



RON JR & RON SR, *living with hATTR amyloidosis*

An important discussion about a family condition

A guide to talking with your relatives about hereditary ATTR (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 genetic 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**—highlighting the hereditary nature of the condition can help your family understand their risk for hATTR amyloidosis and why your condition may directly affect them
- **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 a loved one. 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**—help your family understand that hATTR amyloidosis can affect several parts of the body, including the nerves, heart, and digestive system. Symptoms may vary widely from patient to patient, even among individuals in the same family, though 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**—urge 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, *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 can help your family understand their chances of developing the condition as well as familiarize them with the testing process and implications of a diagnosis. A counselor can 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 may be right for them.

Consider a genetic test



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. On [page 14](#) 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 their 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 helpful 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 [page 13](#) 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 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.amyloidosisupport.org

The Foundation for Peripheral Neuropathy

www.foundationforpn.org

Global Genes

www.globalgenes.org

National Organization for Rare Disorders

www.rarediseases.org



Alnylam Act®

Alnylam Pharmaceuticals sponsors 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.



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 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

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Learn more about hATTR amyloidosis
at www.hATTRbridge.com.



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