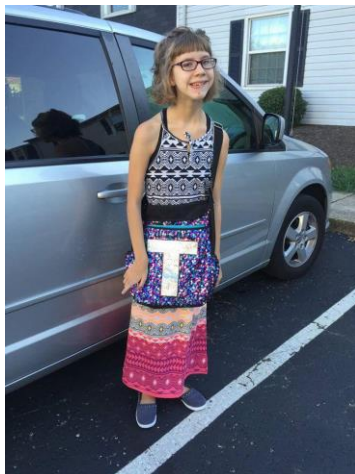


2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

Let's Give a Big Cheer for a New School Year

Good luck AHC students!

Over the last few weeks, some families have already made the giant leap into a new school year. And for others, the first day of classes are yet to come. We've seen some of those first day pictures posted on Facebook and are eagerly waiting for the rest to be posted over the next few weeks.



Trinity's first day of high school

This is an exciting time for our AHC students and families. Since these times can be stressful for some, this may also be a time with increased episodes or behavioral challenges. Let us find opportunities to enjoy these special moments and may we find inspiration in these words from Eleanor Roosevelt.

“We gain strength, and courage, and confidence by each experience in which we really stop to look fear in the face...we must do that which we think we cannot.”

We wish all students and families a very happy and healthy new school year!

Researchers Making Progress in Denmark

Update on Published Research

In the April 10, 2015 issue of *The Journal of Biological Chemistry*, researchers from Denmark published an article called, “Rescue of Na⁺ Affinity in Aspartate 928 Mutants of Na⁺,K⁺-ATPase by Secondary Mutation of Glutamate 314.”

Their research looked at how, “Na⁽⁺⁾,K⁽⁺⁾-ATPase binds Na⁽⁺⁾ at three transport sites denoted I, II, and III. They demonstrated that the asparagine substitution of the aspartate associated with site III found in patients with rapid-onset dystonia parkinsonism or alternating hemiplegia of childhood causes a dramatic reduction of Na⁽⁺⁾ affinity in the α 1-, α 2-, and α 3-isoforms of Na⁽⁺⁾,K⁽⁺⁾-ATPase, whereas other substitutions of this aspartate are much less disruptive.”



The research ultimately found that, “second-site mutation also improves Na⁽⁺⁾,K⁽⁺⁾ pump function in intact cells. Rescue of Na⁽⁺⁾ affinity and Na⁽⁺⁾ and K⁽⁺⁾ transport by second-site mutation is unique in the history of Na⁽⁺⁾,K⁽⁺⁾-ATPase and points to new possibilities for treatment of neurological patients carrying Na⁽⁺⁾,K⁽⁺⁾-ATPase mutations.”

You can purchase the full text of this article at: <http://www.jbc.org/content/290/15/9801.long>

Greenwood Family Hosts Great Event in August

Michigan volunteers are picture perfect!

On August 2nd, Rik and Stacy Greenwood held their **One in a Million Golf Scramble** at Binder Park in Battle Creek Michigan. This year, the Greenwoods went into the scramble hoping to beat their goal of raising \$5000 and doing something extra quirky for their golfers.

Rik had an idea to do a Selfie Challenge asking golfers to post pictures using the hashtags #1InAMillionGolf and #AHCf in order to win a cash prize. Not only did golfers document the great time they were having, they **helped spread awareness in the process by using social media.**



Tyler Asher and his team from Dark Horse Brewing Co. took the **winning picture.**



In addition to the golf scramble, a group of wonderful women offered to raffle off a quilt made beautifully in AHC colors. Melissa Holt, one of our most dedicated volunteers, won the quilt and seeing the look on her face when Rory picked the winning ticket was **just priceless.**

Overall, between the prize raffle, golf scramble, and quilt raffle, we were able to raise \$6,000 for research this year. Not only did we exceed our goal, but we were incredibly grateful to everyone who made it happen. The volunteers, and particularly, Traci Hall, Cathy Katz, the Tucker Family, and the Garver-Peevers family made this an incredible success.

While Rory spent days in an attack, he managed to make it out for lunch and really reminded us all why we put on this event. **The stress, excitement, and hours of planning were worth it after seeing the smile on his face and the funds we raised for research.** Each year it continues to grow and we are all looking forward to doing it again next year!



Kelly Andrasco and Pat Ahern Having Fun at the Rooftop

AHCF Cubs Rooftop Fundraiser Doesn't Play Around

Volunteers want to end AHC!

