



# One Mission: End AHC!

## INSIDER'S EDGE

YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER [www.ahckids.org](http://www.ahckids.org)

DECEMBER 2014

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

*Holiday Greeting*

## AHC Foundation president celebrates with you

Life with AHC can be an emotional roller coaster for many reasons. We are all at different points in our lives with our children affected by AHC.

Some parents are dealing with a recent diagnosis, school and education, teenagers, behaviors, or considering assisted living accommodations.

Sadly, some have even been affected by the death of a child. No matter where we are in dealing with the disease, we have families to raise, lives to live and the challenges of coping day to day.

The AHC community is bound together by AHC.

Together, we are waiting for a treatment that will stop the episodes.

Together we hope for a cure that will allow our children to live a good life.

Together we all have one mission: End AHC.

Let's do it together!

I wish each of you peace, joy and hope this Holiday Season!

*Lynn Egan*  
*AHCF President*



**Blessed is the season which engages the whole world in a conspiracy of love.**

--

**Hamilton Wright  
Mabie**



### Support AHCF When You Shop Amazon

Did you know you can conveniently shop Amazon while supporting AHCF at no extra cost or effort? AHCF is an Amazon affiliate. By using the links below for each purchase you make, Amazon will donate a percentage back to AHCF.

**Your Dollars Matter Most.** Our foundation is 100% donor-supported. Help improve the quality of life of children with AHC today... with your donation. It's safe. It's fast. It's online. Look for the button...

[Donate Now](#)

[www.ahckids.org](http://www.ahckids.org)



### *AHC Community Comes Together*

## Honoring those we've lost this year

During the last month, the AHC community learned about the passing of three AHC friends; Whit Muir (31), Jessica Scaniello (25), and a five year-old girl from China (name withheld by request).

While there is never a “good time” to share this news, we do want to respectfully acknowledge this loss to our collective family and honor the lives they shared with us.

While each of our friends AHC struggle was part of their story, it was not their entire story. They were sisters, brothers, sons, daughters, grandchildren, cousins, and friends. They experienced joy, had fun, laughed, cried, worked hard, and had big dreams.

One of those dreams was also an incredibly generous gift to our AHC community. Whit shared his dream of helping kids with AHC by having his brain donated to research upon his passing. His family and caretakers knew of his wish and worked with Dr. Kathryn Swoboda to make it come true. It was a wish that will have an amazing impact on AHC for years to come.

Whit, Jessica, and all the friends we lost this year had an amazing impact on the lives of their parents, family, friends, and the entire AHC community. We are grateful for having shared our lives with each of these amazing people and are better off for having known them.

We honor you. We thank you. And, we will miss you.

### *Great AHC Resources Just Got Better*

## International AHC consortium is official



We are thrilled to share some exciting news with you this month. An international consortium for the research on AHC and other ATP1A3 related rare diseases was officially announced on November 28<sup>th</sup>, 2014!

**The IAHCRC International Consortium for the Research on Alternating Hemiplegia of Childhood (AHC)** was formed in 2012 to carry out collaborative research that led to the identification of the ATP1A3 gene as the main cause of AHC.

The consortium involves clinicians, geneticists and researchers working at university centers in Europe, the United States and Australia. Additionally, it operates in close collaboration with health professionals and patient organizations.

The objectives of the IAHCRC Consortium are the active contribution to the collaborative study of the pathogenetic mechanisms of the ATP1A3 diseases and the development of effective treatments. In close collaboration with patient associations, the IAHCRC will contribute to the promotion of better care for all affected patients, by developing specific standards for the diagnosis and the management of the diseases and by disseminating the information.

The current scientific coordinator of the consortium is Professor Alexis Arzimanoglou of France and the data manager is Dr. Rosaria Vavassori of Italy.

The AHC Foundation thanks all of the clinicians, geneticists and researchers who have come together in creating the consortium and wishes each member a Happy, Healthy and Prosperous New Year!

*AHCF Responds to Challenge to Raise Money*

## Focus on fundraising keeps focus on research

For over 20 years, the AHC Foundation has been a resource for those with AHC, providing help and hope that is just a call, click or post away. Having achieved greater awareness about AHC and significantly increased the number of researchers interested in AHC, families can begin to see real treatments within reach for our AHC kids.

To make these treatments a reality, the Board of Directors took significant action to make fundraising for research a major focus in 2015. Two directors are now leading the way on our fundraising efforts along with a dedicated fundraising committee. Together, they meet monthly to coordinate our fundraising activities.

We are thrilled to have Mollie Erpenbeck officially assume the role of Major Giving Officer. Mollie has been instrumental in coordinating our major donor program and is looking forward to another successful year.

As the new Development Chair, Vicky Platt continues her work with the foundation after serving almost two full terms as secretary.

The AHCF is here for everyone suffering from AHC and will be here until there is no longer a need. Please help us ensure that we can continue to provide information and support to families while remaining focused on our ultimate goal of ending AHC.

### AHCF Fundraising Committee Members

Shannon Berta  
Nancy Campbell  
Mollie Erpenbeck  
Stacy Greenwood  
Paul Hodes  
Valerie Evans-Miotek  
Vicky Platt  
Sue Richards



**More volunteers  
are always  
welcome!**

## We're looking for a few great volunteers!



Do you love football and someone with AHC?

Do you want to help fund research?

Then, join in on the fun of  
AHCF's FootballMania SuperMatch  
fundraiser.

It is this simple:

Offer to help sell \$5 tickets  
We'll get you the tickets & instructions  
We'll give you flyers to help explain it all

Have fun during the big game while raising  
money for a treatment for AHC.



For more information on how to participate in FootballMania SuperMatch, please contact Paul Hodes at [pnh118@optonline.net](mailto:pnh118@optonline.net)  
With your help we can raise money to fund research into a treatment for AHC.  
[www.ahckids.org](http://www.ahckids.org)

**Donors:** Your gifts fund 100% of our effort to help children with AHC. It is our privilege to coordinate the support and services you find critical to improving their quality of life. Thank you for your steady support. Everything we achieve depends on you.

[www.ahckids.org](http://www.ahckids.org)