



# One Mission: End AHC!



YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER

January 2018

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075



## **A MESSAGE FROM THE PRESIDENT** **Happy New Year to the AHC Community**

On behalf of the AHCF Board of Director's I wish to express our gratitude to all those who make the work of the AHCF possible by once again wishing everyone a happy and healthy New Year!

With the commitment and support of our supporters and donors, in 2018 we plan to continue to pursue innovative research that will lead us to new therapies and bring us closer to our goal of ending AHC.

We are providing opportunities for the next generation of investigators to do the preliminary work necessary to be competitive for more robust funding through federal programs - which is key to keeping talented investigators in the AHC research pipeline.

Progress is exciting and expensive. We look forward to working hard with you to make our mission a reality.

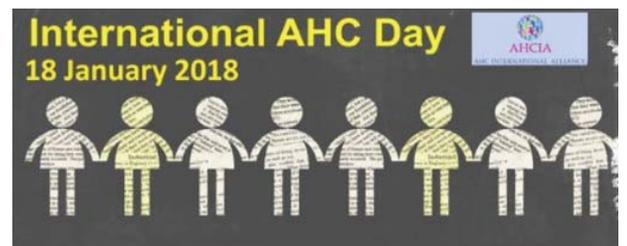
Lynn Egan  
President and Family Support

### **AHCF in ACTION**

## **International AHC Day Behavior Webinar: January 18 2018!**

The AHCF is inviting you to participate in **International AHC Day on January 18th** by joining our exciting webinar at 7:30 PM EST. The topic is: "Coping with Behavior of those affected with AHC."

**Alice Belgrade** MEd., LCPC, BCBA, our guest speaker is a **board certified behavior analyst and licensed clinical professional counselor**. Her experience spans more than 25 years in the fields of education and behavior analysis. She has also attended several AHCF Family Meetings as a guest speaker on behavior.



The first half of the webinar will be a presentation covering behavior issues special needs parents deal with, followed by a Q & A session with parents and caregivers. **The webinar is scheduled for 2 hours so we hope as many people as possible will get a chance to have their questions answered.**

Register in advance for this meeting at the link below. **After registering, you will receive a confirmation email containing information about joining the meeting. We look forward to celebrating with you this month.**

**<https://zoom.us/meeting/register/f2c8622595f000a366858a512be5123a>**

Through research, education and family support, we have **ONE MISSION: END AHC!**

## AHCF in ACTION

### Time to Get Excited about the AHCF in 2018

This is going to be a very exciting year for the AHC Foundation. So many amazing plans are starting to take shape and we hope you will be a part of as many of them as possible.

Whether you volunteer, help fundraise, participate in webinars, or join us in person at an event, we know you are in for an amazing time.



January 18, 2018	AHC Behavior Webinar with Alice Belgrade
February 2018	Valentine Exchange organized by Heather Gates
March 24, 2018	Dine & Dance to End AHC fundraiser in New York
June 24, 2018	AHCF Family Meeting in New Jersey
July 2018	Illinois Golf Outing
August 2018	One in a Million Golf Scramble in Michigan
September 2018	13 <sup>th</sup> Annual AHCF Chicago Walk
October 13 – 14, 2018	7 <sup>th</sup> Symposium on ATP1A3 in Disease in Chicago, IL (AHCF hosting foundation)
October 15 – 18, 2018	Child Neurology Society Meeting (AHCF exhibitor)
November 2018	AHCF Year End Campaign Kicks Off

## AHC INFO EXCHANGE

### ATP1A3-related Disorders: An Update from Europe



On December 21, 2017, an article in the *European Journal of Paediatric Neurology* was published with the title: **“ATP1A3-related Disorders: An Update.”** The article discusses how Alternating Hemiplegia of Childhood (AHC), Rapid-onset Dystonia Parkinsonism (RDP) and CAPOS syndrome (cerebellar ataxia, areflexia, pes cavus, optic atrophy, and sensorineural hearing loss) **are three distinct, yet partially overlapping clinical syndromes that have long been thought to be allelic disorders.**

Growing evidence suggests that AHC, RDP and CAPOS syndrome are part of a large and continuously expanding clinical spectrum and share some recurrent clinical features, such as abrupt-onset, asymmetric anatomical distribution and the presence of triggering factors, which are highly suggestive of ATP1A3 mutations. **In this review, they highlight the main clinical and genetic features of ATP1A3-related disorders focusing on shared and distinct features that can be helpful in clinical practice to individuate mutation carriers.**



## **AHC INTERNATIONAL INFORMATION**

### **AHC Family Makes Belfast Telegraph News**

On January 8, 2018, an article ran in the Belfast Telegraph News about an AHC family living in Ireland. It was about Naomi Alves-Areias, from Magheralin, who has AHC. The article also mentions how over the last four years the family has raised £20,000 towards helping those with AHC. Congratulations to the Alves-Areias family on their hard work on behalf of Naomi and the entire AHC community.

