

AHCF in ACTION **AHCF Family Meeting:** **The Best One Yet!**

After months and months of preparation the 2016 Family Meeting has come and gone, but what a meeting it was! It had a jammed packed agenda with topics of interest to everyone.



Families learned about the latest research and how to **manage some of the symptoms** associated with AHC, but they also **learned alternative therapies** and how to care for themselves as the caregiver and shared their insights in the roundtables. They learned **the importance of a Natural History Database** for clinical trials while listening intently to the hard facts of what it will take to get there and everyone was invited to participate.



These meetings would not be possible without the amazing efforts of the host family. In Indianapolis, **Laura and Josh Marszalek** planned an amazing experience for the children, families, speakers, and physicians.

We also wish to thank all of the volunteers who helped in the kid's room and throughout the meeting. You were patient, kind, helpful, and the rock stars of the meeting! **Thank you for taking great care of our kiddos!**

To everyone who helped, thank you for taking on this challenge and making everyone feel at home in Indiana.

During the meeting, **Lynn Egan** was elected to serve **three more years as president** of the AHCF.

Lynn remarked, "I am honored to continue to serve the AHC community. **My daughter is my inspiration** and I will do what needs to be done for her and for all those affect with AHC. I hope that in the next three years, we will have some answers and potential treatments ready for clinical trials".

Lynn has devoted over 24 years in providing family support and has been a part of building and shaping what the foundation is today. Thanks Lynn for your service!



Look for pictures and the presentations from the meeting to be up on our website soon.

AHCF in ACTION

AHCF Indianapolis Family Meeting: A Meeting of Firsts

The Family Meeting Planning Committee worked hard to offer **new features to this meeting**. The success of their efforts included a number of meeting firsts:

- 13 families joined us for the first time, even from as far away as New Zealand!
- It was the first time we had a mobile app and live webinar of the sessions, both a big hit.
- For the first time we had the families pick the presentation tracks that interested them to help set the agenda.
- The clinic held the 2 days before the meeting also utilized a consult model instead of a research model for the first time.
- We had a record number of sponsors.
- For the first time we invited vendors from 3 different groups who demonstrated their products to help make life easier for AHC patients.
- And for the first time we gathered outside at the famous Monument Circle for our group picture with over 140 family members, AHC kids, physicians, researchers and speakers in attendance.



PATH TO A CURE

Research Team Receives Check for Continuing Key AHC Project



The Alternating Hemiplegia of Childhood Foundation is pleased to announce **an award of \$250,000.00** was presented to Dr. Kevin C. Ess at Vanderbilt University Medical Center and Dr. Alfred George, Jr. at Northwestern University to continue their work on the project, “Molecular Physiology and Pharmacology of ATP1A3 Mutations in AHC”.

The project will build upon their previous work studying the functional impact of the three most common

mutations in the ATP1A3 gene. This will include testing the ability of several compounds identified through computer modeling to **restore pump function**. They will also use human stem cells that were differentiated into neurons to **study electrophysiological dysfunction** as well as the possible reversal of these abnormalities by **treatment with candidate compounds**.

Finally, they propose to use cutting edge genetic engineering techniques to either **introduce or correct ATP1A3 mutations in human neurons**. This will also include rigorous testing of the impact of the most common ATP1A3 mutations on neuronal physiology. **Congrats Dr. Ess and Dr. George!**

In Your Own Words! – “Had such a great time at the AHC Family Meeting hanging out with Keira's friends and their amazing parents, caregivers and siblings. Feeling super motivated to do whatever I can to help end this disease.”
Shannon Leigh

AHCF in ACTION**Dr. Andermann Honored** at Family Meeting for Service to AHC Community

At the Family Meeting in July, the AHCF Board of Directors was honored to present **Dr. Frederick Andermann** with the distinction of being elected the first **AHCF Medical Advisory Board Member Emeritus**.

The presentation was made during a luncheon where friends and families gathered to celebrate our achievements.



The distinction of being “Member Emeritus” acknowledges the numerous contributions of Dr. Andermann to the global AHC community upon the fulfillment/retirement from his professional obligations. This honor also recognizes the **continued need to benefit from the areas of his special expertise** and our desire to continue learning from his experiences.

Thank you Dr. Andermann for your service to our children and community!

AHCF in ACTION**Dr. Kenneth Silver Retires** and a New Award is Established

When Dr. Kenneth Silver announced his retirement from Comer Children’s Hospital at the University of Chicago this year, the AHC Foundation Board of Directors wanted to honor his **service and dedication** to the AHC Community in a special way.

In doing so, the directors established **the new Dr. Kenneth Silver Distinguished Service Award** in his honor.

The DKSDSA was established **in recognition of Dr. Silver’s many contributions to the AHC Community**.

