INTERNATIONAL FOUNDATION FOR ALTERNATING HEMIPLEGIA OF CHILDHOOD

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ID# 04-3204949

Volume 4 Issue 2

© April 1998

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.

International Foundation for
Alternating Hemiplegia of Childhood
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Address Correction Requested

Parent Questions and Tips Needed

Have you ever faced a situation with your AHC child and wondered..."how does everyone else handle this?" We would like to become a clearinghouse of questions and answers about living with AHC. We need you all to help out by sending as many questions as you can think of. In the July newsletter we would like to publish all these questions and then have everyone write in with responses. Future newsletters will have space devoted to the answers as well as additional questions that come up. We will also be listing these on our website in the future.

Here are some examples of questions:

- How do you get your child up the steps when one side is affected?
- What do you do to comfort your child when an episode takes place in public?
- How do you explain AHC to family, friends, school, etc.?
- How does your child communicate when their speech is affected?
- How have you figured out how to deal with insurance companies, school districts, doctors, etc.?

There are thousands more.

We aren't looking for a lot of medical or technical stuff. Just the day-to-day living with AHC questions. You know you've thought about them and have had to come up with answers. Now's your chance to ask everyone else what they have done and share your own brilliant or simple solutions. Write to Lynn Egan or e-mail her at Laegan@aol.com.

This sort of goes hand in hand with our request for a story of how you live with an AHC child. Except that, and we hope, that these questions will generate more questions and many answers.

From Alex Cole

Dear U.S. families of children with alternating hemiplegia,

I have been delighted to correspond with some of you on the internet and the support and information that I receive through it and through your newsletters is helpful and informative. As you will all have experienced, my need for such support was as great as my thirst for information as soon as I realized the seriousness of the diagnosis on my daughter.

My name is Alex Cole and I live in Southern England not far from London and Windsor. My little girl, Alice, is two years old and has alternating hemiplegia. She was diagnosed one year ago by an expert paediatric neurologist in Oxford after being referred there by the local hospital. I was impressed with the way this was handled by our National Health Service and Alice has had no inappropriate treatment or long fruitless examinations. Alice is my second child. My elder one is a boy, Samuel, who has no such problems.

In the U.K. there is a charity called Contact a Family which maintains an up-to-date list of all the support groups for rare syndromes. There is one for alternating hemiplegia and we know of about twenty families. A family meeting is organized every year. The neurologist in Great Ormand Street Hospital in London is carrying out a research questionnaire similar to the ones done in France and the U.S.A. In the U.K. the local authorities are responsible for providing each child with suitable education so we are just beginning to find out what can be offered Alice in our area. I am quite hopeful that Alice will have care similar to that described by some of you, such as a special helper and a place to retreat to when she feels bad. At present she goes to regular day care while I am at work and loves it. I think the interaction with other children and plenty to occupy her mind, is good for her.

We hope to travel as a family to Paris this year to meet the French Association and share in their family meeting.

I look forward to corresponding with you all so if anyone is ever visiting England, please feel welcome to contact us:

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International Activities

Ever wonder why the name of this organization starts with "International"? It's because kids from all over the world suffer from AHC. Our most significant recent growth in new families contacts has come from outside the United States through our website and e-mail. We are now trying to decide how to become a better international organization.

Currently we are attempting the following activities:

- We have filed to become a recognized charity in Canada so that contributions receive favorable tax treatment.
- We have established contacts in the United Kingdom, Italy, Sweden and France so that we can keep abreast of activities in those countries.
- We are looking for ways to educate the medical communities outside the United States about existence of AHC.

These are very new areas for us and we are really just beginning. We have many issues to address, such as language barriers and information distribution.

Results have been favorable so far, but we could certainly use a hand. If you have any particular skills or interests please contact us.

....FUNDRAISING....FUNDRAISING....FUNDRAISING....

Greetings and blessing to you and yours in 1998!

Alot has happened for AHC since my last letter and I am very happy to report that the AHC Concert...Kids for Kids was a huge success! To think of all that was accomplished from a small thought while sitting at my desk at work to the reality and research dollars it has become. Since the concert and benefit run on November 8th and sales of the CD/cassettes, we have to date collected over $15,000! Not bad for Small Town, USA! There are so many reasons why the fundraiser was so well received; hours of planning, media coverage, massive donations, generosity and time of many; determination and mostly God's blessing that we succeed! We, as parents, have the key ingredient to make things successful and that is our motivation factor. The public becomes aware and realizes that we have only one goal in mind and that is to find a cure for our children!

