



AHCF NEWSLETTER

Alternating Hemiplegia of Childhood Foundation

FALL 2010 Volume 19, No. 1



Editor Intro

Vicky Platt, Public Relations Committee Chair

It is with great enthusiasm that the Fall 2010 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. A lot of changes took place in 2010 and the entire foundation board is excited to describe those to our community.

The foundation board created a public relations committee, of which I am chair, to ensure that news is communicated to you in a timely basis. We look forward to increasing the frequency with which we publish the newsletter and hope you find this issue informative.

Please direct any comments, suggestions, or question to me or any my fellow board members. Thanks and enjoy.

Vicky Platt

vaplatt@gmail.com

What's New with the Foundation?

Sharon Ciccodicola, Foundation Coordinator

Beginning March 1, 2010, I was hired by the Board of Directors as Coordinator for the Alternating Hemiplegia of Childhood Foundation. My role is to be the primary source of communication and organization in the foundation. I will coordinate and direct volunteer efforts within the foundation, direct and disseminate news, ideas, and updates, provide direction for families in crisis or those seeking information, and respond to physicians and other support services, whether they be medical, educational, governmental, or religious in nature.

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There is a lot of news to share with you, so let's get to it.

Board President Richard George Resigns Effective August 2010

As a representative of the AHCF Board, I would like to take this opportunity to express my profound gratitude to Richard George for all of the dedication, drive and foresight he showed while President of the Alternating Hemiplegia of Childhood Foundation.

Since the day his son Nicky was diagnosed, he worked night and day to explore every available avenue to find a cure for AHC. Having raised hundreds of thousands of dollars to benefit the foundation, he inspired others to join in these efforts to meet the never ending demands of research funding.

His heartfelt commitment and love for this cause is what inspired me as well as others to volunteer with the foundation. From the bottom of my heart and with a big hug from our AHC family, we say thank you!

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Jeff Wuchich Named New AHC President

On August 10, 2010, the AHC Board of Directors unanimously voted to name Jeff Wuchich President of the foundation. Jeff is an accomplished sales executive with a very impressive resume (see ahckids.org).

Jeff and his wife Renee reside in Rolesville, North Carolina, a suburb of Raleigh. They are parents to Matthew (3) who was diagnosed with AHC at 18 months of age. After Matthew was diagnosed, Jeff immediately became active in the AHC community. He is an engaging conversationalist who is ready to take on this demanding role. Please join me in welcoming Jeff to the AHC Board!

Vicky Platt Announced as AHC Board Member

Vicky Platt is the newest member of the AHC Board, filling the vacancy left by Karen Atchoo earlier this year. Vicky lives in Mount Prospect, Illinois, a suburb of Chicago, with her husband Andy, and daughters Emma (8), and Aria (6). Emma was diagnosed with AHC at 16 months of age. In addition to her responsibilities as board member, Vicky was appointed Public Relations Committee Chair. Please join me in welcoming Vicky to the AHC Board!

Organizational changes that took place the first half of the year are numerous. We now have the ability to accept Pay Pal donations for fundraising activities. We are active on Facebook and are registered with "Guidestar", a database that contains beneficiary information utilized by the group "Causes" on Facebook. Our Medical Advisory Board was updated with confirmations from Drs. Silver, Mikati, and Andermann. Along with Dominique Poncelin of the French association, the Yahoo Discussion group now has a moderator based in the U.S., that's me, Sharon Ciccodicola.

If you haven't been to the foundation website lately, you must give it a look. Jay Gates, with input from Heather, spent hours updating the website for us. Many thanks Jay, it looks great! Thanks also go out to Mallory West (sister of Caroline West who has AHC), for posting a glossary on our website. And thanks to Vicky Platt for creating a bibliography of medical articles on AHC. It is posted on our website and will be updated quarterly.

What's On the Horizon?

- Watch for information about a Family Meeting in 2011.
- We're looking to create a state-by-state list of AHC families.
- We're planning to create a medication registry to determine patterns of usage and effectiveness.
- We're implementing a strategy to keep in contact with AHC groups around the world.
- We're creating "how-to" models to make fundraising easier for our volunteers.
- We're reaching out to other small foundations of rare disorders to learn from their successes.

