

Now's the Time to Discuss Family Health History

A Fred Hutch genetic counselor shares insights about her work and gives advice on how to start conversations.

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As the year winds down and families come together for the holidays, it's an ideal time to discuss family health history. But why would you choose to take on a potentially sensitive subject, you might wonder?

Think of it this way: Knowing your family history can be interesting. But knowing your family health history is important — and could ultimately be life-saving for you or a family member. The reason why is because some cancers and diseases run in families, and having a genetic test so you know your risk for an inherited cancer means you (and biological family members who have this information) can make better informed choices about how to manage your health.

[Kari Thorsen, MS, CGC](#), is a genetic counselor at Fred Hutch Cancer Center who recently shared insights into the work she does as well as offered advice on how to get family health history conversations started this holiday season.

What do genetic counselors do?

Genetic counselors are specialized health care professionals who educate people on genetic testing and explain why they might want to consider it. It's important to understand what tests are available, what they look for and what they can and cannot reveal about a person's cancer risk.

After someone has decided to be tested and the results come back from the lab, I will meet with them again, either by phone, telehealth or in person to interpret their results and discuss what the next steps should be.

What types of patients do you see?

Sometimes I see patients who have been diagnosed with cancer. Often, they have breast or prostate cancer, [both of which can be inherited](#), and they've been referred to me by their primary care physician or oncology team. For these patients, testing can provide more information about their disease. This may help them make decisions regarding surgery or it could mean there are

more treatment options available to them.

However, some people I see do not have cancer. These people may seek out genetic testing and counseling because they have a blood relative who has had cancer and/or a family member known to carry a gene mutation that increases cancer risk, and they wonder if they are at a higher risk to get cancer as well.

I want to add that even people who do not know their biological family and are curious to know their cancer risks can seek out genetic counseling.

How does genetic testing work?

The testing process itself is simple: For most people, it involves a simple blood draw or saliva sample. Occasionally, depending on the situation — such as when we test for certain blood cancers — a skin biopsy might be required.

What happens after the test results come back?

The results will either be negative, positive or inconclusive. If the test is negative, it means the person does not have a mutation in their gene that is linked to an inherited cancer. However, a negative result doesn't necessarily mean you're in the clear if there's a significant family history of cancer. If that's the case, personalized cancer screenings may be needed. We review these screening guidelines from the [National Comprehensive Cancer Network \(NCCN\)](#) when we go over the test results. When needed, I will refer them to a [prevention](#) clinic for personalized recommendations.

The results may also be inconclusive. This means the person has genetic variations whose impact isn't fully understood yet. Often, this is called variants of uncertain significance, or VUS. This means genetic changes were identified during the test that have an unknown impact on a person's health. In these cases, I will review pertinent journal articles, compare results to health data from studies of large groups of people and review your personal and family health history to better understand its impact on your health. The majority of inconclusive results are treated as negative because there is a high probability they are a harmless genetic variation. If any new scientific data is released that suggests a person has cancer risks and should follow screening recommendations, I will notify the patient. These updates can happen months or years after you have your test. Labs notify genetic counselors when there are changes like these, and genetic counselors will contact people who are affected.

Other people will have a positive result. If that's the case, I'll work with the person to get them the appropriate follow-up plan or care they need. For instance, this could mean a person will need to be screened more often, so if cancer does develop, it can be caught in its earliest stages when it is most treatable. I might also refer them to specialists who can recommend healthy lifestyle changes and habits as well. Another important step for patients who are positive is for them to share their results with biological relatives.

Regardless of whether a person's result is negative, positive or inconclusive, I will meet with them to discuss the test findings, answer questions and talk about what next steps may be needed.

How can people talk to their family about their genetic counseling or testing results?

Every family is different, and there is no right or wrong way to do it. Sharing information, like a genetic test result, can feel difficult, but it is a caring act and is about giving loved ones the power of choice and is a tool that can help protect their health.

Some people decide having separate conversations with just a couple people versus a large group works best for them. Sharing stories about friends who have had cancer is another way to open up conversations around family health. Some people find it helps to mention you've been tested and that your genetic counselor discussed how important it is to share your results with biological relatives.

I also understand and respect that everyone has a different background, and because of this, it may not be possible for them to begin a conversation like this. If that is the case, there are options and I can help. For example, I can write a letter to the family that provides clear information that a person can share. In some cases, I can meet with family members and the person who was tested so they can all ask questions. My goal is to support the individual and family in whatever way is best for them.

Getting started with genetic counseling

If you have a family history of cancer and want to know your risk, you can reach out to the Fred Hutch [Clinical Genetics and Genetic Counseling Service](#) at 206.606.6990.

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