



One Mission: End AHC

# INSIDER'S EDGE

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

SEPTEMBER 2014

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

*Top International Researchers Join AHCF*

## Collaborations foster ground breaking research

With completion of the AHCF Family meeting in Minneapolis this past June, it became increasingly clear that broad collaborative efforts in AHC research and awareness are needed.

With that in mind, the Medical Advisory Board (MAB) extended two positions to international researchers who have shown a substantial commitment to patients and families affected by AHC.



**Dr. Sasaki**  
Japan

The MAB is pleased to announce that Drs. Hendrik Rosewich and Masayuki Sasaki have agreed to serve as international representatives on the MAB.

**Drs. Rosewich and Sasaki have proven exceptional in their scientific contributions to the field of AHC and the commitment they showed in traveling to the North American meeting was greatly appreciated. The MAB will be well served by their experience and insight!**



**Dr. Rosewich**  
Germany

*Reports are in from 3<sup>rd</sup> Symposium on ATP1A3 in Disease*

## Need for research funding is great

As a symposium sponsor, the AHC Foundation was proud to once again support this great scientific gathering. The overwhelming message from the meeting was that while we wait for their existing work to be published, huge amounts of money will be needed to continue moving forward.



**Symposium Participants**

**Researchers who presented their findings in Lunteren will need funding to continue AHC research.**

Anita Aperia (Sweden) ■ Allison Brashear (US) ■ Alfred George (US) ■ David Goldstein (US) ■ Alan Fryer (UK) ■ Fiorella Gurrieri (Italy) ■ Karin Lykke Hartmann (Denmark) ■ Erin Heinzen (US) ■ Mohamed Mikati (US) ■ Sona Nevšimalová (Czech Rep) ■ Steve Petrou (Australia) ■ Henrik Rosewich (Germany) ■ Masayuki Sasaki (Japan) ■ Sanjay Sisodiya (UK) ■ Kathy Sweadner (US) ■ Arn van den Maagdenberg (Netherlands) ■ Natascia Vedovato (UK) ■ Bente Vilsen (Denmark) ■ Karl Weigand (Netherlands)

### Upcoming Events

10/6/14

Executive Committee Meeting

10/15/14

Fundraising Committee Meeting

10/20/14

Board of Directors Meeting

10/22/14 - 10/25/14

Child Neurology Society Annual Meeting

11/7/14

Dine & Dance to End AHC

11/5/14

Fundraising Committee 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)

*Midwest families step up for AHC Research*

## Two walks continue AHC fundraising success

On September 27<sup>th</sup>, the **Hope for Connor & Kids - Race for Research and AHC!** was held in Neola, Iowa. The day was a huge success and we thank ALL of YOU who have helped in the past and continue to support the AHC Foundation.



The **9<sup>th</sup> Annual Chicago Walk** was held on Sunday, September 21<sup>st</sup>. Kiley Andrasco and Emma Platt were joined by Dr. Silver and Dr. George as well as several local AHC families. With 25% more people walking and checks still rolling in, this is sure to be the best year ever. Thanks to everyone who came out!

*Anniversary Inspires Donation*

## A rockin' good time

To celebrate a 14 year business anniversary, Will Eastman played a special 6 hour set spinning favorite tunes at the **U Street Music Hall on September 20<sup>th</sup>**. All of the admission proceeds from the evening were generously donated to the AHC Foundation.

This cause is near and dear to DJ and U Hall co-owner Will Eastman's heart because his sister-in-law, Caroline, suffers from the disease.

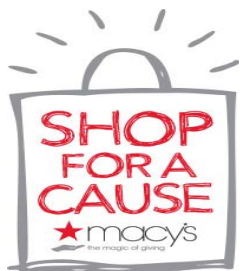
Congrats to Will and his partners on your wonderful business success and thank you for thinking of AHC patients during your celebration!



### AHC Mini Fact

Although the number of patients with AHC has been estimated at 1 in 1 million births, variability in clinical presentation, lack of awareness of the disease, and misdiagnosis may contribute to an underestimation of the true number of AHC patients.

