



**FAMILIES. RESEARCH.
CLINICS. COMMUNITY.**

WITH YOU FOR THE JOURNEY.

2019

ANNUAL REPORT





A Message From Amanda

One of the first things I did after becoming CEO was take the time to listen to your thoughts on what ASF is. In all the heartwarming stories, four words kept surfacing: families, clinics, research and community. Those areas are helping us better serve families today – and driving our vision for the future.

Clinics



Angelman syndrome is a rare disease, impacting approximately 1 in 12,000-20,000 people in the United States and around the world. Because of this, accessing comprehensive, knowledgeable care for AS can be a challenge. ASF is committed to opening more clinics in its Angelman Syndrome Clinic Network to give families access to specialized care closer to home. Our expanded clinical network will support more clinical trials and research to lead to a cure.

15q Clinical Research Network

ASF and Dup15q Alliance combined their respective clinic networks in 2019 to expand access.



"We believe that partnering with the Dup15q Alliance will allow us to increase our reach to the AS community and provide the best care for our families. Comprehensive and specific care is critical for AS families throughout the stages of their journey — by partnering with Dup15q Alliance we are able to reach thousands more families with care and support by bringing AS Clinics to their geographical location."

18
US sites

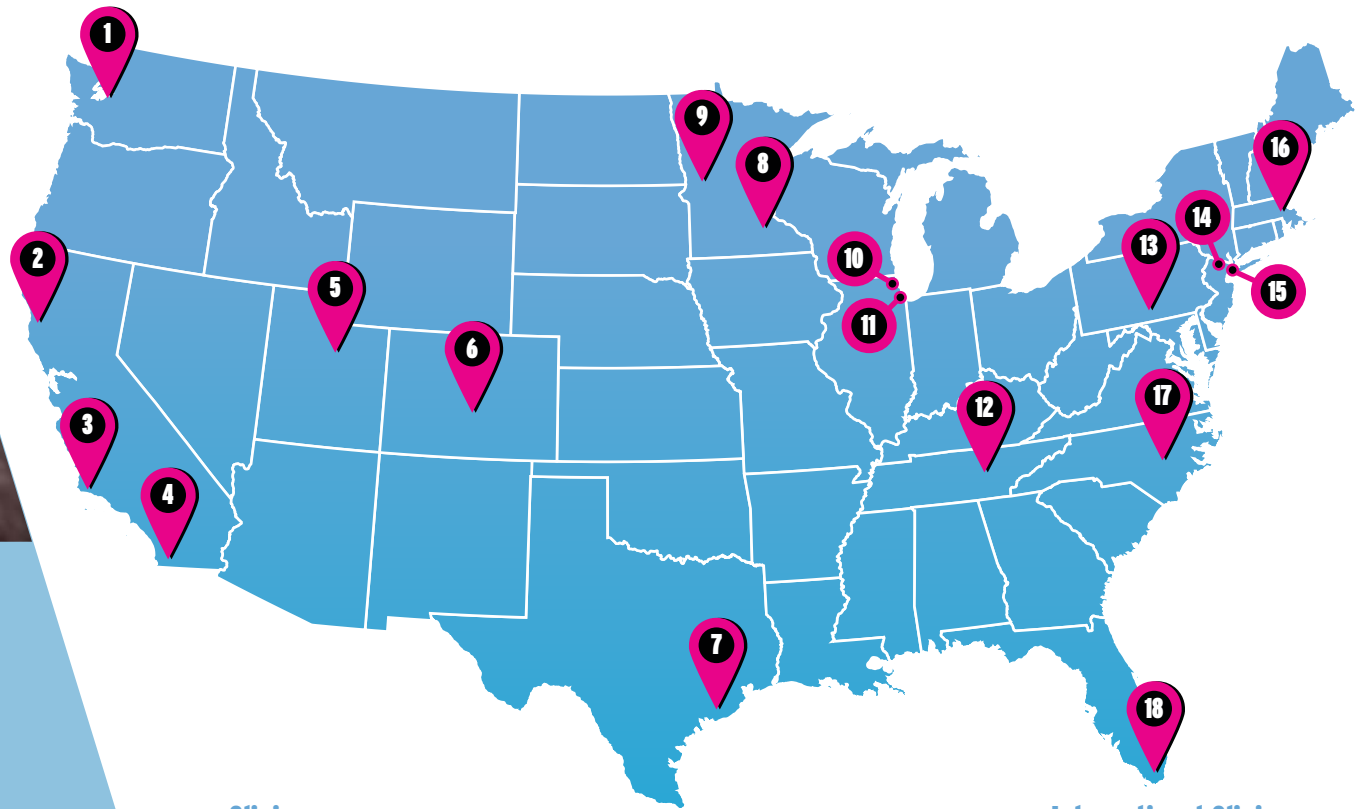
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International Clinics

