INTERNATIONAL FOUNDATION FOR ❖ ALTERNATING HEMIPLEGIA OF CHILDHOOD ❖

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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

Editor's Notes

I can't believe this is our 8th issue! Thanks to all of your contributions over the years, this newsletter continues to be a success. I would like to encourage you to continue submitting articles and also invite you to make comments and ask questions either about AHC or the newsletter or what ever is on your mind. All letters will be published as is. If you wish to remain anonymous, please note.

Together we can continue to make this newsletter a forum for exchanging ideas, thoughts and comments.

I hope that your summer is going well and I look forward to hearing from you.

Keep well, Lynn Egan

AHC Blood Cell & DNA Collection

In the April 1998 Alternating Hemiplegia Foundation (AHF) newsletter there was a very important article by Dr. Louis Ptacek regarding the creation of a blood cell bank that will allow for current and future genetic research. As of June 30, 1998 11 families have contacted Dr. Ptacek's office to receive the kits. This project is extremely important so please make every effort to participate. The number of AHC patients is small, so we need a large response rate.

To participate send or fax your name, address, phone number, child's name, sibling's names and e-mail address to:

Dr. Louis Ptacek
Howard Hughes Medical Institute
University of Utah
Eccles Institute of Human Genetics
Bldg. 533 Room 4425
Salt Late City, UT 84112
FAX: 1-801-585-5597
or e-mail to Catherine Mckenna at:
cmckenna@howard.genetics.utah.edu

Flunarizine Update in the US

There has been a major change as of January 1998 in ordering flunarizine from John Bell & Croyden.

According to John Bell & Croyden, they will no longer accept payment or requests for medicinal products from the patient. This is a law that has been instituted by England and then we have US laws to contend with. Your physician can place the prescription and make payment and then you purchase the flunarizine from him. I also checked with Canada and discovered that they are no longer accepting prescriptions from American physician.

Please check with your physician ordering the flunarizine to see how this procedure will affect you.

This newsletter is sponsored by Greg and Fran Wisyanski of Monongahela (Carroll Township), PA. Greg and Fran are the grandparents of Greg Wisyanski III, age 7, of Port Matilda, PA.

Inside This Issue

From the President

Dear Families,

In the next few weeks I will be preparing my 5th annual contributions solicitation letter. I write each year to family, friends, coworkers and others to tell them how Greg is doing and what is happening with the IFAHC. My mailing list has changed over the years, but I manage to send out about 200 letters per year. During the past 4 years, I have received contributions in excess of $40,000 as a result. I have also collaborated with Rich and Dana Tasi from Huntington, CT on letters that have raised thousands of dollars more.

I'm not telling you this in an attempt to congratulate myself. These amounts have never before been published and I wish they were 10 times as big. My goal is to tell you that it is possible to raise a fair amount of money towards AHC related goals with only a modest amount of time and effort. It takes me less than an hour to write the letter and a couple more hours to address envelopes. My parents help out by sending postcards with thank you's on them. The cost of copies, envelopes and postage is also reasonable and it really helps if you have a generous employer who will supply many or all of these.

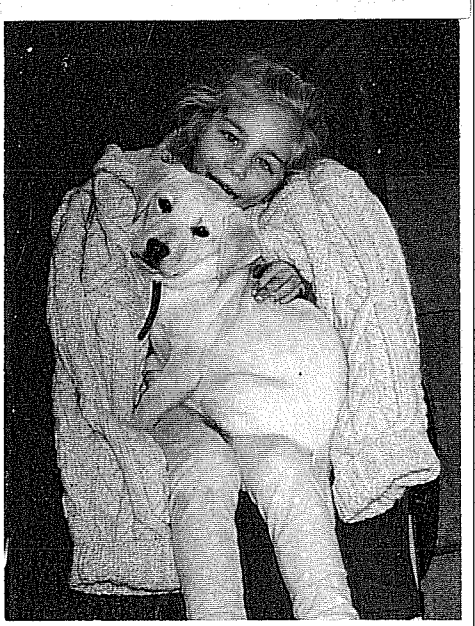
I know, you're ready to say "what should I write?" Let's face it, I'm no literary genius (actually, I'm a tax accountant) but I do know my son and I know about living with AHC and that's what I write about. I got the original idea from Richard George and I've followed it since. I've got all my old letters and you're more than welcome to copy them. The group you are writing to want to hear about your child and they really do want to help out by making a donation. Sometimes it's the only way they can help out.

Let me finish by telling you why we are always harping on money. Many of you can remember when you first received the AHC diagnosis and didn't know anything about the disease or have anyone to talk to. We hope that you appreciate the efforts that are made to publish this newsletter, maintain a website, produce brochures, and make many other efforts on behalf of AHC education and family support. All of these cost money to do. While we are living with AHC, we are also trying to find a cure. The IFAHC and AHF have both spent money towards Dr. Chugani's work and the May 1997 symposium. The AHF is organizing the blood draw for genetic testing and accepting applications for research grants. We would also like to go further with a preliminary study of how diet and metabolism affects AHC. We will never have enough money until a complete cure for AHC is found.

There are very few of us who are doing the majority of the work. We need more help! We have only one rule: do only what you are comfortable with, but do as much as you can. All of our children will appreciate it.

Greg Wisyanski

My Brother, My Sister



Kathleen and Maple

I like to try to do all I can with Kathleen to help my mother. Kathleen always wanted a puppy and last Christmas, she got one. "Santa" in Kathleen's words called her Maple. I like it how her eyes lit up when she saw the puppy. It made me feel good inside. I think its cool to live with Kathleen because you get a chance to help someone that has a disability.

Kathleen is fun to be with and nice to have as a friend and a sister. I think that when Kathleen gets mad, she is really frustrated. I hope that Kathleen gets over AHC and gets to live the rest of her life an AHC free girl.

By Greg Egan, age 10

My brother R.T. suffers from a rare neurological disorder called Alternating Hemiplegia of Childhood. Adolescence is a hard time for every child, but R.T. endures daily obstacles which most of us never encounter.

Hero
Dedicated to my brother R.T.
by: Ashley Peckinpaugh, age 15

Have you ever hurt your finger,
And it hurts way down deep inside,
But you know its not that bad,
So you don't cry.

Have you ever broken a bone,
you know, the pain that makes you want to die,
But you're too tough,
So you don't cry.

Have you ever been called retard, stupid, or just plain dumb.
Those things that stay with you in your mind.
But somehow you make it through,
and you don't cry.

Have you ever been made fun of by strangers,
you know the ones that are just passing by.
They don't even know you and somehow they can judge you,
But you ignore them, and you don't cry.

You know I look up to you,
You're my hero and you'll always be.
You can only fit under one name,
That would be R.T.

