

Understanding Your VUS HHTNext Genetic Test Result

INFORMATION FOR PATIENTS WITH A **VARIANT OF UNKNOWN SIGNIFICANCE**

Result	VUS	The result of your genetic testing shows you have a variant of unknown significance (VUS) in a gene that causes hereditary hemorrhagic telangiectasia (HHT). A VUS represents a change in the gene, but we do not know if it causes disease or not.
Diagnosis	NO CHANGE	This testing does not change your diagnosis. If you have been diagnosed with HHT, that remains the same.
Further Testing	FOR FAMILY MEMBERS	In some cases, testing family members may help add to the understanding of your result. Talk with your healthcare providers about which family members may be helpful to test.
Management Options	PATIENTS WITH HHT	Medical management options may include: medications, surgery, or surveillance. Talk to your healthcare providers about which may be right for you.
Screening Options	PATIENTS WITH A FAMILY HISTORY OF HHT, BUT NO PERSONAL SYMPTOMS	Options for screening and early detection include: physical exams, blood testing, or imaging studies. Talk to your healthcare providers about whether these options are right for you.
Next Steps	DISCUSS	Please share this with family members so they can talk with their healthcare providers and learn more.
Reach Out	RESOURCES	<ul style="list-style-type: none"> • Cure HHT & Backpack Health curehht.org/backpack-health • National Society of Genetic Counselors nsgc.org • Canadian Association of Genetic Counsellors cagc-accg.ca • Genetic Information Nondiscrimination Act (GINA) ginahelp.org

HHT in the Family

Even though your genetic testing result was a VUS, HHT can run in families. All close family members of someone with HHT (like parents, brothers, sisters, children) should talk with their healthcare providers about screening.

Please discuss this information with your healthcare providers. The field of genetics is continuously changing, so updates related to your genetic testing results and/or medical management options may be available over time. This information is not meant to replace a discussion with a healthcare provider, and should not be considered or taken as medical advice.

