



One Mission: End AHC!



YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER

October 2017

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

Click Here to Help!
www.ahckids.org

Hi Friends

Great day for a chat right?

**I am here because
I am trying to get to
Northwestern University
to help kids with AHC.**

Will you help me?



Click Here to Help!
www.ahckids.org

The next phase of AHC research is ready and in need of funding this January.

With your help we can keep the AHC mice working hard to find treatments for AHC in the New Year.

AHC Community in ACTION

The AHCF End of Year Campaign is Ready for You in 2017!

The AHCF Board of Directors is pleased to be building on the huge success of our campaign last year and continue once again with the **Step Up to End AHC 2017 Campaign**.

Our campaign is a fun and simple way for everyone in the AHC community to come together and help raise money for the AHC research taking place at Northwestern and Vanderbilt Universities next year.

We'll provide you with all of the tools you need to **share this important message** with your friends and family during November and December. While everyone is very busy during this time of year, we'll make increasing awareness about AHC a spirited and joyful experience.

When you support the **Step Up to End AHC campaign**, you are helping the AHCF achieve its mission to **fund research, promote year-round education, and provide families with much needed support**. All of your efforts will directly affect the future of every person living with AHC!

WATCH FOR MORE DETAILS NEXT MONTH ON HOW YOU CAN TAKE THE NEXT STEP TOWARDS OUR ONE MISSION: END AHC!

www.ahckids.org

MINOR TIME COMMITMENT, MAJOR IMPACT

AHCF Micro-Volunteer Opportunities are Endless and Easy

Give back to AHC in a small but meaningful way by signing up for micro-volunteering (project based) opportunities, which can range anywhere from 10 minutes a month to one hour a month to a one-time action or activity.

Micro-volunteering can involve anything from sharing Facebook posts, proofreading digital content, looking for grants, to designing event-based graphics.

The key benefit is flexibility. The end result is that your talents move forward the **One Mission: End AHC!**

To micro-volunteer: Contact Lynn Egan at lynn@ahckids.org

IDEAS ON HOW YOU CAN MICRO-VOLUNTEER

- Write cheerful letters to struggling families
- Share Facebook posts
- Proofread digital content
- Create graphics for AHCF events
- Find vendors for one-time projects
- Create slide shows from provided pictures
- Write an article for the newsletter
- Find grant writing opportunities
- Share your story in "Voices of AHC"
- Evaluate resources from a set list
- Use your passion to benefit the community



AHCF IN ACTION

2017 Incredible Achievements

We are **very pleased and proud** to share our annual statement of achievements for the 2016-2017 fiscal year. It is simultaneously a re-introduction of our foundation and an accounting of our stewardship of resources.

The AHC Foundation has garnered enormous support financially, as well as through the time and talents of volunteers, applied toward our mission to support families, educate the community, and advance research. The AHCF understands that good stewardship of the funds donated to us is of the highest priority for those who **contribute to our mission to END AHC!**

Accurate reporting and transparency about our activities is a core value of our foundation. The 2017 Impact Statement provides everyone with **an opportunity to see exactly how the foundation is using its resources.**

Please logon to the www.ahckids.org website to view this year's statement. It is a visually appealing presentation of the work completed during our last year. You can find a PDF version of the statement at:

<http://ahckids.org/foundation/impact-statement-2017>

If you would like a copy mailed to you, or a family member, please contact vicky@ahckids.org and one will be mailed to you.

Your Dollars Matter Most. Our foundation is 100% donor-supported. Help improve the quality of life of children with AHC today...with your donation.





AHC INFO EXCHANGE

Important AHC Research Just Published

A group of French researchers published an article this month in *Orphanet Journal of Rare Diseases* titled, “A Randomized, Controlled, Double-blind, Crossover Trial of Triheptanoin in Alternating Hemiplegia of Childhood.”

The article discussed how they **conducted a randomized, double-blind, placebo-controlled crossover study of triheptanoin** in ten patients with AHC due to ATP1A3 mutations.

Triheptanoin, sometimes called “C7 Oil,” is a triglyceride oil (a fat) that is composed of three seven-carbon fatty acids. It is synthesized by a process of esterification of glycerol with heptanoic acid, each of which is easily derived from common natural oils.

In the study, each treatment period consisted of a **12-week fixed-dose phase, separated by a 4-week washout period**. The primary outcome measured the total number of paroxysmal events. Secondary outcomes included the number of paroxysmal motor-epileptic events; a composite score taking into account the number, severity and duration of paroxysmal events; interictal neurological manifestations; the clinical global impression-improvement scale (CGI-I); and safety parameters.

The study concluded that **the trial failed to show any effect of triheptanoin, at a target dose of 30% of calories**, on paroxysmal episodes in patients with AHC. This study argues against a prominent role of a brain energy deficit in these paroxysmal manifestations. Many lessons for future trials in this group of patients were learned during this study as well.