The foundation welcomes your suggestions and looks forward to bringing in more volunteers to help make our foundation a success.

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

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From the President Jeff Wuchich, President

It is with much enthusiasm and gratitude that I accept the Board's approval to appoint me as President of the Alternating Hemiplegia of Childhood Foundation (AHCF). A public thank you to the entire Board, and particularly my predecessor, Richard George, for the tireless work they have done to advance understanding of this debilitating disorder. A special thank you also to Sharon Ciccodicola, for the incredible work she continues to perform on behalf of the AHC community. While I of course wish that my 3 year old son did not have this disorder, I am thankful for the opportunity to leverage the leadership skills from my professional life to positively impact the lives of all afflicted with AHC.

I have delved into the history of the AHCF during the nomination period, and have gained a rather comprehensive understanding of where we have come from, and more importantly, where we need to go. The foundation has done much, but now stands at a crossroads with some key challenges. I'll outline here those issues and my vision for how we (and by "we" I mean all of us who are touched by AHC in some way) might address them effectively.

1. **AWARENESS/EDUCATION:** While it is clear that AHC is an extremely rare disorder, there are an abundance of cases that go undiagnosed. This fact comes from a lack of understanding in the medical community about AHC. One good way to remedy that is through a concerted effort /campaigns to reach out to the neurological community worldwide. This may involve print, email, video, speaking engagements, and the like. In tandem, must be campaigns to make those families touched by AHC aware of the Foundation's existence and the resources available to maximize their loved one's potential.

2. **DATA COLLECTION AND ANALYSIS:** With the rarity of AHC, one of the fundamental barriers to effective research is lack of data. With so few cases spread across the globe and crossing all manner of socioeconomic strata, it becomes a very daunting task to even begin to potentially isolate the underlying causes of this disorder, let alone treatments or a cure. We must remedy this situation by registering every AHC patient worldwide with the Foundation/research team. We will strive to expand upon existing questionnaires & data collection mechanisms. Most importantly each of us then will have to be as diligent, accurate & thorough as possible in using these data collection materials on a daily basis.

3. **FUNDRAISING:** Naturally, most, if not all, of these initiatives will require one essential element: funding. The foundation's and AHC parents' fundraising efforts to date have been impressive indeed.

Yet if we are to be of maximum service to the sufferers of AHC, we must

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From the President Continued...

work together to dramatically increase the resources available. To date various parents in the AHC community have conducted a variety of different fundraising endeavors. I commend each and every one of these. In fact, it is important that we learn from these different efforts what has worked and what has not. We will strive then to create a duplicable process for these fundraising scenarios, to make it as easy as possible for many events to take place.

Finally, I want to make sure the AHC community knows that I have an "open door" policy. Feel free to approach me with any questions, comments, suggestions, feedback, and the like. I will communicate regularly with the AHC families through a variety of media (newsletter, e-blast, blog posting to the website, etc.) at intervals TBD, but certainly whenever significant events occur or are about to occur. With the arduous task ahead of us, I am certain at times it will appear that we may be stagnating or not progressing at a pace that meets your expectations. Rest assured that the foundation and the researchers will persevere as aggressively as possible to achieve these ambitious goals that I have laid out.

Please remember, however, that scientific advancement is a painstakingly slow process and that success here will depend on each of us doing our part. Again, if we encourage, strengthen, and support each other in all aspects of the race to cure AHC, then we will have the best possible chance of giving our children the most positive outcome. Thank you in advance for joining me on this adventure!

Jeff Wuchich
jwuchich@nc.rr.com

A detailed outline of Jeff's plan can be found at www.ahckids.org.

A New Road

Richie George, Past President

On February 8th, 2010, I submitted my resignation as the AHCF President to the Foundation Board to take effect August 10, 2010. The foundation started back in 1993 and since then, although the road was bumpy, we made many exciting advancements. In the past, we were fortunate enough to fund the phenomenal research done by Dr. Swoboda and her team at the University of Utah. I cannot believe how quickly time passes.

