
INTERNATIONAL FOUNDATION FOR ❖ ALTERNATING HEMIPLEGIA OF CHILDHOOD ❖

Phone/Fax 650-365-5798 website: www.phoenix.net/~ifahc

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The International Foundation for Alternating Hemiplegia of Childhood (IFAHC) is a voluntary, non-profit 501c (3) foundation established to support children who are afflicted with AHC and their parents. The foundation funds research, raises funds, and offers this newsletter, a brochure and fact sheet to those interested in knowing more about AHC. The organization was established in Melrose, Massachusetts in 1993 and has been expanding to include members from around the world. The IFAHC is also affiliated with the Alternating Hemiplegia Foundation (AHF) of Michigan. These foundations work hand-in-hand to raise funds for AHC research, therapies and education.

The IFAHC 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.



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Address Correction Requested

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Editor's Notes

When Kathleen had her first major episode at three months of age, my husband Mark and I did not know what to think and knew in retrospect that she had had an episode at three days old! When she was diagnosed at 10 months of age, we were glad to finally know what she had. But what did it mean? As we started to read up on AHC, I thought "Why couldn't it be something that was known about, understood and treatable?!"

I wanted to know everything about this disorder. I had Medline searches run and pulled articles and read and read. Kathleen was over two years old when I had my first contact with another family. It was eerie to discuss the similarities and the differences. But it also felt good to know that we were not alone.

That was in 1993. With each contact, each family knew of someone else or a few families. I decided that I wanted to form some sort of support group. My own mission was to educate the public and the medical community. As fate would have it, I was not alone. Other families had the same idea and foundations were formed.

With every publication of the newsletter, I ask for information or articles from our membership and our medical board. I try to print exactly what is sent to me, but on occasion I may need to edit. Please bear with me. I will contact you prior to publication for any changes that I need to make.

This newsletter is intended to be a vehicle for all families to share their ideas, concerns, suggestions and comments. I look forward to hearing from you and Happy New Year!

We will be publishing the newsletter four times a year. January 15, April 15, July 15 and October 15. Submission deadlines are the 5th of each month.

Research Update

As you all know, Dr. Chugani has been doing PET studies on AHC patients for the past two years and still needs five to seven more patients to complete his studies.

To date 19 PET studies have been performed. These include 13 FDG PET, 5 Flumazenil PET and 1 AMT PET. The studies using PET scans have not produced an understanding of the basic pathophysiology of AHC, however, something important has been learned. They have learned that with increasing age and number of attacks, these children show areas of damage on their scans, indicating a progressive process. Based on this observation, he is suggesting that Co-enzyme Q-10 may be a useful "brain protection" agent to be used on all of these children. Co-Q-10 works to protect the brain against a small amount of damage with each attack. There are no known side effects and it is available at health food stores.

MRS data has also been collected and is being analyzed for publication. It seems to indicate that the cerebellum may be an important site in the brain involved in AHC.

The present goal of Dr. Chugani's program is to perform AMT PET studies on AHC patients. Because of the relationship of serotonin to migraine, and the alleged relationship between AHC and family history of migraine, it is believed this is a rational avenue to pursue. The one AMT PET performed showed high levels of serotonin, however, medication made the data difficult to interpret. It is hoped that continued research studies using AMT PET scans can produce a better understanding of serotonin in AHC and may lead to alternative treatment approaches. In 1995 this test was only approved to be done on patients over 18 years of age, and has since been approved for all ages.

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Dr. Chugani needs to see more patients in order for these studies to continue. If you are interested in participating, or would like to discuss it further with him, contact him at (313) 993-2867.

Tell us your Story.....

We are going to attempt to put together a booklet about living with AHC. We think this would be useful for both new families as well as those of us who have lived with it for sometime now. We have found that children who are affected by AHC have many different areas of difficulty and we would like to tell as many stories as possible.

We would like each of you to tell us your child's story and how you cope with AHC. We don't want a lot of medical jargon or medical history. We're looking for the day-to-day type of information. For example, tell us your child's name, sex, age, siblings, pet's name, etc. Tell us where they are at developmentally. Tell us about school. Tell us about their social life, family life, activities, etc. Tell us about the type of things you do to accommodate their special needs. Give some helpful tips. Whatever you can think of that tells you and your child's story. This is the type of information that other families are interested in and often request and we want to supply it.

Please write or type a page or two about your situation. Let us know whether you want your name, address, etc published or would you rather stay anonymous. Send all information to Lynn Egan at 239 Nevada St., Redwood City, CA 94062.

Foundation Organizations Update

In the October 1997 newsletter, we asked for additional interested parties to step forward to become trustees. This newsletter contains the names of the updated trustee listing as well as the newly elected officers (see back page). Along with the voting for the officers, a new set of bylaws, membership dues (see below) and numerous operating guidelines were approved. The guidelines cover fundraising, medical research grants, family contact, chapters and affiliates, and trustees and officers. If you are interested in a copy of any of these materials, please contact Greg Wisyanski during business hours at (814) 234-4460.

