



www.alportsyndrome.org has free resources: diagnosis, genetics, treatment, research, and more.

NEW PATIENT REGISTRY

Participation in the ASF Alport Patient Registry is voluntary, free, and open to patients in the U.S. (and U.S. territories). A parent or guardian may enroll a child/children with Alport syndrome.

Learn more:



BENEFITS OF PATIENT ENROLLMENT:

- Help document Alport syndrome genetic mutations.
- Personally support research with anonymous patient data.
- Provide data for understudied complications like hearing loss, eye conditions, esophageal/soft tissue disorders, and more.
- Get notified on how to join the latest clinical trials.

NATURAL HISTORY STUDY

In partnership with NEPTUNE at the University of Michigan, this 3-year natural history study aims to recruit both pediatric and adult Alport patients with diverse genetic mutations. Numerous study sites are available across the U.S. and Canada.

ENROLLMENT DETAILS:

- Travel stipends and reimbursements are available.
- Patients may remain on their current standard of treatment.
- Biosamples collected will provide critical human data to support translational research for potential new treatment options.

Learn more: info@alportsyndrome.org

Alport syndrome patients are encouraged to consider enrolling in these valuable research efforts.