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

It has taken me a long time to put this newsletter together. We all hit stumbling blocks along the way, which is why it is a month late. My energies have been going in many directions, and just being a mom has been top priority.

We took Kathleen to another neurologist this last week. He is actually an adult neurologist however he specializes in movement disorders. We did not get any "new" ideas or answers. Because Kathleen suffers mostly dystonic posturing during an episode, is ataxic and has low muscle tone, we thought he was worthwhile seeing. We were told that the treatment/drugs available to treat dystonia were worse than having dystonia and so we are at the same point. He also has an interest in calcium channels and his thoughts were that we should be looking into genetic testing.

I told him that we were already doing this with Dr. Ptacek. He said that with gene therapy at the forefront of medicine, the discovery of the gene could/would eventually lead to "a designer drug" made specifically for treating AHC. I did not understand the implications of gene therapy or what it would/could do for AHC.

Which leads me to my next request. Since the original publication of the Blood Cell and DNA Collection article (April 1998), only twenty-four families have requested the blood kits and ONLY twelve families have returned it (as of 11/10/98). I realize that it is hard to find the time in our busy schedule but the sooner that Dr. Ptacek's office receives the blood samples the sooner he can start looking for the gene.

Please, please if you have not, take the time to make an appointment with your local doctor, nurse, clinic - someone who can draw the blood (everything has been supplied in the kit - tubes, needles, gloves, labels, etc., so that the person drawing the blood needs only his time), package it back up in the box sent and drop it off at your nearest Federal Express office. There is no cost to you, unless your doctor charges for the visit. I think it is worth the small amount for the eventual outcome.

I wish you happiness and health during the upcoming holidays!

Lynn Egan

This newsletter is sponsored by the employees of the headquarters office of Shaner Hotel Group located in State College, PA. Through contributions and other actions, Shaner Hotel Group is a loyal supporter of the IFAHC and all of its goals

Inside This Issue

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 September 30, 1998, 19 families have contacted Dr. Ptacek's office to receive the kits and only 9 have returned them. 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. There is also a minimum number that is needed before research can begin. It only takes a few minutes and everything can be done via Federal Express (which Dr. Ptacek pays for).

To participate send or fax your name, address, phone number, child's name, sibling's name 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
1-801-444-8638, ext.5-9399
FAX: 1-801-585-5597
or e-mail to Catherine Mckenna at:
cmckenna@howard.genetics.utah.edu

Flunarizine Update in the US, *by Lynn Egan*

As many of you know getting the flunarizine from Canada has had its share of problems, however I think we have now a system that works.

During this time, Dr. Silver and I have been talking with Orphan Drug/FDA and Janssen Pharmaceutical to see if we can somehow get the flunarizine to the United States.

Here is what took place during a recent conference call.

Dr. Haffner, Office of Orphan Products Development (OOPD) gave a chronological overview of the nonavailability status of flunarizine starting with Janssen's investigational new drug (IND) for vasodilatory disorders and aging; Janssen's withdrawal of their IND; their supplying it on a compassionate use bases for AHC patients until the supply was exhausted. It is approved in Canada for migraines and US patients are acquiring the flunarizine from there.

Dr. Pontecorvo (Janssen) said that the biggest studies were done for epilepsy under their IND, in addition for migraines. There was not enough data obtained from their AHC studies. The AHC population was so small that it was not possible to show efficacy.

Mrs. Egan mentioned that there were presently 70 US families using flunarizine for AHC and the severity of episodes has decreased significantly for most patients receiving treatment. She brought up the fact that there have been delays in acquiring the flunarizine due to delay at Customs at the US/Canadian boarder. Dr. Kenneth Silver, Loyola University Medical Center is following eight patients with AHC and is very interested in studying flunarizine for this disorder.

Diane Centeno-Deshield (OOPD) stated that she will contact a representative from FDA's Office of International Affairs to see if there is a mechanism to prevent delays in Customs or a contact to resolve these situations as they arise.

Dr. McCormick (OOPD) added that the ultimate goal is to resolve the questions of efficacy for flunarizine to treat this disorder.

Dr. Levin (OOPD) brought up the fact that Jassen does not have to necessarily carry out the studies, but an individual investigator could do that. However, the investigator (s) would have to have Janssen's concurrence to cross-reference their IND. The investigator (s) would conduct the placebo-controlled studies addressing questions regarding safety and efficacy and submit an IND for these studies.

Dr. McIntyre (Janssen) stated that there are several issues and Janssen needed to understand what the FDA was advocating: 1) importation from Canada to USA; 2) determine efficacy via studies; 3) developing this product or another effective product for this indication (AHC). Janssen would need to assist in supplying the flunarizine to support a study; 4) IND is inactive and the file is not up to date.

Dr. McCormick stated that it is critical that the families agree to allow their children to participate in future studies, IFAHC would be very instrumental in coordinating these efforts for any potential investigators.

Conclusion: Dr. Silver and Dr. Levin will have further talks to discuss putting a protocol together and submitting an IND.

Dr. Silver should speak with Janssen regarding initiating studies for this disorder.

Diane Centeno-Deshields will initiate discussion with the FDA's Office of International Affairs regarding Customs' hold-ups.

Dr. McIntyre would investigate how the IND file could be brought into compliance so that Janssen Research Foundation can authorize FDA to cross reference the IND on behalf of an investigator-sponsored IND.

Another conference call will take place in the future.

(Minutes supplied by Janssen)

In layman terms what this means is that there will probably have to be another study done. Dr. Pontecorvo is currently locating all of the files of patients who participated in the original study. Then those files will be reviewed.

We will keep you up to date on any development regarding this issue.

Sharing our Kids

by Sue Loudon and Donna Busby

We heard about Christa Loudon in the March 1996 and Jayme Busby in September 1996 issue of our newsletter. Here is how they are doing two years later.

Christa Loudon is now 22 and lives in her own apartment! We are so pleased with her. It took a LOT of training and patience to get her ready, but she does a good job of keeping it clean and orderly. She has ALL of her life-long treasures with her. She has a "care-giver" who lives in the house above the apartment, and has set up a routine for Christa so that she gets her medication right on time (she does it herself), and does the usual daily duties. It is great! She does very well when she follows the schedule. She is working two days a week at KB Toys for two hours a day. <Once, while she was there, she had a seizure which was so bad that she wet herself....but they were very supportive, and someone went out and bought her new panties and a pair of pants!...she keeps a wheelchair there "just in case" she shuts down> She has a job coach that just checks up on her occasionally at this point. She also volunteers at Bishop's Attic (used stuff) and at Access Alaska (an Independent Living Center) where I work. Her transportation is provided by VanTran, and they have made exceptions for her due to the "surprise" aspect of her disability (others have to give 24-hr notice of change in schedule). Her apartment is in North Pole (near Santa Claus' house!...<s>)

"They" said it couldn't be done! So we did it!...She is DOing what she was taught...on her own! And she's doing it very well.

She still has flunarizine (from Egypt), and every 8 to 10 days one side or the other side (in between — both sides) "shuts down." When her right side is off, she is fun and sweet, but when her left side is, she is irritable and cranky. She is ambidextrous. She has learned very well how to do most everything with only one hand...even take a shower! She has a quickie wheelchair with a motor on it, so she can take herself wherever, and she also has a tricycle with a motor on it, so if she goes down on one side, she can still get back...or if she gets too tired to move her legs.

She bought herself a baby cockatiel, and is like a mother to it! It sits atop her shoulders as she moves about her apartment. She has her own phone and computer and VCR and boom box, and she pays her bills with some help...writes out the checks. She is going to take another class in ASL in the fall, and is very excited about it. She likes being around other students her own age. The accommodations made for her: at the end of the first class in ASL, the students had to tell a story. Christa was allowed to video. She told her story in sections, but the video looked like it was all at once. She first wrote out the story (on her computer..she knows the keyboard...does touch-typing...about 10 wpm), then when she showed the video, she read her story at the same time.

Her favorite activity is craft class. Adult Learning Programs of Alaska (ALPA) is the "pass-through" for her funding, and her care providers are through them. She receives SSI and Medicaid and APA (Alaska's additional funding source for people on SSI), so all her expenses are covered, and then she has money from work for "fun" stuff.