A few of his achievements include service as the AHCF Medical Advisory Board Vice-Chair, Family Meeting Lecturer and Clinician, author of numerous scientific publications, and over twenty years of service as an AHC specialist.

The inaugural award was presented by Lynn Egan, AHCF President, to Dr. Kenneth Silver in Indianapolis, Indiana. In the future, **the Dr. Kenneth Silver Distinguished Service Award** will be presented to individuals in recognition of their commitment to, and profound impact upon, achieving the mission and goals of the AHC Foundation. The award will typically be presented in the year in which an AHCF Family Meeting is held.

Please join us in congratulating Dr. Andermann and Dr. Silver on their wonderful achievements.



AHCF in ACTION

Sponsors' Support = Family Meeting Success

The AHC Foundation is incredibly grateful to all of the **organizations, businesses, and people** who supported the 11th AHCF Family Meeting in Indianapolis.

Please join us in offering our thanks for their support and generosity.

Dr. J. Thomas & Amy Christie
 Mark & Lynn Egan
 Renee & Paul Hodes
 Dr. Christopher Hollon
 Robert & Rianne Keady
 Brian & Betsy Mader
 Mike & Cathy Pfeiffer
 Dr. Chris Romas
 Tony Parella & SVRA
 Barbara Teerkoski
 Dr. Naderi & Dr. Warren
 Katie & Steve Woo



Flower Power is BACK for 2016!

Order your bulbs for fall planting, and receive **Blooms for Hope** in the Spring.

Hope for a good new year, and Hope for our AHC kids.

50% of your purchase will come to us for use in funding research! Research that will make an impact on our mission to END AHC for all kids and their families.

Join us in planting our Blooms for Hope this year.

<http://www.flowerpowerfundraising.com/i/t/510783/p860no0UR153>



As our kiddos head back to school over the next several weeks, we wish you all many **happy days, good health, and a great education.**

Be sure to share those **first day photos** with us and tell us about your adventures in academia! Have fun!
 Post to our Facebook page, or send to joshua@ahckids.org



GOOD LUCK ON YOUR 1ST DAY!

AHC Community Mourns Loss of Young Canadian Friend Finnigan Danne



It is with great sadness that we share news of the passing of eleven year-old Finnigan Danne of Dundas, Ontario.

On Saturday, August 6th, an Amber Alert was issued in Ontario and a community-wide search was made to help find Finnigan. The Canadian Press reported that he may have been looking for a lost cat.

Finnigan's body was found on Sunday, August 7th within his community.

A community memorial was held where a somber crowd of more than 500 people held candles and balloons, in honor of Finnigan.

Finnigan's family; mom, Vanessa Velke, father, Neal Danne, and his brothers, Sebastian and Colin; all are in need of our support and well wishes.

Please join us in offering our condolences to Finnigan's family as they grieve his loss and deal with this unbelievable tragedy.



In lieu of flowers, the family asked for donations to the Alternating Hemiplegia of Childhood Foundation. The family will be informed of all donations made in honor of Finnigan.

PATH TO A CURE

Research Published in June and July Keeps AHC in the News

Maeshima S, Tsunoda T, Okamoto S, Ozeki Y, Sonoda S. "Alternating Hemiplegia with Ipsilateral Supranuclear Facial Palsy and Abducens Nerve Palsy Caused by Pontine Infarction." *Intern Med.* 2016, Vol. 55 No.15, pages 2073-5.

Holm TH, Lykke-Hartmann K. "Insights into the Pathology of the $\alpha 3$ Na(+)/K(+)-ATPase Ion Pump in Neurological Disorders; Lessons from Animal Models." *Front Physiol.* 2016 June. Vol. 14, No. 7, page 209.

Takeuchi M, Saito K, Kajimoto K, Nagatsuka K. "Successful Corticosteroid Treatment of Refractory Spontaneous Vasoconstriction of Extracranial Internal Carotid and Coronary Arteries." *Neurologist.* 2016 July. Vol. 21 No. 4, pages 55-7.

Kinoshita PF, Leite JA, Orellana AM, Vasconcelos AR, Quintas LE, Kawamoto EM, Scavone C. "The Influence of Na(+), K(+)-ATPase on Glutamate Signaling in Neurodegenerative Diseases and Senescence." *Front Physiol.* 2016 June. Vol. 2 No. 7, page 195.

Gurrieri F, Tiziano FD, Zampino G, Neri G. "Recognizable facial features in patients with alternating hemiplegia of childhood." *Am J Med Genet A.* 2016 Jun 17.

Nicita F, Travaglini L, Sabatini S, Garavaglia B, Panteghini C, Valeriani M, Bertini E, Nardocci N, Vigevano F, Capuano A. "Childhood-onset ATP1A3-related conditions: Report of two new cases of phenotypic spectrum." *Parkinsonism Relat Disord.* 2016 Jun 1.