In 2019, ASF partnered with the Dup15q Alliance, combining our respective clinic networks to create the 15q Clinical Research Network. This partnership allows us to provide AS families with even more clinics staffed by professionals specializing in AS and syndromes affecting the 15th chromosome.





The result of the expanded network is that families won't have to travel as far to reach the specialized, comprehensive care available in Angelman syndrome clinics. These clinics will also expand access to future clinical trials.



Clinics

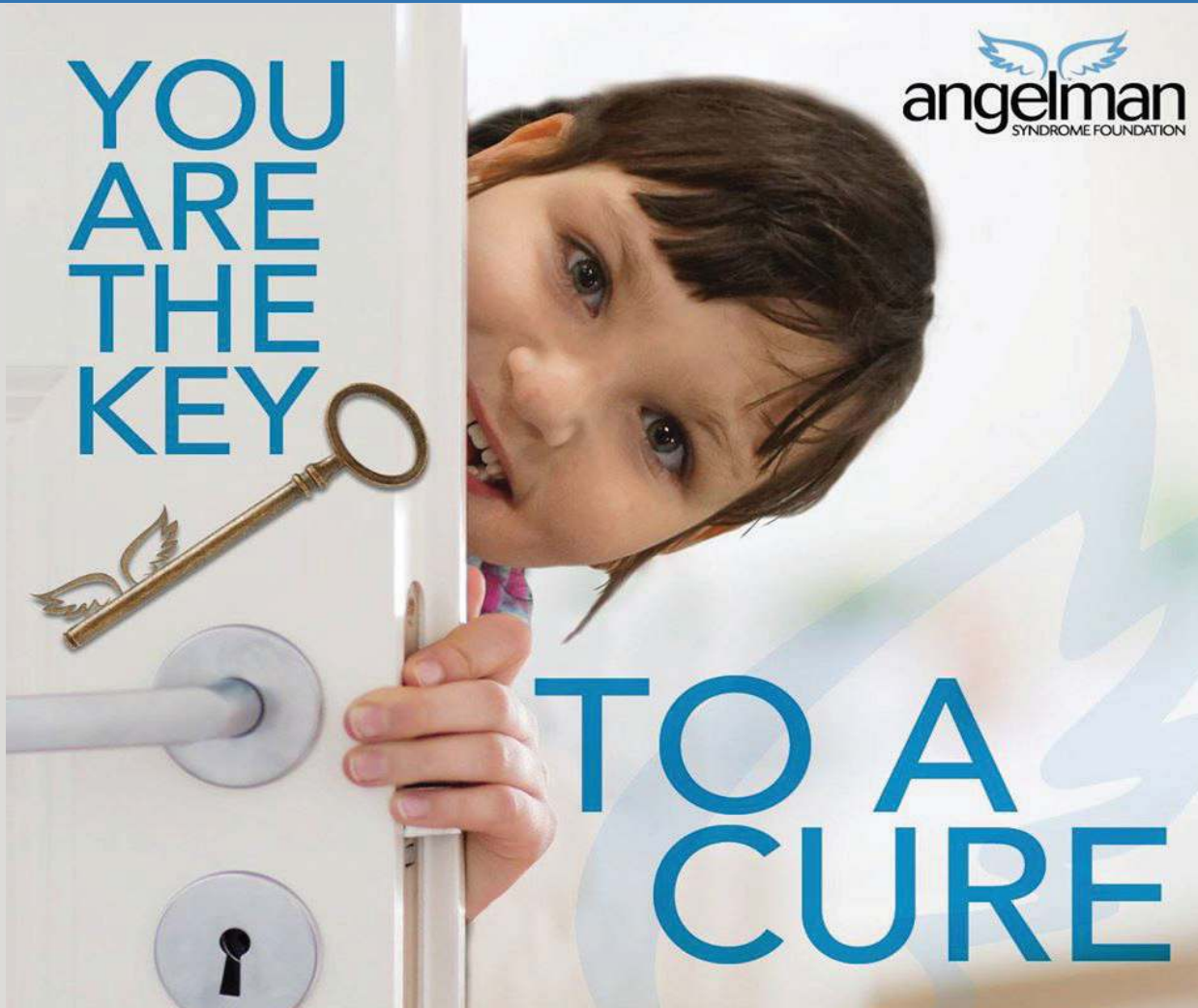
- 1) Seattle Children's Hospital
- 2) UCSF Benioff Children's Hospital Oakland
- 3) UCLA CART Center for Autism Research and Treatment
- 4) Rady Children's Hospital, San Diego
- 5) Intermountain Primary Children's Medical Center
- 6) Children's Hospital Colorado
- 7) Texas Children's Hospital
- 8) Mayo Clinic
- 9) Minnesota Epilepsy Group
- 10) Rush University Medical Center
- 11) Lurie Children's Hospital of Chicago
- 12) Monroe Carell Jr. Children's Hospital at Vanderbilt
- 13) Geisinger Janet Weis Children's Hospital
- 14) NYU Langone Medical Center
- 15) Weill Cornell Medical College of New York
- 16) Massachusetts General Hospital
- 17) UNC Carolina Institute for Developmental Disabilities
- 18) Miami Children's Hospital

