



CELEBRATING 25 YEARS OF SERVING THE AHC COMMUNITY



One Mission: End AHC!

YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER

July 2018

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

A MESSAGE FROM THE PRESIDENT New Jersey Family Meeting Success

The Twelfth AHCF Family Meeting was held in Iselin NJ last month with the theme, “Making Waves for AHC”. 39 “AHC Voices” posters were featured that resonated with the families and medical community alike. Families were able to participate in informal consults before the meeting with medical specialists and had two opportunities to engage in physician panels to answer questions.



Families learned about the advances made in research, spoke to other experienced families, learned how to care for themselves and the very hot button topic of CBD oil which will lead to a follow up study described below. **This year we had a record number of families that came from 10 different states and 6 countries.** There were 18 first time families and many with older AHC “Kids”. We continued with the practice of streaming most of the sessions that benefitted those unable to attend and will be posting those along with the Family Meeting photos on our website soon.



The Dr. Kenneth Silver Distinguished Service Award was awarded to Lynn & Mark Egan in recognition of their long standing commitment to and profound impact upon AHCF.

During the meeting, the Medical Advisory Board, AHCF Board of Directors and scientific researchers put our heads together to create a Strategic Plan for the Foundation going forward.

There was a lot of socializing as families got acquainted

at the "Meet & Greet", enjoyed an AHCF sponsored luncheon, and the highlight of the meeting was an ice cream social with a live band that had everyone rocking, rolling, dancing and clapping to the music! Kids and parents all had a wonderful time! **Thanks to Terri Hammer, Rob Ambrosino- Hambro with Special Guest Leah Hammer.**

We are grateful to the families who attend the meeting, the members of the Family Meeting Planning Committee who worked very hard for many months, for the volunteers who worked non-stop during the meeting.



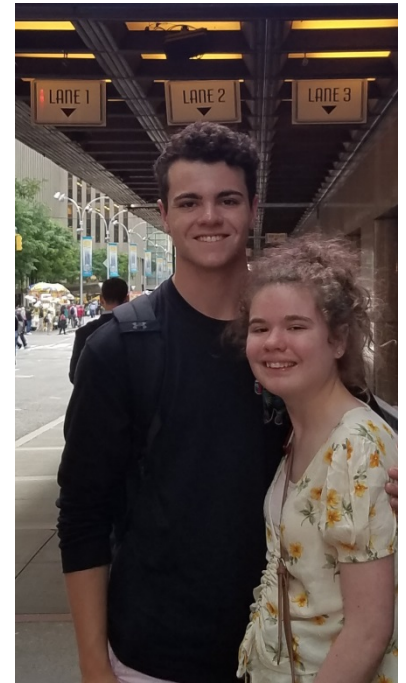
AHCF IN ACTION – AT THE FAMILY MEETING

One of the most amazing sessions at the Family Meeting was one devoted to the siblings of AHC kiddos. The siblings gathered together to chat about what it is like to live in an AHC household.

The session was lead by **Ryan Andrasco and David Hodes**, both very experienced siblings who know a lot about AHC.

Below, Ryan shares some of his thoughts about the session.

“The sibling meeting went very smoothly, and I believe it was a great resource for some of the younger kids who are still learning a lot about the disorder. I also believe that it was great for the few older ones in the group who were able to get a little off their chests and share some knowledge with the younger siblings.”



“The environment of the meeting was very inviting, which was greatly helped by the participants openness, and this fostered a lot of good discussion between siblings. Many were able to connect with each other and exchanged information to be there for each other in the future.”

AHC siblings are a special bunch and we thank all of them for taking time to attend the AHC meeting. You are awesome!



AHCF IN ACTION – AT THE FAMILY MEETING **Putting the Pieces of Collaboration Together**

During the Family Meeting, board members from CureAHC and AHCF met to discuss possible opportunities for collaborative work this year.

The meeting was a wonderful opportunity for both organizations to come together and **talk about new possibilities for AHC research**. When the meeting was over, we left with a plan to continue the dialogues between foundations with the possibility of a joint project in the near future.

Board members in attendance were:

(1st row) Tony Pena, Vicky Platt, Lynn Egan, Renee Hodes, Sharon Ciccodicola, Meredith Schalick, (2nd row) Josh Marszalek, Simon Frost, Jeff Wuchich, Gene Andrasco and Bill Gerber.



Thanks to everyone for their hard work and dedication to the entire AHC community.

