

JULY 2014

## A NEW KIND OF SUCCESS

As I reflect on the success of the family meeting, I am proud of how this meeting was truly amazing! I love reconnecting with families, meeting new families and am always humbled by your presence. The family meetings leave me feeling energized and always strengthen my commitment to the AHC Community.

Attending a family meeting brings forth many emotions: the excitement of meeting others who understand, a better knowledge of the disorder, perhaps apprehension of seeing other children with AHC, and perchance sadness and a fear of the future. All of these emotions are normal and expressed by many.

For those of you unable to join us, the videos will be available in the next few weeks. There are several presentations that will not have videos available due to submission of work for publishing and another for copyright issues. However, the videos will be made available at a later date and summaries will be provided.

Whether you attended or not, you may have questions that were left unanswered so please feel free to contact any board member or myself with any questions, concerns or suggestions you may have.

One mom told me, "I feel so empowered - empowered to now return home and educate and better explain what AHC is to my family and friends".



Life has a way of taking over and as each day passes, our days together fade. However, know that you belong to a greater family and our children and our desire for a treatment connect us. We are a community, a team, and together we have ONE MISSION: END AHC!

I look forward to working with you, continuing to raise awareness and fundraising for research...

WE WILL find a treatment and ultimately a cure for AHC.

Lynn Egan, AHCF President

## KIND WORDS FROM MINNEAPOLIS

"Am glad we could make it and really loving every minute of it." Abimbola Adeleye

"Great job today! So glad to be here and reconnect with everyone." Jennifer Franco

"A big takeaway from the afternoon-AHCF uses its money to fund critical research and has a great record." Janine Roeth

"Family meeting finished today. Very good meeting. Lots of energy. I have never seen the doctors so optimistic." Sigi Johanneson

## AND THE WINNER OF THE RIFTON RAFFLE IS...

An incredibly generous donation was made to the AHC Foundation by Rifton Equipment. An adaptive tricycle was given to the foundation in celebration of our family meeting in Minnesota.



Over \$1,300 in raffle tickets were purchased to benefit the foundation. At the meeting, the winning ticket was drawn and Mark Egan won the trike for daughter Kathleen. Congratulations!

## IN-KIND GIVING

Like other public charities, the AHCF depends on generous donations from private citizens and businesses to continue our good works. However, not all of the contributions that keep us running are cold, hard cash. Some are in-kind donations.

"In-kind giving" refers to contributions of goods and services that are of value to a nonprofit organization. For example, a ski resort donates the use of a villa for one week to the foundation. The retail value of the stay is \$3,000. While the use of the villa is an incredibly generous gift to the foundation, we do not realize the monetary value of the gift.

If the foundation were to raffle off the villa and sell \$4,000 in tickets, then the foundation would recognize a \$4,000 donation. However, if only \$1,000 in raffle tickets were sold, the foundation would recognize a monetary gift of \$1,000. Both very generous gifts in-kind.

## THE AHC FAMILY MEETING GOES TO THE ANIMALS

The meeting planning committee would like to thank all of the people who made in-kind donations to the AHCF 2014 Family Meeting. While most of these people are too modest to accept public thanks, we do want to acknowledge their generosity and appreciate their kindness.

Goods and services which were donated include:

- Projection equipment
- Photocopies and poster printing
- Drinks & snacks for the kids
- AHC pen & stylus
- Toys, games, and entertainment

One particularly fun donation was made by Renee and Paul Hodes. The kids were treated to a variety of animals which they were able to stuff and dress in AHCF t-shirts. What a great souvenir for the kids to take home!



Thanks to everyone who donated to the success of the 2014 AHCF Family Meeting!

Azar, Carol,  
Lynn, Marcia,  
MaryKay,  
Renee, Sharon,  
and Vicky

## DOCTORS, SCIENTISTS AND RESEARCHERS, OH MY!

Doctors, scientists, and researchers from around the world came together last month at the AHCF 2014 Family Meeting.

They attended clinic appointments, consulted with families, advised the AHCF Board of Directors, presented the latest AHC research findings, shared their knowledge in presentations, and attended the AHCF sponsored scientific workshop titled, "Achieving Consensus on Definitions and Outcomes for Natural History Studies and Clinical Trials in ATP1A3 Related Disorders."



A critical goal for this meeting was to inform families about specific AHC topics. The doctors, scientists, and researchers did a fantastic job meeting this goal and far exceeded our expectations.

We are grateful for their participation at this meeting and appreciate the time they spend working within our community all year long.

Thank you for your dedication!

**Sharon Ciccodicola**  
**AHCF Medical Liaison**

## THE AHCF'S INTERNATIONAL G-O-A-L!

While the family meeting took place in Minnesota, many of our families enjoyed watching the World Cup games going on in Brazil. What was even more fun was giving Dr. Rosewich a hard time after Germany beat the US team.

