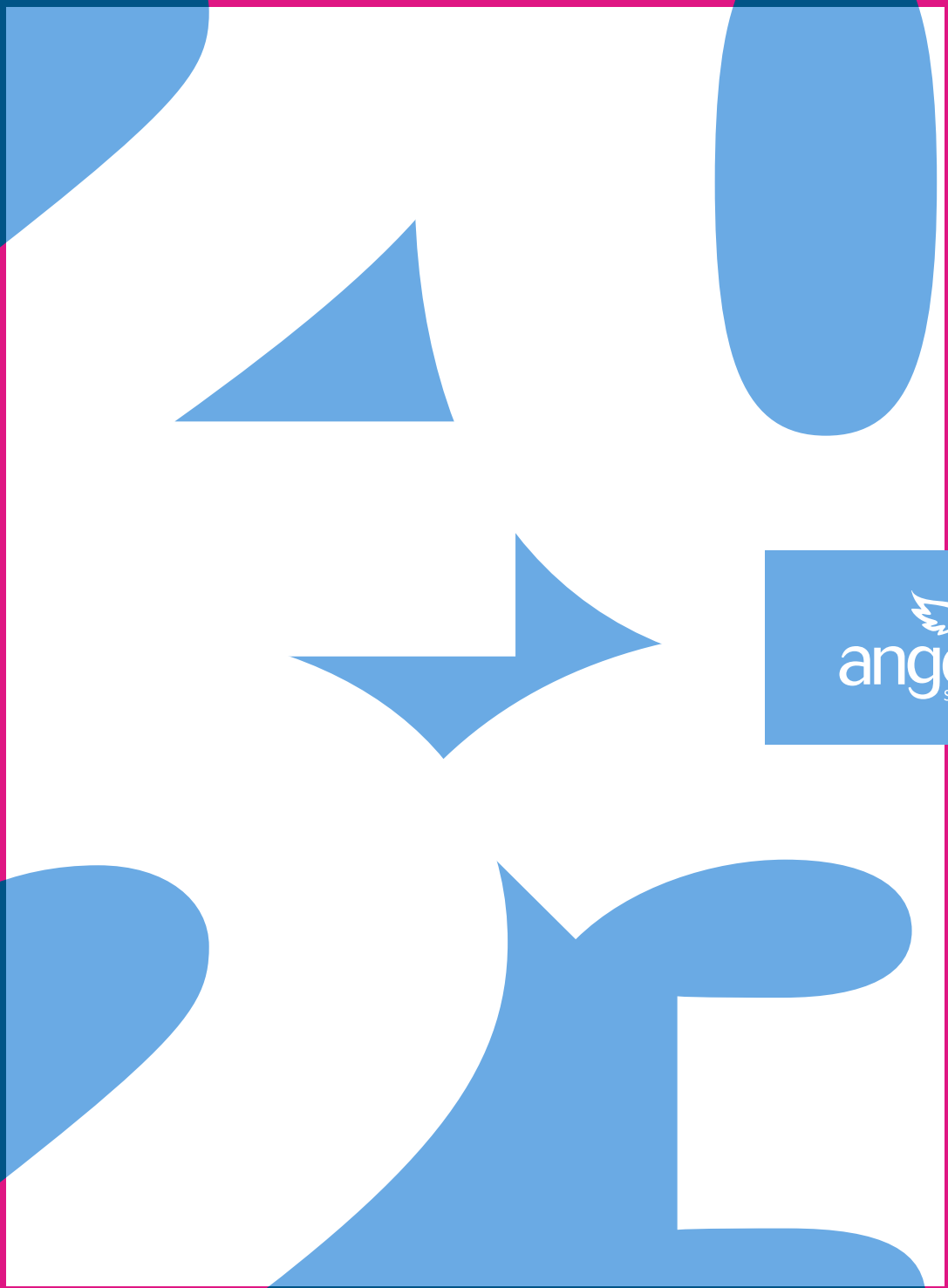
2023



angelman
SYNDROME FOUNDATION

ANNUAL REPORT

DEAR ASF COMMUNITY,

As we close another remarkable year, we find ourselves reflecting on the incredible journey we've undertaken together. It is with heartfelt gratitude and immense pride that we extend our deepest thanks to each and every one of you who has been part of our collective effort.

