ahcf
Alternating Hemiplegia of Childhood Foundation

One Mission: End AHC!

YOUR ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION NEWSLETTER www.ahckids.org JUNE/JULY 2015

2000 Town Center ■ Suite 1900 ■ Southfield, Michigan 48075

Community Shares Time, Talent, and Treasure

Wine + Women + Shoes=Success

On Saturday, June 6th, the Menlo Circus Club in Atherton, California was home to the **Wine Women & Shoes** event benefiting the Alternating Hemiplegia of Childhood Foundation. With the help of wonderful family and good friends, Lynn Egan coordinated the event during the last year.

Thanks to a great team of volunteers and Lynn's incredible efforts, we are pleased to announce that the event was a huge success and raised over $80,000!

On the day of the event, the weather couldn't have been more perfect and the guests were incredibly excited. Our **Shoe Guys** greeted approximately 325 guests who spent the first part of the evening shopping, enjoying wonderful wine, purchasing raffle tickets for the **Key to the Closet**, and bidding on **Silent Auction** items.

Miss Redwood City/San Mateo County, Emily McNiel, worked the crowd with **Best in Shoe Judge,** Dr. Parikh, looking for the Best in Shoe! Our emcee, Catherine Heenan from KRON 4 was fabulous and the **Live Auction** was amazing.

As we moved into the second part of the evening, our shoe guys again, engaged the women and set the tone.

When it came time for the **call to action**, "Research for AHC", Lynn was moved to tears by the generosity of the crowd as they instantly raised over $25,000 to help end AHC! What an amazing group of women!

When we began this journey, the first steps were the hardest: reaching out to businesses, filling out online applications, and attending Chamber of Commerce and Rotary Club meetings. With every person we spoke to, we shared the AHC story and it became easier.

As it all came together during the event, the joy and love that filled the room was overwhelming. **NEXT PAGE**

If you have a story to share, contact Vicky Platt at vicky@ahckids.org

Story of Success Continues…

Wine Women & Shoes

The evening concluded with a fashion show with designs from **Macy's** and 20 incredible volunteers who rocked the runway. As the evening came to an end, our guests received their swag bags and expressed their praises for a fantastic, beautiful, and fun event.

After months of planning and countless hours of work the event went wonderfully **AND** we raised over $80,000 for the AHCF.

Looking back, perhaps even more powerful than telling the story of an AHC parent were the stories shared from the sister, the brother, the aunt, and the good friend.

Each shared the message of a rare, basically unknown disorder and the effects on those affected with AHC. We were not only raising funds for research but also raising awareness while having fun.

AHCF Family Meeting 2016 Announcement

Join us next summer in Indy!

The AHC Foundation is pleased to announce that the 2016 Family Meeting will be held July 13th through 17th in **Indianapolis, Indiana!**

The AHCF Family Meeting will offer access to AHC clinicians, genetic counseling, presentations of current research, and opportunities to connect with AHC families from around the world.

Our 10th family meeting is shaping up to be as helpful, educational, and valuable as the previous nine!

More details are being hammered out by our volunteer planning committee, so look for more announcements in the near future! **We look forward to seeing you in Indy next summer!**

Great News for AHCF & Dr. Kathryn Swoboda

2015 RARE Champion of Hope Nomination Received!

In the sixth year of advocating for rare disease patients worldwide, Global Genes notified us in May that AHCF President Lynn Egan and Dr. Kathryn Swoboda were nominated for this year's:

2015 RARE Champion of Hope – Collaborations in Advocacy Award!

The nomination was received jointly by Dr. Swoboda and Lynn Egan because of their extraordinary efforts in collaborating together as advocates for AHC patients in the United States.

In response to the nomination, Lynn Egan comments, "With over 300 nominations from eight countries, it is indeed an honor to be recognized by our peers in the rare disease community."

Congratulations to Dr. Swoboda and Lynn Egan who helped make this nomination possible.

Funds Awarded to Attend ATP1A3 Symposium in Washington, DC

Dr. Kevin Ess receives AHCF grant

The AHC Foundation is pleased to announce that a grant has been awarded to Dr. Kevin Ess of Vanderbilt University to attend the 4th Symposium on ATP1A3 in Disease.

The symposium will take place in Washington, DC on August 27-29, 2015 at the Double Tree Bethesda Hotel and Conference Center.

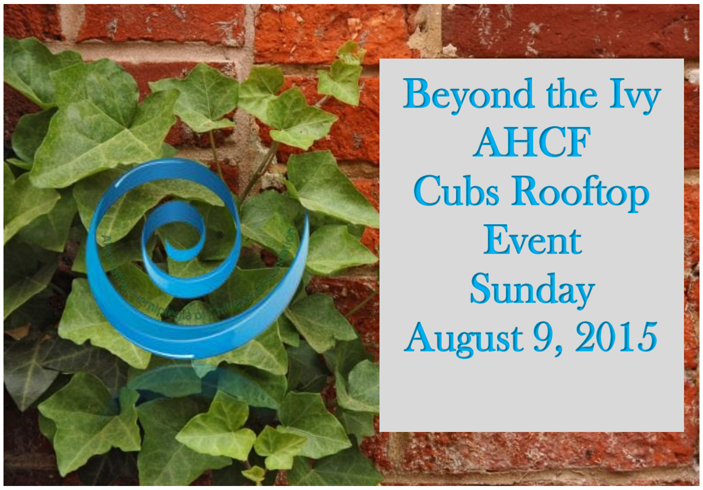
The aim of the symposium is to provide a forum for the **sharing of latest research findings** for ATP1A3 mutations in disease, with an emphasis on Alternating Hemiplegia of Childhood (AHC), to promote the international collaboration and recruit new teams of researchers. This conference builds on previous similar conferences in Brussels, Belgium (2012), Rome, Italy (2013), and Lunteren, Netherlands (2014).

