

# 2021 Annual Report



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



## **Our Mission**

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



## **Our Vision**

is to conquer Alport syndrome.



## **Alport Syndrome Foundation**

P.O. Box 4130

Scottsdale, AZ 85261

Tax Free ID# 20-8237159

Contact: [info@alportsyndrome.org](mailto:info@alportsyndrome.org)

# Growth by the numbers in 2021:

New members that joined our organization:  
250% increase in new members over prior year.

587

Total patient/family members in FB Support Group:  
85 countries represented; 20% growth over 12 months.

3,307

[www.alportsyndrome.org](http://www.alportsyndrome.org) website users:  
266% growth over the course of 12 months.

65,677

[www.alportsyndrome.org](http://www.alportsyndrome.org) page views:  
Increase of 76% over the prior year.

134,276

Full YouTube views of ASF's video resources:  
1,900 hours of watching; a 50% increase over  
prior year.

17,857

*Alport Connect* annual patient meeting registrants:  
Increase of 93% over the prior year.

486

# A sampling of 2021 Accomplishments

## Strengthened and Expanded Patient Resources

- Added a third Staff Member, a Patient Engagement Coordinator, who is also an Alport patient and caregiver, to address the needs of our growing patient community.
- Established an Emerging Leadership Council of volunteers to address the unmet needs of patients ages 25–35. The Council's first project was the creation of a digital, downloadable *Patient Guide* now available in English and Spanish.
- Completed an 18-month-long project documenting the insights and experiences of 25 Pediatric Alport patients (compiled via surveys and virtual meetings), culminating in the *Pediatric Alport Insight Report*. The report is designed to support clinicians and families and address both the physical and psychosocial challenges of growing up with Alport syndrome.
- Created and distributed *Annie Has Alport Syndrome*, an educational children's coloring book to help families talk about this rare disease with their children.
- Implemented a new way to connect patients through "Alport Direct Connect" virtual meetings for subgroups of patients: Ages 18–35, 35–50, 50+, as well as post-transplant-focused meetings.
- Provided live Closed-Captioning for all patient events and translation of several critical resources into Spanish.
- Based on input from the patient community, developed and recorded new educational webinars with medical experts, including an "Understanding Your Kidney Labs" session.

## Advanced Critical Research

- Provided two valuable research grants: Proof-of-concept gene therapy (Dr. Jeff Miner, Washington University in St. Louis) and Hearing loss (Dr. Felipe Santos, Massachusetts Eye and Ear Institute).
- Established a Scientific Advisory Research Network comprised of 8 international experts in Alport syndrome working collaboratively to strategically guide ASF on achieving its research investment objectives.
- Partnered with the National Kidney Foundation to develop the NKF Patient Network – Alport Syndrome, a new registry focused on capturing critical natural history data on Alport patients, including understudied aspects of our rare disease (to launch early 2022).
- Implemented a year-long *Diagnosis Stories* patient survey to better understand the prevalence of misdiagnosis and to collect data points for gaining an accurate diagnosis, with 350+ responses as of December 2021. The first-round report was released mid-year, along with a video companion piece focused on the experiences of female patients.

# 2021 Finances

## Income Sources

GENERAL CONTRIBUTIONS (458 DONORS)

**\$131,183**

ANNUAL CAMPAIGN (379 DONORS)

**\$202,286**

CORPORATE PARTNERS (7 SPONSORS)

**\$210,000**

RESEARCH PARTNERS (2 DONORS)  
(FUNDS RESTRICTED FOR RESEARCH)

**\$450,000**

TOTAL INCOME:

**\$993,469**

## Expenses

PATIENT PROGRAMS & SERVICES

**\$203,146**

RESEARCH

**\$205,932**

GENERAL OPERATING

**\$97,090**

TOTAL EXPENSES:

**\$506,168**

Restricted and pledged toward research projects for the collection of natural history and bio data on Alport syndrome patients:

**\$330,000**

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

**A few  
notes from  
donors in  
2021:**

*We're so happy with the progress being made, everyone at ASF is making a huge impact on the lives of so many. We're big fans of the Foundation, you can count on our support.  
- John & Anne*

*I'm so glad ASF exists and is finding myriad ways to support patients, families, and others. It's truly spectacular! - Dusty*

*The Foundation's work is critical. I wish I had millions to give you.  
- Sheila*

*We are very grateful to everyone at the Foundation for being so dedicated to our cause. Thank you very much!  
- Breno, Christina & Tiago*

*We are always happy to give and will always give what we can. The organization has brought hope to our family and we know it does to others. We are so thankful to have found you all. - Stephen*

*Please continue the great work you are doing. It is greatly appreciated and valued by those of us living with this syndrome! Thank you! - Vint*

*Glad to have found such a great community and resource as we navigate this new diagnosis in our family. So grateful for all that you have done and continue to do! - Amy*

# Board & Staff 2021



**Andrew Kronenberg**  
*Board Chair*



**Sharon Lagas**  
*Co-Founder &  
Past President*



**Marty Dunleavy**  
*Treasurer*



**Ryan Linder**  
*Secretary*



**Janine Reed**  
*Programs Chair*



**André Weinstock**  
*Research Chair*



**Phillip Kumnick**  
*Development Chair*



**Lisa Bonebrake**  
*Executive Director*



**Kevin Schnurr**  
*Associate Director*



**Afton DeLucca**  
*Patient Engagement  
Coordinator*

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