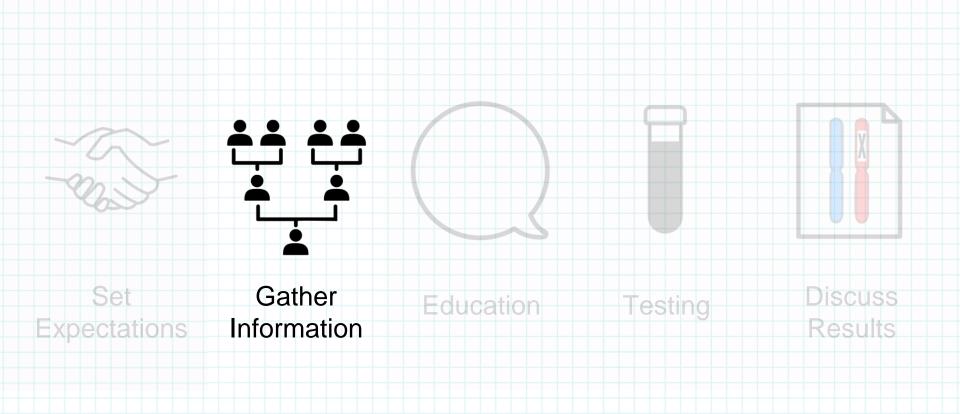
Support

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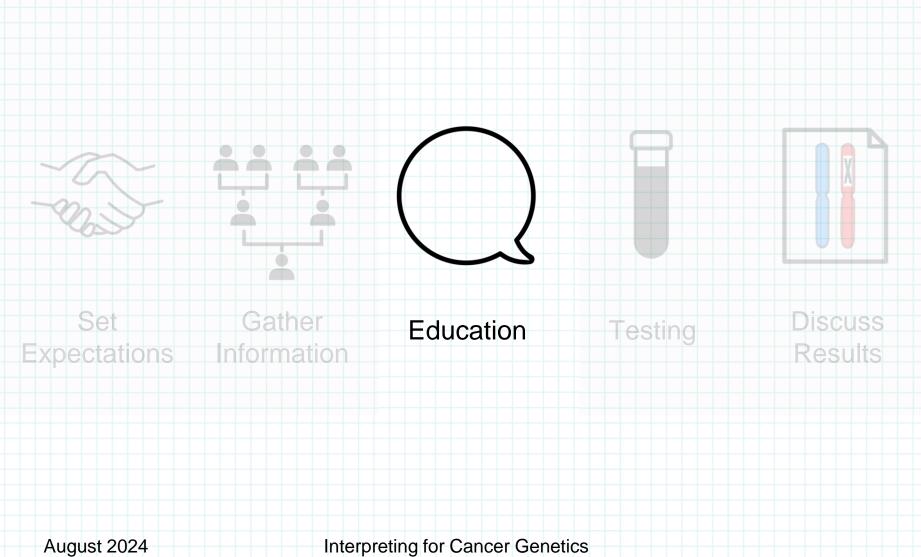
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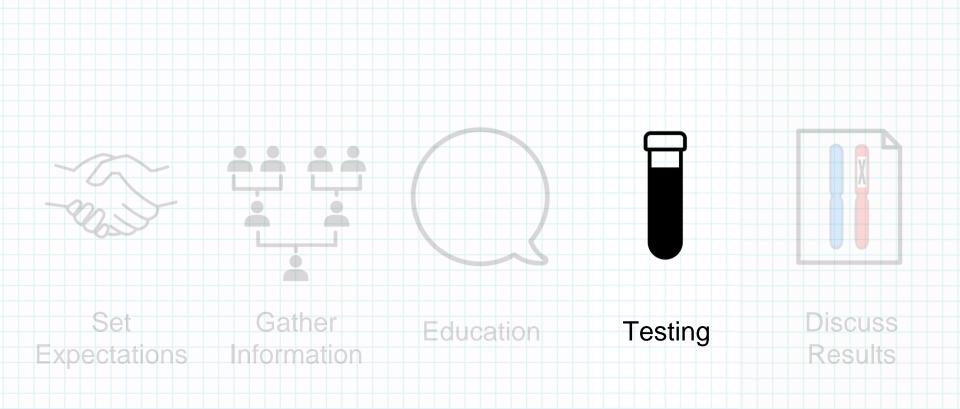
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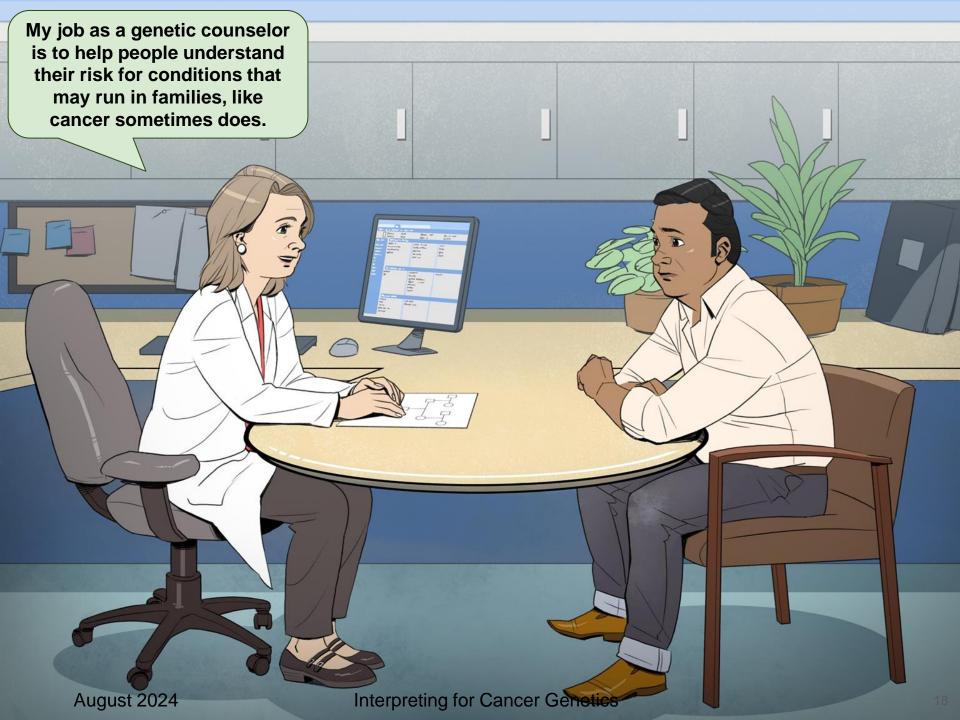
Poll!

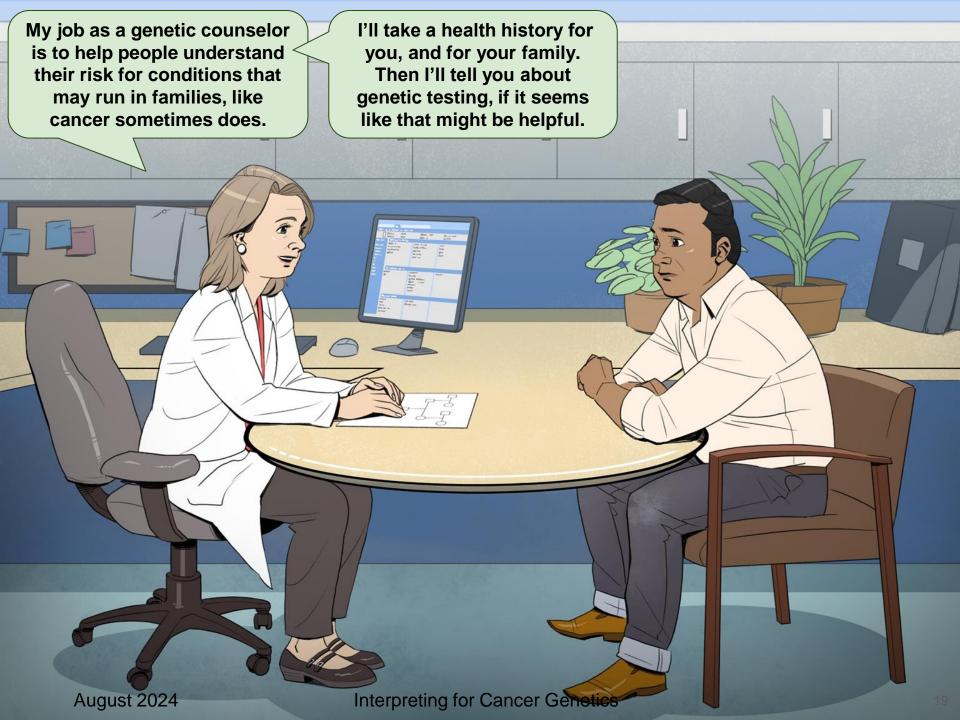












My job as a genetic counselor is to help people understand < their risk for conditions that may run in families, like cancer sometimes does.

