

How to Take Your Next Steps with hATTR Amyloidosis with Polyneuropathy

If your doctor suspects that you have or if you have been clinically diagnosed with hATTR amyloidosis with polyneuropathy, you're not alone. There are many resources available to help you and your family.

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No-cost, confidential genetic testing and confidential genetic counseling

The hATTR Compass Genetic Testing Program is designed to help accelerate or confirm the diagnosis of hATTR amyloidosis with polyneuropathy, along with providing support and resources to patients, caregivers and healthcare professionals throughout the genetic testing process. The program also aims to empower patients and their healthcare professionals to make informed decisions about their health care, through monitoring and keeping track of their health information. hATTR Compass is currently available in the United States, Canada and Puerto Rico.

To get started with hATTR Compass, below is a timeline you can use to track where you are in the process:



Step 1: Order a hATTR Compass Program Genetic Testing Kit Online

Visit www.hATTRCompass.com to order a free hATTR Compass Kit in the mail.



Step 2: Collect DNA Samples

Using the kit, patients should work with their doctors to collect blood or saliva samples and fill out the included Test Requisition Form. Once your doctor has signed the form, follow the instructions provided to submit the kit for analysis.



Step 3: Analyze DNA

Once the lab receives the kit, the DNA samples are analyzed to identify any genetic mutations consistent with hATTR. A report is sent to the doctor and genetic counselor within 2 – 4 weeks.



Step 4: Understand Your Results

Genetic counselors are available to discuss the genetic testing results with you and answer any questions you may have.

Doctors: Ambry Genetic Counselors are available to answer your questions.
Contact +1 (949) 900-5500

Patients: Genetic counseling is available through PWNHealth.
Contact +1 (888) 494-7333



Step 5: Keep Track of Your Health Information

Utilize Backpack Health, a unique tool that helps individuals keep track of their health information so that it's portable, manageable, sharable and translatable. It's important to recognize and keep track of the wide range of symptoms that may be related to hATTR amyloidosis with polyneuropathy, specifically if you have peripheral neuropathy involvement. Join today and receive complimentary access at <https://my.backpackhealth.com/join/hATTRCompass>.



Step 6: Make a Plan

Doctors and patients can work together to make a healthcare management plan based on the results. There are many resources available to help you learn more about hATTR amyloidosis and support options. Try these:

Doctors: Learn more about confirmatory diagnostic tests at www.hATTRGuide.com

Patients: Find tips for living with hATTR amyloidosis with polyneuropathy at www.hATTRChangeTheCourse.com



Step 7: Watch out for Symptoms (If You're Currently Asymptomatic)

If you have a known genetic mutation consistent with hATTR amyloidosis, you can identify the red-flag symptoms of hATTR amyloidosis with polyneuropathy as soon as they manifest and potentially execute your healthcare management plan before the condition gets worse.

For more, visit: www.hATTRCompass.com

www.hATTRchangethecourse.com

 hATTR Change the Course

www.hATTRCompass.com

 @ChangehATTR

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Complimentary patient support program
with the help of a nurse case manager

AKCEA CONNECT offers free, private and personalized support to patients living with a rare disease and their caregivers and is available across the United States and Canada. The program is made up of regionally based nurse case managers who have a wide range of medical knowledge and experience.

Here are a few ways we can help:

- **Knowledge:** Your nurse case manager can provide educational materials for you and your healthcare team to help with day-to-day disease management.
- **Access:** Your nurse case manager can assess your insurance coverage, answer funding questions and research assistance options.
- **Empowerment:** Your nurse case manager can help you connect with people and resources in the rare disease community so that you don't feel isolated or alone.

For more, visit: <https://akceaconnect.com> | Call 1-866-AKCEATX (1-866-252-3289)

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A mobile and web-based app to help manage your health information; a complimentary membership is offered for patients, caregivers and families through the hATTR Compass Program

Backpack Health supports and empowers those living with complex health conditions and their caregivers, providing tools for health management and contributions to research. This is a unique tool that helps individuals keep track of their health information so that it's portable, manageable, sharable and translatable.

The Backpack Health app can:

- Bring all of your health information together in a comprehensive, portable app.
- Manage your loved ones' health information in the same place as your own, seamlessly.
- Securely share health information with those you choose using Share Cards.
- Share and manage multilingual health information in English, Spanish, Italian, French, Portuguese and German.

For more, visit: <https://my.backpackhealth.com/join/hATTRCompass>

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Advocacy Groups

There are many advocacy groups available to support patients, caregivers and their loved ones through the hATTR amyloidosis with polyneuropathy journey. Connecting with other patients can be a great way to cope with your hATTR amyloidosis with polyneuropathy.

To find a support group close to you, please visit:

- **Amyloidosis Support Groups** (www.amyloidosisupport.org)
- **Amyloidosis Foundation** (www.amyloidosis.org)
- **Amyloidosis Research Consortium** (www.ARCI.org)

In addition to these resources, you can email Akcea Patient Advocacy (patientadvocacy@akceatx.com). Support resources are available to you every step of the way!

www.hATTRchangethecourse.com

 [hATTR Change the Course](https://www.facebook.com/hATTRChangeTheCourse)

www.hATTRCompass.com

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