



# One Mission: End AHC! INSIDER'S EDGE

THE ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER [www.ahckids.org](http://www.ahckids.org)  
2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

OCTOBER 2014

*AHCF Directors Join Neurologists in Ohio*

## Child Neurology Society Meeting a Success

The Child Neurology Society Annual Convention was held in Columbus, Ohio on October 22-25<sup>th</sup>. According to Dr. Kevin Ess, Chief of Pediatric Neurology at Vanderbilt Medical Center and founder of the AHC Clinic at Vanderbilt, “roughly 60% of all child neurologists were in attendance at the conference.”



The AHCF found it to be extremely beneficial to attend as an exhibitor. We worked to raise awareness of AHC and discussed important criteria in properly diagnosing the disease to get a better snapshot of the true spectrum of our children.

Additionally, we focused on informing them about our foundation, the support we offer, and the current research we are funding to find a treatment. On all counts, the two days we spent in Ohio were an enormous success!

Cate Cohen, Mollie Erpenbeck, and Josh Marszalek represented the AHCF during the CNS meeting. They interacted with hundreds of child neurologists educating them about AHC! Most were unaware that a foundation for AHC existed and expressed that their families dealing with AHC really need support, parenting tips and the overall knowledge that we provide.

We armed them with our brochures and handouts on our latest clinical and research testing, which they were eager to take back to their offices and also to pass along to their families afflicted with AHC. We had one neurologist in particular that expressed that meeting us and learning about the foundation made his trip to the convention worthwhile.



Overall, we were pleasantly surprised at how many neurologists had heard of AHC and were treating AHC patients that didn't have any support and really needed it. AHC was also mentioned in a presentation on movement disorders at the general assembly.

Our mission to raise awareness of AHC, help families, and educate doctors took a giant step forward with the CNS Annual Meeting, which we were so honored to attend as the premier foundation in the fight against AHC.

We left the meeting feeling positive about the outlook for AHC and the future for our children.

Heard in the exhibitor hall, “Meeting the AHCF and learning about the foundation made my trip to the convention worthwhile.”

**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)

*What Motivates Volunteers?*

# A simple thank you

They run, walk, cycle and swim. They bake. They volunteer. They rally their peers. They spend hours sharing their passion for our cause with neighbors, family members, colleagues, and friends.

And they don't stop there. They engage, connect and inspire others to get involved too.



**Thanks Fundraising Volunteers!**



**Thanks Family Meeting Volunteers!**



Our volunteer's passion for the AHC Foundation raises the money needed to continue our mission. But it doesn't stop here; their efforts result in so much more!

Our volunteers encourage all to create change around the issues and causes they care about. Ending AHC!

**Thanks  
Volunteers  
of All Ages!**



Volunteers start early as siblings, cousins and friends. Others join our ranks as parents, aunts, uncles, and grandparents. And still more come to us as someone who loves an AHC child. No matter the age, they all give the ultimate precious gift to our foundation, their time.

They stand in the rain and cold to help our kids. They drive to family meetings and help care for our kids during parent sessions. Our volunteers show up to support and give voice to our children because they know it needs to be done.

So, thank you volunteers for playing such an important role in helping all AHC children and adults have a chance for a better life and eventually ending AHC!



**Thanks for Standing Up for our Kids!**



## AHC Mini Fact

The Aicardi diagnostic criteria for AHC are:

- Onset of symptoms before 18 mos. of age
- Repeated attacks of hemiplegia involving either side of the body
  - Paroxysmal disturbances including tonic or dystonic spells
  - Episodes of bilateral hemiplegia or quadriplegia
  - Evidence of developmental delay
  - Neurologic abnormalities including dystonia, ataxia or choreoathetosis

### Stay Connected



**Words of Wisdom**

**“Sometimes life knocks you on your ass...get up, get up, get up!!!! Happiness is not the absence of problems; it's the ability to deal with them.” Steve Maraboli.**

*New Research Comes Out in September*

## Clinical and genetic analysis in AHC: ten new patients from Southern Europe.

Last month, researchers from Spain published an article on AHC in *The Journal of the Neurological Sciences*. They sought to find mutations in ATP1A3, CACNA1A, ATP1A2, SCN1A and SLC2A1 in a cohort of ten unrelated patients from Spain and Greece.

They identified three previously described heterozygous missense ATP1A3 mutations (p.Asp801Asn, p.Glu815Lys and p.Gly947Arg) in five patients. No disease-causing mutations were found in the remaining genes. All mutations occurred de novo and carriers presented, on average, earlier than non-carriers.

