AICARDI SYNDROME FOUNDATION

Aicardi News

Fall Edition Vol 3: Issue 2

A Message from President Adam Gumson

It's the time of the year when we give thanks, and, other than my own family, I cannot think of a group of people I am more thankful for than my Aicardi family. It welcomed me with love and support at our first Conference when Ava was 3 months old and now, 22+ years later, it is still the most influential group of people in my life. I have learned so many lessons from so many of you, and your children, both Aicardi children and their siblings, and am thankful to be able to call you my friends.

On the gratefulness front, there are so many people who give their time and effort for the benefit of the Foundation that I'd run out of room if I tried to list everyone; suffice to say that "you know who you are" and know this organization would not run and do all of the good work it does without all of you. However, in the spirit of giving thanks as many are readying for the upcoming Conference in July, 2027, please join me in thanking the following people who have agreed to lead or join a sub committee to assist with conference committee-related projects:

On-Site Sub Committee:
Caroline McClure: Chair
Julie Gilliam, Katie Seeright and Shana Woodman: Sub Committee Members

First Conference Family Welcome Sub Committee:
Natalie Parsons: Chair
Gabrielle Estrella and Adolfo Ramirez : Sub Committee Members

Big Sister/Little Sister Sub Committee:
Megan DaGrava : Chair
Shana Woodman: Sub Committee Member

Sibling Agenda Sub Committee:
Marlee Anne Hopkins : Chair
Zane Gumson, Olivia Earl, George McMullen and Kendall Paup: Sub Committee Members

Social Sub Committee:
Kim Kwiatkowski: Chair
Ceasarae Galvan and Tori Koziara: Sub Committee Members

Child Care Sub Committee:
Jennifer Hughes and Jenny Sarafin: Child Care Committee Chairs

Aicardi News

Fall Edition Vol 3: Issue 2

You may recall that we had set 5 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. I am proud and excited to let you know that many of the Committees are up and running, and that many of you have heeded the call to action. With your collective help, we have made great strides on furthering and achieving our goals, which were, and still are:

1. Website/Social Media: Updating ASF's website and social media presence and utilizing surveys, newsletters and Facebook to raise awareness of Aicardi Syndrome and expand the reach of the Foundation. We've come a long way in expanding our communication so that information is imparted year-round, not just at our Conferences.

2. Regional Coordinators & First Conference Family Welcome: Creating a mechanism to better onboard new families and beefing up the programs both before and after the Conference. Check out our new Regional Coordinators page on our updated website!

3. Conference Agenda: Expanding Agenda Session topics and attracting a variety of speakers with unique knowledge to impart to Aicardi families. The Agenda Committee has been hard at work to bring you a roster of exciting speakers at the next Conference!

4. Research: Justin Tolman and Samantha Bunner have agreed to serve in this area and foster better and more frequent communication with the scientific research community. Per my last Newsletter, Aicardi mom Barbara Kroner is engaged in updating a 20+ year old project relating to the prevalence of Aicardi Syndrome and Baylor University has a full-time research assistant devoted solely to Aicardi Syndrome. Aicardi Syndrome was also featured in a recent article by Rare Revolution Magazine. Check it out: https://bit.ly/RARE-X-Linked-AicardiSyndrome.

5. Fundraising: Ben Wells and Liz Cates have agreed to head up this area. Increasing the number of families who actively fundraise to help subsidize the rising cost of Conferences, including pursuing corporate sponsors. Many of you have attempted fundraisers or donated through PayPal to the Foundation and the Fundraising Committee is working on developing a fundraising package with a FAQ page.

As they say, it takes a village....
Best wishes to all of you for a happy and healthy Thanksgiving holiday!

Aicardi Syndrome Awareness Day

On November 8th of each year, we celebrate Aicardi Syndrome Awareness Day, in honor of Dr. Jean Aicardi, who was born on this day, in 1926. Dr. Aicardi passed away in August 2015 and would have turned 100 years old this year. We are all grateful for his lifetime of work.