

## *A Message from President Adam Gumson*



Hi all - Best wishes as Spring approaches!

You may recall that at our last Family Conference, held in July of 2025 and again in my December President's Message, I mentioned that the Board had set 6 main goals to accomplish in the next few years - and that we needed an influx of new blood and enthusiasm to build, lead and assist the new Committees that were being established to accomplish each of those goals.

Well, one goal already has been completed, thanks to Denise Parsons, MaryEllen Costa, Carrie Paup, Ronda Parsons and a host of others who have planned many of ASF's prior Family Conferences. They knocked it out of the park by drafting a comprehensive "How To" Manual about preparing for and running the Family Conference, replete with detailed time schedules for the myriad issues that impact Conference Planning as well as easy-to-use templates to send to potential Agenda speakers and Child Care volunteers. This Manual will enable current and future AS leaders to identify and navigate the many duties and responsibilities of hosting the "world class" Conference we all have come to know and expect. Thank you to all who had a hand in tackling this important project.

As to some of our other goals, my June President's Message will address our bustling Committees and the work they are doing as well as the Regional Coordinators who will assist new families in their neck of the woods. Stay tuned for more information. Meanwhile, although we've made tremendous progress, we are still in need of volunteers to serve on the following Subcommittees:

- Conference Big Sister/Little Sister Subcommittee Members
- Conference Social Subcommittee Members
- Conference Site Volunteer Subcommittee Chair and Members

If you would like to help, please consider putting your skills to work for the benefit of ASF and email me at [Adam@AicardiSyndromeFoundation.org](mailto:Adam@AicardiSyndromeFoundation.org) and I will put you in touch with the right person. Thank you!

Meanwhile, may you and your family enjoy continued good health and happiness.

**Visit Our Website: [www.aicardisyndromefoundation.org](http://www.aicardisyndromefoundation.org)**



## JENNA'S THROWBACK JAM 1980'S EDITION

Please come join us for our annual dinner dance to support Aicardi Syndrome Foundation. There will be dinner, an open bar, dancing, raffles, silent auctions, 50/50 and so much more!

Our theme is an 80's Jam, feel free to dress according to theme or you can still dress up if you prefer.



**BACK TO THE 80S**

### The Palazzo Grande

54600 Van Dyke Avenue  
Shelby Twp. MI 48316

Saturday, March 21, 2026  
6pm - 12am - Dinner at 7:00pm

#### TICKET PRICES

\$70 (13+) Early Bird Price  
\$75 Tickets purchased after Feb 14th  
\$45 (5 - 12 years old)  
FREE (under 5)

Pay by Check: Sharon Costandi  
13064 Florentine Drive • Shelby Twp. MI 48315

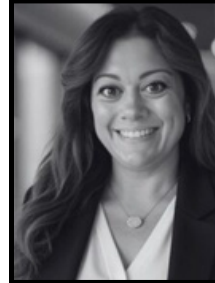
Pay by Venmo: @Sharon-Costandi

For more information, please call: Sharon at (586) 203-7983  
Tickets are available until March 14<sup>th</sup> or until sold out!

## Meet Our Team: The Aicardi Syndrome Foundation Board



Adam Gumson  
President



Carrie Paup  
Vice President



Ronda Parsons  
Secretary



Lissa Gumson  
Treasurer



Linda Tveita  
Member



Terry Tveita  
Member



Ben Wells Jr.  
Member



Justin Tolman  
Member

## A Day in the Life Of... Jenny Barada



My Name is Jennifer Barada. I go by "Jenny". It's hard to believe I will be turning 42 years old on March 18<sup>th</sup>. When I was first born, everything appeared fine. At 1 week old, I started having seizures. By 2 weeks old, I was admitted to the hospital. In spite of many tests and seizure meds, things continued to get worse. After many admissions, I was diagnosed with Aicardi Syndrome at the University of Kentucky Medical Center. This same hospital had diagnosed another girl (Emma Park) the year before.

At this time, there was little known about Aicardi Syndrome, and those of us who participated in the AS Newsletter, relied on each other for information. Most of the time, my parents educated the doctors!

Some of the things I enjoy doing are strolling around the neighborhood, sitting outside and people watching, and spending time with my family. I like music and spinning light-up toys, and watching TV. I used to participate in therapeutic horseback riding until the program closed down. I loved riding that big horse! I continue to have seizures daily, but they are very mild. I can only use my right hand. I can bear weight and with assistance, I can walk short distances. I am non-verbal and I do have some vision.

My parents live in Ashland, Kentucky. I moved to Lucasville, Ohio, less than an hour away, 7 months ago. I live in a group home, also known as an Intermediate Care Facility. I live with 7 other individuals and we all have our own private bedrooms and bathrooms. We have a nurse in our home 24 hours a day. I also attend a workshop 5 days per week. My parents visit with me often and bring me back home frequently. The transition moving to Ohio has been harder on Mom and Dad, than on me. The staff take good care of me and I am happy here.