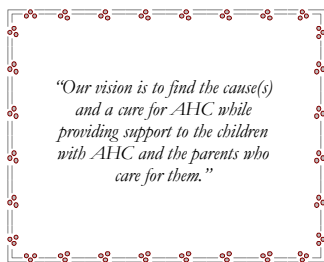




THE ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION

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www.ahckids.org



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The Future, The Cure

Letter from the President, Richard George

Let me start by saying that we're closer to answers and a cure than ever before!! Dr. Swoboda and her team are on the cutting edge of finding the mutated gene that affects our children. Our kids need your help now more than ever before.

In my last article, I wrote that I was lost and needed your help. Thank God for the AH families who heard my cries and were able to take time out of their very busy schedules to do fundraisers.

- Olga and Bill Gerber in Connecticut raised over \$30,120.00 doing a Spring Fling Dance and silent auction.
- Todd and Sara Wagner from Minnesota raised over \$24,000.00 with their 1st Annual Dock Works Charity Classic Golf Outing. In addition, the Foundation received matching funds.
- Vicky Platt and family from Illinois raised over \$14,000.00 by doing their 1st Annual Walk-In-The-Park with numerous matching funds.
- Kelly and Gene Andrasco, also from Illinois, had a garage sale that raised almost \$2,500.00.
- Chrystal Wagner from Utah sent out a solicitation letter that brought in about \$1,000.00.
- Once again, Evelyn Rosado from New York, grandmother to Daniella Sanchez, sent out her annual solicitation letter in honor of Daniella's birthday and raised about another \$1,000.00.
- Hope Holloway, who is acquainted with Daniella and the Sanchez family, was able to support the AHC Foundation with her influence as a board member of the Leroy R. Kinney Memorial Foundation which yielded \$10,000.00 for our children.
- Another \$10,000.00+ was raised again by Dave and Cindy Ryan from Illinois- our resident Energizer Bunnies – with their annual Golf Outing. In total, they have raised approximately \$100,000.00.
- We also received funds from United Way designations, so when you (or any one else you know) gives to United Way at work, please be sure to designate the Alternating Hemiplegia Foundation as recipient.
- Other local families donated their used vehicles to Charity Motors, who sent us the proceeds from the sale of the donated vehicles.
- The Foundation also received Memorials, which is such a wonderful way to honor loved ones.

As you can see we're off to a great start. Now, if we can get more of our families involved in doing a fundraiser, we could more than double the above dollars. Look at it this way.... another dollar, another day closer to a cure for the chil

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AHC Research Update

Kathryn J. Swoboda, M.D., Principal Investigator, AHC Project

Thanks to the extraordinary efforts of the parents of children with AHC, we are moving ahead in our research program to identify the causes and potential treatment of AHC. In the last three years, we have focused our attention on evaluating "candidate" genes – genes that, for different reasons, may be responsible for the disorder. In the next three years, that important and difficult work will continue, but we shall also turn to a new phase of research into candidate treatments of AHC symptoms and promotion of awareness among the medical community.

The search for genetic causes of any disease is vital, but it is also slow and painstaking. Many millions of dollars must be raised and many scientists must be engaged. Because AHC is both rare and complex, genetic research is especially challenging. Our work at the University of Utah, in collaboration with researchers at Harvard and UCLA, is promising, and it will continue. In an exhaustive search of 50 candidate genes, we have identified at least three families with specific mutations, 1 in the CACN1A1 calcium channel gene, and 2 in the ATP1A2 gene. However, to date, we have found that fewer than 5% of our AHC patients have one of those mutations. Thus, this work will continue, using newer more sophisticated gene chip techniques to help scan the entire genome for possible small changes in the genetic code that makes up our DNA.

These results confirm what we already knew: gene analysis must continue, because it provides important clues to helping AHC patients, but we cannot wait for its completion before we begin the hard work needed to identify more effective treatments. We must figure out what we can do to improve the symptoms of AHC as we search for genetic causes.

Thus, our new phase of research will expand into design of clinical trials that will test likely treatments. We have already begun plans to initiate the first clinical trial in this program, which will enroll a total of twelve patients. Our next step is to take this plan to the FDA and the institutional regulatory agency for approval. We hope to enlist the support of the pharmaceutical industry in these efforts, and to enroll the first patients by later this year.

But the move to clinical trials to treat the devastating symptoms of AHC is not the only exciting news. All of us involved in the AHC community know that we need to increase awareness of AHC among pediatric neurologists and related specialists. We need to educate the medical and scientific communities to the importance of studying the disorder and providing optimal treatment. Thus, I am happy to announce that we have formed a fellowship program that will enable focused attention on AHC-related projects. Under my supervision and with the aid of a full-time study coordinator, each fellow will work exclusively on AHC. He or she will be actively involved in our clinical trial program and will also launch a specific mentored research project. The publications that ensue will further promote attention to AHC and help to generate enthusiasm and funding for future projects. Our first fellow is Dr. Matthew Sweeney. Dr. Sweeney received his bachelor's degree in engineering at

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THE FUTURE, THE CURE

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dren. In the last Newsletter I said... *"We have come so far... And for what?? To let our children down?? I can't even bear the thought of this and since the day my son was born, I have used every waking second to find money to help our children. I have run out of steam. I'm at a dead end. Please help me find a way. I'm lost and I need you. I know that God will lead the way, but I also know that it will become easier if you help"* and you have. You have given our children hope that we will find a cure. I am reenergized by families who have stepped up to lead the way. Imagine what we can do if we doubled the amount of families that are able to help. Your family, your friends, your neighbors, co-workers, church family and more will all help if you ask.

