



The AHC Foundation Newsletter

WORKING TO MEET OUR ONE MISSION: END AHC

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September 2018

AHCF IN ACTION

A Message from the Lynn Egan to You

September is **an exciting month** for many reasons. School is back in session and kids are connecting with old friends and making some new ones too. New school routines can sometimes bring anxiety, but can also be a time for growth and enjoyment.



September is also **an exciting time** because calendars start filling up with important events as the seasons starts to change from summer to fall. We certainly don't want to miss out on the opportunities that come around once a year.

This September an **exciting opportunity** occurred when two outstanding volunteers attended their first AHCF Board of Directors meeting. Heather Gates and April Hawk were officially elected to the board in August and are now active members of the board. **We are thrilled April and Heather joined the board in this new way.**

There are numerous exciting opportunities waiting for you too! Please join us in the next month or two as we begin working on a new phase in AHC research and step bolding into a new time for the AHC Community. **We look forward to you joining us and welcome you with open arms.**

JOIN THE MISSION – STEP UP TO END AHC

A Therapy is Waiting For You - Help Make it a Real Possibility

The AHCF is getting ready for **our biggest year end fundraising campaign** ever. We're planning to make the largest investment ever made in AHC research in 2019 and need your help.

Get ready for more information next month so you can help make the end of AHC a reality. If you can't wait, email Rik Greenwood at rik@ahckids.org and he'll get you started right away.



Are you ready to End AHC? Are you ready to leave AHC episodes behind you? **Are you ready to embrace a new future without AHC?** If your answer is yes to any of these questions it is time to **get ready to join the AHCF** and make this a reality for all families living with AHC.



To comment on the newsletter contact:
Vicky Platt at
vicky@ahckids.org



AHCF
Serving the
International
AHC community
since 1993



If you would like
to join the AHCF
Birthday Club
contact Dana Tasi
at: dtasi@snet.net

AHC INFO EXCHANGE

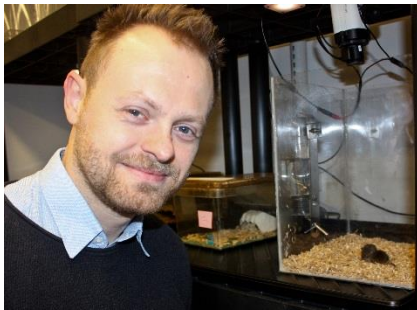
Dr. Kenneth Silver Co-Authors Research Article

In August, the *European Journal of Pediatric Neurology* released an article co-authored by Dr. Kenneth Silver titled, "Benign Nocturnal Alternating Hemiplegia of Childhood: A Clinical and Nomenclatural Reappraisal."

The article described the clinical spectrum of **benign nocturnal alternating hemiplegia of childhood** (BNAHC) and proposed an underlying genetic cause of this disorder.

They underscored the phenotypic homogeneity, including the self-limiting course of BNAHC episodes, and **suggested the condition be renamed** 'benign childhood hemiplegia during sleep' (BCHS). They proposed a role for the PRRT2 gene and the resulting neuronal hyperexcitability as one of its possible underpinning mechanisms and discussed the clinical similarities of BCHS with the recognized PRRT2-related disorders.

We wish to thank Dr. Silver and his fellow researchers for their work on this paper.



AHCF in ACTION You Made \$75,000 Grant Possible for Mouse Model Research

With your help, this month, the AHCF was able to award \$75,000 to **Northwestern University** to continue the research grant "Investigating Mouse Models of Alternating Hemiplegia of Childhood."

The grant, with Dr. Alfred George as Primary Investigator and Doctors Thomas Holm and Christopher Thompson, will cover experiments with two specific aims:

Specific Aim 1 is to determine the effects of various approved drugs and experimental compounds on AHC features in D801Y mice. Investigations will be conducted to determine if any specific drugs or experimental compounds can prevent cold-induced attacks of weakness and dystonia in D801Y mice. These studies may also lead to other drugs for treating AHC that are alternatives to, or complementary to, flunarizine.

Specific Aim 2 is to measure pump current in neurons from D801Y mice. These are important experiments to compare ATP1A3 function between mouse and human neurons, which can further validate the mouse as a model for the human disease.

Funding this grant is only possible because of the dedication and hard work of everyone fundraising to help End AHC. Together with these amazing researchers, we will get the job done!



Dr. Thomas Holm & Dr. Al George



Do You Shop on Amazon?

Great! Simply switch to **AmazonSmile** and the Amazon Foundation will donate 0.5% of the purchase price of eligible products to the AHCF.

This small switch can help raise money for AHC all year long and will cost you nothing extra.

Setting up **AHCF as your charity of choice** will make sure the funds come to us.



