

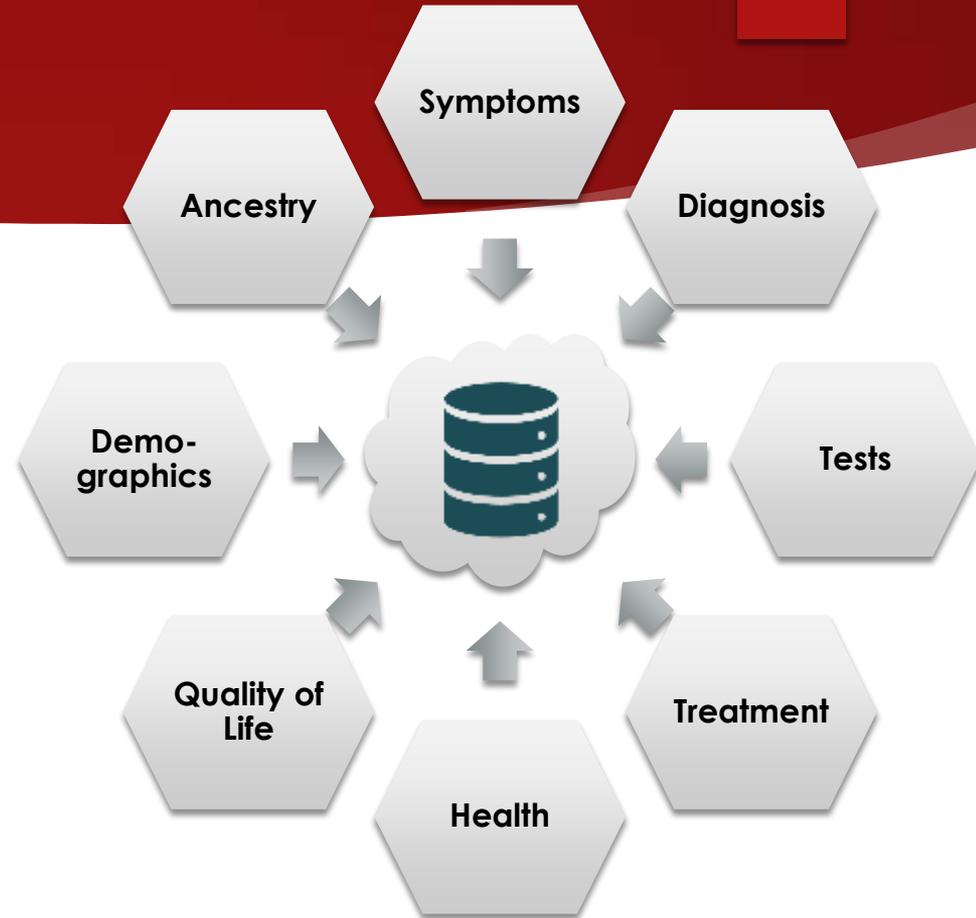
A graphic of a red ribbon that forms the profile of a human head, facing left. The ribbon starts at the top, curves down to form the forehead, then curves back up to form the top of the head, and finally curves down to form the neck and jawline. The ribbon has a slight gradient and a shadow effect, giving it a three-dimensional appearance.

AMYLOIDOSIS
PATIENT
REGISTRY

amyloidosisissupport.org/registry

What is it?

- ▶ **A secure, online database**
- ▶ **Patient-reported data about their experience with amyloidosis**
- ▶ **A resource for the entire amyloidosis community**
- ▶ **Created & managed by Amyloidosis Support Groups**



Why have a registry?



**Document
patterns of
disease
progression**



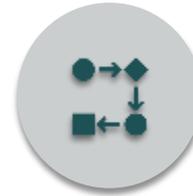
**Provide data
for research**



**Link people
to clinical
trials**



**Identify
effective
self care**



**Understand
common
paths to
diagnosis**

How is this different from existing registries?



Patient Supported



Patient Controlled



**Includes All Types of
Amyloidosis**



**Designed to Serve
Everyone**

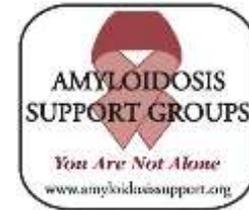
Will my data be private and secure?



PEER securely hosts 32 rare disease registries



Each participant controls who accesses their data



Registry managers certified in Protecting Human Research Participants

What can I do to help?



Patients

Sign up!
Add your data!



Physicians/
Med Centers

**Inform and
Promote**



Supporting
Organizations

**Spread the
word!**

How to sign up

amyloidosisupport.org/registry

1. Click **Register Now!**

2. Create account, sign in

3. Take the surveys!



SITE MENU

- Home Page
- Awareness Building
- Amyloidosis Info
- TTR & Familial
- Important Clinical Trials
- Upcoming Events
- About Us
- Contact Us
- Resources
- Support Centers
- Awareness Items
- AMY Blogs
- Patient's Day
- Survivor Stories
- In Memoriam
- Donations

Were you diagnosed with Cerebral Amyloid Angiopathy (CAA)?
[Click Here](#)



Amyloidosis Support Groups

We are a phone call or email away!

24/7 TOLL FREE HELP/HOT LINE: **866-404-7539**

OR EMAIL: Info@amyloidosisupport.org



Welcome to the Amyloidosis Patient Registry!