I'll always love you,
That's the way it will always be.
I'll always be there for you,
Like you're always there for me!

Louis Wins Medals at the Special Olypmics

I thought I'd share some good news with everyone. My son Louis is 13 and suffers from AHC. His episodes come along about every 10-14 days and last for about a week. Louis takes flunarizine and this seems to lessen the severity of his attacks. Anyway, we live in Florida where Louis participates in the Special Olympics. He is on the cycling team. Louis rides an Adult 3 wheeler and has practice once a week. The bike is great for him and it gives him a chance to socialize with other kids. This year Louis was chosen to represent our county, along with other athletes at the Spring State Games in West Palm Beach, Florida. I was reluctant to send him because this meant that he would have to stay with the other athletes and his coach and I didn't know if we were ready for that. I finally decided about 2 weeks ago that we would go. I was really concerned with what would happen if he had an attack, but about a week before we went he had an episode and I thought this is good, now he won't get sick for the race. We left on Friday and my parents even drove down from New York to be there. Friday night was the Opening Ceremonies and they had music and fireworks and there were 2000 athletes from all over Florida. It was very exciting. Now we all know what happens to our kids when they get excited. Louis started having an attack on his right side and he had to race the next morning. I didn't get much sleep that night knowing that he was sick and for the first time he was sleeping in another hotel. His coach assured me that he would take care of him and that they are trained to handle these situations.

Louis Caruso

The next morning we met them at the track and Louis was still not using his right side. They let him take a practice run around the track and Louis barely made it because he couldn't keep his foot on the peddle. Louis was entered in the 500 Meter and the 1K race. My husband asked his coach if we could tape his foot to the peddle and they said that was OK, so right before the race we taped his foot and he finished the race and he won a silver medal in the 500 meter. We were so excited and proud of him. The next race was not for a couple of hours and we taped his foot again. He had to go around the track 2X and we were all cheering him on and this time he came in 1st Place and got the Gold Medal. I can't tell you how happy and proud Louis was to win. He wears his medals everywhere and shows them off to everyone he sees.

I'm sorry that I went on so long, but I wanted to share some good news for a change. The season is over for cycling now, but next year we'll be sure to buy him the pedals that can strap his feet on. I think that would be an easier solution.

Regards to all, Adele Caruso

Adele had posted this on the internet chat line/bullentin board. Here are comments made.

"What a wonderful heart warming letter! Louis is an inspiration for all our AHC kids. The Special Olympics are a fantastic group. The people who work with children with disabilities are very, very special. I have a sister who participated in the Special Olympics, many years ago."
Lynn *- May 18 -*

"That's fantastic. We will keep this in mind for our Gabrielle. Well done and keep it up."
Paul Shannon *- May 19 -*

"This is from Lena from Sweden mailing. Thank you for an encouraging letter!!! It was real fun reading it - we all need to hear that our children is able to do things - unusual things.
My Boys have the same periods of attacks as your Louis. We try to do all the 'funny stuff' the weeks they are well. Sometimes I can see when it have been to much fun one week - then they will get an attack sooner and with more bad days. And in the bad week I can sometimes see that they are able to force themselves to be better for a while - If somebody special is on a visit etc... I hope that Louis do not need to 'pay' for his remarkable good achievement. Thanks again."
- May 19 -

"It was very wonderful to hear about Louis. Previously when my son would have an attack we would just stay home until he would get better. However, we came to realize that taking him out was better for him. He became more relaxed and really enjoyed the outing. Just taking long drives and exposing him to fresh air and a change of scenery did wonders for him and for us as a family."
Nahid *- May 19 -*

Update on Events

NORD National Medical Meeting:

The American Academy of Neurology conference, April 28-30 was well attended according to NORD. There was an official turnout of 6,400 neurologist, many of whom stopped at the NORD booth to learn more about rare diseases.
All of our 150 brochures (limit allowed) were gone by the end of the meeting.
We will be represented again at the American Academy of Pediatrics, October 17-21 in San Francisco. Lynn Egan will be helping out at the booth.

Alex Cole posted a message to the bulletin board stating that she received an invitation from Mrs. Bailey regarding a meeting of AHC families on July 11 in Slough, England. Alex Cole, whose family just attended the meeting in France, hopes to describe the DNA blood collection project to the UK families not on the internet and explain how they can participate from there.

INTERNET CORNER

Again, many families had a lot to say on the internet chat line/bulletin board. Many topics are covered and as you read through, keep in mind that while all children suffer similar symptoms, the degree of abilities and/or development vary tremendously.

(reprinted with permission)

"....If these are seizures he is having, why not just let them take their course, except for the turning blue of course. Everyone is different I know. With Chad we have found that the attacks (whether seizure or hemiplegia) is better for them to run its course through instead of using the drugs all the time. I don't care what doctors say, some of these meds are addicting to some people. Yes, they are very frustrating attacks and we as the parents want them to stop. But sometimes we can't perform miracles, so we have to take a deep breath and just be there for them as you would be for a friend in need. I have found that this thinking has really calmed my nerves and has helped me deal with the emotional part of all this.
Oh, update on Chad. Thursday 4-23-98, he had surgery to implant the vagus nerve stimulator. The doctors will not turn the device on until the 5th of May. So until then, we just wait. He went thru surgery with no complications and only has taken one dose of Tylenol right after the surgery, no other pain meds were needed. Since the surgery, Chad has had 1-1/2 days of total body paralysis. We made it thru! I will keep you informed on how the device works for him, if anyone is interested."
Roberta - April 28 -

"Roberta, this is the first I've heard of the 'vagus nerve stimulator'. Is this a treatment for the AHC? (I'm sorry if others are familiar with it, I was disconnected from the internet for a while & just re-subscribed to the list so I probably missed past emails on the subject). Can you explain it a little further?"
Kathy - April 28 -

"Let me introduce myself. My name is Mirjana Toullec and I have two daughters. My oldest one, Aurelie suffers from AHC. She is 4 years old and develops quite well. My second daughter, Marina who is 2 is not affected.
I am contacting you as Vice President of the French AHC association: A.F. H.A.
We are going to have our annual meeting on May 23rd. Dr. Goutieres who is in charge of some French AHC cases will be attending our meeting and reply to our questions. If someone of the mailing list has some questions for her, it would be a pleasure for us to ask them for you.
We will keep you informed via the mailing list on her replies and let you know about the meeting. Information would be included in our next newsletter which should be available in June. It would be issued in French. If someone wish to receive it (and the previous version), please let me know and give me your address.
As we are going to have some foreign participants, a summary in English should also be issued.
I am looking forward to receiving your questions."
- May 4 -

