

AHCF Board Member Invited to Speak

Rare disease talk continued

I concluded by letting them all know that when they become doctors and see these patients during a 20-30 minute office visit, keep in mind that the struggles the families face go on beyond that visit on a daily basis.

The students were very engaged and asked several questions touching on current medicines used and how we respond to our child when asked why they have AHC.

We were honored to be invited to this event by Harmony 4 Hope and appreciate their ongoing support of the AHCF. They are working on other events like this at other major teaching hospitals in Chicago to continue to raise awareness for rare diseases.

In addition to presenting to the medical students, we also visited Dr. Al George, the head of the Pharmacology Department at Northwestern University. Dr. George is working in collaboration with Dr. Kevin Ess at Vanderbilt on research that is crucial to finding treatment options for AHC patients. The fourth phase of this research was just funded by the AHCF, so it was exciting to see how the funding was being implemented.

During the visit we discussed some of the work taking place at both universities including a computer model of the ATP1A3 gene that is used to simulate the impact of thousands of pharmacologic compounds, which significantly reduces the time needed to identify potentially useful compounds.



We also met with a few members of Dr. George's staff who are working on different aspects of the research. Dr. George is actively pursuing developing a colony of mice with AHC to take the testing to the next level and move closer to clinical trials.

We appreciate Dr. George inviting us to visit his lab and talking to us about the exciting progress that the teams have accomplished over the last few years. We were encouraged by his optimism and the plans for the future testing.



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We Give Thanks for
Your Support and Generosity

Accelerate Research for an AHC Treatment

Share the Mission this Season

Once again, the AHCF is thrilled to participate in the national phenomenon known as GivingTuesday.



GivingTuesday kicks off the charitable season when we celebrate the generosity and support of our community during the past year.

This year, our campaign is to raise **\$60,000 to accelerate Phase IV research already underway at Vanderbilt & Northwestern Universities**. By doing so, we will speed up the time it takes to find a treatment. Treatments that will help stop these horrible AHC episodes from attacking our loved ones.

There is also the opportunity to donate to the foundation any time you shop on Amazon.com. Simply go to **Amazon Smile** and designate AHC Foundation as your charity of choice. Amazon will generously share a portion of the proceeds with the AHCF. You have access to all of Amazon's merchandise, but at a separate website. Simply go to: www.Smile.Amazon.com

amazon smile Try Prime **ahcf**

AmazonSmile is a simple and automatic way for you to support the AHCF 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

Please join us in sharing our mission of ending AHC while having some fun at the same time.

Watch for more ways to spread the word about GivingTuesday and jump onto www.smile.amazon.com when you begin your holiday shopping.

Thanks for your help.

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

Foundation's Great Work Recognized with GuideStar's Silver Seal

AHCF has achieved the **GuideStar Nonprofit Profile Silver level seal**, a leading symbol of transparency and accountability provided by GuideStar, the world's largest source of information on nonprofits. The logo demonstrates AHCF's deep commitment to nonprofit transparency and accountability.



We hope you will check out this honor and be proud of the work everyone did to help achieve this milestone.

<http://www.guidestar.org/organizations/38-3225425/alternating-hemiplegia-childhood-foundation.aspx>

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

Second Most Trusted Rating Seal, after the Better Business Bureau, Achieved for 2015

AHCF Receives the GreatNonprofits Seal



Thanks to all of our supporters, we have earned the Great Non Profits seal for the 5th year in a row!

Great Non Profits gives a voice to the experiences of clients of nonprofits, volunteers, and involved donors. It is a leading provider of reviews and ratings of nonprofit organizations throughout the U.S. Receiving this seal for the fifth year in a row is a great honor.

We encourage reviews all year long and appreciate the time you set aside to let us know how we are doing. For more details see: <http://greatnonprofits.org/org/alternating-hemiplegia-of-childhood-foundation-inc>

Important Research Looking for AHC Adults to Participate in Project with Dr. Allison Brashear

AHC patient study begins at Wake Forest University



AHC patients who are 18 years or older are invited to participate in a research study at Wake Forest University called:

Longitudinal Studies of the Variable Phenotypic Presentations of Rapid-Onset Dystonia-Parkinsonism and Alternating Hemiplegia of Childhood.

It is a collaborative study with Rapid Dystonia Parkinsonism patients and the principal investigator is Dr. Allison Brashear. You must have the ability to travel to Winston-Salem, NC (travel and lodging paid for by Wake Forest).

Study procedures include:

- Blood draw or saliva sample (even if you have had past genetic testing)
- Patient history
- Family history
- Videotaped movement disorder exam
- Neuropsychological assessment
- Some patients will be asked to undergo MRI of the brain

The data that is collected will help lay the groundwork for developing future drug treatments for patients with ATP1A3 diseases.

For more information go to: website: <https://www.atp1a3diseases.org/>

Or contact: Charlotte Miller, RN, CCRC, ATP1A3 Diseases Project Manager
chmiller@wakehealth.edu



Dr. Allison Brashear
Wake Forest Univ.