Your unwavering support, dedication and generosity have fueled our progress in ways that words can hardly capture. Together, we have achieved remarkable milestones in our pursuit of a brighter future for individuals and families affected by Angelman syndrome.

From the tireless work of our dedicated volunteers to the impactful contributions of our donors and partners, you have all played an indispensable role in our shared mission. The progress we've made this year—expanding our support networks, creating ASF Clinics and advancing critical research—is a testament to your commitment and the power of our community.

As we look forward to the possibilities that the coming year holds, we do so with a deep sense of optimism and determination. Our journey is far from over, but with your continued support, we are confident that we can face the challenges ahead with resilience and hope.

From the bottom of our hearts, thank you for your unwavering dedication to Angelman Syndrome Foundation. Together, we are making a profound and lasting impact on the lives of those we serve.

Sincerely,

KYLE ROONEY, Board of Directors President
AMANDA MOORE, CEO

2023 MILESTONES

1. OPENED FOUR NEW ASF CLINICS IN AMERICA
The four new ASF Clinics that opened in 2023 bring us to a total of 28 ASF Clinics available to Angelman families worldwide. New locations in the U.S. include Children's Health (Dallas, Texas), Children's Mercy (Kansas City, Mo.), Boys Town National Research Center (Boys Town, Neb.) and Kennedy Kriger Institute (Baltimore, Md.).

2. CREATED PARTNERSHIPS TO PROVIDE CARE ABROAD
ASF partnered with .PROT, an organization that is coordinating the efforts of Polish scientists and caregivers through the Projekt Zespół Angelmana (Angelman Syndrome Project), to launch a new Angelman Center to better serve the community in Poland. ASF also partnered with Genefund Future Angelman Syndrome (GFAS Ukraine) to launch a new clinic to better serve the community in Ukraine.

3. FUNDED $1.8 MILLION TO IMPROVE LIVES OF THOSE LIVING WITH ANGELMAN SYNDROME
In 2023, ASF funded a combined $1.8 Million to ASF Clinics, the LADDER Learning Network and AS research, as all three are central to our mission of advancing awareness and treatment for AS.

4. ASF & CASS PARTNERED TO EXPAND NORTH AMERICAN NETWORK
Canadian Angelman Syndrome Society (CASS) rebranded to become ASF Canada. The collaboration allows both organizations to leverage each others' robust networks.

5. WALKED TO RAISE $1.2 MILLION
The 24th annual ASF Walk drew 8,336 registrants across 48 locations nationwide. Our "Angelman Strong" participants raised awareness and vital funds, keeping our growing community connected.

6. ANGELMAN EVENING RAISED +$603K FOR ASF CLINICS
In December 2022, more than 385 supporters attended the Angelman Evening fundraiser in Chicago. The event raised more than $603,000 to support ASF Clinics.

7. LAUNCHED SIB BASHES
Siblings are the future caretakers of Individuals with AS, so supporting them is essential! In 2023, ASF sponsored regional parties in nine cities that were planned and executed by siblings of individuals with AS. Those selected received up to $1,000 to host their events, which were great opportunities for families to have fun and to make connections in their AS communities.

8. EXPANDED MENTAL HEALTH SERVICES
Even though caring for an individual with AS can be rewarding, we know that it can be challenging, stressful and isolating. In 2023, ASF offered 480 counseling services at no charge to Angelman families in the United States.

9. PARTNERED WITH UNITE US FOR MEDICAL & SOCIAL SERVICE REFERRALS
It's often difficult for Angelman families to find medical specialists, dentists and therapists who can care for their individuals with AS. Through ASF's partnership with Unite Us, families can now access a network of local health and social service providers and resources, making finding care easier.

FAMILY SUPPORT

ASF is committed to supporting families when and where they need it most.

