AlnylamAct™

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

Edgar Jr., living with hATTR amyloidosis

No Charge
Genetic Testing and Counseling

The Alnylam Act™ program was developed to reduce barriers to genetic testing and counseling to help people make more informed decisions about their health. While Alnylam provides financial support for this program, tests and services are performed by independent third parties. Healthcare professionals must confirm that patients meet certain criteria to use the program. Alnylam receives de-identified patient data from this program, but at no time does Alnylam receive patient identifiable information. Alnylam receives contact information for healthcare professionals who use this program. Genetic testing is available in the U.S. and Canada. Genetic counseling is only available in the U.S. Healthcare professionals who use this program have no obligation to recommend, purchase, order, prescribe, promote, administer, use or support any Alnylam product.

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 multisystem disease with a heterogeneous clinical presentation that includes sensory and motor, autonomic (e.g., diarrhea, sexual dysfunction, hypotension), and cardiac symptoms.[2,6,7] hATTR amyloidosis can lead to significant morbidity, disability, and mortality, with a median survival of 4.7 years following diagnosis and a reduced survival of 3.4 years for patients presenting with cardiomyopathy. [1-3,8-11]

Patients with hATTR amyloidosis require an early and accurate diagnosis due to the rapid natural progression of the disease.[6,12-13] hATTR amyloidosis is often misdiagnosed due to its constellation of symptoms, which may overlap with other diseases.[12]

No Charge
Genetic Testing and Counseling

Genetic testing and counseling may help to:

- Identify risk of disease for patients and their family members
- Shorten the time to diagnosis and prevent misdiagnoses
- Determine if patients are eligible to participate in clinical trials
- Provide information about support resources such as patient advocacy organizations

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

Patients age 18 or older with a suspected diagnosis or a confirmed family history of hATTR amyloidosis may 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 ~70 genes that cause dominant, recessive, and X-linked hereditary neuropathies, including hATTR amyloidosis

Invitae Cardiomyopathy Comprehensive Panel

Testing for ~50 genes associated with inherited cardiomyopathy conditions, including hATTR amyloidosis

How to Order Genetic Testing Online*

1. Sign up online

Visit www.invitae.com/alnylam-act-ttr to set up an account. Login to order a test. If needed, specimen (blood or saliva) collection kits can be ordered and typically take 2-3 days to arrive.

2. Complete requisition and symptom checklist forms

In the Invitae Partner Code field, enter: TTR

Under Test Type, select: Panel/Gene Test

Under Test Selection, search for and select:

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. Submit sample with completed forms. Specimen and shipping requirements are available on requisition form or online.

4. Receive patient results

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

* For assistance with account set up, test ordering, or alternative ways to order testing and submit samples, call Invitae at 1.800.436.3037

How to Refer to Genetic Counseling

- InformedDNA is the independent vendor providing this service.
- Your 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.
- Genetic counseling is only available in the U.S.

References

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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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