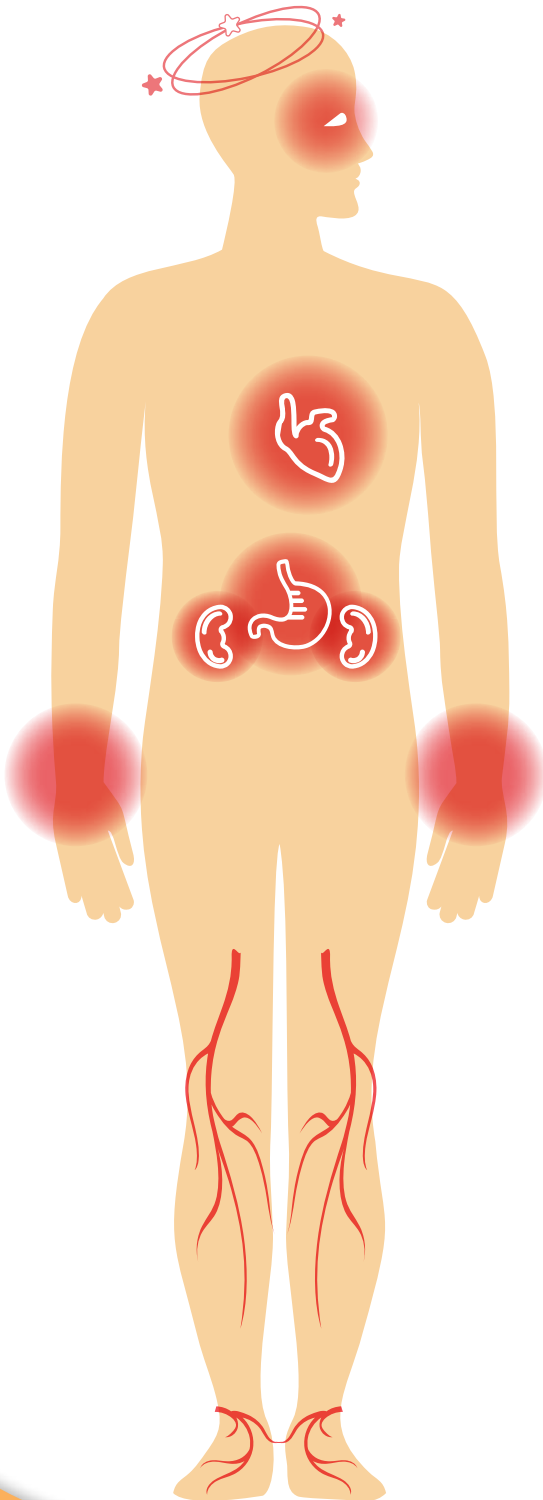


Hereditary ATTR Amyloidosis: What you need to know



What is Amyloidosis?

Amyloidosis is a disease where proteins called amyloids mis-fold in different parts of the body.

- The protein can build up in the heart, nervous system, digestive tract, kidneys, and eyes, which causes damage.
- There is more than one type of amyloidosis.
 - ATTR amyloidosis involves the transthyretin (TTR) protein.
 - Hereditary ATTR, also known as hATTR, amyloidosis happens because of a gene that parents can pass to their children. However, everyone with the gene may not get the disease.
 - Wild Type ATTR amyloidosis happens when you do not have the gene. It occurs at an older age than the hereditary form.

Who is at risk?

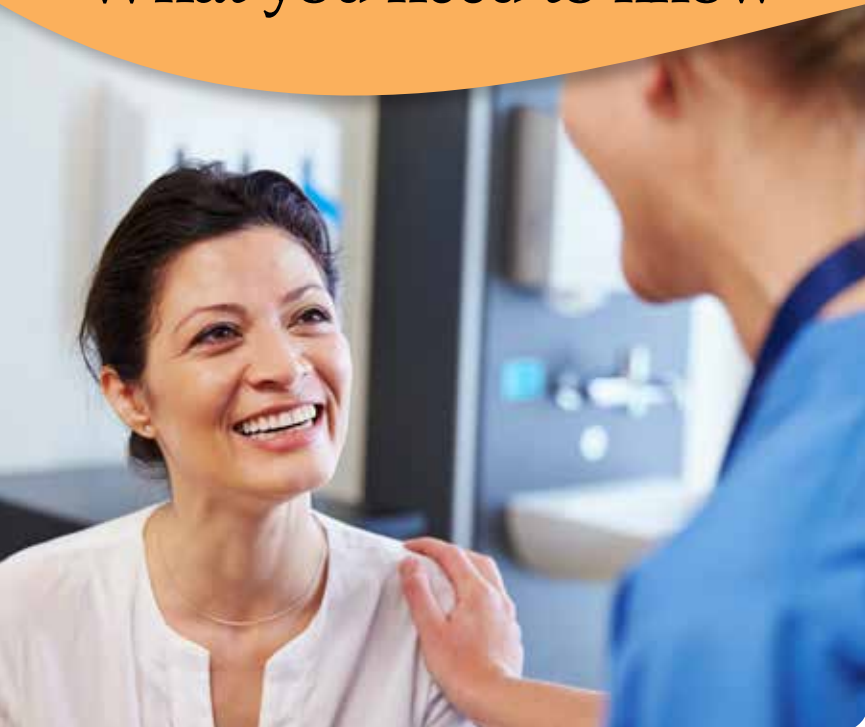
- People in their mid-20s to mid-60s may get their first symptoms of hATTR.
- Men, especially if they have unexplained nerve pain, carpal tunnel syndrome, or irregular heart rhythms.
- People with a family history of heart failure or serious illness that resulted in unexplained death.
- hATTR amyloidosis can happen to anyone, but is more common in people from West Africa, Japan, Portugal, Ireland, and Sweden.
- In the U.S., the most common form of the gene for hATTR amyloidosis can be found among African Americans.

