Welcome to the family.

angelman™ SYNDROME FOUNDATION

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

WITH YOU FOR THE JOURNEY.

A MESSAGE FROM AMANDA

Whether you are newly diagnosed or new to the Angelman Syndrome Foundation, we want you to know that we are here for your family and the journey ahead. This brochure is an introduction to the many benefits the Angelman Syndrome Foundation can offer you. It contains information regarding all aspects of Angelman Syndrome (AS) including investment in research, dedication to the community, genetic, medical, and physiological facts about AS.

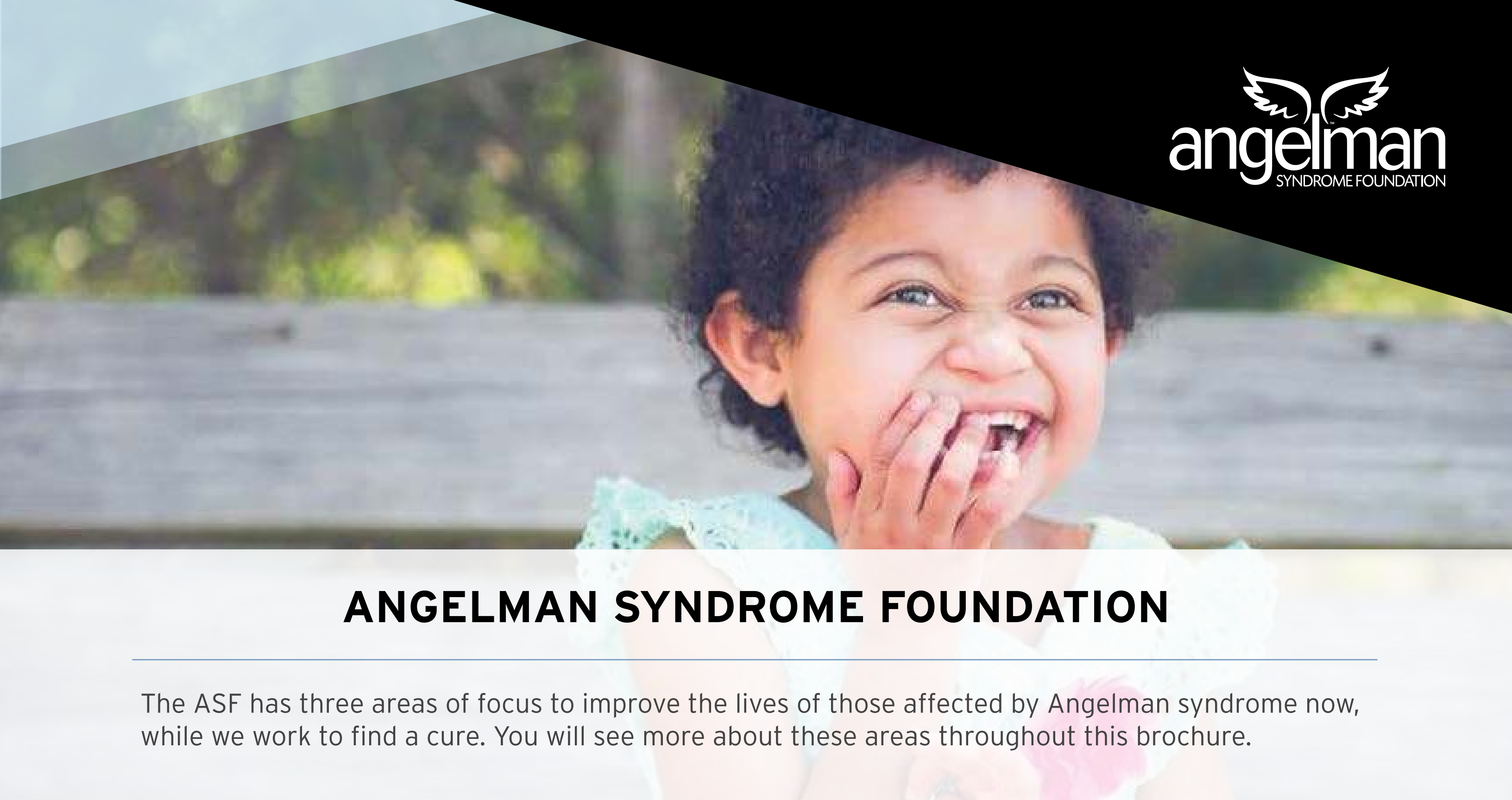
– Amanda Moore, CEO, AS mother to Jackson (deletion +)

