

# AHCF Family Meeting 2011



Raleigh, North Carolina

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July 22nd, 23rd, 24th

Embassy Suites Hotel RDU/Cary

Actively Helping Children and Families with AHC

## AGENDA

Friday July 22nd

12:00 pm - 1:00pm

Families sign in, get badges, folder, shirts and tote.

1:00 pm - 1:10 pm

Welcome by Jeff Wuchich, AHCF President, Introduction of Board members and attendees.

1:10 pm - 2:00 pm

Dr Aga Lewelt will present an update on the Xyrem clinical trials with Q/A to follow.

2:00 pm - 3:00 pm

Dr Matt Sweney will give us a genetics studies update & Dr Erin Heinzen will discuss the study of genetics of rare disease as applied to AHC.

3:00 pm - 3:15 pm Break

3:15 pm - 4:45 pm

Physician panel with Dr Sandra Reyna, Dr Ken Silver, Dr Mohamad Mikati, Dr Aga Lewelt and Dr Matt Sweney, addressing questions and topics sent in by families of AHC children.

Saturday July 23rd

8:30 am - 9:30 am

Dr Ken Silver will present the history of AHC including Flunarizine studies.

9:30 am - 10:30 am

Dr Mikati will discuss the complex management of epilepsy and seizure issues related to AHC.

10:30 am - 10:45 am Break

10:45 am - 11:30 am

Dominique Poncelin AFHA President and Siggí Jóhannesson will report on the European AHC Associations and the International Rare Disease Communities Forum.

## AGENDA (Cont.)

11:30 am - 1:30 pm

AHCF sponsored Luncheon. Group pictures of children, physicians and families. Luncheon served, then raffle and presentation of fundraising awards. Jeff Wuchich, AHCF President will present future goals and plans.

1:30 pm - 2:30 pm

Dr Josh Magleby Phd will address behavior analysis, intervention and management relating to AHC and special needs children and young adults.

2:30 pm - 2:45 pm Break

2:45 pm - 4:45 pm

Behavior issues continued with Q/A from parents.

Sunday July 24th

9:00 am - 10:00 am

Dr Mikati will present new insights into AHC: A perspective on recent European and Japanese data.

10:00 am - 10:45 am

Parent Forum: Experienced AHC parents Karen Venti, Nandana Perera, Mary Kay Riley, Mark Egan, Carol Prunty, and Bill Gerber lead a discussion of everyday issues related to raising and living with an AHC child.

10:45 am - 11:00 am Break

11:00 am - 12:15 pm

Parent Forum continues.

12:15 pm - 12:30 pm

Closing remarks, announcement of next years conference time and place, collection of surveys.

End of Conference

The logo for the Alternating Hemiplegia of Childhood Foundation (AHCF) features the lowercase letters "ahcf" in a sans-serif font. The "a" is blue, the "h" is green, and the "c" is blue.

