



AHCF NEWSLETTER

Alternating Hemiplegia of Childhood Foundation

SPRING 2011 Volume 20, No. 1



Editor Intro

Vicky Platt, Public Relations Committee Chair

It is with great enthusiasm that the spring 2011 AHCF NEWSLETTER is ready for distribution to our AHC family and friends. As you will see, it is full of information and updates from a busy foundation. We hope that you find this issue informative and helpful. Please direct any comments, suggestions, or questions to me, or any of my fellow board members. Thanks and enjoy.
Vicky Platt - vicky@ahckids.org

From the President

Jeff Wuchich, President

What an exciting year 2011 is shaping up to be for our community! There are a number of wonderful events and initiatives underway, as you will see in this newsletter. I'll provide a few highlights here.



- On the heels of the \$250,000 win in the Pepsi Refresh contest, critical genome sequencing work is underway that could at last shed some light on the root cause of AHC!
- The publicity wave that was generated from the contest helped increase awareness of AHC and identify new cases/connect with families who were unaware of the Foundation & the support network we are building.
- That support network is growing and adding new ways to provide resources to families who are coping with the challenges of AHC.
- A big part of that support will be our Family Meeting (in Raleigh, NC) in July.
- We are designating September as "AHC Awareness Month" with 7 walks scheduled to take place around the country, mostly on the weekend of September 17th. It is not too late to get one scheduled in your community. Email me jeff@ahckids.org or call 919.569.5200 and we'll get you plugged into our mentoring group & help you make your walk a success! We will have tools and resources to help as well.
- Our web site is undergoing an "extreme makeover"
- We will have a number of other fundraising events through the year
- We are adding to our Board and volunteer roster to handle these great happenings.

Please do read this newsletter in its entirety, and know that we are doing our very best to get to the cure. My phone/email inbox is always open for comments, concerns, suggestions, a shoulder to cry on, etc. Please know that I care about your AHC child as just as much as I do for my son Matthew. Together we will make life better for all our AHC kids. Hope to see you here in July!

Yours in Service,
Jeff Wuchich

jeff@ahckids.org

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Medical News

Updates on AHC Research at the University of Utah Dr. Sandra P. Reyna

Under the direction of Dr. Kathryn Swoboda's, The University of Utah Pediatric Motor Disorder Research team has been busy working on several current and upcoming projects for AHC. The clinical trial of Sodium Oxybate (SO) is now in its final stages with all of the six targeted participants enrolled. Four of the six participants have completed the entire one-year study and the process of validating and verifying the available data for each study participant is under way. We are continuing to follow-up with the remaining two active participants who have four to six months left in the maintenance

phase of the clinical trial.

The AHC online registry and participants enrolled in the Pediatric Motor Disorder study has continued to grow with 58 families now enrolled! We are also glad to report that 26 families have completed our AHC medical questionnaire, which is an increase from 17 completed last year. The AHC registry and medical questionnaire, have proven to be valuable tools in gaining a better understanding of the characteristics of AHC and in being able to contact families in the future about new treatments for AHC or studies for which they may be eligible. For more information about the AHC registry and Medical Questionnaire please visit our website at: <http://medicine.utah.edu/neurology/research/swoboda/ahc/registry.htm>

The search for the genetic basis for AHC received a significant boost with the award of the Pepsi Refresh grant. As genetic analysis continues to be more and more advanced, the new grant has allowed us to use the latest genetic sequencing technology available. With prior studies into AHC, we have attempted to do targeted analysis, looking for mutations in genes that have been identified in other better-understood diseases, as well as comparative genome and single nucleotide polymorphism arrays that could determine if an abnormal number of copies of a gene or highly variable (but not clearly abnormal) nucleotides are shared in children that have AHC. As yet, no answers have been found, despite extensive investigation. With the current technology, complete sequencing is finally available. As a result, we will have unparalleled resolution of each subject's genome. Theoretically, this should prevent any genetic mutation from being concealed (within the 3 billion nucleotide pairs in the human genome) and give us the best chance to find the cause (or causes) of AHC. However, the sequencing of each patient will generate massive amounts of data, which will take extensive analysis. Patience will be critical, but we are hopeful that this round of testing will give us our best chance yet at finding the answer.

