

# Hereditary ATTR (hATTR) amyloidosis

An introduction for you and your family to a rare condition





#### How is hATTR amyloidosis passed down?

hATTR amyloidosis is an inherited condition, and each child of one parent with hATTR amyloidosis has a **50% chance of inheriting the genetic variant, or change**, that causes this condition. This change in the transthyretin (TTR) gene may also be referred to as a mutation.

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

### What are the symptoms?

Symptoms of hATTR amyloidosis **can vary widely** among people with the condition and even within families. These symptoms can affect multiple parts of the body.

Certain symptoms typically appear early in the disease:

- Carpal tunnel syndrome
- Weakness
- Dizziness

- Numbness in hands or feet
- Diarrhea
- Unintentional weight loss



Talk to your doctor if you think you may be experiencing hATTR amyloidosis symptoms or become aware of a family history.

### How hATTR amyloidosis (ama-loy-doh-sis) develops



TTR is a naturally occurring protein made primarily in the liver and carries substances such as vitamin A.

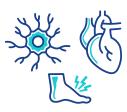


In hATTR amyloidosis, a variant, or change, in the TTR gene causes the protein to take on an abnormal shape and misfold.



Amyloid deposits

This change in shape causes the protein to build up in various parts of the body, including the nerves, heart, and digestive system. The collection of abnormal proteins is called amyloid deposits.



Symptoms of hATTR amyloidosis

These amyloid deposits cause symptoms of the disease.



## Symptoms of hATTR amyloidosis

#### Symptoms related to control over bodily functions

- Recurrent urinary tract infections (UTIs)
- Abnormal sweating
- Dizziness upon standing
- Sexual dysfunction
- Nausea and vomiting
- Diarrhea
- Severe constipation
- Unintentional weight loss

#### Other symptoms

- Glaucoma
- Blurred or spotty vision
- Floaters in the eye
- Worsening dementia
- Stroke-like episodes
- Kidney dysfunction



- Dizziness
- Shortness of breath
- Leg swelling (edema)

**Symptoms related to nerves** in hands, feet, arms, and legs

- Tingling
- Numbness
- Carpal tunnel syndrome
- Burning pain
- Loss of sensitivity to temperature
- Loss of movement control
- Weakness

This is not a complete list of symptoms that may be experienced in patients with hATTR amyloidosis. Each patient has a different experience and you may not experience all of these symptoms, or you may not experience them at the same time. Symptoms of hATTR amyloidosis may worsen over time.



### How is hATTR amyloidosis diagnosed?

If your doctor thinks you may be at risk for hATTR amyloidosis, they may recommend:

- Cardiac and/or neurological tests
- Genetic testing



Your doctor may also recommend you work with a genetic counselor, who can help you and your family learn more about the testing process and if a genetic test may be right for you. Genetic testing can help determine whether a person carries a variant in the TTR gene associated with hATTR amyloidosis.

# Are there genetic testing options available? Alnylam Act®

Alnylam Pharmaceuticals is sponsoring no-charge, third-party genetic counseling and testing for individuals who may carry one of the **120 or more gene variants** known to be associated with hATTR amyloidosis.<sup>a</sup>

<sup>a</sup>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 uses healthcare professional contact information for research and commercial purposes. Genetic testing is available in the US and certain other countries. Genetic counseling is available in the US. 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.









