

# Fall 2024 Family Newsletter

Thank you for being part of the AHC Foundation and helping us support families, raise awareness, and fight to **END AHC!**

## Mark Your Calendar!



### **Biennial AHCF Family Meeting 2025**

The Family Meeting is a powerful medical, educational, and family conference.

**When:** June 19-21, 2025

**Where:** Embassy Suites - Covington, KY (Cincinnati, OH Area)

This year's theme: **A ONE IN A MILLION LIFE!**

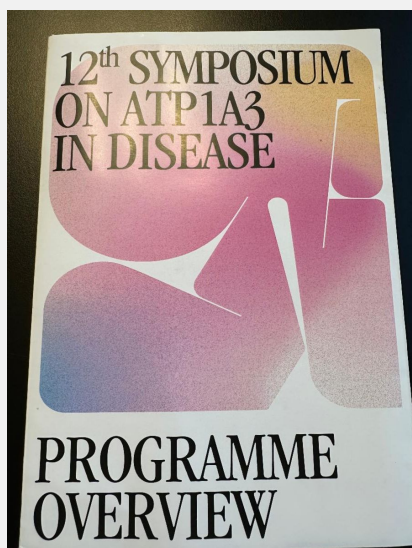
Share the date with your child's medical providers now. AHCF will cover their registration fees.

For letters of need for Visas, email [ahcfoundation@ahckids.org](mailto:ahcfoundation@ahckids.org). Due to Visa wait time, don't delay!

Stay tuned for more info!

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## ATP1A3 Symposium



### **12th Annual Symposium on ATP1A3**

The 12th Annual Symposium on atp1a3 in disease took place in Barcelona, Spain on Nov 14 th and 15th. It is an important annual event for scientific and clinical exchange as well as patient advocacy.

The foundation once again provided funding for the symposium. And, AHCF also funded two clinicians to attend the meeting. Doctors Kathy

Swobda and Dr Elizabeth Gerard.

Representing the foundation were Vicky Platt and Cate Cohen.

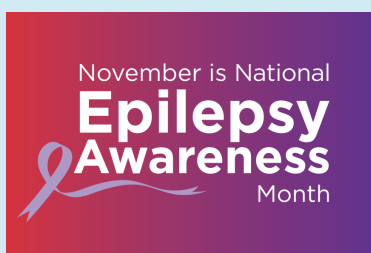
A more detailed summary of the meeting will be coming out soon. We are glad to share a few of the exciting themes from the meeting, including:

- collaboration between research teams and patient foundations.
- sleep study data reported
- spreading depolarization opportunities for AHC
- cardiac issues in AHC
- opportunities for ATP1A2 research

Keep an eye out for more to come.



## Family Support



### November is National Epilepsy Awareness Month

Learn about types of seizures, treatment options, how to recognize a seizure, and become certified in seizure first aid.

*Epilepsy Foundation*



[Zoom Meeting Link](#)

Join us the last Saturday of every month at 11:00 PST/1:00 CST/2:00 EST.

If you have questions, please email Heather Gates at [Heather@ahckids.org](mailto:Heather@ahckids.org).

[Sign up for Reminders!](#)

### Family Circle Zoom

This is a support group for parents and caregivers of individuals with AHC.

Want to share the day to day challenges with parents who get it? Need some encouragement as you prepare for a doctor's appointment or IEP meeting? Have a milestone to celebrate? Connect with others on this journey. We are here!

### Family Resource

The holidays are near. Find gift ideas for your child and make a wish

list for family and friends. Choose by developmental need, interests, and/or favorite activity!



[FatBrainToys.com](http://FatBrainToys.com)

Review Us On  
GreatNonprofits



We need your quick review to get 2025 GreatNonprofits Badge!

Click on

Share Your Story

to submit your review

Volunteer. Donate. Review.

Review Us  
Now!

## Review Us on GreatNonprofits!

Dear families & friends of AHCF,

We can gain more exposure and trust with current and potential donors, volunteers and all supporters by earning a spot on the 2025 GreatNonprofits Top-Rated list.

If you love our work, then please tell the world! Won't you help us raise visibility for our work by posting a review of your experience on GreatNonprofits? All reviews will be visible to potential donors and volunteers.

## Picture This!

The **Picture This!** Campaign has begun! In support of our upcoming Family Meeting 2025, and an ongoing fundraiser, the Picture This! Campaign highlights all of the wonderful things our children CAN do and enjoy!