The Amyloidosis Patient Registry is a new resource for the entire amyloidosis community from Amyloidosis Support Groups. By compiling data on patient experiences with amyloidosis, the Registry will become the go-to resource for medical researchers and caregivers in their pursuit of earlier diagnosis, better treatment, and improved quality of life for those affected by this debilitating disease.

Your participation is the key to the Registry's success. By adding your data to those of other amyloidosis patients we expand the power of the Registry to make a difference for all of us. It is easy to participate and costs nothing but your time. After you register, you will fill out a series of surveys about amyloidosis and how it affects you and your family. The surveys don't have to be done in one visit. You can return to the surveys as often as you like to answer the questions.

Any information you share is private, secure, and completely controlled by you. Your data remains anonymous to researchers accessing the Registry unless you specifically allow them access to identifiable information like your name or contact information. If your anonymized data qualifies you for participation in a clinical trial, the Registry will notify you and ask for permission to release your contact information directly to the trial researchers.

Click on **REGISTER NOW** to get started with your own account or to sign in if you are a returning user.

Please note: the Amyloidosis Patient Registry will launch in a new window through our partner, Private Access, to ensure the privacy and security of your data.

 [Register Now \(or sign in\)](#)

 [Enter Health Information
Answer Survey Questions](#)

 [Let Researchers Find YOU!](#)

Support Group

↓ Meetings ↓

2019 CALENDAR

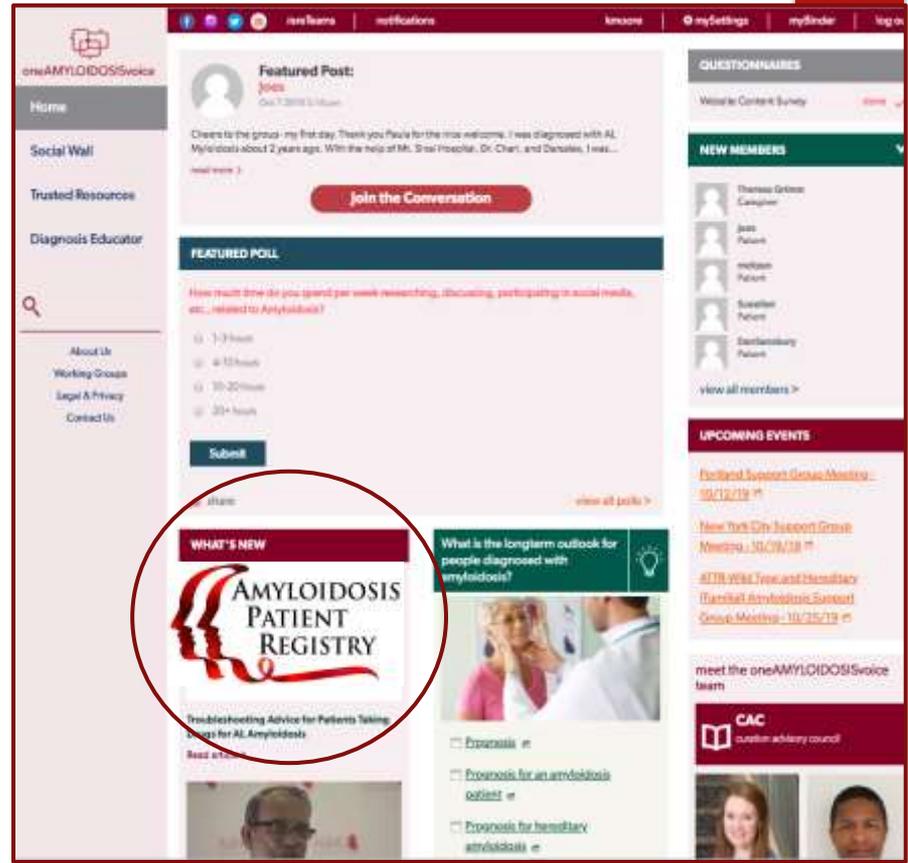
ATTR Hereditary and Wild Type

Non-ATTR Hereditary

- Arizona (Phoenix)
- California (Los Angeles)
- California (San Diego)
- Carolinas
- Chicago
- Colorado (Denver)
- Detroit
- Florida (Jacksonville)
- Florida (Miami)
- Florida (Tampa)
- Georgia/Alabama
- Indianapolis
- Kansas City
- Louisiana
- Maryland (Baltimore/D.C.)
- Maryland (Hagerstown)
- Massachusetts (Boston)
- Minnesota
- Nevada (Las Vegas)
- New York City
- New York (Rochester)
- OSU/Cleveland Clinic
- Philadelphia
- Portland
- St. Louis
- Texas (Dallas)
- Texas (Houston)
- Utah
- Virginia
- Washington (Seattle)
- Washington (Spokane)

No links are pharmaceutical means to our support group meetings to help in our goal of educating and empowering our patients. The financial and/or grant received from these companies are unconditional, and the ASG does not endorse any use of their products over any other type of amyloidosis treatment. These treatments are mentioned at our meetings, on our website, and other electronic format for educational purposes. We encourage you to consult your amyloidosis professional when

You can also link through ASG partner oneAMYLOIDOSISvoice.com



- ❑ Click the Amyloidosis Patient Registry logo in the “What’s New” module!

Need Support?

For help or any questions please contact
Paula Schmitt, Patient Registry Manager
registry@amyloidosisupport.org