International Clinics

- Buenos Aires, Argentina
- Children's Hospital of Eastern Ontario
- Edmond and Lily Safra Children's Hospital, Tel Hashomer
- Erasmus MC, Rotterdam

"Having all the professionals see them at once is great for families for many reasons. One of them is that we all talk so we all try to come up together with the best plan for the family to try to address their major concerns." - Jessica Duis, M.D., M.S.

Because of **YOU!**



ASF is able to open new clinics that serve families and form strategic alliances thanks to the generous support of donors like you!

Last year, your response to our "YOU are the Key to a Cure" appeal enabled us to support families, open clinics and fund research.

**624 DONORS
CONTRIBUTED**

**over
\$263,000**



While the ASF AS Clinics help treat the complex symptoms of AS, they also hold the promise of a brighter tomorrow.

More than

\$10.4 Million

in research funding to date

ASF-Funded Research Studies





Role of UBE3A-HERC2 Complex in Angelman Syndrome: 3D Structure and Quantitative Interactomics

Dr. Gilles Trave, PhD – European Center of Research and Biology in Illkirch, France

\$200,000 (This research project is jointly funded by the ASF and Dup15q Alliance.)

This study looks at the interactions between proteins UBE3A and HERC2 and how they impact brain development.

[Click here to read more.](#)



The Prevalence and Form of CVI in Angelman Syndrome

Dr. Karen Erickson, PhD – UNC Chapel Hill, North Carolina
\$100,000

There is reason to believe that many individuals with AS have cortical visual impairment (CVI) that may affect balance, walking, communication and behavior. This study aims to estimate the number of AS individuals who have CVI, assess its severity, and determine how it impacts communication.