"My name is Nahid and I have a son who has been diagnosed with AHC at 13 months of age. He is developmentally delayed, but has started progressing very nicely since he started taking the medicine. He is now 18 months of age. Was your daughter's development steady since she was born or were there ups and downs? Does she have severe attacks? Do you give her any kind of medicine or herbs? Do you know of any other children who have AHC but are developing normally? Is there a connection between the number of attacks and the development of the child? My son has a lot of erratic eye movements and sometimes he laughs when he has the eye movements. Is there any other parent out there who experiences this? If so, do these episodes decrease as they grow older? I would very much appreciate it if you would send me a copy of your newsletter. I don't speak any french. If you can send me an English version, I would be very thankful. It is very important that we keep in touch for the benefit of our children. By the way my son's name is Waleed and we live in San Ramon, California, USA. I have an older son who is not affected. I hope to hear from you very soon."
- May 4 -

"The vagus nerve stimulator is implanted under the left collar bone and three leads go up the vagus nerve in the neck. This device will send impulses to the brain. This is a fairly new device to help control the seizures. Chads device was turned on today. So we won't know any results for a little while. This is similar to a pacemaker only to the brain instead. There is a web site for this device also. Don't know it off the top of may head. It will come up if you just type it. I will keep everyone informed."
Roberta - May 6 -

"Good luck with the stimulator.... about 4 years ago a similar (if not same) procedure was done for a little boy here in Tennessee. At that time if memory serves me correctly (though I did video tape the ABC news presentation... so if you like I'll look for the tape and send the particulars (ie: doctors name, hospital, etc.) I believe he was 11 or 12 years old.. due to the seizure activity that he'd experienced his "functional" age tested out at age 2 ... 6 months after the surgery the same tests were done and he'd "improved" to test out at the 8 year old levels ... they did a follow up story a year later and he'd just about "caught" up educationally to his age range. I kept tabs on "that family" via news/ acquaintances regularly until our "mini" miracle happened and both my boys suddenly "outgrew" their seizures... they've been seizure and seizure meds free for going on 3-1/2 years "definitely" and suspected of being seizure free for 4 years. We really pushed for a "drug holiday" during the summer vacation. I was on pins and needles but the boys did excellent!!!! I know your going to be busy for a while getting all your "ducks" in a row, but if you get a chance please keep us updated on how everything is going

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INTERNET CORNER

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there for you and your crew. Take care and best wishes."
Elf in TN., Romona - May 7 -

".....Aurelie was diagnosed with AHC at 10 months of age, but she started to have a strange behavior just after she was born. The day after birth, she was transferred to a special department of the hospital. They told us that she had a convulsion and gave her Gardenal. I never saw that convulsion because delivery lasted too long and I left a lot of blood. I felt really weak... We never had the impression that she was delayed, she developed quite normally but with episodes. Strangely, we still now have the impression that after a bad period she has acquired something she did not have previously to the episode (better comprehension, better pronunciation, better balance...) I only hope that one day we will not have the bad surprise to see her regress. It already happened with some children...We often went with her to the hospital because we did not know what she had (neither doctors!!) One day, as we knew that Necker was a good hospital and that they were experienced with strange disease, we decided to fix an appointment with a doctor. I had the chance to obtain one immediately with Dr. Goutieres. According to her during the first consultation, Aurelie had all the AHC symptoms. She suggested to go immediately to the hospital as soon as Lili has another episode. She definitively diagnosed her with AHC at that occasion. When Aurelie was younger, it was really difficult because she had a lot problems to sleep during the night. It was as if she confused night and day. Maybe other children experienced that? She started walking at 22 months, but she was so cautious that we wonder if it was not the reason of the little delay (we were told that a "normal" child can start to walk until 24 months). Still she is doing every thing carefully (and it is better like that).
She is taking Sibelium - trade name for flunarizine (7.5mg per day in the morning). We did not want to increase the dose. She is also taking Nopron. That drug seems to have a positive effect on her. It is a syrup and we give it only when she has a strong attack.
The most important is that for the moment she is really positive and combative. Often when she is only touched on one side she take her hand with the other and say go away crisis!!!
How does your oldest son react when Waleed has an episode?
We have another daughter Marina who is 2 years old. Aurelie and Marina really love each other. Marina has a protective attitude towards Aurelie. She is really helpful. Sometimes she is not so sweet but when I explain to her that Aurelie's episode is painful, she is again sweet with her...
Regarding eye movements, Aurelie still have them sometimes. It often occurs when she is tired, too excited... she needs to have her glasses always on her nose! It seems that most of the AHC children need glasses!
Evolution seems to be different from one child to another. It seems to be different levels. According to Dominique, AFHA President, there is no correlation between the number of episodes and the level of affliction of the child.
Aurelie has good and bad periods. She can be free of episodes during 3 week and then have a really painful and long episode...or have every 2 or 3 days a smaller episode affecting only one part of the body or eyes. Sometimes she has her episode in the evening...when she wakes up she is often really good. I cannot understand that strange disease!!!!!!
I will send you a translation of our newsletter as soon as it will be translated. The problem is that I have to work, so I have not enough time to issue all I would like!!!....."
Mirjana - May 7 -

"I hope everyone is doing fine. I would like to know whether anyone has a child with AHC and is on the ketogenic diet. I would appreciate any information on this diet. Thanks".
Nahid - May 12 -

"We had tried the ketogenic diet approximately 3 years ago. Greg was on it for about 4 weeks and achieved the proper level of ketosis. There was no improvement in his AHC condition and we removed him immediately.
It is only my opinion, but I don't think the keto diet works for AHC especially if there is no associated seizure disorder. It is also a very difficult diet to administer with all the weighing and counting. The portions are terribly small and it really broke our hearts to give him so little food when we knew he was so hungry. He was only about 4 years old at the time and I would never try it again with a kid who wasn't old enough to understand why we were trying it."
Greg Wisyanski - May 12 -

"My son is on the Ketogenic Diet. He has the alternating hemiplegia and also has intractable seizures. He has been on the diet for 3 years. We have seen a tremendous difference in him after the diet started. He has had less attacks and less seizures, but after 3 years he is getting tired of the diet. He did extremely well on the diet as far as eating the foods and they filled him up. Usually, the kids are only on the diet for a few years. We are trying to wean him off now. Taking a very long time just taking precautions.
Also an update on the vagus nerve stimulator. The stimulator was turned on last Wednesday. On Friday, they had to drain fluid build up off it. Come to find out, he has an infection. No other sign, but the fluid. So he goes back in the hospital tomorrow to remove the stimulator to clear the infection. In about 3 weeks he will be put back in the hospital to reinsert the device. Both times he will be in for 3-4 days. Will keep everyone posted."
Roberta - May 13 -