There were many hurdles to cross on our way to the concert. How to get the children in the choir, where to have the concert, where to find a band, how to advertise and not spend much money, who would record our CD/cassette that we could afford, what about the label, how will we get the CD/cassette reproduced, how will we sell the CD/ cassettes once we get all the other questions answered and will anyone show up? To add to all of this confusion; try to balance working and especially time for the family, what if Michael has a spell? To look at all the questions it is easy to get consumed and lose focus, but the reward is definitely worth it!

I hope you believe in angels because we have ran across quite a few! Our committee consisted of 13 people, family, co-workers, and friends. Everyone had there own unique input and ideas. The church was no issue either, do I attend that church, no..do they know me, no... then why offer their facilities that will hold 500 people, beautiful sanctuary, and a great sound system? The pastor saw our need and ran with it. The band, oh yes, I looked up in the yellow pages and found a gospel band that was fantastic and willing to give of their time, no...but pretty close, four people that hardly knew us saw our need and delivered most eloquently! The media has definitely become our friend, we have had articles published and written on behalf of our quest, television, though a humbling experience, has some big hearts also, but I think the most inspiring advertisement was the kids and their coloring pages... they were everywhere! Mike Mason, from Rainy Day Studio, right here in Jacksonville, IL was a God send. Not only was the recording awesome and fun, he donated his time! The label, which is a rainbow, was the most difficult of all the hurdles, but through perseverance and a friend, Ted at the publishing company, it to was complete. The production of the CD/cassette was, to say the least, a blessing. Not only did EMI Capitol Records reproduce the CD/cassette, an angel by the name of Ron Corya informed me that they would make a 1,000 of each for free!!! The CD/cassettes have basically sold themselves, even now, 2 months later we get stopped on the street from people that have been to the concert or bought a tape with comments about the success and how it has touched their lives. The project that started out as two-fold; one to get dollars for research and two to get the kids involved and learn about God has become three-fold; I have found that on bad days I can put in the tape and Michael and I can find a smile and I hope that you and your children can do the same. I would much rather smile than cry any day!

I did not mean to go on, but I felt that there are families out there that feel that they are not able to do "big" things to make a difference, but you can. If you have an idea, go for it! If you need some guidance, we're here... Richard George is not only our finance guru, he is quite the athlete! Thanks, Richard for running those 3 miles and attending the concert, it means a lot to know that we are supported in our efforts. To Laura and Kim Cooper and Lynn Egan, once again you were there for us! I am sending out a CD/ cassette to those of you that I have addresses, the tapes are a gift from Michael and I know your children will enjoy them. I want to encourage all of you to sell the CD/cassettes, the hard work is done and it is a great way to raise research dollars and spread our stories and the "Good News". We have had people buy tapes that have never bought a religious tape in their lives. We have had to order 500 more cassettes due to the overwhelming response in this area. Stacey McCutchan and Mary Prunty have requested some already and we are grateful for that...way to go girls and good luck! Along with getting the tapes out to other families we are working on getting some out to radio stations, so if you have a contact with a station, let us know!
One of our biggest goals is to educate the public about AHC and to run across a group to back our research and let everyone; parents and doctors know about AHC and you know, people are beginning to talk! If you need information, feel free to reach us at the above addresses; cassettes are $8 and the CDs are $13.

Thank you Brooke, Mary and Nick for your videos, the kids were excited to meet you if only on film! There has been talk of another concert... God willing it will happen.

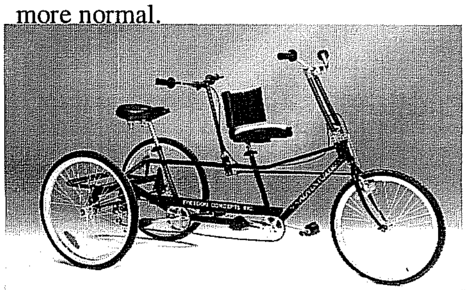
God Bless and Keep Smiling,

The Ryans, Dave, Cindy, Rachel & Michael

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

Getting Around

We all want to give our children as much freedom to be “normal” kids as possible and to also make our lives as parents, more normal.



