



One Mission: End AHC!



YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER

March 2018

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075



A MESSAGE FROM THE PRESIDENT **Happy spring to the AHC Community**

Yes, spring has finally arrived and we are excited to celebrate the latest research being published about AHC and a variety of news going on in our community.

With the Family Meeting just three months away, the foundation is full of anticipation for what looks to be the best meeting to date. We hope you will be able to join us in New Jersey this June as a family or in any way that works for you. All are welcome.

I hope this newsletter finds you and your family well and ready to enjoy all of the excitement this new season brings.

Lynn Egan
President and Family Support



AHCF IN ACTION – FAMILY MEETING **Make Your Plans Now to be in New Jersey this June**

The AHC Foundation has been **hosting a Family Meeting every other year for almost two decades**. We are excited to be hosting another fabulous meeting this year at the Renaissance Woodbridge Hotel in Iselin, New Jersey.

On June 21st, informal consultation **appointments with AHC experts** will be scheduled in the morning. In the afternoon, a workshop will take place with Dr. Swoboda, Dr. Kevin Ess and several members of the AHCF Medical Advisory Board.

The conference meetings will take place June 22 – 24 with a variety of **scientific and daily presentations** as well as **fun social activities**. Meet or reunite with AHC families from around the world. This is the best opportunity you will have to **have your AHC questions answered** by those with the most AHC experience.



The latest information on how to register for the hotel and conference can be found on the meeting website: ahcffamilymeeting.org

Everyone is encouraged to attend. **Come as a family**. Come as a couple and have some “parent time.” **Invite a family member** to join you and learn more about AHC. **Come by yourself**. We always have a group of parents that come by themselves since one parent needs to stay home with the kiddos.

Whether you will be coming as a family or a single parent, you are sure to **have fun, meet great families, and learn from the best AHC specialists** in the world. Come to New Jersey and join the AHC Community in June 2018.

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



"Warriors for Kathryn 2018" was another wildly successful fundraiser this year raising \$19,506 for the Alternating Hemiplegia of Childhood Foundation!

Orchestrated chiefly by two women in Connersville, Indiana, Warriors for Kathryn is a Texas Hold'em Poker & Wine Bingo Game Night.

This is the 2nd year for this event, and new this year was kid bingo, hand painting art, and an ice cream social for children. There is also a dinner served, plus a basket raffle and a wheel of chance drawing.

The entire community supports the event in many ways; they donate the dinner, supplies, wine, and all the gifts for wheel of chance and the basket items.

The community enjoyed the evening so much that many commented that, "We are already looking forward to next year."

The AHC Foundation thanks everyone in Connersville for their hard work!

If you are interested in learning how you can organize an event just like this one, contact Rik Greenwood at rik@ahckids.org and he is happy to help you get started.



Kathryn Marszalek

AHCF in ACTION

International AHC Day Behavior Webinar Follow Up!

The latest webinar held on AHC Day in January was on Behavior given by Behaviorist Alice Belgrade MSEd., LCPC, BCBA. You can access it here <http://ahckids.org/webinarseries/>



The AHCF Webinar Series is designed to offer knowledge and tools to the AHC Community which will help you understand AHC better, address quality of life issues, answer your questions, provide access to specialists and connect you to our community. The webinars will cover a wide variety of topics that delve into various aspects of living with AHC.

Alice Belgrade has graciously offered to let us share her contact info for follow up questions or for those who were not able to attend. Her email is alicebelgrade@comcast.net and office no. is (773) 407-1121. If you send her an email or give her a call she may be able to answer your questions outright or let you know if a more in depth consult is needed.

The AHC Foundation is proud to provide this service to our community while working towards our One Mission of Ending AHC.

AHC COMMUNITY CONNECTIONS

Sad News for Our Global Community

The AHC Community mourns the loss of 2 beautiful AHC patients recently. 18 year-old Agnieszka from Poland passed away in early February from complications of a prolonged seizure.

Amanda, from Germany, passed away a few weeks ago. She was 24 years old. There are no details yet surrounding her death.

Please keep these two angels and their family in your thoughts and prayers.



AHC INFO EXCHANGE

ATP1A3 and the Ketogenic Diet

In the January 2018 issue of *Brain Development*, a group of scientists from Italy published an article titled, “ATP1A3-related epileptic encephalopathy responding to ketogenic diet.” Here is a short summary of their findings.