Our Vision

The future is bright and hopeful. We have the best team of volunteers, health care providers and doctors with the relentless passion and dedication to making lives better and finding a cure.

Our Mission

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.



ANGELMAN SYNDROME FOUNDATION

The ASF has three areas of focus to improve the lives of those affected by Angelman syndrome now, while we work to find a cure. You will see more about these areas throughout this brochure.

Treat and Cure

By investing in the highest quality research, the ASF is advancing the treatment of Angelman syndrome that will ultimately lead to a cure.
We accomplish this by expediting therapeutic treatments and cures, and engaging and retaining high-quality researchers and industry partners.

ASF AS Clinics

The ASF AS Clinics, part of the 15q Clinical Research Network, are where standardized, comprehensive medical care for Angelman syndrome exists. The clinicians understand AS and can provide medical care that individuals with AS need. The network of clinics also provides a foundation to support current and future research and clinical trials. The ASF AS Clinics are established sites with experts and patients in place to conduct trials, as well as a patient database full of information to help find a cure.

Support

No other Angelman organization provides the level of support that the ASF does to the Angelman community. While we work toward finding a cure, we understand that families and individuals need help now. We provide opportunities for community building, respite and education. Through our resources and events, the Angelman community can connect and find friendship, acceptance and answers. We look for opportunities to educate our local communities and raise awareness of this rare disorder, in hopes that the question, "What is Angelman syndrome?" becomes obsolete.

Avie Mae (deletion +) and ASF Family Fund Recipient

HOW THE ASF IS HERE FOR YOUR FAMILY

ASF Family Fund

The ASF Family Fund provides financial assistance to people who support individuals with Angelman syndrome. Family members can apply for funds that are needed to improve the quality of life for an individual with Angelman syndrome. Applications are open twice a year in April and October.
www.angelman.org/resources-education/asf-family-fund

ASF Family Resource Team

This team of three is small, but mighty. They are AS experts who have a child or family member with AS. They provide guidance and understanding on topics such as health, insurance, finance, education, transportation, technology and much more. Find out more and send them your questions on our website under Resources > ASF Family Resource Team.
www.angelman.org/resources-education/asf-family-resource-team

ASF Communication Training Series

Lack of verbal communication is seen in the majority of individuals with AS, but that doesn't mean they can't communicate. The Communication Training Series is a video-based series that can help you and your individual with AS begin to communicate better at any stage.
www.angelman.org/resources-education/communication-training-series

The Behaviors Training Series

This series of video-based modules was designed to help caregivers understand a variety of factors that can contribute to challenging and aggressive behaviors that are sometimes present in people with AS. Caregivers are able to identify potential causes and create an action plan to help modify these behaviors. www.angelmanbehaviors.org

ASF Family Champions

Need advice? Looking for Angelman families that live near you? Have a frustration or celebration that only another AS parent would understand? These fellow AS family members have volunteered to be available to other families to share their knowledge, experience and lend an ear. Get in touch and make a new connection today! www.angelman.org/resources-education/asf-family-champions