Adventurer Tandem

For most AHC children, balance is a problem. Freedom Concepts is a maker of bicycles for our kids. They make several styles which come with high back support, with chest and waist straps, velcro or front hoop strap pedals, adjustable quick release mechanisms and locking brake mechanism for easy mounting (varies by style). For more information call Freedom Concepts, (800) 661-9915 or check their website at www. freedomconcepts.com.

The “chaser” bike was discussed in October by DeAnne McGinley (via the bulletin board). It is a child size bike (age 4-10 yrs) that attaches to the back of an adult’s bicycle thus making it a “tandem” bike. It has it’s own handle bars, pedals/ chain, but only one wheel. The seat and handle bars are adjustable. Both Target and Toys-R-Us carry it.

The Burley Bike is another product which attaches to the back of a bike. However, this one is more like a cart, can seat two children (up to 100 lbs total weight), has seat belts, a protective net cover and space in the back for storage. It can be purchased at bike stores. It’s nice because whether you child is having a good day or bad, you can still get out and enjoy the day.

Racing Strollers Inc. of Yakima, Washington makes a Special Needs jogging stroller. It is for 8 to adult, depending on size and weight. It is wonderful for those walks on the beach or natural trails as it has all terrain wheels. It is 5’ long and 26” wide, not really for the malls. It does break apart for easy transportation and storage. The Racing Stroller phone # is 800-241-1848.

Convaid has just produced a new stroller. It is called the Safari and has the same easy umbrella type folding system, however this one has a tilt feature. Convaid’s # is 888-CONVAID.

For the little ones who want to ride a tricycle but just can’t, the Big Wheels is an excellent choice. It is low to the ground, has a high back and give our kids the support they need.

New Medical Equipment Exchange

At the end of January we received a letter from NORD about a new program that they have started. *(reprinted with permission)*

The National Organization for Rare disorders, Inc. (NORD) annouces the new Medical Equipment Exchange. The program’s purpose is to provide people who have inadequate health insurance with a means to purchase needed medical equipment. This includes, but is not limited to, items such as telecommunication equipment for individuals who are hearing or speech/language impaired, hospital beds, wheelchairs, toileting equipment, and even canes and crutches.

While many people have used medical equipment that is no longer needed by their family, the problem has been linking potential buyers and sellers. NORD, via the Internet, will forge this link through the NORD Medical Equipment Exchange. Eligibility is not limited to only those who are diagnosed with rare disorders but is available to anyone with a medical need. Information about this program can now be found on the Internet by accessing NORD’s home page at <http://www.NORD-RDB.com/~orphan>.

Exchange information may also be obtained by writing to NORD, P.O. Box 8923, New Fairfield, CT 06812. NORD acts as the program’s facilitator and assumes no responsibility for the quality, performance, or medical results of the equipment. All sales are the individual responsibilities of the buyer and seller.

Internet Corner

Questions and answers posted to the APEHA bulletin board continue! It is a great place for sharing ideas. However, since only about 50% of our families have computers/email, I want to make sure that our non-electronic families are included.
(reprinted with permission)

Topics covered were lying on your back, behavior, eye deviation, etc.

“.....Our question is this..For those parents whose children have started school, or some other frequent activity, did you notice that episodes became more frequent in the beginning, and if so, how did you work through them? Also, did they taper off after a time?
Morgan’s attacks are brought on by many things, including even mild to moderate excitement and periods of as little as an hour or so in “new” places, such as church, etc. We believe the time is right to begin some schooling for Morgan, but are concerned about her already frequent attacks becoming more so. If anyone has any thoughts on this, they would be appreciated”.
Chris and Kathryn - Oct. 3 -

“My name is Lena from Sweden. I have twin boys(8 years) both with AHC. The problems with excitement will remain (I guess) but they will learn to cope with it better and better. It is this way with “normal” children too, as they grow they handle more and more. Small things that was a trigger in the beginning they can handle these days. My boys could never take a bath before without being paralyzed, now this problem has vanished. If you take it easy with school/ kindergarten in the beginning so she gets used to it, I think it will work. My boys started when they were three and it went well, but they had a “spot” that was quiet and a little darker so they could rest if they did get to excited. Some things perhaps they never learn to live with, birthday parties, Christmas, etc...
It is very different between the AHC

