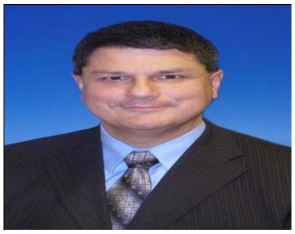
AHCF NEWSLETTER
Alternating Hemiplegia of Childhood Foundation
WINTER 2012 Volume 21, No.1



From the President

Jeff Wuchich, President

Greetings AHC Families,

Remember October, 2010 when we found out we were accepted for the Pepsi Refresh Campaign? We then started gearing up for the big adventure that resulted in a HUGE victory for the foundation and has given us renewed hope! Well, we need your help once again to bring us to victory.

We learned some great lessons from the Pepsi campaign and are now poised and ready to do something TRULY AMAZING!

Are you ready to make history? The AHCF is launching a fundraising campaign called “One in a Million”, named because the incidence of the disorder is believed to be approximately one in one million people. We are striving to get 1 million people to donate $1 to the foundation! Can we do it? YOU BET WE CAN!

We are going to launch this historic campaign on Rare Disease Day, February 29.

We will have materials and a step by step "how to" video for what YOU can do in your community to make this a HUGE success. We'll have clear direction on where the money we raise will be going, so it will be easy for people to get excited about helping us.

We have some great professionals helping us . Kudos to Time Warner Cable, MMI Public Relations, Smart Online, and Customer Magnetism. Make no mistake, this is a very ambitious goal. Some may say we are nuts, that this is impossible. Just remember, they said the same about our Pepsi Refresh run and WE PROVED THEM WRONG!

LET'S PROVE THEM WRONG AGAIN!

We need everyone’s help to make this a success! Stay tuned for details over the coming days.

1 IN A MILLION For AHC

Yours in Service,

Jeff Wuchich
jeff@ahckids.org

Editor Intro

Vicky Platt, Secretary

It is with great enthusiasm that the winter 2012 AHCF NEWSLETTER is ready for distribution to our AHC family and friends. As you will see, it is full of information and updates from a busy foundation. We hope that you find this issue informative and helpful. Please direct any comments, suggestions, or questions to me, or any of my fellow board members. Thanks and enjoy.

Vicky Platt - vicky@ahckids.org

Family Meeting News

Lynn Egan, Family Meeting Chair & Vice President

Are you starting to get the winter blues? Have you begun day-dreaming about summer vacation. Are you looking for a trip that connects you with our larger community? Well, do we have a suggestion for you!

Consider attending the AHCF Family Meeting this year. We have booked the Hyatt Regency San Francisco Airport in Burlingame, California from June 27th – July 1st. The Family Meeting will start with a luncheon on Friday, June 29th and counseling appointments will be available on the preceding days. We'll meet, socialize, share, learn, and rejoice in a variety of topics relevant to our families.

So far, programming includes presentations by genetic counselors, behavior therapists, AHC specialists, and AHC researchers. You'll have several opportunities to social with other families and to hear from foundation board members.

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.

Our registration for the next family meeting begins shortly and be sure to check the www.ahckids.org website for additional details.

Lynn Egan,
Lynn@ahckids.org

WOULD YOU LIKE TO ATTEND THE FAMILY MEETING? IS IT TOO DIFFICULT TO BRING YOUR FAMILY?

HAVE NO FEAR! EVERYONE IS WELCOME TO ATTEND, EITHER BY YOUR SELF OR WITH A FRIEND.

THERE WILL BE SEVERAL PEOPLE ATTENDING WITHOUT THEIR FAMILY.

IF YOU WANT TO, WE HOPE YOU WILL TOO!

Continuing Medical Education (CME) in San Francisco, CA

Sharon Ciccodicola, Meeting Planner

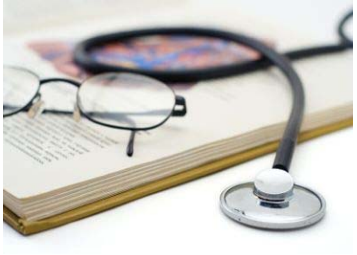
New THIS YEAR.

The Alternating Hemiplegia of Childhood Foundation is pleased to announce our First 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). At the end of this conference, medical professionals will be better able to identify, diagnose, manage and treat the AHC patient.

12 CME credit hours will be awarded to each physician who wishes to become familiar with AHC and complete the conference sessions and required end of meeting survey.

Registration for the conference is $195.00 with lunch and beverage breaks included in the registration fee.



The professionals are also invited to attend the Family portion of the meeting from the afternoon of June 29, through July 1, 2012 with no additional registration fee, starting with a luncheon with the AHC families. During the Family Meeting they will have the opportunity to interact with many families and AHC patients of all ages. They 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 they like.

The CME conference is only for medical professionals and is closed to families arriving early.

However, we would love for you to take the registration letter on our website and share it with the medical professionals working with your family. Feel free to share it with neurologists, pediatricians, therapists, etc.

A summary of the conference will be made available on the foundation website after the conference for those interested in additional information.

If you have any questions about the CME conference, please contact Sharon Ciccodicola at Sharon@ahckids.org

AHCF Office
31250 Plymouth Rd
Livonia, MI 48150
The AHCF is a 501(c) (3) organization
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Fundraising News

PUT THE FUN IN FUNDRAISER

Hello Everyone,

My name is Mollie, mother to Austin. We are in the midst of a Fundraiser to raise $$$$ for AHCF and I'm inviting ALL to participate!!! It’s very simple. HoopsMania is geared for the March Madness College Basketball Tournament.