Let's not forget Dr. Swoboda and her team who have done so much on their own without funding from the Foundation. They have given unselfishly of their research center, their equipment, their time, their energy and much more. Dr. Swoboda and her team are extremely committed and for that, we are so grateful. Without her, we wouldn't have a prayer. She is our sun, our moon, and our stars who is lighting the way. I cannot begin to tell you how much she does for the Foundation. When our Medical Liaison (Sharon Ciccodicola) visited and returned to Michigan with her findings, I was in awe to hear about the commitment that the Swoboda team has put forward. We have God and Dr. Swoboda on our side and now we need YOU!!

LET'S KEEP GOING; LET'S FIND A CURE!!

T here's a rare and special quality in our families who give

H owever busy they may be, they still have time to give

A nything you ask or need, they'll still have time to give

N o matter what the task is or how difficult the request

K indness just comes naturally to this rare and selfless group

S pecial giving people....Who deserve our heartfelt thanks!!

Let me share with you some of the new and exciting developments:

Early in the year, our Medical Liaison, Sharon Ciccodicola visited Dr. Swoboda and her research team at the University of Utah. You can read in detail about her visit in her article also in this Newsletter. We learned that Aloisia Schmid, a researcher and collaborator with the Swoboda Team was successful in receiving a grant for \$450,000.00 from NIH which yielded a special tool — the "Automated Imaging Reader," which is a High-throughput Drug Screening Machine specifically used for finding new drugs for Neurological diseases. This machine looks at single-cell levels in neurons and then replicates the disease's effect in fly embryos. They identify a genotype then produce a gain or loss of function by adding or subtracting genes. This causes a phenotype. They then use 96 plates with the different drugs in them and place all the embryos on the plates. After 24 hours, they read the patterns on the imaging machine and are able to identify the drugs that make the patterns better or worse. This machine allows scientists to develop a better understanding of what is happening at the sub-cellular level. Our hope is that once the gene or genes responsible for AHC are identified we can utilize this machine to come up with a treatment. What a Dream! One of the collaborators Dr. Swoboda is working with uses a

similar machine to look for genetic defects, checking millions of avenues in a matter of 48 hours. In the past, this would take many years to check each of the avenues individually. In short, we now have the sources and tools to help find the mutilated gene in AHC and then be well on our way to finding a drug for treatment. We need the millions of dollars it takes to proceed with the screening. We are closer to a cure now than I could have ever believed possible in my lifetime.

Dr. Swoboda has submitted a new grant proposal to the Foundation requesting over \$200,000.00 per year for each of the next three years to continue her ongoing research. The grant includes testing of the GHB drug, funding for a portion of Dr. Swoboda's and Dr. Reyna's salaries for their complete devotion to AHC, full funding of a neurology resident, Dr. Matt Sweney, full funding for a clinical coordinator/researcher to be used exclusively for AHC, gene studies, and clinical trials. The grant also includes database maintenance costs, computer database software and connection fees.

All this will come together at the next Family Meeting at which I strongly urge you to attend. I cannot express to you the importance of your attendance at the Family Gathering. We will collect more information in one meeting than we could in 10 years scattered all over. Let's help our kids; let's find a cure; BE THERE OR BE SQUARE.....PLEASE!?!?!?

All I can say is if this doesn't motivate us, nothing will! My prayer is that everyone gets involved with fundraising to whatever extent they can to support Dr. Swoboda and her team. I can't think of any better way to love and support our AH children and each other.

Overview and Impressions: Meeting with Drs. Swoboda, and Reyna in the Genetics Lab in Salt Lake City *written by Sharon Ciccodicola R.N. Medical Liaison*

I was recently afforded the opportunity to visit the University of Utah and meet with members of the team working on Alternating Hemiplegia of Childhood. Led by Dr. Swoboda, we met for the better part of the day, first in discussion and later a tour of the facilities. Many related topics were discussed and I shall try to provide an overview of the day with the most important points highlighted.

I was met by Dr. Sandra Reyna and escorted to a clinical area where the other team members would gather. I viewed their pediatric floor and clinic where their AHC children are seen.

Present at the meeting were Dr. Kathy Swoboda, Dr. Sandra Reyna, Karen Mottola, Abbey Smart R.N. and myself.

Abbey Smart is the pediatric nurse that sees all of the AHC children that come to Utah. Karen Mottola is a clinical coordinator and grant writer. She replaced Mark Wride. Both are vital members of Kathy's team. Another new but very important member of the research team is Kelley Murphy who took Ming Hanh's place when she left due to a problem pregnancy.

Dr. Swoboda opened the discussion with an overview of where they were right now and what she felt would be necessary to accelerate the research and also the progress needed in clinical settings to increase the quality of life for our children. She emphasized how important it was to go from a part time endeavor to a full time one. Many parents are frustrated especially as their children get older and they plod along without a definitive medical course of action. The following points were agreed upon:

1) Realizing the complexity of AHC

AHC is one of the most complex childhood diseases with varying symptoms of those affected and differing results with tried medications usually for a "sister" disease trying to alleviate some similar symptoms.

