



One Mission: End AHC!

YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER www.ahckids.org OCT. 2015

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

AHCF Board Member Invited to Speak at Northwestern Feinberg School of Medicine Rare disease educational initiative a success

On October 19th, a rare disease educational initiative presented by Harmony 4 Hope was held at **Northwestern Feinberg School of Medicine**. The session provided medical students with an amazing opportunity to hear from advocates of four rare diseases: Batten Disease, Alpha I, Epidermolysis Bullosa, and Alternating Hemiplegia of Childhood.

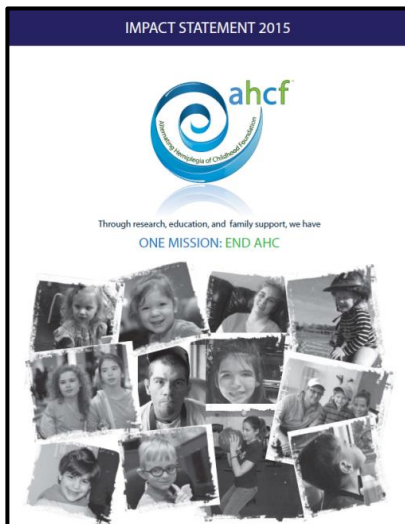
AHCF
Vice President
Gene Andrasco



The AHC Community was well-represented by AHCF Vice President and AHC Parent, Gene Andrasco.

Thank you to Gene Andrasco and **Harmony 4 Hope** for sharing the story of our rare disease community.

Your Story is Your Song. Sing it Out Loud!



AHCF Publishes Annual Report of 2014-2015 Fiscal Year

2015 Impact Statement available

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 momentum created by our generous donors to fund research and family support has encouraged us to reflect on past accomplishments and look ahead to making an even greater impact on the AHC community.

We are very pleased and proud to share our inaugural annual statement of our activities. It is simultaneously a re-introduction of our foundation and an accounting of our stewardship of resources.

Please read, enjoy and share our Impact Statement at:
www.ahckids.org



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.

www.ahckids.org

AHCF Awards \$250,000 Phase Four Grant to Expert Teams at Vanderbilt University & Northwestern University

Major research grant funded to find treatments for AHC



Dr. Al George
Northwestern Univ.

The AHCF Board of Directors is pleased to announce that the Fourth Phase of the Vanderbilt/Northwestern research project will begin this month.

The title of the project is, **“Molecular Physiology and Pharmacology of ATP1A3 Mutations in AHC.”** The program director is Dr. Kevin Ess from Vanderbilt University School of Medicine. Working with Dr. Ess is Dr. Mark Grier, a postdoctoral fellow at Vanderbilt University.



Dr. Kevin Ess
Vanderbilt Univ.

Work on this project will also occur at Northwestern University, Chicago.

Dr. Alfred George is the co-investigator who will oversee Drs. Christopher Thompson and Christine Simmons. As Chair of the Department of Pharmacology, Dr. George is an expert in this field and an incredible asset to the AHC community.

Since there is no treatment for AHC that is supported by empirical evidence, this project is crucial to finding pharmaceutical options for our community. The project will test a small number of drug compounds on animal models to see if the ATP1A3 mutations can be repaired. The optimal result from this project is identifying treatment options that can move us closer to clinical trials.

RESEARCH 101

Pharmacology is a basic science department in the Northwestern University Feinberg School of Medicine.

The department is dedicated to education and cutting edge research, broadly applicable to understanding mechanisms of drug action, as well as exploiting strategies for drug discovery.

After the Board of Directors voted to fund this work, AHCF President Lynn Egan commented, **“This is where the research gets really exciting! Work is finally being done on potential drug treatments for our kids.”**

The price tag for this phase of the project is \$250,000.

Because of the amazing work our community has done over the last four years, this work is able to move forward. While the doctors are incredible for working with our community, **it is the work of AHC parents everywhere that has made the research possible.**

Thank you to everyone, over many years, who have put in countless hours, held fundraisers, and donated their own money to making this a reality.



Love and Hope were The Messages Shared During an October Fundraiser

5th annual Iowa fundraiser a huge smash!

During the weekend of October 3rd and 4th, the 5th Annual AHC Fundraiser, “**Fall in Love**” with **Hope for Connor & Kids** took place in Neola, Iowa.