During my tenure as Board President, I lead the foundation's fundraising efforts. With the advances we experienced in research, it doubled the commitment needed to fund the research. I am excited to share with you the families who gave of their time, energy and love. They included the Gerber's, Wagner's, Platt's, Andrasco's, Rosado's, Holloway's, Ryan's, Manas', Sliwka's, Plotke's, Tasi's, Venti's, Palmerino's, and George's. In addition, we still have funds coming in from United Way designations, Charity Motors, Memorials and Jeans Days. One of the most exciting new ways we are raising funds is via the Internet and more specifically, the Chase Community Giving Contest.

Earlier this year, the foundation decided to hire Sharon Ciccodicola, who in addition to being our Medical Liaison is now the Foundation Coordinator. Sharon is working with our families to provide effective direction of volunteers within the organization. She is the "go-to" person for all questions, ideas, and news about the Foundation. She is responsible for providing direction to families in crisis or those seeking information about the disease. Several years of work has been

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done by Sharon in just a few short months. She has totally reenergized everyone involved with the foundation and THIS IS DEFINITELY THE GOOD NEWS!!! Thanks Sharon.

A new era in the Foundation is starting as Jeff Wuchich assumes the role of AHCF President. Let's welcome Jeff with open arms and hearts to raise money and move forward to achieving our goals for our children. I also ask the rest of our AHC families to get on board to help build our reserves and support our new direction. With more of you coming forward, we will have lots of good news to share!!

THANK YOU again to all families who have helped raise money to help our children. It has been my honor to be your president. I remain at your service and am here for all the families.

Richie George
richardgeorge@ameritech.net

Medical News

Flunarizine

On an emergency basis, the foundation office has the capability to help get Flunarizine to families in danger of running out before their next regular shipment. If you are in need of assistance, please contact Sharon Ciccodicola at sciccocala@comcast.net.

Do You Have Questions?

In the last six months, the Foundation received, on average, 10 to 15 calls or emails per week from physician offices, support services, or individuals seeking information to do with AHC or one of its patients. These are separate from AHC parent calls seeking help, making general inquiries, or suggesting ideas. The goal is to respond to all inquiries and emails in a timely manner and be as helpful as possible. If you are in need of assistance, please feel free to contact any foundation board member or the foundation coordinator.



Join the "AHC Registry" by

Dr. Kathryn Swoboda

All individuals with Alternating Hemiplegia of Childhood (AHC) are invited to join the AHC Registry coordinated at the University of Utah. This study involves a one-page questionnaire, the AHC Registry form, that may be completed securely either online or over the phone.

We are seeking to enroll individuals in the AHC Registry so that we may quickly and efficiently contact you in the future with information about new treatments for AHC, or about studies for which you may be eligible. Additionally, this will provide us with an accurate "head count" of all people with AHC.

The primary benefit to you is that you will be contacted as soon as we launch any AHC research study in which you may be eligible to participate, or as soon as we find a new treatment for AHC. The secondary benefit is that you will know

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Medical News Continued...

that you are accounted for in the AHC Registry, which is our way of counting how many people have AHC. Knowing how many people have the disease is an important piece of information for obtaining funding of studies on AHC. Risks include the very small risk of loss of confidentiality that results from any activity involved in disclosing personal information. Completing the AHC Registry form takes about 10 minutes.

If you, or anyone you know, might be interested, please visit our website:
<http://medicine.utah.edu/neurology/research/swoboda/ahc>.

Or, contact the Swoboda Research Team at 1-801-585-9717.

Dr. Kathryn Swoboda, MD
University of Utah

Individuals with Alternating Hemiplegia of Childhood (AHC) Needed for a Research Study **Dr. Kathryn Swoboda**

We are recruiting all individuals with Alternating Hemiplegia of Childhood to participate in an online or over the phone questionnaire to learn more about AHC.

BENEFITS & RISKS:

The primary benefit is to gain knowledge regarding the characteristics of AHC in children and adults. There is no immediate personal benefit to you for completing the AHC Questionnaire. However, we hope that information gained will help us in our search for effective therapies in AHC. Risks include the very small risk of loss of confidentiality that results from any activity involved in disclosing personal information. You will be asked to submit the AHC Questionnaire once, but we may need to update it in the future. This will involve a minimal time commitment on your part.