"Paigey absolutely LOVES her blanket! Her mom made it for her before she was even born and it has been her best friend. Even if she's paralyzed or in pain, her blanket can cheer her up! Her favorite thing to do is put it over her face! She gets a new one every year for her birthday."



### ***So, what do you do?***

Please send a photo or video of your child doing whatever it is they love to do: horseback riding, swimming, arts and crafts, cooking, playing with siblings, grandparents...whatever it is that brings them happiness.

Along with the photo, please send a quote from your child (if they're verbal) or from you, expressing what it is about this photo/ activity that makes them so happy. It's super easy, just fill out the form [\*in this link\*](#) - it takes you through the process easily.

We will feature your AHC loved one on our socials in the weeks and months to come, and they will also be in our gallery of AHC adults and children "living their one in a million life" at our AHC Family Meeting 2025!

Thank you for your participation!

Submit Now!

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## Season of Giving

### **Tis the season...**

Tis the Season...the Season of Giving! The 2024 Holiday Season is upon us. Can you believe it? This is the ideal time, as the year winds down, to press pause and give thanks. How can you help?

- Please graciously consider making the AHCF your "Charity of Choice" this holiday season. Donate, share on your socials, and consider an email/ letter campaign to friends and family to help spread the word. Ask your inner circle to do the same! You'd be amazed how many people are willing to step in and help.
- Check your company's giving policies. Many companies have a matching gift policy, often at a 1:1 ratio. Double the value of your donation!
- Always remember, donating to non-profits is tax deductible, so there is financial incentive to donate, in addition to feeling good about yourself!

Mark your Calendars: Giving Tuesday this year is Tuesday, December 3<sup>rd</sup>! Keep your eyes out for a special announcement from the AHCF as we are launching a fun campaign to finish out the year! Stay tuned!

Donate to Help END AHC

## Meet Board Member: Gene Andrasco



Gene is the AHCF Treasurer, Finance Committee Chairperson and a member of the Executive Committee. Having joined the Board of Directors in 2011, he found a way to show his daughter Kiley he is fighting for her, while helping advance the mission of AHCF. Kiley was diagnosed with AHC in 2003.

Being passionate about raising funds for research and family support, he and his wife Kelly co-chaired the Chicago Walk for 15 years with the Platt family and assisted with the yearly golf outing put on by his father-in-law hosted by his in laws for many years.

Gene grew up in on the Southside of Chicago and was one of 10 kids! A diehard Illini fan (“long live the Chief”) He graduated from the Gies College of Business at the University of Illinois Urbana-Champaign with a BS in Accounting and went on to earn an MBA, Financial Management & Controls, from DePaul Driehaus College of Business.

Professionally, he is the VP of Finance, Category Management & Supply Chain, for TMS in Chicago. Because his position requires that he make frequent trips to Hong Kong, over time, he has developed quite a love of sushi! At home he loves trying new craft beers. He even has a beer app on his phone where he logs them in.

Other fun facts about Gene: His idea of dessert is fruit (or apple pie). His preferred music is heavy metal and hard rock bands. One of his hobbies is doing yardwork which he finds relaxing, and to stay in shape he values his daily workout which he rarely misses.

Gene lives in Lake Zurich, Illinois with Kiley and his wife, Kelly. Their son Ryan lives in Colorado. Both Kelly and Ryan also volunteer for AHCF in numerous ways.

You can drop Gene an email at [gene@ahckids.org](mailto:gene@ahckids.org).



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*A Letter from the President of Our  
AHC Family*

Giving Thanks

With the holidays quickly approaching, it is hard to believe that the year is coming to a close. And what a year it has been.

This year, we are incredibly thankful for all of the amazing volunteers who work so hard for the community. It is an honor to walk this journey together and your efforts are greatly appreciated.

This year, we also welcomed a variety of newcomers to our community. This included families, clinicians, researchers, medical advisors and board directors. We are grateful they found us and are happy to be on this path with you.

And, we are honored to have known several AHC friends who have left us. Our world was made richer by knowing you for too short of a time.

As you celebrate the holidays this year, we wish you joy, good health and moments of peace. For everyone touched by AHC is living with the knowledge that life can be challenging and full of blessings.

Happy Holidays  
Vicky

**AHCF Board of Directors:** Gene Andrasco, Sharon Ciccodicola, Cate Cohen, Lynn Egan, Mollie Erpenbeck, Heather Gates, Bill Gerber, Vicky Platt, and Kathy Sharo



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313-663-7772 [ahcfoundation@ahckids.org](mailto:ahcfoundation@ahckids.org)



AHCF | 2000 Town Center, suite 1900 | Southfield, MI 48075 US

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