Family and friends came out to pick out goodies from tiny lil’ pumpkins to BIG ones ready to be carved. Gourds galore and Indian corn by the bundles were also available.



All proceeds from the event went to the AHC Foundation to help fund research and ultimately find a cure.

*Holidays are a Great Time for Sharing the
AHC Mission & Making it a Reality*

Bring families together for AHC!

The AHC Community is full of friends and family who want to help us.

Our friends and families have seen how much of a **struggle** it is to live with this disorder and they are eager to help.

Often, our friends and family just don’t know **how they can help** us and are willing to jump in when given the chance.

The upcoming holidays are a great opportunity for **sharing our mission** and allowing your supporters to help you.

**We have a day for giving thanks.
We have two for getting deals.
Now, we have #GivingTuesday,
a global day dedicated to giving back.**

**Join us in the fun on Tuesday, December 1st
As we give back to the AHC community.**

Black Friday. Cyber Monday.

#GIVINGTUESDAY

December 1, 2015

**Contact Vicky Platt to start planning now
vicky@ahckids.org**

A recent article from the journal *Trusts & Estates* touches on how it is okay to talk to our friends and family about helping our One Mission of Ending AHC.

“By opening the door to productive conversations about the family’s values and modeling and encouraging giving behavior, you can have a marked impact on the family attitude toward philanthropy for generations to come.”

So, as you start celebrating the holidays, **share your excitement** for the amazing advancements happening in our community. **Chat about the promising research** that is working on viable treatments for our kids. **Pass along announcements** about fundraising opportunities and ask people to help if they can.

Simply, let your friends and family help and see what wonderful things will happen.

Contact foundation president Lynn Egan for more information on volunteer opportunities lynn@ahckids.org



Video Library Now on Web to Increase Awareness

Checkout new AHC International Media site!

On October 5th, the AHC International Media Video Library was launched via Facebook.

The purpose of **AHC International Media Library** is to collect information about AHC and related disorders and make them visible for everyone.

Doctors, researchers and family can share information on this media and together we can help each other get closer to the goal of having an effective treatment for AHC.

AHCIM will continue to interview interested parties that have information on AHC or related disorders to share.

You may also keep up to date as new videos are added by **joining the Facebook group** for discussions at: <https://www.facebook.com/groups/1628781694073344/>

For more information go to: www.ahcim.com
Or Contact them at ahc@ahc.is

Important Article is Published in Another Leading Medical Journal

Cardiac issues for AHC patients with ATP1A3 mutations

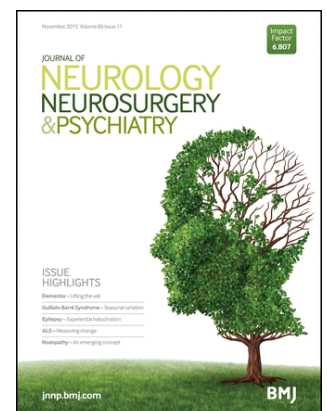
This article presents an abstract from the **ABN Annual Meeting** which took place in London this past September. The topic discussed was regarding the international study of 52 AHC patients with APT1A3 mutations and ECG abnormalities.

ECGs were analyzed for heart rate, cardiac axis, PR, QRS, RR, and QTc intervals, repolarization patterns, and J-point abnormalities.

The study found, “These ECG abnormalities reflect impaired repolarization reserve in AH in an age-dependent manner, and may account for some cases of premature mortality observed. Long-term cardiac surveillance in AH is recommended.”



This new research on cardiac related issues for AHC patients was also mentioned in our September newsletter. **Since this study is the first of its kind in our community, additional work on this topic will be crucial to further understanding its implications.**

We are grateful to the researchers who conducted this study and are bringing new issues to the forefront of the medical community.



Gather Your Friends and Family This Holiday Season to Fund AHC Research in 2016.

Helping raise money can be easy and fun!

AmazonSmile is a simple and automatic way for you to support the AHC Foundation every time you shop, at no cost to you. When you shop at smile.amazon.com, **Amazon will donate a portion of the purchase price to us at no extra cost to you!**

Simply go to smile.amazon.com from the web browser on your computer or mobile device and use your same account on Amazon.com and AmazonSmile. Your shopping cart, Wish List, wedding or baby registry, and other account settings are also the same.