On Sunday, August 9th, Gene & Kelly Andrasco hosted an AHCF Cubs Rooftop Fundraiser during a Chicago Cubs vs. SF Giants baseball game.

The day included watching the Cubs raise the W flag, all-inclusive food and drink, a huge beer garden, two massive bars, skybox-style seating and room to get out of the sun.

It also was incredibly successful at increasing awareness about AHC while **raising money for research to help END AHC!**



VISIT
Indy

AHC
Foundation
Family
Meeting
*Save
the
Date*
July 13th –
July 17th
Indianapolis,
Indiana



Our thanks go out to Rik, Stacy, Gene, Kelly and all the volunteers who attended these events!



Five Part Series on Getting Diagnosed with AHC by Doug Morris

Part five: Acceptance: "It's going to be okay; I can't fight it, I may as well prepare for it."

This is the story of how one family went through various phases of learning about their children's AHC diagnosis to thriving in life.

Acceptance came when a high school classmate, now an MD, simply shared with me that even if the kids did not have AHC that something was still going on. Both girls were truly developmentally delayed and would benefit from special education services.

He was not telling me what I wanted to hear, but what I needed to hear. His comments were professional and realistic. That meant a lot. His comments helped me put the girls' condition in perspective and ground my reality. He coached me, very subtly, not to be fooled by people that would claim cures. His words served as a wakeup call to me. While hope is great for motivation, it's not much for advance planning in getting an expected positive outcome.

Acceptance did not mean that everything in our life is happy. But acceptance does mean that life moves forward and that we should live to the fullest, individually and as a family.

Humans are resilient and such are the traits of AHC kids and us parents. Developmental problems may include difficulties in fine and gross motor function, cognitive function, speech and language and even social interactions. These descriptors fit Haley and Caroline. There is one exception for Hayes, she can chat with you through a set of 20 questions and you can walk away feeling like a lifelong relative catching up at a long-overdue family reunion.

At age 23, Haley works part-time at Pearle Vision, volunteers working with pre-school kids, competes in various sports with swimming her favorite. Caroline attends school and volunteers at sporting events. **These days, both of our adult kids provide as much encouragement to us as we do for them.**

One of the AHCF goals is to provide the most current information about AHC to the newly informed and vulnerable parents. **AHCF provides support towards acceptance and into thriving as a family with all members living a fulfilling life.** Instead of going to the library, come to this AHCF website on the internet. This loving place is your initial, your best, and on-going provider of info, hope, and ultimately cures for our AHC kids.

Loss of Renowned French Pediatric Neurologist Felt Around the World

The AHCF Remembers Dr. Jean Aicardi

By Dr. Kenneth Silver
AHCF Medical Advisory Board Vice-Chair



The AHC Foundation is saddened by the passing of Dr. Jean Aicardi on August 3, 2015. Professor Jean Aicardi was the most distinguished and respected child neurologist. He was born in France and he received his medical education and neurology training there. He had the opportunity to do research training at Harvard Medical School and then later in his career became a visiting scientist at Miami Children's Hospital and honorary professor at the Institute of Child Health in London.

Continued on Page 6...

Foundation Coordinator Committed to Providing Quality Service to AHC Community for the Last Five Years

AHCF proud to continue helping families in need

Many of you already know **Sharon Ciccodicola** from her foundation emails, attendance at our Family Meetings, Facebook posts, or personal telephone conversations. For those of you who have never met Sharon, or are unfamiliar with her work, let us officially introduce her to you.

Sharon and her husband Pasquale first began volunteering with the Foundation in 2003. They helped in the office and with organizing fundraisers. Since **Sharon was a pediatric nurse with a special background in rare diseases**, she was totally intrigued by AHC since she never experienced any disorder like it.



In 2005, AHCF President Richard George asked Sharon to take on the role of Medical Liaison. Her role with the foundation expanded to include the history of the disorder and most importantly, the research that was promising and frustrating all at the same time.



During the next five years, the AHCF grew rapidly. As an international organization with families initially connecting through letters and phone calls, the internet helped us find families, share information, communicate more frequently, and accept donations more efficiently. The group of volunteers running the foundation found it necessary to create a position to handle foundation business and grow the organization.

