



# One Mission: End AHC!



YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER

May 2016

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

## AHCF in ACTION

### Celebrate the Kids This July at the AHCF Family Meeting

The AHC Foundation invites everyone in the AHC community to join us this July for an **interactive Family Meeting in** Indianapolis, Indiana. It focuses on the latest information on AHC and potential treatments while providing multiple opportunities to **make new friends in our ever expanding community.**



**Hear direct from an AHC mom how valuable this experience can be.**

Christine Vona recently shared with us why she has attended the AHCF Family meetings. **The Indianapolis Meeting will be her 8th!** Thank you Christine, for sharing the value you receive personally with our community.

From Christine – “This is my 8th family meeting. I love to go to the family meetings.

#### **First, I get to see all the medical experts.**

They get to evaluate Kathleen each visit. They see her progress; I get to ask vital questions that I cannot get anywhere else about my daughter and learn about the latest research.



Over the last 4 family meetings the research has exploded, **new information** about the identified gene ATP1A3 now has **new possibilities** about research toward treatments.

Her presence at each family meeting and evaluation increased the growing knowledge about AHC. **This has allowed Kathleen to be a small part of the entire puzzle that helps the medical experts find out more and more about AHC.** I am proud to be a part of this research and understanding of AHC.

#### **Second, meeting AHC families from all over the world is amazing.**

No other place in the world will you be around parents and care givers that know exactly what you are going through with episodes, behavior issues and learning disabilities. This is a place to learn, listen, cry and laugh about our children only to come out of it with more learning tools for school teachers and therapists, new information to bring back to your personal doctors and finally a list of new parent resources and friends.”

**Sign up NOW to experience this amazing gathering of wonderful AHC families and experts.**

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

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

**AHCF in ACTION****AHCF Family Meeting: The Best Access to AHC Information****Universities Represented Include:**

Columbia University  
University of Chicago  
Vanderbilt University

Harvard University  
University of Southern California

Northwestern University  
University of Utah

**Professionals Available to You During the Meeting Include:**

Attorneys  
Doctors

Behavior Therapist  
Researchers

Clinicians  
Therapists

Counselors

**Topics for Discussion Will Include:**

AHC History  
Cannabidiol study review  
Getting ready for clinical trials  
Estate Planning  
Round table discussions  
Dr. George updates on drug and mice research at Northwestern  
Dr. Heinzen & Dr. Goldstein Columbia research update

Primer on ATP1A3  
Behavior management  
Epilepsy medications  
Specialized PT & OT techniques

Dystonia management  
Potty training  
Managing relationships  
Sibling support

**PATH TO A CURE****Duke Research Team Shares Treatment Option for AHC**

On April 16, 2016, an article was published in the journal *Neurology* from a team of doctors at Duke University. The title of the article is, “**Effects of Vagal Nerve Stimulation in Alternating Hemiplegia of Childhood.**”



**The objective of the project was to assess the efficacy of vagal nerve stimulation (VNS) to modulate epilepsy and other paroxysmal spells of AHC.**

Data was obtained through retrospective and prospective review of medical records and parent-reported accounts of seizures and AHC spells of **four patients with AHC implanted with VNS** for refractory seizures. Initial response to VNS was determined after 8 weeks of therapy without change in medication. Patients were followed for responses for at least 12 months up to 3 years.

The article concludes that preliminary experience with VNS suggests that it is well tolerated and has shown **promising results in the control of seizures as well as hemiplegia and dystonia spells** associated with AHC.

**To read a copy of the abstract, go to:**

[http://www.neurology.org/content/86/16\\_Supplement/I15.001.short?sid=53c23b4b-5a8e-404d-9dc6-60cf170711c3](http://www.neurology.org/content/86/16_Supplement/I15.001.short?sid=53c23b4b-5a8e-404d-9dc6-60cf170711c3)

## AHCF in ACTION

### Family Meeting Clinic Appointments

Come to the Family Meeting this year **to schedule an appointment with a team of doctors** with expertise in AHC and other ATP1A3 related neurologic syndromes. They will be available to meet with families for informal consultations on Wednesday July 13th and Thursday July 14th.

**Our goal this year is to make these visits more tailored to the individual needs of each family.**

Some visits may focus on **genetics counseling** and others may focus on **concerns with new symptoms** your family member may be experiencing, or simply to **seek an opinion** about whether the current care you are receiving seems appropriate.

Although these visits are not formal medical evaluations, you'll be provided with informal recommendations to discuss with your neurologist or primary care physician once you return home.

No information collected during the meeting will be included in the AHCF Clinical Registry or Redcap (Research Electronic Data Capture) Database unless you previously provided permission for us to record such data. If you are interested in participating in more formal data collecting, we will contact you in the future regarding research opportunities.