WHAT & WHERE:

This study involves completing a questionnaire that asks about demographic data and medical history. The AHC Questionnaire may be completed online or via phone.

COMPENSATION:

This is a voluntary study, and there will be no compensation to participate.

HOW:

If you or anyone you know might be interested in participating, please visit our website:

<http://medicine.utah.edu/neurology/research/swoboda/ahc/Ongoing%20Research%20Studies.htm>. Or, contact the Swoboda Research Team at 1-801-585-9717.

Dr. Kathryn Swoboda
University of Utah



Medical News Continued...

AHC and the Cognitive Research Study **Joshua Magleby, PhD**

It has been a long time since I have written something for the AHC newsletter, and it is my pleasure now to include this update in the current one.

I continue to be involved in researching the cognitive sequelae, condition, of AHC. Currently, I am an investigator with the clinical drug trial being conducted by Aga Lewelt, MD in Salt Lake City, Utah. My part focuses on assessing changes to cognitive functioning to individuals during their use of the drug. Hopefully, some positive changes in thinking skills will be evident, which would then lend further credence to the viability of this particular medication in the treatment of AHC. I traveled to SLC in July to meet with Dr. Lewelt and participate in some of these assessments. Other areas of research include focusing on behavioral symptoms associated with AHC and finding the most effective treatments for those behaviors, as well as continuing to add to the AHC testing database.

As many of you know, I conducted the first research study that examined cognitive and behavioral sequelae of children and adolescents with AHC. This study, which ran from 2003-2007, involved more than 40 children and adolescents and their families. Currently, we are awaiting recommended changes to the manuscript, and hope to have the study published by the end of this year. Once published, I will send a copy to the AHC Foundation that will then hopefully be made available online for all those interested. Once again, my sincerest gratitude to those of you who allowed me to work with your children...I hope that this study is the "taking off point" for future research into cognitive and behavioral assessment of AHC.

In terms of my life outside of AHC, I currently work as assessment supervisor for a large community mental health center in downtown Cleveland, and also maintain a small private practice. In August, I made the move to private practice full-time in Fairlawn, Ohio (just west of Akron). If you ever find yourself in the area, please feel free to stop by...I always enjoy meeting with AHC families. If you are interested in having your child or adolescent participate in our research assessments, please contact me at maglebyphd@gmail.com.

Joshua Magleby, PhD
 Clinical Neuropsychologist



Updates on AHC Research at the University of Utah **Dr. Sandra P. Reyna and Dr. Aga Lewelt**

The Pediatric Motor Disorders Program at the University of Utah currently has 53 AHC families enrolled in our online registry! The AHC Registry allows us to quickly and efficiently contact families in the future with information about new treatments for AHC, or about studies for which they may be eligible. Additionally, this provides us a rough "head count" of all people with AHC. If you are interested in joining our online registry (and have not done so already), please visit our website:

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<http://medicine.utah.edu/neurology/research/swoboda/ahc> and click on “The AHC Registry.”

We also have 17 families who have completed our updated AHC medical questionnaire! The primary benefit of this questionnaire is knowledge gained regarding the characteristics of AHC in children and adults. There is no immediate personal benefit for participating in completing the AHC Questionnaire; however, we hope that information gained will help us in our search for effective therapies in AHC. The questionnaire can also be found on the above website and faxed back to our research office (fax: 801-587-9346). If possible, please complete the online registry before completing the questionnaire.

And last, but not least, our clinical trial of Sodium Oxybate in children with AHC is well underway and making progress. We currently have four participants enrolled and two in the screening process. For this pilot study, our total participation is capped at six. Three of the four participants have completed their six weeks on Sodium Oxybate and are in the follow-up stage of the study. The fourth participant is currently in the six-week initial drug phase. If our last two participants meet all inclusion and exclusion criteria, we hope to have them start the medication soon. This will provide us with the 6 participants we were aiming for.