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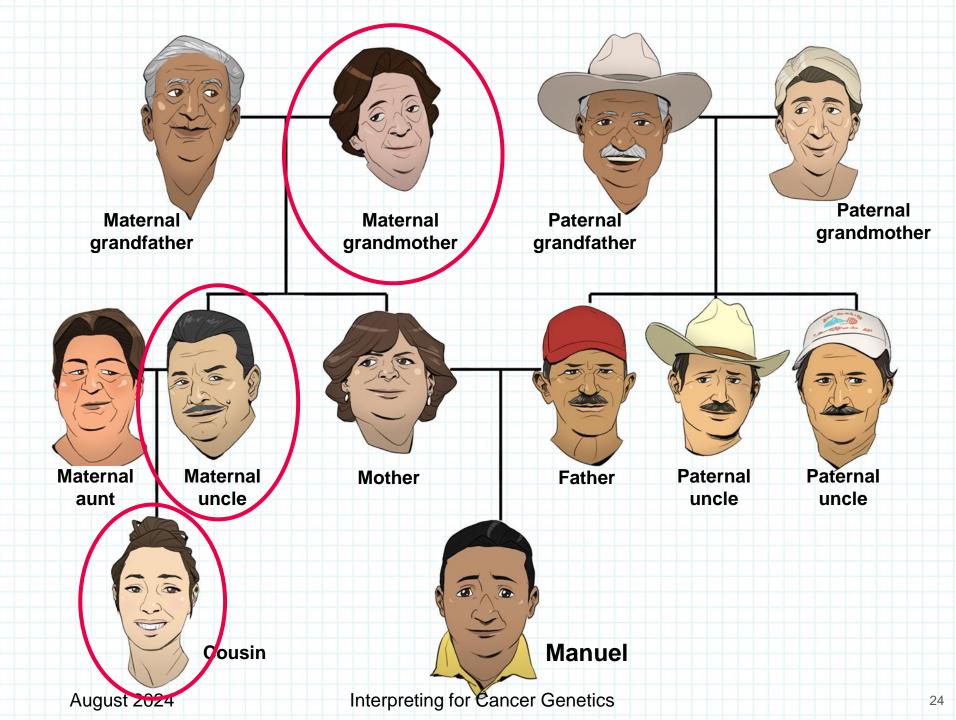
I'll take a health history for you, and for your family. Then I'll tell you about genetic testing, if it seems like that might be helpful.

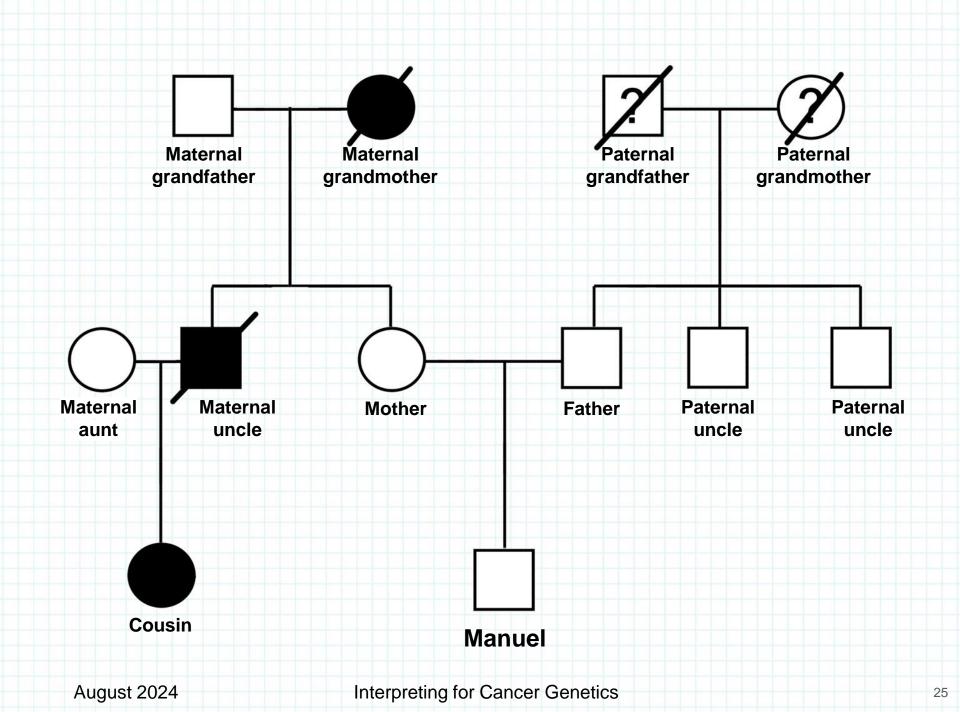
And if you DO decide to get tested, I'll be here afterward to explain the results and to help you decide what to do next.