2023 FAMILY SUPPORT HIGHLIGHTS

$370,923 provided to family support programs

152 ASF Family Fund Grants awarded, totaling $238,992

480 free counseling sessions provided to AS families

Continued Season 2, with **10 EPISODES** and **2,865 TOTAL LISTENS**

ASF FAMILY FUND IMPACT

JAX'S STORY

"Proloquo2Go has helped his communication explode by leaps and bounds." — Jessica Dileo

BECCA'S STORY

"Becca loves all her new chewy items and she uses them every day." — Michelle Stahl

AIDEN'S STORY

"This bicycle is perfect because he does not have the ability to pedal a traditional bicycle." — Duane Cameron

ASF FAMILY SUPPORT PROGRAMS

- ASF Family Fund
- Counseling Services
- Communications Support
- Family Resource Team
- Adult Services
- Sibling Resources
- Care Committee
- The Center for Courageous Kids

ADULT SERVICES IMPACT

BRETT'S STORY
"When our family received the call that a group home spot was available for Brett, we were shocked and filled so much emotion it was difficult to think clearly. Our regional center gave us a week to make a decision, so we turned to the ASF Facilities Checklist to guide us in the decision process. It provided a clear and comprehensive list of items to look for during our tour and a framework of questions and items to consider." — Michelle Brown

THE CENTER FOR COURAGEOUS KIDS

BECCA'S STORY
In March, The Center For Courageous Kids hosted more than 20 Angelman families. Creating opportunities for shared experiences and connection is invaluable, and this was a weekend families will not forget.

"I am so thankful for this incredible opportunity. Our experience at CCK was amazing from start to finish. Our boys loved camp, and riding horses was—by far—their favorite activity! The week- end we spent at camp made us feel like we were a "regular" family—something we haven't felt anywhere since Caden's diagnosis." — Leah Scott

SIB BASH SUCCESS

Siblings are the future caretakers of their siblings and it's a very important role that requires support and lots of planning. Sib Bash events were a great way to have fun and make connections in the AS community.

Caleb's Story with Siblings Myla & Maddie
"The Sib Bash was so incredibly meaningful and memorable for my daughters!" — Jamee Kovacs (Monroeville, Pa.)

Sophie's Story — with Siblings Henry, Vivian & William
"It was a great time celebrating our wonderful siblings who don't always get as much attention as their brothers or sisters with AS." — Betsy Black (Dallas-Fort Worth, Texas)

Jasmine's Story — with Siblings Cecelia, Joselyn, Julisa & Justin
"Parents loved not having to stress about being around the general public. It was a blast!" — Desiree Rizzo (Temecula, Calif.)

RESEARCH

ASF has approved more than $15.7 million in funding for AS research to date, supporting projects worldwide in the quest to find treatments and ultimately a cure.

ASF-FUNDED RESEARCH HIGHLIGHTS

+$15.7M
Approved Funding For Research Since 1996*

7
7 Studies Funded in FY2023

$782K
Approved For Funding in FY2023 & Beyond**

47
Clinical Studies Funded at +3.4 Million*

84
Translational/Applied Studies Funded at +12.3 Million*

Cumulative research investment: $15,773, 906
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.

TYPES OF RESEARCH WE FUND

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 FUNDING PHILOSOPHY

ASF focuses heavily on pilot funding. Essentially, we use a small amount of money 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 started with pilot funding.

When we choose projects to fund, we do so with the knowledge that incremental studies enable the next big leaps. The $15.7 million in research we have funded has led to others contributing an additional +$200 million to the cause.

Instead of leveraging all our resources on one huge idea, this year we funded seven studies. To use a sports analogy, not every study has to be a home run to make an impact. Four base hits also leads to a run scored.

Treatments resulting from our investment in research have helped individuals with AS learn to walk, communicate and live better lives today. But we're not stopping now. We believe AS can be cured, so that those we love can lead better lives tomorrow.

