



Genetic Testing and
Counseling Program*† for
Hereditary ATTR (hATTR)
Amyloidosis Offered at
No Charge‡

**Consider genetic testing and
counseling for your patients;
Alnylam Act® provides one
option for eligible individuals**

*While program is sponsored by Alnylam Pharmaceuticals,
all services are performed by independent third parties.

†Both genetic testing and genetic counseling are available in the US and Canada.

‡To patients, healthcare professionals, or payers.

About hATTR amyloidosis

What is hATTR amyloidosis?

hATTR amyloidosis is a rapidly progressive, debilitating, and often fatal disease. hATTR amyloidosis is inherited in an autosomal dominant manner and is caused by a variant in the transthyretin (TTR) gene that results in misfolded TTR proteins accumulating as amyloid deposits in multiple sites including the nerves, heart, and gastrointestinal (GI) tract.¹⁻³

Why use genetic testing for hATTR amyloidosis?

Due to the rapid progression of the disease, patients with hATTR amyloidosis benefit from an early and accurate diagnosis.³⁻⁵ A genetic test can help shorten the diagnostic journey and expedite clinical management of hATTR amyloidosis.¹

Is family screening important?

hATTR amyloidosis is an inherited disease and may affect multiple individuals within a family.¹ If you have a patient with hATTR amyloidosis, genetic counselors at InformedDNA can facilitate remote genetic testing in at-risk family members, to accelerate diagnosis.



Edgar Sr., living with hATTR amyloidosis

Getting started

Once the decision to undergo genetic testing and counseling has been made:

Step 1 Determine eligibility for genetic testing*

To be eligible for genetic testing through Alnylam Act[®], patients must be at least 18 years old **in the U.S. and Canada** and meet the requirements below:

- Family history of hATTR amyloidosis, **or**
- Suspected diagnosis of hATTR amyloidosis

Step 2 Order a genetic test



Start your order

- Request Invitae specimen collection kits to get started at: [invitae.com/request-a-kit](https://www.invitae.com/request-a-kit)
- Complete the Invitae requisition form for Alnylam Act[®] (hATTR amyloidosis), and fax it to **415-276-4164** or insert the form in the Invitae specimen collection kit before shipment
- Note: You can also place an order for a genetic test through the online ordering portal at: [invitae.com/alnylam-act-ttr](https://www.invitae.com/alnylam-act-ttr)



Submit patient sample

- Collect a sample using Invitae's specimen collection kit
- Follow the collection and shipping instructions inside the Invitae collection kit
- Note: Invitae offers the ability to send specimen collection kits directly to patients



Review results

- Receive results in 10-21 calendar days, on average
- Receive a notification email once the test results are ready. If you created an online account, you can view the status of your order by logging into your account

Questions about variant of uncertain significance (VUS) results? Invitae's Clinical Support Services are available to help aid in interpretation and resolution of VUS results. To discuss, please email clinconsult@invitae.com or call **1.800.436.3037**

Getting started (*continued*)

Step 3 Genetic counseling (optional)



Refer patient and family members for genetic counseling at any time*

- Instruct your patient to call Informed DNA at **1-888-475-3128** to schedule an appointment
- Patient may seek genetic counseling sessions throughout the process, and counseling is available before, during, and after genetic testing



Prepare patient for appointment

Patient will need to reference the Alnylam Act® program and provide your contact information (name, address, phone, and fax number) when scheduling their appointment



Receive results

Invitae will provide you with a detailed summary report through the online portal

*Genetic counseling available in the US and Canada.



Edgar Jr., living with hATTR amyloidosis

FOR QUESTIONS ABOUT GENETIC COUNSELING

Call InformedDNA at **1.888.475.3128**

FOR QUESTIONS ABOUT GENETIC TESTING

Contact Invitae at [invitae.com/contact](https://www.invitae.com/contact) or **1.800.436.3037**

About Alnylam Act[®]

What is Alnylam Act[®]?

Alnylam Act[®] is a sponsored, no-charge, third-party genetic testing and counseling program for patients with a family history or suspected diagnosis of hATTR amyloidosis. The Alnylam Act[®] program was developed to reduce barriers to genetic testing and counseling to help people make more informed decisions about their health.

What genes are tested through Alnylam Act[®]?

Genetic testing for hATTR amyloidosis can be ordered through a single gene test for the TTR gene or as part of larger panels. The larger panels test for variants in the TTR gene as well as for variants in other genes associated with hereditary conditions that may have overlapping symptoms with hATTR amyloidosis.

How much does genetic testing and counseling cost through Alnylam Act[®]?

Through the Alnylam Act[®] program, the genetic testing and counseling services are provided at no charge to patients, healthcare professionals, or payers, including government payers. Genetic counseling is available through all steps in the process.

The Alnylam Act[®] program was created to provide access to genetic testing and counseling to patients as a way 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 may use healthcare professional contact information for research purposes
- Both genetic testing and genetic counseling are available in the US and Canada
- Healthcare professionals or patients who use this program have no obligation to recommend, purchase, order, prescribe, promote, administer, use, or support any Alnylam product
- No patients, healthcare professionals, or payers, including government payers, are billed for this program



References: **1.** Ando Y, Coelho T, Berk JL, et al. *Orphanet J Rare Dis.* 2013;8:31. **2.** Swiecicki PL, Zhen DB, Mauermann ML, et al. *Amyloid.* 2015;22(2):123-131. **3.** Adams D, Coelho T, Obici L, et al. *Neurology.* 2015;85(8):675-682. **4.** Conceição I, González-Duarte A, Obici L, et al. *J Peripher Nerv Syst.* 2016;21(1):5-9. **5.** Obici L, Kuks JB, Buades J, et al. *Curr Opin Neurol.* 2016;29(suppl 1):S27-S35.

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