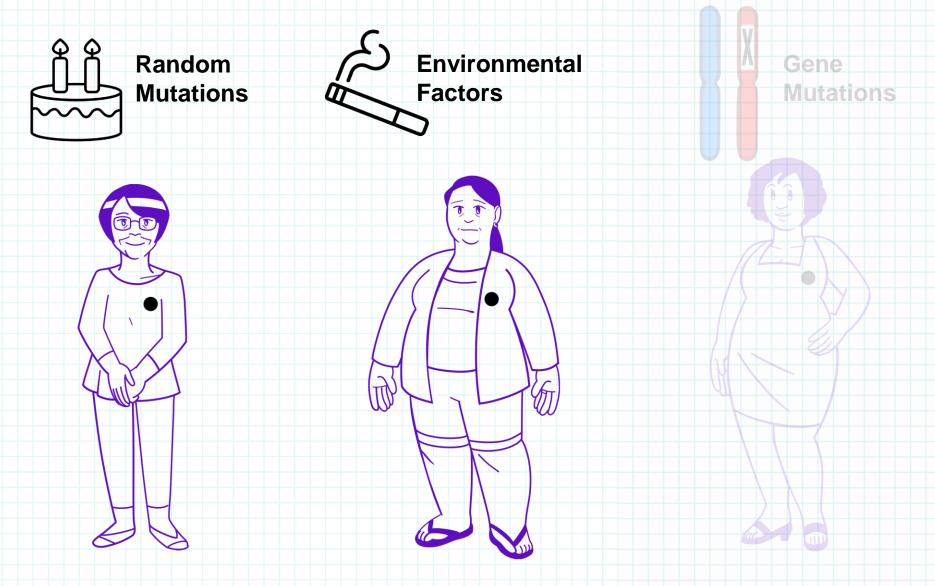




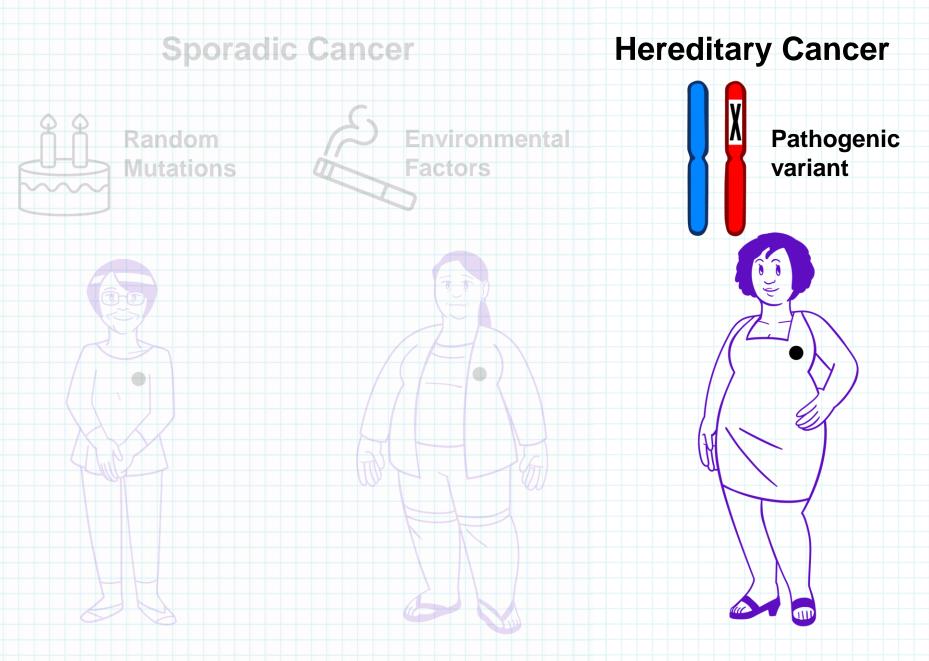


Sporadic Cancer

Hereditary Cancer

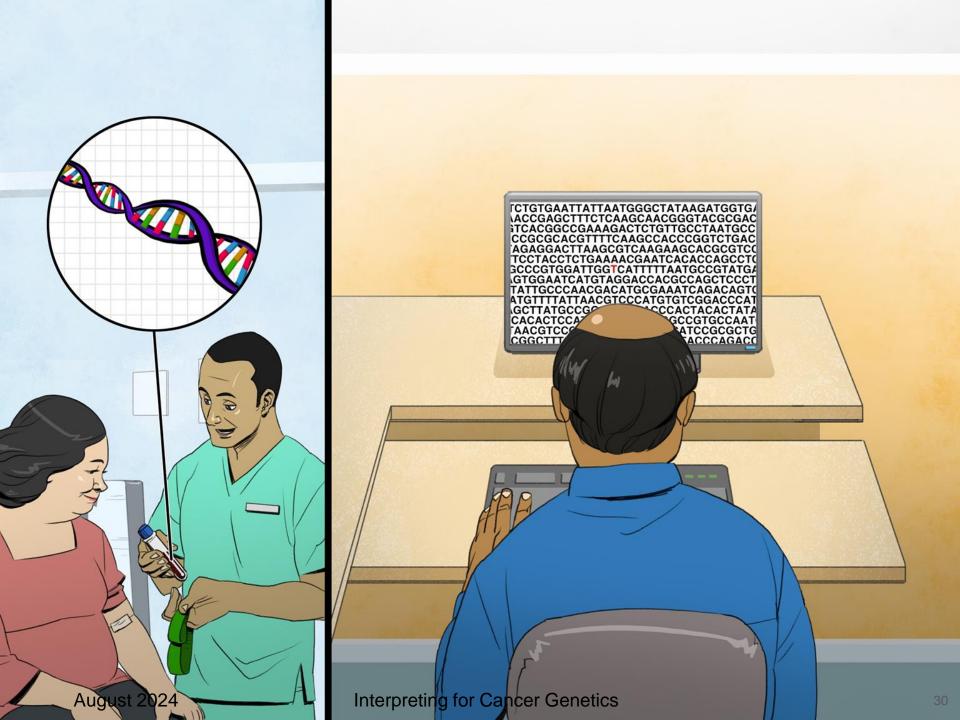


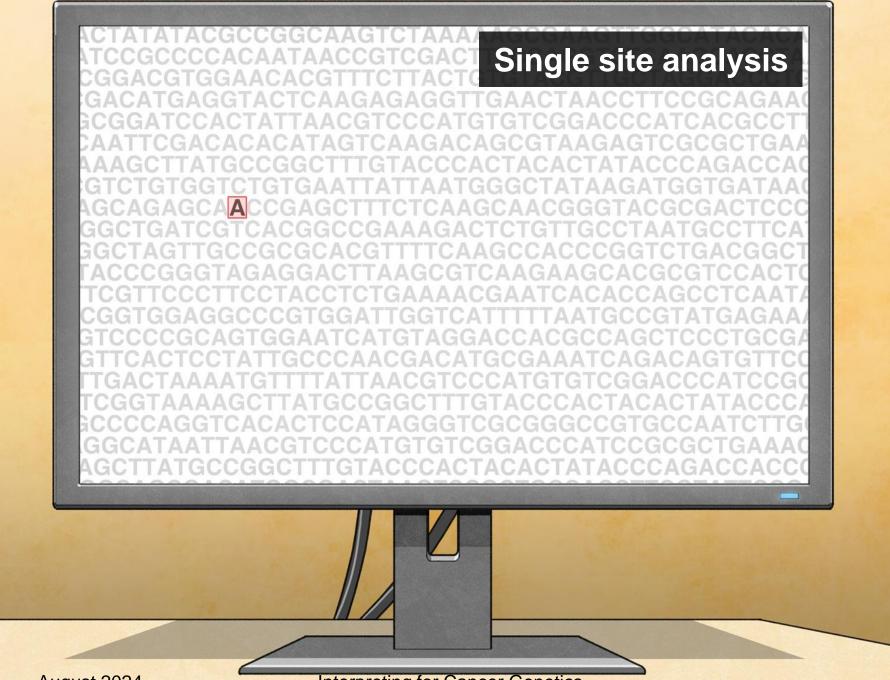
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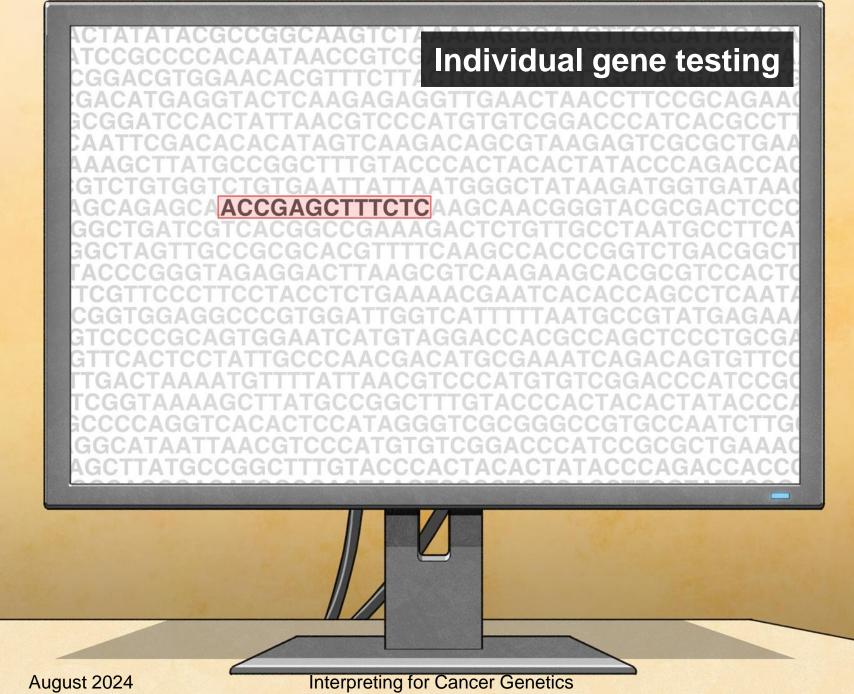