In 2010, Sharon Ciccodicola accepted the position as the AHCF Foundation Coordinator (FC) and is an independent contractor, not an employee, of AHCF. First and foremost, the FC was a liaison between the families, the Board of Directors, various committees, physicians, and researchers. The FC receives all foundation mail, telephone calls, emails, and donations and directs them to the proper person for a response or action.

The FC reports daily to the foundation president and assists members of the board by providing them the information they need. This could be banking deposits, research information for a donor, statistics, history, or copies of foundation governing documents.

“Sharon has been a support for our family since day one. She was the first AHCF contact we met face to face when Rory was newly diagnosed and she continues to be our go-to when we need any questions answered. She is amazing.” Stacy Greenwood.

Committee meetings are set up. Fundraisers are supported. And, assistance with foundation projects (website development, parent directory, newsletter distribution, development of foundation policies, etc.) is provided whenever possible.

As a member of the Family Support Committee, the FC works with committee members to **provide crucial support to families struggling with AHC**. One of Sharon’s favorite tasks is helping plan the biennial AHCF Family Meeting.

Families and physicians from around the globe have contacted the AHCF for information, advice, and help. Sharon is usually the first person to get that call or email. Sharon has received calls and participated in meetings at a football stadium, airport, zoo, and concert. Sometimes the calls come in during the dinner hour. Other times, people need help very late at night (usually from India or China) because of various time zones.

Continued on Page 5

Contact foundation president Lynn Egan for more information on volunteer opportunities lynn@ahckids.org

Foundation Coordinator Continued...

“Sharon is a compassionate and knowledgeable supporter for our family. She’s been there during AHC crises and Flunarizine shortages. She’s always just a phone call away!” Heather Gates

The AHCF is honored to be the first place AHC families come to ask questions, inquire about events, request physician referrals, connect with other families, get help with Flunarizine issues, or just vent about the trials of AHC. **We are also thankful to Sharon for providing professional and quality support to the AHC community over the last five years of her tenure as Foundation Coordinator.**

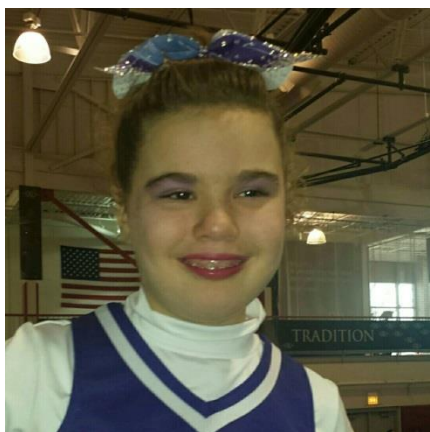
Sharon’s own words sums up why she is so valuable to the AHC community, “The favorite part of my job is to connect with families and learn about their great kids. I feel it’s a privilege to work with such a fantastic community and look forward to hearing your ideas and suggestions of how I can be of further help to you.”

You can reach Sharon anytime at sharon@ahckids.org or 313-663-7772.



Fourth Annual Golf Fundraiser is Another Huge Success

AHC grandparents work FORE an end to AHC!



On July 31st, Terry and Barb Sharo hosted a golf outing in Illinois at Deer Creek Golf Club in honor of their granddaughter, Kiley Andrasco.

Over 110 golfers and 35 sponsors joined 155 dinner guests for another hugely successful event to help net over \$19,000 for AHC research.



Over the last four years, Terry has perfected the art of collecting in-kind donations to make for an extremely exciting raffle and day on the greens.

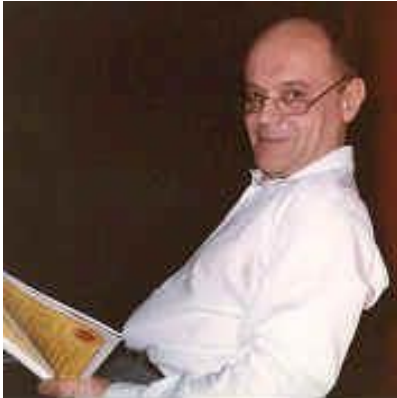
Through his hard work and love for family, Terry and his volunteers have raised tens of thousands of dollars for research.

Thank you Barb & Terry for all you do to help AHC kids everywhere!



Remembering Dr. Jean Aicardi Continued from Page 4...

In the intervening years he helped establish child neurology and pediatric epilepsy as specific clinical interests in France. He subsequently became Director of Research of INSERM (NIH equivalent) and contributed much to the research of pediatric neurological disease. He published in excess of 260 scientific articles and 110 chapters in medical texts. He co-authored seminal textbooks on pediatric neurology including; 1.) Diseases of the Nervous System in Childhood, 2.) Epilepsy in Children, and 3.) Movement disorder in Children.