2) Continue gene research but add clinical trials

Working only on trying to locate "The Gene" or Genes may take a longer period than first thought, although it is important to note that in this process great strides have been made mostly by process of elimination. Therefore Kathy thought the next phase of research should also include relieving clinical symptoms with a series of medical clinical trials, carefully, scientifically conducted with chosen candidates and thus may be able to provide a link or common thread that could lead researchers in a positive direction. As much as we would like to see a cure at this time it is equally important for the children to control their episodes so they can develop and make gains without regression as is commonly the case.

We need to have a drug data base and look at which percent of each drug given generates a response and document in degrees how it helps movement disorders specifically AHC.

We need to educate and develop protocols to distribute to schools so AHC is understood and enables these children to stay in class and managed through an episode without fear.

We need to set up studies to look at neurotransmitters and deficiencies in spinal fluid along with a study of the use of a pulsox machine and it's role in preventing brain stem deaths.

We need to address the psycho-social aspect of AHC and behavior management especially as children enter their teens. Many of these children will not be the recipient of a cure but at the very least should have their quality of life improved by controlling the symptoms and episodes they experience now. It will be our job to teach them to function responsibly and happily in this world.

3) Domestic and International collaboration

Dr. Swoboda speculates the gene or genes affecting AHC is likely a brand new mutation. The most efficient and economically feasible way to approach this research is in joint collaboration here in the US. and to reach out to the international community. As I have seen firsthand, conducting this type of research is vastly complicated with many different approaches, tests and layers in a step by step process that hinges on a chain of results and if one link in the chain doesn't corroborate then you have to start all over. The techniques used are highly sophisticated and require a very knowledgeable researcher as well as a system of checks and confirmation for the researchers findings. Many research labs have established facilities that are conducting studies that have similar properties to AHC and in the end may come across a clue or identifiable marker that is significant to our research. For instance the glutamate transporter that was located at UCLA was a real possibility that had to be eliminated. If we were to attempt to conduct every avenue of this research as an isolated unit the man hours, equipment expense and lab use time would be astronomical.

There are small clusters of AHC patients that have familial inheritance. These appear much harder to define and where the international database may be helpful. The fastest way to build up this database is with a shared collection of DNA.

Dr. Swoboda would like to build on our relationship with Dr. Gusella's lab at Harvard which is taking a candidate gene approach and have special facilities that can tag smaller identifying markers and breakpoints of genes. We would need to formalize our database for them and with their help become part of their trials.

Another desirable collaboration is with Dr. Terry Sanger from Stanford who is a prominent movement disorder researcher.

Dr. Ketchum in Canada has had some success with his own child's development carefully trying different drugs and treatments. He is currently discussing drug trials with a pharmaceu-

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tical company that is willing to fund these efforts.

At the University of Utah all areas of the research lab are open to Dr. Swoboda. Not only is it immensely helpful to have these facilities at her disposal but she gains great value from the feedback she receives from her fellow researchers. Dr. John Carrey is the Medical coordinator for the genetics lab. They have just purchased a very expensive gene chip machine to aid in research.

In the event of the death of one of the children we need to convince parents to have an autopsy and be able to utilize the Maryland Brain Bank Lab to assist in this to determine developmental disorders and degenerative variations in the brain stem in a more sophisticated and complex manner than other autopsy centers in the country.

4) Educating the medical community

Although last years Physician's Symposium was very well attended and showed promise the aftermath has been a flat response. It often takes three years in advance to attach yourself to separate neurology meetings. DR. Swoboda's suggestion was to target those groups most closely associated to our cause as the American Pediatric Epilepsy meeting or the Pediatric Neurology conference. You are more likely to attract Doctors to become interested in AHC that are already interested in other childhood movement disorders. But we must repeatedly try to do this. One, for an increased database of Doctors around the country familiar with the disease and two, increased political clout to deal with drug companies and grant foundations as NIH.

Also, schedule interesting speakers appealing to Neurology Doctors around the country to attend the family meeting, then get the word out to them. This must be done in a timely manner for optimum response. Dr. Swoboda is compiling a list of topics and speakers that she thinks will be an asset.

5) NIH Grant Requirements

Dr. Swoboda has spoken to the NIH coordinators and was told that it is harder to fund rare disorders now be-

cause of the budget cuts in grants from the federal government due to the unbalanced military budget in this country at this time. However based on the model for Rhett Syndrome, (Kathy points out here that they even had their gene) which was the only rare disorder grant funded last year these are the criteria needed to be met:

- A) Establish a network of scientists aggressively working on some aspect of the disease
- B) Move forward with gene research
- C) Conduct small pilot trials
- D) Produce a manuscript of research and outcomes
- E) Mobilize a collective grant effort demonstrating all of the above

Her hope is that the Alternating Hemiplegia Foundation will be able to fund her to this point and that once the above is accomplished they will qualify for an NIH grant.

6) Summary: Needs and expectations

With most of the data collection in place, the next phase of research should include establishing collaborations with other labs and developing a database for these investigators with restrictions and controls in place. Continue to aggressively find the gene or genes responsible for AHC and at the same time move forward with clinical trials.

In a secondary role continue to research cognitive and behavioral studies.

In order to coordinate and push forward all of the agendas described we need qualified personnel. Money is needed first and foremost for a full time Clinical Coordinator to manage the data base, reach out for collaboration, coordinate clinical trials, write grants and drug proposals.

Second, Dr. Matt Sweney, a pediatrician and first year resident in neurology coming to Utah may be our research associate and start clinical trials as he has shown a keen interest in AHC.