There is always something "new" happening with the AH...changes, but since the flunarizine, episodes have not been so long, and having both sides down at the same time is rare. We keep trying different anti-seizure medication <sigh> but she seems to have different kinds of seizures at different times...sometimes it is like grand mal....and others are "focal"...say one leg just moves up and down rapidly. She also occasionally seems to experience nystagmus again (after several years of not having it!), and that is discouraging. Also when one side goes down, her foot may turn in so that it is painful.. (she has braces that she slides into to keep that from happening, but actually, they are uncomfortable for her, so she doesn't use them).

Well.. that brings you up-to-date, yes...ohh....glasses...her vision can only be brought up to 20-30.

Jayme has been on flunarizine for about ten years and he is now twelve years old. He has an attack every 2-1/2 to 3 weeks. Usually a one sided attack but once in a while it's a double sided attack. His attacks have become better as he has gotten older. We have been decreasing his dose of flunarizine since March. He was on 20mg a day, but we have decreased it to 10mg a day, with no difference in his attacks at all. He also has a lot more energy and doesn't sleep so much. We plan to decrease even further. I will keep you updated on that.

Yesterday, July 27, Jayme had dental surgery. He had a severe gum growth over most of his teeth. The dentist suspects it was from long term use of the flunarizine but he's not 100% certain.

But its the only medicine Jayme takes so he's fairly certain. After the surgery he said it was very rubber like and hadn't let Jayme's teeth develop normally. But Jayme has a full set of "uneven" teeth. The dentist removed the excess gum growth and said Jayme's teeth could now grow normally. The dentist assured me it was a gum growth and not just gum swelling.

The best part was Jayme. He didn't have an attack before or after and 27 hours later he still was attack free and showing no signs of one. He is so happy with his new teeth and can talk much clear now.

I'm sorry I went on so long, but I wanted to share this good news about Jayme.

Note: Further reduction of the flunarizine increased episodes and so Jayme has stayed at 10mg daily.

Kids for Kids

Dear Friends,

Once again we are planning a concert and relay run to benefit our kids' research. Last year it was such a joy to see what was accomplished for the future of our kids, kids helping kids. I would like to invite you as our special guests at the concert.

The concert will be held on November 14, 1998 at 4:00pm at the Jacksonville Assembly of God Church on East Vandalia in Jacksonville, IL. We are 30 minutes away from Springfield, IL.

We are a little more organized for this concert with a year's experience under our belt, and would like to invite as many family's possible, but also realize what a task it would be for you to come. We would like to offer your night's stay if you would allow us. We feel that your support is as important as all the people involved in the concert/relay run. We were so blessed last year when Richard George came to visit and RUN!

Last year's concert lasted approximately one hour and a half. I know that if there is any way possible you, your family and/or friends can make the trip you will sincerely be blessed. If anyone would like to be included in the program, please feel free to let us know. I think it is important for the kids in the choir to know who they are helping!

Once again, I am asking for videos and pictures to be included in our concert. We are doing some awesome songs and if we could show footage of our kids and their surroundings it would definitely increase the enthusiasm.

To those of you that have sold the music, we thank you from the bottom of our hearts, I know it is not everyone's "cup of tea" but we have had some wonderful letters thanking the kids for what they have done. It was definitely a good idea to send the cd/cassettes around the world, so that even if the words cannot be understood completely, our music and cause definitely was.

Please let us know as soon as possible if you can help us out with attendance, videos, pictures, etc. God bless and keep smiling, there's more music on the way!

Dave, Cindy, Rachel & Michael Ryan

Foreign Affairs

by Alex Cole

The UK alternating hemiplegia support group held its annual meeting in Slough, UK on Saturday, July 11.

It was great to see the 5 families who came and disappointing that more did not come along. Gill Bailey had organized the meeting in the local social services facility for the disabled, with a playroom for the children and food and drink available. Unfortunately the cold and variable British summer we are having this year meant we all had to be indoors all the time.

At the beginning of the meeting an expert on behavioral difficulties of disabled children talked to the group on how to handle these problems. The families then discussed their different experiences of diagnosis, drugs and doctors. Some of the children take anti-convulsion medication and some flunarizine and some both. We were dismayed to find more children who had been misdiagnosed and given inappropriate amounts of anti-convulsion medication when very young. However the newest arrival, Jack, had been misdiagnosed in this way (our Alice was not) but this had been realized quite quickly and he is being weaned from anticonvulsants; so hopefully this is becoming less of a problem. There is still a lack of knowledge about AHC even among pediatric neurologists as evidence by a comment to one family that the incidence of AHC as a genetic disorder, 1 in 4. I think this shows just how important is the exchange of information between families through the internet, the associations in the different countries or otherwise. I count myself fortunate to have been able to tap into this medium. I hope some other of the UK families will too. We had brought with us our blood kit for the DNA Blood Collection Project and explained this research as best we could. Two families indicated that they would participate also.

Children at the UK meeting:
Lucy, age 11; Joanne, age 12; Toby, age 6
Jack, age 2
Alice, age 2, plus lots of brothers and sisters!

Magnetic Mattress Pads
One family asked about further news of the magnetic mattress pads, so please if you have any comments on the use of these to improve AHC symptoms, please let me know so I can pass them on.

My Brother, My Sister

by Katie Hurley

What is it like to have a sister with AHC? A few days ago, my parents asked me to write a few paragraphs answering this question for the newsletter. At first I thought "Abbie's a kid with AHC, she's my sister, I love her, what's there to write about?"

My name is Katie. I am fourteen years old, and the oldest of four girls. My little sisters are Betsy - 13 years old, Abbie - 9 years old and Maggie - 5 years old. I consider Betsy to be a best friend; someone to share everything with, someone who's always there for me, and one person I can always have a good fight with. Maggie I consider to be the funny one; the family entertainer, the little five year old that's too smart for her own good and the little pest. Abbie is the one I think of as the loving one. She's definitely the most affectionate person I know. She is extremely friendly - always ready and wanting to give big hugs and kisses. She is also somewhat of an annoyance at times, but after all, she is my little sister. She requires more care, understanding, and attention, but to me she is just one of my sisters. I have to protect her, look out for her, set a good example for her, love her, and occasionally baby-sit without pay, but that comes with the territory. Everybody is different in their own way(s). Abbie is just special.

INTERNET CORNER

"It has come to my attention that individuals may have a problem with the fact that the IFAHC has been reprinting questions, etc. from this bulletin board system. It seems that this is resulting in a decreased use of this bulletin board.
It has never been this group's intention to in any way inhibit the discussions that take place about AHC, only further them. WE have gone so far as to contact the individuals that have posted notes to be sure they are OK with the publication. Our feelings was that these are part of a PUBLIC bulletin board system and that it was appropriate to reprint these to the 60% to 70% of the families that do not have e-mail or internet access.
If there is a problem with this or any other action of the IFAHC, please contact myself or Lynn Egan. I'm sorry, but comments heard second hand cannot be considered."
Greg Wisyanski - July 7 -

" I can only personally say that the only way I heard about this mode of support was through the newsletter from IFAHC. It was my thought that the reprinting would give me more access to more families that I would never have known existed.
This disorder is very rare. I feel it is totally appropriate to use the posted questions in the newsletter. We are all separated enough by geography already. This brings us closer together. Hopefully by decreasing the physical distance between us, we will be able to help each other, the doctors we see, and anyone who is searching for answers."
P.S. - just a little update. TJ is now part of a special baseball league. He is able to play during all levels of hemiplegia (fine, half, full). He is so funny when he is playing. He is now trying to run, and he is getting pretty good at hitting. The biggest improvement is in TJ's attitude. TJ is now in the habit of saying "I can't" when only one side is working. During baseball, however, he is able to participate no matter what. Either his buddy can carry him to the base or we can push him in his chair. I really feel this was the best thing I could have done this summer. He has grown so much."
Wendy Walker - July 7 -

