

# Understanding Your VUS HHTNext Genetic Test Result

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

Result	<b>VUS</b>	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	<b>NO CHANGE</b>	This testing does not change your diagnosis. If you have been diagnosed with CM-AVM, that remains the same.
Further Testing	<b>FOR FAMILY MEMBERS</b>	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	<b>PATIENTS WITH CM-AVM</b>	Medical management options may include: surgery or surveillance. Talk to your healthcare providers about which may be right for you.
Screening Options	<b>PATIENTS WITH A FAMILY HISTORY OF CM-AVM, BUT NO PERSONAL SYMPTOMS</b>	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	<b>DISCUSS</b>	Please share this with family members so they can talk with their healthcare providers and learn more.
Reach Out	<b>RESOURCES</b>	<ul style="list-style-type: none"> <li>National Society of Genetic Counselors <a href="http://nsgc.org">nsgc.org</a></li> <li>Canadian Association of Genetic Counsellors <a href="http://cagc-accg.ca">cagc-accg.ca</a></li> <li>Genetic Information Nondiscrimination Act (GINA) <a href="http://ginahelp.org">ginahelp.org</a></li> </ul>

## 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.