Symptoms

Your symptoms will depend on which organs have the amyloid deposits.

- **Nerve damage**
 - Numbness, weakness, and pain in feet and legs
 - Trouble with balance or walking straight
 - Dizziness from low blood pressure
 - Erectile dysfunction
 - Narrowing or blockage in the spaces within your spine, also known as spinal stenosis
- **Eyes**
 - Glaucoma
 - Abnormal blood vessels in eyes
 - Dark floaters
- **Swelling in the hands and/or feet**
- **Heart**
 - Irregular heartbeat
 - Shortness of breath
 - Worsening fatigue
- **Digestive system**
 - Diarrhea, constipation
 - Weight loss, loss of appetite, feeling full after eating just a little
 - Nausea and vomiting
- **Kidneys**
 - Proteins in urine
 - Kidney failure
- **Carpal tunnel syndrome**

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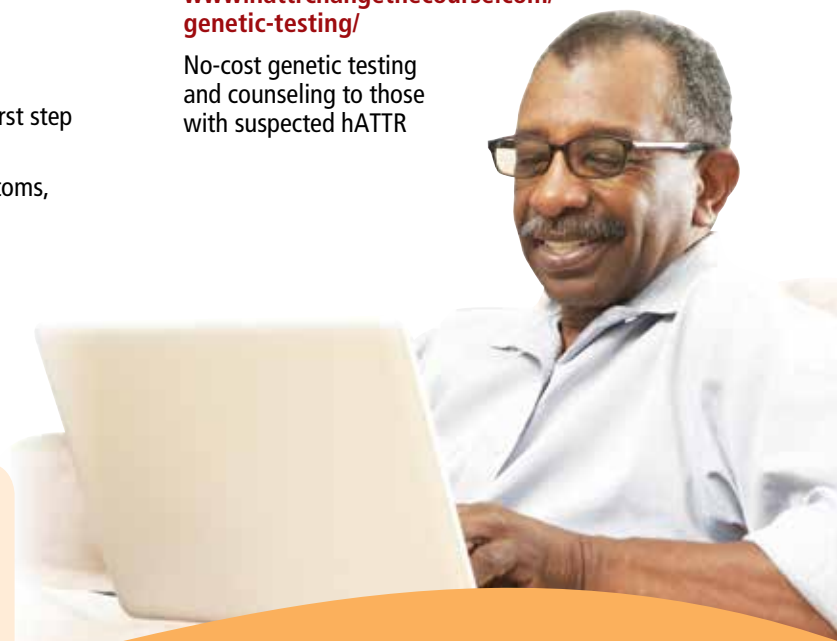


How can I learn more about hATTR?

Information and support for hATTR patients and their family is available through these organizations:

- Amyloidosis Foundation amyloidosis.org/
Patient and healthcare provider resources and services, research grants
- Amyloidosis Research Consortium arci.org/
Research and collaboration on amyloidosis treatment
- Amyloidosis Support Groups amyloidosis.org/
National and local support groups for those with amyloidosis
- National Organization for Rare Disorders rarediseases.org/
Patient advocacy organization focused on identification, treatment, and care of rare disorders
- Global Genes globalgenes.org/
Resource for patients with rare diseases, their caregivers, advocates, and supporters
- hATTR COMPASS www.hattrchangethecourse.com/genetic-testing/

No-cost genetic testing and counseling to those with suspected hATTR



Amyloidosis is often overlooked because of the variety of symptoms. Over time, the symptoms get worse and include more parts of the body. It is important to talk with your health care provider and receive a test for the gene for hATTR amyloidosis. Early detection is the key to management and treatment!

How is hATTR diagnosed?

- Common signs, symptoms and complications of hATTR is the first step in diagnosis.
- Talk with your health care provider if you have signs, symptoms, or complications of hATTR amyloidosis.
- Specific tests may be performed to determine if ATTR is the cause of your symptoms.
- Identifying family history is also important.
- A genetic test for the hATTR gene is the final step to confirm the diagnosis.

Hereditary ATTR amyloidosis is now treatable. The earlier you receive treatment, the better. Talk to your health care provider to discuss an appropriate treatment plan for you. This may include a referral to an amyloidosis specialist.