



Alport syndrome affects all ages, sexes, and ethnicities.

Alport syndrome is a rare genetic kidney disease that may cause end stage kidney failure, hearing loss, eye abnormalities, and other complications. Education and support for patients and families can be found at [www.alportsyndrome.org](http://www.alportsyndrome.org).

One of the most powerful ways that patients can help change their own family's journey with Alport syndrome, as well as improve outcomes for many others in the future, is to participate in research such as The Natural History Study in Alport Syndrome.

## The Natural History Study in Alport Syndrome

Study Period: 3 years

### Examples of Data Collected During the Study Period:

Family history, hearing evaluations, eye evaluations, quality of life surveys, urine collections, and blood draws. A sample of kidney biopsy tissue will also be requested for patients undergoing a clinical biopsy.

Year 1	(Biopsy)				
Screening	if clinically indicated	Baseline labwork	4 month in-person	8 month virtual	12 month in-person
Year 2		18 month virtual	24 month in-person		
Year 3		30 month virtual	36 month in-person		

For more information, email:

**NEPTUNE-STUDY@umich.edu**

Travel & other stipends are available.

