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

1. Click **Register Now**!
2. Create account, sign in
3. Take the surveys!

amyloidosissupport.org/registry
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@amyloidosissupport.org