angelman
SYNDROME FOUNDATION

WELCOME TO THE *family*

A MESSAGE FROM AMANDA

Whether you are newly diagnosed or new to Angelman Syndrome Foundation (ASF), 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 ASF can offer you. It contains information regarding all aspects of Angelman syndrome (AS), including investment in research, dedication to the community and genetic, medical and physiological facts about AS.

— Amanda Moore, CEO

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 ASF 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

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 & Cure

By investing in the highest quality research, ASF is advancing the treatment of AS 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 Clinics

ASF Clinics, part of the LADDER Learning 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. ASF 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 syndrome organization provides the level of support that 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, our 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.

HOW ASF IS HERE FOR YOUR FAMILY

ASF Family Fund

The ASF Family Fund provides financial assistance to people who support individuals with AS. 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. Apply at **Angelman.org** > **Resources** > **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 at **Angelman.org** > **Resources** > **ASF Family Resource Team**

Communication Resources

Lack of verbal communication is seen in the majority of individuals with AS, but that doesn't mean they can't communicate. ASF has resources and training for communication so that you and your individual with AS can reach her/his greatest communication success at any age. **Angelman.org** > **Resources** > **Communication Resources**

Behavior Resources

Angelman syndrome can be accompanied by unique and challenging behaviors. ASF offers assistance and information about dealing with and understanding them. **Angelman.org** > **Resources** > **Behavior Resources**

ASF Family Champions

Need advice? Looking for AS 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!
Angelman.org > **Resources** > **ASF Family Champions**

ADVICE FOR NEWLY DIAGNOSED FAMILIES

From 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 and time.

2. **Be Proactive Apply For Medicaid ASAP.** Apply for Social Security or Supplemental Security Income as soon as possible. Apply for any waivers. Get on 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 AS 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 Loving An Angel.** AS is not always a bad thing. Your child has super powers like his or her contagious smile and the ability to light up a room. They will teach you unconditional love and to appreciate 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 and community members. AWARENESS makes such a difference.

8. **Visit An ASF Clinic.** The quality of care and level of expertise is incomparable.

9. **Think About And Plan For The Future.** Stay in the present, but keep the future in mind. You should always plan ahead for what's coming next.

10. **Family First.** 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 on our blog at Angelman.org

Connect With Local AS Families And Professionals

Please call or email ASF directly so we can personalize resources to fit your specific needs.
U.S. 1-800-432-6435 | Int'l 1-630-978-4245
Email info@angelman.org

ASF EVENTS

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

The ASF Family Conference

The ASF Family 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 AS information. It's a one-of-a-kind experience!

ASF Research Symposium

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.

> **"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 and helped dispel some of our biggest fears, while also opening our eyes to areas we should really focus on."**
>
> **— Steve, AS father**

45+ Locations | $16+ Million

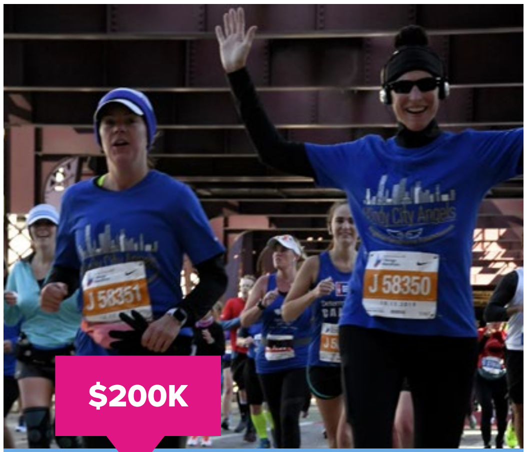
ASF
WALK

The ASF Walk happens every year in 45+ locations across the U.S. It is 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 **angelman.org/walk**

$206K

Quinn's Cocoa $4 The Cure

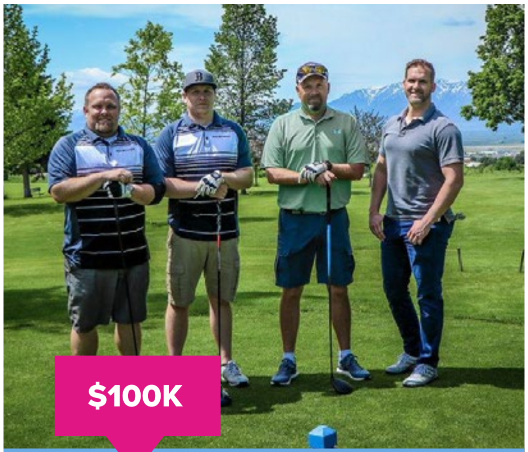
Quinn started selling cocoa to raise money for ASF in honor of his twin sister, Emma. His ultimate goal is to sell 5 million cups. So far, he has raised more than $266K.



$200K

Bank of America Chicago Marathon

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 $250K.



$100K

Meerdo Charity Golf

Andy Meerdo organized the 6th Annual Charity Golf Fundraiser for ASF. 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.
If you have an idea, contact Kitty Murphy kmurphy@angelman.org.
For more information, visit Angelman.org > Make an Impact > Fundraise

ASF-Funded Research has lead to
$150 Million in total AS 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 AS.

UBE3A Activation

AS 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 (topoisomerese 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 percent of individuals with AS 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 percent reduction in seizures.

CBD Oil

ASF also funds research that has found effective treatments for symptoms like anxiety, seizures, behavioral and motor challenges. 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 AS—but no scientific research existed to support it.

Find out more at **Angelman.org > Research**

LADDER
Learning Network

Linking Angelman and Dup15q Data for Expanded Research

LADDER Learning Network, a collaboration between ASF and Dup15q Alliance, launched in 2019. 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 AS, 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.

ASF CLINICS

Life Changing Care Worldwide

AS 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, ASF founded ASF Clinics. These clinics have physicians and staff who know AS and provide individuals with AS the comprehensive medical care they need.

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

Find out more at
Angelman.org > Clinics

CONNECT ON SOCIAL MEDIA

Facebook

The official ASF Facebook page is our primary communication hub on social media. Here you will find updates regarding services, research, fundraising and general ASF community news.
facebook.com/AngelmanSyndromeFoundation

Facebook Group
The ASF Facebook Group is a place where family members, researchers, caregivers and other members of the AS community can converse one-on-one about a variety of topics. www.bit.ly/ASFGroup

Twitter

The ASF Twitter account is where you can find real-time communications from ASF during events and awareness campaigns, plus other general information.
@angelman

LinkedIn

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

Instagram

The ASF Instagram account is where we share photos from our community and our events.
@angelman_asf

YouTube

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

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:
Angelman.org > Resources > ASF Family Champions

For a list of resources and support groups by state, visit:
Angelman.org > Resources > State Resources

> "There is so much to be hopeful for! Organizations like 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 are 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

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