

ASF CLINICS AND LADDER



For Patients. For Providers. Together, Toward The Cure.

Making Connections To Improve Quality Of Life

Each ASF Clinic is comprehensive, yet has its own unique capabilities that leverage the expertise and specialized care available from each partnering location. At ASF Clinics, you'll have access to a variety of professionals specializing in care for those with Angelman syndrome.

Types of Specialists at ASF Clinics include:

- Clinical Geneticists
- Neurologists
- Psychiatrists
- Psychologists
- Speech Language Pathologists
- Physical / Occupational Therapists
- Genetic Counselors
- Social Workers
- Nutritionists



angelman.org/clinics

LADDER Database

A strategic collaboration

LADDER is a database that brings together information about Angelman and Dup15q syndromes, collected from sources all over the world including the Angelman Natural History Study, patient visits to ASF Clinics in the LADDER Learning Network, research studies done on Angelman syndrome and Dup15q and the Global Angelman Syndrome Registry. Both organizations have made significant investments in the search for therapeutics and treatments.

Advancing Research with LADDER

Before LADDER, information about an individual with AS from research studies, doctor visits and registries was stored in disparate systems. There was no connection or way to link a research participant to their information from a clinic visit. Gathering the information in one place and connecting it, creates a higher level of understanding of AS which increases the potential for future discoveries that will lead to clinical trials and treatments. In addition, we will better understand how development, behavior and clinical needs change over time.

The data in LADDER can be accessed by:

- Physicians who treat Angelman syndrome
- Researchers who are working to find treatments and a cure
- Pharmaceutical partners who are working on drug development projects



Linking Angelman & Dup15q Data for Expanded Research



ADULT NEWSLETTER May 2022

Welcome from Amanda



Greetings from Angelman Syndrome Foundation (ASF)! For those of you that I have not met, my name is Amanda Moore, and I have the honor of being CEO at ASF. When I started this position in 2019, I put out a survey to the community to discover how ASF could better serve each of you. The results were pretty powerful. What spoke the loudest was the need for more resources, support and services for adults living with AS and their caregivers. In response to that, we put together an adult services committee to look at ways that we could do just that. What you will find in this newsletter are the resources that have been created to date to support that mission.

We still have a lot of work to do, but our promise is that we will always have services for this population as part of our strategic plan and objectives each year. Please feel free at any time to connect with me and let me know how we can serve you better. We will continue to work hard to support you in this journey and we hope that these resources provide support in the coming days.

Sincerely,
Amanda Moore
Amoore@angelman.org
1-800-432-6435

CONNECTION AND COMMUNITY

Having a strong support system helps people overcome challenges. We firmly believe in the importance of connection within our community.



This summer, the ASF Family Conference is back!

Join us August 2- 5 at the Kalahari Resort in Round Rock, TX. Programs and classes targeted to those caring for Adults with AS include:

- Clinical care panel for adults living with AS
- Hands-on sessions and training centered around communication, AAC and more
- Workshops on financial literacy, guardianship, retiring for three. You will leave with a plan in hand.
- Behavior and anxiety in adults with AS
- Mental health and best practices for caregivers
- Connection meals to bring families with adults together

Register today: [asfconference.org](https://www.asfconference.org)

ASF Family Champions with Adults

ASF Family Champions are family members who have volunteered to be available to other families to share their knowledge, experience and lend an ear. There is a group of Champions who are parents of adults with AS. These families are a great resource for questions, concerns and advice on various aspects of adults with AS transitioning and thriving. Reach out to an ASF Family Champion today [angelman.org](https://www.angelman.org) > Resources > Family Champions

Angel Guardians Meetings

The Angel Guardians group meets a few times a year. These meetings are not only for parents and siblings, but also for extended family members, neighbors or friends who are involved in the care of an adult with AS. Connect with other caregivers, to learn about available resources and to hear from experts.

[angelman.org](https://www.angelman.org) > Resources > Adult Resources

Adult Siblings Meetings

This group is for older teens and adult siblings of an adult with AS. Connect with other adult siblings, learn about resources for your adult sibling with AS and discuss information on future planning.