Your ticket has 8 randomly selected teams, and the most points scored during all rounds wins a prize up to $1000.

Ticketholders have a 1 in 29 chance of winning!!!

Tickets are $10 each and $7 of the $10 goes to the Foundation!

So, the more tickets we sell, the more $$$$ for research! Tickets can be purchased thru me, or online...

Follow this link to purchase online https://www.charitymania.com/give/L2001.

If you would like to sell some, please send me an email at merpenbeck@zoomtown.com and I will drop some in the mail. Last day to activate a ticket is Mar 14, 2012, so we need to sell, sell, sell!!!!
Thank you!!!

Molly Erpenbeck

merpenbeck@zoomtown.com

Foundation News

News from the Research Team in Utah

This is a very exciting opportunity for the research team at the University of Utah. With one abstract, Dr. Aga Lewelt received two different forums to present her paper titled, “Single-Center Phase I/II Trial of Sodium Oxybate in Patients with Alternating Hemiplegia of Childhood” .

Dr. Lewelt will be giving her presentation at the American Academy of Neurology 64th Annual Meeting, April 21 to April 28, 2012 at the Ernest N. Morial Convention Center in New Orleans, LA.

This is a great opportunity to increase visibility about AHC and the challenges ahead for clinical trials - at a very well-attended Neurology meeting. Congratulations to Dr. Lewelt for her hard work.

Foundation News Continued

News from Overseas

With the new year well underway, I would like to briefly update you on the latest news about genetic research, mainly as developed after the International Workshop on Alternating Hemiplegia, held in Genoa, Italy on November 11, 2011.

In parallel to the Workshop, together with the French association (AFHA), we organized a Meeting of the European genetic groups that are currently engaged in research on AHC. Thanks to this meeting, a cooperation agreement was obtained between the participating genetic groups, then refined through following contacts for the establishment of a European consortium for genetic research on Alternating Hemiplegia and specifically; for the realization of a collaborative exome study in European patients.

On the Italian side, the exome study, started by Professors Neri and Gurrieri continues positively. The preliminary results were presented at the International Workshop in March 2011.The study was regarding exome sequencing in the DNA of a first group of six patients selected from the I.B.AHC Biobank, with the funding of A.I.S.E.A.

The second phase of the study is currently going on, with the use of additional genetic material from the I.B.AHC Biobank (of the same six patients and of their parents). This phase of the study is made possible by the funding of the French AFHA and because of the collaboration agreement mentioned above.

On behalf of Professor Neri and Professor Gurrieri, I am also pleased to announce that a new research project, as a continuation of this study, was presented by them to the last Call for projects of the Italian Telethon. In addition, AFHA is among the external collaborators of this project while the French association has agreed to provide the samples, upon request, to the French Biobank for AHC.

Material from the International Workshop in Genoa can be found in the documentation area of the I.B.AHC public website www.ibahc.org/index-eng.html . As soon as possible, we will upload also the video-recordings of all the given speeches, both in the original language and translated.

Other articles about the Workshop can be found on our blog at this link: http://blog.aisea.org/articolo.asp?articolo=92

Many thanks to you all for your attention and collaboration, and best regards.

Rosaria Vavassori

A.I.S.EA
Associazione Italiana per la Sindrome di Emiplegia Alternante

Association Française de l'Hémiplégie Alternante

Foundation News Continued

Congratulations are in Order

The Alternating Hemiplegia of Childhood Foundation Board is excited to announce the election of Cate Cohen and Bill Gerber to the board. Please join the AHCF Board in welcoming Cate and Bill to the board.

Grant Awarded to Utah Research Team

The Alternating Hemiplegia of Childhood Foundation Board is pleased to announce that a grant in the amount of $175,000 was awarded to the Pediatric Motor Disorder Research Program in January 2012. Our friends at the University of Utah are now working on a two phase grant to benefit all families with AHC.

Part one of the grant is the clinical and genetics studies in AHC and genotype/phenotype correlations.

Genotype - This is the "internally coded, inheritable information" carried by all living organisms. This stored information is used as a "blueprint" or set of instructions for building and maintaining a living creature. These instructions are found within almost all cells (the "internal" part), they are written in a coded language (the genetic code), they are copied at the time of cell division or reproduction and are passed from one generation to the next ("inheritable"). These instructions are intimately involved with all aspects of the life of a cell or an organism. They control everything from the formation of protein macromolecules, to the regulation of metabolism and synthesis.

Phenotype - This is the "outward, physical manifestation" of the organism. These are the physical parts, the sum of the atoms, molecules, macromolecules, cells, structures, metabolism, energy utilization, tissues, organs, reflexes and behaviors; anything that is part of the observable structure, function or behavior of a living organism.

Part two of the grant is the creation of an online AHC Database.

The core of the database will be done in 6 months, however there is no way to tell exactly how long it will take to compile 12 years of records. They will target key clinical markers in the data and it will be an ongoing project with additions and changes based on need. For instance, at the end of this compilation we should be able to easily separate patient populations based on determining factors ie... separate epilepsy from non- epilepsy patients, those with abnormal spinal fluid and prolactin levels, diabetics etc...

This grant is building on the work taken on by the Pepsi Challenge Grant. It will assist the foundation in many ways and will move us toward the goal of finding the cause of AHC and helping families affected by AHC. Additional information about this grant, as well as the Pepsi Challenge Grant, will be discussed at the Family Meeting in San Francisco. We hope you will attend. We look forward to sharing many great findings from this ongoing research with you as soon as possible.

Vicky Platt, AHCF Secretary
vicky@ahckids.org