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 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
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

**CONNECTION AND COMMUNITY**

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

**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 challenges.

**Register today:** asfconference.org

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 > 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 > Resources > Sibling Resources

**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 > 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 > 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 > Resources > Adult Resources

**Financial Planning**

At the 2021 ASF Virtual Family Conference, Mary Anne Ehlert, 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. ABLE Act
5. Retiring for three
6. Financial & long-term planning Q&A

**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: dsbroll@urbanbalance.com | Call: (773) 259-4200

**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 > Resources > ASF Family Fund

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