



2024 ANNUAL REPORT

Celebrating Progress.
Building Brighter Futures.

A year in review: research, support and stories of impact from the ASF community.

A MESSAGE FROM THE CEO AND BOARD PRESIDENT



AMANDA MOORE

At the Angelman Syndrome Foundation, hope is more than a feeling—it's a call to action. Every step we take is guided by our commitment to provide care, community and resources for every individual and family impacted by Angelman syndrome.

Our mission includes ensuring that every family has access to expert medical care, therapeutics and support they need throughout their journey. We remain dedicated to addressing gaps in care, eliminating obstacles to treatment, and creating pathways to the best possible outcomes for all. Throughout our ASF Clinic Network, led by expert physicians and specialists, we strive to provide individuals with Angelman syndrome personalized and compassionate care.

This year we continued to uphold our commitment to funding groundbreaking research by partnering with world-renowned experts driven by innovation and collaboration. We also expanded access to vital resources and elevated the voices of individuals with Angelman syndrome and their families through both local and national advocacy efforts.



LESLEY MCCULLOUGH MCCALLISTER

On behalf of the entire ASF team and Board of Directors, thank you for your trust, resilience, partnership, and belief in what we can achieve together. We are not just hoping for a brighter future—we are building it. The milestones we've reached together are not just achievements; they are promises fulfilled, made possible by the dedication and unwavering support from our families, donors and advocates like you.

With gratitude and determination,

AMANDA MOORE,
CEO, Angelman Syndrome Foundation

LESLEY MCCULLOUGH MCCALLISTER,
President, Board of Directors
Angelman Syndrome Foundation



2024 MILESTONES

1. INAUGURAL ANGELMAN SYNDROME CONGRESSIONAL ADVOCACY DAY IN PARTNERSHIP WITH FAST

In March, 65 Angelman syndrome advocates from around the United States met in Washington, D.C. to educate Congressional leaders on Angelman syndrome and the effect a treatment would have on the lives of our loved ones living with AS. In total, 111 meetings took place with 61 house districts and 50 senate districts.

2. ASF FAMILY CONFERENCE

In July 2024, the ASF community reunited at Kalahari Resorts in Sandusky, Ohio, with over 1,200 attendees from 42 states and eight countries. Attendees engaged in workshops, events, and presentations, building connections and fostering hope and collaboration for the future of the Angelman community.

3. ASF RESEARCH SYMPOSIUM

The ASF Research Symposium united 275 researchers, clinicians, and industry members this year. The event hosted 50 speakers and 30 sessions, fostering collaboration, sharing insights, and driving forward new approaches to improving care and advancing research for Angelman syndrome.

4. ASF WALK CELEBRATED 25 YEARS AND RAISED \$1.2 MILLION

The 2024 ASF Walk celebrated 25 years of walking for Angelman syndrome. Across 45 locations, we raised over \$1.2 million. Over 9,300 individuals participated with the support of 500 sponsors and in-kind donors.

5. FUNDED 13 RESEARCH PROPOSALS

Research is key to our mission and improving the lives of those with Angelman syndrome. In 2024, we funded 13 research proposals and over \$1.2 million in ASF-funded research, advancing our understanding of Angelman syndrome and bringing us closer to new treatments.



6. SUPPORTED 149 FAMILIES WITH THE ASF FAMILY FUND

The ASF Family Fund awarded 58 grants, totaling \$159,683, to provide resources and services for families. In addition, the Family Fund awarded 91 scholarships, totaling over \$77,000, enabling families to attend the 2024 ASF Family Conference and connect with the community, access valuable resources, and participate in educational opportunities.

7. STEPPING INTO AAC PROGRAM

The Stepping into AAC program launched to help individuals with Angelman syndrome build communication skills using Augmentative and Alternative Communication (AAC). The program equips families and caregivers with tools and training to implement AAC effectively. The program was honored with the knAAC Resource of the Year Award by Open AAC for its impact.

8. NEW PARTNERSHIPS

In 2024, ASF received invaluable support from our partners, including Abrams Nation, Angelman Academy, Beds By George, Courtney Bed, Ionis, Ladder Learning Network (RTI), Mass Mutual, Safe Place Bedding, Support NOW, Tobii Dynavox, Unite US, and Ultragenyx.



