



One Mission: End AHC

# INSIDER'S EDGE

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

NOVEMBER 2014

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

*Thanksgiving Greeting*

## AHC Foundation President Expresses Our Thanks

As we approach the end of each year and move into the holiday season, I am always struck by how far we have come as a foundation.

Thanksgiving is the time of year that we pause for a moment, focus on how grateful we truly are and give thanks.

**365 days a year and especially on Thanksgiving,**

**I am thankful** for the advancement of technology and science that will afford our children a treatment and a cure.

**I am thankful** for the scientists and physicians that are committed to the AHC community;

**I am thankful** for the amount of awareness that has been raised throughout the medical community and hometown communities as a whole;

**I am thankful** for each of you. For your involvement, your commitment to raising funds for research, and for making a better life for your AHC child.

Most importantly, I am thankful for my family and circle of friends, including all of you. I wish your family a safe, healthy, happy and episode free holiday! From my home to yours, I wish you a very

**Happy Thanksgiving!**

Lynn Egan - President



**“Gratitude is the inward feeling of kindness received. Thankfulness is the natural impulse to express that feeling. Thanksgiving is the following of that impulse.” Henry Van Dyke**



### Upcoming Events

11/27/14

Happy Thanksgiving

12/1/14

Executive Committee Meeting

12/2/14

Giving Tuesday

12/3/14

Fundraising Committee Meeting

12/4/14

Charity Mania Begins

12/15/14

Board of Directors' Meeting

**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)



*AHCF Medical Advisory Board in Action*

## Updated Information on AHC

Thanks to ongoing collaboration between Drs. Swoboda and Brashear, et al, *GeneReviews* has recently updated their chapter on ATP1A3-related neurologic disorders



In this, you will find the most current resources available for identifying core features of AHC, RDP, and CAPOS syndrome, the genetic basis for each disease, as well as access to genetic testing.

*GeneReviews* is an online database containing standardized peer-reviewed articles that cover specific inherited diseases. As a website, it is unique in that subjects covered in the reviews are written by experts specific to the disease and that reviews are screened by others in the scientific community prior to publication.

It is a very valuable resource for clinicians in need of authoritative, comprehensive, and relevant information on rare genetic diseases.

You can find the article at: <http://www.ncbi.nlm.nih.gov/books/NBK1115/>

Distribution

*AHCF Awards Research Grant*

## Getting closer to possible AHC treatment

**2014 Molecular  
Physiology and  
Pharmacology  
of *ATP1A3*  
Mutations in AHC**

The Alternating Hemiplegia of Childhood Foundation is pleased to announce that we have partially funded phase three of a research grant awarded to Dr. Kevin Ess at Vanderbilt University and Dr. Alfred George, Jr. at Northwestern University in the amount of \$140,807.00.

The work will continue to determine functional and biochemical consequences of the three most common gene mutations causing AHC. They will also continue to identify drugs or drug-like compounds through a drug screening program that are capable of restoring normal *ATP1A3* gene function.

Additionally, they have made induced pluripotent stem cells (iPSCs) derived from AHC patients. These again include the three most common gene mutations causing AHC. These patient derived stem cells will be used to investigate electrophysiological abnormalities of neurons and to test whether compounds they have identified can restore *ATP1A3* function in human cells.

**The second half of phase three is due to be awarded in January, 2015. To date we have invested \$404,496.00 and continue to explore all avenues of funding to avoid a cessation of the research that is drawing us ever closer to a viable treatment.**

Dr. Kevin Ess from Vanderbilt had this to add: "We are extremely honored to continue our work with the Foundation and its membership. This is a very exciting phase of discovery for everyone connected to AHC and is critical to expand our knowledge of *ATP1A3* function and to seek new treatment strategies. The very generous donation by the AHCF will enable us to determine mechanisms used by specific *ATP1A3* mutations that cause AHC.