THANK YOU FAMILY MEETING SPONSORS

High Tide Sponsors -DSM Nutritionals & In Faith Community Foundation

Garden State Sponsor – Katie & Steve Woo

Salt Water Taffy Sponsor – The Vona Family

It's a Shore Thing – “Regency Resources” - Maureen Parella

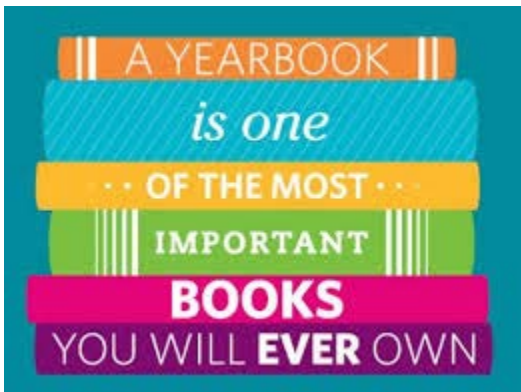
Boardwalk – “Web Words Matter”- Kathy Sharo

AHC COMMUNITY CONNECTIONS

Mapping Out the First Ever AHC Yearbook

The AHC community is putting together the first ever AHC yearbook **featuring children and families from all over the world!**

This year's theme is **"Finding Our Way"** and will include multiple opportunities to submit photos. You may also add photos to featured categories including, "Travel Buddies", "Favorite Co-Pilots", "Can't STOP Won't STOP", "Moving Mountains", "Arrivals", "Enjoying the Ride", "Wanderlust" and "Tour Guides". In addition, there will be a listing of birthdays for those wishing to exchange cards with their friends.



Families will have the **opportunity to customize 4 pages** of their book to make it personal and memorable for their child before they checkout online. Books will be available in hardcover or softcover for purchase at a reasonable price and **there will also be a Spanish and French version available.**

Please join the "AHC Yearbook Pics" group on Facebook or submit 2-3 individual photos to ahcyearbookpics@gmail.com **by September 1st, 2018.** Include the full name of your child, age, and location. **We will also be looking for other opportunities to submit group photos and showcase the strengths of our children!**

This is a global project spearheaded by Stacy Greenwood and April Hawk and all AHC families are invited to participate! Please share and encourage others to participate so our children can have a special book of their friends of which they can be proud!

AHC COMMUNITY CONNECTIONS

Dr. Jennifer Kearney Speaks at Grand Rounds this Month with George Washington University



The George Washington University Grand Rounds online, on Tuesday, July 10, at 8:00 a.m. ET, featured **Dr. Jennifer Kearney PhD** of Northwestern University. The talk was about epilepsy channelopathies.

Dr. Kearney has worked on AHC research with Dr. Alfred George at Northwestern University and Dr. Kevin Ess at Vanderbilt University.

The Epilepsy Foundation in partnership with the Epilepsy Center at George Washington University were proud to host Epilepsy Grand Rounds, a monthly series of lectures covering a wide variety of epilepsy-related topics. The topics discussed are presented by renowned speakers, and the goal of the series is to provide education for the attendees to improve their knowledge, competence, and clinical performance.

To learn more about the series go to:

<https://www.epilepsy.com/learn/professionals/george-washington-university-epilepsy-center-grand-rounds->

**AHCF
Fun
Fact**

The AHCF has our GuideStar Silver Seal of Transparency which indicates that we have provided GuideStar key information in our Nonprofit Profile. By providing the information, we allow potential donors and funders to make educated decisions about the work we do. Check it out.

AHC INFO EXCHANGE

FDA Approves Epidiolex (Cannabidiol) Oral Solution

During the last week of June, the U.S. Food & Drug Administration approved Epidiolex® (cannabidiol) oral solution for the treatment of seizures associated with Lennox-Gastaut syndrome and Dravet syndrome for children two years of age or older.



After the DEA schedules it and states create a pathway, Epidiolex will bring to market the first and only drug derived from cannabis in the United States for those currently living with Dravet syndrome and Lennox-Gastaut syndrome.

Dr. Ess discussed Epidiolex during the Family Meeting in New Jersey. The Foundation will report more on Epidiolex and CBD oil later this year.

The AHCF is grateful to all researchers working towards our One Mission: End AHC!

AHCF IN ACTION

Because of YOU-Big Research Project Funded this Year

The Alternating Hemiplegia of Childhood Foundation is pleased to announce an award of \$243,644 to Dr Alfred George of Northwestern University and Dr Kevin Ess of Vanderbilt University to continue their ground breaking work on the project “**Molecular Physiology and Pharmacology of ATP1A3 Mutations in AHC**”.



Phase seven of this project builds upon their previous work which targets 3 specific aims.

The first aim of this study continues the investigation of basic neurophysiological defects in AHC neurons. Because neurons exist in networks within the brain, they have designed new experiments which will grow both excitatory and inhibitory neurons. A very important goal of these experiments is to discriminate between two distinct genetic mechanisms as potential causes of AHC. One mechanism called haploinsufficiency is explained by the absence of one functional copy of ATP1A3.