FAMILY SUPPORT

SUPPORTING ASF FAMILIES: OVER 30 YEARS OF SUPPORT AND CARE

A core part of ASF's mission is to "support individuals with Angelman syndrome and their families." We fulfill this mission by offering resources and programs to support families, including advocacy, grants, planning tools, webinars, events, podcasts, research, and more.

2024 FAMILY SUPPORT HIGHLIGHTS



ASF FAMILY CONFERENCE

Over **1,200 ATTENDEES** from **42 STATES** and **8 COUNTRIES**

275 researchers, clinicians and industry members in attendance

Over **50 PRESENTERS** and **30 SESSIONS**

91 CONFERENCE SCHOLARSHIPS



COUNSELING SERVICES

Provided **476 FREE COUNSELING** sessions for AS families



PODCAST

Season 3 launched totaling **25 EPISODES**

Over **9,000 EPISODE** downloads

Listeners from **62 COUNTRIES**



ASF FAMILY FUND

58 grants awarded, totaling **\$159,683**



ASF FAMILY VOLUNTEERS

58 family champions

15 family conference committee members

54 ASF Walk Coordinators across the nation



ASF FAMILY SUPPORT PROGRAMS

ASF continues to expand its Family Support resources and programs to help families during all stages of life.

Learn more about each program at angelman.org/resources-education

Advocacy

ASF Family Fund

Counseling Services

Communications Support

Family Champions

Adult Services

Sibling Resources

Crisis Fund

Sunshine Committee

Mentoring Program

ASF FAMILY FUND IMPACT



DYLAN'S STORY

“The ASF Family Fund has enabled Dylan to continue his therapeutic horseback riding lessons. He has been riding for years and looks forward to it each week. He has a precious bond with his sidewalkers, who give up their Saturday mornings to support him. The benefits are numerous – physical, social, communication, vocalization and fine and gross motor planning. He is still learning how to interact with his horse, use his reins to guide his horse, and consistently sign when he is ready to “walk on.” Over the past year, his confidence on the horse has increased immensely and his riding reflects this! Thank you ASF for providing the means for this to continue!”

ADULT SERVICES



LOGAN'S STORY

“Being part of the ASF family conference committee was the best experience I have ever done. Planning the event and being involved with this special group of women that has the same passion as I do to make sure that our angels are taken care of.

The ASF Family Conference helps families of adults with AS learn from other parents. We learned a lot from the doctors, caregivers, counselors, etc. as well as different types of equipment to use for our angels.”

SIBLING EXPERIENCES



“The sibling sessions at the ASF Family Conference have helped me learn a bit about what’s going on inside my sister’s head and have helped me to get her to stop pulling my hair. I also learned what to do if she has a seizure. That makes me feel more confident.”

- Vivian, 12

“Sitting in sessions at the ASF conference helped me understand the genetics of Angelman syndrome, and more specifically, the mutation genotype which my sister has. This knowledge has helped me explain AS to friends more easily.”

- William, 16





RESEARCH

ASF has invested over \$15.7 million in Angelman syndrome research, funding projects across the globe to advance treatments and work toward a cure.

ASF-FUNDED RESEARCH HIGHLIGHTS

\$15.7M+

**Research Investment
Since 1996***

13

**Research Studies
Funded in 2024**

\$1.2M+

**Research
Funded in 2024****

* Cumulative research investment
** Total includes first- and second-year grants from current and / or prior year funding rounds. Full award amount is not fully expensed during a fiscal year if the study is multi-years.

OUR RESEARCH FOCUS

We focus on funding the highest-caliber research in the following areas:

1 High-Risk, High-Reward
Strategies to find a cure, including topoisomerase inhibitors, ASOs, gene therapy and CRISPR

2 Clinical Studies
To alleviate symptoms and improve quality of life

3 UBE3A Studies
To help us learn about UBE3A and what it does in the brain

OUR PHILOSOPHY: ASF FOCUSES HEAVILY ON PILOT FUNDING

We grant a modest amount of initial funding that a researcher can use to "test drive" an idea. If the test drive looks good, the researcher is then able to ask larger agencies, like the National Institutes of Health, Simons Foundation and

other pharmaceutical companies to provide more funding to expand the project. Every pivotal idea starts with pilot funding. When we choose projects to fund, we do so with the knowledge that incremental studies enable the next big leaps.