**Pediatrics**  
March 2009  
Vol. 123, No. 3  
Sweeney, Silver,  
Gerard-Blanluet,  
Pedespan,  
Renault,  
Arzimanoglou,  
Lewelt, Reyna &  
Swoboda



*Shopping for an End to AHC*

## Families come together in August

Thanks to Renee Hodes for organizing the successful **Macy's Shop for a Cause** day in August. Eight families joined in the fun and helped raise \$1050 for AHC research. Be sure to join us next year at Macy's!

**Stay Connected**



**Words of Wisdom**

**"We may encounter many defeats but we must not be defeated." Maya Angelou**



*AHC Community Mourns*

## In loving memory of Ryleigh Hart

On Sunday September 14th, Ryleigh Marie Hart, age 4, of Three Rivers, Michigan passed away suddenly at Bronson Methodist Hospital. The daughter of Austin and Becky Hart, Ryleigh died of complications from an infection which affected her ability to breath.

Ryleigh was born on November 13, 2009 in Kalamazoo, Michigan. Ryleigh traveled to fundraising events, in and out of Michigan, and was a shining presence at AHC Family Meetings. She had a large support network and was loved by everyone who met her.

Over the last two years, the west Michigan community rallied around Ryleigh by supporting two softball tournaments her family held to raise money and awareness of AHC. She will be greatly missed by all who had the privilege of meeting her.

For those wishing to send condolences to Becky and Austin, you may send them to the foundation office and we will forward them on to the family.



Condolences may be mailed to:  
**AHC Foundation**  
 2000 Town Center, Suite 1900  
 Southfield, Michigan 48075



### VOLUNTEER

Your help is needed to end AHC.

The skills you have will help the foundation achieve our goal of ending AHC.

The amount of time you do have will make a difference in the lives of people with AHC.

Volunteering is as simple as saying, "I want to help!"

To volunteer email Lynn Egan at [lynn@ahckids.org](mailto:lynn@ahckids.org)

*Community Comes Together*

## Honoring our children through images



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### AHCF Medical Advisory Board Updates

## Matt Sweney, MD

As the new Chair of the Medical Advisory Board, I would like to start by saying thank you to the AHC Executive Board as well as the AHC community for the opportunity to contribute in such a meaningful way.

For the past 8 years I have seen wonderful progress unfold in the field of AHC and ATP1A3-related research. I am hopeful the future holds even greater news! It is the goal of my tenure as chair to bring the proceedings of the MAB to the AHC community in a fashion that is straightforward and useful. In doing so, I intend to call on the considerable talents and experience of our existing MAB members.

Assisting me in this process will be Dr. Kenneth Silver, Vice Chair of the MAB, and long-time contributor to the AHC Foundation. Over the course of his career, Dr. Silver has served as one of the pioneers in AHC-related research as well as a committed member of the MAB. I will be drawing on his extensive experience as the MAB helps to move AHC research forward.



Lastly, as I mentioned above, I feel it is important for the MAB to alert families to tools that might be useful in the care of their child with AHC. One important resource that has helped considerably in the care of patients with epilepsy is [www.seizuretracker.com](http://www.seizuretracker.com).



This web-based application allows easy, reliable event tracking through your smartphone. It is great for picking up on subtle patterns, effects of medications, and possible triggers in challenging, unpredictable disorders like AHC.

Additionally, the video interface allows you capture an event in the moment, making it easier for physicians and care providers to see an episode firsthand. Please don't let the name mislead you; I assure you the program is for more than just seizures!

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**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.

### Learning Opportunity

## Dystonia Overview & Treatment Options

### Dr. Allison Brashear

If you didn't have the opportunity to hear her speak at the AHCF Family Meeting this past June, be sure to join a free webinar.

### The Dystonia Medical Research Foundation

is hosting a webinar on September 30<sup>th</sup>, 2014 at 7:00pm to 8:00pm.

This is a special opportunity to hear from movement disorder experts from Wake Forest Baptist Health in a free online webinar about dystonia and treatment options.

Speakers include:  
Allison Brashear  
Ihtsham ul Haq  
Jessica Tate

Click here to register  
<http://www.dystonia-foundation.org/site/event/8047>



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

Vicky Platt at  
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