The Alnylam Act™ (formerly known as Alnylam Assist™) program was created to potentially enable diagnosis and to provide genetic counseling to help people make more informed decisions about their health. These services are available only in the United States. While Alnylam provides financial support for this program, all tests and services are performed by independent third parties. At no time does Alnylam receive patient identifiable information. Alnylam receives contact information for health care providers who sign up for this program.
What is genetic counseling?

Genetic counseling is a service that provides information and support to people who have, or may be at risk for, genetic diseases. Genetic counseling is available before, during, or after genetic testing. Individuals who have a diagnosis of hATTR amyloidosis, have a known family history of hATTR amyloidosis, or who are undergoing a clinical evaluation with a doctor for hATTR amyloidosis, may schedule a telephone-based genetic counseling session directly with InformedDNA, the independent vendor who provides this service.

What is hATTR Amyloidosis?

hATTR amyloidosis is an inherited, progressive disease caused by a genetic mutation that results in the buildup of misfolded transthyretin (TTR) protein. This results in the formation of amyloid deposits in the heart, nerves, and gastrointestinal (GI) tract. Misdiagnosis of hATTR amyloidosis is common because of the number of symptoms that overlap with those of many other conditions, which may result in potentially ineffective or harmful treatment(s).

What is genetic testing?

Genetic testing will tell you if you carry a mutation in the TTR gene associated with hATTR amyloidosis. Genetic testing for hATTR amyloidosis can be ordered as an individual test or as part of a larger panel such as a neuropathy panel or cardiomyopathy panel. These panels include additional genes associated with hereditary conditions that have some symptoms that may overlap with hATTR amyloidosis.

Once a gene mutation is identified, family members of an affected individual can use this information to help determine their own risk.

We encourage you to speak with your doctor and/or a genetic counselor about the benefits, risks, and limitations of genetic testing as well as the appropriateness of genetic testing for you.

Genetic Testing Process

1. Your health care provider (HCP) will need to sign up for the program.
   HCP sign up can be done at www.invitae.com/alylam-act
   Invitae is the independent vendor providing this service.

2. Provide a blood or saliva sample.
   Your HCP will select the most appropriate test (single gene or panel) and submit your sample for testing.

3. Get results from your HCP.
   Genetic testing results will be sent to your HCP within 2-3 weeks.

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To schedule free genetic counseling, call InformedDNA at 1.888.475.3128. Please have the information below available and reference the Alylam Act™ program when scheduling your appointment:

Your Doctor’s Information:

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After your genetic counseling session, your HCP will be sent a detailed summary report.

Sources:
Please visit www.alnylam.com/patients/patient-connect for the latest updates on each of our programs.