GENETIC TESTING

Amyloidosis Research Consortium

FREE RESOURCES FOR HEREDITARY ATTR (hATTR)

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 transthyretin (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. They are sponsored by different drug companies, but both use Prevention Genetics as their testing provider. There is very little difference between them, and either is a good choice. Follow the URLs below for more information.

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

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

HOW TESTING WORKS

Your healthcare provider can order the test. Any provider that ideally is familiar with you can place the order, including primary care physicians, nurse practitioners, cardiologists, orthopedic surgeons, and other specialists.

The test will be conducted at your provider's office, where they will take a blood sample (preferred), or collect saliva or buccal (cheek) cells. Results usually come back in 3 weeks. You will be offered free genetic counseling through Genome Medical before testing and after to help you understand your results and the next steps.

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

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