## Alnylam Act

Genetic Testing and Counseling Programs<sup>\*†</sup> for **Hereditary ATTR (hATTR) Amyloidosis** Offered at No Charge<sup>‡</sup>

A healthcare professional will help you determine if genetic testing through Alnylam Act<sup>®</sup> is the right choice for you. Family affected by hATTR amyloidosis

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

 $^{\scriptscriptstyle \dagger}$  Both genetic testing and genetic counseling are available in the US and Canada

\*To patients, healthcare professionals, or payers.



# Make more informed decisions about your health

#### Why is genetic testing important for hATTR amyloidosis?

Genetic testing can help identify your risk of hATTR amyloidosis by looking for a variant, or change, in the TTR gene. Genetic testing may also help to shorten the time to diagnosis and prevent misdiagnoses.

#### What is genetic counseling?

Genetic counseling can help you and your family members learn more about hATTR amyloidosis and the chances of inheriting the disease and what may happen after a diagnosis.

#### How much does genetic testing and counseling cost through Alnylam Act<sup>®</sup>?

Alnylam Act<sup>®</sup> is a sponsored program, and the genetic testing and counseling services are offered to eligible patients at no charge.

#### Will any genetic or personal information be shared with Alnylam?

While Alnylam receives de-identified patient data from this program, at no time does Alnylam receive identifiable patient information. Third-party companies that support Alnylam Act<sup>®</sup> abide by applicable data privacy laws, including HIPAA and PIPEDA. Your information is safe and protected.

Talk with your healthcare professional today about genetic testing for hATTR amyloidosis



### About hATTR amyloidosis

#### What is hATTR amyloidosis?

hATTR amyloidosis is a rare, inherited condition caused by a genetic variant, or change, in the TTR gene. This affects the function of a protein called transthyretin (TTR), which is made primarily in the liver and carries substances such as vitamin A. hATTR amyloidosis can affect multiple parts of the body, including the nerves, heart, and digestive system. **An early diagnosis can help you better manage your symptoms and discuss the best plan with your doctor and family.** 

#### Who is at risk?

Although anyone can be at risk for this disease, it is more common for certain ethnicities, such as people of African, Portuguese, Irish, Brazilian, French, Japanese, and Swedish descent.

#### How is it diagnosed?

Diagnosis of hATTR amyloidosis involves various tests and procedures, but genetic testing can help confirm the diagnosis.

#### Why is family screening important?

hATTR amyloidosis is an inherited condition that is autosomal dominant, meaning that if one parent has hATTR amyloidosis, each child will have a 50% chance of inheriting the genetic variant that may cause the condition. A family member may inherit the TTR genetic variant, but that does not necessarily mean they will develop hATTR amyloidosis. **A genetic test can help your family members determine their risk for hATTR amyloidosis**.



**Edgar Jr.**, living with hATTR amyloidosis

Through Alnylam Act<sup>®</sup>, Alnylam Pharmaceuticals is sponsoring no-charge, third-party genetic testing and counseling for eligible patients who may carry gene variants known to be associated with hATTR amyloidosis



### How it works

#### **Get started**

Ask a provider about genetic testing for hATTR amyloidosis through Alnylam Act®

#### Provide a sample for genetic testing

- Provide a sample using a PreventionGenetics sample collection kit (ask your doctor about sample collection options), or
- Ask your doctor about the at-home specimen collection option offered by PreventionGenetics

#### Pre-test genetic counseling (optional)\*

Speak with a genetic counselor to learn more about what to expect during the genetic testing process

#### **Review results**

Results are ready in 3 weeks, on average. They will be sent directly to your doctor for review

#### Post-test genetic counseling (optional)\*

Speak with a genetic counselor to review your test results and what they may mean for you and your family

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

### The Alnylam Act<sup>®</sup> 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



### Genetic testing process

If your doctor determines you are eligible, genetic testing is available through PreventionGenetics, an independent genetic testing company.



### Genetic counseling process (optional)

Your doctor may order pre-test and/or post-test genetic counseling when they order your genetic test. If genetic counseling is ordered by your doctor:



Genome Medical will contact you by phone or email to schedule your appointment, either before or after genetic testing



 You will speak with a
genetic counselor to discuss the genetic testing process and/or your results\*



After the appointment, you
can download a summary
of your genetic counseling
session to review and share
with your healthcare provider

\*Genetic counseling after the testing is complete may be in the form of a one-on-one telephone visit or an educational video.

**GENETIC COUNSELORS** are able to help you understand the testing process and your results.



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