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**AHCF
Fun
Fact**

The AHCF has our GuideStar Silver Seal of Transparency which indicates that we have provided GuideStar key information in our Nonprofit Profile. By providing the information, we allow potential donors and funders to make educated decisions about the work we do. Check it out.

AHC COMMUNITY CONNECTIONS

International Meeting of Specialists

Coming to Chicago in October



The 7th Annual ATP1A3 in Disease Symposium will take place on October 13-14, 2018 at the Feinberg School of Medicine at Northwestern University in Chicago, Illinois.

Experts on Na⁺/K⁺-ATPase and ATP1A3-related diseases from all over the world were invited to attend this scientific meeting with a very impressive program.

Many of the **2018 organizing committee** members will be familiar to you. They include doctors: Allison Brashear, Kevin C. Ess, Alfred L. George, Kenneth Silver and Kathleen Sweadner. The AHCF is proud to be helping with local support of the meeting. Watch for more information to come out of this amazing meeting.



NEW AHC RESOURCES FOR YOU

AHC Bibliography Updated thru June 2018

Keeping up with the latest AHC research can be difficult. The **AHC Foundation just made it easier** for everyone to see what is being published on a variety of AHC-related topics.

On www.ahckids.org, you will find the **AHC Bibliography**. The bibliography is a list of articles selected to help parents locate information on a variety of topics related to this disorder. The topics include: **the Most Recent Articles (published within the last 6 months), ATP1A2, ATP1A3, Behavior, Dystonia, Epilepsy, Genetics, Medication, Migraine, Treatment, and General.**

The bibliography is **updated every quarter** and will provide a link to the abstract or full text of the article. Be sure to check back often for updates to the topics which interest you most.

While this bibliography is in no way complete, it is a comprehensive record of academic and scientific publications relevant to our community. If you have any questions about the bibliography, you can contact Vicky Platt at vicky@ahckids.org.

AHC FUNdraising

New Look to AHCF Fundraising Platform

The AHCF Fundraising Committee is proud to announce the addition of **the latest technology to our fundraising platform**. NeonCRM is a cloud-based software suite that provides tools built to support the work we do very day.

We will use Neon to manage fundraising, membership, events, and websites; **making it easier on families** to host successful events. Keep an eye out for this awesome upgrade.



**SHARE
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INFO**

If you know of friends, family members, teachers, or therapists who would benefit from reading our newsletter, share this issue with them & ask if you can send us their contact info.



To
volunteer
with the
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contact
Lynn Egan
at:
lynn@ahckids.org



AHCF
Donating
over
\$3 million
to help
fund
AHC
research



**Check out
our website**

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AHC EDUCATIONAL BRIEFS

A Brief Bit About Lower Limb Dystonia

This column is dedicated to sharing information on a variety of issues AHC patients may experience. It is meant to be a short introduction into a topic and increase awareness about the challenges involved in living with AHC.

Lower limb dystonia refers to **dystonic movements and postures in the leg, foot, and/or toes**. It may also be referred to as focal dystonia of the foot or leg.

Individuals often must adapt their gait while walking or running to compensate for the dystonic symptoms, and/or may require the assistance of mobility devices such as crutches, walkers, or wheelchairs. Ironically, symptoms of lower limb dystonia may occur while walking forwards, **but improve or disappear when walking backwards**.

Some individuals may be able to temporarily **lessen symptoms with a 'sensory trick'** to another part of the body, such as gently touching the face or head.

To learn more about living with dystonia, check out the Dystonia Medical Research Foundation.



AHC FUNdraising 13th Walk to End AHC was Held September 23rd in Lake Zurich, IL

With AHC families from the Midwest joining together, the **13th Annual AHCF Chicago Walk** was held on a beautiful Sunday afternoon at Paulus Park in Lake Zurich, Illinois.

This year, participants not only gathered to **increase awareness about AHC and raise money for research**, but to have a **fun day**. In addition to enjoying a walk around the lakefront, Culver's Custard, an amazing playground, and balloon animals from RC Juggle, everyone rocked-out the day and listened to The Rand Band.

As always, a big draw at the walk are **amazing raffle baskets** coordinated by Kelly Andrasco. She takes pulling donations together to a whole new level and brings in the money to End AHC.

The walk has been so successful over the years because of **an amazing group of volunteers**.

Together, AHC families and friends make raising money for research not only possible, but a lot of fun too. **Thanks everyone for your help.**



WHO
WHY
WHAT
WHEN
WHERE

Do you have questions about AHC?
Are you looking for people who understand life with AHC?
We're here to help.
www.ahckids.org



To verify the financial strength of our foundation, check out our status with GuideStar or Great NonProfits.

AHCF 2018

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Sharon Ciccodicola
Lynn Egan
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