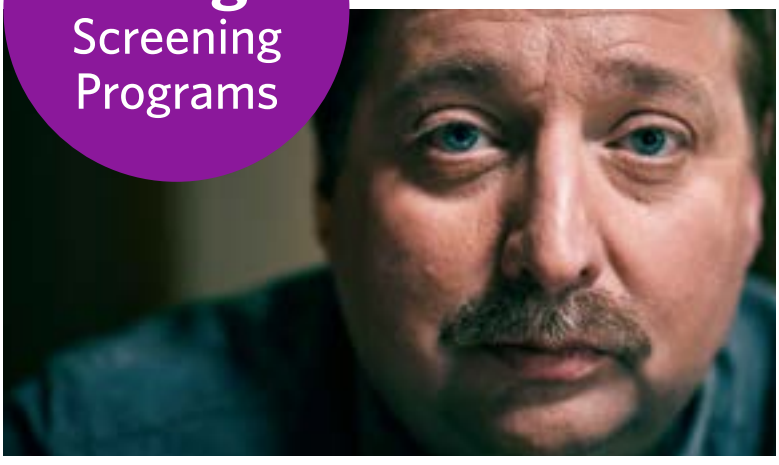
Alnylam Act™

Alnylam Sponsored Third-Party Genetic Testing and Counseling Programs for Hereditary ATTR (hATTR) Amyloidosis Offered at No Charge

No Charge Screening Programs



Edgar Jr., living with hATTR amyloidosis

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.

AlnylamAct™

Why screen your patients for hATTR Amyloidosis?

Hereditary ATTR amyloidosis (hATTR amyloidosis) is an inherited, rapidly progressive, life-threatening disease.[1-3] It is caused by a mutation in the transthyretin (TTR) gene that results in misfolded TTR proteins accumulating as amyloid fibrils in multiple tissues including the nerves, heart, and gastrointestinal tract.[1,4,5] hATTR amyloidosis is a multisystemic disease with a heterogeneous clinical presentation that includes sensory and motor, autonomic (e.g., diarrhea, erectile dysfunction, hypotension), and cardiac symptoms.[2,6,7] hATTR amyloidosis can lead to significant morbidity, disability, and mortality within 2 to 15 years.[1-3,8]

Patients with hATTR amyloidosis require an early and accurate diagnosis due to the rapid natural progression of the disease.[6,9,10] hATTR amyloidosis is often misdiagnosed due to its constellation of symptoms, which may overlap with other diseases.[9] Since the etiology of hATTR amyloidosis is different from that of other types of polyneuropathy and cardiomyopathy, misdiagnosis could lead to ineffective or possibly detrimental treatment.[6,8]

No Charge Screening Programs

The benefits of genetic testing and counseling include the ability to:

- Identify risk of disease for patients and their family members
- Shorten the time to diagnosis
- Tailor care to a patient's specific needs
- Help patients determine if they are eligible to participate in clinical trials
- Connect patients and families with patient advocacy organizations and support services

Genetic testing for 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.

Edgar Sr., living with hATTR amyloidosis

Eligibility

Patients with a suspected diagnosis or a confirmed family history of hATTR amyloidosis are eligible to take part in the Alnylam Act™ program.

Testing options for your patients

Invitae is the independent vendor providing this service.

Invitae Transthyretin Amyloidosis Test

Single-gene testing for the TTR gene, which is associated with hATTR amyloidosis

Invitae Comprehensive Neuropathies Panel

Testing for up to 79 genes that cause dominant, recessive, and X-linked hereditary neuropathies, including hATTR amyloidosis

Invitae Cardiomyopathy Comprehensive Panel

Testing for up to 105 genes associated with inherited cardiomyopathy conditions, including hATTR amyloidosis

How to order genetic testing

1. Sign up online

Visit **www.invitae.com/alnylam-act** to set up an account and order a test or specimen (blood and saliva) collection kit.

2. Complete requisition and symptom checklist forms

Under reason for testing, select **Collaboration/Research study**
Enter study code: **TTR**

Search for and select one of three tests:
1. Invitae Transthyretin Amyloidosis Test
2. Invitae Comprehensive Neuropathies Panel
3. Invitae Cardiomyopathy Comprehensive Panel

Under billing information, select **Institutional Billing** and leave all fields blank to order testing at no charge

3. Submit patient sample

Use a standard 4.0 mL lavender-top (EDTA) tube or saliva tube included in kit. Submit sample with completed forms. Specimen and shipping requirements will be provided.

4. Receive patient results

You will receive a notification email when results are ready, typically within 2-3 weeks.

Referring Your Patients to Genetic Counseling

- **InformedDNA** is the independent vendor providing this service.
- Your eligible patients can schedule a telephone-based genetic counseling session by calling **1.888.475.3128**.
- Patients will need to reference the Alnylam Act™ program and provide your contact information including your name, address, phone, and fax when scheduling their appointment.
- You will receive a detailed summary report of your patient's genetic counseling session.
- Genetic counseling is available before, during, or after genetic testing, and you do not need to set up an account for your patients to utilize this service.

Sources:
1. Hanna. Curr Heart Fail Rep. 2014;11(1):50-57.
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6. Conceição et al. J Peripher Nerv Syst. 2016;21(1):5-9.
7. Shin et al. Mt Sinai J Med. 2012;79(6):733-748.
8. Castaño. Heart Fail Rev. 2015;20(2):163-178.
9. Adams et al. Curr Opin Neurol. 2016;29(suppl 1):S14-S26.
10. Obici et al. Curr Opin Neurol. 2016;29(suppl 1):S27-S35.

Alnylam® PHARMACEUTICALS

Alnylam is a biopharmaceutical company developing a potential new class of innovative medicines. We have a core focus on therapeutics toward genetically defined targets for the treatment of serious, life-threatening diseases with limited treatment options for patients and their caregivers.

To learn more about Alnylam, please visit www.alnylam.com.

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03.2017

For assistance with genetic testing, call Invitae at 1.800.436.3037

For assistance with genetic counseling, call InformedDNA at 1.888.475.3128