DOCTOR DISCUSSION GUIDE

CECE, *living with hATTR amyloidosis*

Talking to your doctor about hereditary ATTR (hATTR) amyloidosis

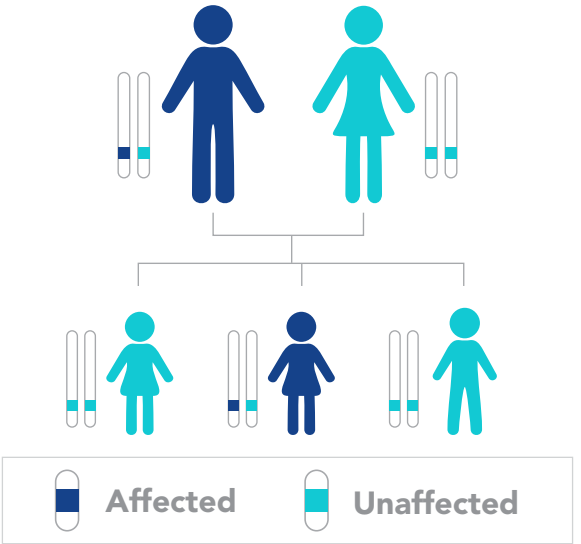
Tips and information to help you start a conversation with your doctor

the BRIDGE® hATTR amyloidosis

What is hATTR amyloidosis?

hATTR amyloidosis is caused by an inherited gene variant, or change, in the transthyretin (TTR) gene.

hATTR amyloidosis is passed down through family members in an autosomal dominant fashion, which means that a person only needs to inherit one copy of the affected gene from one parent in order to be at risk for developing the condition. If one parent has hATTR amyloidosis, **each child will have a 50% chance of inheriting the genetic variant**.



A family member may inherit the TTR gene variant, but having the variant does not necessarily mean that they will develop hATTR amyloidosis.

For more in-depth information, see the Educational Brochure in The Bridge Kit and at www.hATTRbridge.com.

As I have navigated the medical system, I have met some wonderful doctors. They work with me to make sure I'm carefully monitoring all the things that need to be monitored.

RICK, *living with hATTR amyloidosis*

hATTR amyloidosis can cause a range of symptoms

The symptoms of hATTR amyloidosis **can vary widely** among people with the condition, even within families. Different symptoms may appear at different times for each person. The age that symptoms typically appear ranges from the **mid-20s to the mid-60s**.

hATTR amyloidosis can affect several parts of the body, including:

The **somatic nervous system**, which is made up of nerves that connect the brain and spinal cord to the skin and muscles, controls sensation and voluntary movements.

- **Nerve damage** in this system can lead to a range of symptoms, including loss of voluntary movement of the hands and feet, and loss of sensitivity to temperature

The **cardiovascular system**, which is made up of the heart and blood vessels, transports blood through arteries and veins to deliver oxygen to cells and helps to remove metabolic wastes from cells.

- Damage to the heart muscle can lead to **heart failure**

The **autonomic nervous system**, which is made up of nerves that connect the brain and spinal cord to parts of the body, including the heart, stomach, and intestines.

- When this system is not working correctly, it may affect **involuntary bodily functions such as breathing, digestion, and heart rate**

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We now have the tools to fight—not just for our family, but for all families afflicted with this disease—by keeping up with the latest research. We are all one big family fighting for disease awareness.

SUE, *living with hATTR amyloidosis*

Start the conversation with your doctor

Get the right diagnosis

hATTR amyloidosis symptoms are similar to those of other conditions. Knowing what to look for can help you recognize the symptoms sooner and work with your doctors to determine an accurate diagnosis.

Your doctor should be looking for at least one of the following:

- **Family history of hATTR amyloidosis or similar symptoms**
- **Appearance of symptoms throughout several parts of the body**

If you or your family experience symptoms or become aware of a family history of the disease, speak to your doctor about next steps. **Tell your doctor about all of the symptoms you are experiencing**, even if you think they're unrelated or don't apply to your doctor's specialty.

Because the condition is rare and affects different parts of the body, your doctor may need to refer you to an hATTR amyloidosis specialist.

Before your visit with a doctor, be sure to write down any questions you or your family have about hATTR amyloidosis.

Learn about genetic counseling and testing

Genetic counselors can help you and your family understand your chances of developing the condition as well as familiarize you with the testing process and implications of a diagnosis. Genetic counselors can also help you understand the issues related to genetic testing—from personal risk to possible insurance impact—and can help you determine if a genetic test may be right for you.

A genetic test will determine whether a person carries a variant in the TTR gene associated with hATTR amyloidosis. If a gene variant is identified, family members of an affected individual can use this information to help determine their own risk.