The second aim is to continue to investigate various compounds on the cell derived neurons that have been identified through computer modeling, hoping to restore sodium pump function and reverse electrophysiological dysfunctions with treatment with candidate compounds.

The third aim is to evaluate the success of genetic therapy on cell derived human neurons with a technique called Base editing. They believe this new base editing approach is simpler and safer than CRISPR/Cas9, and may offer a gateway to human gene therapy which is a topic of great interest to many families impacted by AHC.

Based upon their findings in the previous phases of this project, Drs Ess and George were able to publish the following article ‘Direct evidence of impaired neuronal Na/K-ATPase pump function in alternating hemiplegia of childhood’ in the journal *Neurobiology of Disease*.

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AHCF IN ACTION Because of You-CONTINUED

Thank You

This paper reports the first successful use of induced pluripotent stem cell (iPSC) technology to study AHC and provides new evidence to explain exactly how *ATP1A3* mutations cause AHC. Their findings represent an important technical advance in studying *ATP1A3* mutations and provide new information on the fundamental molecular and cellular defect in AHC.

To Dr. Ess, Dr. George and your teams - thank you for your passion and commitment to this project, as we get closer each day to our mission to END AHC.

To the AHC families - each step of this project represents the judicious use of AHCF funds that were raised by you the families of AHC and without whom it would not have been possible!

AHC FUNdraising 13th Annual Chicago Walk – Sept. 23rd in Lake Zurich, IL

Everyone is welcome to join us at the 13th Annual AHCF Chicago Walk, on Sunday, September 23rd. It is a fun and amazing opportunity to come together with other AHC families and enjoy our community. There will be balloon animals, a band, amazing raffle baskets, frozen custard, and much, much more.

This year we are selling t-shirts and pull-over sweat shirts to raise additional funds for AHCF and to wear during the walk. **Whether you come to the walk or not, everyone is welcome to purchase items** from the link: <https://www.customink.com/fundraising/chicago-ahcf-walk> and have them delivered to your own home.

**T-shirts are \$15 and pull-over sweatshirts are \$32.
Please note, the design for the sweatshirts is on the back.**

If you would like more information about the Chicago Walk, or have questions about the t-shirts, please email Vicky Platt at vaplatt@gmail.com. **We look forward to another successful fundraiser for AHC.**

Chicago Walk for AHCF
Organized by Vicky Platt | 0 Shares

Help End AHC - T-shirt Sale
All funds raised will go directly to ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION INC.

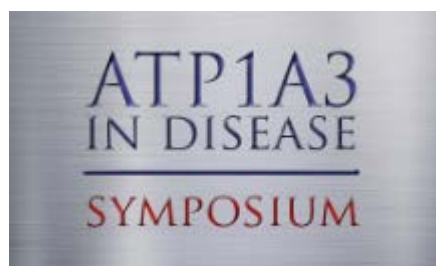
0 items sold

50 goal 28 days to go

\$15
Gildan Ultra Cotton T-shirt
Unisex - Sapphire

Buy / Donate

Orders are delivered about 2 weeks after the campaign closes.



<http://atp1a3symposium2018.org/>

Check out the website for the 7th Annual Meeting of the ATP1A3 in Disease Symposium taking place from October 13-14 in Chicago, Illinois at the Feinberg School of Medicine at Northwestern University.

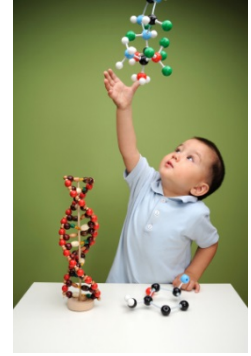
The symposium is a **scientific meeting** held in coordination with the Child Neurology Society. The AHC Foundation will help at the symposium and work a booth during the CNS meeting. Great for AHC!

**“Courage is not having the strength to go on; It is going on when you don’t have the strength.”
Theodore Roosevelt**

AHC INFO EXCHANGE

Major AHC Research Published Recently

The last few months have seen **an incredible amount of research** published regarding AHC, ATP1A3, and ATP1A2. There is so much material that instead of picking one article to summarize, we are listing all articles with links where you can find the full text or abstract. These are scientific articles which cover complicated issues. Please consult with your physicians before making any decisions based on information in these articles.



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Younes TB, Benrhouma H, Klau H, Rouissi A, Chaabouni M, Kraoua I, Youssef-Turki IB. "Early Life Epilepsy and Episodic Apnea Revealing an ATP1A3 Mutation: Report of a Pediatric Case and Literature Review." *Neuropediatrics*. 2018 Jul 16. Abstract: <https://www.thieme-connect.com/DOI/DOI?10.1055/s-0038-1667024>

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Join in on the fun with your friends or family at one of our upcoming events