



Alport Syndrome Foundation Fast Facts

Who We Are:

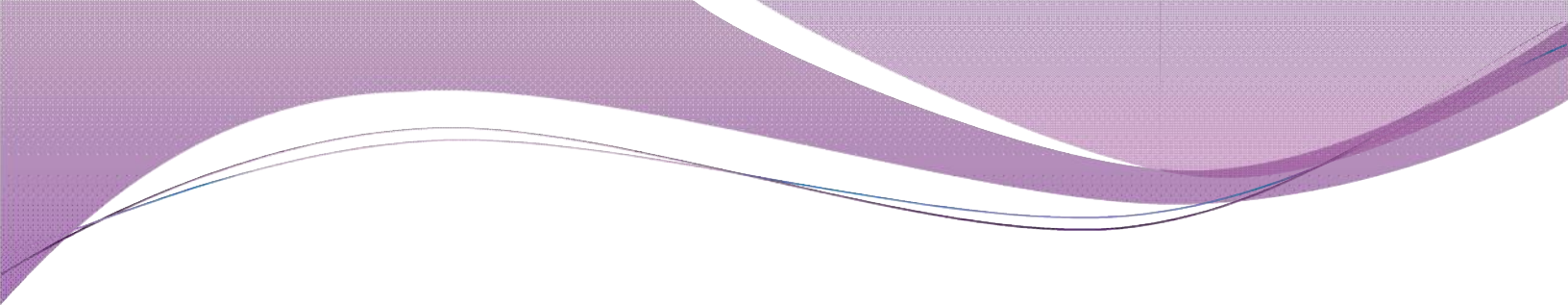
- ASF is a 501(c)3 non-profit founded in 2007 by families impacted by Alport Syndrome.
- ASF is guided by a Medical Advisory Committee of renowned Nephrologists and is the leading independent, non-profit organization in the U.S. educating and giving a voice to the Alport Syndrome community.
- ASF's vision is focused on finding novel treatments and a cure to prevent kidney failure and hearing loss in all patients with Alport Syndrome.

Why We Matter:

- Alport Syndrome is a rare inherited kidney disease that causes kidney failure, hearing loss and vision problems. An Alport Syndrome diagnosis devastates families because it often affects multiple family members in every generation.
- Most people have never met another patient outside their own family who has the condition. ASF provides a network of support and resources for families impacted by Alport Syndrome who feel isolated, vulnerable, and desperate for answers. ASF gives comfort and hope to thousands of men and women impacted by this disease.
- ASF works to raise awareness in both the medical and patient communities to maximize the resources available to patients and educate the community on the most current treatment guidelines.
- As a disease classified as both rare and orphan, Alport Syndrome receives relatively little attention and funding. ASF is working to change this and has directed the majority of the Foundation's resources to medical research.

What We Do:

- Fund research aimed at making finding better treatments and a cure to prevent kidney failure and hearing loss.
- Support the patient registry, Alport Syndrome Treatments and Outcomes Registry (ASTOR) at the University of Minnesota.
- Educate and inform patients on how they can impact research by joining the registry and participating in clinical trials.

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- Sponsor medical and patient conferences, meetings, and symposia for families, medical practitioners, and researchers, including at the American Society of Nephrology Kidney Week and the International Pediatric Nephrology Association Congress.
 - Create programs targeted to supporting teens and young adults, the age group hit hardest by the disease, including special programs at family conferences, a dedicated Facebook page called Alport Avengers, and the Paul Silver Tribute Awards.
 - Form strategic alliances and coordinate international resources with Alport Syndrome advocacy organizations around the world.
 - Maintain medical resources and distribute information about Alport Syndrome online and through social media, such as posting of educational materials, medical resources, a monthly newsletter, a patient blog, and conference and patient videos for both the patient and medical communities.

Our Accomplishments:

- Funded over \$1 million through the Alport Syndrome Research Program and to support the patient registry.
- Developed international partnerships, strategic alliances and research collaborations to increase resources applied to finding better treatments and a cure.
- Developing a research agenda for Alport Syndrome with global stakeholders (patients, clinicians, researchers, biotech/pharma industry) to prioritize the most promising or critical areas of research.
- Sponsor patient meetings or family conferences every year to connect patients with support and resources.
- Connected more than 7,000 patients, families, physicians and researchers in 74 countries.

Go to www.alportsyndrome.org to learn more.