"My son is six years old and was diagnosed with AHC at 14 months old. Up until now, he has not had any seizures. Last night he did something completely new. He was screaming in pain, had the sweats but has a low temperature (96.3), very sleepy and sensitive to the light (kept covering up his head). Prior to this, his bowels let go (also unusual). The doctors think he either had a migraine or a

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INTERNET CORNER

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seizure. Have any of your children experienced anything like this?"
Wendy Walker - May 25 -

"Jake does something similar to this at times. He will wake up screaming in pain and is usually very sweaty. He also does not like the TV being on at this time. He will stiffen up his body (dystonia). He gets better if we sit him up. I will usually hold him on my lap, in the dark, and rock him. I rub his back and sing to him until it passes. He will usually go right back to sleep. This can happen several times a night, for several nights in a row. Since he started flunarizine, it has decreased some, but hasn't stopped. I think that he has no recollection that it happens, but he is unable to verbalize enough to tell me. He is also usually cranky the next day. If you would like to know more, please feel free to email me. Our sons are the same age!"
Becky - May 25 -

"I have never heard of this nor have we any experience with this. Wendy, please keep me posted on any further developments and Becky, when did this start with Jake? I will be very interested in seeing how many other children have similar episodes/attacks."
Lynn - May 26 -

"I guess my husband and I figured that this was the norm! I had him read Wendy's message too to see if he agreed that this was similar to the nighttime attacks that Jake has and he felt the same. We started noticing these attacks about July of last year. Jake has always been a terrible sleeper and awakens frequently at night. He would get these attacks during prolonged episodes of hemiplegia. At night, he would go to sleep for about an hour or two. Then, he would have the screaming, similar to what he has during a bad hemiplegia/dystonia attack. You know that cry that they get. We have found that sitting him up helps him through it. He doesn't really seem awake during these times. Usually his legs are straight and stiffen up. If he is in our room, we have to turn our TV off as it seems to bother him. They usually last about 10-15 minutes but can recur several times during the night. He used to only get these during periods of hemiplegia, but now they occur on any given night now that he is on flunarizine."
Becky - May 26 -

".....I don't mean to ask so many questions, I am just....dealing with more stuff with my son. Also how old is your son? My TJ is now 6 years old. When he is having good days, he is doing great. He is walking, almost running, he is speaking in at least 8 word sentences, he is almost totally toilet trained and a very independent personality.
We have not tried the keto-diet, and no longer use flunarizine. The flunarizine didn't help TJ much. TJ also has a lot of autonomic disturbances including temperature changes, circulation problems, apnea, slow heart rate and other stuff, so we have to be careful what we give him.
Well, I am going on and on so....."
Wendy - May 27 -

"Last Thursday we gave our son his 18 month vaccine. Previously he never got the "P" in the DPT, however this time his doctor felt that it was ok to give it to him. Saturday night, he was crying out in pain all night. The next day he woke up with his left side not working. This was the most intense episode because only his left eye was moving side ways and he had fast breathing. He was very uncomfortable and appeared to be in pain. This is the 5th day and his left side is still not working. He is also very tired and weak. I am worried that maybe the vaccine has interfered with the medication. He usually has these attacks but he recuperates quicker. His left side is very weak. Did anyone experience the same problem when vaccinating their child? Please, I need your input. I am just very worried. I hope that everyone else is doing fine."
Nahid and Khalid - May 28 -

"I know exactly how you feel. Every time Jake has a bad attack, I start to feel guilty, wondering if something I did caused him to have the attack. There are certain things that we know for certain can cause Jake to have an attack - excitement, water, sun/heat - but he cannot live in a cocoon. As your son gets older, he will have to make some choices that are not easy, do something you enjoy and chance the attack, or sit and watch while others have fun or find something enjoyable to do that doesn't cause an attack. We can counsel them but there comes a time when they have to choose.
Did your son have a fever from his vaccinations? We have found that Jake has attacks with fevers or when he is congested. Jake hasn't had the pertussis vaccine since he was one year old. His pediatrician doesn't want him to get it. pertussis (whooping cough) has made a comeback recently and I questioned whether he should get the vaccine, but she said no.
These long attacks feel like they will never end, but they do. Jake would have attacks that lasted for 10 days at a time. We knew to feed him as soon as he woke up because it is so hard to feed them once they are so weak. I was always afraid of him choking. He would be so pale and look so bad, we were always worried. Sometimes he would recover instantly, and other times it would take days for him to slowly get back to where he was before the attack."
Becky - May 28 -

"I just wanted you all to know, TJ has not had the whooping cough vaccine and has had whooping cough. It really wasn't that bad, the whooping cough. Well not for him anyway. He was somewhat OK, he just gave it to me. It was awful.
TJ is currently having another couple of bad days. First the migraine (?) and now he has gone full blown yesterday and today. Keeping in the air conditioning is helping a little.
Just a quick question to all...my son is hooked up to a heart monitor at night because he tends to stop breathing and slowed heart rate when he sleeps. He has been on it for two years now and we have seen an increase in the frequency and the duration of both. Anyone else lucky to experience this?"
Wendy - May 29 -

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INTERNET CORNER

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I would be interested in knowing at what heart rate TJ's monitor is set. When Jake was in the hospital last July, his heart rate went into the high 30's, which I felt was very slow for a 5 year old. They were starting him on Inderol for migraines and I refused to let them give him the Inderol as it is a beta blocker and would further slow his heart rate. The doctors said that the Inderol was at a low dose and shouldn't effect his heart rate much. He tried the Inderol for a few weeks, but it didn't seem to make any difference.

Jake has never been on an apnea monitor, but I have noticed that he seems to be very quiet for a while, then jerk in his sleep and his breathing will get heavier. We do not have air conditioning, but we do try to keep Jake as cool as possible as heat really effects him. I noticed in an earlier email that you mention that TJ has autonomic problems. Does he have vagal episodes - such as with pain or having a BM? This is really becoming a problem with Jake. He's beginning to have vagal episodes (profuse sweating, slow heart rate, dizziness) even with mild scrapes. Is TJ on any medication at all?

Sorry for all the questions, but sometimes I feel like this is the only place I will really learn anything!"

Becky - May 29 -

"TJ's monitor is set at "less than 60 beats per minute at 6 second's"... This basically means his heart can only miss a few beats. Plus as far as I know, 30 beats is extremely low, means only one beat every other second. The main thing to keep in mind, is the monitors work on averages.

TJ is not on any medications. We tried chloral hydrate, which doesn't suppress the respiratory system, but that didn't work. We now just use time and patience. Sometimes I wonder what is worse, the disorder or the meds.

An interesting thing we have found is that after TJ has had prolonged bilateral episode, he seems steps above his old self. His vocabulary will have increased and he will seem more independent.