We greatly appreciate your support and dedication to our efforts in moving AHC research forward.

Warm Regards,
Dr. Sandra P. Reyna
<http://medicine.utah.edu/neurology/research/swoboda/ahc>





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Living with AHC

Lynn Egan, Family Support Chair

It has been an amazing year since Kathleen graduated from high school. Purely by accident we found an adult education program that allowed Kathleen to continue with her studies. We found a wonderful aide to be with her each day. And, Kathleen is thriving!! It took a lot of searching, phone calls, questions and visiting many programs to find one that was appropriate for Kathleen.

In February 2009, we were informed that Kathleen passed the California High School Exit Exam (a requirement) and would not be able to stay another three years and attend the life skill classes that were available to her until her 21st birthday. While we were proud and thrilled with Kathleen’s achievement, we asked ourselves, “What do we do now?”

So, the search began and I soon discovered that not much existed, or, not what I thought would be best for Kathleen.

Kathleen was first recommended to a program that had day services, transition for young adults, life skills development, and vocational services. She was assessed for a week and didn’t like it at all. The next two programs were just out of the question.

Having exhausted all suitable and non-suitable programs, I called Kathleen’s case manager for more suggestions. However, he was on vacation and I was directed to the case manager on call. I explained what we had done so far and what I was looking to find. She listed various programs which I had already contacted or visited until she said, “Hope Services.” It sounded perfect! It was a work program and had adult education classes. So, the following day we visited Hope, but came away disappointed. The client needed to be totally independent! Kathleen needed an aide. What we didn’t realize was that Kathleen could attend the classes independent of the work program. Three weeks later, Kathleen started at Hope Services.



So, here we are! Her aide drives her to and from Hope, takes her to the library, the dog park, coffee (hot chocolate), and Carl’s Jr. We are very lucky to have found a great opportunity for Kathleen!!

AHCF Office
31250 Plymouth Rd
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Fundraising News

Jeff Wuchich, Fundraising Chair

This is an exciting year for the Foundation and fundraising.

- We received the first half of the \$250,000 from Pepsi and the second half will arrive in July.
- Fundraising activities were completed & more are planned:
 - Brendan O'Brien's Rickshaw Run across India in January. Brendan is Uncle to Katelyn in Ireland.

- Dave & Cindy Ryan's "Crazy for a Cure" variety show on February 5th raised \$11,000. They are parents to 15 year-old Michael.
- Brian Weiler hosted a Poker Tourney on February 26th. Brian's efforts made \$1586. Brian is Uncle to Austin Erpenbeck.
- Gara Sliwka: After running 1,000 miles in 2010 to raise money for the AHC Foundation, she has decided to bake in 2011 See: <http://www.runningfordel.com> for details. Gara is Aunt to Delaney Johnson.
- Richard George Thrift Store donates a portion of each sale to AHC. Richard is dad to Nicky George.
- April 14th Lake Travis Middle School, Austin, TX - Social Awareness Fair & Auction of Artistic pieces done by the students to honor Carter Wagner and AHC. These kids raised \$3000.00 for AHC!
- May 14th – Mollie Weiler Erpenbeck held a silent auction and party at the Drawbridge Inn in Fort Mitchell, KY. They made over \$35,000.
- May 18, 19 and 20 was the Sliwka's 1st Annual Spring Garage Sale Fundraiser for AHC and they raised approximately \$1,000. The Sliwka's are grandparents to Delaney Johnson.
- June 30th-Paul Hodes has arranged with the Hudson Valley Renegades (a minor league baseball team) to host three fundraisers for his daughter Lisa Marie on June 30th, July 19th and August 10th. A portion of each ticket sold will go to AHC.
- We've received money from memorials, United Way, Allstate Giving, non-uniform day to raise money for Rare Disease Day, test drive a Dodge day, jeans day @ work, Birthday Wishes through Causes and generous single donations from supporters!
- September is designated "AHC Awareness Month" with 7 walks planned around the country. It is not too late to get one going in your community. Please email me at jeff@ahckids.org.
- A special campaign aimed to create buzz is in the works for the fall.
- Most exciting is our ambitious, but very achievable, goal of **\$1,000,000 raised in 2011!** With your help we will make it! We welcome your ideas & participation.