**To request an AHCF Family Meeting Clinic appointment,**  
email Dr. Mario Merida with your contact information: MRMERIDA@mgh.harvard.edu



**JUNE 23RD:**  
\$12  
GA TICKET  
GADES GROUP HAT

**JULY 24TH:**  
\$10  
GA TICKET  
GADES GROUP HAT

**AUGUST 5TH:**  
\$12  
GA TICKET  
GADES GROUP HAT



### AHC & THE RENEGADES

Join us on  
 June 23rd at 7:05pm - Fireworks  
 July 24th at 5:05pm  
 August 5th at 7:05pm - Fireworks



Portions of the proceeds will benefit AHC Research

Purchase online at [GadesGroups.com](http://GadesGroups.com)  
 Password: AHC

TICKETS MUST BE PURCHASED BEFORE YOUR SELECTED GAME DATE AND CANNOT BE PURCHASED AT THE GATES

Questions? Call the Emery + Webb Dutchess Stadium Box Office at 845-838-0004

## DOUBLE the FUNdraising AHC Research Hits a Home Run

**Paul Hodes is planning to hit a grand slam for AHC research this summer.**

Paul once again set up **three great days** for the entire family to enjoy a fun outing with the Hudson Valley Renegades baseball team.

**What could be better than watching a great game while raising money for AHC research?**

Paul is taking orders or you can use link below to purchase tickets. Advanced ticket purchase is required and if you have any questions please contact Paul. **Hope to see you there.**

[http://hv1.glitnirticketing.com/hvticket/web/gpcaptc\\_ha.php?&refresh](http://hv1.glitnirticketing.com/hvticket/web/gpcaptc_ha.php?&refresh)

## AHCF in ACTION

### Family Meeting Neuro/Psych Clinic Appointments are Available



#### Neuro/Psych appointments are available at the AHCF Family Meeting this July.

The evaluation will involve completing a **standardized test** measure of intelligence, academics, attention/concentration, verbal fluency, verbal and visual memory, novel problem-solving, and language. It takes about one hour to do so.

The parent[s] will also be asked to **complete rating forms** on their child's adaptive [activities of daily living] functioning, behavior, and emotional functioning. All parents are encouraged to provide a flash drive so that results can be given to them prior to the end of the family meeting, but for those that cannot, the results will be sent via email within a week.

The research involves a **continuing study examining the neurocognitive, behavioral, adaptive, and emotional functioning of individuals**, mostly children and adolescents, with AHC. Partly, the research is looking to determine if there is a specific part of the brain that can be identified as being uniquely affected by AHC.

Research information may also be used **to track individuals as they get older** to see what pattern in progression, if there is any, of skill loss.

**To schedule your AHCF Neuro-Psych appointment,**  
email Sharon Ciccodicola [sharon@ahckids.org](mailto:sharon@ahckids.org)

## DOUBLE the FUNdraising 4<sup>th</sup> Annual Michigan Golf Scramble

Rik and Stacy Greenwood are happy to announce that the **4th Annual "One in a Million" Golf Scramble** in honor of Rory Greenwood is officially a go!

It's an open golf scramble **for all ages and player levels!** It takes place on August 7<sup>th</sup> at Binder Park Golf Course in Battle Creek, Michigan. Shotgun play starts at 8:30 am.

**Come out and join us for a day of fun to support the AHC Foundation!**

Please like and or share the heck out of the flyer as well as visit his honorarium at [www.ahckids.org/rory/](http://www.ahckids.org/rory/)



For your hard work and dedication, we thank our volunteers!



## ***PATH TO A CURE*** How Can I Participate in Research?

This is a question that the AHCF is frequently asked.

There are a variety of ways that people with AHC, and their family members, can support AHC research discoveries:

- **Attend the AHC Foundation Family Meeting** this July to meet specialists aware of current research and clinical trials.
- Join the **AHCF Global Registry**: Clinical information collected from patients can be helpful for future clinical studies.
- Search Online: [www.ahckids.org](http://www.ahckids.org) maintains the most up to date information on AHC research.
- **Donate**: Financial contributions to the AHCF support cutting-edge research.
- Register as a Brain Donor: **To learn more** about this program, contact Sharon Ciccodicola for details at [sharon@ahckids.org](mailto:sharon@ahckids.org).

Join Us

Join Us

**Registration for the family meeting is now open.**

We are also interested in sponsors and possibly vendors that would help pay for the conference and in return be able to demonstrate their product like special needs strollers, educational toys etc... Do you have any suggestions for who might be interested in doing this? Would you be willing to check them out?

Lastly, we would really like to celebrate the kids and for this we need your help. We want to highlight things they love to do, their successes, and what makes them happy. If you would like to share any of your videos or photos which tell a little bit about them, please let us know by the end of April.