"I have to say that I agree with Wendy and Greg. I know of a family that does not have a computer and were not even aware of the information available to them until they read about it in the newsletter. We were very fortunate to meet in person. It was wonderful to be able to talk to someone in person who knows exactly what your child is going through and has the same questions and concerns. Of course, with the small number of children affected by this disorder, it is not possible for us all to be able to link up with others.
I would suggest to those who didn't want their comments published, that they answer email to another's personal email and not to the group.
We have been so busy lately that I haven't had a chance to write. We also lost our electricity for 72 hours and boy was I lost without my computer!!!
Swimming season has started again and although it is rough on Jake, I think that he is finally starting to realize that he has to limit the amount of time he spends in the water, or else he will be hemiplegic the rest of the day.
We have also reached a major milestone. Jake can now ride a regular two-wheeled bike with training wheels independently!!! Hooray! I have to thank Lynn Egan for her wonderful suggestion of trying a big wheel. He practiced on that for months. I don't know if it strengthened his leg muscles or helped him in coordination, but it certainly helped with the transition to a regular bike. We also have noticed that bright sunlight really affects Jake poorly and make sure that we always carry a baseball hat and try to stay in the shade.
Sorry this is so long. I hope that everyone is having a great summer!"
Becky - July 7 -

"Even though I have access to the internet and am able to read the notes that are sent to the AHC list, I still look forward to reading them again when they're published in the newsletter. Its also a way for me to pass them around to family and friends who are interested in our daughter's disorder, but who do not have access to the information via a computer.
I can only say that Greg and Lynn have done such a great job - I for one am very thankful for all your efforts. And my thanks go out to Chris as well who has done an outstanding job with the IFAHC website."
Katey Hurley - July 7 -

"Our Gabrielle (11 years old) is our fourth child (and has AHC) and our older children are now 15, 17 and 19, and are asking about the genetic implications for themselves and their future families. We have been told by Gabrielle's neurologist that the probability of them carrying the gene and "matching" with their partners is low. The inference is that my wife and I had gene's which matched to cause the AHC to occur which in our case was one chance in four of it happening again. However the chance of our children carrying the full gene is low.
Can anyone help us out with a little more science on this fairly important question from the kids?
I am aware of the DNA/blood sample project but I am not sure we can participate due to the difficulties in sending samples overseas, as we live in Australia."
- July 9 -

"I too have wondered about my other children "passing on" AHC. Perhaps the DNA testing will be able to answer this question.
You might want to ask this question and about participating in the DNA/blood collection to Dr. Ptacek's office. The email address is cmckenna@howard.genetics.utah.edu."
Lynn - July 8 -

"Wendy, I am so enthusiast to hear about TJ playing baseball and Becky, I am so glad and proud of Jake who has just learned to ride the bike! My son Alberto, who was five last March, started to ride his little tricycle by himself when he was three and last summer he began to use a normal bicycle (I mean, normal for his age) with the little training wheels and now he is very clever with it and even a little daring.
But I have to put him on the bike and take him down when he stops because he can't stand on his feet, nor walk, by himself. In fact he has no balance at all, the doctors call it 'ataxia', and especially in this last year he made very little progress in this respect, even if he started with the flunarizine and the frequency of the attacks remarkably decreased.
We recently saw Prof. Dalla Bernardina, who made the AHC diagnosis last year, and he told us that Alberto still has too many bilateral attacks to be able to acquire a more steady balance.
So I am asking all of you if you have had a similar problem, at what age your children began to walk/run/jump, and in case if you have ever tried something specific (drugs, physiotherapy,....).
My son also had a bad congenital luxation of the hip: he was surgically operated twice (at 8 and 18 months respectively) and was blocked in plaster until he was two.
Well, thank you very much in advance for any help you can give me. When I hear such good news from you I feel so encouraged: we do have wonderful children. CIAO! and keep well."
P.S. - Greg, since I subscribed the AHC list

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INTERNET CORNER

(Continued from page 6)

year, I have always thought that the messages on it were directed to any people (parents, doctors, teachers, friends..) involved in AHC, and not only to the subscribers. I think that the list is the greatest and most fantastic help we could ever hope to receive in order to deal at best with the everyday life with our children and not feel alone in this struggle against AHC.

I think that limiting this opportunity to the people who can use Internet would be really unfair.

Personnally, I am translating all the messages in Italian and forwarding them to all the other AHC Italian families which are always so pleased to read them!"

Rosaria - July 9 -

"I must say that every accomplishment our kids make is the GREATEST!!!

Kathleen started walking at 20 months. Her "running" is more of a rapid walk of which she is propelled forward and scares me to death! Earlier this year she learned to jump and is very proud of herself. She has even been able to jump without holding on to anything.

There have been three children born with a hip problem and had surgery. It sounds very similar to what Alberto went through."

Lynn - July 8 -

"When Greg was just a few months old we saw a genetics expert at Yale University. At that time we still did not have the AHC diagnosis. This person's opinion was that Greg's condition was not hereditary and that it was only one of one-in-a-million type of things that children are born with.

This person and one other doctor interviewed us, examined Greg and reviewed his medical files that included the tests he had undergone to that point. However, since we didn't know he had AHC, I wonder how correct the answer we got was.

If these children haven't inherited AHC from their parents, then isn't the only other way they could have gotten it is from something that happened during pregnancy? There also doesn't seem to be any evidence about either.

I know this doesn't give any answer but its just one experience. As the parent of another child who is unaffected, I really hope we can answer these questions through the blood testing or some other means."

Greg - July 10 -

"This was one of the questions I asked Dr. Chugani when we went to see him in January. He told me that one of the theories about AHC involved migraine headaches. Although every child with AHC does not have a close relative with a history of migraine, it is very common. He explained to me that they believe that the gene that causes migraine headaches (which my sister, my mother-in-law, and I suffer from) could have "mutated" and caused the AHC. Some of the symptoms are similar between the two, such as the fact that migraines are often relieved by sleep, some children have headaches during attacks, and some children have an aversion to bright lights or flickering lights. Also, some children have an aura before their attack. My aura is double vision, and often I have great difficulty keeping my eyes from crossing. There is also another disorder called hemiplegic migraine found in children. These children become hemiplegic during a migraine. In fact, Jake was first thought to have this and was started on Inderol, a common anti-migraine drug. We were also encouraged to let Jake drink coffee during an attack (he now loves it as much as I do!) Not all researchers are convinced of this, but it is one of the theories out there.

The book that I have mentioned before "Alternating Hemiplegia of Childhood" mentions the similarities and differences in PET scans and MRI's in AHC and migraine"

Becky - July 10 -

"I do agree with you, I believe that it is something in the pregnancy. The problem I have found is that no one wants do discuss their pregnancy in detail. If you can find anyone that would speak about it let me know."

Roberta - July 11 -

"I monitor this list because I'm a clinical psychologist, not because I have a child with AHC.

Nevertheless I'm also a mother of five children. My fourth baby, a little boy, died of a one in a million disease, "Ivermark's syndrome."

I have been turning things in my mind for years, about pregnancy, not pregnancy, everything you can imagine, and I unfortunately reached the conclusion that it was nothing but a one in a million stuff. As to why me, why you, no other response than RANDOM.

My other children are all healthy, there is one case in the literature of siblings with Ivermark's syndrome, but it does not mean anything.

It is definitely written somewhere in our genes, but the occurrence that the disease appears is free to do it. I reviewed mine at least 50 times, from day one to day 270 :-)"

Regina Mazloum-Martin, PhD - July 11 -

"Well, today is another full blown day. Oh well, life goes on, right?

TJ has had another severe migrane. It happened yesterday and man did it knock him out. He was rubbing his eye all morning and then in the afternoon, he became really fussy and kept pulling pillows or blankets or what ever over his eyes. He finally fell asleep after I put him in a room with no windows and got rid of as much noise as possible. Even his heart monitor disturbed him.

Well, just thought we would keep you updated."

Wendy - July 11 -

"Well I think that I can blow your pregnancy theory as Jake is a fraternal twin. His twin brother Luke is a "normal" child with above average intellegence (according to his teacher), and has no problems medically or physically. I carried the twins to full term and had not one problem with my pregnancy or labor. The twins weighed 6 pounds, 11 ounces and 6 pounds, 12 ounces and had no problems at birth. We went home from the hospital 36 hours later.

I think that the genetic theory is the key. It does not mean that you carry the gene for AHC, but that somehow a gene become abnormal."

Becky - July 11 -

"I have spent the last six years going over with myself, doctors, family and friends what happened during the pregnancy of my son. I did nothing wrong. Don't you know what it is like knowing you quit drinking coffee, tea, or caffine, stopped smoking, ate properly, gained the "right" amount of weight and still hear that you may have done something wrong to cause the disorder of your child?