A free copy of the article is available at:

<https://ojrd.biomedcentral.com/track/pdf/10.1186/s13023-017-0713-2?site=ojrd.biomedcentral.com>



This important work was funded by the hard work and generosity of the French AHC Association.

Thank you for taking on such a challenging task!

AHC INFO EXCHANGE

ATP1A2 Research Has Something to Say about AHC



A group of Canadian researchers published an article this month in *Pediatric Neurology* titled, “An Infant with Epilepsy and Recurrent Hemiplegia due to Compound Heterozygous Variants in ATP1A2.”

The article discussed how variants in the ATP1A2 gene have most commonly been associated with familial hemiplegic migraine. However, a wide spectrum of phenotypes that include alternating hemiplegia of childhood and epilepsy have been described.

Continued on next page...

www.ahckids.org

AHC INFO EXCHANGE

ATP1A2 Research Cont.

The article concluded that this is only the second report of compound heterozygosity of the ATP1A2 gene. It demonstrates **the spectrum of paroxysmal neurological events that can arise as a result of ATP1A2 variants, with unique features overlapping alternating hemiplegia of childhood, hemiplegic migraine, and epilepsy.** This child illustrates the diagnostic challenges that these disorders can present and the importance of genetic diagnosis in guiding management.



AHC INFO EXCHANGE

Additional New International Research

This is an incredibly exciting time in AHC-related research. Numerous articles from around the world were recently published. While we would like to cover everything, it just isn't possible. A list of articles not already covered in this, or previous issues, is provided below. They include:

From Saudi Arabia: "More Than a Decade of Misdiagnosis of Alternating Hemiplegia of Childhood with Catastrophic Outcome." *Case Reports in Medicine*, August 2017.

From China: "Diagnosis of Alternating Hemiplegia of Childhood," *Chinese Journal of Contemporary Pediatrics*, September 4, 2017.

From China: "Alternating Hemiplegia of Childhood and Epilepsy in an Infant." *Chinese Journal of Contemporary Pediatrics*, September 4, 2017.

From Italy: "ATP1A3 Mutant Patient with Alternating Hemiplegia of Childhood and Brain Spectroscopic Abnormalities." *Journal of the Neurological Sciences*, August 15, 2017.

From the United Kingdom: "Challenges Describing Motor Profiles in Alternating Hemiplegia of Childhood." *Developmental Medicine & Child Neurology*, August 2017.

From Japan: "Progressive Brain Atrophy in Alternating Hemiplegia of Childhood." *Movement Disorders: Clinical Practice*, May/June 2017.

OUR THANKS AND APPRECIATION TO THE INTERNATIONAL RESEARCH COMMUNITY!



WHAT DO YOU WANT TO HEAR ABOUT IN NJ?

WHO WOULD YOU LIKE TO MEET?

WHICH TOPICS INTEREST YOU MOST?

"Getting an audience is hard. Sustaining an audience is hard. It demands a consistency of thought, of purpose, and of action over a long period of time."

Bruce Springsteen

Hello there AHC Families and Friends!

We can't believe the **AHCF Family Meeting** is just over 8 months away! We are currently working on a rich, high quality content agenda for you all and we want to make sure that you feel part of the process.

Please send us an email at <sharon@ahckids.org> with **topics you would like to see discussed** at our next Family Meeting and, as always, we are looking forward to seeing you all in **June 2018!** "

AHC COMMUNITY IN ACTION

Join in on the fun and Sign Up for the New Birthday Club

We are excited to announce that in September we started the **AHCF Birthday Club** for all of our AHC Hero's. We want to celebrate with your child and send warm wishes for a wonderful year.

AHC Hero **Brooke Tasi**, who loves crafts, will be making the cards that will be sent to your 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.**



AHCF FUNdraising 12 Annual Chicago Walk Huge Success

The Twelfth Annual AHCF Chicago Walk was held on Sunday, September 17th at Paulus Park in Lake Zurich, Illinois. The walk has been organized by Gene and Kelly Andrasco in honor of their daughter Kiley, and by Andy and Vicky Platt in honor of their daughter Emma.

The walk is actually pulled off each year because of the amazing group of family and friends which come together to help make this event happen.

This year, we were fortunate to have **Dr. Ken Silver and Dr. Al George** attend the festivities once again. It is an amazing experience to be outside and chat with AHC doctors who have been committed to our community for years.

Their willingness to talk to everyone who had questions about AHC was greatly appreciated by all.



AHC volunteers helping with everything from registration, selling raffle tickets and cleaning up the park.

Also this year, we were fortunate to have numerous AHC families drive short and long distances to join us.

Whether from Illinois, Wisconsin, Michigan, Minnesota, Missouri, Kentucky or Ohio, attending the Chicago Walk is a joyous and fun filled day for everyone who loves a child with AHC.

Thank you to everyone who came out to the walk and has helped raise over \$300,000 for AHC research. You all have helped pursue our goal of Ending AHC.

Many Thanks!



Emma with her sister Aria and friend Abby



Kiley on the path followed by friends