Reflecting through the year, we had a chance to meet with the founders of this organization. We are so humbled by their leadership and thankful for the vision they cast 30 years ago.

Now as we reflect on an amazing year and look forward, we are proud to say we have made tremendous progress on our mission. New family supports have been added, multiple ASF Clinics have been created and millions of dollars in research have been given to get us closer to therapeutic treatments.

We are so thankful for you—each of you who have felt the power of our mission and have been compelled to get involved. Thank you for organizing walks, special events in your hometowns, Facebook fundraisers and so much more. Thank you to each of those who have raised their hands and answered the call to volunteer for a committee, support a newly diagnosed family or volunteer at our conferences. It is because of you that we can serve the community and meet each individual where they are in their journey.

We still have work to do. Our journey isn't complete until we've overcome every challenge our loved ones with Angelman syndrome experience. Until then, we promise we will never stop.

Sincerely,

KYLE ROONEY, Board of Directors President
AMANDA MOORE, CEO
2022 MILESTONES

1. LAUNCHED LADDER LEARNING NETWORK
   In a strategic collaboration with Dup15q Alliance, we established the first network of medical providers specializing in 15q syndromes. Cross-disorder investigation is, and will remain, key to driving discovery.

2. OPENED FOUR NEW ASF CLINICS
   Many families expressed difficulty finding doctors who understand the complexities of AS. We now have a total of 25 ASF Clinics worldwide to connect those who have experience treating AS to families who need it most.

3. FUNDED SEVEN RESEARCH PROPOSALS
   Research is key to improving the lives of individuals with AS. In 2022, we funded more than $1 million in studies for ASO treatments, gut health, parent-infant interaction, motor skills impairments and more.

4. ESTABLISHED THE JACOB PRITZKER FELLOWSHIP PROGRAM
   As need for medical providers specializing in AS continues to grow, we established this fellowship to support a junior investigator or clinical training program for an early-career physician.

5. HOSTED THE BIGGEST ASF FAMILY CONFERENCE EVER!
   We reunited the ASF community at Kalahari Resorts in Texas for the most largely attended ASF Family Conference in history. We welcomed 1,000+ attendees, 50+ speakers and 245+ industry members.

6. LAUNCHED THE ASF PODCAST
   As another way to help families on their journey, we launched the ASF Podcast. Discussion from experts touch on topics ranging from genetics to siblings stories to clinical treatments for seizures.

7. LAUNCHED STRATEGIC PARTNERSHIPS
   Knowledge comes when forces combine. We established partnerships with Ambit Care, PAN Foundation and other Angelman syndrome organizations across the globe. (See Page 12)

8. SUPPORTED 135 FAMILIES WITH THE ASF FAMILY FUND
   This year, we provided $252,853 to support families with items needed to improve quality of life. Awards included items like safety beds, strollers, AAC devices and travel grants to visit an ASF Clinic.

9. WALKED TO RAISE MORE THAN $1.2 MILLION!
   Our annual ASF Walk drew 7,158 registrants across 48 locations nationwide. These “game changers” not only raised awareness and funds, they continued to keep our growing community strong.
FAMILY SUPPORT

SUPPORTING ASF FAMILIES FOR 30+ YEARS

ASF is committed to supporting families on their journey through its abundance of resources and programs. Through grants, committees, contacts, checklists, planning tools, webinars, meetings and more, we steadfastly provide support when and where families need it most.

2022 FAMILY SUPPORT HIGHLIGHTS

ASF FAMILY CONFERENCE:
1,000 ATTENDEES — the largest turnout to date

ASF FAMILY FUND:
135 grants awarded, totaling $252,853

COUNSELING SERVICES:
PROVIDED 759 free counseling sessions for AS families

ASF FAMILY CHAMPIONS:
54 generous family volunteers

PODCAST:
Launched Season 1 with 8 episodes
Adults with Angelman syndrome and their families have unique needs. Families often feel alone and afraid due to the scarcity of support and services for adults. ASF, through adult services, is dedicated to using a pragmatic approach to continue to work toward meeting the needs of our adults with AS and their families.” — Robin Wilkerson, Parent

“I struggle to find the right words to express our thanks for the support from the ASF Family Fund. As we age, it gets harder to manage some of the simplest things in life, like going for a walk as a family. ASF Family Fund helped us acquire a heavy duty portable power chair for David. Now we can enjoy walks together and not risk our own health pushing him. He LOVES it!!” — Dawn Bly, Parent

ASF FAMILY SUPPORT CONTINUES TO GROW

Core to our mission, we provided $372,293 to family support programs in 2022, with a significant focus on the ASF Family Fund to help improve quality of life.
ASF has invested more than $12.9 million in AS research to date, supporting projects worldwide in the quest to find treatments and ultimately a cure.

**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 million in research we have funded has led to others contributing an additional +$200 million to the cause.

