



Aicardi News

Fall Quarter Vol 1: Issue 1

President's Message



Hello Aicardi families! I am the new president of the Aicardi Syndrome Foundation ("ASF") and the first thing I want to do in my official capacity is to thank Al and Cindy Meo for all of their efforts on behalf of ASF over the past 30+ years. Lissa and I met them at our first conference in 2004 when Ava was just 4 months old, and they welcomed us with open arms with a

Adam Gumson

vision of funding conferences, research and support for families in financial need through grass roots fundraising by Aicardi families. Their tireless devotion to the cause is the reason we, 30+ years later, are part of a growing worldwide organization which raises awareness about Aicardi Syndrome, and special needs children in general, and their leadership and friendship has been invaluable over the years and especially to me in the last few months as we have embarked on this transition. And, they are not riding into the sunset just yet; they plan to continue to remain active and stay on the board. Thank you Al and Cindy!

I also want to thank Carrie Paup and Ronda Parsons for all of their time and input in countless meetings to get this newsletter off the ground. As they say, it takes a village. This newsletter is the outgrowth of realizing that the camaraderie we share at conferences sometimes wanes in the two year period between them and is meant to engage more regularly and consistently so that we can all "keep in touch" during that time. While we have a Facebook page, not everyone is active on social media and this digital newsletter, which we intend to publish quarterly, will furnish important information, updates, "hacks" and general interest stories about our families.

We hope that all of you will share your stories, photos of our Aicardi warriors doing awesome things and other relevant information in a positive, uplifting way so that we can disseminate it to all Aicardi families regularly, and not have to wait until the next conference to discover such information. Please see our contact information below. Feel free to send us anything you believe our community would find interesting and helpful. Let us know what you think. Read on!

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2025 Conference

It's official! The next Conference is scheduled for July 3-July 6, 2025 at the Franklin Marriott Cool Springs in Franklin, TN (about 30 minutes outside of Nashville). The Conference is a 4 day opportunity to meet and learn from other families as well as attend sessions on various topics including medical and legal issues, advocacy, equipment and much more! Some sessions are parent-led, while others are led by professionals, and all have Q&A time during and/or after the session. We also offer a bereaved agenda to those who have lost a child, with sessions on grief and life after loss combined with support and guidance from other bereaved families who have walked in those shoes. It's truly one-stop shopping for everything Aicardi.

Note that we scheduled it on a holiday weekend because: 1) It is easier for most families to plan a trip around a holiday where taking off from work is not as difficult or detrimental financially; and 2) We receive substantial price reductions for booking a large group on a holiday weekend. ASF funds the entire conference and also covers the cost of one (1) hotel room per Aicardi family and dinner for Thursday, Friday and Saturday nights, brunch on Friday and Saturday and breakfast on Sunday morning. Registration begins on March 1, 2025, and will include the full conference agenda, so you can plan which sessions to attend. Mark your calendars, start mapping out your travel plans and we look forward to seeing you next July!

Upcoming Fundraiser

Hats off to Ben and Carley Wells who are about to launch the first Tee Off for Tates Golf Tournament at Elks Run Golf Club in Batavia, Ohio on September 27, 2024 (their daughter Elizabeth "Tates" Rose Wells is 4). This is their first foray into raising monies, on behalf of ASF. The QR code is below in case anyone reading lives nearby or has contacts in the Ohio area who want to play in the tournament, or help them or just donate. Good luck Ben, Carley and Tates!

