

What is the #1 thing you can do to support research? Join the ASF Alport Patient Registry!

Enrollment is voluntary, secure, free of charge, and the most important research step we can take as a patient community.

Enrollment Criteria

- Reside in the U.S. (and its territories/islands)
- Confirmed clinical diagnosis of Alport syndrome*
- Any age; parents/caregivers can enroll affected children
- Any stage of disease (pre- and post-transplant)

*Examples of clinical diagnoses include: positive genetic testing and/or biopsy, and/or a diagnosis from a medical professional based on an individual's symptoms and/or family history.

What Happens After Enrollment

- Complete brief online surveys to capture health data
- Enter lab values, symptoms, treatment meds, and other important data, which can be updated every 90 days
- Upload genetic test results and audiogram files at any time

Benefits of Enrollment

- Have your voice heard by those studying Alport syndrome
- Help document specific genetic mutations
- Report understudied aspects of our disease
- Get notified about clinical trials



Learn more at:

https://alportsyndrome.org/about_ourpatientregistry/ or scan the QR code below:

