



Aicardi News

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A Message from President Adam Gumson

Happy Holidays and Happy New Year to all of my extended Aicardi Family! May this coming year bring our Aicardi children a better year of unprecedented good health, reduced seizures and no hospitalizations! If you haven't started to make plans to attend the Conference in Franklin, TN (July 3- July 6, 2025), it's time for you to put that on the front burner. As we all continue planning for the Conference, I wanted to take a moment to address the important role the Conference plays in all of our lives, the costs of putting on a Conference and how critical it is for more of our families to raise monies to support these Conferences.

1) The Conference. When Lissa and I attended our first Conference in 2004, Ava was 3 months old. We entered the ballroom to an eyeful of wheelchairs and an earful of girls moaning and screeching while having seizures. It was definitely sensory overload. But, amazingly, the people in the room were not gloomy or downtrodden; to the contrary, they were hugging each other, happy, going about their business just like "normal people" would do. We were greeted by welcoming veterans (the Hopkins, the Drakes, the Costas, the Paups, the Meos and the Tveitas, to name just a few) and met a host of other families, all of whom made us feel relieved that joining this new "club" was not as bad as we had feared. After 20 years of attending Conferences, we have made so many friends who have guided us through some very tough challenges and, hopefully, we, too, have assisted other families during their tough times. Although no one wanted to be in this club, joining together at the Conferences has confirmed to us, as well as our other children, Lilly and Zane, that we were not alone in the unique challenges that Aicardi families face, and that support has been and continues to be invaluable. When Covid forced the cancellation of two straight Conferences, and then we attended the last one in 2023, we realized how much we missed seeing everyone and how much the Conferences mean to each and every one of our family members. If you are reading this and have not attended a Conference before or haven't attended recently, please make every effort to attend – we want to help you and we also want you to help us so we can all help our Aicardi children and Aicardi families!

2) The Cost of Conferences. Until recently, I had no idea how much it cost to put on a Conference. Take a guess as to how much. Nope, higher! Just one Conference costs \$100,000-\$150,000 (considering the rooms, food and miscellaneous hotel fees) and these costs just continue to rise for each Conference. Although many of the speakers are Aicardi parents or local experts who donate their time when attending the Conference, and our Board Members (thank you Carrie Paup and Ronda Parsons!) negotiate the best deals possible, there are certain expenses that we must accept if we want to continue putting on a world class Conference. Currently, we have enough funds to cover the upcoming and next Conference (thanks mainly to having cancelled the Covid-era Conferences), but we need more families to commit to doing fundraising. And, that commitment needs to start now as we enter 2025.

3) What Can You Do? None of us is a professional fundraiser, but you don't need to host black-tie events with lobster and champagne to raise money for the Foundation. My own experience has taught me that friends, family and local businesses WANT to help; they just don't know what to do and need a little push. The Foundation has received donations from cookie and jewelry sales, in honor of a grandparents' death or wedding or Bar Mitzvah, from a local Boy Scout or church "giving" project, and from readers of articles in local newspapers who were touched by an Aicardi story. Many local businesses support charities by discounting expenses or donating a percentage of revenue (think movie theaters, bowling alleys, mini-golf, pizza parties, etc.) and other chains have annual budgets for donations to charities. However, the time to plan for 2025 is now because many of these businesses finalize budgeting at the beginning of the year. Read on about two recent fundraisers and hopefully it will inspire you and "your people" to jump in. We definitely need more help in raising money, and, if every family did just a little something, it would make a huge difference.

Recent Fundraisers

"Tees for Tates"



The Wells Family

On September 27, 2024, Ben & Carley Wells (and Elizabeth "Tates") hosted their first annual "Tees for Tates" golf tournament and raised over \$40,000 for the Aicardi Syndrome Foundation.

"Grease is the Word!"



The Gumson Family

On October 19, 2024, Adam & Lissa Gumson (and Ava) hosted their 19th Annual Halloween Costume Party. The Gumson family raised over \$625,000 for the Aicardi Syndrome Foundation since inception.