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children how often they get an attack and for how long. Marcus and Jacob have one week free and one week with rightsided paralysis and the week they are bad they stay home from school because they should be very bad if they went - that they can't cope with! So we/ they do "everything" when they are good and nothing when they are bad".
Lena Hermansson - Oct. 3 -

"My daughter's neurologist has recommended a cerebral angiogram to rule out any vessel pathology. I know this is a risky procedure, especially in children. Has anyone on the list ever experienced this with their children, and if so, please tell me about your experience."
Mindy Jonkoski - Nov. 11 -

"My daughter had an angiogram and had no trouble. Like all the other tests that she had, the angiogram came back normal."
Lori Baker - Nov. 11 -

"My son Nicholas had an angiogram and all results were normal. The reason for having it done sounds like the same as for your daughter— to rule out possible causes for the hemiplegia. Nick came through it fine but it was probably the most frightening experience for me to have to wait until he was back in the recovery room and I knew everything had gone OK. It helped me to know that it was done through a Children's Hospital and the doctor had done surgery on smaller kids than Nick."
Mary Kay Reily - Nov. 16 -

"How many of the children with AHC wear glasses? I just found out that my daughter has pretty bad vision and was wondering if that is something that affected other children with AHC."
Mindy - Dec. 10 -

"...... yes, our daughter Haley who is 5 has AHC and has not great vision. She also had eye surgery almost a year ago to straighten the alignment, too. She seems to do fine with her glasses, although we have observed that she struggles with depth perception, etc."
Chris Morris - Dec. 20 -

"My daughter's left side is down this time but I just noticed that when she is sucking on her bottle her eyes are darting to the left. I can get her to look at me, but it's like they are being pulled back to the left. I never noticed this before. I will have to pay attention to the next episode. Has anyone ever experienced this?"
Mindy - Jan. 4 -

"The eye deviation was actually our first sign of a problem. Our doctor confused it with a seizure. Our first experience with it was to the right side at age 3 months.
We continue to deal with the eye problem. We still have the pull to one side or the other. But, we also have eye-crossing or rolling when our son is tired or during an episode. (Our son is 6-1/2 yrs old).
I know you may not feel lucky, but you are in knowing what is wrong with your daughter while she is so young. You don't have to put her through unnecessary and perhaps detrimental treatments like many of the rest of us have. Best wishes!!"
DeAnne McGinley - Jan. 4 -

"Our son had similar episodes when he was young. The eyes would "pull" to one side or the other. I don't remember if they pulled towards or away from the side with the problems. His eyes used to also roll up and he would have to tilt his head back to look down at things.
Now that he is older (7 yrs old) his eyes still move at times but only very little and its very hard to tell anymore. I would say that his eyes started to get a lot of control when he was 2 or 3 yrs old, if I remember correctly."
Greg Wisyanski - Jan. 5 -

"My son Louis is now 12, almost 13 and he too experienced nystagmus during his attacks, but this happened mostly when he was very young. I would say by the time he was 4 or 5 it stopped. It has happened since but it is very rare. Louis has just started wearing glasses. He also sits very close to the T.V. I don't feel the attacks have affected his eyesight, both my husband and daughter wear glasses, so I figured he took after them."
Adele Caruso - Jan. 5 -

"Jake is 6-1/2 yrs. old. He had crossed eyes at birth and throughout infancy had problems with his eyes. At age two, he was diagnosed as having exotropia (wall-eyes) and the eye doctor recommended patching. Jake didn't like it very well and since it only occurred when he was tired, or during a spell, we didn't push it. Now he only has eye problems during attacks. His eyes veer to this affected side. During prolonged episodes (days) his eyes tend to get "lazy" and he seems to have problems focusing. This resolves when the episode goes away or after sleep."
Becky Sproul - Jan. 5 -

"Chad (9 yrs old) has had his eyes checked. Nothing has been found to be wrong with his. He also has movement with them. Chad has always sat right up against the T.V. to watch it. Continue trying to get him to move back from it. Tried just about everything, it seems. He says he can't see it when he is far away. That is what made us think something was wrong with his, but no luck for us. Still a mystery. Does any of the other kids sit that close also?"
Roberta - Jan. 5 -