Kelley Murphy will continue to do research in the lab on our behalf under Dr. Swoboda's and Dr. Reyna's direction.

Lastly, we would provide 15% of Dr. Swoboda's salary as she would be the principal investigator and with Dr Sandra Reyna would work closely with the coordinator, resident, and research associates. We would provide 20% of Dr. Reyna's salary.

Dr. Swoboda will be providing an updated grant request to cover the next 3 years. She envisions the amount to be significantly more per year than the previous years to accomplish this. Obviously, more money available means a better chance for success in all areas.

Drs. Swoboda and Reyna were genuinely thrilled to have a representative from the Foundation show interest and come to the University of Utah. I know they wish that you were able to visit but as the foundation's messenger they answered all my questions without hesitation. They were generous with their time including showing me the facilities. (covering about 4 miles we guessed!)

I have the greatest confidence in this team and have no reservations as to the determination, honesty and integrity of their efforts. They are investing themselves in this research body and soul and I believe we can expect and will receive the best "bang for the buck" that we could hope for.

Weighted Blankets are available from

"Salt of the Earth Weighted Gear".

**For a discount call Annie at 402-723-5229 and
mention Richard George, President, AHCF**

F U N D R A I S I N G

Advocates for our Son

*Written by Olga & Bill Gerber,
South Windsor, CT*

Our son Sean was born almost 5 years ago after a perfect pregnancy. He was 9lbs, 3oz, 21" at birth. He was afflicted at by AHC at birth.

It was shortly after the Boston Conference in July of 2005 that we realized we were racing against the clock for a cure. It was a tough grasp.

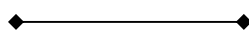
One of our friends always talked about doing a makeup or jewelry party to donate a partial of the sales to the AHC. She never did the party, but indeed did plant the seed for our "Silent Auction Spring Fling Dance". Neither one of us had any experience with a fundraiser, but decided to do it anyway. Beginning of January of 2006, we booked a banquet facility for May 5, 2006; wrote a letter to our friends and family explaining AHC and how it affected Sean; invited over 500 physicians to expose awareness; solicited/invited thousands of Hartford area businesses; every professional sports team; hotels in Boston, Cape Cod and Newport, RI with an explanation of AHC requesting auction items or to sponsor a table for \$100. We received endless amounts of items and approximately nine corporate sponsors.

It took us 3 ½ years to tell anyone why Sean was not average. Our friends and family were thankful that we finally explained and shared Sean's diagnosis and symptoms. In return, they have shared the information with other family and friends. Our friend, Beth Shaw raised \$500 through a Pampered Chef party. Our cousin, Mary Felman raised thousands through her circle of family and friends. Billy's partner, Dennis Najjar raised \$5,000 through clients. Another cousin, Scott Janicola, did a 100 mile bike ride pledge to the AHC

and raised \$3,200. Some other family and friends raised money at work. My former employer dedicated a dress down Friday where people who wore jeans paid \$2. The proceeds for that dress down Friday were mailed to the AHC. These are just a few of the things that were done. Our family and friends were exceptional in helping raise over \$30,000 in last year's fundraiser.

In addition, we contacted every newspaper in Connecticut. We had three separate articles printed and Fox news did a "Special Assignment" on our family and AHC. This allowed for readers and viewers to send letters and donations but mostly to become familiar with AHC.

We are not professional fundraisers. We are just advocates for our son and the AHC children. We, as AHC parents are in desperate search of answers but mostly for a cure. The research will only continue if we can fund it together. We hope these suggestions for fundraising will help everyone raise a few dollars this year.



Making a Difference

Written by Todd & Sara Wagner, Alexandria, Minnesota

Have you seen the video of the "World's Strongest Dad?" The video is a living diary of Dick Hoyt's way of sharing LIFE with his disabled son. He is an incredible father who traveled the world competing in marathons and triathlons with his 110 pound son strapped to his back, his bike, and an inflatable raft. Many of us may never dream of "making a difference" in his manner and we don't have to. We don't have to prove to the world that we're strong enough to accomplish that type of feat. We have a different opportunity and different level of responsibility. We can make a difference to our kids by raising money and creating

different opportunity and different level of responsibility. We can make a difference to our kids by raising money and creating awareness, specifically for AHC.

Our son, Carter, was born in August of 2003 with AHC. As devastated as we were to think about raising a child with mental and physical disabilities, we dug in our heels and did everything we could to "research" our end of the "information superhighway". We learned a lot about the medical world in 12 months, but there wasn't a lot to learn about AHC. So many kids deal with AHC in so many different ways. Although the kids share similar core symptoms, we never really knew what to expect with Carter. The frustration eventually led to inspiration. How can we make a difference for Carter and all these other kids? How can we make it easier for new families to learn about AHC?

It took some time to shake the sorrow and the grief and get on with making a difference, but when we did, it was an incredible feeling. We talked for a year-and-a-half about different ways to raise money. Our friends and family members mailed letters to the likes of Oprah and Bill Gates without success. We feared asking people to "give us" money. We were afraid that they would think it was for our family. We talked about a lot of different things before we settled on a fundraiser that we knew we would enjoy while raising money at the same time. We have four boys and we all enjoy golfing. As members of a local golf club and owners of a small family business, we created a charity golf outing with incredible success. It was called the Dock Works Charity Classic. The inaugural event was held in July, 2006 in Alexandria, Minnesota.

