



# THE ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION

Phone / Fax 650-365-5798

www.ahckids.org

*"Our vision is to find the cause(s) and a cure for AHC while providing support to the children with AHC and the parents who care for them."*

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The AHCF does not provide medical advice. The material contained in this newsletter is provided for informational purposes only, and should not be used for diagnostic or treatment purposes. Please consult your physician before acting on this or any other medical information.

AHCF  
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**SAVE THIS DATE !!!** We will be having our Family Meeting July 29-31, 2005. We have chosen Boston, Massachusetts as our location. We do not have the exact information at this time, but we will send a separate letter in February with the details. We hope to see you there!

## Life marches on.....

By Lynn Egan

We are all at different points in our lives with our children with AHC. Some are dealing with a new diagnosis of AHC, others dealing with teenagers, behaviors or looking at assisted living accommodations. Sadly some of us have even been affected by the death of a child.

We are families from all walks of life; different social economic backgrounds, religions, and cultures, divorced or single parents, one child with AHC or several children affected with AHC. No matter where we are in dealing with the disorder, we have families to raise, lives to live and the challenges of coping day to day. We are also bound together by AHC. We are waiting for that treatment that will stop the episodes, offer prevention or a cure that will allow our children to live a normal life.

I have watched this foundation grow, I have seen parents get involved and then step back. We as a group need to stick together; we need to be involved, not only for our children's sake but for each other.

I have found myself in the position of having to step back, not because my passion for AHC has diminished but because of life. Like many moms, I am working full time, have other children. I am almost finished with two and a half years of higher education and my 14 year old AHC child is behaving like a teenager and then some. However I am determined to still stay involved with the foundation and the disorder. It's too important to me and to the life of our children.

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The foundation needs your support and involvement too. Anyway that you can contribute, such as through fundraising, writing an article for the newsletter or signing up and participating on the bulletin board or mentoring another family, all advance the cause.

Remember that we are all here - join us in what ever manner you can.

Have a wonderful New Year!

### Flunarizine HDL (generic)

One of our parents contacted me recently to let me know that she had found flunarizine for a great price from Canada. It turns out that it is a generic form of Flunarizine. I got a little nervous because I was not aware of a generic form. A few years ago, a parent who was getting a good deal was not getting flunarizine at all.

I made several phone calls to pharmacies in Canada to verify that there is a generic form and that it is equivalent to the brand name Sibelium. Each pharmacist guaranteed that it was the same. One pharmacy gave a price for the generic form of approximately \$28.00/per 60 5mg capsules; another pharmacy was \$34.00/per 60 5mg capsules. The trade name Sibelium made by Janssen Pharmaceuticals is roughly \$52.00/per 60 5mg capsules. Prices may vary due to exchange rate and if the website lists in American or Canadian dollars.

As always, please check with your physician before purchasing generic products.

### Letter from the Editor

Hello family and friends of Alternating Hemiplegia of Childhood. This is my first attempt at creating the newsletter with much help from Lynn Egan. As you will read in her article, you will see she has a huge amount of things on her plate right now and not enough time to do it all. I have offered to help in any way I can, hence this position. However I need your help. If there is something you wish to contribute, an article you would like to write or something you would like to know more about, please let me know. I can be reached at (408) 626-8506 or e-mail me at [sunplace@pacbell.net](mailto:sunplace@pacbell.net).

Lynn will still be very involved dealing with families and coordinating the conferences and following up on any research. We need each and every one of you to do your part in order to keep this foundation a strong organization. Included in this newsletter is a donation form which funds the production of the newsletter. We're asking for minimum annual donation of \$6 (tax deductible). If you find the newsletter of any value please consider donating. Let's save our fundraising dollars for the important research still to do.

Thank you,  
Carol Presunka

### Bulletin Board

The AFHA hosts a bulletin board. Everyone can subscribe. Families post their questions, concerns and ideas regarding AHC and their children.

To sign up, go to [www.yahoo.com](http://www.yahoo.com). Click on 'Groups' on the left hand side under Connect. Type 'AFHA' in the box under Join a Group. Follow the direction and subscribe.

### New Toll-Free Number

Lynn Egan now has a toll-free number that you can reach her at

**888-225-3353.**

Call backs will be within 24 hours of receiving your call.

# Alternating Hemiplegia of Childhood Research Update, 2004

Kathryn J. Swoboda, M.D.