Jeff Wuchich
jeff@ahckids.org

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Financial News

Jeff Wuchich, President

Great news happening on the Financial/Administrative front!

- As announced elsewhere in this newsletter, we have new Co-Treasurers: Gene Andrasco and Doug Morris.
- Renee Wuchich, CPA, did a phenomenal job (in my not so humble opinion) revamping our 990 so that not only is it acceptable to the IRS (as ours have been in the past), but also it is fit for transparency (published on our website as a great tool to attract larger donors/grants).
- We passed an interim budget of \$62,200 to take us from April 1, 2011-June 30, 2011 (copies available upon request). Our new Co-Treasurers are busy putting together our Fiscal 2011 budget to take us from July 1, 2011-June 30, 2012. This is huge, as we have not done budgets previously. This is part of our process improvement efforts to attract donors as well.
- We restated our By-Laws & Articles of Incorporation to make sure they are in line with IRS requirements to maintain our 501(c) (3) designation (another process improvement).
- We purchased Quick Books for Non-Profits and signed up for the Click & Pledge Donor Management/Payment Management system to automate our financial reporting capabilities. (yet another process improvement)
- We also will be applying to the BBB Charity Seal and Charity Navigator for evaluation and accreditation this next quarter that will let potential donors know we are an approved, worthy charity.



Moving forward Doug & Gene will be providing news in this section. We are grateful for their service.

Jeff Wuchich

jeff@ahckids.org

Supports for AHC PATIENTS

Lynn Egan, Family Support Chair

SureHands Lift and Care System

I wish I could have put a brick on Kathleen's head and kept her little forever. But, that is not what happened. She grew up.

In 2008, at 5'4" and 120 pounds, it was becoming increasingly difficult to lift Kathleen by myself and it was taking its toll on my body. It usually took two or three of us to lift Kathleen. So, we started looking for some way, or something, to

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move her around our home. That's when a co-worker told us about SureHands. After watching a DVD on how the lift worked, we realized that this system would work well for Kathleen; especially in an episode. We did research other types of lift systems, but decided SureHands would work the best.

It is ceiling mounted and starts in her bedroom, goes to the bathroom where there is a turn table that takes her to the toilet, into the shower and then into the family room. We finally had it installed in June 2010, after almost two years. During that time, we remodeled Kathleen's bedroom and bathroom and worked with the insurance company to approve coverage. After an appeal, the insurance company agreed to pay 60%.

It is amazing! The remote control allows us to move her from place to place and the unit can drop to the floor. Kathleen is now 5'6" and 140 pounds and I can move her with ease and know that neither of us will get hurt. Ironically, Kathleen calls her new ride, "drop zone" after an amusement park ride.

For more information, you can visit www.surehands.com.

Foundation News

The AHCF Board is excited to announce the addition of five new board members to the foundation. Please join us in welcoming them to the board.



Gene Andrasco and his wife Kelly are parents of two children, Ryan age 11 and Kiley age 9. Kiley has Alternating Hemiplegia of Childhood and was diagnosed when she was 20 months old. Gene has 20 years of corporate accounting and finance experience with Amoco Oil (BP), McDonald's Corporation and Kraft Foods Inc. He is currently a Finance Director for Kraft. Since 2006, he has helped coordinate the AHCF Chicago Walk and raise over \$130,000 for the AHCF. His primary responsibility is to coordinate the finances for the Walk, including collecting, recording, and submitting donations to AHCF, sending donation tax receipts, and soliciting sponsorships from local businesses.

Mollie Weiler Erpenbeck is a mother to three children, Ava, Owen, and Austin, and a wife to Eric. The family resides in Union, Kentucky. Austin was born in 2009 and was diagnosed with AHC at 5 months of age. She currently holds the position of Accounting VP for Intelligent Phone Systems, Inc., located in Newport, Kentucky. Mollie holds a bachelor's degree in business management and an associate's degree in dietetics. Mollie's hobbies include walking, cooking, wrapping gifts, and travelling.

