

JUNE 2014

COMING TOGETHER

One of my favorite things to do for the foundation is to meet with AHC families at the AHCF Family Meeting. It is an incredible opportunity to catch up with old friends and meet new ones, hear from researchers, chat with doctors, and learn from everyone attending the meeting.

With the help of a wonderful planning committee, many months of preparation have gone into making this event a success. Everyone has been working hard to make certain that this meeting is educational and inspirational.

Unfortunately, not everyone who would like to attend the meeting is able to join us this year. In an effort to provide our community as much information from the meeting as possible, the foundation hired a videographer to record the sessions during the meeting. The recordings will be uploaded to our website after the meeting and available for everyone to view.

I look forward to seeing many of you in Minneapolis later this month and am excited to share wonderful stories with everyone come July. Travel safe and enjoy the summer.

Lynn Egan, AHCF President



AHCF GOES TO THE LAND OF 10,000 LAKES

The AHCF is proud to share our family meeting with the great people of Minnesota. Since this meeting is the single largest gathering of AHC patients in the world, it is sure to be an amazing experience for everyone able to attend.

Not only are we looking forward to families from around the United States converging on Minneapolis at

the end of the month, but attendees from eight international countries will be welcomed to Minnesota. Those countries include: Australia, Canada, France, Germany, Iceland, Japan, Nigeria, and South Africa.

If we can do anything to make your stay in Minnesota more enjoyable, please reach out to us as soon as you arrive.

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

ACCUEIL
VELKOMNIR
WELCOME
YŌKOSO
EK'ABO
Willkommen
Welkom



AHC PROFESSIONALS HEAD NORTH FOR THE SUMMER

Doctors, researchers, and professionals from around the world are coming together this month at the AHCF Family Meeting.

They will all attend the AHCF sponsored scientific workshop titled, "Achieving Consensus on Definitions and Outcomes for Natural History Studies and Clinical Trials in ATP1A3 Related Disorders." The workshop will be co-chaired by Dr. Kathryn Swoboda and Dr. Allison Brashear.

The primary purpose of the workshop is to bring together key stakeholders from diverse backgrounds to better educate the community about the diversity and complexity of neurologic phenotypes associated with mutations in ATP1A3, and to identify and prioritize key milestones for success in moving towards targeted therapies for ATP1A3 disorders.

A critical goal for this meeting includes working towards consensus on definitions and outcome measures that are both clinically meaningful to patients as well as practical to assess in the context of clinical studies and trials.

We are grateful for their participation at this workshop and appreciate the time they spend working within our community.

Thank you for your dedication!

Sharon Ciccodicola
AHCF Medical Liaison

THE AHCF WELCOMES

Dr. Eva Andermann
McGill University (Canada)

Dr. Fred Andermann
McGill University (Canada)

Dr. Allison Brashear
Wake Forest Baptist Health

Dr. Suzanne DeBrosse - Case Medical Center

Dr. Kevin Ess - Vanderbilt University

Dr. Alfred George Jr.
Northwestern University

Dr. Aga Lewelt, MD, Psychiatrist
University of Utah

Dr. Joshua Magleby
Integrative Neuropsychology Inc.

Tara Newcomb - University of Utah

Dr. Laurie Ozelius
Mount Sinai School of Medicine

Dr. Sandra Reyna - University of Utah

Dr. Hendrik Rosewich
Georg August University (Germany)

Dr. Masayuki Sasaki National Center
of Neurology and Psychiatry, Japan

Dr. Ken Silver MD - University of Chicago

Dr. Matthew Sweney - University of Utah,

Dr. Kathryn Swoboda - University of Utah

Dr. Louis Viollet - University of Utah

WHAT DO THESE COUNTRIES HAVE IN COMMON?

China
Denmark
France
Germany
Japan
Poland
Spain
United States

Answer:
AHC
RESEARCH

Over the last six months, researchers from each of the above countries published articles on AHC research. Articles cover topics from the number of AHC patients in Denmark to the expanding clinical and genetic spectrum of ATP1A3 related disorders.

For a bit of perspective on this impressive achievement, take a look at the amount of AHC research published in the past.

<u>Time Period</u>	<u>AHC Articles</u>
Jan. 2014 – June 2014	21
2013	23
2012	13
2011	9
2005 – 2010	37
2000 – 2004	24
1990 – 1999	54

MAKING RESEARCH AVAILABLE TO YOU

To keep up with the wonderful increase in AHC research, every quarter the AHCF updates a bibliography of relevant articles related to AHC. While we are unable to provide copies of these articles to our families (due to copyright law), we are happy to keep you up to date on the latest AHC research.

To download a copy of the bibliography, visit our website at www.ahckids.org. By using the bibliography, you can then go to the web and look at the full text (when available) or read an abstract of each article. Abstracts provide a short summary of the article, giving you a feel for the work within the article. Abstracts of these articles can be found at <http://www.ncbi.nlm.nih.gov/pubmed>.



The increase in international attention to AHC is wonderful news for patients with AHC and their families. With so much work to be done, there is great opportunity for all researchers interested in helping our AHC loved ones. I wish them all well in their work.

Vicky Platt
AHCF Secretary

MINNESOTA'S FINEST - RIFTON EQUIPMENT

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. To raise funds for the foundation, the tricycle will be raffled off at the meeting and the winner gets to pick the appropriate size for their loved one.



Rifton Raffle for Adaptive Trike!

"Most of us have fond memories of childhood bike rides. At Rifton we

believe everyone deserves the chance to ride, especially someone with physical disabilities."

The AHCF Rifton Raffle starts June 1st and ends June 25th. Tickets are \$10 each or 3 for \$25. The winner will be able to select the appropriate bike size and it will be shipped directly to the winner by Rifton.

Click here to purchase tickets.
<https://co.clickandpledge.com/advanced/default.aspx?wid=79472>

After you purchase your raffle tickets, you will receive your ticket numbers via email. The winning ticket will be drawn at the Family Meeting Luncheon on Saturday June 28th. You need not be present to win. Only families living in the contiguous United States are eligible to win.

For additional information, click here.
<http://ahckids.org/rifton-raffle-for-adaptive-trike/>

FUNDRAISING MAKES THIS ALL POSSIBLE

Hosting a family meeting is a huge responsibility that the AHCF Board of Directors takes very seriously. It is a significant financial investment that we are happy to make, as well as a time consuming endeavor we gladly commit to as often as possible.

Without our **ahcf** 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.

Mollie Erpenbeck
Fundraising Chair

The 2014 AHCF Board of Directors (& team players)

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

