



# Family Meeting – 2012 Agenda

Wednesday & Thursday June 27 - 28, 2012 – Clinic/Genetic Counseling Appointments  
Thursday June 28, 2012 – Individual Behavior Question Sessions

**Doctor/AHCF Board Dinner with Spouses – 5:30 – 7:30pm**

**Friday June 29, 2012**

**7:00 am – 8:00 am** Executive Board Breakfast Meeting  
**8:30 am – 9:30 am** Medical Advisory Board/AHCF Board Meeting  
**9:30 am – 10:30 am** Foreign Association/Executive Board Meeting  
**11:00 am – 11:45 am** Families Sign In, Distribution of packets, T-shirts, Badges, Raffle Ticket  
**11:45 am – 12:00 pm** Group Picture in Front of the Main Staircase  
**12:00 pm – 1:30 pm** Kick off Luncheon - Families & Physicians  
**1:45 pm – 2:30 pm** AHC Genetics Research Update – Tara Newcomb, MS, CGC  
**2:30 pm – 3:45 pm** Behavior Therapy Presentation - Alice Belgrade, M.S.Ed., L.C.P.C., BCBA, Behavior Analyst  
**3:45 pm – 4:00 pm** Break  
**4:00 pm – 5:30 pm** Behavior Q/A  
**6:00 pm – 7:30 pm** Dinner Meeting - Italian Quality of Life Study/ Executive Board  
**8:00 pm - 9:00 pm** AHCF Closed Board Meeting  
**9:00 pm – 10:00 pm** Open Board Meeting

**Saturday June 30, 2012**

**8:00 am – 8:45 am** Overview of AHC - Dr Ken Silver  
**8:45 am - 9:30 am** Epilepsy and AHC - Dr Mohamad Mikati  
**9:30 am – 10:00 am** SUDEP – Dr Kathryn Swoboda  
**10:00 am – 10:15 am** Break  
**10:15 am - 11:00 am** Dystonia Management in AHC - Dr Terry Sanger  
**11:00 am – 12:00 pm** AHC Association Reports from Italy – Rosaria Vavassori, Iceland - Sigurdur H Johannesson, and France - Dominique Poncelin  
**12:00 pm – 1:30 pm** Lunch Meeting Exec Comm/ Rosaria/Dominique  
**1:30 pm – 2:30 pm** Medical Home Presentation, Family Needs & Support, Medical Background & Referral, Ongoing Medical, Forms & Resources - Dr Mary Coleman (Developmental Pediatrician)  
**2:30 pm – 3:30 pm** Ice Cream Social -  
**3:30 pm – 5:30 pm** Medical Home continued, IEP'S & Transition - Joe R Goyas (Education Manager)

**Sunday July 1, 2012**

**9:00 am – 10:00 am** Parents/Caregivers addressing difficulties in raising an AHC child - moderated by Dr John R McQuaid, Ph.D. Professor of Clinical Psychology  
**10:00 am – 10:45 am** Panel of Young Adults with AHC, describing Life with the disorder – moderated by Dr John R. McQuaid, Ph.D.  
**10:00 am – 10:45 am** Sibling Support Meeting, exchanging ideas and thoughts when you have a brother or sister with AHC – moderated by Stephanie Egan  
**10:45 am – 11:00 am** Break  
**11:00 am – 11:45 am** Nutrition Guidance in AHC – Maria Raspolic, RD  
**11:45 am – 12:15 pm** AHCF direction for the future, closing remarks - Jeff Wuchich, AHCF  
End of Conference