2024 RESEARCH UPDATES

ULTRAGENYX ANNOUNCES SUCCESSFUL END-OF-PHASE 2 MEETING WITH FDA

July 7, 2024

Ultragenyx Pharmaceutical Inc. successfully completed an end-of-Phase 2 meeting with the U.S. Food and Drug Administration (FDA) regarding GTX-102, an investigational antisense oligonucleotide therapy for Angelman syndrome. The FDA agreed on the design and endpoints for the upcoming Phase 3 study, which was scheduled to begin by the end of 2024.

The primary endpoint will assess cognitive improvement using the Bayley-4 cognitive raw score, with a key secondary endpoint evaluating the Multi-domain Responder Index (MDRI) across cognition, receptive communication, behavior, gross motor function, and sleep. This pivotal trial aims to enroll approximately 120 patients with a confirmed diagnosis of full maternal UBE3A gene deletion.

Additionally, Ultragenyx plans to initiate a separate study to evaluate GTX-102 in patients with other mutations, broadening the potential treatment scope for individuals affected by this condition.

IONIS RELEASES DATA FROM THE PHASE 1/2 HALOS CLINICAL TRIAL

July 22, 2024

Ionis Pharmaceuticals announced positive results from the HALOS study of ION582, an investigational antisense medicine for Angelman syndrome. The study demonstrated significant improvements in communication, cognition, and motor function across a broad patient population, with 97% of participants in the medium and high dose groups showing overall symptom improvement as measured by the Symptoms of Angelman Syndrome–Clinician Global Impression-Change (SAS-CGI-C).

Notably, enhancements in cognition, communication, and motor skills, assessed using the Bayley-4 scale, surpassed those observed in natural history studies. ION582 exhibited a favorable safety and tolerability profile at all dose levels. Based on these encouraging findings, Ionis plans to initiate Phase 3 development in the first half of 2025.

NEUREN RELEASES RESULTS FROM PHASE 2 CLINICAL TRIAL OF NNZ-2591

August 12, 2024

Neuren Pharmaceuticals announced positive top-line results from its Phase 2 clinical trial of NNZ-2591, an investigational oral liquid treatment for Angelman syndrome (AS).

The trial involved 16 children aged 3 to 17 years and demonstrated that NNZ-2591 was safe and well tolerated, with no serious adverse events reported. Significant improvements were observed in key areas such as communication, behavior, cognition, and motor abilities. Clinician assessments using the Clinical Global Impression of Improvement (CGI-I) showed that 11 out of 13 children exhibited improvement, with a mean score of 3.0 ($p=0.0010$). Caregiver assessments mirrored these findings, with 8 out of 12 children showing improvement, yielding a mean score of 3.2 ($p=0.0273$). Notably, all children aged 3 to 12 years demonstrated improvements in both clinician and caregiver evaluations. These results bolster confidence in NNZ-2591's potential to address core symptoms across multiple neurodevelopmental disorders.



LADDER

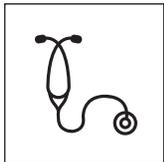
Learning Network



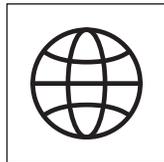
FOR PATIENTS. FOR PROVIDERS. TOGETHER, TOWARD THE CURE.

The LADDER Learning Network provides high-quality medical care for individuals with AS or Dup15q. The network connects those who practice evidence-based medicine with a high level of excellence for these two rare syndromes.

2024 HIGHLIGHTS



1,145 PATIENTS
Served at ASF
Clinics Worldwide



2 NEW ASF CLINICS
Opened



972 INDIVIDUALS
Enrolled in LADDER



402 GENETICS REPORTS
Reviewed and Classified
in LADDER



2024 ADVANCEMENTS



SYSTEMATIC COLLECTION OF PATIENT DATA

The LADDER Learning Network (LLN) is now systematically collecting patient number data from each site for the first time, signifying a significant step toward building a comprehensive and unified dataset. This enables the LLN to facilitate data-driven decision-making, support research, and identify trends.