IFAHC ON THE WEB

www.phoenix.net/~ifahc

The IFAHC website is open for business! Thanks to the tremendous efforts of Chris Farthing the website contains lots of new information and links.

It contains medical information, contacts, fundraising tips, a guest sign in book and other good stuff. One of the most important parts (listed under "About IFAHC") is a link to the AFHA organization in France who maintains a discussion bulletin board. You can post and receive e-mail about AHC related topics from people around the world. Do you want to know about another family's situation or need some other advice? Just write a note and ask! We published some of the discussions that had taken place and there can be even more.

We hope you enjoy the site and comments are always welcome. Contact Chris at stoph@hia.net.

President's Letter

I've been involved with the IFAHC for a number of years as the Treasurer and now I'm excited about an expanded role as President. I'd just like to make a few comments about how I view the IFAHC and its possible future direction.

I became involved because I was interested in medical research to try and cure my son. I took a cue from Richard George and started raising money by soliciting family and friends. I continue my annual solicitations and will always be interested in finding treatments or a cure. I have also come to realize that cures to medical problems such as AHC may take a lot of time and therefore I have become very interested in "quality of life" issues for families with AHC. As President, I would like to see the IFAHC fully explore the family support aspect of AHC.

Some of the ways that we are trying to help families with AHC are items like the caregiver's guide, included in this newsletter, which was the direct result of a request from a parent. We have put together the website with information on AHC. We have a package of information to send out to new families. We are going to attempt to put together a practical day-to-day handbook about living with AHC. As other ideas are suggested and as people request things, we will try to develop them.

All of these documents can help our children lead better lives. I will always want my son to be cured of AHC, but while we wait for the cure I want him to have the best life possible. I think this is possible because of the support from other AHC families and the knowledge they provide.

Always, I would like to see everyone become a part of the process. Feel free to give us comments, suggestions, recommendations and ideas. We want to accomplish as much as possible and can't do it without you.

Greg Wisyanski

Annual Dues

Individual members (children and parents)	free
Professional members (doctors, etc.)	\$100
Associate members (relatives)	\$ 25
Special members (friends, etc.)	\$ 25

.....**FUNDRAISING**.....

Fundraising can be done in many ways. First and foremost, you have to be comfortable with the type of fundraising you are doing. It can be small or it can be huge. You can be very involved and put it together yourself, you can be working with an organization who has offered to sponsor and give the profits to AHC kids or you can be getting help and support from the foundation.

Every single dollar raised by a fundraiser, donation or contribution is gratefully accepted and appreciated.

But remember, your membership is not based on how much or if you have a fundraiser. We are all linked by the fact that we have these very special children, forever, and we are all working together toward a common goal.

TIPS

Memorials - the death of a loved one can be a busy and confusing time where its difficult just to get through each day. If you are able to make the effort, putting a "contributions in leau of flowers" notice in the obituary naming the IFAHC would be wonderful. Try to think of it as bringing some good from a sad situation and looking forward to the future.

Letter writing - send a letter to friends, relatives, associates etc., describing AHC and our group. A sample letter is posted on the website or can be mailed to you. Tell them what your child and yourself go through and how important the research is. If you agree to send 100 or more letters, the IFAHC will send you a \$50 check to cover postage, etc.

Network - contact local charitable groups or foundations. Many hold fundraisers and are looking for groups to donate to. Many will also assist you in a fundraising drive by providing volunteers and suggestions.

For more fundraising ideas, see the website.

Video and Audio Tapes Available

During the May 1997 medical symposium in Washington State, the Cooper's arranged to have the conference video and audio taped. The video tape is 1-1/2 hours and is a summary from the doctors of what was covered during the two days. The audio tapes (4 tapes) are 6 hours and are the actual discussions between the doctors during the two days. You, your doctor or other interested parties can hear or see everything that was discussed. If you would like to purchase copies of either or both tapes, they are now available.

The video tape will cost \$20, the audio tapes will cost \$15 or you can order the set for \$30. Postage is included in both amounts. If you would like copies please contact Lynn Egan at 650-365-5798 or send a check to her at 239 Nevada St., Redwood City, CA 94062. Please allow approximately 4 weeks for delivery.

T - Shirts for Sale

Richard George has some T shirts remaining from his 1996 and 1997 fundraising events. These are colorful, heavy cotton shirts with the name of the events and the sponsors. He currently has 200 of the 1997 shirts (sizes L and X-L) and 50 of the 1996 shirts (size S). If you would like either, please send a check for \$20 per shirt, payable to the Alternating Hemiplegia Foundation, c/o Richard George, 30303 Plymouth Drive, Livonia, MI 48150. Specify the sizes with your order.



Through parent involvement and doctors research, may we find the cure for Alternating Hemiplegia of Childhood in the near future.

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Please notify Lynn Egan when you have a change of address or phone number.

Also let us know if you have an e-mail address.