"Haley, our 6 yr old does like to sit fairly close to the TV when watching; approximately 5-8 feet. I try to get her to move back and she will, but she would prefer to sit closer. She does wear glasses and has fair vision. She also did have surgery on both eyes at the age of 5, for esotropia with much improvement. Her prescription has not changed in the past 2 years."
Chris Morris - Jan. 5 -

"My daughter Abbie, age 8, also sits close to the TV - I think mostly because

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she gets so absorbed in it and enjoys it so much. I know her eyesight is fine - she can spot things a mile away that I cannot see for the life of me. As far as the eye movements - this is what first happened with her at age two months that at the time led us to believe she was having a seizures. Over the years, the episodes of paralysis have been a lot less frequent that the erratic eye movements - but both have decreased to a great degree. The eye movements are pretty rare not - sometimes they get a little "droopy". On the rare occasion that she does get the erratic eye movements, she is cognizant of it and even says to me: "Mom, I'm getting wobbly" - so much for the seizure theory. Anyway, they have definitely decreased over the years."

Kathy Hurley - Jan. 7 -

"Jake has a great aversion to lying on his back, especially during an attack. When he is having prolonged episodes (days) he even wakes up at night and we have to sit him up. He gets much better after sitting up. His special stroller is wonderful as it supports his head, neck, and back and is his most comfortable place during an episode. At night, he prefers lying on his side or his stomach."

Becky Sproul - Jan. 9 -

"Our daughter is 16, and still sits with her nose almost against the TV screen."

Don Kilpatrick - Jan. 14 -

"Don, I'd be interested to know more about your 16 yr old. What are her current symptoms? How is she now compared to earlier years? How is she doing in school? I've noticed that my daughter, Abbie has improved over the years and continues to progress and that there has been no regression at all (so far). I haven't know of many children older than her, so have no idea what to look forward to but am hoping (praying) for continued improvement. Thanks."

Kathy Hurley - Jan. 15 -

"One thing that I have not heard about with other children is that my daughter's paralysis attacks always occur in the early hours of the morning - she wakes up with the paralysis, usually about 5:00 or 6:00 am. As soon as we hear her cry out, we can tell by the way she's crying that she is having as episode. She has never had an episode of the paralysis or dystonia at any other time or as a result of any other type of situation. Has anybody else's child experienced this? The doctors think its somewhat ironic since sleep seems to be what usually ends an episode."

Kathy Hurley - Jan. 15 -

"Because I wanted to learn more about this disease, I signed out the book "Alternating Hemiplegia of Childhood" edited by Drs. Andermann, Aicardi, and Vigevano from a local university. It is part of the International Review of Child Neurology Series published by Raven Press. It costs about $90.00 and is about 240 pages long. It is also quite technical, so I used a medical dictionary. There is a chapter that describes benign nocturnal AHC. This differs from classic AHC as the episodes always arise from sleep whereas classic AHC is usually relieved by sleep. The children described in this chapter also do not have the developmental delays seen in AHC children.

It also details older children, there are some that are now adults, who can go on to develop other neurological problems. This disease is considered pretty new since it was first described in 1970. I have not found any mention of children actually dying from this disease, but a few have succumbed to pneumonia.

It can be pretty depressing reading at times, but I believe that with the research being done and new advances in medicine, our children have a fighting chance.

Becky Sproul - Jan. 15 -

"As Becky Sproul has replied there is a variant in the literature of nocturnal alternating hemiplegia. This is described in the book Becky referred to and in an original article by the authors. The conclusion is that the nocturnal variant is a distinct variant of AHC which is not associated with developmental delay and which improves over years (see Kathy's earlier message). The nocturnal version is documented but said to be rarer than classic AHC.

Perhaps someone who was at the symposium last year could comment on whether this was discussed amongst the doctor's or families?

In the articles the point is made that it is important to identify children who exhibit the nocturnal form so as to specifically include information somehow...why are attacks only at night when sleep alleviates all AHC, why no developmental delay..So, if there are other children like Abbie on the list it would be important and very interesting to know.

Also Kathy, how is Abbie's coordination? I apologize if this is well understood by the list but it seemed important to make the point.

Alex Cole - Jan. 19 -

"Here is our experience of Alice who is just two.