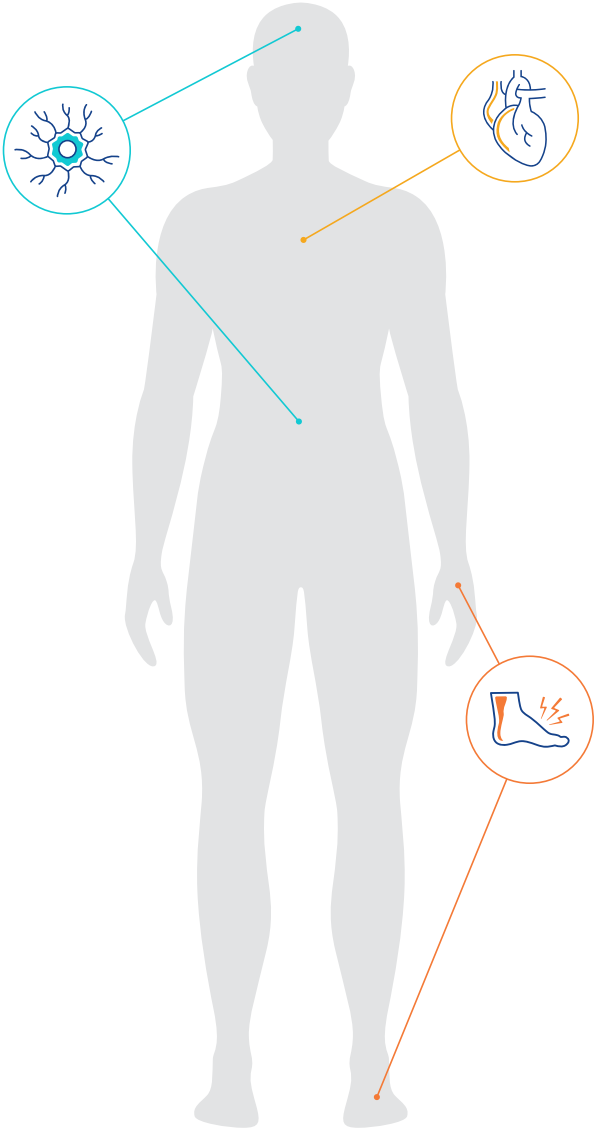
For more information, check out the **Family Discussion Guide** and **Caregiver Brochure** in The Bridge Kit and at **www.hATTRbridge.com**.

Track your health

Which symptoms have you or your family members experienced?

On the next page is a list of symptoms that patients with hATTR amyloidosis might experience. **Check off which ones you or your family members have experienced.**

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.



Track your family history

You can use this checklist along with the **Family Health Tree** tool that's included in The Bridge Kit to map out your family's history of hATTR amyloidosis, which can help you talk with your doctor.

Even if you haven't experienced any symptoms but are aware of a family history, your doctor may refer you to a genetic counselor. Your doctor may also conduct a genetic test to confirm the presence of a TTR variant.

Symptoms related to control over bodily functions

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

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

Myself	Family	
☐	☐	Tingling
☐	☐	Numbness
☐	☐	Carpal tunnel syndrome
☐	☐	Burning pain
☐	☐	Loss of sensitivity to temperature
☐	☐	Loss of movement control
☐	☐	Weakness

Symptoms related to the heart

Myself	Family	
☐	☐	Fatigue
☐	☐	Dizziness
☐	☐	Shortness of breath
☐	☐	Leg swelling (edema)

Other symptoms

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

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Discover more helpful resources

Learn more about hATTR amyloidosis at **www.hATTRbridge.com**, a program designed to help raise awareness and provide education and helpful tools for patients, their families, and caregivers.

Sources for additional information and assistance

Amyloidosis Foundation
www.amyloidosis.org

Amyloidosis Research Consortium
www.arci.org

Amyloidosis Support Groups
www.amyloidosissupport.org

Caregiver Action Network
www.caregiveraction.org

The Foundation for Peripheral Neuropathy
www.foundationforpn.org

Global Genes
www.globalgenes.org

Mackenzie's Mission
www.mm713.org

National Alliance for Caregiving
www.caregiving.org

National Organization for Rare Disorders
www.rarediseases.org

oneAMYLOIDOSISvoice
www.oneamyloidosisvoice.com

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Alnylam Act® Genetic Testing and Counseling Program

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

AlnylamAct®

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

Discover more helpful resources and learn about hATTR amyloidosis at www.hATTRbridge.com.

Alnylam PHARMACEUTICALS

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