AS RESEARCH STUDIES IN PROGRESS

The Prevalence and Form of CVI in Angelman Syndrome
Researcher: Karen Erickson, PhD | **Year 2 of 2**
Why This Study Is Important: There is good reason to believe that many individuals with AS have cortical visual impairment (CVI). This is a specific type of vision impairment that may affect balance, walking, communication and behavior. Dr. Erickson believes that in identifying and understanding CVI in individuals with AS, it will allow for early intervention, which may improve communication and behavior outcomes. This study, will accomplish three things:

- Estimate the number of individuals with AS that have CVI
- Assess the severity of CVI in individuals with AS
- Determine whether CVI has an effect on communication in children with AS

ASO Treatment For A Better Understanding of AS Pathology and Optimizing Therapeutic Efficacy
Researcher: Ype Elgersma, PhD, Erasmus Medical Center | **Year 2 of 2**

- **Why This Study Is Important**: ASOs are exciting therapeutics because they replace the very gene product missing in individuals with AS. However, we don't really understand how well they work when administered at different of development. We also don't know how well they work in individuals with AS due to different causes (i.e. UPD or deletions). Even with two papers published in this area using UBE3A mutation mice, different ASOs may have different effects, and restoring UBE3A from both copies in mice with UPD and/or large deletion may have different results.

Individuals with ICD/UPD Mutations Participating in ASO Trials
Researcher: Ype Elgersma, PhD, Erasmus Medical Center | **Year 2 of 2**
Why This Study Is Important: ASOs are exciting therapeutics because they replace the very gene product missing in individuals with AS. However, we don't really understand how well they work when administered at different times during development, and we also don't know how well they work in individuals with AS due to different causes (i.e. UPD or deletions). Even with two papers published in this area using UBE3A mutation mice, different ASOs may have different effects, and restoring UBE3A from both copies in mice with UPD and/or large deletion may have different results.

Natural History Study
Researcher: Wen-Hann Tan, MD, Boston Children's Hospital | **Year 1 of 4**
Why This Study Is Important: This study will help better our understanding of how development, behavior and communication change in individuals with AS over the course of their lives. The study takes place in six locations in the U.S. Nearly 40 papers have been published using data from the Natural History Study.

AS RESEARCH STUDIES IN PROGRESS

Development & Implementation of a Novel Comprehensive Panel for the Early Detection of Angelman Syndrome

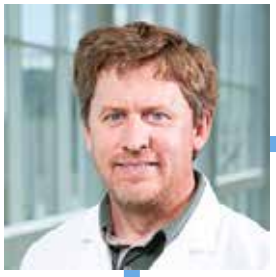
Researcher: Emily Farrow, PhD, CGC, UMKC School of Medicine | **Year 1 of 2**

Why This Study is Important: A classic phenotype of AS has been described which includes developmental delay, intellectual disability, speech impairment, gait ataxia and a happy demeanor. However, these features are not apparent in infancy. Further, initial symptoms of developmental delay are non-specific, which often complicate a diagnosis. The underlying molecular mechanism of AS is complex, and is known to be caused by methylation defects, deletions, and pathogenic single nucleotide variants in UBE3A, currently requiring multiple clinical tests to access. Taken together, despite the prevalence of AS, many patients do not receive a timely molecular diagnosis, may receive an incorrect diagnosis, or receive no diagnosis at all.

Contribution of Hemizygous HERC2 Deletion to Angelman Syndrome Pathophysiology

Researcher: Eric Levine, PhD, University of Connecticut | **Year 2 of 2**

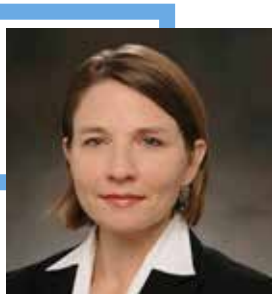
Why This Study Is Important: Loss-of function mutation of HERC2 itself causes a severe neurodevelopmental phenotype with Angelman syndrome-like features. We hypothesize that the hemizygous loss of HERC2 contributes to the more severe behavioral phenotype in deletion AS individuals, and in conjunction with loss of UBE3A, will result in increased severity of cellular phenotypes in human AS stem cell-derived neurons.



