

Understanding Your Positive *SUFU* Genetic Test Result

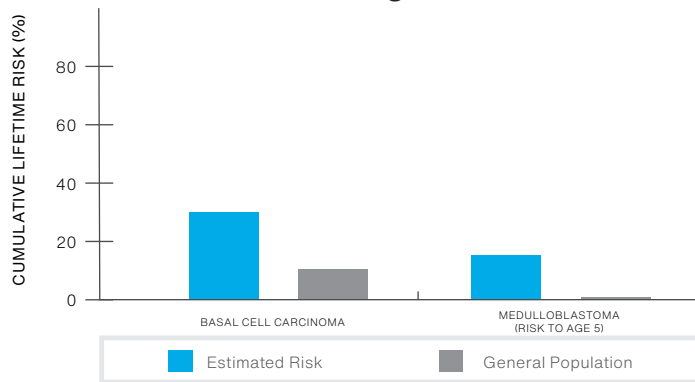
INFORMATION FOR PATIENTS WITH A PATHOGENIC OR LIKELY PATHOGENIC VARIANT

6 Things To Know

1	Result	Your testing shows that you have a pathogenic or likely pathogenic variant in the <i>SUFU</i> gene.
2	<i>SUFU</i> -related disorders	Pathogenic or likely pathogenic <i>SUFU</i> variants can cause a condition similar to nevoid basal cell carcinoma syndrome, a higher risk for certain brain tumors, and other medical concerns.
3	Cancer and other tumor risks	You have an increased chance to develop multiple basal cell carcinomas (a type of skin cancer), medulloblastoma* or meningioma (types of brain tumors), and specific ovarian or testicular tumors (also known as gonadal tumors). Though basal cell carcinoma (BCC) is common in the general population, people with a pathogenic or likely pathogenic <i>SUFU</i> variant have a higher risk to develop BCC particularly before age 50, and a higher risk to develop multiple BCCs.
4	Other Medical Concerns	Some individuals with a pathogenic or likely pathogenic <i>SUFU</i> variant have oculomotor apraxia (which affects eye movement), ataxia (which affects muscle control and coordination), abnormal brain MRI imaging, or motor delays in childhood. These features are highly variable even among the same family, and may or may not be present in every person with a pathogenic or likely pathogenic <i>SUFU</i> variant.
5	What you can do	Risk management decisions are very personal. There are options to detect cancer early or lower the risk to develop cancer. It is important to discuss these options with your healthcare provider and decide on a plan that works for you.
6	Family	Family members may also be at risk – they can be tested for the pathogenic or likely pathogenic <i>SUFU</i> variant that was found in you. It is recommended that you share this information with your family members so they can learn more and discuss with their healthcare providers.

*This tumor is often diagnosed in childhood prior to age 5

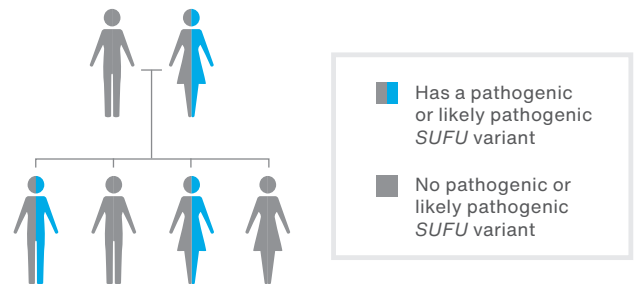
SUFU Cancer Risks to age 50*



* Because risk estimates vary in different studies, only approximate risks are given. Cancer risks will differ based on individual and family history.

SUFU in the Family

There is a 50/50 random chance to pass on a pathogenic or likely pathogenic *SUFU* variant to each of your children.



RESOURCES

- American Brain Tumor Association abta.org
- American Cancer Society cancer.org
- Basal Cell Carcinoma Nevus Syndrome Life Support Network gorlinsyndrome.org
- National Society of Genetic Counselors nsgc.org
- Canadian Society of Genetic Counsellors cagc-accg.ca

Please discuss this information with your healthcare provider. The cancer genetics field is continuously evolving, so updates related to your *SUFU* result, medical recommendations, and/or potential treatments may be available over time. This information is not meant to replace a discussion with a healthcare provider, and should not be considered or interpreted as medical advice.