[Click here to read more.](#)



Structure-Function Studies to Characterize UBE3A Missense Variants

Dr. Jason Yi, PhD - Washington University, St. Louis
\$100,000

This study will create the first complete functional catalogue of UBE3A missense variants. This will potentially aid in diagnosis by estimating the likelihood that a particular missense mutation causes AS and potentially uncover new information about how UBE3A works.

[Click here to read more.](#)



To what Extent are Striatal Deficits Underlying Clinical Features of Angelman Syndrome?

Dr. Ype Elgersma, PhD - Erasmus Medical Centre, Rotterdam
\$99,825

It's not clear which brain areas directly contribute to the different phenotypes of AS. Knowledge of critically affected brain areas will help identify the most relevant cell and brain dysfunctions that contribute to AS and will help us to understand why the success of UBE3A gene-reinstatement strategies appear to be sensitive to age at treatment onset.

[Click here to read more.](#)



87 CURE CLUB MEMBERS DONATED NEARLY \$30,000

This special group opens their hearts monthly with a donation that truly makes a difference. Each gift adds up as a big impact for AS families, and we are so grateful for their generous support.

Learn more about the ASF Cure Club here.
www.angelman.org/make-an-impact/asf-cure-club

\$10 EACH MONTH
\$120
YEARLY IMPACT

\$25 EACH MONTH
\$300
YEARLY IMPACT

\$50 EACH MONTH
\$600
YEARLY IMPACT

\$100 EACH MONTH
\$1,200
YEARLY IMPACT

Scientific Advisory Committee

This group of 18 Angelman syndrome researchers and professionals is responsible for overseeing research grants funded by the ASF. Members donate their time and talent to review all research applications submitted to the ASF for funding.



*Stormy Chamberlain,
PhD- SAC Chair*



*Arthur Beaudet,
MD*



*Charles Williams,
MD*



Ben Philpot, PhD



Dan Harvey, PhD



Michael Ehlers, MD, PhD



Steven Katz, MD



Jane Summers, PhD



Mark Nespeca, MD



Wen-Hann Tan, MD



Fred Pritzker, JD



Ron Thibert, DO, MsPH



Coral Thompson, BSc., RT



Katharine Grugan, PhD



Lora Meerdo



Elizabeth Berry-Kravis MD, PhD



Rebecca Burdine, PhD



Joseph Horrigan, MD

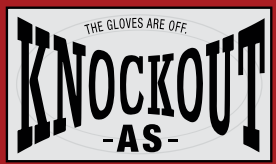
Learn more about them at: www.angelman.org/about/scientific-advisory-committee



In 2019, the ASF Family Fund was created to assist families supporting individuals with Angelman syndrome. Whether families need help paying for travel expenses to visit an ASF AS Clinic, communication devices, safety beds, adaptive bikes or more, they are invited to apply for funds that would help improve the quality of life for an individual with Angelman syndrome.



Learn more at www.angelman.org/resources-education/asf-family-fund



In July, AS families, clinicians and researchers came together to #KnockoutAS in Louisville, Kentucky. The ASF Family Conference is the most comprehensive AS meeting in the world, allowing families to learn how to address the physical, emotional and life-changing challenges an AS diagnosis brings in a supportive and uplifting environment. At the same time, the ASF Research Symposium brings together premier, global AS researchers to collaborate and discuss the most current research in an open forum. Having families and professionals under the same conference roof allows unprecedented access to knowledge in an informal environment.

2019 AWARD WINNERS



*Dr. Stormy Chamberlin
Claudia Benton Award for Scientific Research*



*Erin Sheldon
Angelman Award for Meritorious Service*



*Eileen Braun
ASF Lifetime Achievement Award*



*Art Beaudet
The Eileen Braun Lifetime Achievement Award*

We were thrilled to come together with families and researchers in Louisville to recognize and celebrate the contributions of these individuals who are an integral part of the ASF family

Supporters like you made it possible for AS families to experience this amazing, all-encompassing conference free-of-charge. Thank you!

Center for Courageous Kids

This past spring, generous donors once again helped families enjoy three days at Center for Courageous Kids.