Although Dr. Aicardi practiced child neurology mostly in France his reputation quickly spread throughout the world, frequently invited to give talks and receive many awards from different professional societies.

For those of us who had the pleasure to meet and work with Dr. Aicardi one could not help but admire his brilliance, patience, and depth of knowledge. Dr. Aicardi stood as a pillar of child neurology throughout the world and a testament to the foremost French neurologists dating from the times of Charcot who have set standards of neurological knowledge that we all strive for.

Dr. Aicardi was instrumental in aiding our understanding of Alternating Hemiplegia of Childhood. He recognized AHC early on and published papers on AHC in 1987 and 1993.

The latter paper reported 22 cases of AHC where he succinctly describes in detail the clinical manifestations in his patients. His interest in childhood neurological disorders, epilepsy and movement disorder as described in his well-read textbooks all attest to his clear understanding of AHC patients. He crystallized the six diagnostic clinical criteria of AHC which we continue to use today to identify our classical patients.

Dr. Aicardi will be greatly missed by many.

Volunteers Make Big Things Happen for AHC Community

Families help find cure for AHC by working together!

**Hopefully, you are excited by this headline
and are willing to help make it come true!**

Join the volunteers already working towards making this headline a reality by supporting one of the already established fundraising events.

There are many opportunities for your talents and skills to add to the fundraising success of these events. Simply contact the volunteer listed for each event and ask how you can help.



Join Paul & Renee Hodes in New York State for their Second Annual Event

Dine and Dance to End AHC is a social evening of dinner dancing, and fundraising in honor of their daughter Lisa. Attendance at the event, a 50/50 Raffle, and general donations raise funds that go directly to funding research that will bring

all AHC kids closer to a treatment or a cure.

For more information go to:

<http://ahckids.org/dinedance/>

Volunteers Make Big Things Happen for AHC Community CONTINUED...

Leverage your personal contacts all around the country and ask them to participate in any one of the upcoming events. Share your passion for achieving our One Mission: End AHC!


We have a day for giving thanks.
We have two for getting deals.
Now, we have #GivingTuesday,
a global day dedicated to giving back.

Join us in the fun on Tuesday, December 1st
As we give back to the AHC community.

Black Friday. Cyber Monday.
#GIVINGTUESDAY
December 1, 2015

Contact Vicky Platt to start planning now
vicky@ahckids.org


AHCF Blooms for Hope



We are at it again this year! **AHCF Blooms for Hope Campaign** has begun! Buy your spring bulbs this fall through this quality company and 50% of your purchase price goes towards research to treat and end AHC!

Be sure to share this great product and fundraising opportunity with your family and friends.
http://www.flowerpowerfundraising.com/campaign?campaign_id=21973

Contact Josh Marszalek for more information:
Joshua@ahckids.org



Sunday, Sept. 20th in Lake Zurich, Illinois
9:30 am to 1:00pm

Help us break \$300,000 for AHC Research

Ask your Friends & Family to Join Us
For more info contact:
gene@ahckids.org or vicky@ahckids.org

Please come join us this Sept.

10th Annual AHCF Chicago Walk

amazon smile **ahcf**
Try Prime

AmazonSmile is a simple and automatic way for you to support the AHCF every time you shop, at no cost to you. When you shop at smile.amazon.com, **Amazon will donate a portion of the purchase price to us at no extra cost to you!**

Simply go to smile.amazon.com from the web browser on your computer or mobile device and use your same account on Amazon.com and AmazonSmile. Your shopping cart, Wish List, wedding or baby registry, and other account settings are also the same.

On your first visit to AmazonSmile (smile.amazon.com), you need to **select AHCF Foundation** to receive donations from eligible purchases before you begin shopping. It will remember your selection, and then every eligible purchase you make at smile.amazon.com will result in a donation. **And, Amazon does the rest!**

Supporting: Alternating Hemiplegia Of Childhood Foundation Inc

Create your own event and we'll help you be successful. "Variety's the very spice of life" and you might be surprised at how many others support your idea!

www.ahckids.org



Words of Wisdom

"I am only one; but still am one. I cannot do everything, but still can do something. I will not refuse to do the something I can do." **Helen Keller**