

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 capillary malformation-arteriovenous malformation (CM-AVM) syndrome. 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 CM-AVM, that remains the same.
Family Members	POSSIBLE TESTING	Your report will indicate if testing family members may help us learn more about your specific VUS. Please speak with your healthcare provider to determine if they might also benefit from a test to evaluate their personal risk of developing a disease.
Management Options	PATIENTS WITH CM-AVM	Medical management options may include: surgery or surveillance. Talk to your healthcare providers about which may be right for you.
Screening Options	PATIENTS WITH A FAMILY HISTORY OF CM-AVM, BUT NO PERSONAL SYMPTOMS	Options for screening and early detection include: physical exams or imaging studies. Talk to your healthcare providers about which may be 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	National Society of Genetic Counselors nsgc.org Canadian Association of Genetic Counsellors cagc-accg.ca Genetic Information Nondiscrimination Act (GINA) ginahelp.org

CM-AVM in the Family

Even though your genetic testing result was a VUS, CM-AVM can run in families. All close family members of someone with CM-AVM (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 providers, and should not be considered or taken as medical advice.