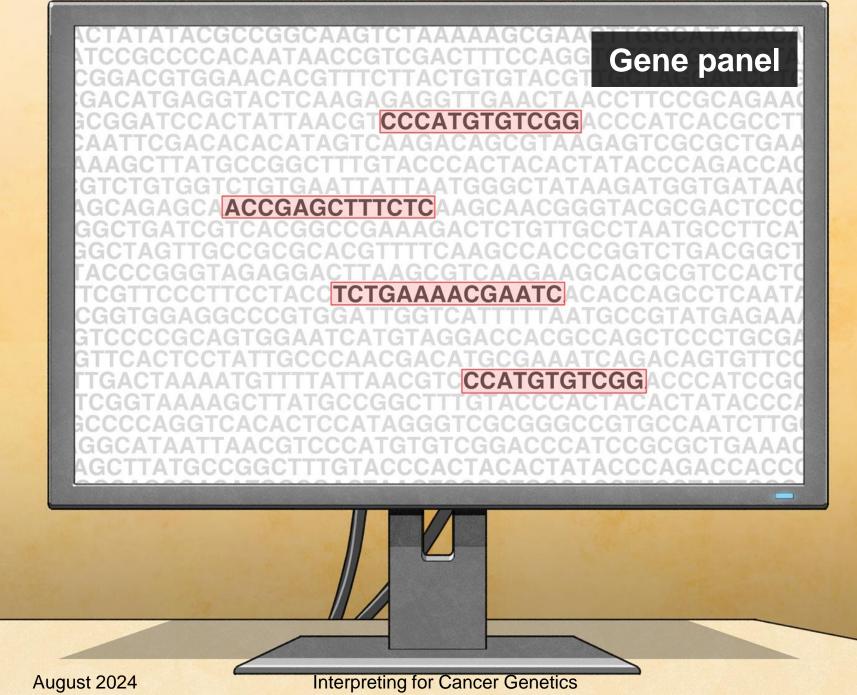


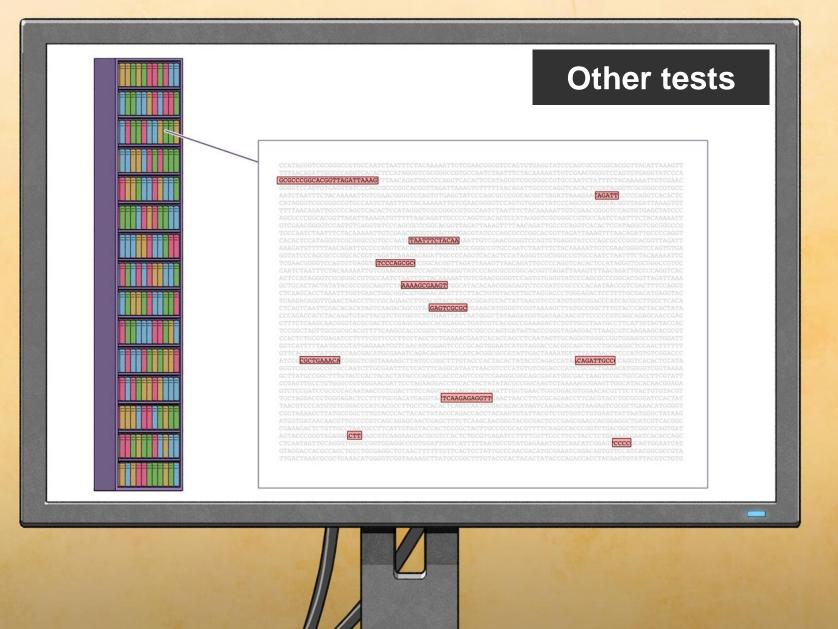


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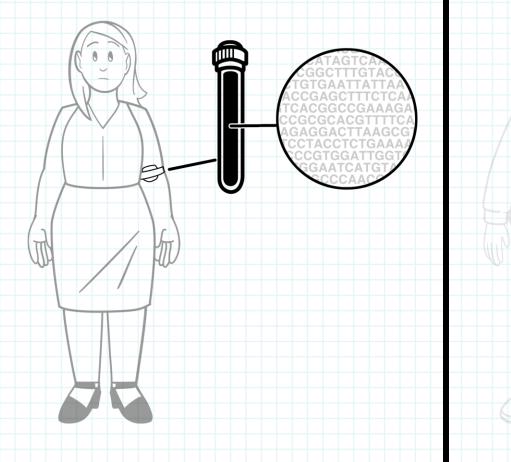




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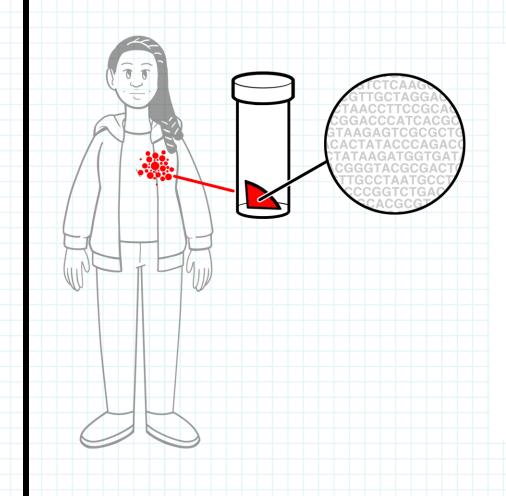
Germline Testing

Tumor Testing



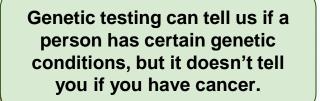
Germline Testing

Tumor Testing



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Genetic testing can tell us if a person has certain genetic conditions, but it doesn't tell you if you have cancer.

> It tells you if you have a gene that makes it more likely for you to get certain cancers in the future.

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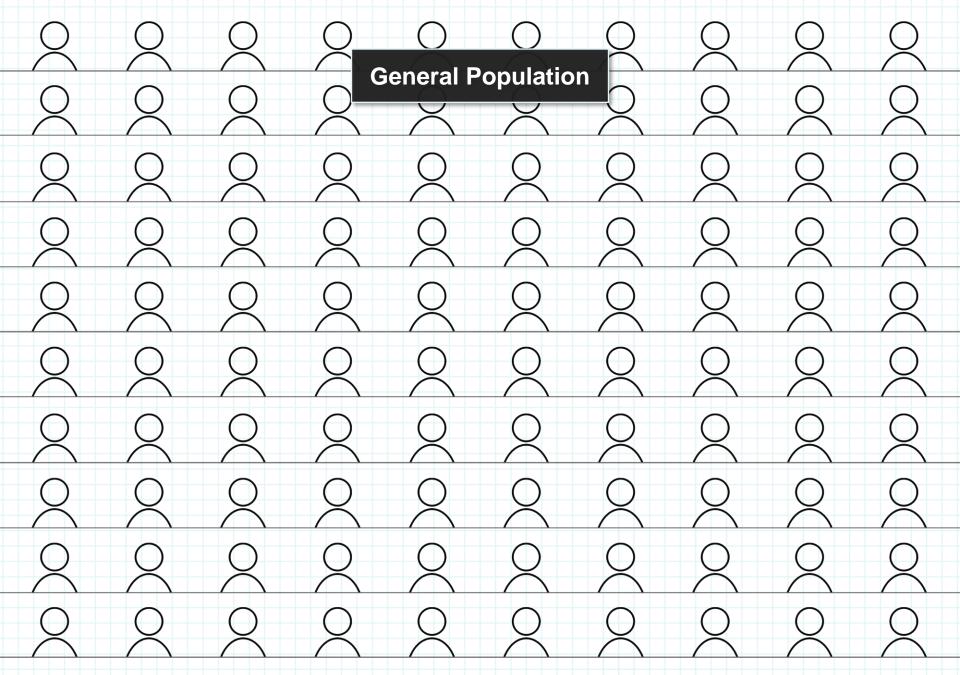
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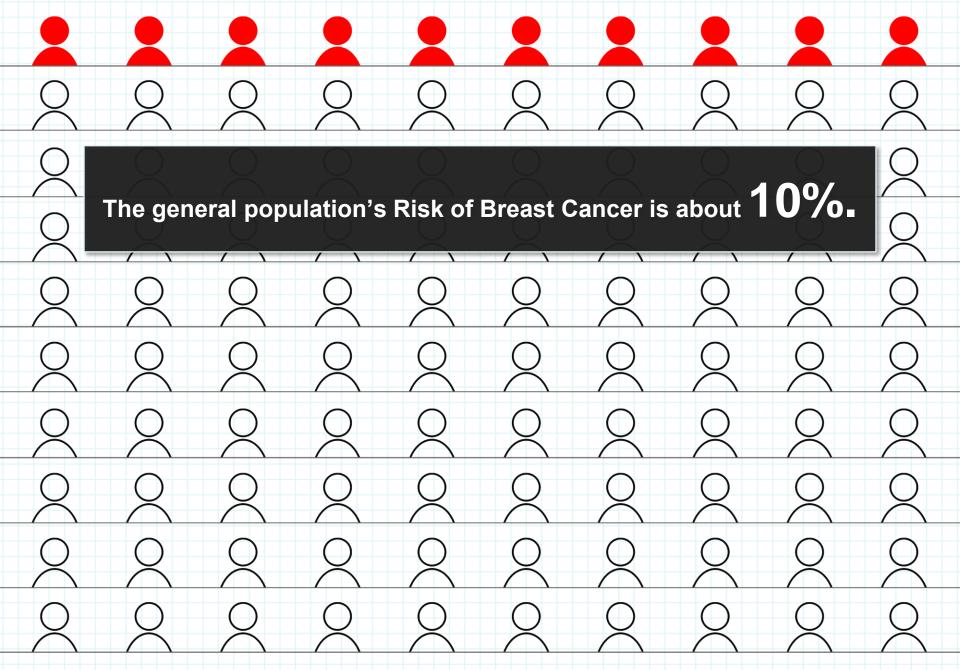
But even then, we can't know if you would develop the disease or condition for sure.

