

A Message from President Adam Gumson

Happy Everything to all of you!

The past few months have been a hotbed of activity in Aicardi-world and I am excited to relay the following information to you:



1. The Board. The Board, prior to the Conference, consisted of 8 members in addition to me: (Al and Cindy Meo, Terry and Linda Tveita, Julie Litza, Carrie Paup, Ronda Parsons and Lissa Gumson). Following our Conference, Julie Litza and Al and Cindy Meo left the Board. Al and Cindy will remain involved as consultants. Thank you to Julie Litza for her years of service and to Al and Cindy for their unyielding dedication to the Foundation for 30+ years. As they say, when one door closes, another opens: Justin Tolman and Ben Wells have joined the Board. Welcome aboard Justin and Ben!

2. Committees. We have started coordinating some of the ASF goals that were referenced at the conference: 1) creating a “new” First Conference Family Welcome Subcommittee and beefing up the Big/Little Sister program; 2) increase the number of families who actively fundraise to help subsidize the rising cost of Conferences, including pursuing corporate sponsors; 3) foster better and more frequent communication with the scientific research community; 4) update our website and social media presence and expand the reach of the ASF; 5) expand Agenda Session topics and attract a variety of speakers with unique knowledge to impart to Aicardi families; and 6) create and maintain a “how to” Manual detailing the timing/planning necessary to host a successful Conference, so future Conference Committees do not have to re-invent the wheel. If you would like to throw your hat into the ring on a specific topic, then feel free to email me at Adam@AicardiSyndromeFoundation.org and I will put you in touch with the right person. Even if you’re not sure where you fit on the above list, you likely have a skill set that would add value somewhere. We are all unpaid volunteers, so the more volunteers we have, the more we can accomplish. So, don’t be shy!

3. Fundraising. There have been a number of successful fundraisers since the Conference, including the Adkison/LaBar family “Strides for Strength: Ella’s Walk for Aicardi Syndrome”, the Bonds’ “Gifts of Grace”, the Wells’ “2nd Annual Tee off for Tates” golf tournament and dinner, the Paups’ sale of Aicardi Syndrome Awareness flags and my own family’s 20th Annual Halloween Costume Party. A few more are in the hopper, and we’ll relay the information about those events in a future Newsletter. As you can see, the variety of different ways that all of us can contribute to the Foundation is unlimited, and with a little imagination, every one of our families should be able to do something. Remember, your family and friends want to help in some way, but don’t know what they can do, and aside from the limited number of people we would trust caring for our Aicardi daughters, contributing money to the cause is something that many of them will willingly and happily do instead of doing nothing. So, do something fun that you and your family love doing anyway, and, like the oft-quoted line from Field of Dreams, “If you build it, [they] will come.” One reminder though: as much as the Foundation appreciates any efforts to raise money, any event or advertising on behalf of the Foundation must be approved by the Board well in advance of the event. If you have questions about the logo protocol, please contact me or any of our Board members for further directions.

Finally, as the clock ticks down on 2025 and the New Year’s Eve ball soon ushers in 2026, may I wish all of you and your families and friends a very safe and happy New Year!

Recent Fundraiser Spotlight



Strides of Strength: Walk For Ella

The Adkison/LaBar Family held their very first Walk/Run/Roll Fundraiser in honor of Ella's 1st Birthday on October 4, 2025 in Lexington, MO. They had a great turn out to their event, and they were able to raise an amazing \$3,526 for the Foundation!



Tee Off For Tates

The Wells Family held their 2nd annual golf fundraiser in Batavia, Ohio, on September 19, 2025 at Elks Run Golf Course. This fundraiser was in honor of their daughter Elizabeth "Tates" Rose Wells. They were able to raise an incredible \$32,000 for the ASF!



Gumsons' 20th Annual Halloween Party

The Gumsons' Roaring 20's themed Halloween Party on October 25, 2025 was a roaring success! Dressed as gangsters, flappers and jailbirds, attendees ate, drank, danced and were very merry, generously contributing over \$35,000 to the Foundation. The Gumsons have raised over \$700,000 on behalf of the Foundation since their first party in 2006.



Gifts of Grace

The Bond Family has created a 501(c)3 called Gifts of Grace. They generously held their first fundraiser to benefit the Aicardi Syndrome Foundation. They sold stickers, magnets and yard signs and raised a total of \$1171 for the Foundation! The Bond Family lives in Morgantown, West Virginia and held this fundraiser in honor of their daughter, Caroline.



Happy Holidays to all of our Aicardi Families!

