

A Message From President Adam Gumson

The Conference is Coming! The Conference is Coming!



Hello ASF Families and Friends:

In my last Newsletter, I have sung the praises of attending the Conference and, lo and behold, it's right around the corner (July 3- July 6, 2025 in Franklin, TN), with Registration opening on March 1, 2025. Below are a few informational tidbits about the Conference:

1) Booking Rooms at Discounted Rates: Raising money to pay for the Conference and to help subsidize AS families' in-person attendance is THE most important mission of the Foundation (along with funding research). The Foundation pays for the cost of a family's food and lodging from the first day of the Conference (Thursday) to the last night (Saturday), including breakfast on Sunday morning. We recognize that many families plan to arrive the night or several nights before the Conference, and some stay that Sunday night or longer. Those bookend nights are each family's individual financial responsibility.

However, the Foundation has secured the same discounted rates, \$134 plus tax, for those nights (three days prior to July 3rd and three days post July 5th) so long as you book the rooms at the same time, with the link provided when you register for the Conference. We chose this option, rather than having one link for the Conference dates and having another link (or phone call) to book the additional nights not paid for by the Foundation, because we thought it would be easier for all of AS families to book at same time instead of having to do it twice. God knows our families have enough to do without having to do things twice! So, if your travel plans include some extra nights on either end of the Conference, be wary of which dates are covered by the Foundation and which nights are not.

2) Bringing Food to the Hotel: Almost every hotel contract includes a provision stating that hotel patrons cannot bring "outside food" into the hotel (since the hotel makes it money via the food/beverage served during events). We fully understand that our AS children have special diets necessitating bringing some special foods as well as snacks for siblings, but please use your best judgment to avoid openly disregarding this provision (i.e., if you bring a giant cooler filled with homemade sandwiches/chips/drinks, etc., distribute these items in your room as opposed to openly having a picnic at the pool) to avoid violating our contract.

3) Encourage Other ASF Families to Attend: The Conferences are the best way to meet/mentor new AS families, give/receive helpful information/hacks and build a network of friends who are the only people in the world who understand what it's like to raise an AS child or deal with the loss of one. If you are already planning on attending, great! If you are on the fence, please join us.

And, if you know another AS family (especially new families), please reach out to them, and encourage them to attend. The reason these Conferences are so essential is that we share information with families from all over the country and world from diverse backgrounds, and everyone has something to offer and to gain. The more the merrier!

4) Thank You: Shout out to our Conference Committee Members: Co-Chairs (Cindy Scheer, Cindy Hodgeman and Ellie Scheer), Agenda (Elizabeth Cates, David Seeright, Crystal Graf, Julie Wright, and Annie Koozer), Angel Agenda (Maryellen Costa, Carrie Paup, Tanya Fleming, Denise Park Parsons, and Gail Zitnay), IT (TJ Baker and Nick Graf) Childcare: (Nicole Babinec and Jenny Sarafin), BigSis/Little Sis (Megan DaGrava and Lindsay Lorimer-Stewart), Social Committee (Jesse VanLeeuwen and Lindsay Lorimer-Stewart), Conference Merchandise (Julie Gilliam), and Hotel Negotiations, Discounts and Accommodations: (Carrie Paup and Ronda Parsons).

A Day in the Life of.. Victoria Mahusky

In the beautiful town of Renfrew, Ontario, Canada, 25-year-old Victoria has carved out a life full of adventure, laughter, and love. She lives there with her parents, Jo & Bernie Mahusky.

Diagnosed with Aicardi Syndrome at just three months old, Victoria has always been a reminder to those around her that life is meant to be lived to the fullest. Growing up in a skiing family, sparked a passion for Victoria to try skiing, after a friend introduced them to the adaptive ski program. 17 years later they are still participating!

Her Dad Bernie says that Victoria often can be heard saying "Go!Go!Go!" as she zips down the slopes and adds that she loves things fast! For Victoria's family, skiing is more than just a sport; it is a way to include their daughter in adventures usually enjoyed only by typical kids. With every descent, they have learned the importance of inclusion over seclusion.

Victoria's love for speed isn't limited to skiing. She loves spending time on her skidoo too!



Aicardi Shirt Fundraiser: Coming Soon!

Laurie Costa & Aimee Bond are working hard on a Shirt Fundraiser that will be coming this SPRING! Stay tuned for more details which will be posted on the Foundation Facebook page, when the fundraiser starts. ALL funds raised will go to the Aicardi Syndrome Foundation.

We appreciate the amazing efforts of Laurie and Aimee on this fundraising campaign!



The Costa Family sporting their Aicardi Shirts!