Don't you think we feel hurt enough? Sure our kids are great and I love my son totally. I would never want to start over and not have the child I was blessed with. But on a day like today when he is full blown and having problems breathing, swallowing, and can't stand the light, how do you think I feel looking for support, and hearing it may be my fault.

You want to know about my pregnancy? Ask then. You have never asked how my pregnancy was or what happened.

I apologize for sounding so angry to those that did not pose the question."

Wendy - July 11 -

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INTERNET CORNER

(Continued from page 7)

"You know I am really sick of this disorder today. It is summer. My son should be able to play outside, alone, with his friends. But no. He has to have his mother follow him around.

I just went outside to see how he was and I found him full blown after having a time of being able to move everything. And if that wasn't enough, he then peed himself in front of all his friends. Then when I brought him in to get changed, he asked me why he went full blown.

What the hell am I supposed to say to that? That his genetic make-up made him this way? That I did something wrong while I was pregnant? That he is just special and not to worry about it?

All I could say to him was "I don't know lovey, I don't know". At this point I really don't care why or what may or may not happen when he goes to have children. Right now all I want is for my son to play with his friends without me having to follow him around.

I guess we are both having a really bad day."

Wendy - July 11 -

"Wendy, I don't believe anybody is suggesting that any of us did anything "wrong" during our pregnancies. Similar to Cerebral Palsy, I think people are just wondering if something happened at some point during the pregnancy or even during labor that caused our children to end up with AHC. I wonder about that myself. I certainly don't drive myself crazy thinking about it, but it would be nice to know in the quest to come up with a cure or even to prevent it from happening to future generations.

As far as "asking" about each other's pregnancies, Lynn Egan had sent out a questionnaire a few years ago when the IFAHC was first forming, that asked several questions. I'm sure she will be happy to share the conclusions. And, since the question has come up thru this chat line, then I'm sure others will be happy to share their experiences as well.

We are all here to support each other - I don't think anybody who has written means to offend or anger anybody else. We should all be able to feel free to speak our minds and ask any questions that we might have without worrying about offending someone. Remember too, that people join the chat line at different times, so they may ask questions that the rest of us may have already discussed. That should be okay too.

We do understand your frustration and the anger that you feel when your son is having a bad day and about AHC in general. Its very difficult living with AHC - it can get in the way of even the simplest pleasures in life. We are all dealing with this and really need each others support and sympathy to make it a little more bearable. Its okay to vent - especially to this crowd, we all understand. Sometimes it helps.

I hope you're having a better day today and that your son is feeling better. We're all pulling for you!"

Kathy - July 12 -

"We have a 6 year old daughter with AHC, and will soon be relocating from Australia to Budapest, Hungary (for about 3 years). Does anyone know of any AHC aware doctors in either Budapest (or possibly Vienna) or, of other AHC sufferers in Hungary who we might be able to contact?"

Tim Powell - July 12 -

"I'll way in one last time on this issue because my first note, which described my singular family experience, seems to have caused a brisk discussion.

First and foremost, my family's experience with a geneticist was only one experience and should NOT be considered an absolute answer to anything. Second, I'm no doctor so when I "think out loud" about possibilities everyone should consider the information for what its worth — the rambling of another confused parent who doesn't know genetics from a box of cereal.

No one in my family has had a history of migraines or other things that are thought to be associated with AHC. Then again, any gene can be sitting around for a long time or need the combination of mother and father before AHC or something else hits. Maybe my wife and I are just that unlucky (we sometimes think we are).

As for pregnancy, my wife "did all the right things" and had an uneventful pregnancy and child birth. That doesn't mean that she may not have been exposed to something around her that caused AHC. Even in the case of twins, maybe after conception, there could be some exposure that we wouldn't think about in a million years. I see so many news stories about contaminated water, air, etc that I wonder about what it may have done to Greg. Then again, why is my other child O.K. when he went through the same set of conditions?

I certainly do not know the answers, but can certainly make a case for either/both lines of thinking.

Let's all participate in the blood draw and DNA testing and maybe this issue can be solved and put aside.

Greg - July 13 -

I have been away for a few days. This topic of genetics and pregnancy has plagued me off and on over the years. I have no answer. In some ways, I say it does not matter. But it does from the stand point of wanting to know WHY do these kids have AHC and what caused it.

It will do nothing for our day to day living, it will not change the diagnosis, but perhaps from DNA testing some form of treatment will be available to make our children have a better life and it will put to rest our question as mothers, fathers, and parents that it had nothing to do with us, it was out of our hands.

My pregnancy was uneventful. I too did everything I was suppose to. Kathleen was about 1-1/2 lbs larger then my other two kids and so I was more uncomfortable, but I felt that something was different about her pregnancy. Maybe intuition.

In February 1995, I sent out the results of the questionnaire. Twenty-nine families responded and here are their answers regarding pregnancy.

Was it a difficult pregnancy?

22 - NO 7-YES

If difficult pregnancy, why?

high blood pressure; at 8 months - camplylobacter. Child had breathing problems at birth. Required ventilation - was told levels were fine at birth; pregnancy was termed "high risk or multi-problem pregnancy"; ovarian cysts until 5 months; low blood pressure in later months; had high leak (premature rupture of membranes) Delivered at 36 wks. Had water retention and elevated blood pressure; bleeding for 5 months, was threatening a miscarriage.

Was labor & delivery normal?

15 - NO 14 - YES

Many c-sections had hard and long labors.

You can see from the answers above, that many different things happened to less than half of the families and that they all could have happened with the delivery of a child without AHC.

I think that when we are having a bad day or some question comes up, this bulletin board is the best place for us to go. We can share experiences and ideas, ask questions, cry out for help, and vent. We may not always like what shows up, but at least it is more that we

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had before. I thank god every day, that I have "met" each and everyone of you because you have helped me and helped others."
Lynn - July 12 -

"This weekend was the long awaited church festival. My kids were so excited about it. Jake was so bad he couldn't even hold his head up. We took him anyhow in his chair and he did seem to enjoy being around people. We ended up leaving after two hours and were lucky enough to watch the fireworks from home.
We, too, have to watch Jake every second of every day. One evening I was outside talking to my neighbor. I told Jake and his brother to go home and get ready for bed.
When I left about ten minutes later, I found Jake standing in her yard, in the dark, unable to walk or talk. I couldn't believe he was still standing! His brother thought he had come back with me, and I thought he was at home. The poor kid was standing there all that time unable to do anything. No wonder he gets so angry sometimes. He tries so hard to be independent. As much as I grumble about having to carry him at times (he weights 45 pounds), I have to remind myself that he didn't ask to be like this and hates it probably more that I do."
Becky - July 13 -

"I agree with how you feel about dealing with AHC. Whenever I get "down" about how hard it is on "me" - I very quickly snap out of it - Its my Abbie who has it hard. I'm sure she would give anything in the world to have my problems or the problems of any other of her family members. I tell my "normal/healthy" daughters that we are in fact very lucky - we are not the ones afflicted with AHC. And, as unlucky as Abbie is to have the disorder, she is nevertheless very lucky to be given very healthy and able bodied parents and sisters who will see it it that she has the best care possible for as long as she lives."
Kathy - July 13 -

"As I respond to Greg's last Email from 7/13, under the Subject: heading I deleted the "pregnancy" part. Although I am just one person, I feel very strongly that this disorder has nothing to do with pregnancy complications but rather all to do with genetics. As a parent of two children with AHC (both of normal pregnancies and uncomplicated deliveries), I can share with the group similar findings from our consultation with a geneticist. It was felt in our situation with again it was a recessive gene (1 in 4 chance of reoccurrence) on both sides due to the fact that our families had no history or other migraine-related disorder. Again, this is just our family's situation, but I really feel we need to spend our monies and energy focusing on the genetic link of AHC."
Chris Morris - July 15 -

"I was just wondering. Lately when my daughter has her episodes her whole body is down not just one side anymore. Is this something that happens with AHC?....."
Mindy - July 21 -

"We have noticed "full body shutdown" much more frequently since Jake started flunarizine. He doesn't have as many one-sided attacks. Also, Jake's one sided attacks are just like Kathleen's. In children that are left-handed, though, they should lose speech and swallow when their left side is affected."
Becky - July 21 -

