A Post-Conference Message from President Adam Gumson

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Until we meet again…

And, just like that, it's over. Months of telephone calls, emails, texts, Facebook posts, Newsletters and coordinating travel plans and BOOM, the *2025 Aicardi Syndrome Foundation Conference* (*ASFC*), the most attended conference ever, is behind us.

A special thanks to the many people who assisted with planning, setting up, decorating and cleaning up. There are too many people to name in this space, but I would be remiss if I did not at least mention the ones who did the heaviest lifting: Cindy Hodgeman, Cindy Scheer and Ellie Scheer (Co-Chairs), Carrie Paup and Ronda Parsons (scouted out and selected the conference site and negotiated contract with and managed relationship with the Marriott), David Seeright and Elizabeth Cates, who headed up agenda, the Babinec family & friends, as well as Mark and Jenny Sarafin (coordinated and staffed Child Care), and Ceasarae Galvan (designed the pink conference booklet & other conference related materials). Without the generous gift of their time, we would not have had the rousing success of a conference that we did.

Hopefully, you met some new people, caught up with old friends, and garnered a few pearls of wisdom that you can take home and implement. I am always energized when I see a wave of purple lanyard *Aicardi*-shirt wearing people, from all walks of life and all parts of the world, pushing an army of wheelchairs in the hotel's lobby, elevators and hallways. The feeling I get when I watch the *Aicardi* invasion reminds me of being at a big sporting event where everyone is wearing the home team's colors, united as one, rooting on and cheering for the same team. Except, of course, the team we are rooting for and cheering for is our Aicardi children and their families.

Now that the 2025 *ASFC* is in the books, it is time for all of us to address the growing pains of the vibrant organization known as the *Aicardi Syndrome Foundation* (*ASF*), and join together to build a more formal structure of "*who does what and when*", so we can create and mentor a unified team.

During and after the conference, many of you volunteered to help via QR code, a handwritten sign-up sheet at the post-conference meeting, or approached me or other Board Members or Co-Chairs to offer your assistance. That is a wonderful step in the right direction and thank you to all of you who are stepping up. To those of you who have not yet said "*what can I do?"*, we need you, too. Here is a "Top 5" list of ASF's goals that, with your help, we will accomplish by the time we next see each other at the 2027 conference.

1. ***Creation of "How To" Conference Manual/Handbook:*** This will be handed down to future generations of *ASFC* leaders to be used as a blueprint in planning and holding a conference, covering everything from: 1) time deadlines to identify/lock in hotels, agenda/speakers and breakout room facilitators (to introduce the speakers and manage each session room) and child care volunteers[1]; 2) developing a core curriculum of session topics[2] for future conferences; 3) coordinating the social events on the nights of the conference as well as the setup for conference fundraising tables and events; 4) creating more detailed survey forms to identify the pros/cons of the conference, as well as the ability to review and implement changes for the next conference. Denise Park Parsons created an excellent and thorough outline for the whole gamut of conference tasks, which is a wonderful head-start, which we can build upon and enhance. If you have experience in this area, or would be interested in assisting with any of these issues, we need you!

2. ***Onboarding New Families and Big Sister/Little Sister Program:*** Many families first hear about *ASF* via our website or Facebook. In the "old days", a regional ASF representative would contact the new families to "*welcome*" them to the club and answer initial questions so they felt less "alone" and more connected to the AS family. We are now a much bigger group, and need a more uniform process, with scripts, to make sure we are disseminating the same information to whomever contacts us. This is an area where both veteran and new families can work together. The veteran families will be handling the variety of questions that newer families have, with that "*deer in the headlights*" feeling when first diagnosed and attending their first conference. New families: if you liked the way you recently were brought into the fold, then this is your chance to let us know AND share your experience on what you liked about the process. If it wasn't as impactful as you had hoped, then let us know that, too, and help us improve. The *Big/Little Sister* program, too, is vital to the new family experience, and could also use more hands on deck.