ADVICE FOR NEWLY DIAGNOSED FAMILIES

From The ASF Family Champions

1. **Your Angel Might Be More "Typical" Than You Think.** Your child WILL meet milestones and have AWESOME progress! Just in their own unique and perfect way & time.
2. **Be Proactive Apply for Medicaid ASAP.** Apply for Social Security or Supplemental Security Income as soon as possible. Apply for any waivers ASAP. Get on the waiting list(s)–DO NOT WAIT for any reason…including that you don't need the support right now.
3. **Find Support. Make Connections. Ask for help. Join support groups!** The [Angelman journey] is the road less traveled and there are times it can get a bit lonely and overwhelming. Support is out there in whatever way is right for you.
4. **Recognize the Positive and Enjoy the Experience of Being with an Angel.** Angelman syndrome is not always a bad thing. Your child has super powers like their contagious smile and the ability to light up a room. They will teach you unconditional love and appreciating the little things more than you can ever imagine.
5. **Keep Working. Slow And Steady. You'll Get There.** Parents will adjust to unique sleeping habits and patterns…keep trying everything you can . . . something will eventually work, even if it's temporary…
6. **Give Yourself Credit.** Don't be too hard on yourself (your spouse, your other children). Everyone in the family is not going to be in the same place emotionally when dealing with situations.
7. **Participate in the ASF Walk.** Support your local ASF Walk and invite friends, family, school people, community people – AWARENESS makes such a difference.
8. **Visit a 15q Clinic.** The quality of care and level of expertise is like no other. You will learn more than you can imagine.
9. **Think About and Plan for the Future.** Stay in the present/day to day but keep the future in mind as you always need to be planning ahead for the next steps.
10. **Couple of Other Things.** It is important to spend quality time with your spouse/significant other and your other children-both as a family and individually. Every member of the family is important.

Read more advice in the blog section www.angelman.org/articles/ten-pieces-of-advice/

More Resources and Information

To learn more or see a full list of resources and educational opportunities, visit the Resources section of our website at www.angelman.org/resources-education

Connect with Local AS Families and Professionals

Please call or email the ASF office directly so we can personalize these resources to fit your specific needs.

U.S. 1-800-432-6435 | Int'l 1-630-978-4245
Email info@angelman.org

Family Conference – Louisville Kentucky

ASF EVENTS

The ASF hosts, participates in and facilitates events across the country. Events are a great way for Angelman families to connect with other Angelman families in their community, raise awareness for this rare disorder and fundraise for research and family support.