This weekend allows families to get away from day-to-day stress and enjoy time together. CCK allows families to truly experience camp – with no barriers, no questions – just space to BE themselves.



ASF Family Resource Team

The ASF Family Resource Team is a group of compassionate AS experts and family members who help other AS families handle a variety of needs, from finding general resources, to solving Individual Education Plan issues, to finding medical equipment.

This group serves as a lifeline for AS families across the country. In 2019, they spent more than 100 hours providing one-on-one support to families, and they've spent a total of 1,612 hours with families since 2014.



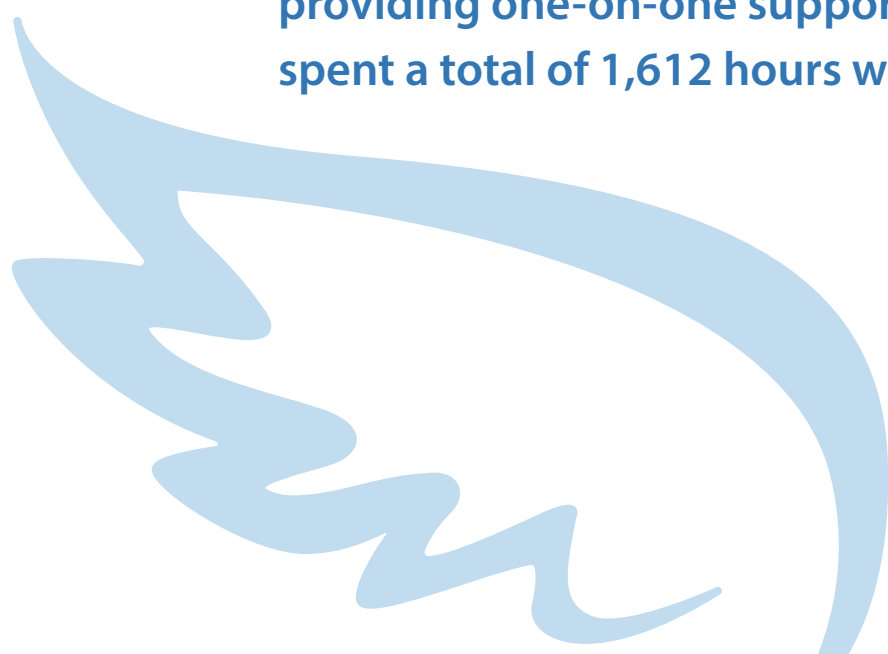
Michelle Harvey



Lizzie Sordia



Dr. Eric Wright



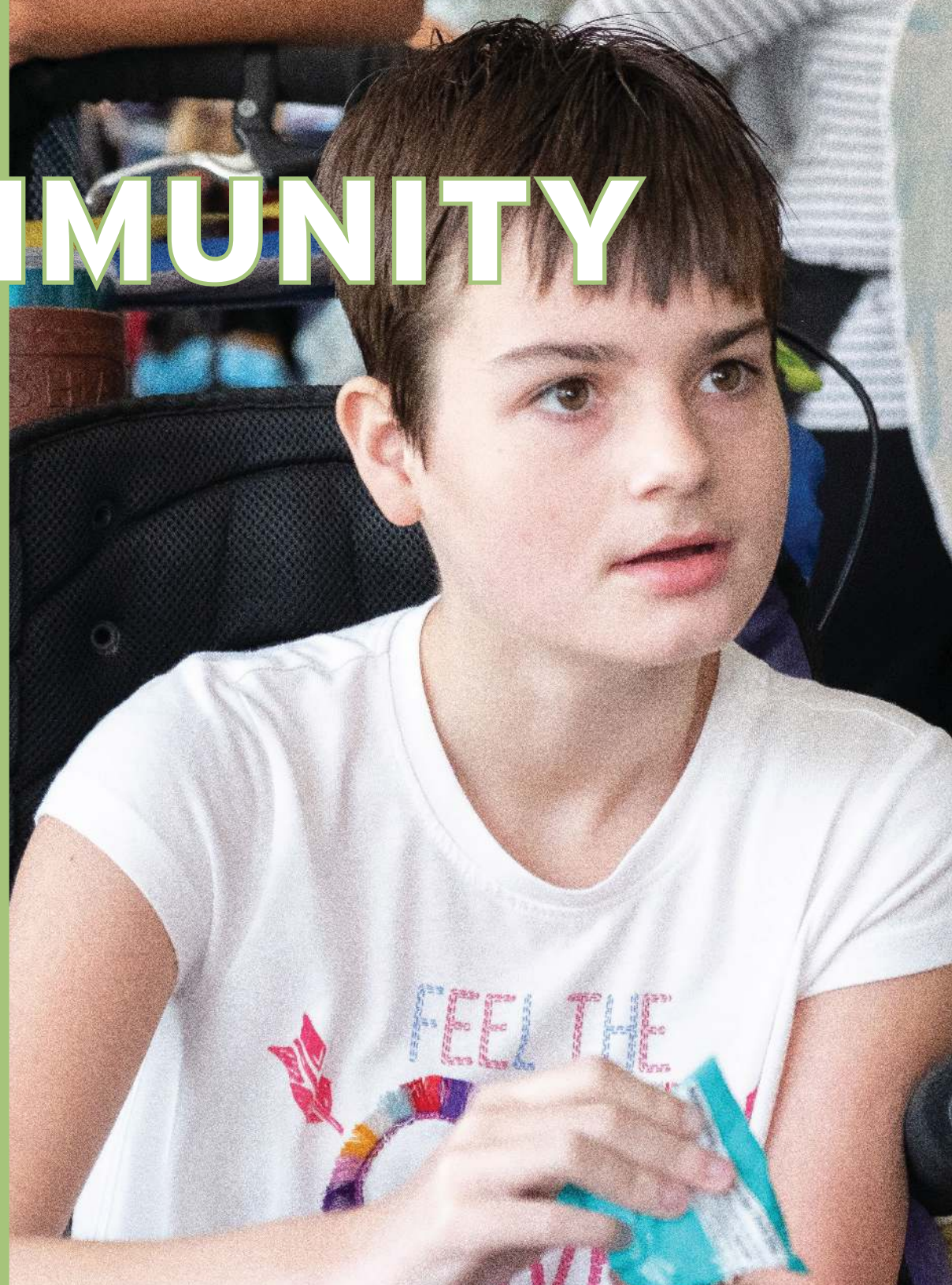


ASF IS

COMMUNITY

The heart of our community is each and every one of YOU! A large portion of the funds that allow us to support families, launch clinics and fund research come from grassroots fundraisers across the country and around the world. Here's a snapshot of what YOU did in 2019.

"Our fundraisers support programs that have a tremendous impact on families each and every day."



2019 FUNDRAISING

John Mace, from Parker, CO, created 27 CrossFit Workouts of the Day in honor of his son Cameron. The 27 Hour Challenge was done individually or as a team. John did all of them beginning September 28.

**27 HOURS
FOR CAMERON**

\$4,551



**CENTERCOURT
LACROSSE**

\$10,473



**SKATING
ANGELS**

\$26,865

Arch Creek

Andy Meerdo organized the 6th Annual Charity Golf Fundraiser for the Angelman Syndrome in Smithfield, UT. Through this annual event, Andy has raised more than \$100K in support of AS Utah and the Angelman Syndrome Foundation.



MEERDO CHARITY GOLF
\$15,000

QUINN'S HOT COCOA FOR A CURE
\$35,522



Quinn started his Hot Cocoa for a Cure to raise money for his twin sister Emma, who has AS. Now in its third year, Quinn is working toward his ultimate goal of selling 5 million cups!

We are thankful for all of the people who have helped raise money for the Angelman Syndrome Foundation online through Facebook Fundraising.

