

FREE GENETIC TESTING RESOURCES

For Hereditary ATTR (hATTR) Amyloidosis



WHAT IS hATTR?

Hereditary ATTR (hATTR) amyloidosis is a rare disease that runs in families. It happens because of a change (variant) in a gene called TTR. This change causes protein to build up in parts of the body, like the heart or nerves, and can make them stop working properly. There are over 120 known variants of the TTR gene. Not everyone who inherits a TTR variant will develop hATTR. Those who do develop the disease may experience it differently from their family members. Without treatment, hATTR can become serious and even life-threatening. That is why genetic testing is important.

ELIGIBILITY FOR FREE GENETIC TESTING & COUNSELING

You may be eligible if you are an adult (18 and older) and:

- Have a diagnosis of ATTR amyloidosis
- Have symptoms of ATTR amyloidosis
- Have a family history of hATTR.



HOW CAN I BE TESTED FOR FREE?

Currently, there are two programs that offer the testing at no charge through Prevention Genetics. There is very little difference between them, and either is a good choice. You will be offered free genetic counseling through Genome Medical before testing and after to help you understand your results and the next steps. You or your healthcare provider can order the test, but it must be conducted at your provider's office and sent back to Prevention Genetics by your provider. Results typically come back in 3 weeks, and you can review them with your provider.

ALNYLAM ACT | arci.org/AlnylamAct | Sponsored by Alnylam, available in US and Canada

NAVIGATTR | arci.org/navigATTR | Sponsored by AstraZeneca & Ionis, available in US

If you have a cardiomyopathy diagnosis and suspect it could be hATTR, you can get genetic testing through Heartgene Sciences at no charge. This testing can be ordered and conducted by you, with no provider necessary and no medical visits. Results typically take 4-8 weeks to come back.

HEARTGENE | heartgene.com | Partners with Broad Clinical Labs and Mass General Brigham

Ask ARC Your Questions:
(617) 467-5170 or support@arci.org