She has no aversion to lying on her back that I have ever noticed. Like many children with AHC our first real sign of trouble was the nystagmus accompanied by crying out in pain from four months old which was diagnosed as AHC when she started the characteristic hemiplegia at 11 months. While undergoing investigations Alice had two EEGs, two CT scans and one MRI, all normal. She was also referred to the eye hospital in Windsor (England). There a thorough examination was made of her eyes (her pupils were dilated) by two consultants and they told me afterwards that "the cameras worked fine." I took her back to the eye hospital when she was having an episode with hemiplegia and the doctors then said that they thought the nystagmus was a result of one eye being paralyzed and the other going into spasm because it was trying to correct for the one paralyzed. The nerve crossover in the back of the neck means that the opposite eye to the body is paralyzed and the same side eye has nystagmus. At this time Alice had only ever had nystagmus in one eye at a time. Now she sometimes

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has other strange eye movements like rolling both her eyes up when having a bad episode but I have still never observed nystagmus in both eyes simultaneously; during a bilateral attack they can both go to the far corners of the sockets as if stuck.

When well, her eyesight seems just fine and shows no eye deviations. Her completely healthy brother with fine eyes would sit inside the telly if I would let him, I think; he gets so close."

Alex Cole - Jan. 20 -

"Actually, Abbie is developmentally delayed. She is 8 years old and in a special needs kindergarten. Its hard to say at what age level she is at mentally. with some things she seems to be age appropriate and with others, way behind. She has a 5 year old sister who she can sometimes keep up with but often cannot. For example, her sister can easily handle Abbie's homework, whereas Abbie sometimes struggles with it. Her writing is very poor - she's spelling and writing her first name but it is all over the place and hard to decipher if you don't already know what she's written - but, she is improving all the time. Her speech is good, but not perfect. She has trouble with "st", "h", "wh", "er", "th" etc. Her coordination is off, she has low muscle tone, walks with a cerebral palsy type gait. So, it sounds like she has the nocturnal version with respect to the attacks of paralysis, but has many of the symptoms of regular AHC. Such a puzzlement!"

Kathy Hurley - Jan. 21 -

"Is there anyone on this list that has AH themselves or has a child old enough that I could ask questions? My daughter is one year old and I would like to know how she is feeling...If she can tell when it's coming...if it always hurts.

It is so frustrating since she doesn't speak yet and I can't communicate with her.

I would like to know about children who are older that have AH..Have they had it since they were little or I should say how old when diagnosed? How it effects them mentally...Does it always get worse as time goes on?...

I just wish there was an answer!!!!!!!!!

Mindy Jonkoski - Jan. 27 -

"This is Wim Bollen from Holland. My daughter Annebel is 7 years old, and she can tell us to some (limited) extent what's wrong before and during attacks (if attacks are not too serious). During serious attacks she stops talking. She complains of pain in her neck before and during seizures (1/2 to 3 days duration).

Carefull/gentle massage (stomach/belly / neck) is giving her much relief during these attacks. She then also sleeps a lot. The day before, she shows aggressive behavior. Currently we experience a higher attack frequency, but this coincides with her changing teeth (accompanied with more and frequent pain in her stomach/belly). Migraine has been a long-ago diagnosed root/ cause, but we are not quite so sure about that anymore.

Medical treatment consists of Flunarizine (Sibelium) and Tre-Leptal (against Epilepsy).

- Jan. 27 -

"My son Nick is almost 8 years old and has complained of headaches immediately before, during or after an attack. Since he has been on Dilantin (not for seizures but for the AHC), his attacks rarely go beyond one day. I believe the first time he was able to tell us an attack was coming was when he was about 4-1/2 years old. He told us his hand wasn't working (our clue works for an attack). I held his hand and asked him to squeeze my hand and lift his arm and didn't notice any limpness or weakness. About a half hour after he said this — his arm/hand wasn't working. So he did sense something about to happen.

Mary Kay Riley - Jan. 27 -

"I had noticed about a year ago that Jake would lightly rub one side of his face and his hair before an attack. His neurologist thought that this was like an aura (at that time they thought he was having seizures). Jake also gets very aggressive before an attack and he will ask me to pick him up all the time. He also tells me "look at my hand, Mom" but that is usually once it has started. I notice that he doesn't sleep well at night before an attack.