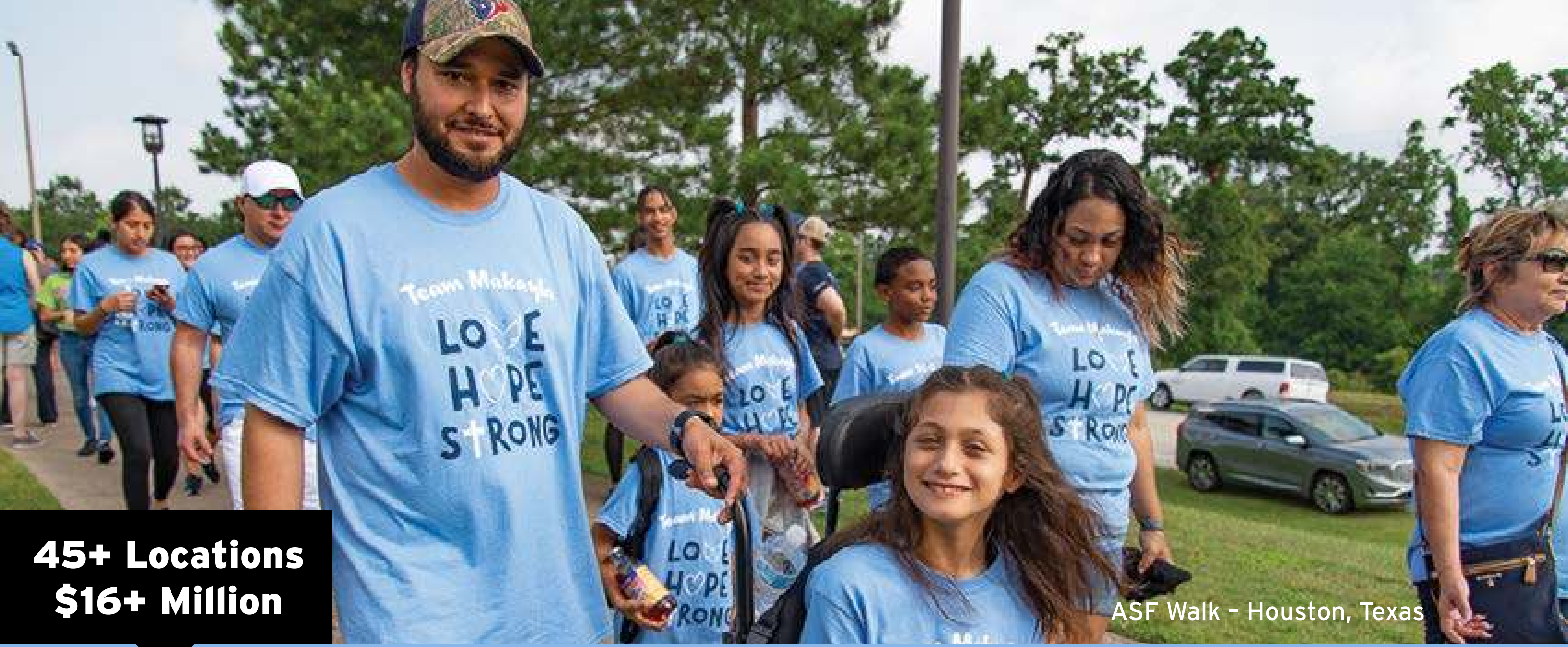
The ASF Family Conference

This conference is held every other year in a different location and gathers families, care providers, therapists, teachers, researchers and doctors in one place to learn and discuss the latest information on Angelman syndrome. The ASF Family Conference is a one-of-a-kind experience!

> *" Going to the family conference was definitely one of the best decisions we've made. It helped remove so many of the mysteries and unknowns for us and helped dispel some of our biggest fears, while also opening our eyes to the areas we should really focus on."*
>
> *– Steve, AS father (Mason deletion +)*

ASF Research Symposia

The research symposium is held every year in a different location. It is a chance for leading researchers, scientists and doctors to discuss the latest research in the world of AS. The symposium is a unique opportunity for researchers to present the latest findings in their unpublished work and compare notes with colleagues from around the globe.



ASF Walk – Houston, Texas

45+ Locations
$16+ Million

ASF WALK

The ASF Walk happens every year in 45+ locations across the US. It is the ASF's biggest fundraiser and an opportunity for those who love someone with AS to reconnect, learn new things and celebrate our individuals with AS. Find out more at www.angelman.org/walk

$206K

Quinn's Cocoa $4 the Cure
Quinn started selling cocoa to raise money for the ASF in honor of his twin sister, Emma. His ultimate goal is to sell 5 million cups. So far, he has raised more than $206K.

