

# The hATTR Compass Genetic Testing Program FAQ

## What is the hATTR Compass Program?

Akcea Therapeutics and Ambry Genetics are partnering to offer no-cost, confidential genetic testing and confidential genetic counseling to patients suspected of having or who have a family history of hereditary transthyretin amyloidosis (hATTR) with polyneuropathy.



### The hATTR Compass Program is designed to:

- **Help** accelerate or confirm the diagnosis of hATTR amyloidosis with polyneuropathy
- **Provide** support and resources to patients, caregivers and healthcare professionals throughout the genetic testing process
- **Empower** patients and their healthcare professionals to make the most informed decisions about their health care

## What is the cost of the hATTR Compass Program?

The hATTR Compass Program is being offered at no-cost to patients by Akcea Therapeutics.

## Who is eligible to participate in the hATTR Compass Program?

The hATTR Compass Program is available for patients 18 years and older who have a family history of or are experiencing symptoms of hATTR amyloidosis with polyneuropathy.

## Where is the hATTR Compass Program available?

The hATTR Compass Program is currently available to residents of the United States, Canada and Puerto Rico. While Akcea provides financial support for this program, all tests and services are confidential and performed by independent third parties.

## What information does Akcea receive?

At no time does Akcea receive any patient identifiable information.

## Will patient genetic information be stored? For what purpose and for how long?

De-identified patient results will only be stored in the Ambry database per Health Insurance Portability and Accountability Act (HIPAA) regulation. HIPAA is a U.S. law designed to provide privacy standards to protect patients' medical records and other health information provided to health plans, doctors, hospitals and other health care providers. This means that your results will not be connected to your personal information, including your name or contact information. Ambry Genetics never shares any patient-identifiable information.

## What happens to the genetic sample after testing has been completed? Is the sample stored and for how long?

The original patient sample will be stored for 30 days in case further tests are necessary or requested. Extracted DNA will be stored for six months except for samples from New York State. DNA samples from New York State will be stored for 30 days.

[www.hattrchangethecourse.com](http://www.hattrchangethecourse.com)

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[www.hATTRCompass.com](http://www.hATTRCompass.com)

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## What is the genetic testing process through hATTR Compass?

**Order Online:** If you are interested in participating, order your free hATTR Compass Program Kit at [www.hATTRCompass.com](http://www.hATTRCompass.com). **TIP:** Be sure to indicate whether you would like to receive pre- and post-test confidential genetic counseling on the order form.

**Collect Samples:** Take the hATTR Compass Program Kit provided to you by mail or Ambry Genetics representative to your doctor to help you collect your blood or saliva DNA samples. Your doctor should also complete the Test Requisition Form provided with the kit.

**Submit for DNA Analysis:** Submit the hATTR Compass Program Kit for DNA analysis with the completed Test Requisition Form using the mailing instructions provided in your kit.


**Receive Results:** Your results will be sent to your doctor and/or genetic counselor within 2-4 weeks. **TIP:** Ambry Genetic Counselors are available to help you interpret the test results. For assistance, contact 949-900-5500.

**Make a Plan:** Work with your doctor to make a healthcare management plan based on your test results. The hATTR Compass Program is the first step on the diagnostic pathway to treat the condition. For more details on the submission process, visit [www.hATTRCompass.com](http://www.hATTRCompass.com).

**Watch out for Symptoms:** With a confirmed genetic test result, 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. If you'd like to learn more about hATTR amyloidosis, start here at [www.hattrchangethecourse.com](http://www.hattrchangethecourse.com). To find a hATTR amyloidosis specialist in your area, visit [www.myamyloidosispathfinder.org](http://www.myamyloidosispathfinder.org).

## What additional services or resources does the hATTR Compass Program provide?

**Genetic Counseling:** As part of the hATTR Compass Program, genetic counselors are available at no-cost to consult with patients through pre- and post-test counseling. Akcea and Ambry Genetics have partnered with PWNHealth, a third party, virtual care company that enables confidential access to diagnostic testing, treatment and professional guidance.

**Backpack Health:** hATTR Compass has partnered with  **Backpack Health**, a mobile and web-based app that helps patients and caregivers manage their health. Backpack Health supports and empowers those living with complex health conditions, providing tools for health management and contributions to research.

For more information, please visit: [my.backpackhealth.com/join/hATTRCompass](http://my.backpackhealth.com/join/hATTRCompass)

## Where can I go to get more information regarding hATTR amyloidosis with polyneuropathy, hATTR Compass and genetic testing?

For more information on hATTR amyloidosis with polyneuropathy, patients can visit [www.hattrchangethecourse.com](http://www.hattrchangethecourse.com) to gain access to a variety of education resources and support materials.

More information on the hATTR Compass Program can be found at [www.hATTRCompass.com](http://www.hATTRCompass.com) and by contacting Ambry Genetics at 949-900-5500.

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