



Alternating Hemiplegia of Childhood Foundation

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Dear Medical Community,

The Alternating Hemiplegia of Childhood Foundation is pleased to announce our First Annual CME Scientific conference to be held in conjunction with the AHCF Family Meeting on June 28 and 29, 2012 in beautiful San Francisco, California.

The main focus of this conference is to educate the medical community about Alternating Hemiplegia of Childhood (AHC). AHC is a rare neurological disorder in which repeated, transient attacks of hemiplegia occur. At the end of this conference you will be better able to identify, diagnose, manage and treat the AHC patient.

12 CME credit hours will be awarded to physicians who wish to become familiar with the rare disease AHC (see attached agenda) and attend the conference.

Registration for the conference is \$195.00 with lunch included in the registration fee.

You are also invited to attend the Family portion of the meeting from the afternoon of June 29, through noon on July 1, 2012 with no additional registration fee, starting with an AHCF sponsored luncheon with the AHC families. During the Family Meeting you will have the opportunity to interact with many families and AHC patients of all ages. You will learn what the AHC patient and family has to deal with on a daily basis and can attend as many of these lectures and parent discussions as you like.

We also welcome case studies of potential or complicated AHC patients to be presented during the conference. Medical histories, videos and photos should be submitted. These cases will be reviewed and then discussed by the AHC medical panel of experts. If you have a potential AHC patient who needs diagnostic confirmation or a complex AHC patient who needs medical management and would like their case presented, please contact Tara Newcomb at taran@genetics.utah.edu for more information



Hotel information: A block of rooms are reserved at the beautiful Hyatt Regency Burlingame for \$112.00 a night. To register, go to <https://resweb.passkey.com/go/althgeneralmtg> or if you prefer call Toll Free Reservations at (888-421-1442) and refer to the Alternating Hemiplegia of Childhood Foundation Meeting.



To register please go to <http://conta.cc/AfY4DP> or if you prefer, fill out the registration form below and send it with a check made out to AHCF:

AHCF
31250 Plymouth Rd
Livonia, Mi 48150

Name _____ Title _____ Discipline _____

Email _____

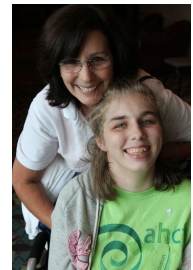
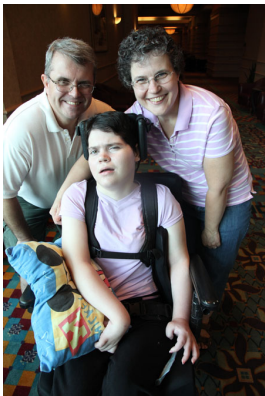
Phone _____

1. I will attend the Luncheon on Thursday June 28, 2012 - Yes _____ No _____
2. I will be staying for the Family Meeting – Some sessions _____ Entire Meeting _____
3. I will attend the Family Meeting Luncheon on Friday June 29 - Yes _____ No _____
4. I have an AHC patient in my practice Yes _____ No _____
5. I would like to donate the \$35 CME Certificate Registration fee to AHCF Yes _____ No _____ (please add this amount if paying by check)
6. I would like to order an AHCF T-shirt: (They are available in white or lime green with the AHCF logo on the front and San Francisco on the back) they are \$15 each. Place number and color for each size below and include the amount if paying by check.

Size: Adult Sm _____ Adult Med _____ Adult Lg _____ Adult XL _____ Adult XXL _____

Total Cost:	Registration	\$195
	CME donation	_____
	T-shirts	_____
	Total:	_____

Thank you for your interest in AHC and we look forward to seeing you in June!



Agenda:

Thursday, June 28, 2012

- 7:30-8:00 Registration, distribution of packets and badges
8:00-8:15 Welcome by Jeff Wuchich, AHCF President and Meeting Co-Director, Dr. Sandra Reyna

Session I: Clinical Features, Differential Diagnosis and Diagnostic Workup in AHC

Moderator: Dr. Kathryn Swoboda

- 8:15-8:45 Overview of AHC – Dr. Kenneth Silver
8:50-9:20 AHC clinical experience – Dr. Frederick Andermann
9:25-10:10 Differential Diagnosis and Workup in the patient with suspected AHC – Dr. Matt Sweney
10:15-10:45 **Coffee Break with Expert Panel Question and Answer Period**

Session II: Neurodevelopmental Issues and Non-paroxysmal Neurologic Symptoms and Signs

Moderator: Dr. Sandra Reyna

- 10:45-11:15 Non-paroxysmal motor signs and symptoms in AHC – Dr. Kathryn Swoboda
11:20-11:40 Sleep-disordered breathing, autonomic symptoms and signs – Dr. Kenneth Silver
11:45-12:30 Neurodevelopmental Issues and Quality of Life: Evaluating and optimizing functional outcomes in children with AHC – Dr. Aga Lewelt
12:30-1:30 Lunch (video or slideshow of AHC pictures & family stories)
1:30-2:00 Epilepsy Management in AHC Patients – Dr. Mohamad Mikati
2:05-2:35 SUDEP: Lessons from epilepsy patients and relevance to AHC- Dr. Matt Sweney
2:40-3:10 Panel Discussion: The importance of patient-relevant outcomes for therapeutic trials
Drs. Andermann, Silver, Mikati, Swoboda, Sweney, Lewelt, Reyna,
3:15-3:30 Coffee Break
3:30-4:00 Genetics Research Update: Identifying gene(s) causing AHC – Erin Heinzen, PhD
4:05-4:35 Summary of genetic studies in AHC: implications for improved diagnosis and future directions – Dr. Kathryn Swoboda
4:40-5:10 Lessons from Friedrich's Ataxia, from gene identification to therapeutics development -Jennifer Farmer, MS, CGC

Friday, June 29, 2012

- 7:30-8:00 am Sign in, distribution of surveys
8:05-8:35 Genetic Counseling in AHC: guidelines for testing and counseling in sporadic disorders due to new potentially dominant mutations – Tara Newcomb, MS, CGC

- 8:40-9:50am Case Presentations, - Submission of Videos/Documented Case Histories of Potential AHC Patients to be discussed by AHC Medical Panel including Dr. Kathryn Swoboda - Dr. Sandra Reyna – Dr. Matt Sweney - Dr. Aga Lewelt – Dr. Josh Magleby – Dr. Terry Sanger – Dr. Suzanne DeBrosse – Dr. Marcio Sotero de Menezes – Dr. Kenneth Silver – Dr. Mohamad Mikati and Dr. Frederick Andermann.
- 9:50-10:05am Coffee Break
- 10:05-11:00am Case Presentations continued with Panel Review
- 11:00-12:00pm Behavior Management in AHC Patients, Cognitive and Behavior Study - Josh Magleby, Phd
- 12:00-1:30pm Lunch with AHC Families/Physicians (informal and relaxed with family introductions, raffles, etc...)
- 1:30pm Beginning of the Family Meeting

For questions or further information please contact Sharon at sharon@ahckids.org