Germany Iceland  
France Canada  
Japan Nigeria  
South Africa  
United States  
Australia

The AHCF wishes to thank the international families, physicians, and researchers who traveled to the US to join our meeting this year.

We recognize the extra challenges this places on your families and appreciate the time and effort you put forth to join our community.

Your participation with our foundation not only supports our mission, but makes us a true international foundation.

**Thank you for continuing to join us.**



## ALL KINDS OF PEOPLE COME TOGETHER IN MINNESOTA

This year, I was able to attend the 2014 AHCF Family Meeting with my husband and two children. We were incredibly fortunate to have met many wonderful families from around the world. We caught up with doctors who've cared for Emma over the years. We were introduced to scientists working on AHC research with amazing results. We shared meals with AHC families we've come to know well. And, we laughed and cried over the emotional stories about what it is like to live with AHC.

**“WHAT WISDOM CAN YOU FIND THAT IS GREATER THAN KINDNESS?”**

**JEAN JACQUES ROUSSEAU**

As a member of the Board of Directors, I also had responsibilities to meet throughout the week. For two days, I went to the hotel lobby early in the morning to complete some work before my family woke up. On the second morning, a hotel staffer noticed I had been hard at work and brought me

a muffin and bottle of water. It was just what I needed to start the day.

On Saturday, as the meeting was coming to end, my family received some disturbing news. Someone had left a nasty note on the windshield of our van and run their key along the entire length of the driver's side.

With a handicap placard in the window and a

sticker identifying the need for extra space for a wheelchair ramp, someone was too annoyed with our presence and acted out. Once again, the hotel staff came through for us. They offered us a credit on our hotel bill to help minimize the negative actions of one of their guests.

It definitely takes all kinds of people to influence the outcome of a meeting like this one.

- The doctors and scientists who take time away from their work and families to educate us about AHC.
- The speakers who prepare their presentations to help families struggling with the many challenges of AHC.
- The organizing committee who spend countless hours planning the meeting.
- The Board of Directors who carry out the operations of the foundation in addition to having children with AHC.
- The hotel staff which help make the meeting run smoothly.
- And, the AHC kids who managed the many obstacles of being away from home and in an unfamiliar environment.

When looking back at the meeting in Minneapolis, it would be easy to be angry about the one person who damaged our van and acted so childish. However, I choose to focus on the kind acts of so many people who helped make this an amazing experience for my family. Without their kindness and generosity, this meeting would not have been possible.

With our van already fixed, I look forward to the next family meeting and seeing many of you once again.

**Vicky Platt, AHCF Secretary**

## FUNDRAISING MAKES THIS ALL POSSIBLE

Hosting a family meeting is a huge responsibility and a significant financial investment for the foundation. Because of the generous support we received last year, it was just one of the numerous initiatives we were able to support.



Here is a summary of the projects your donations to the AHCF made possible.

MONTH	COST	PROJECT
July 2013	\$169,154	Vanderbilt Research Grant
August 2013	\$10,000	Mission & Donor Video created with staff at Engauge Marketing
September 2013	\$6,000	Sponsored 2 <sup>nd</sup> Symposium on ATP1A3 in Disease-Rome
October 2013	\$13,000	Co-funded Koenderink's research in The Netherlands
November 2013	\$10,000	Scientific workshop initiated
December 2013	Priceless	Flunarizine meeting with FDA took place in Wash,D.C.
January 2014	\$30,000	AHCF Family Meeting announced for Minnesota
February 2014	Priceless	Vanderbilt AHC Clinic opened in Tennessee
March 2014	\$1,300	Became sponsor of 3 <sup>rd</sup> Symposium on ATP1A3 in Disease for August 2014
<b>TOTAL</b>	<b>\$239,454</b>	

## WHAT KIND OF DIFFERENCE CAN YOU MAKE NEXT YEAR?

**Answer: A huge one.**

Every volunteer plays a significant role in supporting the needs of AHC patients. Every dollar raised helps fund important research towards finding a treatment. Every hour worked for the foundation is a commitment to ending AHC.

Build on all of this excitement and begin thinking about what kind of difference you want to make. With more projects planned for the next year, there will be plenty of opportunity.

**"No act of kindness, no matter how small, is ever wasted." Aesop**

Without our families and friends raising money for the foundation, none of this would be possible. Thank you to all of those who donated to the foundation and shared our message over the last year. Your work is greatly appreciated.

### The 2014 AHCF Board of Directors

Gene Andrasco, Sharon Ciccodicola, Cate Cohen, Lynn Egan, Mollie Erpenbeck, Bill Gerber, Renee Hodes, Josh Marszalek, Doug Morris, Vicky Platt, Carol Presunka, Mary Kay Riley, and Sue Roberts