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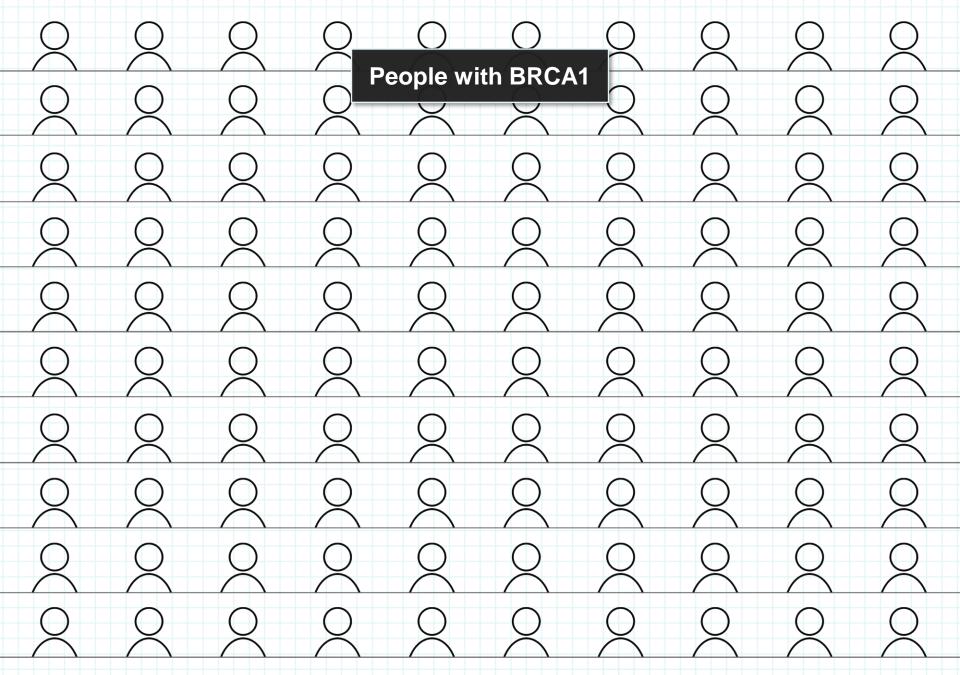
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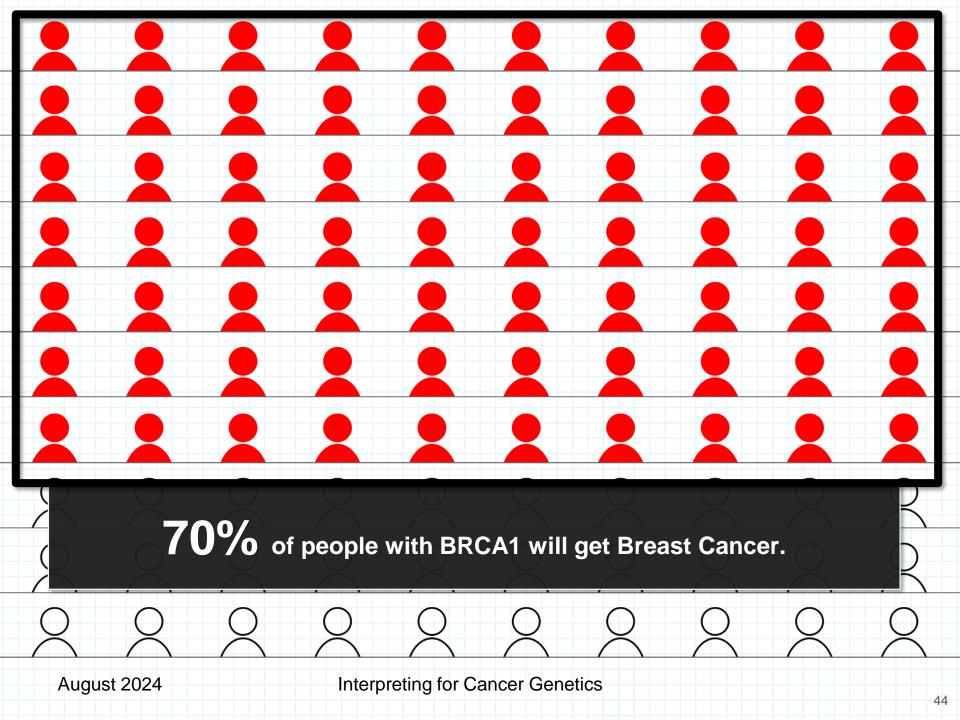
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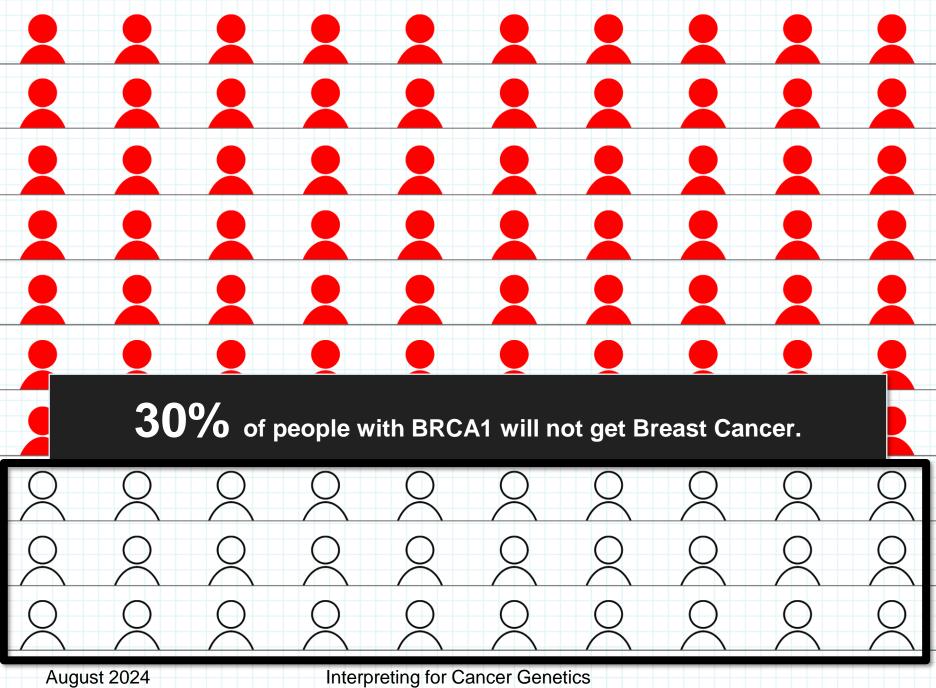


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Poll!



This test just tells me if I have a higher risk than everyone else of getting cancer, right?

But so what? If I'm going to get cancer, there's nothing I can do about it, right?

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This test just tells me if I have a higher risk than everyone else of getting cancer, right?

100

But so what? If I'm going to get cancer, there's nothing I can do about it, right?

> So why bother getting tested? What does it matter?

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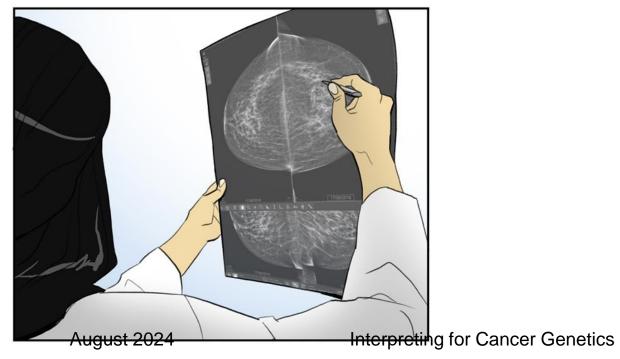
"It actually does matter..."

