

2014 AHCF Family Meeting

June 26 – June 28, 2014

Minneapolis, Minnesota



Hilton Minn/St. Paul Airport

Mall of America

One Mission: End AHC!

Thursday, June 26th

- 8:30-9:30 am E.C. Breakfast Meeting
- 10:00–11: 00 am [Optional Coffee Gathering](#)
- 12:30-1:00 pm Begin Checking in Children
- 1:00-1:15 pm Welcome to the AHC 2014 Family Meeting with AHCF [President Lynn Egan](#)
- 1:15 – 2:30 pm Research Update: Vanderbilt in Collaboration with Northwestern University
[Dr. Al George & Dr. Kevin Ess](#)
- 2:30-3:30 pm New Insights in Phenotypic Variability in ATP1A3-Related Disorders with
[Dr. Hendrik Rosewich](#)
- 3:30-3:45 pm Break
- 3:45-4:45 pm Epilepsy & AHC Connection with
[Dr. Frederick Andermann](#)
- 4:45-5:45 [Welcome to Minnesota Gathering at Hotel. Meet the AHCF Board of Directors, Socialize with AHC Families, and Have Some Fun](#)
- Enjoy the Sights with your Friends & Family
- 6:30-9:00 PM Board of Directors Dinner Meeting with Doctors (invitation only)

Friday, June 27th

- 8:30-9:00 am Begin Checking in Kids
- 9:00-10:00 am AHC & Behavior – How to Survive it
- 10:00-10:15 am Break
- 10:15-11:15 am AHC & Behavior with Behaviorist
[Alice Belgrade](#)
- 11:15-12:00 pm Break Out Session Options
- Track 1: AHC & Behavior Self Defense
- Track 2: My Sibling Has AHC and What Does that Mean to Me
- 12:00-2:00 pm Lunch Break
- 2:00-2:15 pm AHCF 411-President Lynn Egan
- 2:15-3:15 pm The Road to a Treatment Part 1: with Paul Hodes and Tobe & Cate Cohen
- 3:15-4:15 pm Break Out Session Options
- Track 1: Young & School Age Kids
- Track 2: Older Kids
- 4:15-7:00 pm Dinner Break and Family Time
- 7:00-8:30 pm [Ice Cream Social at Hotel](#)
- 8:00-10:00 pm AHCF Board of Directors Meeting

Saturday, June 28th

8:30-9:00 am Check in kids

9:00-10:00 am Two Session Options

Track 1: AHC 101 Dr. Kenneth Silver

Track 2: Hello AHC, I am your Hormones

10:00-10:15 Break

10:15-11:15 Rock Bottom is More than a Beer

Dr. Kathryn Swoboda & Parents Vicky & Andy Platt
and Carol & Kevin Prunty

11:15-12:00 pm ATP1A3 - What Does it Mean to
AHC Patients and Families

Tara Newcomb

12:00-2:00 pm Group Luncheon and Picture

2:00-3:30 pm The Way AHC Moves-The Dystonia
Connection Between AHC and RDP

Dr. Alice Brashear

3:30-4:15 pm Ask a Doctor Questions

Doctors Swoboda, Reyna, Silver, and Andermann

3:30-4:15 pm Who Would Have Thought My Child

Could Ride a Roller Coaster – Lynn Egan

Road to a Treatment Part 2 – Gene Andrasco

An Important Workshop Takes Place In Minnesota

Friday, June 27th 9:00 – 5:00 pm

Doctors, researchers, and professionals from around the world are coming together at the AHC Family Meeting for some very important work.

They will all attend the AHC 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.

The **2014 AHCF Family Meeting** is an amazing opportunity for families to come together with researchers and doctors who have first-hand knowledge of AHC. The AHCF Board of Directors is extremely grateful to all of those who helped make this happen.

We wish to acknowledge local businesses that helped us make this meeting a wonderful experience for our families.

Holiday Stationstores

BlueCross BlueShield of MN

Minnesota Lynx

Minnesota Vikings

Minnesota Twins

Old Country Buffet

Rifton

Special thanks to the meeting planning committee:

Sharon Ciccodicola Lynn Egan

Renee Hodes Marcia Perkins

Carol Presunka Mary Kay Riley

Vicky Platt Azar Yazdanpanah