According to the article, intellectual disability was more severe in patients with the p.Glu815Lys variant. Also of note, three of their patients exhibited remarkable clinical responses to the ketogenic diet. The research confirmed ATP1A3 mutations in half of their patients. The article citation is: *J Neurol Sci*. 2014 Sep 15;344(1-2):37-42.

*AHC Community Involvement*

## Families share AHC info with friends in November

The AHC Foundation is running a campaign from November 1<sup>st</sup> to November 15<sup>th</sup> to encourage people to sign up to receive the monthly newsletter via email. The purpose of the campaign is to increase awareness about AHC and to provide parents with a means of sharing information about AHC with their family, friends, and colleagues.

And, for everyone who signs up from Nov. 1<sup>st</sup> through Nov. 15<sup>th</sup>, they will be entered into a drawing to win a Google Chromecast device.

**Signing up is quick and easy to do.** Simply go to [www.ahckids.org](http://www.ahckids.org). On the left side of the home page, there is a box to click and sign up for the newsletter. Just one click and you're on the way to having the newsletter sent directly to you each month.

Encourage your friends and family to sign up and learn about AHC and the amazing community we serve!

### Upcoming Events

10/31/14

Happy Halloween

11/3/14

Executive Committee Meeting

11/5/14

Fundraising Committee Meeting

11/7/14

Dine & Dance to End AHC

11/17/14

Board of Directors Meeting

11/27/14

Happy Thanksgiving

Sign up to receive the AHCF newsletter between Nov. 1<sup>st</sup> and Nov. 15<sup>th</sup> to be entered into a drawing to win a free Chromecast for all of your WiFi enabled devices

[SIGN UP HERE](#)

[Donate Now](#)

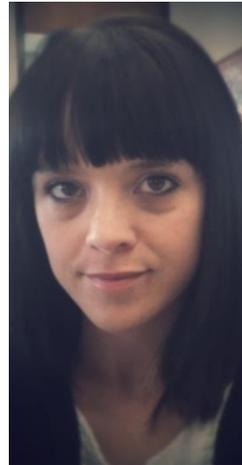
[www.ahckids.org](http://www.ahckids.org)

*AHC Foundation Update*

## New director comes on board

At the September Board of Directors Meeting, Shannon Berta was elected to serve the foundation as a director for a three year term.

Shannon lives in upstate New York with her husband and two little girls, Keira (5) and Autumn (13 months). After Keira was diagnosed with AHC in 2010, Shannon became determined to learn everything she could about AHC and how she would be able to help her daughter live the best life possible.



Shannon is currently working on her B.A. in Literature at Empire State College and works as an Executive Assistant with the NYS Office of Information Technology. She is determined to raise AHC awareness and find fundraising opportunities to benefit the children suffering from AHC.

Foundation President, Lynn Egan, had this to say about Shannon joining the board, "Shannon brings her individual expertise, energy and commitment to the AHCF and is a great addition to our organization. Please join me in welcoming Shannon to the board!"

Shannon can be reached via email at [Shannon@ahckids.org](mailto:Shannon@ahckids.org)

*AHCF Board Size Increased in October*

## Looking for more great volunteers!

To allow for increased interest in serving the foundation on the Board of Directors, a vote was passed at the October director's meeting to increase the number of board positions from fifteen to seventeen.

**Picture Yourself  
Here!**



**AHCF and international volunteers  
lead AHC efforts**

If you are interested in volunteering your time to help raise awareness for AHC and fund research to end AHC, than the Board of Directors would love to hear from you.

There are numerous ways you can help and serve the AHC community. Feel free to reach out to President Lynn Egan and together you can find the perfect fit for your talents within the foundation.

*Learning Opportunity*

## "One in a Million" Alternating Hemiplegia of Childhood

**Pediatric Grand Rounds**  
featured  
**Dr. Kenneth Silver**  
at the  
**The University of Chicago  
Comer Children's Hospital**

Dr. Silver hosted a continuing medical education seminar on October 30<sup>th</sup>, 2014 from 12:00pm to 1:00pm.

This was a special opportunity to share information about AHC with medical professionals in Chicago.



**Thank you Dr. Silver for  
educating more physicians  
about AHC!**



If you have any questions or comments regarding this newsletter, please contact Vicky Platt at [Vicky@ahckids.org](mailto:Vicky@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.

**Donate Now**