EPILEPSY WORKING GROUP

An Angelman Syndrome Epilepsy Working Group was established in 2024. This group focuses on advancing research by streamlining data collection across clinical sites, aligning on shared research questions, and collaborating on the upcoming LADDER seizure experiences survey publication to enhance understanding and care in Angelman syndrome-related epilepsy.

PROVIDER EDUCATION CALLS

The LADDER Learning Network Provider Education Series hosted eight calls in 2024. These calls aim to share the latest research, clinical practices, and insights from the LADDER Learning Network. Topics discussed included:

- LADDER Data Review
- Genetics
- LLN Colleagues Networking
- New Movement Phenotypes
- Refractory Sleep Disorder
- Growth Patterns in AS

TWO NEW CLINICS

In March, Cedars-Sinai Guerin Children's opened its clinic, led by Cesar Ochoa-Lubinoff, MD, MPH. Later in August, Cincinnati Children's Hospital Medical Center launched its clinic under the leadership of Kate Zappia, MD, PhD.

CENTERS OF EXCELLENCE

Children's Hospital of Colorado, Children's Hospital of Los Angeles, Carolina Institute for Developmental Disabilities at UNC and Richmond University Medical Center all received a renewal as a Center for Excellence for the next three years. ASF Clinics welcomed a new Center of Excellence in 2024, at Bethesda Children's Hospital in Budapest.

LADDER DATABASE PROTOCOL PUBLICATION

An article published in Sage highlights the development, functionality, and collaborative potential of the innovative LADDER database, showcasing it as a pioneering model for rare disease research while celebrating the collective efforts behind its creation.

NEW LADDER FAMILY REPORT

A new, family-friendly report was published by Anjali Sadhwani, PhD, available in LADDER, providing insights into developmental milestones and daily living skills for individuals with Angelman syndrome, helping clinicians and caregivers set realistic goals based on genotype.



FUNDRAISERS

2024 ASF WALK | *Raised +\$1,294,800*



The 2024 ASF Walk marked its 25th anniversary, showcasing the event's remarkable growth since its inaugural walk in 1999, which raised \$26,000. This year, the walk raised over \$1.2 million, uniting more than 9,300 participants across 45 locations nationwide. With the support of 500 sponsors and in-kind donors, the event not only generated critical funds but also raised awareness, strengthening connections within the Angelman syndrome community.

2023 CHICAGO MARATHON | *Raised + \$196,000*

The Angelman Syndrome Foundation's Windy City Angels team made a powerful impact at the 2023 Chicago Marathon. The team consisted of 45 dedicated runners, including the first Windy City Angels duo team. Together, the team raised over \$196,000 to support individuals and families affected by Angelman syndrome. This incredible effort highlighted the community's strength and determination, blending athletic achievement with a heartfelt mission to raise awareness and funds.



ANGELMAN EVENING | *Raised +\$678,600*

The 2023 Angelman Evening raised over \$678,600 to support individuals with Angelman syndrome, funding research, clinical care, and essential resources while celebrating community achievements and fostering hope for brighter futures.



COMMUNITY FUNDRAISERS

In 2024, families and friends came together through fundraisers, raising over \$290,000 for ASF. Driven by their love for someone with Angelman Syndrome, they achieved incredible milestones while enjoying the journey and making a meaningful impact!

Below are just some of the many fundraiser that took place in 2024.

Blarney Cup
Raised \$11,000

ASF Fashion Show
Raised \$10,500

Brooklyn Half Marathon
Raised \$6,390

Go Team Maddy
Raised \$18,998

Chip Away at AS Golf Tournament
Raised \$7,650

Golf Outing for Logan
Raised \$11,123

Oregon Cornhole Tournament
Raised \$7,569

Sutton Smith Golf Outing
Raised \$10,000

Cornhole for a Cure - Colorado
Raised \$45,742

The Granville Angels
Raised \$9,500

Erin Jenkin's Golf Outing
Raised \$7,000

The Hope Classic
Raised \$11,363

Ragnar Relay
Raised \$46,673



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THANK YOU TO OUR VISIONARY LEADERS

Donations received October 2023 to September 2024.