Anyways, if there are any more questions, don't be afraid to ask. That is how we know about each other. I will always try to answer to the best of my ability."

Wendy - May 30 -

"We have a six year old daughter who was diagnosed with AHC at 15 months of age. Ashleigh currently attends kindergarten at a mainstream school. Ashleigh's paralysis attacks last for around 5 days (swapping sides in between) and occur every 3 weeks or so. She does not attend school during the attacks, mainly due to mobility problems (we do whatever school work we can from home during these times).

Ashleigh is academically age appropriate but has very little speech capacity. She communicates by gestures and uses a 'green macaw' communication device (which she doesn't particularly like using). Because of her poor fine motor skills, Ashleigh does most of her work at school on a computer.

We read recently on this chat line of one school setting-up a 'quiet area' for an AHC child. Does anyone know of any other innovative ideas or educational devices we should know about that would help our daughter at home or school?"

Tim and Chimene - June 6 -

"We have tried a number of communication devices over the years. Our daughter Kathleen is 7-1/2 and has just completed first grade in an inclusion class with an aide. Expressive language has always been her biggest delay. When she was little, we started with sign language, of which we still use some today. We moved on to a picture board/book, of which had separate pages of like things. Example: places to go; people; activities; objects; etc... As her speech has developed we have left these behind, but because speech is still hard to understand all of the time, we looked at a communication device called Dynovox, which has screen after screen like the picture book, categories, however, it could be programmed so that each screen was appropriate for your child. I found it difficult to sort through. And of course as technology goes, they have since come up with a smaller, more user friendly Dynomite. We looked at it in December at an Abilities Fair, however we decided not to get it at this time. Over the last year, Kathleen's speech has really improved. What I mean is that she is understood by more people, not just her family. It is still hard to understand her, especially when she goes on and on. But with increased speech therapy and occupational therapy to straighten her facial muscles, we are seeing great improvement.

I can remember when Kathleen was but two or three and a mom said to me, 'My daughter did not start talking until she was 7 years old!' I wonder now, is this what she meant?

As far as quiet places, we have a bean bag chair at school for Kathleen when she has an episode. It is in the "book corner" behind a chinese screen. So far it has been very effective. The bean bag chair conforms to her body, and I think this really helps.

We too use a computer for all written things. She has learned to read/recognize about 150-200 words and this spring was able to do her spelling tests on the computer. She does enjoy the computer, for which I am thankful (she must get it from me). We are also fortunate that during the summer we are able to bring her computer home. She is attempting to write her letters, but these are very gross."

Lynn Egan - June 4 -

"A few years ago we had also tried a macaw system and it wasn't very good at all. Our son Greg (7-1/2) has been using a Dynomite for 9 months now and it has been terrific. It is easy to program and he picked up on it immediately. Greg has very low muscle tone and poor find motor skills but he can manipulate the Dynomite very well. It has screens and keys for all of his daily school routines, his daily lunch choices, and many of his home activities. They are even beginning to look at its infrared capabilities because it can somehow communicate with a PC and even work the TV! (the TV part probably isn't the greatest idea!). Its a pretty expensive machine, however, we have found that it has really helped Greg

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become involved in many more aspects of his schooling and home life. If you can't find information on this let me know and I'll dig up the 800 number.

The other device school has found helpful is an attachment to the PC called Intellikeys. It goes right into the keyboard port of any PC (DOS or Mac). The panel is slightly bigger than a standard keyboard and it has slide in panels depending on what you are doing. For example, one panel has only the four arrow keys and the enter button. They are all about 1.5"x 1.5" so they are easy to hit and move around the screen. They have inlays for numbers, letters, and the keyboard sorted alphabetically instead of QWERTY layout. I also have information on this if you are interested.

Lastly, we also have a quiet area for Greg at school when he feels bad. We switched from a rocking chair to a bean bag as he got older and bigger. It works well and the teacher and other students all understand."

Greg Wisyanski - June 5 -

"I wanted to add that the Dynovox/Dynomite are speaking devices. (in case you are not familiar with this communication system). Whatever has been typed in, such as "I want breakfast" a button is pushed and these words are spoken. It stays on the screen until it is deleted or changed.

I have another question. How many of you have used high top shoes and/or foot orthotics? I was asked the other day about this and we have used both. Kathleen is flat footed, but so far that has not been a problem. However the physical therapists over the years have recommended inserts and last year orthotics and just about all have said that high top shoes will give an added support while walking. Initially we all agreed that these items made an improvement. Earlier this year she outgrew the orthotics and we have decided not to have a new set made. I wonder if seven months of using them has helped enough that she does not need them. Any thoughts?

We continue to use high top shoes or at least a shoe that has a good support, however with summer approaching, we do use sandals and go bare foot."

Lynn - June -

"We used shoe inserts with Kyle (7 years old) for about 9 months until he outgrew them and have not ordered any more. Like Lynn, we are not sure how much benefit they were but the therapists working with Kyle thought that the inserts would help him out so we tried it. Kyle has not worn high tops but he does wear 'climbing' boots/shoes occasionally that do provide some support in the ankle higher than just tennis shoe styles."

David McGinley - June 5 -

".....About equipment and support... Currently we send TJ to school full time, even on full blown days. We set this up starting in preschool and have kept it going ever since. We do not use a "quiet room" and keep him fully integrated no matter what. We have found he continues to learn even on the very bad days and after he regains full tone, he has jumped in stages.

We do have a wheel chair for the very bad days. We use the "Wizard". It is very good for his swallowing problem and reduces the number of posturing, holding breath, and screaming episodes. It tilts and reclines and is lighter than most. I can even turn the chair part around if I need to keep an eye on him.

We also used to have AFO's (braces from below knee to foot) and have found the hinged ones with a locking mechanism for 1/2 days. We used the braces only one at a time and for the affected leg. We also don't use them anymore. He has learned how to compensate for the weaker leg.

For communication.. we are still looking. Right now he is speaking lots...and lots and lots. When he is full blown, however, all he can do is move his eyes and sometimes his fingers. The finger movement allows him to sign either 'yes' (a fist) or 'no' (index finger on top of thumb). For the eye gaze, we use a picture communication book with the pictures being small little squares that can be removed and held apart if there is confusion about what he wants."

Wendy - June 5 -

"Our son Nick is 8 years old and is in a regular classroom at school. He is taken out of the classroom for one on one held with speech, math and reading. He does have an aide. He has a bean bag chair in his classroom as well as one in the special services area. If at all possible, they do not take him out of the classroom. Both his speech and special ed teachers will adapt what they are covering that day but both have mentioned they are pleased with how hard Nick tries even on those bad days. His teachers held a special class for Nick's classmates at the beginning of the year to explain what Nick has and what they might see. Other than the temper tantrums Nick has, he does very well at school.