Becky Sproul - Jan. 28 -

"This seems to be very common with a lot of children. They seem to get aggressive right before an attack. Very moody in all ways. I find this very interesting. We all keep looking for something in their body genes, blood etc. Often wonder if it is something that is so simple, we just continue to overlook. God, wouldn't that be nice. Always gotta have hope."

Roberta Creech - Jan. 28 -

"My son who is 14 years old takes 100mg a day of Coenzyme Q10. I haven't noticed an increase in energy, in fact the opposite. I attributed it to the flunarizine since fatigue is one of the side effects."

Charlotte Barnett - Feb. 4 -

"I think you are correct in stating that your children who are not affected most likely may be carriers, but would not be at risk for having offspring with AHC any more than the general population. I believe that goes for your affected child as well. It would be a different story if it was indeed a dominant gene. One of us should probably look into this information, and of course this is all under the assumption that this is.

Chris Morris - Feb. 12 -

"Since we started Jake on flunarizine 7 weeks ago we have noticed a major decrease in the duration of his hemiplegia spells. It has been wonderful and nothing short of a miracle. He has missed less days at school and our lives are a little more predictable. His previous episodes usually were about 3-4 week apart and lasted anywhere from 3-10 days. During these times, he would have hemiplegia on either side with periods of quadriplegia. Also, he would have severe dystonic episodes during which he would cry and appear to be in

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pain. These dystonic episodes would occur both during the day and night. Now, Jake has had a few short periods of hemiplegia (about 4 hours in duration) and one episode of quadriplegia. He has almost daily episodes of dystonia that involve his right arm and leg, which appear to be more uncomfortable than painful. These are usually about 10-20 minutes in duration. I have noticed, though, that there are times when Jack is "different". Call it parent's intuition, but I swear that if Jake wasn't on the flunarizine he would have had hemiplegia. There is just a difference in this attitude and he seems to walk differently and have poor balance. He is also prone to cry easily and wants to be held a lot. I wonder if any other parent had noticed this. Even before Jake started the meds., there were times when he was like this, usually before an episode.

The one episode of quadriplegia that Jake had occurred the other night. He and his dad were in the garage making a bird house. My husband took him out there because Jake was in one of these "moods". When my husband turned on his power saw, Jake instantly became quadriplegia. Jake had never done this before. His quadriplegia always occurred during a prolonged episode of hemiplegia. Jake had the severe dystonia during this spell. He slowly came out of it over about 2 hours. He went to bed shortly afterwards and (as usual) was fine the next day.

I had noticed before that loud noises appeared to trigger dystonia in Jake, but he has never had a response so severe before.

Jake is delayed intellectually but he can talk, although at about a 2-1/2 year old level. He has never been able to tell me anything about these episodes other than "my arm" just before or at the onset of an episode. Does anyone's child talk about their episodes, what they feel, if they hurt? I also noticed that Jake would run his hand through his hair before an episode. If I asked him if his head hurt, he would just look at me."

Becky Sproul - Mar. 22 -

"Our daughter Gabrielle is 11 years old and has AHC. She is always turning off the radio, CD player and sometimes the TV saying "too loud, too loud". The loud noise effect on Jake is consistent with our observations of Gabrielle although more pronounced.

I am glad you have had success with flunarizine, it was a great relief to us as well when Gab was eventually put on it about 8 years ago."

Paul & Carmel Shannon - Mar. 22 -

"My son Greg also had some bad experiences with certain loud noises, especially when he was younger. The one that used to bother him the most was the vacuum cleaner so we never did it when he was in the room. He never had a problem with things like the TV, music, etc.

I don't know if the loud noises startle them or if its something in the frequency or volume.

Greg Wisyanski - Mar. 23 -

"........Loud noises don't bother Alice. She startles violently at a sudden noise although this has never induced an attack. We are pretty sure now that she has had three recent episodes precipitated by over excitement at something new and surprising.

Like Berit she will sometimes pick up an arm at the onset of an attack and show it to me...as if I could do something to help. I wish I could do more. When Laura describes the moans of pain she has heard I can hear them in my head too. There is something very distinct about the cry of pain Alice has during a bad attack. It is obviously a very specific pain that they suffer......."

