

AmylamAct 

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

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

Edgar Sr., living with
hATTR amyloidosis



*While program is sponsored by Amylam 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 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.

What genes are tested through Alnylam Act[®]?

Genetic testing for hATTR amyloidosis can be ordered through a single-gene test for the TTR gene.

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.

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

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 can answer questions and review genetic test results to explain what they mean for your patient and at-risk family members.



Edgar Jr., 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 PreventionGenetics specimen collection kits to get started at preventiongenetics.com/ttr
- Complete the PreventionGenetics requisition form for Alnylam Act[®] (hATTR amyloidosis), and fax it to **715-406-4175** or insert the form in the PreventionGenetics specimen collection kit before shipment
- Note: You can also place an order for a genetic test through the online ordering portal at Alnylam.preventiongenetics.com



Submit patient sample

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



Review results

- A notification email will be sent to you once the test results are ready (3 weeks, on average)
- 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? PreventionGenetics' Clinical Support Services are available to help aid in interpretation and resolution of VUS results. To discuss, please email support@preventiongenetics.com or call **715-387-0484**

Getting started (*continued*)

Step 3 Genetic counseling (optional)



Refer patient for genetic counseling when you order a genetic test*

You can select optional pre-test and/or post-test genetic counseling when filling out the test requisition form. Genome Medical will contact the patient directly to schedule an appointment



Prepare patient for the appointment

It is recommended the patient set aside thirty minutes free from interruptions or distractions. The patient may consider asking family members about their family medical history ahead of the appointment. It is helpful for the genetic counselor to understand if any family members have been diagnosed with medical conditions and at what age they were diagnosed



Receive results**

Genome Medical will email the patient a summary report, and patients may access the report through the online portal. The patient may then share the report results with you

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

**If the test result is negative, Genome Medical will provide the patient with an educational video explaining the results.

FOR QUESTIONS ABOUT GENETIC TESTING AND COUNSELING

Contact PreventionGenetics at preventiongenetics.com/contactUs or **715-387-0484**



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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