Beverly Hensley moved to Raleigh, North Carolina from Dallas, Texas in 1985 and is originally from Syracuse, NY. She has two adult children, a son who resides in Merritt Island, Florida and a special needs daughter who resides at home with Beverly. Previously, Beverly worked for General Medical Corporation, Kaiser Permanente, and Umicor Marketing Service. Currently, Beverly is the Vice President of the Homeowners Board of Walden Woods Condominiums. She enjoys cooking, reading, yoga, and movies.

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Douglas Morris, married for 23+ years, is the father of two children with AHC, Haley and Caroline. Doug has served as an executive officer and board director for a Fortune 10 subsidiary. He has extensive international experience in culturally diverse countries in Asia and Europe and is an effective communicator of complex situations and problems to a diverse audience. Doug's financial planning and analysis experience includes supervising annual operating budget preparation for retail business units. His prior volunteer work includes the Special Olympics.

Mary Kay Riley is the parent of Nick, 21 years- old, who was diagnosed with AHC at age 2 ½. She currently lives in a suburb of Minneapolis along with Nick's dog, Max. Nick has an older brother Chris. Her main focus has been to help Nick become the best person he can and help him learn to live with AHC. Nick is completing his final year of school (transition) and will move to a day program in June. For 30 years, Mary Kay has worked at the Home Office of a life insurance company and held various positions from call center representative to department manager. Her last position there before taking early retirement was in the IT department as a designer, tester and trainer for the new administrative system the company was installing.



Help Needed!

Over the years we have received numerous offers to help with different areas of the Foundation. Most of the time it was difficult to utilize these offers and bring people on board because we had no real structure or avenues to implement the ideas suggested. Now the Foundation is on track, exploding with ideas, and is exploring numerous avenues to fulfill our mission statement. Our Board is strong and we have developed committees to tackle pressing issues as well as investigate various ways to spread awareness, increase research and support the families.

Now we need your help!

Family Support

If your interest lies in family support, creating ideas to help families connect, developing introductory and welcoming materials for new families, researching physical, social and developmental resources that would assist the kids and parents, please put your ideas into action and help us develop a support system to benefit the families and kids. Maybe you are interested in compiling a list of federal and state-by-state resources or a much needed registry of all of the AHC knowledgeable physicians/neurologists in the US? Please think about sharing your ideas and give some of your time to making AHCF a strong advocate for the families!

Please contact Lynn Egan at lynn@ahckids.org to become a volunteer on the Family Support Committee

Public Relations

If you have a passion for spreading the word about AHC, feel strongly about educating physicians/neurologists, teachers and caregivers, public and our legislature, please consider bringing your talents and energy to the Public Relations Committee. Maybe you would be good at utilizing and engaging the media, or developing a network of symposiums where we could advocate for AHC. We also need help creating informational materials, and work to develop a relationship with Eurordis and NORD. Within the Foundation you could help with the submission of articles for the Newsletter, or awareness campaigns or help with our social media and digital footprint!

Please contact Vicky Platt at vicky@ahckids.org to become a volunteer on the Public Relations Committee

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Fundraising

Calling all people that like to network, aren't afraid to ask for donations and love raising money!

The crux of our Mission Statement is to provide funds for research and find treatments and a cure for AHC. We need dedicated people willing to work together to identify potential fundraising opportunities, reach out to possible donors and create ideas to generate the kind of funding needed to accomplish this lofty goal. Once a goal is established and a campaign is launched, we need help developing strategic efforts to be successful. If you have held successful fundraisers in the past we also need you to help mentor first time fundraisers and create templates for various fundraising events that others can follow. [Please contact Jeff Wuchich at jeff@ahckids.org](mailto:jeff@ahckids.org) to become a volunteer on the Fundraising Committee

Please Note: Here at the Foundation our roles often overlap. We work together and expect support from each other in our efforts, so a project from one committee is very likely to generate assistance from the other committees.

Thanks for your consideration to help AHCF

Board of Directors

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