Dear AHC Foundation Friends and Supporters,

It is hard to believe another year has almost passed. It has been 5 years ago now since the AHC database was first established. When I met my first patient with AHC in Boston in 1992, I could not have foreseen the tremendous impact that AHC would have on my life and work, and the work of so many others. We as physicians and scientists are incredibly privileged to have the opportunity to work with such dedicated families in search of answers for their children. We are grateful for the participation of families both nationally and internationally, and the cooperation of family support groups from France and Italy. While progress in uncovering the genetic mechanism may seem slow, we have made tremendous progress in collecting a large amount of valuable information and resources for ongoing research with the tremendous and unselfish help of so many families and physicians. We continue to work together to spread the word about AHC. We draw our ongoing motivation and strength from the many families struggling to find answers for the often puzzling and unexpected symptoms affecting their children, while sharing in the joy of small achievements. We, and others throughout the country and the world, continue to work to identify the precise cause of the genetic disorder causing AHC. We are excited to report developing collaborations with scientists in Los Angeles and Boston in the USA, and expanding collaborations with physicians in Italy and France, a measure of the growing interest in AHC within the international medical and scientific communities. As neurologists and geneticists, we can try to treat the associated problems, but real progress will only come when we fully understand the cause, and can work to directly fix the underlying problems that come with it. Five years seems like a long time, but is far from unusual in rare genetic disorders. Tremendous progress is being made with so many rare disorders, and new discoveries are being made on a daily basis, facilitated by the tremendous impact of new technologies, the internet, and the ability of families to come together with support organizations and their doctors to find answers. I believe that the unraveling of the genetic mechanism causing AHC will have a significant impact on our understanding of the complex problems seen in children with AHC, and undoubtedly lead to information which will ultimately benefit those affected with this often heartbreaking disorder. The AHC Foundation continues to play a vital role in bringing empowerment to families searching for answers, and all those involved have shared the burden of so many parents struggling along the same path. We are saddened by the loss of Robert Castaneda, who has been an incredible friend of the AHC



**Dr. Swoboda needs pictures of your children. She needs frontal head (from shoulders up) and a profile shot. She has begun to build a data base of this information to compare features of AHC children.**

**Also needed are any videos you have of your children during an episode.**

**Please send them to:  
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University of Utah  
Department of Human Genetics  
15 N. 2030 E. Rm. 7160  
Salt Lake City, UT 84112  
801-585-9717 phone  
801-581-7404 fax**

**swoboda@genetics.utah.**



## From the President's Desk

Richard George

I want to send out a special thank you and welcome to two new Board Members: Sharon Ciccodicola, Medical Liaison and Laurie Pecchia, Secretary. Laurie will be replacing Dan Johns and Sharon will be replacing Kim Cooper.

Sharon is a registered nurse and has been since 1972. She has a background in maternal child nursing. She worked in the neo-natal units in 2 different Michigan hospitals and was head nurse for the high-risk ante-partum and post-partum moms and their infants. She has also been involved in the infectious disease unit and other infant care units. Sharon is currently in case management for the elderly. Her husband, Pasquale Ciccodicola is a prominent lawyer in Michigan and they have raised 2 beautiful children.

Laurie Pecchia, has bent over backwards to help our children in a variety of ways. Not only has she donated her time here at the Foundation Office and has donated dollars since she became acquainted with our children. She has spend untold hours in the evenings typing, brainstorming, coordinating events, working with families, tracking donations, bookkeeping, keeping me sane and much more. Besides her administrative position working for the CFO of Ford's Asia Pacific Operations for the past 28 years, she still finds time to sing in her church choir, get in her much-needed exercise as well as volunteer for untold amounts of charities (Food Banks/Homeless Shelters/Elder Care). She is respected in her community and has raised a beautiful daughter for whom she is proud.

Both Sharon and Laurie are well acquainted with Alternating Hemiplegia since they volunteer their time on a regular basis. A very special thank you to Elaine Bau who has volunteered countless hours of her time and energy working at the Foundation Office, helping at Fundraisers, stuffing envelopes at her home on her own time and constantly brainstorming on ways in which we can pull in dollars for our kids -- how can we ever thank these people (and those who have served and still serve on the Board of Directors) for all they have done for the Foundation?

THANK YOU -- THANK YOU -- THANK YOU!!

## FUNDRAISING

By Elaine Bau and Laurie Pecchia

New ideas made 2004 a success!!

Texas Hold-Em, the newest poker craze, has benefited AHCF in a big way. On November 5<sup>th</sup>, we held our first annual Texas Hold-Em fundraiser at a local Michigan country club. Male and Female alike came to play Texas Hold-Em and donated thousands of dollars for our kids. There was great food, cigars, celebrities, prizes and camaraderie next to none. Thanks to Richard George, players can't wait for the next one!!

Let's not forget the 2004 Biker's for Kids Motorcycle Run, which is always fun, fascinating and wild. Freddie G. and his Gang along with American Steel Motorcycles, were successful in raising funds -- more and more every year. This year was greater than last year and we have him and his Gang to thank!! If any of you ride, consider joining us next year.

The International Order of Foresters, year after year, have been here helping our kids. This year was no different!! Thank you to Art and Deborah who volunteer all their time to the Foresters and make us the recipient of funds from their events.

