An important discussion about a family condition

A guide to talking with your relatives about hereditary ATTR (hATTR) amyloidosis

RON JR & RON SR, living with hATTR amyloidosis

the BRIDGE
hATTR amyloidosis
My family and close friends coalesced as a loving team of support, kindness, and compassion.

CECE, living with hATTR amyloidosis, with her son
Become an advocate for you and your family

hATTR amyloidosis is a genetic disorder that may affect you and others in your family. An open and honest conversation about your experience may encourage others to seek a diagnosis sooner and allow them to have more informed conversations with their doctor.

Creating awareness is an important first step in ensuring your family learns about hATTR amyloidosis—whether they have the condition or whether you are the only one who has received a diagnosis. By educating your family members about hATTR amyloidosis, you may inspire them to make more informed decisions about their health.

This guide includes information, tips, and suggestions that are designed to help you have meaningful discussions with your family about hATTR amyloidosis.

Now is the time to have the conversation. Let’s get started.
The first steps to having a family conversation

Conversation starts with education

• **Arm yourself with facts**—your family will probably have questions about this rare condition. Knowing the basic facts can help you take the first steps to starting the conversation with your family. Use the Educational Brochure and the Caregiver Brochure available in The Bridge® Kit, or the resources on www.hATTRbridge.com

• **Explain that hATTR amyloidosis is hereditary**—understanding that the condition is inherited can help your family members understand why your condition may directly affect them. The more they know, the more prepared they’ll be to have a discussion with their doctor about the risk of inheriting the disease

• **Know your resources**—not everyone will inherit this disease within a family, but others may be affected by it if they become a caregiver for someone in their family. The Caregiver Brochure offers tips and information for adjusting to this lifestyle change. For further assistance, speak with a doctor or genetic counselor
After Rick was first diagnosed, we reached out to our family and friends and let everyone know. One might say they are the supporting characters in our story and have all been a huge support for the both of us.

LYNN, caregiver of a loved one living with hATTR amyloidosis

- **Describe the variability in symptoms**—explain that hATTR amyloidosis may affect several parts of your body, such as the nerve (nervous), heart (cardiac), and digestive (gastrointestinal) systems. Although symptoms may vary widely from patient to patient, even among individuals in the same family, some patients do experience a similar pattern of symptoms within their families.

- **Explain that misdiagnosis is common**—hATTR amyloidosis symptoms are similar to those of other conditions. Knowing what to look for can help family members recognize the symptoms sooner and work with doctors to receive an accurate diagnosis.

- **Encourage communication**—help your family members to speak with their doctors about genetic counseling and testing, and about how hATTR amyloidosis runs in their family. Encourage them to discuss the impact of the condition and develop a plan with their doctors for managing it. If you feel comfortable, you may want to share your own journey to diagnosis with them.
My family’s experiences with hATTR amyloidosis have taught me the importance of acquiring educational tools, empowering us all to advocate for one another’s health.

SUE, member of a family living with hATTR amyloidosis
Inspire your family members to take action

Encourage a visit to a doctor

Whether or not your family members have experienced any symptoms, it is a good idea for them to speak with their doctors to find out how this condition could affect them.

Talk to a genetic counselor

Genetic counseling can help your family members learn more about hATTR amyloidosis. Genetic counselors may talk about your family members’ chances of inheriting the disease, how testing works, and what may happen after a diagnosis. A counselor could also help your family understand the issues related to genetic testing—from personal risk to possible insurance impact—and can help determine if a genetic test is right for them.

Consider a genetic test

Genetic testing can help determine whether a person carries a gene change, or mutation, associated with hATTR amyloidosis. Once a gene mutation is identified, family members of an affected individual can use this information to help determine their own risk. On pages 14 and 15 of this brochure, you can find more information about genetic counseling and testing options available to you and your family.
Share the story of your journey

Plan ahead

Create an outline of the topics and points you’d like to talk about during your conversations. If you feel comfortable, you can discuss your personal experience of having hATTR amyloidosis. This can help put your family members at ease by sharing information that may be useful.

Anticipate questions

It may be helpful to write down the questions you asked when you first received a diagnosis. This may give your family members some ideas of questions to ask their own doctors.