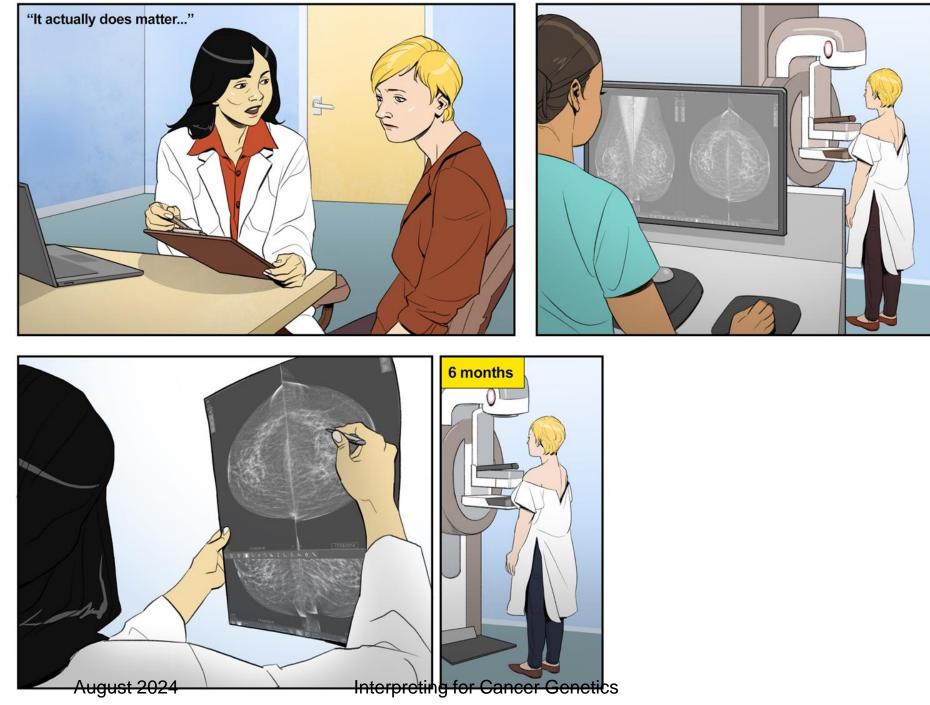


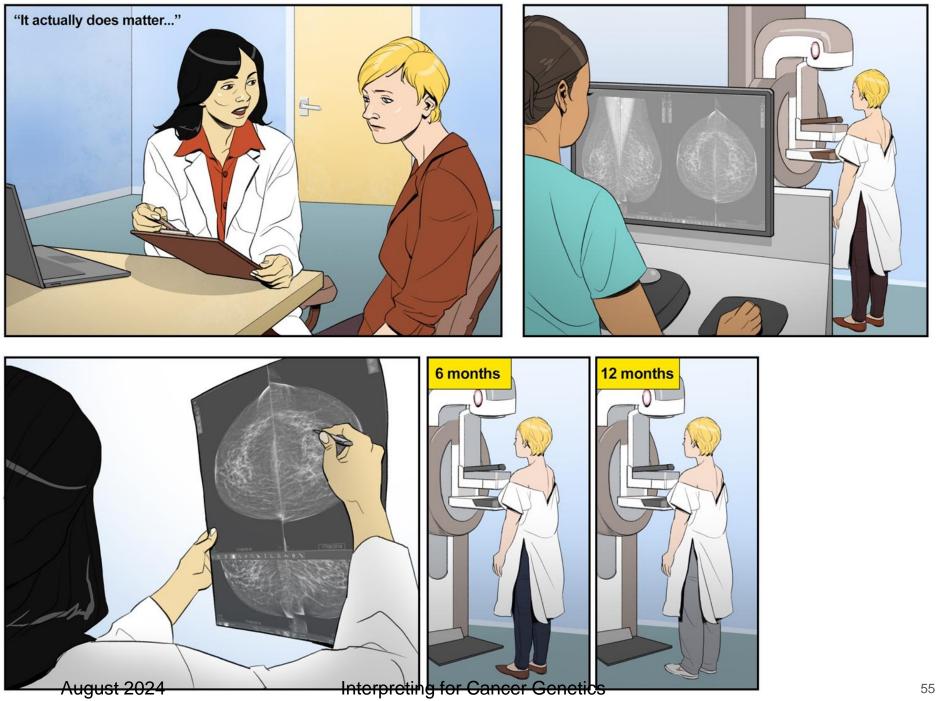


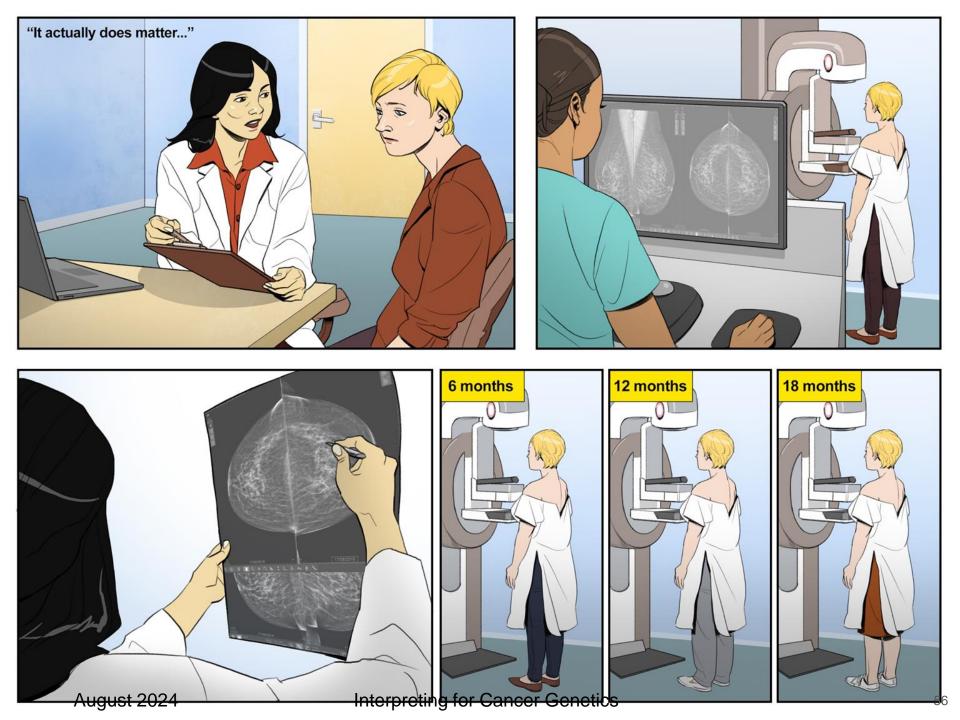












And what if it turns out that I DO have this genetic mutation? It will just make me worry.

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> And if my family finds out I have a genetic mutation, what will they think of me?

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Or what if they terminate my health insurance because they know I'm going to get cancer? And if my family finds out I have a genetic mutation, what will they think of me?

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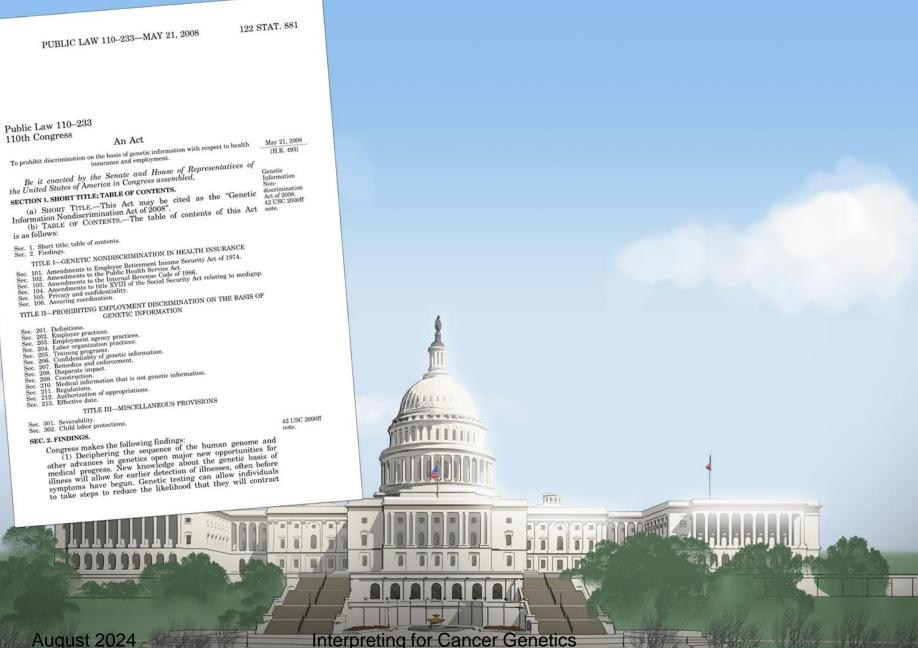
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If they find out at work, could I get fired?