We want to thank all the families who have participated in our studies. We greatly appreciate their time and dedication to AHC research. We also would like to invite all families who have not yet registered with our AHC Registry or filled out the updated medical questionnaire to please do so at <http://medicine.utah.edu/neurology/research/swoboda/ahc/Ongoing%20Research%20Studies.htm>.

Dr. Sandra P. Reyna and Dr. Aga Lewelt
<http://medicine.utah.edu/neurology/research/swoboda/ahc>
University of Utah

Fundraising News

The First Annual AHCF North Carolina Walk

The first annual AHCF NC walk took place on Saturday, September 18, 2010. It was a fun filled day at Silvermont Park in beautiful Brevard, NC. We had activities for all ages. We kicked off the morning with a 5K run. Registration began at 9am, and the race started at 9:30am. Then for those who like to take it slow, we offered a leisurely 1.5 mile walk with registration at 10:15am and the walk at 10:45am. There was also a kid’s fun run, a cake walk, DJ, clowns, and face painting. Hope you will join in on the fun next year. For more information please visit www.ahcfncwalk.com.

Fifth Annual AHCF Chicago Walk

The fifth annual AHCF Chicago walk took place Sunday, September 19th at Paulus Park, Lake Zurich, Illinois. Registration began at 9:30 am with the kickoff at 10:00 am. We were pleased to be joined by “Skates” from the Chicago Wolves and “Scoopie” from Culvers Restaurant. The unofficial amount collected was over \$32,000. Please join us next year and watch our site for more information, www.ahcfwalkforkids.com.

Chase Community Giving Contest

With a huge collective effort, over the summer we won \$20,000 in the Chase Community Giving Contest held on Facebook. Thanks to everyone who helped get the word out.

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Fundraising News Continued...

Pasta Patrons for AHC

On April 18, 2010, at the Wyandotte PLAV Post 74, a spaghetti dinner fundraiser for AHC was held. With 300 people attending, \$8,400 was raised to help our cause. A committee of well-connected and talented people organized the evening which included three separate raffles and a gourmet meal; salad, bread, spaghetti, and an assortment of desserts.



The star of the event, Delaney Sliwka Johnson, was in attendance and won the hearts and support of all present. Donations came from two main sources: the entry fee of \$10 per adult and from the contributions of 60 raffle items. All the food was donated by American House Senior Living Centers and Terri's Catering. The hall and kitchen accommodations were supplied free of charge, and a crew of 40 volunteers helped to set up the event.

The day exemplified "love in action", according to Gara Sliwka, Delaney's aunt. Her blog, www.runningfordel.com, has more details and pictures of the dinner and is a source of information for people who want to know more about AHC or would like to donate to the cause.

Gary and Ursula Sliwka ursulasliwka@hotmail.com



Pepsi Refresh Project

The Pepsi Refresh Project is now in full swing. The foundation was accepted to participate in the \$250,000 challenge for the entire month of November. The award will give us access to the most **advanced genetic technologies** available. We will screen affected DNA samples to identify the responsible gene mutation. Once found, doctors can **create treatment plans and researchers can find a cure.**

Your vote is worth \$250,000 in the Pepsi Refresh Project.

If you haven't heard about the initiative, here are the simple voting instructions.

Vote once a day, every day, all thru November!

HOW IT WORKS

- From your computer go to
 - <http://www.refresheverything.com/cureahc>
- Click on the VOTE NOW button and follow the directions
 - You can also text a vote every day
 - **Dial #73774 and text the message 104112**
- Find additional voting instructions at www.ahckids.org

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AHCF Financial History and Report

Sharon Ciccodicola, Foundation Coordinator

The goal of the Alternating Hemiplegia of Childhood Foundation is to raise funds for research and to find a cure and treatment(s). Over the years, the foundation has funded the following grants related to this goal:

1995 (\$19,000) A study to evaluate treatment approaches in AHC, and to investigate underlying causes of the disorder. Dr. Chugani, Primary Investigator.

1996 – 1997 (\$20,000 from AHF & \$10,000 from IFAHC) A study of AHC patients using Positron Emission Tomography. Dr. Chugani, Primary Investigator.

1998 – 2000 (\$40,000) Research for molecular understanding of AHC. Dr. Ptacek, Primary Investigator.