Our Car Donation Program is still up and running (hopefully your cars aren't so you'll donate them). We appreciate all of you who donated your cars in 2004 designating AHCF for the proceeds. If you would like to donate a vehicle, please call Richard George at 1-888-557-5757. Also, donations made by some of you to the United Way have brought in dollars for our kids. If anyone is donating to the United Way or United Foundation, it is possible for you to designate AHCF as the recipient of funds. If you need help with the donation process, please contact Richard George.

Thank you also goes to Karen Venti who is raising funds in Boston -- SEE "Fundraising in Boston" on page 6.

Cindy and Dave Ryan are happy to report on the golf tournament; it was the biggest success yet! It was another perfect day! The food, the friends, and the support. The pictures turned out great, again, thanks to Jennifer Stice, Curt Gentry, John and Judy Craig. The winners of this year's event was Plum Creek's very own; Joe P, Tanner Hurrelbrink, Perry Peak and Danny Burk. The first flight registered 17 teams and the second flight registered 15! God bless all of you; Plum Creek Golf Course, Cheryl Day, for all her artistic talent on our corporate sponsor signs, WJVO, the golfers, the sponsors, the workers, the donators for the

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auction; for caring and sharing! Our Condo Raffle in South Carolina, donated by JoEll Allen of Peoria, brought in much needed funds.

Ms. L. Goetz from Springfield, IL was the winner! We are planning yet another tournament for 2005 on June 11! Mark your calendars for great golf and family fun!

Evelyn Rosado, year after year after year, is so diligent. She sends out her solicitation letter on behalf of her Granddaughter, Daniela Sanchez, and raises thousands of dollars for ongoing research. A good friend of theirs, Hope Holloway, who is a Trustee of the Kinney Memorial Foundation, has been extremely generous in funding a large Grant to the AHC Foundation this year. What an awesome way to honor everyone involved.

Thank you to an anonymous donor who made a generous donation to our children and their employer was kind enough to match those funds. Thank you is hardly enough for your wonderful gift to finding a cure for our children.

For the past couple of years, Karen and Paul Glink have donated directly to the Foundation in support of one of Karen's co-workers who has a young daughter with AHC. They prefer sending money directly here rather than through United Way because there are no administrative fees taken from their donation (approximately 20% taken away). Their direct donation allows them to know that all of their money goes directly toward helping the children. They hope and pray that their efforts will yield a cure one day. They want the AH families to know that "there is a light at the end of the tunnel -- You are not alone -- there are others that care!!"

Thank you also goes out to Betty Joe Fredrickson and her family who has had many fundraisers thru the years also Mindy Jonkoski and family for years of fundraising and who have raised tens of thousands of dollars. There were others of you who simply made donations from your own personal accounts to help find a cure for our kids. You will not be forgotten. Your never-ending love and support give us hope to carry on our mission.

In total an incredible \$50,000.00 plus was raised in 2004, thanks to all who are helping make our children better.

## **GRANT FUNDING UPDATE**

By Sharon Ciccodicola

Thank you for your gracious welcome to the AHCF Board. I am excited to take on the responsibility of Medical Liaison and look forward to working with all of you.

I am pleased to announce that we will continue to fund Dr. Kathryn Swoboda's ongoing research for one additional year. Upon her request, she will receive \$66,890 to advance the research for our children. After discussions with Dr. Swoboda, I can see how devoted she is to helping the AH children. I can also see that the advancements she is making will yield fruit in the years to come. I will be paying close attention to the research updates and will keep all of you informed in future Newsletters. FYI: Dr. Swoboda was published in the June, 2004 American Neurological Association Journal, *Annals of Neurology* (Volume 55; No. 6). If anyone would like a copy of this publication, please let me know.

Please feel free to call me with questions, suggestions and information. You can reach me by e-Mail at [cicco@ruralfree.net](mailto:cicco@ruralfree.net) (preferred). You can also get a hold of me at 1-888-557-5757. If I am not in, please leave a message and I will return your call.

I am looking forward to meeting all of the wonderful people associated with the Foundation in the upcoming months.

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foundation over the years. We mourn with his family, who attended nearly every AHC meeting. Words cannot express our sadness at the loss of this incredibly vital human being who reached out to everyone: fellow AHC children, parents and physicians alike. He touched all of us in a way that is difficult to express in words. We are aware that every death of an individual with AHC affects the entire community; we continue to work hard to understand more about the rare and unexpected deaths observed in some of the children. Unfortunately, the answers are not yet clear. We are forever grateful for his impact on our lives, and for the support of each and every single one of you who join together with us in this effort. We are committed to the continued search for answers, and know that with your continued support, we will succeed.