Support of the SHRNA/AAVO Approach to Treat AS

Researcher: Ryan Butler, PhD | **Year 1 of 2**

Why This Study Is Important: This study is expected to determine if shRNA/scAAV9 gene therapy is efficacious in reducing deleterious phenotypes associated with AS in mouse and human models. This will provide a crucial step required to test of the potential feasibility of AAV-mediated CNS gene therapy as a treatment for AS. If successful, the long-term goal is to proceed onto IND-enabling NHP safety and clinical trials with industry and foundation partners. The work described in this proposal is expected to have an important positive impact on the field of AS therapy development because it is highly likely that the approach will prove successful in restoring UBE3A protein and neural function with minimal off-target effects.



Development and Validation of an Angelman-Specific Behavior Measure

Researcher: Anne Wheeler, PhD, RTI International | **Year 1 of 2**

Why This Study Is Important: Individuals with Angelman syndrome (AS) are known to have an increased likelihood of exhibiting challenging behavior, especially in situations that are anxiety provoking. These behaviors substantially affect family functioning and caregiver mental health. However, there is not a well-established and validated measurement that helps capture the frequency, nature, and severity of challenging behavior in people with intellectual disability, much less in conditions like AS, where communication challenges are a significant problem.

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.

Explore what's happening with the LADDER Learning Network!

PROVIDER EDUCATION CALLS

Sharing information is essential to our success. In 2023, we hosted six provider education calls with our AS clinicians, discussing topics like:

- Adult Care
- Behavior Management Over the Lifespan
- Genetics
- Epilepsy Management
- Non-Epileptic Myoclonus
- New Movement Phenotypes

40+ AS/dup15q experts across the globe to share knowledge, discuss challenging cases and to progress toward standardizing care.

COMING SOON

- Epilepsy Working Group: A team of neurologists and epileptologists will review data from the LADDER Seizure Survey to create a new publication on epilepsy management in AS.
- Bi-Monthly Calls: ASF/Dup15q clinic coordinators will connect, share ideas and problem-solve.
- Speech Language Pathologist Group: A small team with expertise in AS will collaborate and provide mentorship to new SLPs seeing clients with AS.

Explore what's happening with the LADDER Database!

CLINICAL NEEDS STUDY

This study aims to document the medical needs of patients with AS and Dup15q visiting a network clinic site. Before the clinic visit, the parent/caregiver completes a survey documenting their child's clinical needs. After the clinic visit, the clinician completes a survey documenting clinical variables captured during the visit (neurologic and physical exam elements).

GENETICS REPORT CLASSIFICATION

A team of genetics professionals are reviewing, classifying and documenting key details from each AS genetic testing report in LADDER. This project will result an incredibly valuable large database of professionally reviewed and verified genetics data for AS

Explore what's happening with ASF Clinics!