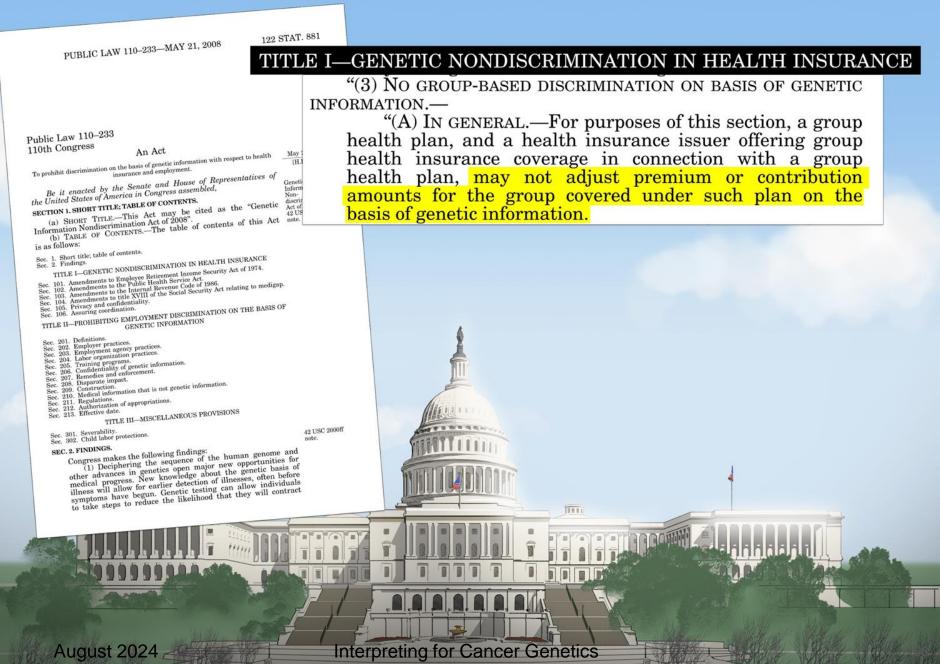




GINA: the Genetic Information Nondiscrimination Act of 2008



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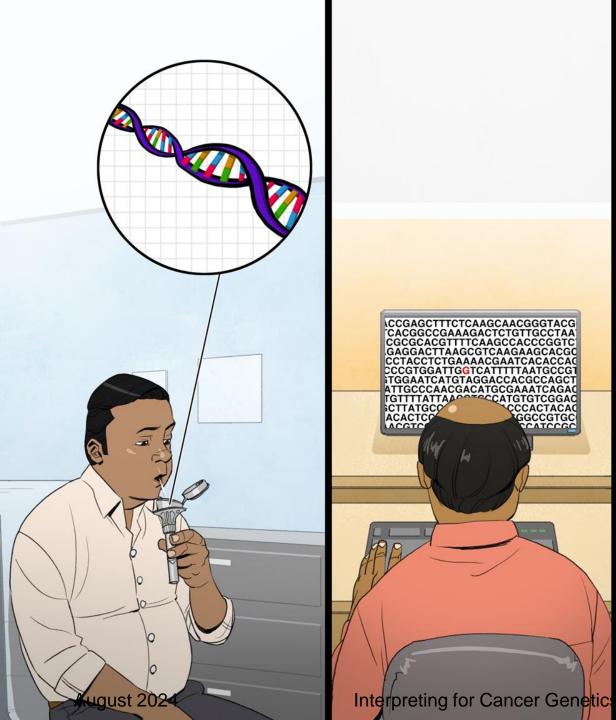
122 STAT. 881 PUBLIC LAW 110-233-MAY 21, 2008 TITLE I—GENETIC NONDISCRIMINATION IN HEALTH INSURANCE "(3) NO GROUP-BASED DISCRIMINATION ON BASIS OF GENETIC INFORMATION.- $\ensuremath{``}(A)$ IN GENERAL.—For purposes of this section, a group health plan, and a health insurance issuer offering group Public Law 110-233 110th Congress An Act To prohibit discrimination on the basis of genetic information with respect to health health insurance coverage in connection with a group May [H.] health plan, may not adjust premium or contribution Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, Genet amounts for the group covered under such plan on the basis of genetic information. Inform Non-SECTION 1. SHORT TITLE; TABLE OF CONTENTS. (a) SHORT TITLE-This Act may be cited as the "Genetic discri Information Nondiscrimination Act of 2008". (b) TABLE OF CONTENTS.—The table of contents of this Act Act o 42 U is as follows: Sec. 1. Short title; table of contents. Sec. 2. Findings. TITLE I-GENETIC NONDISCRIMINATION IN HEALTH INSURANCE Amendments to Employee Retirement Income Security Act of 1974.
Amendments to the Publical Revenue Code of 1986.
Amendments to the Willion Revenue Code of 1986.
Amendments to title XVIII of the Social Security Act relating to medigap.
Privace and emfloardinality. TITLE II—PROHIBITING EMPLOYMENT DISCRIMINATION Sec. Privacy and confidentiality. TITLE II-PROHIBITING EMPLOYMENT DISCRIMINATION ON THE BASIS OF ON THE BASIS OF GENETIC INFORMATION Sec. 201. Definitions. Sec. 202. Employment agency practices. Sec. 203. Employment agency practices. Sec. 204. Labor organization practices. Sec. 205. Training programs. Sec. 206. Confidentiality of genetic info Sec. 206. Remedies and enforcement. Definitions. (a) DISCRIMINATION BASED ON GENETIC INFORMATION.—It shall Labor organization of the second secon be an unlawful employment practice for an employer— Sec. 208. Disparate impact. Sec. 209. Construction. Sec. 210. Medical information that is not genetic information. Sec. 211. Regulations. Sec. 212. Authorization of appropriations. (1) to fail or refuse to hire, or to discharge, any employee, or otherwise to discriminate against any employee with respect TITLE III-MISCELLANEOUS PROVISIONS Effective date. to the compensation, terms, conditions, or privileges of employ-Sec. 213. Sec. 301. Severability. Sec. 302. Child labor protections. ment of the employee, because of genetic information with 42 USC 2000ff Congress makes the following findings: (1) Deciphering the sequence of the human genome and respect to the employee; or SEC. 2. FINDINGS. other advances in genetics open major new opportunities for medical progress. New knowledge about the genetic basis of illness will allow for earlier detection of illnesses, often before symptoms have begun. Genetic testing can allow individuals to take steps to reduce the likelihood that they will contract

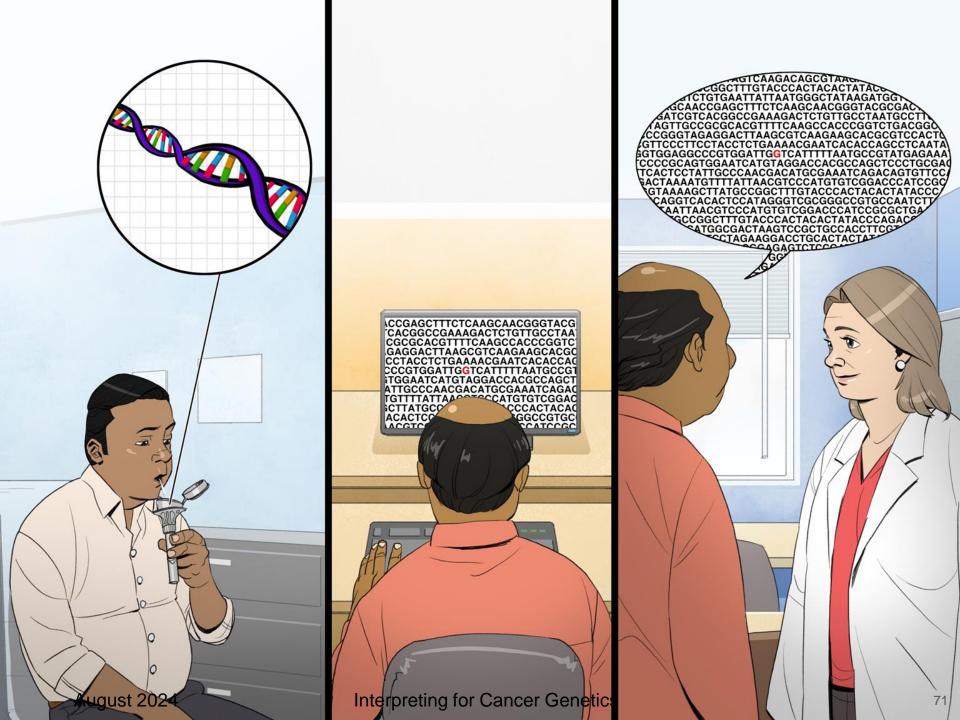
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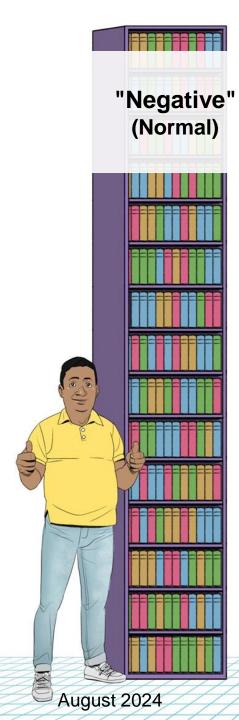
Quiz!

- What could be some of the benefits to genetic testing?
- Why might some people be wary of testing?
- What is GINA?





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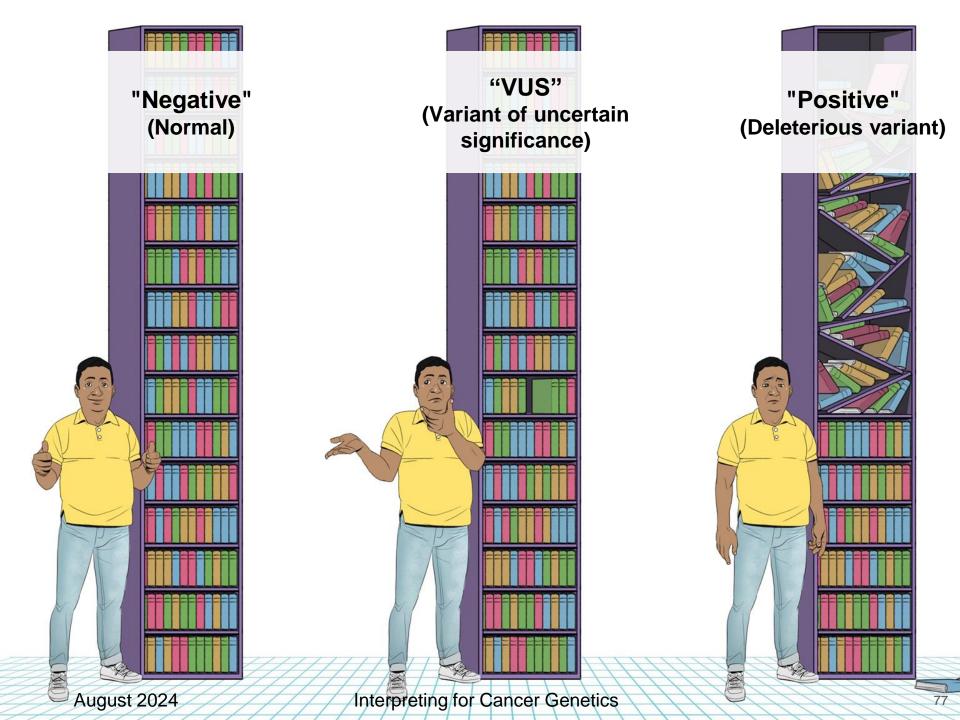