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## Research Clues

As we all know, Alternating Hemiplegia of Childhood is very rare and unique. Research is our life line to understanding the mechanism, pathophysiology and the eventual treatment or cure of AHC.

Many of us have participated in the DNA research that Dr. Kathryn Swoboda is conducting. Her research is based on blood analysis. Another part of research is the gathering of brain and tissue after a person dies. The following information is available for any family who would like to participate: Brain and Tissue Bank, University of Maryland, Baltimore, [www.btbank.org](http://www.btbank.org) 1-800-847-1539.

The foundation is not suggesting or promoting this research, only enlightening and informing you of its potential impact to future research and understanding of AHC.

In the event of a loss, have a family member or close friend make the following notifications:

Your Neurologist

Dr. Kathryn Swoboda (801)-585-9717

Lynn Egan (888) 225-3353 toll free or (650)796-1910 (cell)

## Fundraising in Boston

By Karen Venti

On a beautiful fall day this September we held the 3rd annual Addie Rose Venti fundraiser to benefit AHC Research. We had a couple of hundred friends and family come enjoy a wonderful silent auction stocked with terrific items, BBQ provided by a local pub, music, face painting, moonwalk, cakewalk, ice cream sundaes, cookie decorating and more! The kids ran around the outdoor pavilion and everyone left with something in hand.

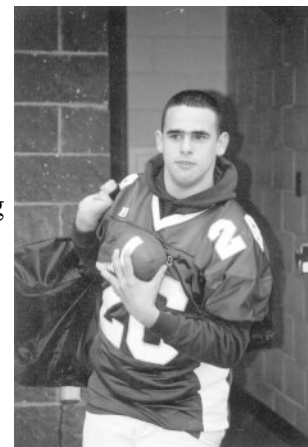
This fundraiser was started by my sister in law and her wonderful group of friends who I think, can accomplish anything they set their mind too. My extended family helps with drumming up donations from our local community stores. My nieces and nephews help set up and clean up, serving ice cream and snow cones and ticket selling. It is a great family affair and the younger children really get the chance to do something to help Addie and her friends with AHC. We raised a little over \$8,000 I think by the time donations finished coming in. We hope to try something new next year like a casino night or Texas Hold Em night to raise research funds. Every little bit helps.

We would all like to say Merry Christmas and Happy New Year to all our fellow AHC friends. May all our children be happy and strong. We think of you always.



From Adele Caruso

## *The Will to Succeed...by Frank Petrigani*



Louis Caruso has the heart of a champion. Born with the rare disorder, Alternating Hemiplegia of Childhood, this young man has a special determination that allows him to accomplish whatever it is his heart desires.

AHC is an uncommon disorder in which one side of the body becomes paralyzed, often alternating between sides and in some instances the whole body can become paralyzed. The hemiplegia (paralysis portion of the body) ranges from simple numbness in a part of the body to full loss of feeling and movement.

"When he was about six months old we knew something was wrong. He was treated for the first two and a half years as having a seizure disorder" said Adele Caruso, Louis' mother. Unfortunately this is a common occurrence for those children who possess this uncommon disorder. Due to its rarity many doctors are unaware of what symptoms are correlated with the disorder.

The number of children diagnosed with AHC in the world is less than 350 and there are less than 160 diagnosed cases in the United States. Louis is the only diagnosed case on Long Island, New York.

Louis has attacks approximately every seven days. The attacks come when he gets excited, nervous or happy. Any emotion can really bring it on; however, this doesn't stop him from participating in competitive sports. Louis' desire to compete has brought him two Special Olympic medals in cycling.

In 1998, the night before the cycling race, the opening ceremonies were held for all the athletes, complete with music, fireworks and all types of excitement. As a result Louis became so excited that he had an attack on his right side. He was scheduled to compete the following morning.

As Louis made his way onto the track the following morning he was still not using his right side and had trouble biking it around in a practice run because he couldn't keep his right foot on the peddle and right hand on the handle bar. Determined to compete, Louis taped his foot and wrist to his bike and made his way to the starting line.



With one side of his body paralyzed Louis competed in the 500-meter and won a silver medal. The next race, the 1-K, was not for a couple of hours and Louis decided he had enough left in him to do it again, only this time the race was twice as long.

With unheralded determination and pure grit, Louis peddled his way past the competition and across the finish line before any of the other competitors, earning him the Gold Medal in the 1-K competition for cycling defeating all other Special Olympic competitors in the entire state of Florida. "I was only thinking of the Gold," Louis said. The fact that he was paralyzed on his right side made no difference to him.

Louis is currently manager of the undefeated William Floyd High School football team. He wears the number '26' and serves as an inspiration to the players. Whether on the sideline, in the locker room or on the team bus he makes his presence felt and is always there to show his support of the players and coaches.

When asked what he wants to do next Louis responded with a bright smile and two words: "Weight lifting."

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