We will continue our success from last year by identifying novel potential drug therapies that can correct the defect caused by specific *ATP1A3* mutations. Notably, we are using human cell lines including induced pluripotent stem cells (iPSCs) that harbor *ATP1A3* mutations. Our experiential approach was designed to most quickly identify disease pathways as well as potential therapeutics that can help those afflicted with AHC."



AHC Community Responds to Challenge to Raise Money

## Shop on Amazon & they donate to us

1. Go to [www.smile.amazon.com](http://www.smile.amazon.com)
2. Select Alternating Hemiplegia of Childhood Foundation as your charity of choice.
3. Amazon donates 0.5% of the price of your eligible AmazonSmile purchases to us. It's that simple.

Donations are already rolling in

## Tips for sharing the message about #GIVINGTUESDAY™

We have a day for giving thanks. We have two for getting deals. Now, we have #GivingTuesday, a global day dedicated to giving back. On Tuesday, December 2, 2014, charities, families, businesses, community centers, and students around the world will come together for one common purpose: to celebrate generosity and to give.

It's a simple idea. Just encourage your family, your community, your company or your social organizations to come together to give something more. Tell everyone you can about how you are giving to the AHC community with the AHC Foundation. Make a phone call, send an email, post on Facebook, or hand out flyers. Do anything.

This year, we need to raise \$149,870 to finish funding the research at Vanderbilt and Northwestern Universities. If everyone shares this message with 5-10 people, research will continue in 2015 towards our mission of ending AHC. **Make Tuesday, December 2<sup>nd</sup> the day we give the gift of a treatment to our AHC kids!**

**Join the AHC Foundation and be a part of a global celebration of a new tradition of generosity.**

**Go to [www.ahckids.org](http://www.ahckids.org) to donate**

Black Friday. Cyber Monday. After two days of shopping, a day of GIVING. December 2, 2014.

## #GIVINGTUESDAY™

### Giving Tuesday Challenge: Raise \$140,870

to fund research **underway** at Vanderbilt University to find a treatment for Alternating Hemiplegia of Childhood in **2015**.

ONE MISSION: END AHC



**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)

*November Fundraising Event in New York State*

## Dine and Dance to End AHC raises money & spirits



Pictured above from left to right:  
**Bill Gerber Shannon Berta  
Renee Hodes & Paul Hodes**

On November 7<sup>th</sup>, Paul and Renee Hodes hosted an incredible gala to honor their daughter Lisa and to raise money for the AHC Foundation.

Family, friends, and AHCF Board of Directors traveled from all over the east coast to attend this amazing event.

By the end of the evening, well over \$10,000 was raised with donations still coming in after the event.

In addition to the dance, Paul and Renee were busy all summer long working to increase awareness about AHC and raising money for research. What a power couple!



Keep your eyes peeled for more news from Paul & Renee next month. They have yet another fundraiser scheduled for December and January. Thanks Paul & Renee!

*November Newsletter Campaign a Huge Success*

## Over 30% increase in new followers

From November 1<sup>st</sup> through the 15<sup>th</sup>, the AHCF held a campaign to increase awareness about AHC through adding new followers to our monthly newsletter. The campaign was well received and the size of our list increased by over 30 percent.

From all of the new followers who joined during the campaign, one was selected to win a Chromecast dingle. Congratulations to our winner, Brent Munsell from South Carolina and watch for our next campaign!

Thank you Brent and all of the family and friends who signed up to receive our newsletter in November. Thank you for your support.

*Board of Directors Make Announcement*

## New mission statement for foundation

In October, the Board of Directors met to consider a new mission statement for the foundation. As a formal summary of the aims and values of the foundation, the directors are extremely excited to share our new message with the AHC community.



**Please give today.**

**It's safe.**

**It's fast. It's online.**

**Donate Now**

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



If you have any questions or comments about this newsletter, please contact

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**Through research, education and family support, we have one mission: end AHC!**