"TJ has been having full body attacks for as long as I can remember... his first one taking place in October of 1992. Since then, although they still occur, they do not occur as often.
When TJ was an infant the longest episode for a full body attack was 35 days long. Now the longest has been 2-3 days long with a short relief time of around 15 minutes up to 1-1/2 hours. During these attacks, TJ is unable to speak, is very floppy, can move a finger sometimes so he can sign yes or no, stops breathing occasionally, has body temperature fluxuations, problems swallowing with an increase in choking, and an increase in funny eye movements. During the nights following these episodes, he has an increase in apeneas and bradicardic episodes.
When he losses his left side, he is still able to walk, slurs his words and is harder to understand. When he losses his right side, he is still able to walk but he "forgets" words..he knows what he wants to say, but it isn't there to recall.
Then there are days like today. He started out fine, woke at 7:30 with no problems. He was very energetic and happy. At 9:30 he crawled back into bed and covered his head to block out the light and noise. He then slept for 3 hours with 4 apneas and 2 bradicardic attacks. From 12:30 to 12:47, he was fine but then lost the use of his left side. After 2 hours of dealing with that, he went full blown. Then at 4:30 he regained control of his left side but his right side remained paralyzed. That continued until he went to bed.
As you can see, we go through the gamit regularly.
I hope this helps answer any questions. Feel free to ask me anything else when you need."
Wendy - July 21 -

"Lately we have been facing an increasingly difficult time providing Greg with adequate day care so that my wife can maintain her job. We pay a local day care center an hourly rate, yet we still send our own aide (they won't take him without an aide). We get the aide thru a local home health care agency that then bills Medical Assistance.
My understanding is that the MA reimbursement rate is very low and the agencies claim not to make any money on this deal. They are therefore not very helpful when things come up such as the aide being sick, when we need to change our scheduled hours (which they want us to schedule months ahead of time), or when the aide leaves for a better paying job (she just gave notice yesterday!!).
Is it just us or does everyone have this problem? Aside from grandparents or other relatives (they live too far away), does anyone have other ideas or solutions to this problem?"
Greg - August 5 -

"We too initially encountered child care problems when Kyle became school age. Our problem did not deal with health issues, but the fact that he was not toilet trained. We contacted our local child care association and they helped us compile a list of in-home, licensed child care providers that would work with special needs children. I interviewed three individuals; one had been a registered nurse, one had a young adult child with special needs, the other had cared for special needs children in the past. We have been fortunate to find a person/family that have been very helpful with Kyle. Child care is such an issue with any child for working families but even harder for our special children. Hope this helps in some way."
DeAnne McGinley - August 6 -

"Does anyone have any suggestions about crying during attacks...my daughter is 18 months and her attacks are lasting about 5 days and she is crying morning till night...I don't know what to do...if she is in pain or just frustrated.
Also my daughter Hailey never ever sleeps through the night...is this something that

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comes along with AHC?"
Mindy - August 13 -

"Our daughter is 11 years old and not only cries during a full paralysis "attack" but screams as if in tremendous pain which appears to be a massive migraine, although will always point to her stomach to indicate where it is hurting.
We have found that the most comforting position for her is to nurse her over our shoulder like a baby with colic and although not always successful seems to help at least a little. As she gets older this is becoming more and more difficult to do but so far its still possible as she is a very small 11 year old.
In respect to sleeping, she rarely sleeps all night. She has been waking up and getting into bed with my wife and I for years. I hope this helps."
Paul and Carmel Shannon - August 13 -

"When Kathleen was that age we experienced the same type of crying periods during episodes. And like Paul and Carmel, we carried her over our shoulder. We could not in anyway sit or even lean up against something or it would resume.
She will still get them once in a while and it still helps to hold her that way. From age one to about four were our worst years when episodes would last for 3 to 5 days with breaks of 10 to 14 days in between and then all of a sudden they were less. It doesn't mean we don't have them, just not as often. We still have dystonic posturing almost everyday but for only minutes and it does not seem to "hurt" her.
We have been lucky with sleeping in that one she is asleep it is for 10-12 hours every night."
Lynn - August 13 -

"We had another stay in the hospital two days ago. This time it had to do with the fine tuning the medication Depakote for the newly presented seizure disorder that Morgan has developed. I was wondering how many kids are on Flunarizine and Depakote? And if you have any trouble with achieving therapeutic levels. We started out with 250mg per day and our level was good for about 3 weeks, then dropped drastically and we had a severe Grand Mal Seizure. We then increased the medication to 375mg per day and her new level was therapeutic for about 2 weeks, then elevated dangerously high which was the reason for the hospital stay. I've now gone to 312.5mg per day. I just thought if anyone had already gone through this little problem, I could gain some knowledge on what to do for Morgan."
Kathryn - August 21 -

"I am Aurelie's mom. She is 4 years old. I experienced days with crying all day long. It is really hard to live because we do not know how to react. If the episode is painful, or just frustrating...When we now ask Aurelie if she has pain when she has an episode, she answers for some that it is not painful but that it drives her crazy not be able to do anything...and it should really be like that because sometimes when we tried to distract her by singing (I know it can appear crazy to sing in that moment...) by telling stories she was able to calm down and fall asleep. Only few seconds sometimes were enough to feel better, few minutes. We did not know what to do. I remember once, she was around 8 months old and was crying all day long and we did not know what to do. We were angry with each otherbecause we were unable to calm her down....it was in November and it was cold outside. Nevertheless we took our coats and walked for a while...she progressively calmed down and ourselves too. It was such a relief...poor little girl with such pain, we thought...but we still now do not know if it was frustration or pain at that moment.
I am sure that awful disease express itself not always in the same way. Indeed, Lili is now 4 years old and is able to speak very well. She now has sometimes episodes lasting a moment and she is able to reply when we ask her if it is painful that it is not, that it is frustrating not to be able to do anything. Sometimes when she is only affected on one side, she takes her arm and says go away crisis, leave me alone...some other times she says that it is painful and that it is like cramps. Maybe she heard me telling that because her arm or leg becomes as hard as a stone....
More and more often she can be totally paralyzed with her head neck going in the back and as if she won't have enough breath. In these moments I try to stop that position because I have the feeling that it can stop her breathing..it's an awful feeling...it last not a long but it occurs too often in my opinion...I am so afraid by these episodes...Does someone already experience similar attacks?
I hope you spent all good holidays."
Marjana - August 21 -

".....She screamed when she first saw the sea.. she had quite immediately an episode, but when we requested her to calm down, she did it..and rapidly recovered one side, and played with the sand.
At the end of our holidays she was able (when she decided) to bath short in the sea and play with her sister in the water...we were so proud of her and happy for her to be able to do that. Her determination to succeed when she decided to do something is so encouraging...she never gives up..it is so encouraging as well.
It seems to be easier for her to go to the sea side than to the swimming pool...Dominique should be right when he says that our children behavior depend on their mood and their bad or good periods. We have the impression to experience the same.
She also had 3 days with sorts of terrible cramps and she cried a lot. It seemed to be so painful and we couldn't help her. That's what I hate the most in that disease..I noticed that when I compress her painful leg, she recovers faster its usage...
In September she is going to to to school, in the middle section. I hope it will be ok."
Mirjana - August 21 -

"We've been giving Alexander (15 months) baby Tylenol or Children's Motrin. It seems to calm him down, or perhaps we just feel better because we've done something to try and ease his pain. He usually falls asleep shortly after as well which helps."
Carol Presunka - August 22 -

"...Thanks for getting back to me about my questions. Hailey who is 19 months now has those attacks where her head goes back... her whole body is down and she can't even hold her head up..we try to keep her head forward too because it does stop the breathing..it's so scary isn't it..lately Hailey's attacks are all like that... can I just ask you some questions..you said your daughter can speak normally right?...does she walk and do other things?....I just don't know what to expect with this disease...."
Mindy - August 25 -

"....I totally agree with you, it is scary. Aurelie is not delayed a lot. We always had the impression that after an episode she evolved a lot.
She is now able to speak, walk normally but not yet to run as other children do. She is reluctant to speak about her episodes but sometimes she gives us some information on her feelings. Most often she just doesn't want to speak about it.

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She is now able to play with her disease and tell that she has an episode when she has not. It is curious... for instance yesterday morning she told me " Mummy the episode !! " and she mimicked a right episode just because she wanted me to carry her downstairs... I immediately saw that it was not an episode because she laughed when she did it...I explained her that we would not believe that she is touched when she will really have an episode... I don't know what to think about this attitude.