1999- 2002 (\$37,485) Determine effects of Flunarizine on neocortical GABAergic Glutamatergic function. Dr. Van Brederode and Dr. Rho, Primary Investigators.

2003 – 2006 (\$66,890 each year, for three years, for a total of \$200,670) University of Utah, Neurogenics Laboratory, to identify the genetic cause of AHC. Dr. Kathryn Swoboda, Primary Investigator.

In March of 2006, there was a meeting of the AHCF Board of Directors. Dr. Swoboda was finishing the third year of her grant in December 2006 and we knew that going forward would require a substantial increased investment to accomplish the next phase of research (announced in the July 2006 newsletter).

2006 (\$3,100) Cognitive and Behavior Research Study. Dr. Josh Magleby, Primary Investigator.

2007 Dr. Swoboda submitted a new grant proposal to cover the period July 1, 2007 through June 30, 2010. The decision to move forward was based on two factors: (1) we believed that we could replace the monies used each year through fundraising, and (2) Dr. Swoboda's team felt there was a good chance that they could obtain an NIH grant. Therefore, we voted to fund the grant covering July 1, 2007 through June 30, 2010 (announced in the July 2007 Newsletter).

By June 30, 2009, three major events happened simultaneously that affected the research grant from moving forward; (1) the US economy was in a deep recession, (2) fundraising dollars did not meet expectations, and (3) NIH severely decreased money for rare disorders projects while imposing stricter requirements. Considering all of the above, the Board voted to decrease the third year grant by 38%, from \$219,931.34 to \$134,873.50.

2009 – 2011 (\$25,118) Single-center Phase I/II Trial of Sodium Oxybate in patients with AHC. The Foundation has funded the Single-center Phase I/II Trial of Sodium Oxybate in Patients with Alternating Hemiplegia of Childhood. Initially, Jazz Pharmaceutical was offering to supply the drug for free and provide partial funding in the amount of \$10,000.00. However, they too experienced a decrease in revenue and personnel and rescinded their offer of monetary support. They still have provided the drug free of charge. If the Board had voted to fund a grant for this next fiscal year (7/1/2010 – 6/30/2011), in the same amounts as the previous years, it would have depleted our reserves well below \$200,000.00

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AHCF Financial History and Report Continued...

In June of 2007, the sum total of available funds in all of our accounts was \$576,008.24.

Period Covered	Money Raised: fundraising, donations, investment interest	Research Grant Funding	Office expenses: insurances, licenses, fees, utilities, supplies and postage	Subtotal	Running Balance:
					\$576,008.24
7/1/2007 - 6/30/2008	\$136,352.00	-\$203,339.45	-\$8498.00	- \$75,485.45	\$500,522.79
7/1/2008 - 6/30/2009	\$110,718.00	-\$211,473.02	-\$10,083.00 (Includes Chicago Conference costs)	- \$110,838.00	\$389,684.79
7/1/2009 - 6/30/2010 Approximate values, certified financials not complete	\$107,555.50	-\$134,873.50 (Grant was decreased by 38%, see below)	-\$16,428.00 (Includes Coordinator salary, March thru June)	- 43,746.00	\$345,938.79
7/1/2009 – 6/30/2011		-\$25,118.00 Clinical Trials		- \$25,118.00	\$320,820.77
Totals: 7/1/2007 – 6/30/2010	354,625.50	-\$574,803.97	-\$35,009.00	-\$255,187.47	\$320,820.77

Beginning Balance	\$576,008.24
Shortfall between fundraising and expenditures	<u>-\$255,187.47</u>
Ending Balance	\$320,820.77

To move any research funding forward, we need to increase our fundraising efforts significantly. We thank all of those working to do so. For complete details of the foundations financial history please go to www.ahckids.org.

Sharon Ciccodicola
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AHCF Financial History and Report Continued...

This brings us to where we are today.

Please encourage all your friends and family to help us win the \$250,000 Pepsi Refresh Project.

Vote once a day, every day, all thru November!

HOW IT WORKS

- From your computer go to
- <http://www.refresheverything.com/cureahc>
Click on the VOTE NOW button and follow the directions
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