[angelman.org](https://www.angelman.org) > Resources > Sibling Resources

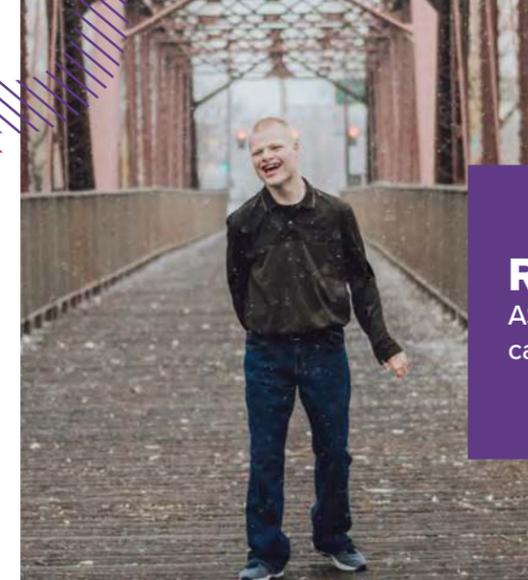
Be Part of The Community

Did you know we post all of our important information on our social media channels? Please follow us!

 ANGELMAN SYNDROME FOUNDATION

 @ANGELMAN_ASF

 @ANGELMAN



RESOURCES FOR YOUR JOURNEY

ASF has an abundance of resources for families and caregivers of adult individuals with AS.



Behavior Resources: With Angelman syndrome comes some unique and challenging behaviors and increasing anxiety. ASF is happy to offer assistance and information about dealing with and understanding these behaviors, free of charge. The following behavior resources are not intended to replace efforts already in progress with doctors and/or therapists, but rather to provide supplementary information and further assist with understanding the complex factors that result in these behaviors.



BEHAVIOR CONSULTATION: Dr. Christopher Keary, MD can provide a one-time 45-minute phone consultation for families dealing with challenging behaviors who are unable to travel to his outpatient clinic in Massachusetts General Hospital (MGH) for ongoing care. This consultation may include discussion with your local physician or therapist.

Keary is the Behavioral Director of the MGH Angelman Syndrome Clinic and the psychiatric consultant for various specialty clinics at MGH. He is a child, adolescent and adult psychiatrist with a specific interest in the care for individuals with developmental disabilities including Angelman syndrome.

[angelman.org](https://www.angelman.org) > Resources > Behavioral Resources

BEHAVIOR TRAINING SERIES: Angelman Syndrome Behaviors Informational Series is available to help explore the possible root causes of challenging and aggressive behaviors and to identify possible solutions.

Modules in the series:

1. Social and Environmental Influences on Aggressive Behavior
2. Aggression as Communicative Behavior
3. Cognitive Issues and Sensory Impairments
4. Mental Health Influences on Aggressive Behavior
5. Neurologic and Medical Influences on Aggressive Behavior

[angelman.org](https://www.angelman.org) > Resources > Behavioral Resources



Printable Resources: These documents were created by our Adult Taskforce. We hope that you will find them beneficial for any situation that might arise with your adult with AS.

- Transition to Adulthood
- Adult FAQ
- Comprehensive Care Binder
- Facility Tour Checklist
- All About Me Template

[angelman.org](https://www.angelman.org) > Resources > Adult Resources

Recordings & Past Webinars

At the ASF Family Conference, there are sessions dedicated to various topics on adulthood in AS and transitioning to adulthood. ASF has held educational webinars about the topic of Adulthood in AS.

[angelman.org](https://www.angelman.org) > Resources > Adult Resources

Financial Planning

At the 2021 ASF Virtual Family Conference, Mary Anne Ehler, CFP, from Protected Tomorrows presented a series of videos on financial and long-term planning for special-needs futures.

You can find these videos in the Adulthood Playlist or Financial Planning YouTube Playlist.

1. Overview
2. Government benefits
3. Legal
4. ABL Act
5. Retiring for three
6. Financial & long-term planning Q&A

www.angelman.org > Resources > Adult Resources

Counseling Services*

Even though caring for an individual with AS can be rewarding, we know that it can be challenging, stressful and isolating. Therefore, ASF is proud to offer counseling services at no charge to Angelman families in the United States. Counseling Services are available for help in areas like (but not limited to):

- Caregiver stress
- Support with marital problems
- Substance abuse issues
- Self-esteem concerns
- Stress management

*This service is not meant to replace a traditional counseling program.

Email: sbarlow@urbanbalance.com | Call: (773) 259-4200
[angelman.org](https://www.angelman.org) > Resources > Counseling Services

ASF Family Fund

The ASF Family Fund was created to provide financial assistance to families supporting 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 annually from October 1 to 15 and April 1 to 15.

[angelman.org](https://www.angelman.org) > Resources > ASF Family Fund