Lili can have terribel episodes lasting up to 10 days (the longest episode she had) with the same symptoms as you described (the head back, the whole body down..), and shorter and less uncomfortable ones (most often for the moment).

She is going to go in September in the middle section of the nursery school, but the time she spends there has been discussed and adapted with her teacher and school academy. Last year, she had not so much episodes in school, but had a lot during week-ends (I am often wondering why?). Because of her fine motivity delay she goes once a week to see a psycho motivity therapist, Mr. Valla. He helped her so much to express herself and to use her body the most efficiently possible.

When she was a baby, she only had episodes with one side and both sides affected without these cramps and attacks where her head goes back. These ones appears to me as being more dangerous for our children. Dominique asked Dr. Aicardi about these tonic posturing and he was told that it was another expression of AHC but the same as when our children body goes down..

My personal point of view is that we all have to participate in the genetic research program, because Dr. Ptacek is our latest chance to find out something and he has the willing to help us.

The unique hope to find out a medicine to cure that disease, or only something helping our children being more comfortable when having an episode can be found if doctors and researchers try to think about it and find out a solution. For the time being we only have US doctors wanting to cope with it and some (very few) local doctors (in Italy, France, UK I have heard about) collecting information on AHC possible treatments..

According to Dr. Goutieres Niaprazine seems to have positive effect on 50% AHC cases. We actually use the drug on Aurelie with a dose of 7.5 ml when a strong episode appears. She became a right episode yesterday evening and we gave her 7.5 ml Nopron (commercial name of Niaprizine in France). This morning when I left her, she was in an excellent health. I presume that the drug associated with sleep helps stopping episodes for a moment (Dr. Goutieres spoke about a delay of 8 to half a day..and it seems to be the case for Aurelie). We started using that drug last March when we did not know what to do because her episode lasted too long (10 days with strong episodes, both with body down, cramps and night problems...). Dr. Goutieres told me to give her 7.5 ml. Her episodes were stopped rapidly without second effect (we tried to use before the hydrate chloral and it was dramatic on her because she wasn't able even to sleep quietly and became nervous...). Once I gave her Nopron and she only had the attack again in the evening the day after. We gave her again that drug and her "big" episode finished in 3 days instead of lasting more.

In few times Dr.Gobbi and Goutieres are going to organize a European survey of Niaprazine. I suggested to extend it to USA and world-wide if possible but for the time being I have no news on how they are going to proceed. I will let you know as soon as I have more information. Rosaria from Italy is in a close contact with Dr. Gobbi. She first wrote about that survey and it was confirmed by Dr. Goutieres during our last May meeting."

...Just a precision: All I described about are my personal experiences with Aurelie and my personal feelings about AHC. I am not a doctor and as such cannot give you any medical advice, just share some experiences that seems to be efficient with Aurelie. Prior to testing any drug it is important to have your doctor's point of view."

Mirjana - August 26 -

"Yesterday Greg and I went to his annual neurological visit. No new ground was broken, but the doctor was curious as to whether anyone had any experience with certain drugs in treating AHC. Many of them fall into the beta blocker category. The drugs he mentioned are (with the brand name in brackets): propranelol (Inderal), sumatriptan (Imitrex), gabapentin (Neurontin), topiramate (Topamax), lamotrigine (Lamictal).

If anyone has any information or experience with any of these it would be greatly appreciated, even if we put it on the long list of drugs tried that don't work."

Greg - August 27 -

"...I have no recent news about the European survey on NIAPRAZINE (NOPRON). The first time I heard about it from Dr. Gobbi was in a message of his last May in which he told me that he was gong to make a proposal for a survey to the Societe European de Neurology Infantile; as a matter of fact Dr. Gobbi is a member of the Board of Directors: The General Meeting of the Societe will be held in Lisbona next November, maybe it could be worth while speaking about it with Dr. Gobbi and Dr. Goutieres and asking if someone of us parents can join it. I know that Dr. Gobbi is on holiday now but when he is back, in September, I will ask him for more updated news about his project.

Dr. Gobbi likes very much the idea of joined studies for new treatments of drugs on a larger scale, that's why he is a strong supporter of an European organization of AHC families which could lead the doctors of all nations to work together on a larger number of patients. Dr. Gobbi visited my son Alberto last July and on that occasion I told him that NOPRON didn't work with us. In fact, like Valium, it makes Alberto even more nervous and upset. So he suggested that we should try the chloral hydrate and that's probably what I will do sooner or later. Fortunately, during the summer, Alberto was very well and hadn't got very serious attacks. As about attacks, in July I sent a message to the list with a description of Alberto's ones, but I too had the feeling that something didn't work and the message didn't reach you, so I am repeating it now, more or less. Since we started with Flunarizine, in April 1997, the duration of the attacks dramatically decreased: before that date they usually lasted two or three weeks each month and their main feature was a lot of involuntary movements affecting the plegic side (the leg shook and the hand withered). Soon after the Flunarizine, all these movements disappeared and only the hemiplegia remained. At present the attacks last only few hours, they usually come one or two afternoons each week and are mainly bilateral, some of you call them "full body shutdown", I guess. But, I think that Alberto's tremors got worse after flunarizine and also his lack of balance. Anyway, all the attacks start one-side, usually the left for Alberto, but very often they immediately spread to the whole body and become bilateral. When Alberto has one of such attacks, he is completely floppy, he doesn't speak nor moves his eyes, he's got tremors if he tries to move an arm, but he is always conscious and he smiles and even laughs if he hears a funny remark.

When he is in such a condition we usually read him some stories or let him watch TV

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until he relaxes and gets to sleep or, if he is not too weak or tired, we go out for a little walk in his strolley. His neck is completely weak and his head is always left back, he can't swallow and has difficulties in breathing. Sometimes he chokes with his saliva and start coughing, so I pull gently his head forward and I pat on his back. Anyway he's never had serious episodes of choking and has never become dystonic. He also yawns a lot during bilateral attacks.

During the last springtime we saw very painful attacks during which Alberto was completely stiff and cried a lot. Dr. Dalla Bernardina and Dr. Gobbi told me that the children get so stiff because they are having very painful pangs (sharp pain???). Fortunately these attacks were very few and didn't last long.

Alberto comes out of an attack (bilateral or one-sided) only by sleeping. If he manages to sleep, even for a few minutes, he wakes up completely free and usually he is well for an hour or two, if we are lucky he is well for the rest of the day. Fortunately the attacks occur in the afternoon, during which Alberto is still used to having a nap, or in the evening very rarely, if he sleeps too little after a long bilateral attack, he wakes up and becomes immediately hemiplegia, left or right.

In general, however, the recovery after a sleep is really complete: even the doctors who saw him riding a bike along the corridor of the hospital after sleeping for only 10 minutes, could hardly believe that few minutes earlier he was fully blocked?

Just another hint: Mirjana, also Alberto started with his attacks during the week-end, when he was with me and his father all the day long, and instead he was well during the rest of the week when he was with his granny and his baby-sitter. My husband and I have always wondered why, we felt also a little guilty and didn't know what we were doing to him that caused such attacks. But this happened before Alberto started the school, now it is exactly the opposite; he has the attacks during school-time and he is well during the week-end or holidays. It's all so strange!!"

Rosaria *- August 27 -*

"It's so interesting hearing about other children and comparing notes. Since we all don't have a chance to meet other children, this is the next best way to learn more about the disease.

Jake's attacks are very similar to Alberto's Rosaria, how old is Alberto? From what I have read from other parents, it seems that the attacks change as the child gets older, and if the child begins taking Flunarizine, they also change. The duration of my son's attacks has decreased dramatically since he started flunarizine. However, I believe that the intensity of the attacks has increased. Prior to starting Flunarizine, Jake would often get one sided attacks that he could still function with. Now, his attacks are almost always bilateral (with the floppy head). Lynn Egan gave us a wonderful idea of using a bean bag chair for Jake when he gets like this. You can mold the chair to support the child's head. He is getting so big it is difficult to hold him for long periods of time. We talk to him, read to him, and play with him during this time because he gets so very sad. The other attacks, where the child stiffens up and cries, I was led to believe this is dystonia. This almost always occurs on Jake's right side. He pulls his right arm tightly up to his chest and his hand is fisted so tight you can hardly open it. His right leg gets very straight and he cannot bend his knee. He usually gets like this after physical exertion, swimming, or during emotional upset. I know of another child who required braces due to repeated attacks to her ankles.

