



AHCF NEWSLETTER

Alternating Hemiplegia of Childhood Foundation

SUMMER 2011 Volume 20, No. 2



Editor Intro

Vicky Platt, Public Relations Committee Chair

It is with great enthusiasm that the summer 2011 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



From the President
Jeff Wuchich, President

Greetings AHC Families,

What an exciting summer we have in store for us here at the AHC Foundation! Lots of wonderful activity all designed to help make the lives of those suffering with AHC (and their families) better!

Here are some of the highlights:

- We already launched our new logo and redesigned our website! It is packed with information for our families and resources to inform potential donors, the media, and the medical community.
- Currently, we are in the midst of an online voting contest for a \$250K grant (like the Pepsi Refresh, but easier to vote) through Vivint. See www.ahckids.org to **VOTE & SHARE SO WE WIN!** We'll also be gearing up for several walks around the USA in September, and a major fundraising campaign in November.
- Speaking of the Pepsi Refresh Project, the genome sequencing of the samples should be finished soon and the complex analysis will begin thereafter. Our research team in Utah will be hard at work sorting through ENORMOUS amounts of data (so we'll have to be patient).
- Our family meeting is just around the corner July 22-24 in Raleigh, NC (which means your president will be your host). Kudos to Lynn Egan, Renee Wuchich, Sharon Ciccodicola, Vicky Platt, and many others for the effort they are putting into making this event a huge success!

Check out the rest of this newsletter and you'll find more details! As always you can reach me via phone or email with any questions! Have an awesome summer and I hope to see many of you soon!

Yours in Service,

Jeff Wuchich

jeff@ahckids.org

AHCF Office
31250 Plymouth Rd
Livonia, MI 48150
 The AHCF is a 501(c) (3) organization
Our federal tax ID# is 38-3225425

Actively Helping Children and Families affected by AHC
www.ahckids.org



New Logo for AHCF!

Sharon Ciccodicola, AHCF Coordinator

In the last year AHCF has undergone many changes. As we have examined our organization one of the most important things we identified in need of updating was our Logo. This is “our brand.” It instantly identifies us and should be recognizable worldwide.

Because our title includes the word “Childhood,” we recognized the need to make people aware that although AHC is diagnosed in childhood the children don’t outgrow it. In fact, since AHC became widely known, many families now have a person with AHC that is 20 years-old, or older, in their household.

The logo also needed to be “modernized”, so to speak, in order to be vibrant and eye catching in this day of the digital footprint and ever increasing social media. We wanted it to be memorable and yet evoke a feeling of hope.

It was quite a learning experience with several setbacks to overcome. Vicky Platt and her sister, Diane Evans, worked together to capture the spirit of our organization and designed a beautiful representation of AHCF! Thanks to you both for your creativity!

The original idea was for a spiral with inside. The executive board liked the Vicky worked to get it just right with to our marketer, Michelle, and she enhancement. At first glance it looks shiny, representing hope. People release of a hand in dystonia or a mirror image reflection perhaps also reflecting about AHC and the way to



our Foundation name cradled concept immediately. Diane and our feedback. We then showed it gave it to her logo team for playful and bright, colorful and have interpreted the spiral as a simple beautiful rose. It sits on a meaning that we are always a cure.

The full name “Alternating Hemiplegia of Childhood Foundation” personifies the more mature person with AHC and is cradled inside the spiral while the younger children are represented by the lower case lettering, playfully on the tip of the spiral. The alternating use of green and blue represent one of the most distinguishing characteristics of AHC episodes. I’m sure others will find their own interpretation!

We will be able to use this design in its entirety; or use the **ahcf** as a stand-alone logo. We also can incorporate the coloring and lettering in our Foundation Tag Line – **actively helping children and families with AHC.**

The logo is available in a number of different file formats for use on fundraising and awareness materials, as well as business forms and official documents. Contact the AHCF office or find it on our website to obtain the logo templates and look for it everywhere as we spread the word about AHC!