Fundraisers

About

Explore

Trayvean's Birthday Fundraiser for Angelman Syndrome Foundation

Manage

Shortcuts

Jacqueline's Birthday Fu...

Liz's Birthday Fundraiser...

Stewart's Birthday Fund...

Jonah's Birthday Fundra...

Fundraiser to cure Angel...

See more

+ Raise Money



Trayvean's Birthday Fundraiser for Angelman Syndrome Foundation

Fundraiser for Angelman Syndrome Foundation by Trayvean D. Scott · 🌐

Donate to Nonprofit

Invite

Share

More

Fundraiser Ended

Trayvean reached his birthday goal! Thanks to everyone who donated.

\$1,520 / \$1,500 raised ⓘ

45
donated

3.5K
invited

0
shared

Created By



Trayvean D. Scott

On Facebook since 2009

5,000 friends

Frequently Asked Questions

Learn More

▶ How do I create my own birthday fundraiser?

▶ How do nonprofits receive donations?

FACEBOOK FUNDRAISERS

\$96,706

A yellow banner held by three people at a marathon. The banner features a blue skyline of Chicago buildings, the text 'Windy City Angels', a logo of two wings, 'Angelman Syndrome Foundation', and the website 'www.angelman'.

**CHICAGO
MARATHON & 5K**

\$55,700

Our Windy City Angels didn't step on the brakes this year! They ran 26.2 miles and along with our 5K runners and countless supporters, combined to raise \$55,700 to bolster our families and clinics.

YOUR Impact

Much more than the dollars raised is the impact they represent - families supported, clinics funded, research advanced.

Even more than the dollars raised is the dedication those dollars represent – almost everyone associated with ASF has played some role in organizing, supporting, or cheering on these efforts, and we are tremendously grateful for your support.



ASF WALK



On May 18, enthusiastic Difference Makers from across the nation came together for the 2019 Angelman Syndrome Foundation Walk. Our largest annual fundraiser is a time to build community and connect with other families who are on similar journeys.

**YOU RAISED
nearly \$1.1M!**

Summary of Revenues & Expenses

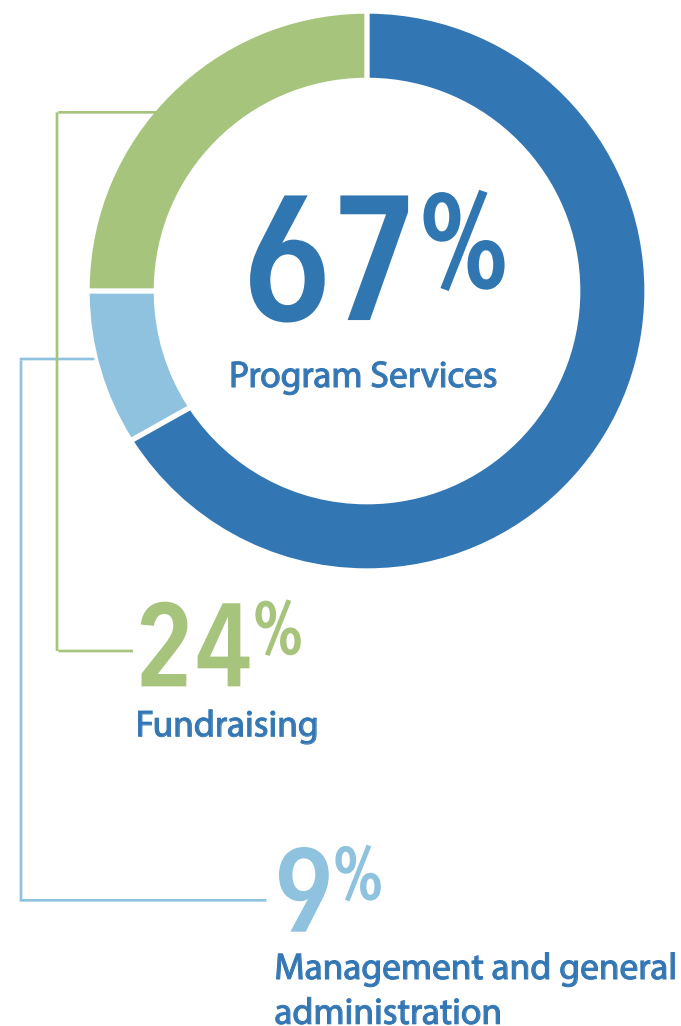
	FY2019	FY2018
REVENUES		
Description		
Contributions	\$1,060,649	\$722,681
Conference & Symposium	\$108,854	\$23,969*
Special Events (Net)	\$1,005,519	\$1,174,675
Investments	\$13,549	\$27,066
Other Income	\$71,132	\$5,252
Donated Professional Services	\$73,500	\$147,000
Total Public Support and Revenue	\$2,333,203	\$2,100,643