We asked our local Subway owner

to sponsor sandwiches for lunch. We solicited silent auction items and door prizes throughout our community and it was very easy. We charged each golfer \$150 to attend the event and provided them with a bag lunch, 18 holes of golf, and a buffet dinner during the silent auction. We only had about 90 players take part in the event, but you could barely find a chair during the silent auction and dinner. People we had never met before came out to support the cause.

Knowing that most golfers aren't actually good at golf, we steered away from making the event competitive and focused entirely on having fun. Our head golf pro is a close friend of ours and he told us to set our expectations low. He has seen so many events come and go that have a hard time raising money through golf. We touted the event as a four-person "goofy-golf" scramble and the people loved it!! Each hole had something "goofy" about it and there were small prizes for each unique challenge. We used wrong-handed clubs, croquet mallets, and hockey sticks. We put the pins in places where three-putts were inevitable. Our best hole was the "race for a cure" hole. All four players on a team spread out and actually raced for the shortest time to get the ball in the hole. We had volunteers keep it safe while they ran the stopwatch. We gave prizes for the teams that finished in first, fifth, tenth, and last places. We had "Cure fore Carter" t-shirts made that identified our primary sponsors and each participant received a shirt. We mailed invitations to 400 clients and many of those who could not attend sent small donations. Some donations from those who could not attend were as large as \$1,000. Many corporate employees are eligible for "matching funds" from their corporate employers, which we took advantage of.

During the dinner and silent auc-

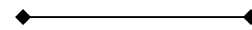
tion, we talked about AHC and how it affects our family. We shared our vision for creating more awareness and more specific research. I spent the last hour of the dinner adding up all the checks. I was amazed. With my eyes pouring tears all over the floor, I grabbed the microphone and announced that we raised nearly \$25,000 for AHC. The entire room exploded into applause with a standing ovation that lasted nearly two minutes!! I am not sure if there was a dry eye in the room. With less than 150 people, we raised \$25,000. What an incredible feeling. I don't know what emotions the "world's strongest dad" felt while running marathons with his son; all I know was that as I stood in front of that banquet room with Carter in my arms and 150 people celebrating our efforts, there are few words that could describe my feelings.

We made a difference. Whether that money goes to fund the medical research we so greatly need or it's spent on stamps to mail out this Newsletter, we are proud to have made a difference. Plans are in place for our second annual event in July and we intent to exceed \$50,000 for AHC in 2007. Get out there and made a difference. Our kids need our support. New families will need information. Please join us in our efforts. The domino effect is amazing. People you have never met before will come out of nowhere with assistance in one way or another.

In closing, our event did more than raise money for AHC. As a result of our charity fundraiser, our local newspaper did a story on Carter labeling him as a "Billion Dollar Baby". We heard from people from all over the country that "knew somebody who knew somebody" that could help. We eventually received a tip from a Sioux Falls, South Dakota family that recommended a vitamin supplement called Ambrotose. Carter has been taking this powder vitamin for

about five months. Whether it's from the vitamins or not, they have been the best five months of his life. His episodes are much shorter in duration and much less severe. He has only had one episode of "full-body" or "bi-lateral" paralysis since we started the powder. His degree of communication is much improved and physically he is becoming stronger and more competitive with his brothers. We are aware of controversial discussions about the validity of this glyconutrient, but it has changed our lives and Carter will continue its use.

Join in and help raise funds. We ALL need to make a difference and raise more awareness!!! We need to do more research..... ask people to help raise money..... Start your own event. We could have raised \$10,000 with our eyes closed and I will be ashamed if we don't raise \$25,000 each year for the next ten years. There is so much help out there through volunteers and local businesses. You just have to let them know you want to make a difference. If we each raised \$10,000 each year, our Foundation would drive medical research to new heights. Thank you and good luck with your events!!



Help Our Kids - It's a Wonderful Feeling

*Written by: Kelly & Gene Andrasco,
Lake Zurich, Illinois*

After reading the last issue of the AHC Newsletter, I was so inspired to do something to help raise much needed research funds for our children. I'll admit, I am a control freak and this disorder is wreaking havoc on me because it is so unpredictable!! What could I do to help? I read through all of the examples for fundraising, hoping one

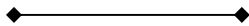
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FUNDRAISING

(Continued from page 7)

of them would jump out at me. I was in luck!! A garage sale was right up my alley!! I excitedly told my husband about it and talked to neighbors and friends about donating items to sell. I sent out fliers explaining AHC and the need to raise funds for the Foundation for research. Before I knew it, we had a garage full of stuff waiting for a new home. We priced everything "to sell", but we were filling to negotiate thinking it was better to make some money on an item than none. That philosophy worked in that we were able to get rid of a lot and earned a respectable amount of money for the Foundation (almost \$2,500). We also added a bake sale and hot dog lunch (hot dog/chips/drink for \$2.00) to our garage sale. My sister popped popcorn right on the front lawn, selling bags of it for .25 a piece. It was a big seller!! We also had a coffee station set up with Starbucks donating coffee and all of the fixings. We placed a conation can near the coffee. Yes, it was a lot of work, but I enjoyed every minute of it knowing that I was doing this to help our kids. I was overwhelmed by the kindness and support of friends and neighbors too!! I know we all lead very busy lives, but gather friends and family to help with some sort of fundraising event. It's a wonderful feeling!!