All of this information about education aids is coming at a perfect time. The school district recently did an update on Nick' s progress. It appears he has narrowed the gap between his chronological and developmental age a little bit. His biggest gaps are in his gross motor and fine motor skills. His case manager was mentioning the district buying a computer program that could decipher language and type out what was said. It could be adjusted to fit Nick's speech pattern exactly. She has not yet convinced the principal to buy this because of cost. They also have been using a computer touch screen on a trial basis.

I think it would be great if we could compile some information about the teaching methods used for our children. This then could be shared with all of the teachers and perhaps used in the educating of our children. I know that children develop differently but there is so much technology out there that if we know something has been successful that may be helpful in selling it to those who decide how to spend the money."

- June 5 -

".....TJ is 6 years old and has had the apnea/heart monitor for just over 2 years. We first got it because of frequent and long apneas (usually 4-5 a night up to 45

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sec. long). This of course only happened after a sleep study and the doctor being nice enough not to push me and wait until I was ready.
From what I understand to be the problem behind the apneas and low heart rate, is the autonomic disturbances. This means the things the brain is supposed to do automatically, it forgets. This includes the pupil dilation, changes in blood pressure, changes in body temperature, problems with temperature control (sweating), the changes in color of limbs, and breathing and heart rate. Unfortunately, there is nothing that can help. Well, nothing concrete. Using biofeedback techniques, like the apnea/heart monitor, can help by reminding TJ to breath. We have found this the best result of using the apnea/heart monitor. It reminds TJ to breath when he is in a deep sleep without waking him fully."
Wendy - June 7 -

Write/Phone In Questions

To meet the needs of all, we will be including questions received from families by phone or mail. If you would like to respond or have a question of your own, please send to me and I will include them in the next newsletter.

"Has anyone's child been affected by mosquito bites?"

Sue McCutchan daughter, Stacy has been bitten and the result is that the bite swells so big over a period of time, that she has had to have surgery to cut out the lump that has appeared.

TIPS....
Many parents have found that wearing sun glases in stores as well as outside seem to help.

Alternatives Products

My name is Marcy Atoigue. My twelve year old daughter, Jessica, was diagnosed with AHC when she was about 18 months old. We had her on flunarizine for about 7 years until Janssen discontinued their study. After that we tried many different alternatives. We would have some small short term success but nothing that would warrant continuing. Her attacks averaged 10-14 days with periods of complete paralysis in the middle which would last 3-5 days. But in April of 1997 we began giving her two products made by Mannatech, Plus and Ambrotose. The results were dramatic. She has not had a complete paralysis since we began the products. She still experiences the one-sided paralysis and dystonic attacks but we are trying high doses of the Ambrotose to see if we can obtain further improvement.
The fact that the improvement as been sustained for almost a year is very encouraging. If anyone is interested in hearing more I would be very happy to answer your questions."
(This appeared on the chat line/bulletin board in April 1998.)

"In 1994, my doctor (Dr. George) asked me to try a dietary supplement called "Mannatech". I am the biggest skeptic in the world, but Dr. George told me that he felt it would help my hiatal hernia. I have been looking for an alternative medicine for my son, Nicholas, and felt that I could be a guinea pig for this supplement. I went to a few meetings, did a lot of reading, and in late 1994, I started taking the product. To my surprise, my hiatal hernia had been controlled by this supplement. I then tried these products on my son Nicholas, hoping that they would help him. Nicholas seemed to have improved, had a lot of extra energy and at times would not even go to bed. By the time he had been taking them for 8 months, he had fewer attacks than before the Mannatech.

After about 1 year, he seemed to have gone back to his old self, so we decided to take him off the Mannatech products; he then reverted into a more severe stage than before the Mannatech. We have now put him back on the Mannatech products and whether it helps him or not, I feel comfortable that since it is helping me, that it may be helping him. I am not promoting this product in any way and would not recommend that anyone take it, but it might be something that you could investigate for your own personal satisfaction." *by Richard George*

What are Mannatech Products?

Mannatech is at the forefront of a widespread trend in research and development of carbohydrate-based products. However, rather than attempting to develop synthetic carbohydrates as drug companies are doing, Mannatech has developed naturally occurring, plant-derived, carbohydrate-based products. Rather than waiting until a person is sick to provide assistance, Mannatech's products are designed to use nutrients working through normal physiology to maintain optimal health through improved nutrition.

Ambrotose - Ambrotose complex (patent pending) is designed to support cellular communication through a dietary supplement of monosaccharides needed for glycoconjugate synthesis.

Phyt-Aloe - A proprietary blend of ripened freeze-dried raw fruits and vegetables which contain vitamins, minerals and newly discovered compounds called phyto-chemicals. In addition to the known benefits of nutrients, phytochemicals have shown evidence of supporting various defense mechanisms in the body.

Plus - designed to help support the endocrine system's influence on energy production and fat metabolism.

website address: www.mannatech-inc.com
(Information on products comes direct from Mannatech publication, Vol. 1, No.1. For more information contact Marcy Atoigue at (925) 634-9660, email SAtoique@aol.com; Richard and Rhonda George at (888) 557-5757, email richahf@hotmail.com.)

We recommend that you check with your physician before using these or any other product.

Foreign Affairs

In the April newsletter, we informed you that several meetings were taking place in Europe. Rosaria Vavassori, whose meeting took place May 2 and Dominique Poncelin, President of AFHA, whose meeting was May 23, have both kindly provided summaries. Edwin and Els van der Drift of the Netherlands provided us with their thoughts of the Paris meeting.

ITALY

My name is Rosaria Vavassori. I live in Italy and I am the mother of Alberto, a five year old child who is affected by AHC. He is my only son and my greatest treasure; he is a lively boy, cheerful, willing and determined and I am so proud of him. The AHC that hit him, however, caused us a lot of sufferings and distress, mainly during Alberto's initial four years of life, when we didn't know of its existence! In fact, my son had the right diagnosis only one year ago; for four years we fought against wrong diagnoses like dystonia, tetra-paresis, epilepsy, while living in pain and in the doubt. We didn't know what was our son's real disease. We didn't know how to help him and what the future would bring us. The real problem wasn't to do something; everyday we met people who suggested to us therapies and treatment and new tests (examinations), but they usually were people who didn't understand anything of Alberto's disease and kept on ignoring my husband and me while we tried to describe his problems.

When at last, after four years of lonely search and struggle against the doctors' indifference and incredibly, we succeeded in finding a name, AHC. We felt so relieved because we could really help our son at last! In fact we immediately started with the flunarizine and obtained wonderful results!