EXPENSES		
Program Services	\$1,260,158	\$1,585,521
Management and General	\$159,289	\$140,010
Fundraising	\$442,809	\$410,929
Total Functional Expenses	\$1,862,256	\$2,136,460
Change in Net Assets	\$467,947	-\$35,817
Net Assets Beginning of Year	\$1,326,379	\$1,362,196
Net Assets End of Year	\$1,794,326	\$1,326,379

Schedule of Programmatic Expenses (How we used funds to meet our mission)

	FY2019	FY2018
Family Support & Education	\$287,687	\$274,687
AS Clinics	\$140,301	\$297,300
Research	\$553,300	\$927,528
Conference and Symposium	\$278,870	\$86,006
TOTAL Programmatic Expenses	\$1,260,158	\$1,585,521

Annual Operating Expense Ratios



*Scientific Symposium only in FY2018

ASF BOARD OF DIRECTORS

We are honored to have this team of leaders steering our course as ASF heads into the future and would like to extend heartfelt thanks to Eric Hamberg, Elizabeth Jalazo and our new CEO Amanda Moore who rotated off the Board this year.



Justin Grill
President, Spring Lake, MI



Tim Bousum
Vice President, Ipswich, MA



Kathy Rokita
Treasurer, Indianapolis, IN



Michael Cecere
Secretary, Kingston, MA



Stormy Chamberlain
SAC Chair, Oxford CT



Dan Harvey
Director, San Diego, CA



Shannon Pruitt
Director, Los Angeles, CA



Jim Kubicza
Director, Cheshire, CT



Kyle Rooney
Director, Twin Cities, MN



Eric Wright
Director, Louisville, KY



Anna Blanding
Director, Hamden, CT



Rebecca Burdine
Director, Princeton, NJ



Leslie McCallister
Director, Charleston, WV



Susan Ravellette
Director, San Diego, CA



Jim Lamb
Director, Stow, MA

FROM OUR PRESIDENT

"2019 has been a time for change and great promise within our Angelman syndrome community. During the year the ASF announced that Amanda Moore would serve as the next CEO of the Angelman Syndrome Foundation. Next was the announcement that ASF was partnering with the Dup15q Alliance to greatly expand the reach of clinical care for individuals with both syndromes, bringing the number of clinics within our network to 20, and spanning the entire geography of the United States. The LADDER project has also been operationalized, bringing the clinical data from this network into a singular location with the data from the Natural History Study, creating the single largest compilation of clinical AS data in the world. This will be a key asset as we enter the next phase...clinical trials. Lastly, it was announced that four of our industry partners intend to bring therapeutic treatments to Phase 1 and 2 clinical trials in 2020. Certainly, 2019 was an exciting year and we cannot wait to see what 2020 has in store for our community."

- Justin Grill
Board President



For all YOU do, and so much more,
thank you for changing the lives of people with
Angelman syndrome and their families.



**FAMILIES. RESEARCH.
CLINICS. COMMUNITY.**

WITH YOU FOR THE JOURNEY.

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