AMYLOIDOSIS ALLIANCE THE VOICE OF PATIENTS

UKATPA ATTR AMYLOIDOSIS PATIENTS' ASSOCIATION

ATTR AMYLOIDOSIS ALL IRELAND SUPPORT GROUP

Find your path to better health with **STAR: The Symptom Tracker** app for people with **ATTR amyloidosis.**

Download on the App Store

GET IT ON Google Play

For more information, please refer to the sources of information within this booklet.

STAR: The Symptom Tracker app does not pursue a medical purpose. It is designed to keep a record of users' symptoms, how they change over time and their impact on users' well-being and lifestyle. The app is not intended as a disease monitoring tool or as a symptoms checker. To have symptoms checked, users are advised to talk to their healthcare professional. Furthermore, STAR: The Symptom Tracker app does not make any medical diagnoses. Users are advised to seek the advice of a medical professional if they are concerned about their health.

Alnylam PHARMACEUTICALS

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the BRIDGE hATTR amyloidosis

Family Health Tree

Map your family's history of hereditary ATTR amyloidosis

Alnylam PHARMACEUTICALS Developed and funded by Alnylam Pharmaceuticals®

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Keep track of your family's health history

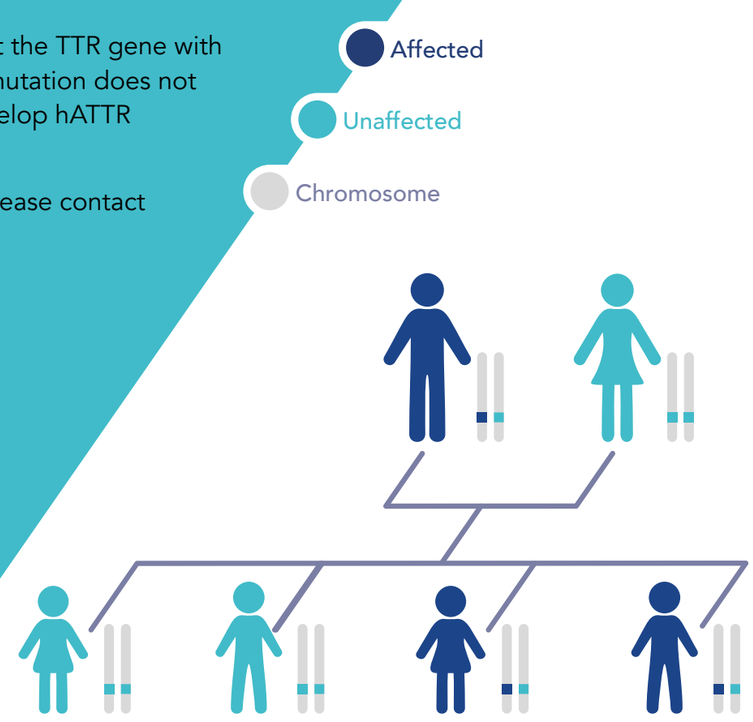
This chart can help you map your extended family relationship and determine who may be at risk of hereditary ATTR (hATTR) amyloidosis.

hATTR amyloidosis – an inherited condition

hATTR amyloidosis is a rare condition that affects an estimated 50,000 people worldwide. It is an inherited condition caused by a gene change (mutation) that affects the function of a protein called transthyretin (TTR). The age that initial symptoms appear may vary, ranging from the mid-20s to the mid-60s. It's passed down in an autosomal dominant pattern, which means a person only needs to inherit one copy of the affected gene from one parent in order to develop the disease risk. When one parent carries an autosomal dominant mutation, any child will have a 50% chance of inheriting that mutation.

A family member may inherit the TTR gene with a mutation, but having the mutation does not mean that he or she will develop hATTR amyloidosis.

If you have any questions, please contact your healthcare provider.



Working with your family members to complete this chart can help educate them about hATTR amyloidosis, its symptoms, and how it is passed down through generations. You can use the other materials in this pack to learn about the cause and symptoms of this condition.

Here is an example of how to fill out cards for each family member's "branch". Once the cards are filled, connect them by drawing lines as relevant to create your family health tree.

Father

John

Experienced symptoms of hATTR amyloidosis? Yes ☐ No ☑

List symptoms:

Other major medical conditions: Diabetes

Not ☐ Age diagnosed ☐ Age of onset of symptoms

Mother

Hannah

Experienced symptoms of hATTR amyloidosis? Yes ☑ No ☐

List symptoms: carpal tunnel, consistent dizziness when standing up, leg swelling, chest pain

Other major medical conditions: Heart condition

Not ☐ Age diagnosed ☐ Age of onset of symptoms

This chart assumes that you have hATTR amyloidosis, so starting with yourself in the middle, map those family members you have a genetic relationship with.

Keeping track of your health history

Use this space to record any important notes from conversations with your family members, including points about your family's history and follow-up steps.

Notes

Sources of support

the BRIDGE hATTR amyloidos

https://www.hattrbridge.eu

The Bridge™ is a website developed and produced by Alnylam Pharmaceuticals; it is designed to help raise awareness of hereditary ATTR (hATTR) amyloidosis and promote education on the condition for patients and their families.

AMYLOIDOSIS ALLIANCE THE VOICE OF PATIENTS

Amyloidosis Alliance is an international umbrella patient advocacy organisation, aiming to raise awareness and improve the quality of care of amyloidosis patients.

ATTR AMYLOIDOSIS ALL IRELAND SUPPORT GROUP

amymattrs@gmail.com

ATTR Amyloidosis All Ireland Support Group offers support to patients affected by Hereditary ATTR Amyloidosis or Wild Type ATTR Amyloidosis. We are committed to raising awareness to ensure people are diagnosed and have access to available treatments at the earliest opportunity.

UKATPA ATTR AMYLOIDOSIS PATIENTS' ASSOCIATION

info@UKATPA.org

https://www.ukatpa.com

UK ATTR Amyloidosis Patients' Association acts to provide extensive patient information and support.

Grandfather

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Grandmother

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Grandfather

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Grandmother

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Aunt/Uncle

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Aunt/Uncle

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Aunt/Uncle

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Mother

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Father

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Aunt/Uncle

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Aunt/Uncle

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Aunt/Uncle

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Sister/Brother/Cousin

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Sister/Brother/Cousin

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Sister/Brother/Cousin

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

You

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Partner

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Sister/Brother/Cousin

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Sister/Brother/Cousin

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Sister/Brother/Cousin

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Child

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Child

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Child

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Child

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Child

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Child

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Child

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms

Child

Experienced symptoms of hATTR amyloidosis? Yes No

List symptoms:

Other major medical conditions:

Age diagnosed

Age of onset of symptoms