One Mission: End AHC!

YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER August 2017
2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

AHC Community in ACTION

Back to School Well Wishes for All

The AHCF Board of Directors sends our best wishes to everyone returning to school this fall. Going back to school can be exciting and nerve-racking all at the same time. Hopefully, everyone will be able to enjoy the joy of starting something new and the challenge of learning another year's worth of knowledge. Good luck kids and parents alike!

AHCF in ACTION

AHCF Webinar Coming in August

The next AHCF webinar will take place on **August 29, 2017 from 6:30 pm to 8:00 pm (CDT).** Dr. Terry Sanger will present a talk on dystonia with a question and answer period for parents to **learn what dystonia is and how to deal with it.**

Dr. Sanger's NIH funded research includes work on **understanding motor learning in children**, work on the use of kinematic measurements of children to design assistive communication interfaces, and multiscale modeling of large-scale neural systems for control, with particular application to **understanding the development of spasticity and dystonia.**

Call-in directions for the webinar are as follows:
(#1)Join from PC, Mac, Linux, iOS or Android: https://zoom.us/j/8947177639
(#2) Or iPhone one-tap (US Toll): +16465588656,,8947177639# or +14086380968,,8947177639#
(#3) Or Telephone: Dial: +1 646 558 8656 (US Toll) or +1 408 638 0968 (US Toll) and use the Meeting ID: 894 717 7639
(#4) International numbers available:
https://zoom.us/zoomconference?m=2XK2TESHLKHcVngeUzbkZ_ksVa1UKW5v

AHCF in ACTION

Join the new AHCF Birthday Club Starting this September

We are excited to announce that in September, we will start 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.**

AHC Info Exchange

AHC Documentary a Big Winner

Congratulations to **Human Timebombs** director, Agusta Fanney, for winning the 2017 award for **Best Global Impact Award Short** for the 7th edition of Move Me Productions' Online Film Festival.

The AHCF is honored to have supported the production of this documentary and recognizes the outstanding efforts of everyone involved in making this film a reality.

Congratulations one and all!

Make Waves for AHC!

Come join us near the Jersey Shore for the AHC Foundation's Bi-Annual Family Meeting, which will be held June 22nd – June 24th, 2018 at the **Renaissance Woodbridge Hotel in Iselin, NJ!**

The AHCF Family Meeting is the largest gathering of AHC doctors, researchers and families from all over the world. Please join us to learn the latest news from top researchers, and connect with wonderful families, and their children, who are experiencing a similar journey.

We look forward to seeing you there!

For more information, please visit for our Family Meeting Facebook Page
https://www.facebook.com/AHCFamily2018/

For updates, check out www.ahckids.org <http://www.ahckids.org> <http://www.ahckids.org/>

SAVE THE DATE

AHC FOUNDATION

2018 FAMILY MEETING

June 22nd – June 24th, 2018

Renaissance Marriott, Woodbridge, NJ

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

Funding Research & Supporting Families.
The AHCF-serving the AHC community since 1993.

AHC INFO EXCHANGE
Important AHC Research Just Published

A group of Canadian researchers publishing an article last June in the journal *Pediatric Neurology* titled, **"An Infant With Epilepsy and Recurrent Hemiplegia due to Compound Heterozygous Variants in ATP1A2."**

The article discussed how pathogenic heterozygous **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 also been described.

The article concluded that there are **a 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 paper illustrates the diagnostic challenges that these disorders can present and **the importance of genetic diagnosis in guiding management.**

A free copy of the article is not available. To purchase a copy, go to:

http://www.sciencedirect.com/science/article/pii/S0887899416307081?via%3Dihub

AHCF in ACTION
Join the AHCF Support Group

Do you know that AHCF hosts a support group on Facebook? This is a closed group for parents only. It is for the AHC community and is a wonderful place for parents to share their experiences, frustrations, fears and joys with other families.

"Unity is strength… when there is teamwork and collaboration, wonderful things can be achieved."
Mattie Stepanek

It is also a place where **you can ask any question to parents** who know what you are going through. Or you can **simply vent your frustrations**.

All posts are private and can only be seen by other members. **It is your safe haven** where understanding and kindness prevail and judgments of any kind are not tolerated. To be admitted to join click here:

https://www.facebook.com/groups/1436035426663331/

Information on the new

AHCF Family Grant

program is located at:
www.ahckids.org

For questions please email:
Shannon@ahckids.org

AHCF in ACTION

"Voices of AHC" is Something You Shouldn't Miss


"Our Lives are the perfect imbalance of fear, unconditional love, and undying optimism."
-Kimberly Holmes
Mom to Violet, 5

As a foundation supporting those with a rare disease, **getting the public to understand and empathize with our families can be challenging at times.**

Using the power of social media and the role it plays in advocating for those who often cannot speak for themselves is a huge priority.

Through a collaborative effort, the AHC Kids Foundation started the **Voices of AHC campaign** to do just that- let families and AHC children speak out, showing the complexity, beauty, and heartbreak in dealing with a disease others know very little about.

The campaign has allowed families to combat loneliness and **reach the public in a way that is both candid and inspiring.**

Together, we will strive to continue the effort of advocacy and awareness and hope families will join in to facilitate outreach for this ongoing project.

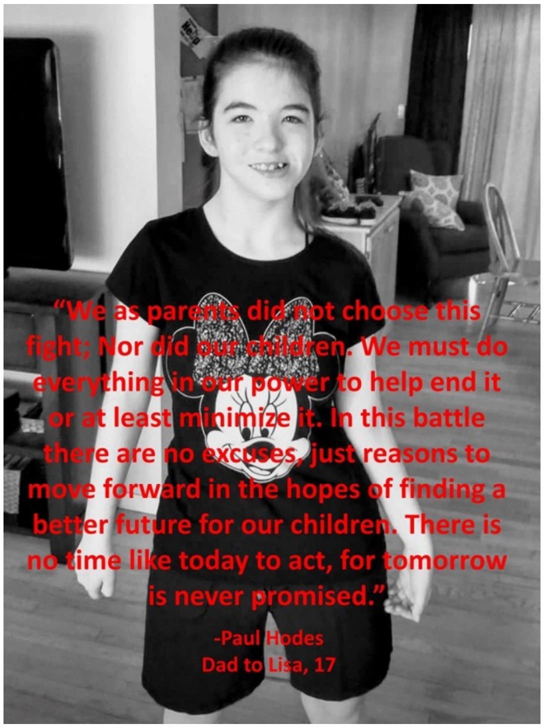
Please visit and like our **AHCF Facebook** page to meet more kids with AHC.

https://www.facebook.com/AHCKids

If you would like to have your families voice heard, please message:

Stacy Greenwood at roosky41@gmail.com or

Shannon Berta at shannon@ahckids.org


"We as parents did not choose this fight; Nor did our children. We must do everything in our power to help end it or at least minimize it. In this battle there are no excuses, just reasons to move forward in the hopes of finding a better future for our children. There is no time like today to act, for tomorrow is never promised."
-Paul Hodes
Dad to Lisa, 17

12TH ANNUAL CHICAGO WALK

Come join us in Lake Zurich, Illinois for the
12th Annual AHCF Chicago Walk on
Sunday, September 17th
Stepping off at 9:30

We'll have fun and raise money for AHC research!
Everyone is welcome!!!

Email: Vicky@ahckids.org for information