**Please don't hesitate to register, comment, or share you memories.**

Contact Lynn at [lynn@ahckids.org](mailto:lynn@ahckids.org) or 650-796-1910 or Sharon at [sharon@ahckids.org](mailto:sharon@ahckids.org) or 313-663-7772.

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

**DONATE**

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

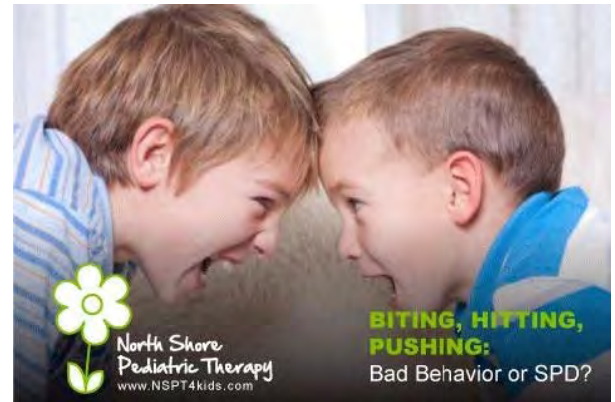
**DONATE**

## INFO EXCHANGE

### Biting, Hitting and Pushing: Bad Behavior or Sensory Processing Disorder?

Kate Mulry, of North Shore Pediatric Therapy in Illinois, posted an interesting article on May 13, 2016.

**The topic: how to tell the difference between sensory system issues and bad behavior.**



**Parents and teachers often ask if a child's sensory processing is causing them to behave badly in school.** "Bad behavior" manifests in many ways: kicking or hitting peers, biting friends, spitting, or yelling at others. In some cases, the child's sensory system may be to blame. In others, bad behavior could be contributed to the child seeking out attention, or avoiding work or non-preferred play.

When a child's nervous system **cannot respond logically to incoming sensory input** (such as loud talking in the cafeteria), the result may cause the child to appear disorganized, clumsy, or disobedient.

Oftentimes, children who are **seeking out movement (vestibular input) or body position (proprioceptive input)** are often the children who crave bear hugs or body squeezes. These are the climbers, the explorers, and the daredevils as they are attempting to seek out extra information from the environment to feel more organized. When they are not given these opportunities, they may resort to inefficient ways to help seek out information which may manifest into tackling, hitting or biting friends.

Behavior, which can be defined as **the way in which one acts or conducts oneself**, especially toward others, often is the result of a conglomeration of events. For example, a child's bad behavior may be a response to a negative sensory experience, or it may be the child's way of receiving more attention from parents, teachers and friends, or it may be both.

**There is no easy solution for recognizing the difference between bad behavior and sensory processing disorder.** Oftentimes, parents and teachers may need to take each event on a case-by-case basis to determine whether or not the breakdown occurred as a result of a sensory processing difficulty. To help decipher the difference between the two, it is recommended that you keep track of the specific behaviors in a journal to help identify any triggers or common events that provoke the child and cause the disruption.

To view the entire post, go to  
[www.nspt4kids.com](http://www.nspt4kids.com)

	<p><b>The AHC Foundation</b>  <b>The First Website for AHC Information</b>  <b>The One Place for All Things AHC</b>  <b>All One Word</b></p> <p><a href="http://www.ahckids.org">www.ahckids.org</a>  <b>One Mission: End AHC</b></p>
<a href="http://www.ahckids.org">www.ahckids.org</a>	<a href="http://www.ahckids.org">www.ahckids.org</a> <a href="http://www.ahckids.org">www.ahckids.org</a>

## ***INFO EXCHANGE***

### **529A Accounts Let Disabled Save Without Risk to Government Aid**

On May 6<sup>th</sup>, Ann Carrns wrote an article in the *New York Times* providing an update on a long-awaited benefit for people with AHC. People with disabilities will be able to open new, **tax-free savings accounts** under at least two programs offered nationally this summer.

*The New York Times*

The state-sponsored accounts are known as **529 ABLE, or 529A**, accounts. Authorized in 2014 by the Achieving a Better Life Experience Act (ABLE Act), the accounts are modeled loosely on 529 college savings accounts.

The main benefit of the new accounts is that they allow disabled people to accumulate significant savings **without jeopardizing their eligibility** for need-based government help like Supplemental Security Income or Medicaid. Disabled people, their families and friends can contribute as much as \$14,000 a year without putting federal benefits at risk.

**For more information, go to:** <http://www.nytimes.com/2016/05/07/your-money/529a-accounts-let-disabled-save-without-risk-to-government-aid.html>

# **HAPPY MEMORIAL DAY**

## **Memorial Day...**

...Is the day that's set aside to remember with gratitude and pride all those who served and died for our country and our freedom. May your day be filled with memories and peace.

**God Bless America**



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