PATH TO A CURE **Research Success** is in Need of Everyone's Help



Because of the hard work, determination, and dedication of the AHC Community, a truly amazing amount of progress has been made towards achieving our **One Mission: End AHC!**

While the AHCF is honored to have invested the funds trusted to us by the AHC Community, we are, unfortunately, **unable to fund additional, important and worthwhile research.** The projects that have been vetted and are currently waiting funding include:

COST	RECIPIENT	UNIV. / LOCATION	FOCUS
\$150,000	Dr. Kenneth Silver	Univ. of Chicago	Pharmaceutical Treatment
\$ 50,000	Dr. Kathryn Swoboda	Harvard Univ.	Database for Drug Trial Preparation
\$ 80,000	Dr. Kevin Ess	Vanderbilt Univ.	Accelerate Treatment Research
\$ 50,000	AHC Episode Tracker	International	Improve Quality of Life
\$ 10,000	Alice Belgrade	U.S. based	Behavior Study
\$340,000			



Help AHC patients benefit from these projects this year

Volunteer a little of your time towards achieving these goals and it will go a long way to **providing** real results for those with AHC

LET'S ACHIEVE FUNDRAISING SUCCESS TOGETHER!

DOUBLE the FUNdraising **Join 11th Annual Chicago Walk** to Support AHC Research



Everyone is invited to attend the **11th Annual Chicago Walk** on Sunday, September 18th from 10:00 am to 12:30 pm at Paulus Park in Lake Zurich, Illinois.

Come meet other AHC families, AHC doctors, researchers working on treatment options, members of the board, and dedicated supporters.

If you don't live in the area, invite your friends and family members to join in the fun. With over \$270,000 raised in the first 10 years, help us double that in the next five!

For more information please contact:
Vicky@gmail.com or Gene@ahckids.org

***DOUBLE the FUN*draining** 4th Annual Michigan Golf Scramble a Huge Success

Rik and Stacy Greenwood hosted the 4th Annual "One in a Million" Golf Scramble in honor of Rory Greenwood on August 7th at Binder Park Golf Course in Battle Creek, Michigan.



The Greenwood's did an excellent job of creating a fun and inspirational day not only for Rory, but for AHC friends and family. Traci Hall commented, "I always have so much fun, thank you for letting me be a part of this! Can't wait to see what happens in the future!"

The AHCF wishes to thank all of the hole sponsors, donors, scramble winners, and participants in the A creative "selfie" contest for making the day a success while raising money to help End AHC.

Thanks to all of our friends in Michigan.



***DOUBLE the FUN*draining** Illinois Golf Outing Breaks Records

A great big THANK YOU goes out to Terry and Barbara Sharo of Illinois. At the end of July, the grandparents of Kiley Andrasco hosted their 5th annual golf outing benefiting AHC research!

They had **105 golfers, 160 diners, raffles, and a silent auction**, all before storms moved through the area! The day was another huge success and a generous gift to AHC families everywhere.

The Sharos also keep busy in the fall by supporting the AHCF Chicago Walk. For the last ten years, the Sharos have volunteered during the walk and helped raise awareness for AHC research. We've seen them at Family Meetings and know them to be incredibly generous and kind.

Thank you Terry and Barbara for continuing to support our mission to End AHC!

***DOUBLE the FUN*draining** Paint, Wine & Party Pays Off

We offer our THANKS to Shannon Leigh for organizing a Sunday **Paint and Sip Party** at Saratoga Paint and Sip Studio in New York State.

Using your **artistic talents** to raise money for AHC is an amazing gift to us all.

Thanks to everyone who participated!



***DOUBLE the FUN*draising AHC Research Hits a Home Run**

Paul Hodes just finished another baseball season of fundraising for AHC research this summer.

On August 5th, Paul hosted the last of 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?

Ending AHC Forever!

Our deepest thanks go to Lisa, Renee, and Paul for their continued efforts of reaching our mission.

Thanks!



AHC & THE RENEGADES

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

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

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

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

Portions of the proceeds will benefit AHC Research

Purchase online at 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 845-838-0094

***DOUBLE the FUN*draising Kathryn's 5K Held in Indiana**

On July 2nd, the inaugural 5K for Kathryn was held in Indiana to honor Kathryn Marszalek, daughter of Laura and Josh Marszalek.

Josh reported that, "the run was a smashing success because Jillian Rodman and Wes Rodman created a monster of an event that will grow as we go!!"

The Indiana weather was beautiful, the trail was an awesome run through scenic Fort Harrison State Park, the participants had fun, and over \$5,000 was raised for AHCF research!

THANKS to everyone who participated in the event and special thanks to the Rodman family for organizing the run!



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