$200K

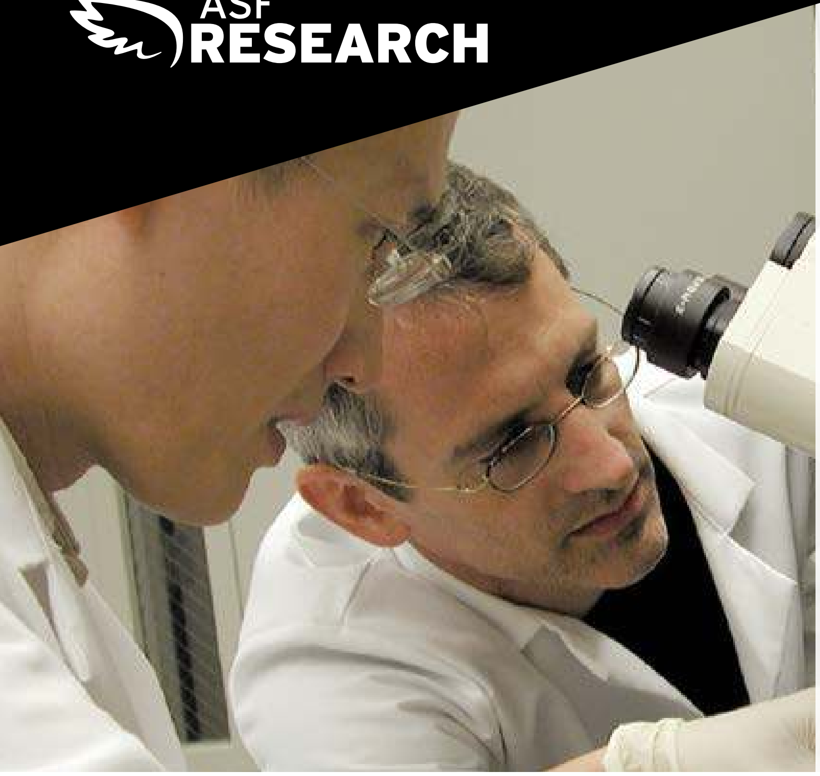
Bank of America Chicago Marathon
The ASF is an approved charity of choice for the Bank of America Chicago Marathon. The Windy City Angels are our team of runners who are dedicated to making a difference in the lives of people with AS. The team has raised $200K.

$100K

Meerdo Charity Golf
Andy Meerdo organized the 6th Annual Charity Golf Fundraiser for the Angelman Syndrome Foundation. This event has raised more than $100K.

Have an Idea for an Event?
We are so grateful for people who plan and host their own events as fundraisers for the ASF. If you have an idea, contact Kitty Murphy kmurphy@angelman.org.
For more information, visit www.angelman.org/make-an-impact/fundraising-for-asf/

ASF RESEARCH



ASF Funded Research has lead to **$150 Million** in Angelman Research.

INVESTED IN RESEARCH. COMMITTED TO A CURE.

Research is the key to finding a cure.

ASF funded research has led to the most promising, current treatments and pathways to a cure. With cutting edge advancements, discoveries and clinical trials underway, it is an exciting time in Angelman research.

A CURE FOR ANGELMAN SYNDROME

Gene Therapy

ASF funded research in multiple gene therapy techniques have recently led to partnerships, licensing agreements and massive additional funding to continue to study and develop these techniques for Angelman syndrome.

UBE3A Activation

Angelman syndrome is caused by a problem with the mother's copy of a gene called UBE3A. The father's copy of the gene is silenced or "turned off." It is believed that one way of curing AS will be to turn on (activate) the father's copy of UBE3A.

ASF funded studies discovered ways to turn on the silenced copy of UBE3A using two different drugs (toposiomerese inhibitors and antisense oligonucleotide (ASOs)).

These groundbreaking studies proved that father's copy of UBE3A can be activated. ASOs are currently being developed by several pharmaceutical companies and some are in clinical trials.

TREATMENTS FOR ANGELMAN SYNDROME

Low Glycemic Index Treatment (LGIT)

As many as 90% of individuals with Angelman syndrome will at some point suffer from life-threatening seizures. ASF funded research found that individuals that follow the LGIT's high-fat, low-carb diet have a 90% reduction in seizures.

CBD Oil

The ASF also funds research that has found effective treatments for symptoms like anxiety, seizures, behavioral and motor challenges.

The ASF funded the first pre-clinical evaluation of cannabidiol (CBD) in AS. It was believed that CBD could be a powerful drug to address some symptoms of Angelman syndrome—but no scientific research existed to support it.