At the same time, we also understood that we were given a great chance not to be alone any more despite the rarity of AHC, we would have done anything to find other families with our same problem. Thus we started searching on the Internet and besides finding a lot of medical and scientific information, we immediately got in touch with all the families who talk on the mailing list and struggle everyday against AHC, supporting the research and spreading the information.

By the help of Prof. Vigevano, who organized the first international congress on AHC in Rome, 1992, and of Dr. Gobbi, who was at the Symposium in Seattle last year, we managed to contact six other AHC Italian families and everyone of us felt so happy and relieved because for the first time we could feel free to talk of our children, of their everyday life and of our distress for their future. So we decided to meet in order to know each other personally and on May 2nd, five of the seven families came to my parents' house from every part of Italy with their children and for a whole day the kids played together and became immediately great friends.

In the meanwhile we parents had the chance to share our experiences and ideas and talk about the things we could do to help our children, by supporting the research of the AHC causes and of new treatments, but above all by promoting the knowledge of AHC also in Italy in order to support (encourage) their social introductions and obtain a more suitable medical assistance.

For the time being, I and another mum, Laura, have been given the task to represent all the families while contacting the doctors and the foreign families and parents organizations and while collecting more information about AHC and the creation of an official AHC organization here in Italy too. While doing this, we have the greatest support of Dr. Vigevano, Dr. Gobbi and many other doctors we are contacting in order to search for other AHC families in Italy. The doctors have suggested that we should co-operate with the other families and organizations in Europe, aiming in the long run to form a strong European foundation which would group together a meaningful number of AHC cases, co-ordinate work and medical studies in the different countries and which could profit from the support, not only an economical one, from the European Community.

In this regard attending the AFHA meeting in Paris was really helpful. I heartily thank the French people for asking foreign families to join their annual meeting and I congratulate them on the brilliant work they did to organize it. They gave us a wonderful chance to meet several families, from France, England, Holland, Sweden and the USA. Moreover, Dr. Goutieres' presence was very valuable; she explained where the medical research and knowledge have come and she kindly answered our questions giving much useful information.

During the day, the families started to talk and see how we could organize our efforts here in Europe; now it is clear for all of us that the basic medical research should be done in the USA; several doctors agree with that. I think it's good for us to know that there are American families and organizations so busy in raising funds and in "pushing" for new research projects. We are prepared to give them our support and to join their efforts in collecting data and samples for the creation of an international data base on AHC. We also hope to be able in the near future to help them raise funds to support the projects.

However, there are a lot of things that we can and must do here in Europe; we must support and help all AHC families, give them all the useful information we have and collect new data on as many children as possible, we must work hard so that our doctors in European Community get to cooperate in testing new medical treatments and in devising specific therapies of rehabilitation. We also must spread knowledge on AHC among the public and the institutions in order to facilitate our children's receptions by instructions (school, work, free time facilities...); we must educate our local doctors and our local health structures, give them information on AHC and the problems linked with it so that they can give our children a more appropriate assistance. I think that meeting European people in Paris was helpful and gave us

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the chance to make the first step towards the setting up of an European organization.

The experience made by AFHA is really instructive; they gave us the example of how to set up an official organization, how to keep it to work, how to keep in touch with the institutions and to spread information among the public.

I agree with their suggestion that we should plan other European meetings. I look forward to meeting the friends I got to know in Paris, and maybe new ones.

In the meanwhile here in Italy I keep on getting information and news for the Internet and from the doctors I meet. I translate and send them to the other families. We wrote a brochure with information on AHC which some families have already handed out in the schools and among the local doctors. We are getting some posters ready which we are going to hang at hospitals and clinics. We also plan to write articles to be published on newspapers and magazines. Working all together for our children is wonderful!

I thank all the families I got to know personally or via Internet. Your strong will and your enthusiasm greatly helps me and supports me in facing daily problems and bad periods. Thanks to you, we are not alone any more! Thanks a lot.

FRANCE

The French 1998 meeting organized by the French organization for AHC "A.F.H.A." took place on May 23rd, near Paris.

Around 40 persons attended this meeting: 16 families (11 French & 5 foreign families), 3 professionals and 5 people involved in the organization.

Dominique PONCELIN (President of the A.F.H.A.) and Mirjana TOURLLEC (Vice-president), introduced the meeting by welcoming all the families, and by thanking those who have accepted to help us with the meeting (especially Dr. GOUTIERES - neurologist and our translator, as well as the different sponsors).

Dr. F. Goutieres, neurologist at NECKER hospital in Paris made a very interesting report about actual knowledge of AHC. She talked about Dr. PTACEK genetic research project. According to her, this project is nowadays the most serious project. French doctors are ready to help him if necessary by sending blood samples of French cases. Dr. Goutieres agreed with the fact that it is better for the future to concentrate research (at least genetic research) in one place, and for the time being in USA.

She spoke about the project of Dr. GOBBI (Italy) to perform a European study on the efficiency of the medicine "NIAZAPRINE" to stop hemiplegia attacks without sleeping.

Then she answered families' questions on various topics (contraception - outcome of AHC - different used treatment in the world - relations and contacts between specialists of AHC - treatment for epileptic seizures for instance).

After lunch, the afternoon was devoted to two general topics:

* relationship between brothers and sisters: It was directed by a French organization specializing in difficulties and necessary precautions to be taken in the relationship between handicapped children and their brothers or sisters. This was illustrated by humorous drawing slides showing several situations which may happen in such cases (often using a good sense of humor!)

* psycho-motivity for disabled children: It was explained by a French professional. He spoke as well about his own experience with handicapped children and made a short overview of different techniques for "relaxation" (we spoke, in the morning, about the benefit of relaxation to cope with light hemiplegic or dystonic attacks, which are often due to excitement, and how to shorten them).

The latest part of the meeting was devoted to define the aims of the French organization for next year:

a/ to keep on establishing close contacts with families world-wide and to encourage them to create a group concerned by AHC in each country, with regular contacts between the head members. We would concentrate on Europe as there is already a great action within USA and the nearby countries.

b/ to keep on making AHC to be better known in Europe, by:

* Sending firstly in France a leaflet explaining what AHC is (which is nearly ready) to professionals which may be concerned at least one time by AHC. We project then to translate it into different languages for the other European countries. (At the opposite of USA, each country has his own language in Europe).

* Joining the French organization AFRG, which is a federation of different rare disorders. They organize each year a national fund raising campaign (THE RED NOZE OPERATION consisting in selling as many NOZES, PINS or chocolates as possible) in order to support their members in different ways (financial support, information campaign with the help of laboratories, research allowance, maintenance of a library on rare disorders, etc.).

c/ to stay in very close contact with USA organizations and Dr. Ptacek's project (especially by helping the genetic study in providing French blood samples).

d/ to think about the possibility of organizing a meeting on a larger scale in Europe with the participation of families and several doctors and professionals from different fields, with selected subjects. This kind of meeting could be organized every 3 or 4 years.