Instead 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.

**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. **Studies that help us learn about UBE3A and what it does in the brain**

“ASF has funded the novel ideas, that became bigger ideas, that then became therapeutics. Without this small amount of funding from ASF, advancements would not happen.”

— Stormy Chamberlain, PhD
Section Head Neurogenomics at Roche
Member of ASF Scientific Advisory Committee
Since funding its first clinical trial in 1996, ASF-funded research has continued to lay the foundation for future discovery.

**UBE3A**
ASF funded the first studies of the UBE3A gene. Impairment of this gene causes AS, and these studies helped us better understand how, when and where UBE3A is made. Incremental studies have since followed to understand UBE3A targets, to understand its gene and protein regulation and to understand the structure of the protein.

**MOUSE MODELS**
ASF funded the first mouse models to help with safe testing of potential therapies and to show how different brain regions contribute to AS symptoms. ASF-funded mouse studies proved that earlier restoration of UBE3A would give better outcomes following genetic therapies.

**GENE THERAPY**
ASF funded the first gene therapy study. This led to funding two more innovative twists to make an optimal gene therapy. These studies, along with the gene activation strategies, have attracted several pharmaceutical companies to develop potential therapies for AS.

**ASO STUDIES**
ASF funded the first antisense oligonucleotide (ASO) studies proving that the therapeutic approach would work, which led directly to the three clinical trials by Ionis, Roche and Ultragenyx/Genetx. These studies will help answer questions like: How much ASO and how much UBE3A protein is needed? Is ASO treatment required throughout life? When does ASO treatment need to start?
FOR PATIENTS. FOR PROVIDERS. TOGETHER, TOWARD THE CURE.

In 2022, ASF and the DUP15q Alliance partnered to launch the LADDER Learning Network to provide 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. Then, we ensure as many families have access to it as possible through ASF Clinics or Dup15q Clinics worldwide.

1. **CONNECTS PATIENTS TO CARE**
Connects AS/dup15q individuals to comprehensive care from highly engaged, highly specialized medical experts who have demonstrated a passion for and an ability to specifically treat these rare disorders.

2. **CONNECTS PROVIDERS TO ONE ANOTHER**
Serves as an avenue for communication among 40+ AS/dup15q experts across the globe to share knowledge, discuss challenging cases and to progress toward standardizing care.

3. **SUPPORTS CLINICAL TRIALS**
Provides a foundation to support clinical trials by having established sites with experts and patients in place to conduct those trials when they become available.

4. **OPERATES LADDER DATABASE**
Operates the global network of patient-powered data, to enhance understanding of both syndromes. Increased insight into data from AS/dup15q individuals informs better treatment options and will pave the way for a cure.

2022 ASF CLINICS HIGHLIGHTS

- **4 NEW ASF Clinics**
  - Opened

- **25 ASF Clinics**
  - Now Exist Worldwide

- **50,000 DATA POINTS**
  - In The LADDER Database

- **ESTABLISHED**
  - AS Center of Excellence Designation

LADDER LEARNING NETWORK ESSENTIAL FUNCTIONS

**1. CONNECTS PATIENTS TO CARE**
Connects AS/dup15q individuals to comprehensive care from highly engaged, highly specialized medical experts who have demonstrated a passion for and an ability to specifically treat these rare disorders.

**2. CONNECTS PROVIDERS TO ONE ANOTHER**
Serves as an avenue for communication among 40+ AS/dup15q experts across the globe to share knowledge, discuss challenging cases and to progress toward standardizing care.

**3. SUPPORTS CLINICAL TRIALS**
Provides a foundation to support clinical trials by having established sites with experts and patients in place to conduct those trials when they become available.

**4. OPERATES LADDER DATABASE**
Operates the global network of patient-powered data, to enhance understanding of both syndromes. Increased insight into data from AS/dup15q individuals informs better treatment options and will pave the way for a cure.
WITH SEIZURES CONTROLLED, 
ASF CLINICS HELPED OUR DAUGHTER GROW

“Emily had her first seizure at a year old. Before visiting the ASF Clinic at Children's Hospital Colorado, she was having multiple seizures in a 24-hour period once a month. At the clinic, she saw a team of doctors, therapists and other specialists who focus on caring for kids with AS.

They gave Emily a new seizure medication and developed a care plan to reduce her seizures and aid her development. She hasn’t had a seizure since November 2021. It is a dream come true!”

— The Waibel Family
FUNDRAISERS

ASF WALK | Raised $1,259,601

The 2022 annual ASF Walk drew 7,158 registrants across 48 locations nationwide. It raised the most funds since 2018 and continues to be ASF’s largest fundraiser. These “game changers” not only raised awareness and funds, they continued to keep our growing community strong.