## **AHCF in ACTION**

### **Countdown to the 2018 AHCF Family Meeting has begun!**

Mark your calendars now and be sure to **join us in New Jersey June 22nd – 24th, 2018** as we come together for the AHCF Family Meeting **at the Renaissance Woodbridge Hotel in Iselin NJ.**



**The Marriott Renaissance** will be a perfect venue for our meeting with the “Kids” room right next to the conference room, plenty of space to stretch out, free parking and internet. There will be a block of rooms set aside for us at the **discounted rate of \$132 per standard room – \$152 suites** with a discounted breakfast buffet for \$5 for every member of your party.

Take the **free shuttle** to local attractions or to the Metropark Train station to visit the sites of New York City!



Look for many more details and announcements each month.

**This is your meeting** and the Family Meeting Committee would love to hear your suggestions for agenda items, activities, topics, speakers etc... Please email [lynn@ahckids.org](mailto:lynn@ahckids.org) or [sharon@ahckids.org](mailto:sharon@ahckids.org) with your thoughts or comments to make this the best meeting ever!

Start planning now and we'll see you all there!

## **AHC COMMUNITY CONNECTIONS**

### **AHCF Year End Campaign Success Because of You**

The AHCF 2017 Year End Campaign was a success because of the supporters, partners, donors and volunteers who came together to raise money for the foundation in November and December 2017.

Because of you, our programs continue to fund critical research as well as ensure access to information, the development of new resources, and the continuation of AHC-specific programming.

Thank you to everyone for all of your help with this campaign!



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

## AHC "HOW-TO" TIP OF THE MONTH

### How to Request a One-to-One Paraprofessional for Your Child



Throughout the year, the foundation will share helpful and interesting tips and ideas to help improve the quality of life of AHC families. The articles may focus on topics that occur in the home, at school, or in the community. If you have ideas for topics, please let us know.

When parents request a "one-to-one" aide or paraprofessional for their child with AHC, they are often frustrated by the school district's response. Even when the district agrees to their request, parents may be dissatisfied with the results. Parents need to know what they want, how to get it and the outcomes they expect.

Wayne Steedman is a partner at The Steedman Law Group with a practice devoted primarily to the representation of children with disabilities. He has represented his clients in administrative due process hearings and state and federal courts. Mr. Steedman has written many articles about special education law and advocacy. The following are excerpts from his article featured on [wrightslaw.com](http://wrightslaw.com).



Wayne Steedman

**How Can Parents Make a Case for a One-to-One Aide?** Remember that the school district is only required to provide the services, program, or placement that the child needs to receive a free appropriate public education (FAPE). The IEP is the vehicle by which the school delivers a FAPE. The child's IEP must identify the special education, related services, and supplementary aids and services the child needs to receive a FAPE.

In general, the decision about whether the school will provide your child with a one-to-one aide will be **determined by an evaluation of your child**. This evaluation may be conducted by school district personnel or by an evaluator in the private sector. Be sure the evaluation **provides a complete description of the child's unique educational needs** and makes it clear that the child requires an aide to receive a free appropriate public education.

As an old saying goes, "**It is never safe to assume.**" This warning also applies to assumptions about one-to-one aides. Does the child need one individual who is **assigned to work with the child during the entire day**? You need to **clarify the settings** in which the child needs the aide. Does the child need the **aide in specific classes or at specific times during the day**? It is important that the classroom teacher know about the aide's assignment so teacher does not "pull" the aide away to work with another child or group of children.

Does the child only need an **aide for transitions (class changes, etc.)**. If the child needs an aide for transitions, it is important that the child does not miss class time waiting for the aide to arrive. Schools assign one-to-one-aides to children for various reasons: **behavior management, instructional support, activities of daily living** (i.e. toileting, dressing, hygiene, etc.), **social skills training, task redirection, discreet trial training, etc.** If the child needs the support of a one-to-one-aide to receive a free appropriate public education, the aide should be assigned to the child, no matter what the task.

Since the evaluation describes the child's needs, the evaluation also defines the services, program and placement that the child needs.

The parents' success in obtaining a qualified aide will turn on how specifically the IEP defines the child's needs and how specifically the IEP defines the aide's role in addressing these needs.

**Your Dollars Matter Most.** Our foundation is 100% donor-supported. Help improve the quality of life of children with AHC today...with your donation.