

agenda: friday

- 8:00 am – 8:45 am** Families sign in, Distribution of packets, T-shirts, Badges, Check in children to “Kids” room
Meridian West
- 8:45 am – 9:00 am** Welcome from President Lynn Egan, and Hosts Laura and Josh Marszalek
Meridian Center
- 9:00 am -10:00 am** Drs Silver and Yano explain AHC, brief history, Meds, rescue meds, autonomic symptoms, how it changes as kids age with Q & A.
Meridian Center
- 10:00 am – 10:45 am** Dr Al George - Primer on ATP1A3 plus update on Northwestern drug and mice research
Meridian Center
- 10:45 am – 11:00 am** **Break**
- 11:00 am – 11:45 am** Dr Kevin Ess- update on Vanderbilt ISP cell line research
Meridian Center
- 11:45 am – 12:15 pm** Dr Erin Heinzen - Columbia research update and Epilepsy Genetics Initiative
Meridian Center
- 12:15 pm – 2:00 pm** **Family Lunch Break**
- 2:00 pm - 2:45 pm** Gene Andrasco- AHCF Impact statement, honorariums, research Working toward the Cure!
Meridian Center
- 2:45 pm – 3:30 pm** Rebecca Geyer - Attorney discussing insights to estate planning for special needs children
Meridian Center
- 3:30 pm – 3:45 pm** **Break**
- 3:45 pm – 4:30 pm** **Track One:** Nancy Beatty - PT with OT overlap, demonstrations in transferring kids, unconventional therapy ideas
Meridian Center
- Track Two:** Kim Nicholson - IEP’s and Navigating the school system
Circle East
- 4:30 pm – 5:00 pm** **Track One:** Dr Matt Sweney - Reviews the GW Pharma Epidiolex (Cannabidiol) study - will it work for AHC? -
Meridian Center
- Track Two:** Jane Furler – Life, Love & Cherished Memories of my daughter Danielle
Circle East
- 5:00 pm – 5:50 pm** AHC Documentary viewing “Human Timebombs”
Meridian Center
- 5:00 pm** **Dinner Break & Family Time**

agenda: saturday

- 8:00 am – 9:00 am** Families check in children to “Kids” room
Meridian West
- 9:00 am – 10:00 am** Dr Sandra Reyna – What will it take to get us to clinical trials and what is the role of a Natural History Database? (Interested families to submit video clips)
Meridian Center
- 10:00 am -11:00 am** Dr Terry Sanger – Dystonia management and AHC
Meridian Center
- 11:00 am – 11:15 am** **Break**
- 11:15 am – 12:00 am** **Track One:** Rinda Hall – Managing relationships in a stressful lifestyle
Meridian Center
- Track Two:** Deborah Hurst – Speech and Hippo therapy, developing trunk control to help control breath sounds and speech
Monument Suite
- Track Three:** Sibling session - I have a Sister or Brother with AHC and this is what I Think! Moderator - Phil Peckinpaugh
Circle West
- 12:00 pm – 12:30 pm** **Group Picture at Monument Circle**
- 12:30 pm - 2:00 pm** **AHCF Family Luncheon**
Meridian East
- 2:00 pm – 3:00 pm** **Track One:** Dr Kevin Ess Epilepsy and AHC, Meds- the good, the bad, the ugly
Meridian Center
- Track Two:** Alternative Therapies - CRA – Maria Dobbertien, Niagen - Tobe Cohen, Music Therapy - Melissa Munsell
Monument Suite
- 3:00 pm – 4:30 pm** Alice Belgrade - Behavior through the ages & how to survive it!
Meridian Center
- 4:30 pm – 5:15 pm** Dr Kathryn Swoboda & Dr Laurie Ozelius - ATP1A3 Where are we now? Where are we headed?
Meridian Center
- 5:15 pm – 5:50 pm** AHC Documentary viewing “Human Timebombs”
Meridian Center
- 5:15 pm** **Dinner Break & Family Time**
- 7:00 pm – 8:00 pm** **Ice Cream Social - games, quilt raffle, face painting**
Meridian East

agenda: sunday

- 8:00 am – 9:00 am** Families check in children to “Kids” room
Meridian West
- 9:00 am – 10:00 am** **Roundtable Discussions**
Meridian Center
#1: Transitioning to Adulthood, Living situations, Unique Young Adult Programs, Work, Activities
Moderator: Chris Vona
#2: Comfort Measures, Helpful Equipment, Social Media, Compassionate Talks, How to handle the changes in episodes as they get older
Moderator: Heather Gates
- 10:00 am - 11:15 am** Alice Belgrade - Behavior Part 2 - Your questions and her suggestions!
Meridian Center
- 11:15 am – 11:30 am** **Break**
- 11:30 am - 12:15 pm** Jae Chung – Fitness & Changing Habits for parents & caregivers
Meridian Center
- 12:15 pm – 12:45 pm** Lynn Egan – Conference wrap up –Foundation progress over the years, where we are today, announcing the location for the 2018 Family Meeting and lastly, our kids are special and going away thought is to **Celebrate them!**
Meridian Center

THANK YOU!
SAFE TRAVELS HOME.