Find out more at
www.angelman.org/as-research

Nicholas (Mutation) and Dr. Bacino at ASF AS Clinic, Texas

ANGELMAN SYNDROME CLINICS

Life-Changing Care | World-wide

Angelman syndrome is a rare disorder, and sometimes there are health issues that a local pediatrician or specialist may not be familiar with. By partnering with leading medical and research institutions around the world, the ASF founded the Angelman Syndrome Clinics. These clinics have physicians and staff who know AS and provide individuals with AS the comprehensive medical care they need.

In 2019, the ASF and Dup15Q Alliance combined their respective clinic networks to create the 15q Clinical Research Network, expanding the clinic network to 22 locations. (Dup15q syndrome and Angelman syndrome are both rare disorders that are caused by a problem with the 15th chromosome.)

Find out more at www.angelman.org/angelman-syndrome-clinics

LADDER

Linking Angelman and Dup15q Data for Expanded Research

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LADDER, another collaboration between the ASF and Dup15q Alliance, launched in 2019. Built by RTI International, LADDER is a database that houses data collected at the Dup15q Clinical Research Network clinics and through research studies.

The information in the database can be accessed by physicians who treat Angelman syndrome, researchers who are working to find treatments and a cure, as well as pharmaceutical partners who are working on drug development projects. The heightened level of data analysis and discovery will increase our understanding of the disorder and help researchers target therapies and advance clinical trials more quickly and efficiently.

CONNECT ON SOCIAL MEDIA

Facebook | Twitter | LinkedIn | Instagram | Pinterest | YouTube

Facebook
The official Angelman Syndrome Foundation Facebook page is our primary communications hub on social media. Here you will find updates regarding Services, Research, Fundraising and General ASF Community News.

Page Name: Angelman Syndrome Foundation
www.facebook.com/AngelmanSyndromeFoundation/

Facebook Group
The Angelman Syndrome Foundation Facebook Group is a place where family members, researchers, caregivers and other members of the Angelman syndrome community can converse one-on-one about a variety of topics.

Group Name: Angelman Syndrome Foundation
www.bit.ly/ASFGroup

Twitter
The Angelman Syndrome Foundation Twitter account is where you can find real-time communications from the ASF during events and awareness campaigns as well as other general information.
Account Name:
www.twitter.com/angelman

LinkedIn
The Angelman Syndrome Foundation LinkedIn page provides updates on all activities organized by the ASF and the AS community, such as fundraisers, events and research.
Account Name:
www.linkedin.com/company/angelman-syndrome-foundation/

Instagram
The Angelman Syndrome Foundation Instagram account is where we share photos from our community and our events.
Account Name:
www.instagram.com/angelman_asf/

Pinterest
The Angelman Syndrome Foundation Pinterest page is where we share ideas and crafts.
Account Name:
www.pinterest.com/angelmansyndfdn/

YouTube
The Angelman Syndrome Foundation YouTube Channel hosts videos from ASF events, research and other announcements, media coverage, family videos, educational webinars, and our National Public Service Announcement (PSA).
Account Name:
www.youtube.com/user/AngelmanSyndromeFdn

"There is so much to be hopeful for! Organizations like the ASF fight for our angels and families like ours every day. They offer a wealth of support, knowledge and resources through all ages and stages. Their website is full of helpful info or a quick email or phone call, can help with whatever you need. There is also incredible research and clinical trials starting this year! The future has never looked more bright and hopeful for our little ones."

– Sarah, AS mother to Logan (deletion +)

MAKING THE CONNECTION

In Person Support

If connecting online is not your preference, there are in person support groups that can help you find answers to questions, connect with parents and feel part of a community.

- Special education parent advisory council (through the school district)
- Advocates for special needs children programs in your area

Look for an ASF Family Champion in your area:
www.angelman.org/resources-education/asf-family-champions

For a list of resources and support groups by state, visit:
www.angelman.org/resources-education/state-resources

CHARITY NAVIGATOR
★★★★
Four Star Charity

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