FAMILIES MAKE AN IMPACT

Without our community, none of the breakthrough work we do would be possible. Angelman families gave back in a big way in 2022, raising more than $1.6 million through fundraising opportunities. The passion and drive of these fundraisers move us even closer to life-changing treatments for AS.

“When our family participated in our first ASF Walk in 2014, it was in Naperville, Ill. My son Gavin was three years old. We felt so vulnerable as parents of a child with a lifelong disability. I couldn’t even talk about Angelman syndrome without crying. Our family and many friends were at the Walk to support us. After that first event, I said, ‘Someday we’ll host an ASF Walk in our hometown of Bettendorf.’ Ten years since receiving Gavin’s diagnosis, 2023 is our year.

We aren’t raw and vulnerable anymore. We are loud and proud of all that Gavin has accomplished and hope to pass on that same spirit to others.” — Julie Stabb, Parent

*Fundraising efforts affected by Covid-19 pandemic
Raised $190,316

Fundraisers organized by families and friends collectively raised more than $190,000 in 2022. Fueled by their love for someone with AS, they’ve done great things for ASF and had fun while doing it!

SOME INSPIRING FUNDRAISERS

Quinn's Hot Cocoa For A Cure
Raised $266,000*
Los Angeles, CA

Chip Away at AS Golf Tournament
Raised $44,716*
Atlanta, GA

Labor Day Tractor Cruise
Raised $49,260*
Everest, KS

24 & 27 Hours of Crossfit
Raised $21,392*
Parker, OH

Centercourt for Lacrosse Tournament
Raised $12,203*
Mount Olive, IN

Suds For Silas
Raised $11,763*
Nashville, TN

BANK OF AMERICA CHICAGO MARATHON
Raised $125,974.16

25 runners joined the Windy City Angels team at the 2022 Bank of America Chicago Marathon. Together, they raised nearly $126,000.

The ASF Cure Club is a special group of givers who make a huge impact by setting up recurring monthly donations. As we know, those smaller gifts really add up!

In 2022, the ASF Cure Club raised the most it has since 2018. Incremental donations from 88 members provided nearly $40,000 in funding to ASF in 2022. Since the program began in 2016, it has raised nearly $195,000.

*Cumulative totals to date
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Penelope Hatch, PhD
Carole Zangari, PhD, CCC-SLP
Courtney Castelli, EDS

OUR PARTNERS

ASF is proud to partner with groups and organizations whose values and services align with our mission.

Ambit Care
Angelman Syndrome Alliance
Angelman UK
Autism Brain Net
Canadian Angelman Syndrome Society
DEE-P Connections
Dup15q Alliance
EveryLife Foundation
Families in United Arab Emirates
FAST
Global Genes
IONIS Pharmaceuticals
National Organization for Rare Disorders
OVID Therapeutics
Parent Empowerment Workshops
PAN Foundation
PTC Therapeutics
Rare Epilepsy Network
Rare and Ready
Roche/Genentech
Ultragenyx
THANK YOU TO OUR VISIONARY LEADERS

Fred Pritzker Visionaries $250,000+
  Renee Pritzker and Fred Pritzker*

Betty J. Shaw Benefactors $100,000+
  Ionis Pharmaceuticals

Harry Angelman Champions $50,000+
  Ultragenyx Pharmaceutical, Inc

Heroes Giving Hope $10,000+
  Anonymous Donor, Antonieta Arango, Arthur and Marjorie Beaudet, Janet and Michael Bell, Biogen U.S.,
  Four Apple Cross, LLC, Genentech, Inc., Gloria Gibson, Merewyn and Alan Harrington, HundredX Inc.,
  J's and G's Golf, James and Renee Kizziar, Bonnie and Dennis Knoedler, Michael and Emily Leighton, James
  and Ana Libby, Agatha and Steve Luccio, Lesley and Drew McCallister, Tim and Gretchen McCarty, Tom and
  Ruthann McCarty, Ovid Therapeutics, Clint and Lia Perryman, Radius Health, Rakoczy Molino Mazzochi
  Siwik, LLP, David and Jenny Routh, Texas Children's Hospital, Bryan Schnick and Allyson Tole, Alexander and
  Sierra Smith, Victor and Clara C. Battin Foundation

Sustainers $5,000+
  Acco Brands USA, LLC, Anonymous Donor, John and Christine Bakalar, Barbara L. Griffith Fund, Lincoln Benet,
  Anna Blanding and Garfield Pilliner, William and Katherine Burford, Richard and Ann Carr, Michael and
  Lori-An Cecere, James and Susan Edberg, Randy and Betty Eisenbach, Enterprise Holdings Foundation,
  Eubanks Humphrey Engineering, EveryLife Foundation for Rare Diseases, Genetx Biotherapeutics, LLC,
  Dan and Karen Harvey, Christian and Hilary Hommes, David Lloyd Kennell and Mary Clare Lindsay, Lea Family
  Fund, David and Laurie Morren, Janet and William Neal, John R. Niepold, Christian Pache and Anna Hsu,
  William A. Paridon*, Clint W. Perryman P.C., Richard Piluso, John and Mary Pipal, Wayne and Jana Pott, PTC
  Therapeutics, Inc., Deirdre and Mark Rajkowski, Susan and Steven Ravellette, Martin and Angela Reggette,
  David Rosenblatt and Karen Hoerst, Jonathan Ruckdeschel, Dudley Ryan, Pamela Scholten, Setpoint Integrated
  Solutions, Inc., John Sugden and Ana Monaldi, Jonathan Timbers, UAW Local 2209, U.S. Anesthesia Partners