Walk-In-The-Park

Written by Vicky Platt, Mount Prospect, Illinois

It is with great excitement that I get to share with you the wonderful success of the first annual AHC Walk-In-The-Park. On Sunday, September 17, 2006 over 80 people came out to McCollum Park in Downers Grove, Illinois for a three-mile walk to raise funds and awareness for Alternating Hemiplegia of Childhood. The walk started

at 10:00 am with Emma Platt and Kiley Andrasco starting us off.

Emma's Godparents, Bill & Valerie Miotek, came up with the idea to raise funds for the AHC Foundation just as the Sale Lake City, Utah research team requested an increase in funds for their next project. To make the event a success, behind-the-scenes workers stuffed envelopes, created signs, designed t-shirts and filled goodie bags. The talents of Grandma Rose & Judy, Aunts Lynda & Diane, and neighbor Kelly were greatly appreciated.

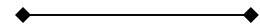
During the walk, there were a host of people cheering along the path, staffing the registration table, and handing out water bottles. Another big contributor to the event was "Skates", the mascot of the Chicago Wolves hockey team. If participants weren't busy walking or taking their picture with Skates, they were enjoying the free coffee donated by Starbucks in Downers Grove.

The hard work of so many of our friends helped to raise over \$12,000 to benefit the AHC Foundation. The overwhelming generosity of everyone who contributed to this endeavor filled our hearts with joy and appreciation. We would especially like to thank corporate sponsors: Allstate Insurance Company, Signore Service Business, Tellabs, and Willamette Management Associates. The philanthropy of corporate America may work quietly, but it certainly works graciously.

It is without argument that American's are the most generous people in the world. It is also without argument that there are extreme demands on our time. When so many wonderful people come together for the benefit of our kids, it speaks volumes on the kindness and compassion of our family and friends. We have made a difference in the lives of the AH families,

and especially the AH kids by helping the research efforts to continue. Charity was one of three words the Greeks used for love. In the New Testament, Paul stresses that we are to walk "charitably" toward our weaker brothers (Romans 14:13-15). He praised the Thessalonians because "the charity of every one of you all toward each other aboundeth" (2 Thessalonians 1:3).

We hope you will all find it in your hearts to share your time, talents or treasures to help the Foundation move forward.



Easy Fundraiser

Written by Chrystal Wagner, Lehi, Utah

My name is Chrystal Wagner. In March of 2006 my son Hunter was diagnosed with AHC. Since then, I have been trying to find out as much as possible about this disorder. I am lucky to live in Utah where Dr. Swoboda does her research. It is very important for the research to continue. For this reason, I find it very important for all of us that are affected by AHC to do our part and do some kind of fundraiser in support of research. Now I'm sure like me, most of you are very busy. But I did a really easy fundraiser and managed to raise quite a bit of money for the Foundation. I decided for my fundraiser, to do a solicitation letter. I looked at the sample letter on the AHC website and changed it to fit our situation. I sent this letter to everyone that I could think of. Within a week, I was receiving money for the Foundation. It was really easy and not very time consuming. If you are looking for an easy fundraiser, this is the one to do. There are also many other fundraising ideas that are available to view on the AHC website if this one doesn't interest you. Remember if we don't raise the money, no one else will.

Do You Know Your Child's School Evacuation Plan ??

By Lynn Egan

Just before spring break, the fire alarm went off at my daughter Kathleen's high school. Most of the buildings are single story however there is one building, a huge 'L' that is two stories. The plan for students who are on the second floor in the event of fire is to go to one of two designated classrooms (at either end of the 'L') if they cannot get down the stairs and wait for professional help.

Kathleen and her Kendra (her aide) were on the second floor. Since they could not use the elevator (normal procedure anywhere in the event of fire), they went to one of the classrooms. Since the stairways were clear, all students were evacuated from the building. Designated teachers were making sure that staff and students were off the second floor. By the time the teacher got to the classroom that Kathleen and Kendra were in, it had been determined that there was not a fire but that a student had pulled the fire alarm. However, Kendra was still instructed to leave Kathleen and evacuate. Kendra refused to leave. And so they waited in the classroom until students were allowed to return to the building.

There are only four students in wheelchairs at Kathleen's school (Kathleen can walk but uses a wheelchair at school for safety and episodes). One other student happened to be on the second floor also during that alarm and his aide did leave him in the other designated classroom.

I received a phone call from Kendra about half an hour after this all happened. Kathleen was so upset from the noise of the alarm, commotion in the hallways and then having heard a teacher say to Kendra, "You need to leave Kathleen" that she went into a total episode. I picked her up early that day.

I was appalled to find out that this kind of procedure existed. I made some phone calls and the procedure was changed immediately. Aides can stay with their students. But I question the very essence of the procedure its self – If a fire existed and the stairs were clear and all other staff and students were already evacuated down that same stairway, why wouldn't a staff member carry a wheelchair bound child down and out of harms way?

School evacuation procedures are something I never questioned or thought about. Probably because Kathleen's elementary schools were all single story buildings. I would encourage everyone to check with their child's school and question all school evacuation procedures. We were lucky that this was a false alarm. I don't even want to think what could have happened if there was a real fire and if Kathleen had been left alone in a classroom to wait for help!

2007 AHC FAMILY MEETING... MEET THE RESEARCH TEAM!!

Due to an exhaustive list of circumstances and variables, we were unable to locate a suitable site in the Midwest for this year. However we are very excited that the meeting will be held right where all the action is in Salt Lake City at the Marriott University Park, 480 Wakara Way, on the campus of the University of Utah!