OPENED 4 NEW LOCATIONS IN 2023

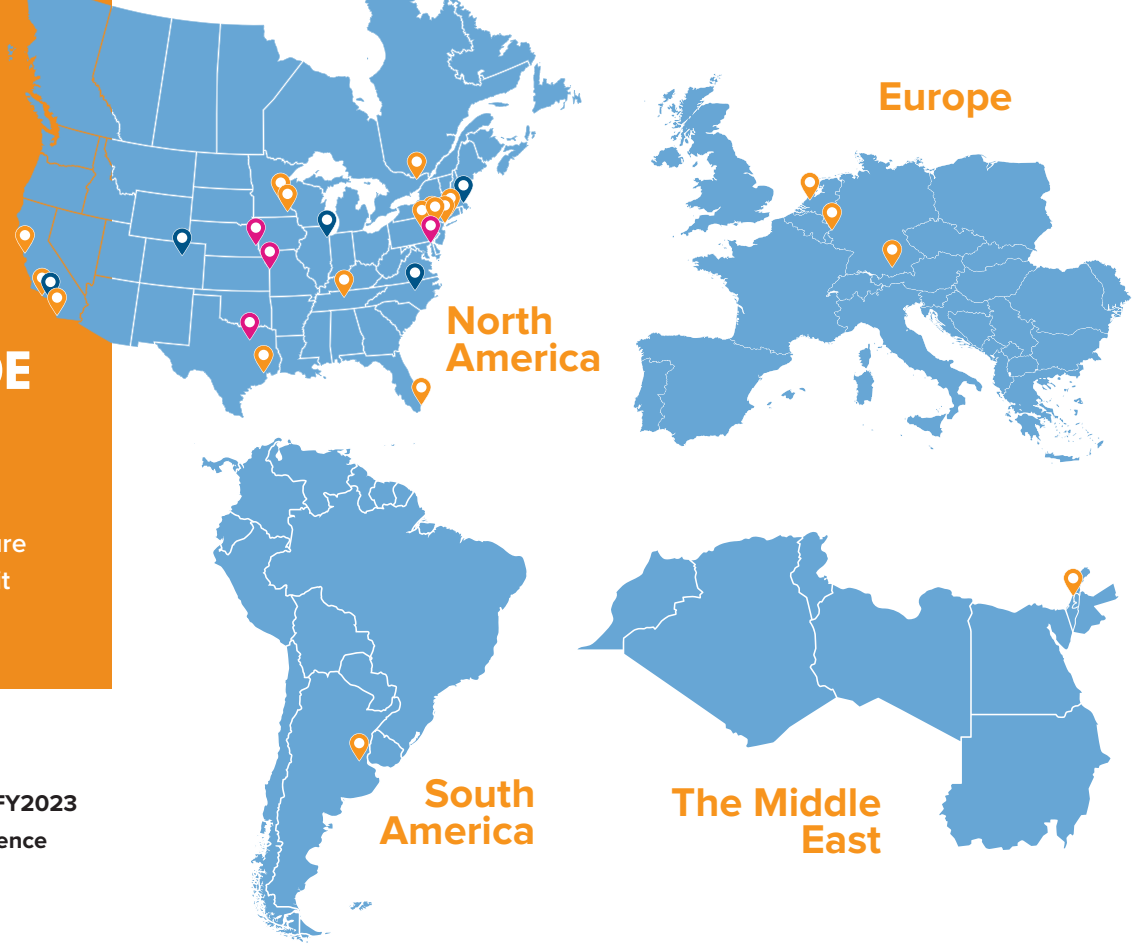
- Children's Health (Dallas, Texas)
- Children's Mercy (Kansas City, Mo.)
- Boys Town National Research Center (Boys Town, Neb.)
- Kennedy Krieger Institute (Baltimore, Md.)

ESTABLISHED NEW CRITERIA & PROCESSES:

- All new clinics were onboarded via a new protocol including a formal new clinic application and application approval by the Medical Advisory Board.
- We published more stringent and measurable criteria for ASF Centers of Excellence (COEs). All COEs will now be required to have a transition or referral plan in place for adults by the end of 2024.

ASF CLINICS PROVIDE LIFE-CHANGING CARE WORLDWIDE

We connect those who practice evidence-based medicine for Angelman syndrome (AS) with a high level of excellence and ensure as many families have access to it as possible.



- Existing Locations
- Locations Added in FY2023
- AS Centers of Excellence

2023 HIGHLIGHTS

4 NEW
ASF Clinics Opened

28 ASF CLINICS
Now Exist Worldwide

96 TOTAL DATASETS
In The LADDER Database

15,670 VARIABLES
In The LADDER Database

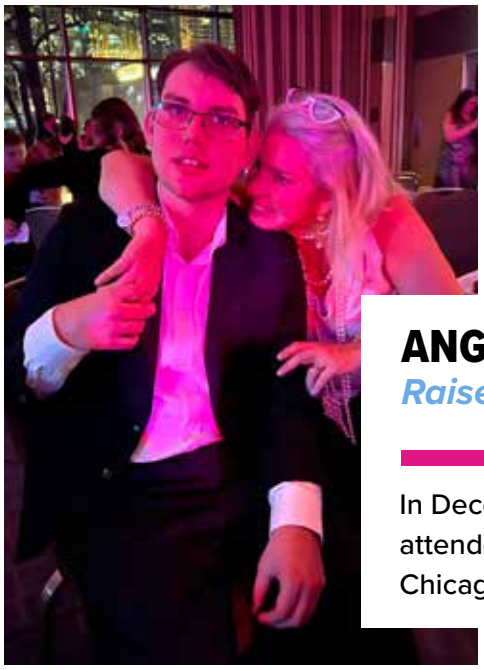
"I'm overjoyed to report that Logan is 10 and has been seizure-free for six years, since we started visiting the ASF Clinic. But honestly, we count our lucky stars every day. Many with AS have ongoing struggles to keep seizures under control."
— Sarah & William Cobb

