

2023 Annual Report



Led by and dedicated to the
Alport syndrome community
of patients and families



Our Mission:

To improve the lives of those affected by Alport syndrome through education, empowerment, advocacy, and research.



Alport Syndrome Foundation

P.O. Box 4130

Scottsdale, AZ 85261

Tax Free ID# 20-8237159

Contact: info@alportsyndrome.org

2023: Reach + Growth Numbers

New ASF Members:

This includes individual patients, caregivers, family members, clinicians, researchers, and donors who joined ASF in 2023.

578

Contacts that received our monthly e-newsletter:

This primary form of communication with our community covers research updates, events, educational resources, and more.

7,375

Total patient/family users in our private, moderated Facebook support group:

Individual members from more than 80 different countries.

4,514

www.alportsyndrome.org page views:

Received views from 180 countries.

180,318

Full YouTube views of ASF's video resources:

1,888 hours of viewing time.

20,564

ASF Community App users:

Downloadable from the App Store and Google Play.

643

A Sampling of 2023 Accomplishments

Strengthened and Expanded Patient Resources

- Held the first in-person patient and family meeting since 2019, Alport Connect San Diego in October 2023. It was also our largest in-person event to date – hosting patients, family members, and medical experts from around the country.
- ASF Board, Staff, and volunteers represented the needs of the Alport community at in-person events with key stakeholders. We provided insights and guidance from the patient perspective related to pediatric clinical trials at a July meeting organized by the Kidney Health Initiative, NephCure, and the FDA. In November, ASF exhibited at the American Society of Nephrology's Kidney Week conference in Philadelphia, PA, which brought together over 12,000 participants in the nephrology space.
- Received the largest number of applications to date from a tremendous group of young adults living with Alport syndrome during the 2023 Paul Silver Enrichment Award cycle. Due to their outstanding applications, seven individuals were awarded funds provided by the Silver Family, ASF, and several anonymous donors. We are honored to have the opportunity to support their interests and individual goals.
- Increased the growth and strength of ASF membership. We welcomed 578 new members to our community, who are largely individuals interested in awareness, understanding, and advancement of research in Alport syndrome. Additionally, our international, moderated Facebook support group for patients and family members grew by 675 users in 2023.
- Developed new educational resources for the patient community, including a "Frequently Asked Questions: Life Insurance and Long-Term Care" document with the assistance of an ASF Emerging Leadership Council member who is also a professional in the insurance industry. This new resource addresses the major concerns of Alport patients who are considering purchasing a life or long-term care insurance policy for themselves or a child.

Advanced Research & the Pharmaceutical Pipeline

- Launched the ASF Alport Patient Registry in August 2023, which is fully funded and administered by ASF. Based on guidance from experts in Alport research, we believe this is the most critical way U.S. patients and caregivers can advance research that may lead to potential treatments and/or a cure.
- Established relationships with a wide range of industry partners from across the world working toward novel Alport treatments and/or a cure – these include preclinical studies, to those preparing to launch in 2024. Our investment in collection of human data (via the patient registry and NEPTUNE natural history study) is an important investment to support the growing pharmaceutical industry pipeline.
- Supported and facilitated publishing of a relevant case report of a female Alport patient who experienced an aortic aneurysm, along with a review of all cases of aneurysms in Alport patients that have been published to date. These initial findings, published in BMC Nephrology, seem to point toward a probable association of Alport syndrome with risk for aortic aneurysm.

2023 Finances

Income Sources

GENERAL CONTRIBUTIONS:

\$112,166

EVENT CONTRIBUTIONS:

\$110,847

ANNUAL CAMPAIGN:

\$317,829

CORPORATE PARTNERS:

\$120,000

CONTRIBUTIONS RESTRICTED FOR RESEARCH:

\$300,000

TOTAL INCOME: (807 DONORS)

\$960,842

Expenses

PATIENT PROGRAMS & SERVICES:

PATIENT MEETINGS, WEBSITE, COMMUNICATIONS TOOLS AND TECHNOLOGY, STAFF TIME MEETING WITH PATIENTS AND FAMILIES, AND MORE.

\$304,339

RESEARCH:

REGISTRY, NATURAL HISTORY STUDY, RESEARCH CONFERENCES, PUBLICATIONS, AND MORE.

\$200,678

GENERAL OPERATING:

INSURANCE, ACCOUNTING, AUDIT, ADMINISTRATION, FUNDRAISING, ADVERTISING.

\$95,749

TOTAL EXPENSES:

\$600,766

RESTRICTED AND CURRENTLY CONTRACTED FOR MULTI-YEAR RESEARCH PROJECTS FOR THE COLLECTION OF PATIENT NATURAL HISTORY AND BIOSAMPLE DATA, AND/OR BASIC SCIENCE RESEARCH IN ALPORT SYNDROME IN 2024:

\$293,886

Reported income and expenses have not yet undergone an annual audit. This Annual Report will be updated should any modifications be recommended through the professional audit.

A Few Notes From Our Members in 2023:

I want to thank you all for an amazing weekend of love, support, hope and education (at Alport Connect 2023). I truly felt blessed to be there. You guys are amazing. - October 2023

I think everyone with Alport syndrome or caring for a person with Alport syndrome should get connected to ASF! - October 2023

I have learned that even a nephrology appointment is not Alport-specific, so we need to learn Alport syndrome content and advocate for ourselves through ASF. - October 2023

My wife and I would like to say a warmhearted thank you for your time today. The knowledge and information provided was amazing and your stories inspiring. It's difficult to find the words to describe the respect we had for the both of you as we listened. As we start this journey, there are so many emotions. I cannot thank you enough for helping us work through them at the onset. - January 2023

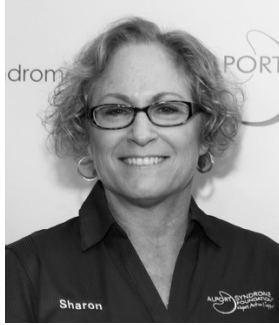
We are very appreciative for the support we have received from ASF so far in the last couple of months since diagnosis. It turned our world upside down but we are focused on the solution instead of staying in the problem. Referrals to doctors and therapists have been the best resource so far for us. Thanks again to the whole team and all you are doing to fight for the answers for all of us! - September 2023

The Alport online community through ASF has been so great at supporting one another and definitely reduces my anxiety knowing I have so many people for support and who will answer my questions. I was able to connect with another family in my direct community through the Facebook connection as well. Keep up the great work. - June 2023

Board & Staff 2023



Andrew Kronenberg
Chair, Board



Sharon Lagas
*Co-Founder &
Past President*



Marty Dunleavy
Treasurer



Ryan Linder
Secretary



Amy Rhodes
Board Member



André Weinstock
Chair, Research



Phillip Kumnick
Chair, Development



Stephen Malach
Chair, Mental Health



Dan Kilpatrick
Board Member



Lisa Bonebrake
Executive Director



Kevin Schnurr
Associate Director



Afton DeLucca
*Patient Engagement
Coordinator*

Contact: info@alportsyndrome.org
www.alportsyndrome.org

Emerging Leadership Council 2023



Adam Jardine



Sarah Kraut



Joseph Lagas



Maxwell Lagas



Kelly Lamanna



Maddison Martin



TJ Mayfield



John Watson

Mission: To ensure the voice of diverse patients and families is well-represented in ASF's decision making, and to help develop the next set of leaders to sustain ASF into the future.

Role of Members: Advise ASF Board and Staff on matters related to the needs and priorities of Alport patients and families.