We also noted that Jake would have much more frequent attacks on the weekend. For a long time, I thought that it was something that I did, as my husband stays home with him during the week. Now I think that it is because his life is much more structured during the week, and during the weekend we are often on the run, and we don't eat and sleep at the same times. My husband is also better at getting Jake to participate in "quiet time" with less physical activity. After Jake turned five, and stopped taking naps, his attacks became much worse. He now will say to himself "calm down" when he knows that he is getting too excited as this can bring on an attack. We haven't been able to make him understand that he needs to take frequent rests, he wants to run and play all the time with the other children.

Sorry this is so long winded. Please keep up the correspondence. When I try to explain Jake's attacks to people who don't know him, I often feel like they don't believe me. To hear other people say the same things is very reassuring (I'm not crazy!!!)"

Becky *- August 27 -*

"It is so weird how know one really knows about this disease or how to treat it but we all totally do the same exact things to care for our children...reading everything everybody writes is like everyone is living in my house. I guess it just makes me feel good that I'm not doing anything wrong since all we can do is guess what to do."

Mindy *- August 27 -*

"Jake was on Inderal for a short time. This was when they weren't sure what was wrong with him, they thought that maybe he had hemiplegia migraines. They really didn't seem to do much for him, but we only tried it for about 6 weeks."

Becky *- August 27 -*

"I took my son Louis (13) to his neurologist for his annual checkup about 2 weeks ago and she wants me to start him on Neurontin, she gave me the medication and wrote a schedule out for me to follow. I have to be honest, I have not started him on it yet because I'm afraid to start something new and I really don't know much about it. Louis is taking 20 mgs of flunarizine a day and his attacks come along every 7-10 days. I just don't know if I want to mess with his meds right now, he just started school and if Neurontin is like other seizure meds then I don't know what effect it will have on him. If there is anyone who has tried this medication on their child, please let me know what your experience was.

On the brighter side, we were just informed that Louis was chosen to compete in the 1999 World Games for the Special Olympics. His name was chosen at random from all the 1st Place winners of the Florida Spring State games. He will be going to Raleigh/Durham North Carolina next June and will compete with they Cycling team from Florida. This is very exciting for him and we are all looking forward to it."

Adele *- August 27 -*

"Our neurologist also suggested Neurontin last year and even gave us samples to use and a schedule for implementing it's use. We tried to give it to our son, but we had a horrible time giving it to him because the capsules were so large! He was also going to have to take several capsules multiple times a day once fully implemented. Because we didn't hold out much hope for it's effectiveness and the difficulty administering it to him, we did not follow through after approximately 2 weeks.

We recently weaned Kyle off of his flunarizine. We are mainly wanting to re-evaluate it's effectiveness for him. We certainly don't want to cause him any further problems with this condition but if a medication really has

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limited effect....."
DeAnne McGinley - August 27 -

"....I have another daughter age 2-1/2. I never thought I can have another child with AHC (maybe because there are so few cases world-wide, and there were not 2 cases within the same family). My husband was totally scared about having another child... Our second daughter name is Marina and she is in excellent health condition. She already speaks properly, is toilet-trained, and ready for school.. It is a great chance to have her, for Lili and ourselves. She helps her sister so much just by being there..She can also be terrible with her sister but it is even usual with "normal" children...
Regarding Hailey preparation for school, it seems that you have done everything possible to ease her integration at school. Rely on her capabilities. We are often surprised by what our children are able to do by themselves...
I think that a possible explanation for episodes during weekend may be the fact that they relax themselves more at that moment, just as we do during week-ends..."
Mirjana - August 28 -

"Louis was also taken off the flunarizine last year for the same reason. It had gotten to the point where we didn't know how effective it really was, but after a short period the episodes became much worse and they never went away. It was then that Louis went from 10 to 20mgs a day. I just hate putting him through all this, our Dr. also gave us samples and wrote out a schedule for the Neurontin but after reading the info I was given with it, I really don't want him to take it....."
Adele Caruso - August 28 -

Note: Dr. Harry Chugani was asked what his thoughts were on the use of Neurontin. "Neurontin is not proven to be effective in AHC, but is a reasonable drug to try. It is not good as a seizure medication, but surprising good for painful nerve pain in diabetics! My mother is on it! This may therefore be helpful. It was brought up in the Seattle meeting in fact."
Harry Chugani

"...my son Alberto is five 1/2 years old. You are right when you say that people don't believe us when we describe our children's problems. Indeed for the four initial years of Alberto's live, even the doctors didn't believe me and thought I was crazy and that's one of the main reasons why we got to the right diagnosis so late. But this is my present strategy: at the first sign of incredulity when I speak with doctors, teachers and people in general, I immediately start to speak to them about the experiences of all the other families I know, personally here in Italy, or via Internet, I tell them about the international organizations of parents, about the international research projects and so on, so that they eventually come to believe that yes, AHC is rare, odd,... but it is real!!! and it is a terrible disease for a child and his family to cope with. Thus they are more sympathetic towards Alberto's problems and needs and more willing to help him. That's why it is so important that all the AHC families stay in close contact: if we are isolated, who will take notice of us? And it is also important and reassuring for a parent to learn that other families have very similar problems with their children and do the same things in order to cope with them.
We too have noticed that, after a year of flunarizine, the attacks are now much shorter as for duration but much more intense, as if they were more concentrated.
Also, Alberto is very unwilling to stop and relax when he feels that he is getting over-excited and that an attack is coming: many times he gets even more frantic and angry as if he wouldn't give up to it. Indeed sometimes when I intervene too brusquely and force him to stop his activity and relax, I have the impression that the attack wouldn't come if I would be less intrusive and let Alberto cope with the attack by himself. Just an impression.
Alberto never had a dystonic attack like the ones you describe for Jake, I mean stiff on only one side, but I know another Italian girl, aged 11, who got something like that. Many times, especially during a bilateral attack occurring after an intense physical effort, Alberto is rather more stiff than floppy, mainly the arm and the leg on one side, not always the same, and has got a lot of spontaneous tremors especially if we don't pay attention to him even for a little while. If we change his position, or simply gain back his attention, by speaking to him or caressing, etc., the tremors stop and he gets floppy again. Has anyone of you every noticed something like that?
Anyway, Alberto's attacks greatly changed during the years: the greatest change was due to the flunarizine but I guess that they change also because Alberto is growing and is getting more and more aware about his problems and more active in coping with them. I wonder if a psychologist could help him.
Thank you very much again for sharing your experiences and ideas."
Rosaria - August 28 -

"...last July Dr. Dalla Bernardina visited my son Alberto and told me that, in order to further reduce the attacks, I should try first of all DIAMOX, a drug used for a specific kind of channelopathy, and in case of failure, gabapentin (Neurontin).
I know that other families have already tried DIAMOX and it didn't work but I don't know of anyone who has already tried gabapentin or any other of the drugs you mentioned.
Also Dr. Gobbi visited my son: he is quite in favor of DIAMOX but more sceptic about gabapentin. He is much more interested in Memantine, a very new drug.
So, I am a little upset about the idea of trying both these drugs, DIAMOX and GABAPENTIN: the first one because I know that very likely it won't work and the second one because no one else has already tried it.
Dr. Gobbi suggested to try triptophane (a precursor of serotonin) specifically for Alberto's movement disorders (tremors and ataxia): this week we reached the useful dosage but until not we have not seen any appreciable result. It will take other two or three weeks to evaluate it."
Rosaria - August 28 -

"Our daughter Margaret has tried propanolol, sumatriptan and lamotrigine over her 17 years, and none of them did any good."
Don Kilpatrick - August 28 -

"I am Teddy, Diana's father and I want to know if somebody knows something about MMR vaccine, and if I can make this vaccine to Diana. She is 4 yrs. 8 months.
Diana's doctor said that this vaccine is a complex vaccine. I don't know if this vaccine is in AHC."
Teddy - September 1 -