The Dates are **NOVEMBER 1st (Thursday),
2nd (Friday) and 3rd (Saturday).**

Thursday - the Swoboda team will be conducting physicals, blood draws, interviews, photos and videos. New patients wanting to be evaluated and participate in the research project as well as returning patients for follow-up should schedule an appointment by e-mailing Dr. Sandra Reyna at sreyna@genetics.utah.edu or Dr. Matt Sweney at sweney@genetics.utah.edu The appointments take approximately 1½ hours each. Also Thursday Evening there will be an informal "Meet & Greet" to meet the Foundation Board Members welcome the families and get acquainted.

Friday - will be a full conference day. Dr. Swoboda will give us an overview of the research to date and the exciting direction it will take over the next three years. Families will have a chance to meet the entire Swoboda Research Team including Dr. Matt Sweney a new Neurology Resident that will be working on AHC exclusively!!!

Saturday – will be a wrap up lasting approximately until noon, including group discussions and a question and answer period.

During the conference the children will be in close proximity to their parents. There will be volunteers needed to watch and entertain them. Dr. Sandra Reyna has already volunteered her young adult children to help out here.

The Marriott has a pool, in house restaurants, a grassy area for the children to expend their energy and there are rollaways and cribs available for an additional charge. Parking is free but there is a charge for the Internet. At the Foundation's request the Marriott has set aside a limited number of rooms at a discounted rate of \$85.00 for 2 people/single bed and \$89.00 for 3-4 people/2 beds. If you'd like to check them out their website is www.marriott.com/hotels/travel/slcup-salt-lake-city-marriott-university-park.

Please e-mail Lynn Egan if you are going to attend at laegan6@sbcglobal.net before July 31st so we have an accurate count and know how many rooms to reserve before we sign the contract. We will then let you know when to start making reservations. Also if there are topics or speakers you would like to hear let us know. Dr. Swoboda is very excited and hoping to see you there as we start this next phase of research!!

Questions can be directed to Sharon Ciccodicola
cicco@ruralfree.net; Lynn Egan laegan6@sbcglobal.net or

Richard George Richardgeorge@ameritech.net

Public Health Bill #6110 an Act Increasing Awareness of AHC

Written by Lynn Egan

Olga and Bill Gerber are just like all of us – they have a child with AHC. I had the opportunity to meet the Gerber's in Boston in 2005. Sean was three and had been diagnosed at one year old. They were expecting their second child. Attending the Boston meeting was very nerve racking. They were nervous and scared, as all of us were when our children were diagnosed. I kept in touch after the meeting and during a phone call, Olga told me that Bill had wished he had not gone to the meeting – "What he didn't know, wouldn't hurt him". He knew more about AHC than he wanted to.

Well, the Gerber's turned this around. They decided to take action to raise funds for research and to raise awareness. They had their first fundraiser last May (see page 6). From this fundraiser, they received a donation from a local, highly involved politician who included a bill that was passed over 10 years ago for another rare illness. In September 2006, Olga ran into her town Representative, Rep. Aman. After much conversation and mailing information about AHC, they followed up in January and Rep. Aman submitted the bill. At this same time the donor who had made the suggestion to create the bill, approached Connecticut senator, Sen. Gary Lebeau and received endorsement from both the Democratic and Republican parties.

In order to convince law makers in CT to pass the bill, the Gerber's argument pertained to the cost savings to insurance companies, hospitals and parents. In addition, they had their child's pediatrician, neurologist and teacher write a letter to the Public Health Committee emphasizing the importance for the medical field and educators to know what AHC is.

The bill was heard on February 26, 2007 and voting of the bill was to take place on or before March 26, 2006. So far, voting has not yet

taken place and they may not know the outcome of the bill until Legislative Session in Connecticut ends June 30.

Olga sent me the following information about the hearing: "If you are interested in viewing the short testimony, you could catch the clip on <http://www.ctn.state.ct.us>, go to "watch Archived CTN videos" (4th one down on the left), put the date in (2/26/07) and click on Public Health Committee Public Hearing. They are @1hour and 7minutes into the viewing of the tape. Representative Aman and Senator LeBeau did a tremendous job introducing the bill. We are very fortunate to have had both Representative Aman and Senator LeBeau endorse the bill as well as support AHC awareness.

Congratulations Olga and Bill. You have taken a great step in raising awareness of AHC.

Proposed Bill #6110

On February 26, 2007, the Public Health Committee gave our Representative Bill Aman, Senator Gary Lebeau, my wife and myself the time and opportunity to express the importance of Connecticut Health professionals to know what Alternating Hemiplegia of Childhood (AHC) is www.ahckids.org.

The bill should be passed for both monetary business purposes and obviously personal monetary and emotional reasons. Our first born was hospitalized over 10 times at Connecticut Children's Hospital, misdiagnosed each time. We also went to Yale New Haven Hospital for a second opinion. Yale is supposed to be great but Yale also misdiagnosed our son. Our hospital stays consisted of four to eight days at a time. Sean was on 13 different medications the first year of his life. The 13 medications did not include the ones given to him during the hospitalizations or the ones used to sedate him for the numerous spinal taps, Cat Scans and MRIs. He also had countless EEGs, blood work and metabolic testing. It was not until we went to Boston Children's Hospital for a third opinion that Sean was finally diagnosed with AHC.

