

# agenda: thursday

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- 8:00 am – 12:00 pm** Informal Medical Consultations  
*Garnet, Platinum Boardroom, Silver A, Silver B*
- 1:30 am – 3:30 pm** Parents' Workshop - Q & A.  
*Diamond Ballroom C, D*
- 4:30 pm – 5:30 pm** **Welcome Gathering at the Hotel – Meet & Greet – 'Get to know the other families'**  
*Diamond Ballroom A*



**WELCOME!**  
**AHCF FAMILY MEETING**  
**#12**

# agenda: friday

- 7:45 am – 8:30 am** Families sign in, Distribution of Totes, Folders, T-shirts, Name Tags, Check in AHC children & young adults to “Kids” room (Sapphire room)  
*Diamond Ballroom Hallway and Sapphire Room*
- 8:30 am – 9:00 am** Welcome from President Lynn Egan, What a remarkable 25 year journey!  
*Diamond Ballroom A*
- 9:00 am -9:45 am** Dr. Kathryn Swoboda – MGH/Harvard- Longitudinal follow-up of a cohort of patients with AHC from the AHCF International Database.  
*Diamond Ballroom A*
- 9:45 am – 10:30 am** Cate Cohen – “When the Queen is happy, there is peace in the kingdom” Coping mechanisms and ways to manage parent’s health in the chaos of AHC.  
*Diamond Ballroom A*
- 10:30 am – 10:45 am** **Break**
- 10:45 am – 11:30 am** Dr. Mikati – Duke research update and Introduction to the Observ-AHC study  
*Diamond Ballroom A*
- 11:30 am – 12:00 pm** Dr. Matt Sweney – University of Utah & Brooke Tasi – Embrace device study, will it work for AHC?  
*Diamond Ballroom A*
- 12:00 pm – 1:45 pm** **Family Lunch Break**
- 1:45 pm - 2:00 pm** Check in AHC children & young adults to “Kids” room  
*Sapphire Room*
- 2:00 pm - 2:45 pm** Dr. Alfred George - Northwestern - Investigating the function and pharmacology of ATP1A3 mutations in human neurons and mice.  
*Diamond Ballroom A*
- 2:45 pm – 3:30 pm** Donata Viazzo-Trussell – “Moving Along with AHC” Tackling Mobility Issues!  
*Diamond Ballroom A*
- 3:30 pm – 3:45 pm** **Break**
- 3:45 pm – 4:15 pm** Vicky Platt– Dory Finds AHC. Lessons for Parents and Caregivers. In the Disney-Pixar movie, Finding Dory, it is Dory who has become lost and a cast of characters travel across oceans to try and find each other. This session will use the wisdom of Dory, and her friends, to discuss some of the challenges parents and caregivers experience while raising a child with AHC.  
*Diamond Ballroom A*
- 4:15 pm – 5:00 pm** Dr. Kathryn Swoboda – Challenges to effective Clinical Trial Design in patients with ATP1A3 related Neurological Disorders and Next Steps  
*Diamond Ballroom A*
- 5:00 pm** **Dinner Break & Family Time**
- 6:30 pm – 8:30 pm** **Ice Cream Social & Dance** Band (Terri Hammer, Rob Ambrosino- Hambro with Special Guest Leah Hammer)  
*Diamond Ballroom B,C,D*

# agenda: saturday

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- 8:30 am – 9:00 am** Check in AHC children & young adults to “Kids” room  
*Sapphire Room*
- 9:00 am – 9:45 am** Dr. Kevin Ess – Vanderbilt – “Induced pluripotent stem cells and AHC, now we literally have skin in the game”  
*Diamond Ballroom A*
- 9:45 am -10:45 am** Mary Anne Ehlert – Aging Parents want to Know... “What happens when I’m gone?”  
Special needs Financial planner highlights Guardianship & Lynn Egan shares her personal experience  
*Diamond Ballroom A*
- 10:45 am – 11:00 am** **Break**
- 11:15 am – 11:45 am** **Track One:** Mary Ann Ehlert – part 2- Able Act -Respite care, Insurance, SSI, Trusts, Emergency Fund  
*Diamond Ballroom A*
- Track Two:** Sibling session – I have a Sister or Brother with AHC and this is what I think! Moderated by David Hodes & Ryan Andrasco who have AHC siblings  
*Silver Room*
- 11:45 am – 2:00 pm** **Group Picture**  
*Lobby under Mezzanine or Outside*
- 11:45 am – 2:00 pm** **AHCF Family Luncheon**  
Dr. Silver Award Presented, Google Mini raffle  
*Diamond B, C, D*
- 2:00 pm - 2:15 pm** Check in AHC children & young adults to “Kids” room  
*Sapphire Room*
- 2:15 pm – 3:15 pm** Physicians Panel – Parents opportunity to ask questions with AHC, Dystonia, Epilepsy and other Specialists  
*Diamond A*
- 3:15 pm – 4:15 pm** Gene Andrasco – Fueling the Research Engine  
Joshua Marszalek – If Not You, Who?  
*Diamond A*
- 4:15 pm – 4:30 pm** **Break**
- 4:30 pm – 5:15 pm** Luis Barros – Safety Care, De-escalation, Aggressive Behavior Management  
*Diamond A*
- 5:15 pm** **Dinner Break & Family Time**

# agenda: sunday

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**8:30 am – 9:00 am** Check in AHC children & young adults to “Kids” room  
*Sapphire Room*

**9:00 am – 10:00 am** **Roundtable Discussions**  
**#1:** Behavior stories & Tips - Parent to Parent  
Moderated by Renee Hodes & Kelly Andrasco  
*Diamond C Ballroom*  
  
**#2:** Comfort Measures & Managing symptoms of AHC  
How to handle the changes in episodes as they get older  
Moderated by Vicky Platt & Chris Vona  
*Diamond D Ballroom*

**10:00 am -10:15 am** **Break**

**10:15 am - 11:45 am** “Hope vs Hype! – CBD Oil - Mom Laura Heimgartner, Dad & Patient Advocate Sigurdur Johannesson, & Dr. Kevin Ess present the different sides to this Hot Button Topic.  
*Diamond A Ballroom*

**11:45 am – 12:00 pm** Lynn Egan – Lynn Egan – What’s next for AHCF?  
*Diamond A Ballroom*

*“We often swim against the tide,  
but we must never stop making waves for AHC”.*

**THANK YOU!**  
**SAFE TRAVELS HOME.**