Alex Cole - Mar. 25 -

Annual Dues

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

Sponsorship

Starting with the July 1998 newsletter, we would like to have a "sponsor" for each edition. The idea of the sponsorship is to cover the printing and mailing costs of the newsletter. The sponsorship will cost only $100 per edition. This cost can be split among a few people. The newsletter will prominently feature that edition's sponsor with a brief statement regarding their connection to an AHC child. For example:

This edition of the IFAHC newsletter has been sponsored by John and Mary Doe of New York. John and Mary are the grandparents of Sally Doe, age 10, also from New York.

This is a great way for friends, relatives or classmates to show their support. Please contact the editor, Lynn Egan at 650-365-5798 or Laegan@aol.com to sign up.

Protect your Child

Have you ever thought about using a Medic Alert bracelet or necklace in the event that your child has an emergency and you are not there?

We did some research and this is what we discovered. Medic Alert is a 24 hour a day Emergency Response Center that keeps medical information on your child. Medic Alert is for adults, too. They are recognized around the world.

The bracelet/necklace itself, is engraved with the medical condition, allergies, medication and the Medic Alert patient ID number.

When called, Medic Alert will provide your vital medical facts and will list up to five persons to notify (ie. pediatrician, neurologist, etc.)

Medic Alert's toll free number is 1-800-432-5378.

Upcoming Events

NORD National Medical Meetings:

We are continuing to try to get the word out to the medical community about the existance and diagnosis of AHC. Through our assocation with NORD we have signed on to distribute information about AHC at the American Academy of Nuerology conference April 28-30 in Minneapolis and also at the American Academy of Pediatrics conference October 17-21 in San Francisco. We hope both events continue to help our doctors understand more about AHC and allow more families to contact us. Lynn Egan will be attending the San Francisco conference.

The AFHA (French association) will be having their annual family meeting in Paris, May 23. Several families from other countries are planing to attending.

In Milan, Italy, on May 2, several Italian families will be gathering to form a organization /foundation. Rosaria Vavassori has been doing a great job in organizing and locating other families thru the help of Drs. Gobbi and Guerrini (who both attended the symposium).

For the second time, Richard George is raffling off a Harley Davidson 1998 Road King. The second prize for this raffle is $1,000. Tickets are 1 for $10, 6 for $50 and 13 for $100. Deadline is October 15, 1998. They can purchased by mail or phone (M/C - Visa - American Express excepted) thru:

Richard George, AHF
31250 Plymouth Rd.
Livonia, MI 48150
(888) 557-5757

If you would like to sell tickets for this raffle ticket in your area, please contact Richard. You do not need to be present to win.

The drawing for the Harley will be on October 29, 1998 at the Bonstelle Theatre, Detroit, MI, where the production of "Dracula" is playing. Tickets for that event are $15.

The 3rd Annual Rock N Blues Festival at Heritage Park, Taylor, MI is happening on July 10th and 11th. In additiona to the Rock N Blues concert, a Chile Cook Off will be held on July 11th. Admission is Free.

Remember......

-Disney World, Florida - We are still planning to have a family "Convention" in the fall of 1999. We have had about eight families say they would like to come. Please let us know if you are interested in attending, so we can begin making arrangements.

-Tapes of the 1997 Symposium, are 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 6 weeks for delivery.

- Our Fiscal Year End is May 31. Anyone who would like to become a trustee, please contact Donna Cyr at 810-776-1168 or email gc1mvan@moa.net.

- We received several stories from families for our booklet about Living with AHC. We would like a few more, so please , take a few minutes and share your story. Let us know if you wish to remain anonymous or want your name address, etc published. You can send all information to Lynn Egan, 239 Nevada St., Redwood City, CA 94062.

- For those of you recieving the newsletter for the first time, previous copies are available through Lynn Egan or they are posted on the IFAHC website at www.phoenix.net/~ifahc.

Congratulations

Eileen and John Richards had a baby boy, John McKinney Richards on January 20th, 1998. Big brother, Joey and big sister, Ann, (who has AHC) are thrilled with the new addition.

Neal and Karen Jackson had a baby girl on February 14, 1998,Valentine's Day. Katherine Devon Jackson has three older brothers to follow; Ian, Nicholas and Colin (with AHC).

Both families are doing well!

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