3. ***Research*:** Continuing to fund research is what gives ASF credibility and what prompts so many families to get involved and attend the conferences. We are blessed with many parents/family who are savvy medical professionals, and a Scientific Committee could serve as a liaison to the researchers and encourage more families to participate in research. If you have any insight into the medical world, or interest in being involved in this way, we would welcome your participation.

4. ***Fundraising:*** Until now, all of our fundraising efforts have been individual efforts, that have been completed in a vacuum, with very little coordination or communication to other families. We should be publicizing what other families are planning to do, what they did and how they did it, encouraging other families to say "*we can do that too*" and help guide them through their first events. ASF needs to develop a fundraising network of information to encourage more families to engage in raising funds, so that each fundraising family does not feel like they are doing it alone.

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[1]including contacting local resources (health & social service agencies, colleges/universities, church groups, disability advocacy organizations, high schools, etc.) to staff Conference childcare needs.

[2]We have identified 5 key groups of the AS community, with some overlap (new families, young families, families with mildly affected girls, families with medically complex girls, older families and Angel families) and 5 main Core Session categories: 1) Medical [Neurology, Orthopedic, Pulmonary, Gastro-intestinal, Gynecological, Pharmaceutical], Therapies (OT, PT, Speech, etc.); 2) Legal (Estate Planning, Probate, Guardianship, Medicare, Medicaid, etc.); 3) Financial (Planning, Social Security); 4) Educational Issues (Preschool, School-age, Post-school age) and 5) Angel issues. There is also room for sessions on miscellaneous hacks, such as DIY household renovations, conversion vans, etc.)

New Families Share Their Conference Experiences:

"The conference made a profound impact on our family. We have a hope we didn't even think was possible and feel like we've been wrapped in one big hug that we didn't even know we needed."

Hannah Adkison
(Mom to Ella-- 9 months old)

"This group has given so much hope to my family, and we are beyond thankful to God for this community and found family."

Aimee Bond
(Mom to Caroline—3 years old)

fundraising continued…

The costs of hosting a Family Conference have risen substantially and are likely to continue to increase in the future. We need more family fundraising efforts to meet the rising costs. We also need to communicate with the families who raise money, to publicize their events in advance, and list upcoming events on the website/social media and to inform other families who might duplicate these efforts in their home venue.[3] Another idea I've heard: all of our families creating a Facebook Fundraiser or hosting an event on November 8TH (*Aicardi Awareness Day* in honor of Dr. Aicardi's birthday). If you are experienced in fundraising, or would enjoy being involved in publicizing these events, this is the committee for you!

5. ***Website/Social Media*:** Although we have someone who does the technical side of our website, we must send her the content and photos for her to upload which, often, has come to a standstill because our existing volunteers have been spread too thin to address these issues. Consequently, our website has become stagnant, lacking updated information. Our website, Facebook page and other posts need to be aligned and consistent, with updated links to Aicardi-related articles and separate pages devoted to New/Existing Families, Research, Fundraising, Conference Information and other Aicardi-related topics. If virtual technology is your jam, we need you!

As the *AS* family grows, we need to grow, too, by taking the step from a "*mom and pop*" grassroots organization, to one that is more organized, able to educate our families, and attract bigger-dollar contributions to ASF. That way the foundation can continue to provide the benefits that we all have come to expect and enjoy, and perhaps even more benefits in the future. I can't say it any better than Maryellen Costa did: The people who comprise ASF are your/my family, your/my people, and, together, we all can do great things for our Aicardi children and our families.

[3]As an example of how much more we can accomplish if every family does something, no matter how small, consider some of the fundraising efforts that took place during this past Conference: the children's table, via cash and Paypal contributions, is approaching $5000, Pam Drake sold pens ($415), ASF sold tote bags, pins, frames ($324), Bernie Mahusky sold snack items ($320), Elaine Joost sold bracelets ($240) and Oliver Seeright donated $1. Cash payments were paid directly to the Marriott to reduce the overall final bill!