Start with the basics

Beginning the conversation could be as simple as, “I want to talk to you about a condition I have.” You can help set the tone by sharing the information that seems most important to the person you’re speaking with. Consider talking about your first symptoms, the doctors you visited, how you received an accurate diagnosis, and how you manage the condition now.
Talking with children

Speaking to children about hATTR amyloidosis can be difficult, and you may ask yourself if or when you should have the conversation. Here are some ways you can discuss this topic with a child:

What are you thinking right now? It’s okay to be scared, angry, or anything else.

I feel sad and a little scared myself.

I have some news to share with you. We found out what is going on with your dad.

Be open with children and encourage them to ask questions.
Consider where to have a discussion

Keep conversations intimate
You can speak with each family member individually, or invite his or her spouse or significant other along, as long as everyone is comfortable. Consider meeting for coffee or lunch, or visit your relatives in their home.

Make a phone call
Your family members may not live close by, but a phone call is still a great way to start the conversation.

Host a discussion
If many of your relatives live close by, invite them to your house for a discussion about hATTR amyloidosis and about your family’s health history. Consider filling out the Family Health Tree tool included in The Bridge® Kit, or print one out from www.hATTRbridge.com. Ask your relatives to complete it so you can discuss the results together.

You may find it’s better to revisit the conversation with certain people at a later time when they have had the opportunity to process the information.
You can be your family’s most valuable resource

For some family members, it may be helpful for them to know they have support from other people in their family. Building a support system can help the entire family continue to make educated decisions about their future.

Find more support

Advocacy and support groups can help your family members learn more about hATTR amyloidosis. See the next page for more information about these groups.

Accepting my diagnosis was an emotional time for my family, but we had to move through it together to get the care I needed. Giving up was not an option.

CECE, living with hATTR amyloidosis
As I began dealing with hATTR amyloidosis, I encountered some doctors who didn’t know what this disease was and were hesitant to accept me as a patient. Throughout all of this, my wife was relentless in helping me get everything worked out.

**RICK, living with hATTR amyloidosis, and LYNN, his spouse and caregiver**
Get the facts about hATTR amyloidosis

Learn more about hATTR amyloidosis at www.hATTRbridge.com, a program designed to help raise awareness, promote education, and provide valuable 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

The Foundation for Peripheral Neuropathy
www.foundationforpn.org

Global Genes
www.globalgenes.org

National Organization for Rare Disorders
www.rarediseases.org
Alnylam Act®

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

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 uses healthcare professional contact information for research and commercial purposes
- Genetic testing is available in the US and Canada. Genetic counseling is only 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 payers, including government payers, are billed for this program
Consumer genetic services

In addition to genetic tests ordered by your doctor, direct-to-consumer genetic services, like 23andMe, are available for purchase to help you learn more about how genetics may influence your risk for certain hereditary conditions.

Alnylam has teamed up with 23andMe to offer consumer genetic services for the 3 most common genetic mutations associated with hATTR amyloidosis. The home-based saliva collection kit is quick and simple—no needles or blood required. This report does not identify all TTR variants that can cause hATTR amyloidosis, nor does it diagnose hATTR amyloidosis or any other health conditions. Please talk to your doctor if this condition runs in your family, you think you might have this condition, or you have concerns about your results.

If you have a TTR variant detected by the 23andMe test, the Alnylam +myFamily program will provide 23andMe Health + Ancestry Service Kits to your first-degree family members (parents, full siblings, and biological adult children)—at no charge.a

a23andMe services provide information on a person’s risk for certain diseases, but cannot provide a diagnosis. The Hereditary Amyloidosis (TTR-related) Genetic Health Risk Report provides information on the 3 most common TTR mutations in the United States. There are over 120 mutations associated with hATTR amyloidosis. If you have symptoms of hATTR amyloidosis or other symptoms you are concerned about, regardless of results reported by a 23andMe Health Risk Report, it is important to talk to your doctor as soon as possible. Only a doctor can confirm a diagnosis of hATTR amyloidosis.
Learn more about hATTR amyloidosis at www.hATTRbridge.com.