FUNDRAISERS

ASF WALK

Raised +$1.2 Million

The 2023 ASF Walk drew 8,336 registrants across 48 locations nationwide. The ASF Walk continues to be our largest fundraiser. The “Angelman Strong” participants raised awareness and vital funds, keeping our growing community connected.



ANGELMAN EVENING

Raised +$603,000

In December 2022, more than 385 supporters attended the Angelman Evening fundraiser in Chicago to directly support ASF Clinics.

COMMUNITY FUNDRAISERS

Raised +$197,000

Fundraisers organized by families and friends collectively raised more than $197,000 in 2023. Fueled by their love for someone with AS, they've done great things for ASF and had fun while doing it!

SOME INSPIRING FUNDRAISERS

angelman SYNDROME FOUNDATION
GOFUNDWINGS

GoFundWings
raised a combined total of +$19,000

Cornhole Events
raised a combined total of $40,323

Golf Outings
raised a combined total of $46,248

Race for a Reason
raised a combined total of $13,484

Cooking for Angels
raised $12,800

The Hope Classic
raised $10,255

**Cumulative totals to date*

BANK OF AMERICA CHICAGO MARATHON

Raised +$126,000*

The Windy City Angels was represented by 41 runners each raising funds for ASF!
*Stats reflect the 2022 Windy City Angels Team which falls into FY2023.

the cure CLUB

Raised $36,065

A special group of givers make a huge impact by setting up recurring monthly donations. Incremental donations from 63 members provided $36,065 in funding in 2023.

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THANK YOU TO OUR VISIONARY LEADERS

Fred Pritzker Visionaries $250,000+

Anonymous Donor

Harry Angelman Champions - $50,000+

Dan and Karen Harvey, F. Hoffmann-La Roche AG, Ionis Pharmaceuticals, Triad Foundation, Inc.

Heroes Giving Hope - $10,000+

Anonymous Donor, Antonieta Arango, Javier Arango, Tracy and John Atkinson, Anna Blanding and Garfield Pilliner, Mark and Jan Delaney, Paula and Michael Evans, Gloria Gibson, Amy and Jay Granzow, Deborah and Scott Guagliardo, Steve Hanna, Laura Kantor, Bonnie and Dennis Knoedler, Keith F. Lauder, Michael Layman, James and Ana Libby, David A. Lowe and Steven M. Murphy, Steve and Agatha Luczo, Lesley and Drew McCallister, Timothy and Gretchen McCarty, Tom and Ruthann McCarty, Laurie and David Morren, Susan and Marshall Mortenson, Rosalie O'Brien, Richard Piluso, Steven and Mia Piluso, John and, Mary Pipal, Wayne and Jana Pott, William Rakoczy, David and Jenny Routh, Laura and Patrick Sargent, Bryan Schnick and Allyson Tole, Pamela and Rick Scholten, Melissa and Adam Stone, John Sugden and Ana M. Monaldi, Bryan and, Tina Thompson, William and Joyce Veldman, Ambit, Inc., Blarney For Angelman Foundation, Clint W. Perryman, P.C., Enterprise Holdings Foundation, Genentech Inc, Global Genes, Howard Gilman Foundation, HundredX, Inc. (Express Feedback for Good), J.W. Kieckhefer Foundation, Jack's, Maverick Capital Foundation, PTC Therapeutics, Inc., Rakoczy Molino Mazzochi Siwik LLP, Raytheon Technologies, The MJB Philanthropy Fund, UAW Local 2209 - GM Fort Wayne Assembly, Ultragenyx Pharmaceutical, Inc., US Anesthesia Partners, Voice for Maddie Inc., WNPC Foundation

