



Alternating Hemiplegia of Childhood Foundation - Family Meeting Agenda

(All Times Eastern Daylight Time)

Saturday, June 26th

10:00 am – 10:45 am

- Welcome by AHCF President Joshua Marszalek and Treasurer Gene Andrasco
 - Joshua Marszalek - Introduce the Board, what the foundation can do for you
 - Gene Andrasco – “Daddy, did you find a cure?” Funding for research projects

10:45 am – 11:30 am

- Megan O’Boyle – Rare X - Introducing the AHC Data Collection Program and why it is critical for the advancement of research...”

11:30am – 12:15 pm

- Dr. Al George - Northwestern - Investigating the fundamental mechanisms of AHC

12:15 pm – 12:45 pm

- Dr. Kathy Swoboda/Helen Chen – MGH/Harvard - Longitudinal follow-up of a cohort of patients with AHC from the AHCF International Database, (Natural History Study) + Flunarizine study

12:45 – 1:30 pm – Lunch

1:30 pm – 2:45 pm (Choice #1 or #2)

1) Alice Belgrade BCBA– Part 1 - Behavior issues of older AHC patients (**12 yr to adult**) - de-escalation of aggressive behavior, anxiety

2) Mary Anne Ehlert CFP– Part 1 - Special needs Financial planning, - What happens when I’m gone, planning ahead, insurance, government benefits, and Retiring For 3.

2:45 pm – 3:30 pm

- Parent Panel – Carol Presunka, Heather Gates, Lynn Egan, (parent interactions, managing episodes on your own, when to see a Doctor, dystonic storm, dehydration, helpful equipment

3:30 pm – See you tomorrow – President Joshua Marszlek



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Sunday, June 27th

10:00 am – 10:45 am

- Alexander Sousa – CRISPR - Base editing, Prime editing, and their application to potential AHC treatments

10:45 am – 11:30 am

- Simon Frost – Inserting a functional copy of the ATP1A3 gene into a virus (an adeno-associated virus or AAV)
- Comparisons between the three Gene Therapy projects

10:45 am – 11:30 am

- Sibling Meeting – Ryan Andrasco moderator ([separate zoom room](#))

11:30 am – 12:45 pm (Choice #1 or #2)

1) Alice Belgrade BCBA– Part 2 - Behavior issues of children (**toddler - 11 yr**)

2) Mary Ann Ehlert CFP– Part 2- Special Needs Will & Trust, Guardianship, conservatorship, Document critical information, and Building a life-long support network

12:45 pm – 1:30 pm - Lunch

1:30 pm – 3:30 pm

- Physician’s panel – Dr. Kevin Ess, Dr. Kathy Swoboda, Dr. Ken Silver, Difference between ATP1A3, ATP1A2 and no mutation, how does AHC change in adulthood, medication precautions, relief measures for dystonia, is it AHC or Epilepsy?

3:30 pm – Wrap up - President Joshua Marszalek – What’s next for AHCF?