.....(The local organizations would have their own meeting between these common meetings).

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e/ to start "fundraising" in France, (which is far more difficult than in USA, because of the very conservative European mentality):

* By issuing and distributing a leaflet which explains AHC in "general terms for non-professional people", with a giving form. Each member of the French organization will receive some of them to distribute among their families/friends/colleagues.

* By organizing a "TOMBOLA" or "raffle" which could take place during the next French family meeting next year or organized by families in each city. We ended the meeting in a typical French restaurant which seemed to be appreciated by foreign families!!

The complete version will be available on the French website by September.

Dear AHC families,

On May 23, 1998 we visited the annual general meeting of the French parent organization. As parents of a boy of 4.5 years old, Sebastiaan, affected with AHC we were very excited by the idea of going to a meeting with parents with children with the same disorder. It was our first time that we could meet parents from outside the Netherlands.

The meeting started with an update of research. This update was given by Dr. F. Goutieres. Although no new results came forward it was good to get an explanation on the research programs. After a good lunch a presentation was given with regard to the relation of handicapped children and their families. Furthermore, a presentation about psycho-motivity was given.

We benefited most from the contacts with the other parents as well as seeing other children with AHC. As mentioned in literature the severity of the disorder varies from child to child. During the meeting we experienced this with our own eyes. The meeting was closed with a dinner in a typical French restaurant. It was wonderful that we were able to share our experiences with other parents and we hope that we can stay in contact with them in the future. We thank the French organization for inviting us as well as for their efforts put into this meeting.

With kind regards,
Els and Edwin van der Drift

Miriam, *by Antonietta Castellucio of Padova, Italy*

Miriam was born with caesarean operation on the 8th of March 1991 in the Hospital of Cittadella (Padova), twelve months after our first child. Her weight was 2.550 Kg.

She was immediately admitted to the department for newborn of the same hospital and she was discharged after fourteen days with the diagnosis of prematurity and the prescription of a pediatric visit for a check-up to be made two months later. On that occasion, and again at the visits which followed that first one, I told the doctors my doubts about my daughter's health; the frequent lack of sucking and a strange movement of the eyes, which at a following optometrist visit turned out to be nystagmus due to immaturity.

In time Miriam grew older, made progress which often and mysteriously disappeared. But I couldn't resign myself that Miriam was able to hold her head and her trunk, stand up, walk on her fours or make her first steps while kept with one hand just on occasions, that sometimes I had to force her to eat at risk of stifling her.

Since nobody could understand me, I insisted on her having an EEG, for I suspected it to be a disorder similar to epilepsy. We told Miriam to the Policlinico of Padova and there the doctors, after learning our story, kept our daughter under observation for several days. She was eventually discharged from that hospital with the diagnosis of AHC and immediately treated with flunarizine. This proved to be helpful in limiting the symptoms of the disease. Before flunarizine, Miriam had her crises every one or two days; after beginning the cure they occurred every 3-4 days and the signs that came before them (drooling, nausea, crying, tachycardia) were less intense.

When she was 17 months, Miriam started to make her first, hesitant steps. We went to the Policlinico of Padova five more times to check Miriam's clinical, biochemical and neurological situation. She had several tests, including the chromosomes map. After the last hospitalization, the doctors suggested physiotherapy for some months. This worked well, Miriam learned to discriminate colours and her manipulation skills improved. The same year, at a optic check up made on a local basis, they found out that Miriam had hypermetropia in both eyes.

She attended the kindergarten in our village, where she had an aide for a few hours a week. She enjoyed going to the kindergarten and attended almost every day, except when she had an episode.

Now she's attending the first class of Elementary School. She hasn't got any special aide or teacher. I think that Miriam has developed a good socialization and her speech is good, while her writing skill is somewhat difficult. She's a happy girl, full of enthusiasm, sometimes she pushes herself beyond her real possibilities and she gets some bumps. Even when she's well her strength is limited, she can't go for long walks, she can't run by herself because she leans forward too much and keeps on looking downwards; she can't jump even if she tries hard. I've noticed that while she's having a temperature the attacks come very late. I wonder if it's true or if I'm just imagining things.

During all these years of living with AHC, I've learned that if Miriam's body shuts down (stops) I must comply with it. I try to make her relax and I lower her eyelids to get her to sleep (sometimes sleeping a few seconds is enough to recover completely)

From Dr. Mikati

Based on the recently published memorials of two AHC children, we have received many questions regarding the mortality rate associated with AHC. The following are the comments of Dr. Mohammed Mikati, medical advisor to the IFAHC.

It is known that patients with chronic debilitating diseases may have an increased risk of mortality usually due to aspiration, choking or infection and that patients with epilepsy, for example, also have increased mortality rate because of the risks associated with seizures such as aspiration and prolonged seizures.

We do not have any specific data for AHC and any final statements should really await collection of such data. In the data base and questionnaires we collected for the USA AHC registry (the article was recently sent for consideration for publication for the journal Neurology) the doctors in the Child Neurology Society that responded did not mention early death as a frequent problem and this is reassuring but still we need more data. In our registry we became aware of 72 patients in North America and possibly you now have even more. If every few years we hear of the unfortunate death of one, then, it may be that the rate may not be much more than that of the general population or that of epilepsy. For example, the standardized mortality rates for epilepsy are about twice those of the general population. I would like to emphasize that double a very low risk is still very low. Even though we would like to see no increase in mortality in epilepsy or AHC, if there is an increased risk, then probably the less severe the condition, the less the risk. Also guarding against aspiration, good medical care, and precautions against seizures for those who do suffer from seizures, are bound to reduce any increased risk that may exist.

Remember.....

-Disney World, Florida - We are still planning to have a family "Convention" in the fall of 1999. Many families have responded. 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. Please allow approximately 6 weeks for delivery.

- We received several more 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.

- The financial statement for fiscal year ending May 31, is available upon request. Please contact Greg Wisyanski.

- For those of you receiving 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.

AFHA/AHF website

Don't forget to take a look at the newly opened AFHA(France)/ AHf website at www.mygale.org/05/afha. Philippe Jourdain has set this up and continues adding to it. It also has a wonderful bulletin board system to allow AHC parents to ask questions and communicate. Try it out!

AHF
Alternating Hemiplegia Foundation
Richard George, President
31250 Plymouth Rd.
Livonia, Michigan 48150
(888) 557-5757

Please notify Lynn Egan when you have a change of address , phone number, or if you have added an e-mail address. Thank You.

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