Actively Helping Children and Families affected by AHC
www.ahckids.org



AHCF NEWSLETTER

Alternating Hemiplegia of Childhood Foundation

SUMMER 2011 Volume 20, No. 2



Family Meeting News

Lynn Egan, Family Meeting Chair

Our family meeting begins in a month! I'm very excited about the agenda and our speakers! Our meeting begins on Friday afternoon and ends Sunday at 12:30. Our arrangements at the Embassy Suites are ideal, with the children right next door. Jeff and Renee Wuchich have organized an amazing group of volunteers to entertain and watch our 26 children/young adults/adults ranging from 1 ½ yrs to 28 years old.

It's still not too late to book a room at the discounted rate. We gained a few days and will release all 'unbooked' rooms on Wednesday, June 22. If you have booked a reservation that was not covered under the AHC group discount or you have booked two rooms and would like adjoining room, contact Kiella Pate at Embassy Suites at 919-459-1510 or email kiella.pate@jgh.com. Include in your email your confirmation number.

I look forward to meeting all new parents and connecting again with those families that I have meet! See you soon!

Tentative Agenda

Wednesday 7/20/11

8:30 am – 5:00 pm Physicals

Thursday 7/21/11

8:30 am – 5:00 pm Physicals

Friday 7/22/11

8:30 am -12:00 pm Physicals

12:30pm - 1:00 pm Families sign in, get name badges, packets etc...

1:00 pm - 2:00 pm Conference begins,

2:00 pm - 3:00 pm Genetics update by Dr Matt Sweney with Dr Erin Heinzen

3:00 pm - 3:15 pm Break

3:15 pm - 5:00 pm Physician panel

7:30 pm - 9:30 pm AHCF Board Meeting (Closed session first, open session second half)

Saturday 7/23/11

8:30 am - 9:30 am Dr Silver, The History of AHC / Flunarizine Studies

9:30 am - 10:30 am Dr Mikati, Epilepsy, Seizures and AHC 40 min /20 min Q/A

10:30 am - 10:45 am Break

10:45 am - 11:30 am Reports on European AHC Associations and The International Rare Disease Communities Forum

11:30 am - 1:30 pm Foundation sponsored Luncheon with dessert and Group picture

1:30 pm - 2:30 pm Josh Magleby PhD. Behavior management relating to AHC and special needs children

2:30 pm - 2:45 pm Break

2:45 pm - 5:00 pm Behavior continued with Q/A from parents

Sunday 7/24/11

9:00 am - 10:00 am Dr Mikati, Insights into AHC: Perspective on Recent European and Japanese Data

10:00 am - 10:45 am Parent Forum

10:45 am - 11:00 am Break

11:00 am - 12:15 pm Parent Forum

12:15 pm - 12:30 pm Announcements, Surveys and Farewell

End of Conference

Actively Helping Children and Families affected by AHC

www.ahckids.org



Meeting in Raleigh, North Carolina

Renee Wuchich, Site Coordinator

We are very excited about the Family Meeting and are looking forward to seeing everyone in Raleigh, NC. Accommodations are at the Embassy Suites in Cary, NC. It is a beautiful hotel where every suite consists of a private bedroom with one king size or two double beds, a desk, a separate parlor with a sofa bed and well-lit dining/work table. Each room contains a kitchenette, which includes a wet bar, microwave oven, refrigerator and a coffee maker with service for 4 people. Also included are high speed internet access and two televisions. Some hotel highlights: complimentary cooked to order breakfast, complimentary manager's reception, complimentary 24 hour shuttle service to and from the airport, indoor pool, fitness center, basketball and tennis courts. In addition, there are many good restaurants within walking distance of the hotel.

When you arrive at the hotel you will receive an official visitor's guide for Raleigh outlining all the great places to visit. If you would like to plan ahead, please go to the following website: http://www.visitraleigh.com/visitors/things_to_do. Raleigh has great parks and beautiful greenways, or if it's too hot outside, we have wonderful family museums.

During the family meeting childcare will be provided. We have reserved a large room for the kids and young adults next to the conference room. I have lined up some great volunteers to entertain the kids. Some of them are special education teachers, daycare/nursery providers, EMT's, moms and teenagers. For the younger children activities will include toys, games, puzzles, books, music, outside time and if we are lucky hopefully a nap after lunch. For the older kids there will be one TV set up with a DVD player and one TV set up with a Wii station. There will also be board games. If your child has a favorite movie or game please let me know and I will try to have it available.

If you have any questions regarding childcare, accommodations or local attractions please email me at rwuchichcpa@nc.rr.com. If there is anything I can do to assist with your travel plans, please let me know.