They described a patient who developed a severe early onset drug-resistant epileptic encephalopathy and months later, he presented episodes of hemiplegic attacks and monocular nystagmus. Thus, AHC was hypothesized and a novel mutation in ATP1A3 gene was found. Interestingly, the ketogenic diet (KD) was started and both epileptic seizures and classical AHC paroxysmal episodes stopped. Long-term follow-up shows a global improvement of neurological development.

They concluded that their case reinforces the role of KD as a novel therapeutic option for ATP1A3-related conditions. However, proper dedicated confirmatory trials on KD are necessary.

As always, please consult with your physician before starting any new treatments.



AHC INFO EXCHANGE

New Research from Japan

In the March 2018 issue of *Brain Development*, a group of scientists from Japan published an article titled, “A de novo p.Arg756Cys mutation in ATP1A3 causes a distinct phenotype with prolonged weakness and encephalopathy triggered by fever.”

Patients with a mutation at Arg756 in ATP1A3 have been known to exhibit a distinct phenotype, characterized by prolonged weakness and encephalopathy, triggered by febrile illness. With only eight reports published to date, more evidence is required to correlate clinical features with a mutation at Arg756. Here we report an additional case with an Arg756Cys mutation in ATP1A3. A four-year-old boy showed mild developmental delay with recurrent paroxysmal episodes of weakness and encephalopathy from nine months of age. **This report therefore provides evidence of genotype-phenotype correlations in ATP1A3-related disorders as well as in patients with mutations at Arg756 in ATP1A3.**

AHC FUNdraising - SUPPORT AHCF ALL YEAR LONG **Any Shopping on Amazon Can Help End AHC**



AMAZONSMILE

Supporting: Alternating
Hemiplegia Of Childhood

Whether you're getting a jump start on graduation shopping or making a routine online purchase for yourself, **remember to use AmazonSmile and your purchases** will help to support the AHC Foundation!

Just go to smile.amazon.com, select AHCF as your charity of choice and Amazon will take care of the rest. It is that simple.



AHCF in ACTION **Valentine Exchange a Huge Success**

The 2018 Valentine's Day card exchange was a huge success with 30 participants, the best ever! **Thank you to Heather Gates for organizing this fun activity each year.**

AHCF in ACTION

Join the AHCF Birthday Club that Started in September

We're still looking to celebrate the birthdays of all our friends in the AHC Community.

AHC Hero Brooke Tasi makes birthday cards to send to your AHC child. If you would like to participate, please send your mailing address, along with your child's age and birthdate to Dana Tasi at dtasi@snet.net.

We look forward to celebrating with you soon!



We are looking for suggestions on which topics to present during future webinars.

If you have ideas about what would be most helpful to you and other AHC families please let us know.

Please pass along your ideas about future topics to Lynn Egan at lynn@ahckids.org.

AHC INFO EXCHANGE

AHCF Medical Advisory Board Member is Published

The AHCF would like to congratulate MAB member **Dr. Henrik Rosewich** on the February 2018 publication of his article, "The CAPOS mutation in ATP1A3 alters Na/K-ATPase function and results in auditory neuropathy which has implications for management."


Dr. Rosewich works at the Division of Pediatric Neurology, Department of Pediatric and Adolescent Medicine, University Medical Center, Göttingen, Germany.



Congrats to you and your colleagues on this important work.

March 24th

4th Annual Dine & Dance to END AHC



Join us for an affair to remember at our 4th Annual Dine and Dance to End AHC.

Paul and Renee Hodes are hosting this amazing event to honor their daughter, Lisa.

There will be appetizers, open bar, dinner, dancing, raffles and much more!

To join Paul, Renee, and Lisa, at Putnam County Golf Course go to <http://ahckids.org/dinedance/> for more information.

We hope to see you there.

2018 AHCF Board of Directors

Come to New Jersey in June and Meet Them in Person

Gene Andrasco - Shannon Berta - Sharon Ciccodicola - Lynn Egan
Bill Gerber - Rik Greenwood - Renee Hodes - Josh Marszalek
Mario Merida - Carol Presunka - Vicky Platt - Meredith Schalick

Through research, education and family support, we have **ONE MISSION**: END AHC!