As the primary investigator of the foundation's latest research grant, we are honored to award Dr. Ess with this grant. This is a wonderful opportunity for researchers and physicians to gather and exchange information about AHC and ATP1A3 related diseases. In addition, the foundation will be represented by President Lynn Egan. **Thank you to everyone who is attending this symposium!**

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

AHCF Cubs Rooftop Fundraiser 2015

Cubs vs Giants game to support AHC research!



Come One! Come All! Invite your Friends to Have a Ball!

Everyone is welcome to attend an AHCF Cubs Rooftop Fundraiser on Sunday, August 9th. The event takes place at Beyond the Ivy, the official rooftop venue of the Chicago Cubs, at 1010 Waveland Avenue.

Admission to the venue includes huge bleachers for viewing the game, all-inclusive food and drink, a huge beer garden, two massive bars, skybox-style seating and room to get out of the sun. Tickets cost $125 per person and include a donation to the AHCF.

To reserve your ticket, go to the following link today: **https://secure.beyondtheivy.com/fundraiser/ahcf**

Board of Directors' News

Erpenbeck earns our thanks & gratitude

Please join us in thanking Mollie Erpenbeck for her years of service to the foundation as a member of our board.

Mollie began volunteering for the foundation by holding fundraising events in honor or her son, Austin. She soon increased her service to the foundation and was elected to the Board of Directors. And, not long thereafter, Mollie was elected to the Executive Committee and served as Fundraising Chair.

Mollie was also instrumental in welcoming Dr. George and Dr. Ess into the AHC community and helping to establish the AHC Clinic at Vanderbilt University. Her efforts will be felt for years to come!

We wish Mollie well and look forward to working with her on new projects in the future.

Success Continues for Illinois Golf Outing

Cindy Ryan reports $11,000 effort

Our thanks to Cindy and her entire team of volunteers who hosted another successful golf outing in June!

In addition to raising awareness for AHC and donating the proceeds to the AHCF, the community comes together to support Michael and his entire family. **Thank you everyone!**

Michael and his dad having fun!

Everyone is FORE a cure!

Lessons for Today from the Mayo Brothers and the Mayo Clinic

Teaching the values of sharing

In a 1978 installment of the ValueTales series, the authors of *The Value of Sharing* examined the role that sharing played in the lives of William James (1861-1939) and Charles Horace (1865-1939) Mayo.

The book tells the life stories of Will and Charlie, two brothers living in Minnesota, where their father worked as a doctor. Their whole family worked to learn as much as possible about medicine. Will and Charlie worked hard to become doctors, too. And they worked together for the rest of their lives, sharing their knowledge to conduct research and develop better medical care.

Like other books in the ValueTales series, this book uses a real-life person to exemplify an important value. It is suitable for reading by children in the later elementary school grades. A "Historical Facts" section at the book's end summarizes the Mayo Brothers' lives in a single-page bio form suitable for adults.

A closing quote from the book reads:

"Of course not everyone has the same things to share. You may not have much money and you probably don't have a microscope. You may not even want to share what you have with anyone. That is for you to decide. But if you do choose to give something to someone else, or accept what others are giving to you, you may just discover something very important about yourself. You may discover that sharing makes you feel happy, just as it did our good friends the Mayo brothers."

Five Part Series on Getting Diagnosed with AHC by Doug Morris

Part four: What is wrong with my child?

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

Poor Haley. Poor Caroline. Life will be terrible for them. Life for us will be burden of caring for them. Our collection of glasses was well beyond half-empty.

Lack of knowledge fed depression. While we learned more about AHC, much of it came from our own kids. Some stories came from other parents but no solutions. We talked to various doctors to understand the symptoms better but often realized that the doctors learned more about AHC from our kids than we learned from the doctors.

With seemingly no viable outcome, why live? What was the point? I burdened myself with sadness, depression, fear of the future, regret of choices that created the uncertainty of kids with AHC. Family life seemed pointless.

Yet the kids smiled, laughed, played, and developed personalities. Being a parent trumped being a parent of kids with AHC. I accepted that life was worth living as my kids pulled me there. Depression was replaced by life and we journeyed on.

Part Five Continues in the August Newsletter.

10 Suggestions for Families to Consider when Caring for a Loved One with Medical Challenges

Food-for-thought for families

Hopefully, you already are doing a few of these and might find a few others helpful.

10 Tips for Family Caregivers

1. Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.
2. Watch out for signs of depression, and don't delay in getting professional help when you need it.
3. When people offer to help, accept the offer and suggest specific things that they can do.
4. Educate yourself about your loved one's condition and how to communicate effectively with doctors.
5. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
6. Trust your instincts. Most of the time they'll lead you in the right direction.
7. Caregivers often do a lot of lifting, pushing, and pulling. Be good to your back.
8. Grieve for your losses, and then allow yourself to dream new dreams.
9. Seek support from other caregivers. There is great strength in knowing you are not alone.
10. Stand up for your rights as a caregiver and a citizen.

Share your AHC Family Story in Pictures

July Facebook Challenge

Simply look at the prompt for the day. If it is the 15th day of the month, look at prompt number 15.

Share one of your pictures that is somehow related to the prompt. It can be literal or not. We love metaphors and funny interpretations too!

Whatever comes to mind for you is the right picture to share.

Let's just have a little fun together this July.

20. Transformation
21. Start
22. Complete
23. Laugh
24. Surprise
25. Deep Thoughts
26. Relax
27. Blue
28. Drink
29. Team
30. Solo
31. Vacation

Join us this month in the #NPCommPix July Challenge. It is super easy.

Words of Wisdom

"Unity is strength…when there is teamwork and collaboration, wonderful things can be achieved." Mattie Stepanek