* in memoriam

Donations received Oct 2021 - Sept 2022

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WHERE YOUR CONTRIBUTIONS GO

80% of every dollar spent in 2022 funded programs and services core to our mission.

WHERE YOUR CONTRIBUTIONS GO

HISTORICAL TRENDS

Annual expenses allocated to our core Programs and Services continue to show our commitment to family support, educating our community and to scientific discovery.
## Financial Breakdown

### Statement of Financial Position

<table>
<thead>
<tr>
<th>Description</th>
<th>2022</th>
<th>2021</th>
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</thead>
<tbody>
<tr>
<td><strong>Current Assets:</strong></td>
<td></td>
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<tr>
<td>Cash &amp; Cash Equivalents</td>
<td>$1,214,351</td>
<td>$918,772</td>
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<tr>
<td>Pledges Receivable, Current Portion</td>
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<tr>
<td>Investments</td>
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<td>$897,812</td>
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<td>Prepaid Expenses</td>
<td>$49,326</td>
<td>$21,321</td>
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<td><strong>Total Current Assets</strong></td>
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<td>$1,837,905</td>
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<tr>
<td><strong>Property &amp; Equipment (at cost):</strong></td>
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<tr>
<td>Office Furniture, Fixtures, &amp; Equipment</td>
<td>$2,921</td>
<td>$2,921</td>
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<td>Computer Hardware</td>
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<td>LADDER</td>
<td>$533,285</td>
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<td>Website</td>
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<tr>
<td>Less - Accumulated Depreciation</td>
<td>($424,490)</td>
<td>($267,142)</td>
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<td><strong>NET Property &amp; Equipment</strong></td>
<td>$149,932</td>
<td>$304,280</td>
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<td><strong>Other Assets:</strong></td>
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<tr>
<td>Pledges Receivable, Long-Term Portion</td>
<td>$40,000</td>
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<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td>$2,249,648</td>
<td>$2,142,185</td>
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### Statement of Activities

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<tr>
<th>Description</th>
<th>2022</th>
<th>2021</th>
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<tbody>
<tr>
<td><strong>Public Support &amp; Revenue</strong></td>
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<tr>
<td>Contributions</td>
<td>$2,336,706</td>
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<td>Biennial Conference</td>
<td>$152,724</td>
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<td>Special Events</td>
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<td><strong>Net Investment Return (Loss)</strong></td>
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<td>Other Income</td>
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<td>Forgiveness of PPP Loan</td>
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<td>Loss on Disposal of Fixed Assets</td>
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<td>($1,067)</td>
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<tr>
<td>Net Assets Released From Restrictions</td>
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<tr>
<td>- Satisfaction of Program Restrictions</td>
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<tr>
<td><strong>TOTAL PUBLIC SUPPORT &amp; REVENUE</strong></td>
<td>$3,676,179</td>
<td>$2,344,765</td>
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<thead>
<tr>
<th>Description</th>
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<tr>
<td><strong>Functional Expenses</strong></td>
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<td>Program Services</td>
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<td>Research</td>
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<td>Biennial Conference &amp; Symposium</td>
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<td><strong>TOTAL PROGRAM SERVICES</strong></td>
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<td>$1,519,138</td>
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<td>Management &amp; General</td>
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<td>Fundraising</td>
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<td><strong>TOTAL FUNCTIONAL EXPENSES</strong></td>
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<tr>
<th>Description</th>
<th>2022</th>
<th>2021</th>
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<tbody>
<tr>
<td><strong>Net Assets</strong></td>
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</tr>
<tr>
<td>Change In Net Assets</td>
<td>$35,361</td>
<td>$233,368</td>
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<td>Net Assets, Beginning Of Year</td>
<td>$1,948,513</td>
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<tr>
<td>Net Assets, End Of Year</td>
<td>$1,983,874</td>
<td>$1,948,513</td>
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<tr>
<td><strong>TOTAL LIABILITIES &amp; NET ASSETS</strong></td>
<td>$2,249,648</td>
<td>$2,142,185</td>
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Financial information presented here has been summarized from financial statements audited by Dugan + Lopatka dated September 30, 2022 and 2021.
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.