Memorial Sloan Kettering Cancer Center

PATIENT & CAREGIVER EDUCATION

About the Multi-Gene Panel Test for Hereditary Paragangliomas and Pheochromocytomas

This information explains the multi-gene panel test for hereditary paragangliomas and pheochromocytomas. It also explains how your results may affect you and your family.

In this resource, the word “family” means family members related to you by blood. They are not related to you through marriage or adoption.

This multi-gene panel test is done to check your DNA for gene mutations linked to hereditary paragangliomas (rare tumors that form in the nerves in the head and neck) and pheochromocytomas (rare tumors that form in the adrenal glands). Normally, these genes help prevent cancer. A mutation in these genes causes them to stop working like they should. This increases your risk for certain types of cancers.

For more information, read *Frequently Asked Questions About Hereditary Cancers* - www.mskcc.org/genetics/faqs-hereditary-

cancer

What is a multi-gene panel test?

We can test for mutations one gene at a time or multiple genes at the same time. A multi-gene panel test is when we test multiple genes at once using the same saliva or blood sample. By testing multiple genes at once, it may be possible to find a hereditary cause of cancer more quickly.

Your genetic counselor will review your genetic test results with you. They'll talk with you about whether you have a mutation and what cancer(s) it's linked to. As we learn more about these mutations, we may learn that they increase the risk for other types of cancers.

What happens if I have a mutation?

If you have a mutation, your genetic counselor will review your results and your personal and family history of cancer and give you cancer screening recommendations.

They may recommend you start having cancer screenings at a younger age, have them more often than most people, or get specialized screenings to help find cancer as early as possible.

Some examples of these cancer screenings include:

- Having computerized tomography (CT) or magnetic

resonance imaging (MRI) scans.

- Visiting a dermatologist (skin doctor) to have your skin checked for signs of cancer.
- Having specialized blood tests.

Depending on which gene mutation(s) you have, your genetic counselor may also talk with you about having surgery to try to keep cancer from developing, such as:

- Surgery to remove your thyroid to prevent thyroid cancer.
- Surgery to remove the uterus to prevent uterine cancer.

If you decide to have surgery, talk with your genetic counselor about the right time to have it. Surgery to remove the uterus affects fertility (ability to have biological children). If you plan to have biological children, your genetic counselor can talk with you about your options.

What happens if I don't have a mutation?

If you don't have a mutation or if we find a variant of uncertain significance (a change in your gene that isn't called a mutation or normal because we don't know enough about it yet), your genetic counselor will review your personal and family history. They'll talk with you about the general cancer screening guidelines you should follow.

What does a gene mutation mean for my blood relatives?

Most of the mutations you'll be tested for are passed down in a dominant pattern. This means you only need to inherit the mutation from one parent to have an increased risk for cancer. If you have a mutation in one of these genes, your biological parents, siblings, and children each have a 50% chance of having the same mutation in that gene. This means there's an equal chance they will or won't have the mutation. Your distant family members may also be at risk for having the same mutation.

Contact Information

If you have any questions or concerns, talk with a genetic counselor in the Clinical Genetics Service. You can reach them Monday through Friday from 9:00 AM to 5:00 PM at 646-888-4050.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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