Renee Wuchich

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 YOURSELF OR WITH A FRIEND.

THERE WILL BE SEVERAL PEOPLE ATTENDING WITHOUT THEIR FAMILY.

IF YOU WANT TO, WE HOPE YOU WILL TOO!

Actively Helping Children and Families affected by AHC
www.ahckids.org



Fundraising News

Jeff Wuchich, Fundraising Chair

Hello AHCF Families and Friends,

Starting **Tuesday June 14th, 2011** we need your help to vote every day in the **Vivint** contest to **win \$250,000.00** to further research into AHC, develop treatments and trial medications, teach the public and professionals about AHC and ultimately find a cure!

Once you are on Facebook, a must to participate, it's easy!

- Click on the banner on the left or go to <http://www.vivint.com/givesbackproject/charity/57>
- "like" Vivint on Facebook, (login)
- Vote for Alternating Hemiplegia of Childhood Foundation, **ONE VOTE EVERYDAY UNTIL AUGUST 27TH.**

We will need thousands and thousands of votes to win and are up against some tough competition, so please **SEND A MESSAGE to each and every Friend you have on Facebook.**

Remind your friends daily to vote and recruit as many new Facebook groups as you can to help: alumni associations, churches, support groups, sports teams, etc...

We've been victorious before, we can do it again! It takes millions of dollars to find a cure and the AHC kids are counting on us

Top prize is \$250,000.00. Top Charity in each region wins \$100, 00.00. For reference, we are in the Eastern region.

Matching Gifts from Vivint during contest

Want to make a donation to AHCF? Vivint will match donations made by the public on a one-to-one basis, up to \$2,500 per finalist charity.



All gifts must be made through the Vivint Gives Back website <<http://www.vivint.com/givesbackproject>> during the matching period to be eligible. For a public donation to qualify for a match through the Vivint Gives Back Project, the donation must be a charitable contribution. These contributions are deductible on your federal income tax return.

Vivint Gives Back will match up to a maximum of \$50 for each individual donor. Vivint Gives Back will match public donations up to \$2,500 for each finalist charity.

Jeff Wuchich
jeff@ahckids.org

Actively Helping Children and Families affected by AHC
www.ahckids.org



AHCF NEWSLETTER

Alternating Hemiplegia of Childhood Foundation

SUMMER 2011 Volume 20, No. 2



Foundation News

Check out the New AHCF Website!

Last week, we entered the digital age with a new look, and outlook, by updating the AHCF website.

Our goal is to provide comprehensive information about AHC and extensively develop our areas of support for families living with AHC. We want to be press ready and will soon have a complete media kit available. We are working on templates and guidelines for fundraising and event planning. What is the information you'd like to see?

We now have many ways to get connected, involved, and engaged with other AHC families, friends and supporters. Everyone is invited to sign up for our Email list to keep up with the latest information about AHC and AHCF. Don't miss the Events Calendar with all of our Conferences, Campaigns, Fundraisers and the Walks posted. Please let us know if you have an event to post!

If you would like to send pictures of your kids to be integrated into the site, please send to Sharon Ciccodicola. We also hope to post new press releases, articles or videos of your AHC child/adult and your family.

In the future, look for an e-commerce store, an "ask a doctor" feature, and digital storytelling. We are actively exploring ways to attract donors to help us reach our goals and have planned the new site to educate them about AHC. The website will continue to evolve so please check in often and send us your feedback and ideas!

Board of Directors

Jeff Wuchich, President
jeff@ahckids.org

Lynn Egan, Vice President
lynn@ahckids.org

Sharon Ciccodicola, Medical Liaison
sharon@ahckids.org

Gene Andrasco, Co-Treasurer
gene@ahckids.org

Doug Morris, Co-Treasurer
doug@ahckids.org

Vicky Platt, Secretary
vicky@ahckids.org

Mollie Weiler Erpenbeck, Member
mollie@ahckids.org

Beverly Hensley, Member
Beverly@ahckids.org

Dr. Joe George, Member
mg092242@aol.com

Mary Kay Riley, Member
marykay@ahckids.org

Carol Presunka, Member
carol@ahckids.org

Actively Helping Children and Families affected by AHC
www.ahckids.org