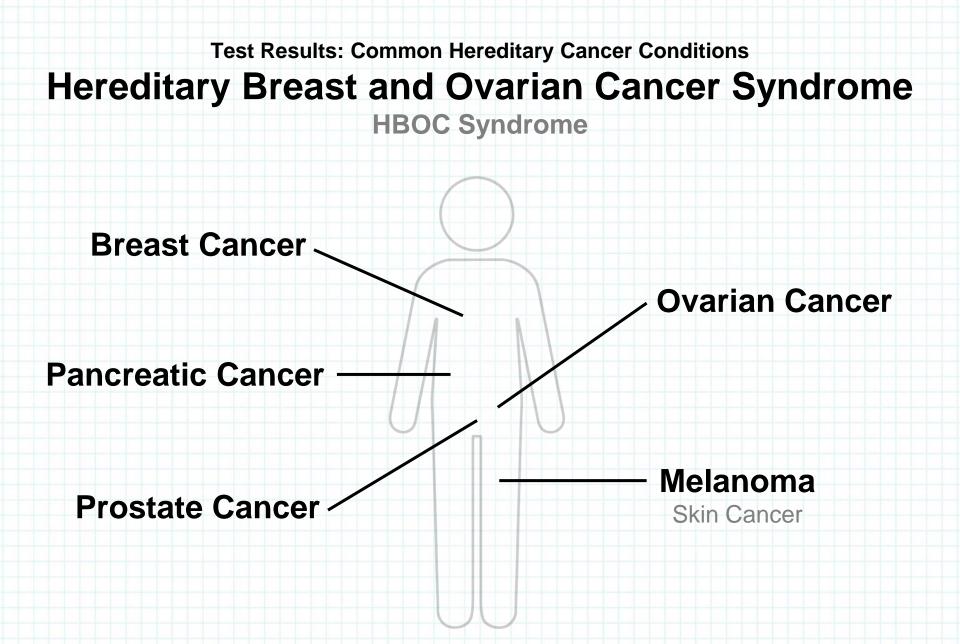
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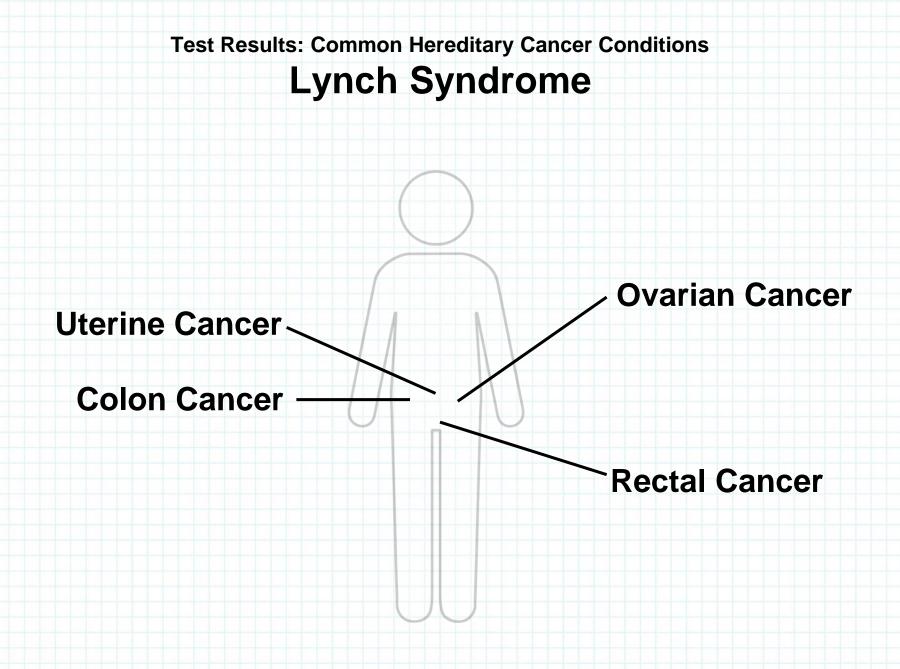
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"Positive"

(Pathogenic variant)







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Manuel, our test found that you do have an altered MLH1 gene.

> That means that you are at higher risk than the general population to get a number of cancers such as colorectal cancer, liver cancer, pancreatic cancer and others.

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That means that you are at higher risk than the general public to get a number of cancers such as colorectal cancer, liver cancer, pancreatic cancer and others.

This condition is called "Lynch Syndrome."

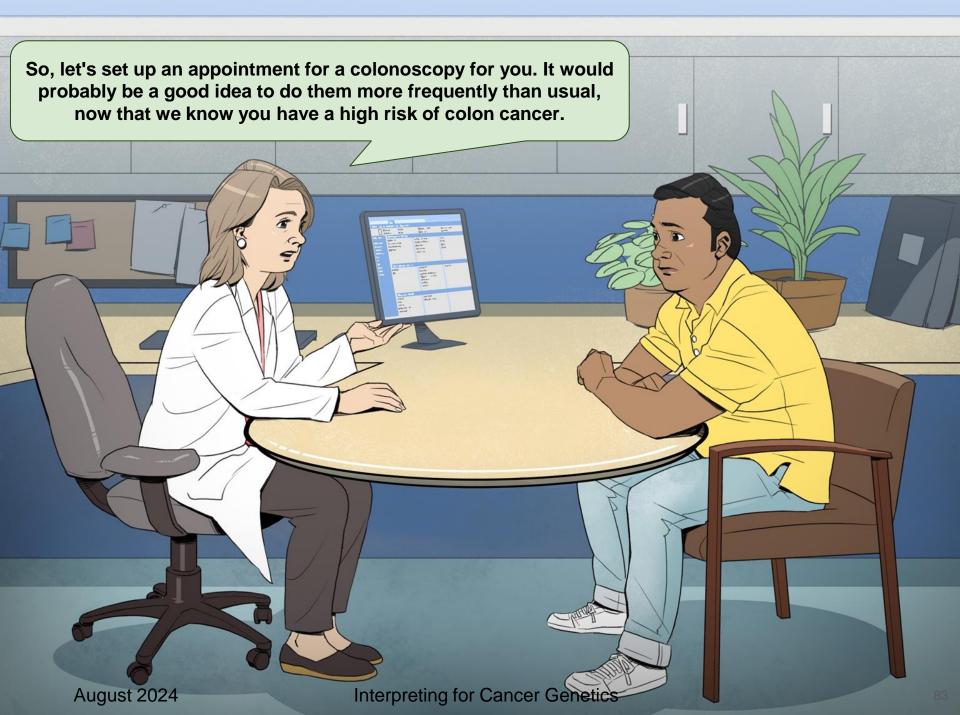
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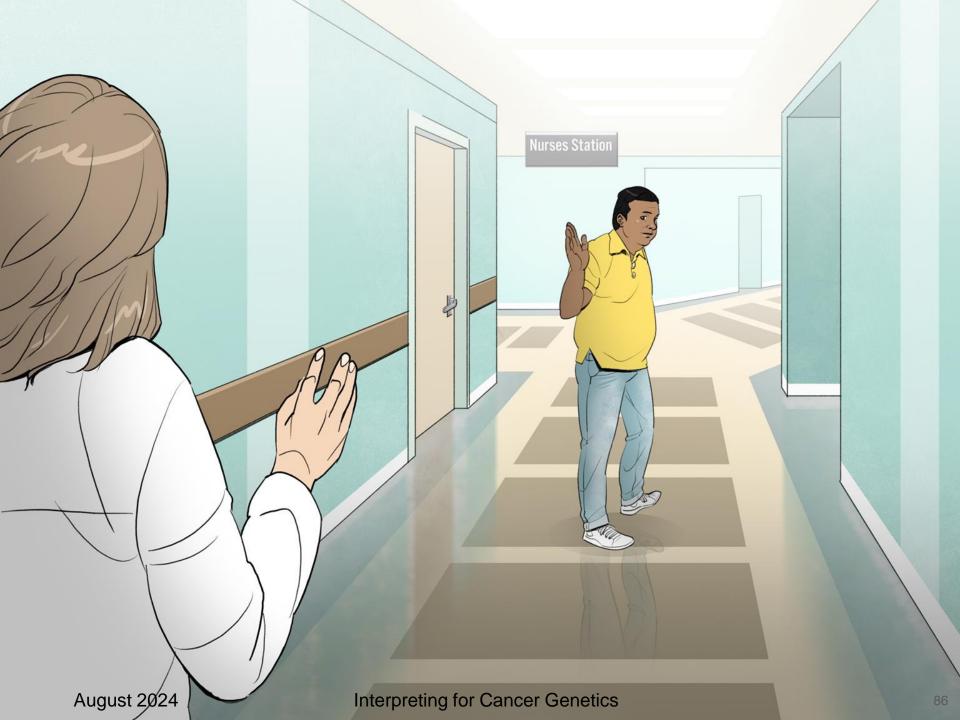


So, let's set up an appointment for a colonoscopy, which is a procedure that screens for colon cancer. It would probably be a good idea to do them more frequently than usual, now that we know you have a high risk of colon cancer.

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We know that removing polyps can help prevent cancer, AND catch it early if it starts.





Questions?