*in memoriam

Sustainer - $5,000+

Anonymous Donor, Arthur and Marjorie Beaudet, Richard and Ann Carr, Zachary and Diandra Chebul, Nicholas and Allie Cox, Merewyn and Alan Harrington, Doug and Lindsey Hene, Michael and Emily Leighton, Dan and Sherry McGravey, Richard Miga, Paul Molino, Jane O'Leary, Douglas and Angela Patterson, Deirdre and Mark Rajkowski, Michael Schuster, Mary Strike, Acco Brands USA LLC, Barbara L. Griffith Fund, Columbia Family Foundation, Cope Family Foundation, Eric T Webster Foundation, FM Global Foundation, Occidental Petroleum Corp (OXY), Ron and Mary Pott Family Foundation, Texas Oncology, The Griffis Foundation, Truettner Family Foundation, W.Y. Campbell Family Foundation

FINANCIAL BREAKDOWN

STATEMENT OF FINANCIAL POSITION
FOR THE YEAR ENDED SEPTEMBER 30, 2023 AND 2022

Current Assets:	2023	2022
Cash and Cash Equivalents	$758,252	$1,214,351
Pledges Receivable, Current Portion	$10,000	$10,000
Investments	$1,360,979	$786,039
Investments	$13,391	—
Pre-paid Expenses	$62,147	$49,326
Total Current Assets	**$2,204,769**	**$2,059,716**

Property & Equipment (at cost):	2023	2022
Office Furniture, Fixtures and Equipment	$2,921	$2,921
Computer Hardware	$19,172	$14,216
Software	$533,285	$533,285
Website	$24,000	$24,000
Less - Accumulated Depreciation	-$539,671	-$424,490
NET Property & Equipment	**$39,707**	**$149,932**

Other Assets:	2023	2022
Pledges Receivable, Long-Term Portion	$29,889	$40,000
TOTAL ASSETS	**$2,274,365**	**$2,249,648**

Liabilities & Net Assets	2023	2022
Current Liabilities		
Accounts Payable	$183,453	$216,417
Accrued Payroll Expenses	$63,549	$49,357
Deferred Event Revenue	$40,492	—
Deferred Event Revenue	**$287,494**	**$265,774**

Net Assets	2023	2022
Without Donor Restrictions	$1,234,241	$1,234,241
With Donor Restrictions	$752,630	$752,630
Total Net Assets	**$1,986,871**	**$1,983,874**
TOTAL LIABILITIES & NET ASSETS	**$2,274,365**	**$2,249,648**

STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED SEPTEMBER 30, 2023 AND 2022

PUBLIC SUPPORT & REVENUE

	2023	2022
Contributions	$2,338,736	$2,336,706
Biennial Conference	$37,149	$152,724
Special Events, net of related expenses, which includes:		
In-Kind Revenue of $177,827 and $206,733 for 2023 and 2022, respectively	$1,158,174	$1,204,052
Net Investment Return (Loss)	$100,472	-$107,929
Other Income	$3,794	$3,626
Forgiveness of Payroll Protection Program Loan	-----	$87,000
Net Assets Released From Restrictions - Satisfaction of Program	-----	-----
TOTAL PUBLIC SUPPORT & REVENUE	**$3,638,325**	**$3,676,179**

FUNCTIONAL EXPENSES

Program Services	2022	2021
Family Support	$2,125,761	$1,464,448
Research	$557,838	$1,061,322
Biennial Conference & Symposium	$65,673	$375,340
TOTAL PROGRAM SERVICES	**$2,749,272**	**$2,901,110**
Management & General	$261,308	$219,898
Fundraising	$624,748	$519,810
TOTAL FUNCTIONAL EXPENSES	**$3,635,328**	**$3,640,818**

NET ASSETS

	2023	2022
Change In Net Assets	$2,997	$35,361
Net Assets, *Beginning Of Year*	$1,983,874	$1,948,513
Net Assets, *End Of Year*	$1,986,871	$1,983,874

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