

# Understanding Your VUS Genetic Test Result for Thoracic Aortic Aneurysms/Dissections (TAAD) or Related Conditions

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

Result	<b>VUS</b>	Your (or your family member's) testing shows that you have a variant of unknown significance (VUS) in a gene that causes TAAD or a related condition. A VUS is a gene change, but we do not know if it causes TAAD or not.
Diagnosis	<b>NO CHANGE</b>	This testing does not change your diagnosis. If you have been diagnosed with TAAD or a related condition, that remains the same.
Family Members	<b>POSSIBLE TESTING</b>	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	<b>PATIENTS WITH TAAD OR RELATED CONDITIONS</b>	Treatment options include: medications, surgery, or avoiding certain athletic activities. Your doctor may also recommend tests for other medical problems that are sometimes associated with TAAD. Talk to your doctor about which may be right for you.
Screening Options	<b>FAMILY MEMBERS</b>	Options for screening and early detection include: physical exams, echocardiograms, or cardiac MRI. Talk to your doctor about whether these options are right for you.
Next Steps	<b>DISCUSS</b>	Share this with family members so they can talk with their doctors and learn more.
Reach Out	<b>RESOURCES</b>	<ul style="list-style-type: none"> <li>• Ambry's Cardiology Site for Families <a href="https://patients.ambrygen.com/cardiology">patients.ambrygen.com/cardiology</a></li> <li>• National Society of Genetic Counselors <a href="https://nsgc.org">nsgc.org</a></li> <li>• The Marfan Foundation <a href="https://marfan.org">marfan.org</a></li> <li>• Loeys-Dietz Syndrome Foundation <a href="https://loeysdietz.org">loeysdietz.org</a></li> <li>• The Ehlers-Danlos National Foundation <a href="https://ednf.org">ednf.org</a></li> <li>• Genetic Information Nondiscrimination Act (GINA) <a href="https://ginahelp.org">ginahelp.org</a></li> </ul>
Participate	<b>RESEARCH OPPORTUNITIES</b>	You may wish to contact Dr. Dianna M. Milewicz and her research staff of the University of Texas Health Science Center at Houston, regarding a study of gene changes that can lead to TAAD and related diseases. Participation in research is optional. You may contact the study office at (713) 500-6715 or <a href="mailto:JRRP.research@uth.tmc.edu">JRRP.research@uth.tmc.edu</a> . For more information about the John Ritter Foundation, you may visit <a href="https://johnritterfoundation.org">johnritterfoundation.org</a> .

## TAAD and Related Conditions in the Family

Even though your (or your family member's) genetic testing result was a VUS, TAAD could still be running in your family. All close family members of someone with TAAD (like parents, brothers, sisters, children) should talk with their doctor about screening.

Please talk with your doctor or genetic counselor about this. The field of genetics is continuously changing, so updates related to your 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 taken as medical advice.