Betty J. Shaw Benefactors, \$100,000+

Anonymous Donor

Harry Angelman Champions, \$50,000+

La Vonne S. Bressler*, Donna O'Regan, Ultragenyx Pharmaceutical, Inc.

Heroes Giving Hope, \$10,000+

Angelman Roofing & Restoration, Anonymous Donor, Antonieta Arango, Javier Arango, John and Tracy Atkinson, Larry and Cathrine Blain, Blarney For Angelman Foundation, Cody's Quest. Inc., Coldwell Banker ABR Cares, Columbia Family Foundation, Kurt Fenzan, Genentech Inc, Gloria Gibson, Jay and Amy Granzow, Karen Hoerst and David Rosenblatt, Lee Hudson, HundredX, Inc., Ionis Pharmaceuticals, Jack's, Ryan and Anne Jacob, James Lee and Annanette Harper Family Foundation, Ladies Philoptochos Society of HTGOC, John and Kelsey Laskowski, Keith F. Lauder, James and Ana Libby, Little Switzerland, Maddie's Mission Foundation, MassMutual SpecialCare, Maverick Capital Foundation, Drew and Lesley McCallister, Timothy and Gretchen McCarty, Tom and Ruthann McCarty, Keith and Elise McDonald, Denise Nelson, Christian Pache and Anna Hsu, Wayne and Jana Pott, Renee Pritzker, Protective Packaging Corporation, Inc, Rakoczy Molino Mazzochi Siwik LLP, Patrick and Laura Sargent, Bryan Schnick and Allyson Tole, Timur M. Siddiq, Dorothy Stell, Adam and Melissa Stone, Patrick Terrio and Margaret McGrath, William and Joyce Veldman, Victor and Clara C. Battin Foundation, Vivint Gives Back

Sustainer, \$5,000+

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*in memoriam



ASF STORIES



We've been participating in ASF events since 2018 and have always cherished the incredible support from the community. However, this year marked our first Family Conference—and we had no idea how much we'd been missing out! From connecting with other Angelman parents and sharing our journeys, to watching our two younger children light up with excitement every time they entered the SibShop room, the experience was truly unforgettable.

What made it even more special was bringing along my parents and my oldest niece and nephew. My parents found a welcoming space where they could connect with other AS grandparents, sharing their experiences and offering support to those new to this journey. Meanwhile, my niece and nephew, who have been integral to Marlee's life, were able to relax and gain a new perspective. Their biggest takeaway was seeing older individuals with AS, which helped them realize that Marlee understands much more than she can express right now and will continue to grow in her understanding of the world, even though she is nonverbal.

The Family Conference was an extraordinary experience that strengthened our family's bond and renewed our hope for the future.

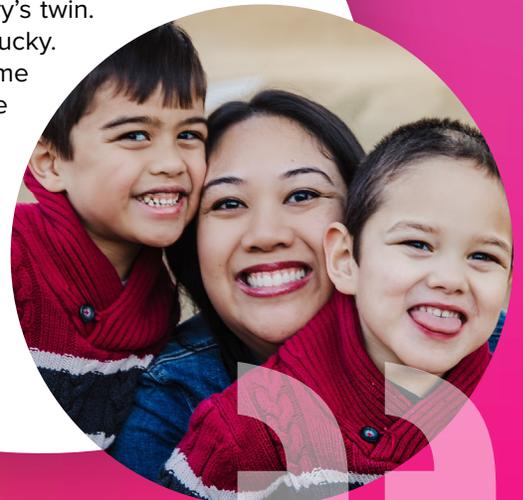
– Taylor Geathers

I want to say THANK YOU and express my gratitude for the ASF Family Conference. It has had such lasting effects for all of us, but especially for Zachary's twin, Parker. Prior to the conference, I could see his growing frustration with Z with the typical struggles siblings go through with having a sibling with a disability—less time with us, hitting, wrestling, too many hugs, sadness over his brother not talking. It was taking its toll.