Passing the bill will save

insurance companies thousands of dollars because they will not have to pay for repetitious, endless and meaningless hospitalizations, medications and tests. Once a child is diagnosed, there is nothing the ER and/or hospital can really do. Hospitals will save time and money by freeing up space and staff instead of looking for something they do not about. This is of course, assuming that the family has health insurance and is not going broke because they have to pay out of pocket. All the while, Mom and/or Dad are taking time off from work. One of our unnecessary medications alone was over \$800 without accessories.

Mandating CT health professionals to know about AHC would allow for families to be informed of AHC as well. Parents can make informed decisions on the foreign substances they will give their child. Parents can prepare for the care and education of the child. AHC children require immense occupational, physical and speech therapy, not to mention, special care. Most importantly, the family can start coping and eventually living.

With the amount of time my wife and I took off work, we think of others may not have had a job to go back to. You can imagine the burden on our employers. Paying for our time off and getting backlogged. We are also privileged to have health insurance to cover that very costly year. We were also extremely fortunate to have had our son diagnosed in a year. We have spoken to other families where their child was not diagnosed for years and we know there are more that are still being misdiagnosed leaving physicians puzzled and parents frustrated.

Our son is diagnosed and there is no treatment or cure for him. We do not have anything to gain from this bill being passed, other families may. The insurance companies will save tons of money and so will the hospitals.

This is what the committee may do with a bill:

1. have the bill drafted in legal language;
2. combine it with other bills and have it drafted as a committee bill;
3. refer the bill to another committee; or
4. take no action, so the bill fails. The committee may also write a new "raised" committee bill. Because of #4, is probably the reason the bill is considered dead.

AHC research update

(continued from page 2)

the University of Nebraska in 1997 and a master's degree in biomedical engineering at the University of Minnesota in 2000. He received his M.D. from the University of Oklahoma in 2004. He has just completed his pediatric residency in June, 2007, and is committed to begin formal training in pediatric neurology in July of 2008. Thus, his background and interests make him ideally suited to contribute to advancements in our understanding and treatment of the complex problems faced by individuals with AHC. We are excited and fortunate for the opportunity to have him join us this year.

You can meet our team and hear more details of our research program at the AHC Foundation Families and Research Meeting, to be held in Salt Lake City in November.

Please contact Dr. Sandra Reyna at sreyna@genetics.utah.edu for additional details.

We are confident that the continuing expansion of our research program to focus not only on genetic research but on clinical trials to help advance treatment options will prove fruitful and enhance our mission. The AHC foundation's help in establishing funding for career-development fellowships is a big step in our battle against this terrible disorder. We believe that working together with families to explore new directions is our best hope for future success.

Cognitive and Behavioral Study

Written by Josh Magleby

The AHC Cognitive and Behavioral Study explored the cognitive and behavioral functioning of children 6 to 16 years of age diagnosed with AHC. Forty-one children with a valid diagnosis of AHC participated in this study. Participants were administered various standardized neuropsychological and psychological tests designed to assess a variety of cognitive skills including general intellectual functioning (IQ), academic achievement, executive functioning, attention, language, visual perception, visual-motor integration, and memory. In addition, behavioral and adaptive functioning was assessed including social and emotional skill sets, communication, daily living, community knowledge, and maladaptive behaviors.

Descriptive measures including mean, standard deviation, and range of scores were used in the interpretation of test performances. Results showed well below age-expected cognitive and adaptive functioning. Behavioral functioning was found to be within age-expected limits, with the exception of at-risk hyperactivity and poor leadership. The total sample was divided into two ability groupings based on Full Scale IQ score, and the subsequent analysis showed significant differences on many measures. Frequency and severity of hemiplegic attacks had variable influences on scores, and medication status did not appear to influence participants' scores.

Some trends were found regarding cognitive and behavioral functioning in this sample. Not surprisingly, participants with higher IQ demonstrated more age-appropriate cognitive skills than their lower IQ counterparts. Also, the range of performances by higher IQ participants was consistently more widely dispersed. It is possible that, due to the nature of AHC and its effect on cognitive functioning, some skills are more developed and


spared, at least for a time, from the effects of AHC. In terms of age, younger participants, on average, demonstrated more intact and functional cognitive and adaptive skills than older participants. This trend appears to point to a cognitive decline related to aging, which has been reported in previous research (Silver & Andermann, 1993). Gender had less of an impact with the exception of academic achievement. Males in the present study demonstrated better academic achievement than females on all reading and mathematics measures. It is noted that there is an extensive range of scores on these measures for males, pointing to a wide discrepancy in academic achievement among males in the present study. Therefore, it is plausible that these results may not adequately characterize academic functioning in males with AHC. Nevertheless, these results are unique and have not been described in previous research.

A question often asked by parents is "What can be done to help these children in school?" This is a difficult question to answer at the present time; as described in the present study, children and adolescents with AHC appear to have global cognitive deficits and poorly developed specific cognitive and neuropsychological skills as well as below age-expected adaptive functioning. However, these deficits are highly variable and unique to each child and adolescent with AHC. Therefore, the intervention should be individualized based on the educational and social needs of the child or adolescent with AHC.

Future research studies might include: examining behaviors in-depth including teacher ratings and direct observations; behavioral interventions that may or may not need to be unique to AHC; follow-up of children evaluated in the present study to better understand pattern of decline.

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