On your first visit to AmazonSmile (smile.amazon.com), you need to **select AHC Foundation** to receive donations from eligible purchases before you begin shopping. It will remember your selection, and then every eligible purchase you make at smile.amazon.com will result in a donation. **And, Amazon does the rest!**

Supporting: Alternating Hemiplegia Of Childhood Foundation Inc

VISIT



AHC Foundation Family Meeting

Save the Date

July 13th – July 17th
Indianapolis, Indiana



Families are Getting Ready for the Most Important Time of our Year

Fundraising
season is
stepping off big
in
New York
Come Join Us



DINE & DANCE

FRIDAY, NOVEMBER 6, 2015



Join Paul & Renee Hodes in New York State for their Second Annual Event

Dine and Dance to End AHC is a social evening of dinner dancing, and fundraising in honor of their daughter Lisa. Attendance at the event, a 50/50 Raffle, and general donations raise funds that go directly to funding research that will bring **all AHC kids closer to a treatment or a cure.**

For more information go to:
<http://ahckids.org/dinedance/>

AHCF Board of Directors

- | | | | | | |
|----------------|---------------|--------------------|-----------------|-------------|---------------------|
| Gene Andrasco | Shannon Berta | Sharon Ciccodicola | Lynn Egan | Bill Gerber | Renee Hodes |
| Josh Marszalek | Vicky Platt | Carol Presunka | Suzanne Roberts | | Julie Wright-Rivera |

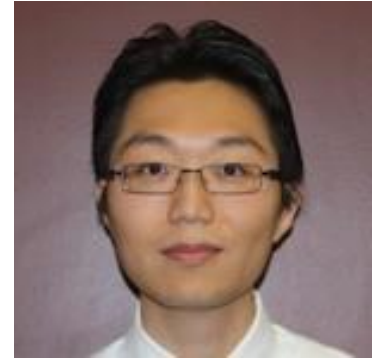
AHCF Medical Advisory Board Expands with Excellent Addition from the University of Chicago

The AHC community welcomes Dr. Sho Yano

The AHC Foundation Board of Directors is pleased to announce that Dr. Sho Yano has accepted a chair with the AHCF Medical Advisory Board.

Dr. Yano completed his MD at the University of Chicago Pritzker School of Medicine with a PhD in molecular genetics and cell biology. He is currently at the University of Chicago Comer Children's Hospital and is training as a pediatric neurology fellow.

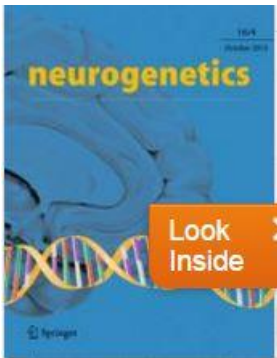
In August, Dr. Yano presented an abstract and did an oral presentation at the ATP1A3 Symposium on "Fever-induced paroxysmal weakness and encephalopathy: a new phenotype of ATP1A3 mutation".



In the future, he hopes to pursue research to understand the molecular basis of neurological disorders as an essential step toward effective treatment. Please join us in welcoming him to the AHC community!

Research from International Team of Researchers Just Published this Month

Announcing work from an AHC mouse model



An interesting article authored by doctors from Canada and the United Kingdom was published this month in the journal, *Neurogenetics*.

The article found that missense mutations in ATP1A3 substantially reduce Na⁺,K⁺-ATPase α₃ activity. They show that Myshkin mice carrying a wild-type *Atp1a3* transgene that confers a 16 % increase in brain-specific total Na⁺,K⁺-ATPase activity show significant phenotypic improvements compared with non-transgenic Myshkin mice. They conclude that interventions to increase the activity of wild-type Na⁺,K⁺-ATPase α₃ in AHC patients should be investigated further.

A copy of the article can be downloaded at:

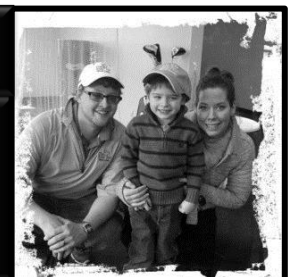
<http://link.springer.com/article/10.1007%2Fs10048-015-0461-1>



WORD FROM THE WEBSITE

"This year, with great pride, he jumped with both feet off the ground for the first time. More importantly, he is happy."

Rory Greenwood with this parents Rik and Stacy



www.ahckids.org



DONATE

\$10 a month
can help find a cure



VOLUNTEER

Sign up
online today



EMAIL

Stay up-to-date
on Mission news



CONNECT

Connect with the
Mission online



www.ahckids.org