I'm not sure what magic was done in the SibShops (we couldn't even make it to the first one!!), but he came home with a very different perspective. On the first day of school, he told the class his favorite part of summer was the ASF conference. He's so proud to be Zachary's twin. When we've had 1:1 time with Parker, he has told me, "Mom, we're like REALLY lucky. Angelman is super rare and I just can't believe how lucky we are." For the first time in three years, Parker asked to have a joint party with his twin. He picked a place he said "everyone can enjoy" and has been super excited to go to parties of Zachary's friends because "special needs parties are the best ones!"

I know their sibling relationship will have different seasons, but I'm SO grateful to be in this one right now. You all put together an incredible event and it's made SUCH a huge difference in our lives, even 4 months later! Oh, and Z is about 80% potty trained and can tell us on his talker when he wants to go... another thanks to the conference!

Hugs,
Carmen



FINANCIAL BREAKDOWN

STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED SEPTEMBER 30, 2024 AND 2023

Current Assets:	2024	2023
Cash and Cash Equivalents	\$1,122,681	\$758,252
Pledges Receivable, Current Portion	\$15,518	\$10,000
Investments	\$1,391,676	\$1,360,979
Inventory	\$6,813	\$13,391
Pre-paid Expenses	\$47,455	\$62,147
Total Current Assets	\$2,584,143	\$2,204,769
Property & Equipment (at cost):	2024	2023
Office Furniture, Fixtures and Equipment	\$2,921	\$2,921
Computer Hardware	\$19,172	\$19,172
Software	\$533,285	\$533,285
Website	\$69,687	\$24,000
Less - Accumulated Depreciation	\$(575,568)	\$(539,671)
NET Property & Equipment	\$49,497	\$39,707
Other Assets:	2023	2022
Pledges Receivable, Long-Term Portion	\$20,000	\$29,889
TOTAL ASSETS	\$2,653,640	\$2,274,365
Liabilities & Net Assets	2024	2023
Current Liabilities		
Accounts Payable	\$98,619	\$87,751
Grants Payable	\$563,922	\$95,702
Accrued Payroll Expenses	\$74,829	\$63,549
Deferred Event Revenue	—	\$40,492
Total Current Liabilities	\$737,370	\$287,494
Net Assets	2024	2023
Without Donor Restrictions	\$1,074,253	\$1,234,241
With Donor Restrictions	\$842,017	\$752,630
Total Net Assets	\$1,916,270	\$1,986,871
TOTAL LIABILITIES & NET ASSETS	\$2,653,640	\$2,274,365

STATEMENT OF ACTIVITIES FOR THE YEAR ENDED SEPTEMBER 30, 2024 AND 2023

PUBLIC SUPPORT & REVENUE		
	2024	2023
Contributions	\$1,601,206	\$2,338,736
Donated professional services	\$12,128	
Biennial Conference	\$212,824	\$37,149
Special Events, net of related expenses, which includes:		
in-kind revenue of \$453,530 and \$269,750 for 2024 and 2023, respectively	\$1,701,796	\$1,158,174
Net Investment Return (Loss)	\$330,532	\$100,472
Other Income	\$5,123	\$3,794
Net assets released from restrictions - satisfaction of program restrictions	----	----
TOTAL PUBLIC SUPPORT & REVENUE	\$3,863,609	\$3,638,325
FUNCTIONAL EXPENSES		
Program Services	2024	2023
Family Support	\$1,218,228	\$2,125,761
Research	\$1,334,111	\$557,838
Biennial Conference & Symposium	\$487,769	\$65,673
TOTAL PROGRAM SERVICES	\$3,040,108	\$2,749,272
Management & General	\$252,761	\$261,308
Fundraising	\$641,341	\$624,748
TOTAL FUNCTIONAL EXPENSES	\$3,934,210	\$3,635,328
CHANGE IN NET ASSETS		
	2024	2023
Change In Net Assets	\$(70,601)	\$2,997
Net Assets, <i>Beginning Of Year</i>	\$1,986,871	\$1,983,874
Net Assets, <i>End Of Year</i>	\$1,916,270	\$1,986,871





angelman

SYNDROME FOUNDATION

The mission of the Angelman Syndrome Foundation is to advance the awareness and treatment of Angelman syndrome through education and information, research and support for individuals with Angelman syndrome, their families and other concerned parties. We exist to give all of them a reason to smile, with the ultimate goal of finding a cure.

Join Our Community



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