"It would help me if you could precise what the letters MMR mean? Is it an English abbreviation?
Did you receive the attestation for Janssen delegate and can you now benefit from Flunarizine? I wrote in one of my previous messages about Mentadine but I made a mistake, the name of the new drug is Memantine. I will investigate as soon as possible on it and let you all know (I had

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not the time yet).
Mirjana - September 1 -

"...I'm not sure if this is what your doctor meant, but here in the U.S., our children receive the MMR vaccine. It is to prevent the child from getting measles, mumps and rubella (also knows as German Measles). Our children get the vaccine at around 15 months old.
There is another vaccine that is given here called DPT. It prevents diphtheria, pertussis (whopping cough) and tetanus. In many children with neurological problems, the pertussis portion of the vaccine is not given. That is true for my son Jake, he has not received the pertussis portion in his last two immunizations.
Many school districts will not allow you child to attend public school it they have not received these vaccines. "
Becky - September 1 -

"Jake had already had his first episode of hemiplegia when he got the MMR vaccine. Jake probably had episodes while he was an infant and he didn't get the MMR vaccine until he was 15 months. I don't remember him having a reaction to the vaccine. I believe he got another MMR booster shot a couple of months ago. The doctor told me that if he had a reaction, it usually shows up 3-4 weeks later.
The MMR and DPT vaccine help to prevent different types of diseases. Where we live, it is mandatory for a child to receive them or they cannot attend a public school. I believe though that a child can be exempt from getting the vaccines if they thought it could be detrimental to the child.
These diseases can be fatal and are very contagious. That is why the school requires them.
Jake is 7 years old. He started Flunarizine in March and it currently taking 10mg a day. This medication has decreased the duration of his attacks: he still has attacks, they just don't last as long. We do not give him any other medication except tylenol because at times he does seem to have a headache during his attacks.
Are you from Romania? If other children nearby are not vaccinated for these diseases they can pass it along to Diana and because she has AHC, she may become sicker than other children.
If anyone else has any information on these vaccines, please pass it along. I'm afraid that my memory isn't very good about when children get the vaccine and possible reactions.
Becky - September 2 -

"well, TJ definitely had his first episode before his MMR shot. To be exact, he was 31 hours old. I know we are all looking for answers on how this happened to our kids. Today, I am in a good mood so I can say honestly for today, I am glad TJ is the way he is.
Unlike my friend's children, mine cuddles still to this day, he gives me kisses just because, I don't have to chase him around the neighborhood, I don't have to worry about him learning the "f" word before he is 10, and I don't have to be concerned about him smoking.
Sure, I admit it, on a really bad day, it is hell. I wish he didn't have to go through the pain of being different than those in our area or at school, that I didn't have to be concerned about how the school will alter the program to suit him, but for today I am glad he is him and he has AHC.
Man do I sound mushy....."
Wendy - September 2 -

"I was just reading an article in the Boston Globe this morning about the wonders of horseback riding as therapy for children with disabilities. Has anybody ever tried it? Apparently it has been very successful with children who have Cerebral Palsy - 20 minutes on horseback can be equivalent to two hours of physical therapy exercises on a mat. It strengthens muscles, improves motor control, and increases coordination etc.
We are going to look into it for Abigail (age 9). Unfortunately, our health plan won't cover the cost & it is fairly expensive (a horse farm on Cape Cod charges $695 for a nine week session) but it seems to get rave reviews. Plus, I think Abbie would absolutely love it.
I'd be interested to hear if anybody has tried it and/or if such a program is available in different ares."
Kathy - September 4 -

"We have been taking Greg for horseback therapy sessions for about a year now. We have gone about 30 to 40 times in the last year. They have a pony that he rides so that it isn't so intimidating for him.
Greg has always had very low muscle tone in his trunk area which is the main reason he can not walk unsupported. The riding sessions are very could for these muscle because he has to constantly work those muscles to sit up while the horse is always shifting his weight around.
The price you quoted is pretty high based on what we have been paying, however, we live in a pretty rural area (about 2,000 people and cows and horses probably out-number the people) and the farm is just down the street from us. We have been paying $15 per session (30 to 45 minutes). Based on that price, I'd let him go to ride the horse even if there weren't any exercise potential."
Greg - September 4 -

"We moved to Florida 2 years ago and our school district in Sarasota County had it as part of Louis' physical therapy program. They would come to the school once a week and all the children that received PT would also receive it. I may be wrong but I believe its called hippotherapy. Louis really enjoyed this program and the services were provided for free. The amount you quoted seems high, I have heard of another program in the NY area that also provides this for free. Unfortunately, now that Louis is in middle school it is not offered there. Louis did enjoy it and I think he will miss it."
Adele Caruso - September 4 -

"We are trying to get Jake enrolled in horseback riding also. We have heard from other parents that if you can get it
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added into the child's IEP (individual education plan) that the school district will pay for it. We don't want to go that way as it is such a hassle. There is a woman nearby who gives riding therapy FREE but you have to take out insurance for the season (about $35) for once a week 45 minute class. We are on a waiting list. I bet that the local chapter of the Cerebral Palsy Foundation would have a list of places that give lessons or therapy."
Becky - September 9 -

"It is with tremendous sadness that I need to inform you of the death of another AHC child.
Stacy Lynn McCutchan was found yesterday morning, September 15th, by her mother Sue. She died in her sleep. She was 24 years old.
The McCutchans have generously donated Stacy's brain for the AHC research that is under way and have expressed a desire to continue to help in any way they can in the future.
Stacy will be buried on Friday, September 18th. At this time if you have any questions the family requests you call me at 1-888-263-2454 or e-mail me.
Condolences can be sent to:
The McCutchan Family (sue and Wayne)
R.R. #2 Box 120
Ladoga, Indiana 47954
USA"
Laura Cooper - September 18 -

Note: The McCutchan's will keep in touch and update as information is available to them.

"I thought I would share with you our family's experience of taking part in the DNA Blood Collection Project. I sincerely hope it will give useful information on the causes of AHC and in the short term it made me feel good to take part. I encourage all who can to do so. Taking part took us little time and trouble and only a small cost. Dr. Ptacek's office sent a complete kit by FedEx with EVERTHING in it for the AHC child, a sibling and the parents to have blood taken. The Dr. had given us some numbing cream to apply at home so that in the surgery the veins were already desensitized on both children. Samuel was a star and lay down, had his blood taken and did not murmur. My husband helped with Samuel and I held Alice to watch. She couldn't wait for her turn and lay down and had the needle put in the blood taken with not a sound! At only two years old! We were so proud of both of them and they were too. It was a hard act to follow. I called FedEx immediately so the blood could be shipped the same day and e-mailed that it was on its way. This allowed Dr. Ptacek's office to smooth the way for EPA and customs clearance so our precious samples did not sit around awaiting formalities. All we have had to pay for is the access and copying of Alice's medical records which was 13 pounds. This charge depends on the Drs. discretion. Anyway this is how it worked out in the UK. Good luck to the rest of you.
I was sad to hear of the news of the death of Stacy Lynn McCutchan and express my condolences to all who knew her.
I hope all is well with all the other children."
Alex Cole - September 29 -

TIPS....
- Several parents have made the observation that giving flunarizine at the same time everyday, seems to make a difference.
- Kathleen Egan and her dad devised a form of sign language when she is unable to talk. One finger means "yes", two fingers means "no", and Kathleen's little funny, three fingers means "maybe".
- Massaging the head, neck, arms and legs during an episode, seems to have a very positive, calming effect on many of the children.
- With the invention of inflatable furniture it is a great place for our kids as they get bigger. Like the bean bag chair it conforms to their bodies.

Write/Phone in Questions

"How many children are expressing behavioral problems or aggressiveness at school or home? How are teachers and parents dealing with this issue? What medications besides flunarizine are being used and are any being used to treat this issue? When Jimmy was younger, on occasion, he would engage in "head banging" against the wall and floor.
Are there any other kinds of physical behavior problems evident with your children; ie biting, pitching, hitting, tantrums?
Dennis and Elsie Kiernan

Publications of Interest

by Greg Wisyanski

I recently ran across a couple of publications that may be of interest. All three books deal with occupational therapy and treatment of hemiplegia. All of them deal with adult hemiplegia (usually as the result of a stroke), however, I have purchased one and the information can be adopted for individuals who are not yet fully grown. My wife and I have found the book useful for tips on exercises, positioning and other situations we find ourselves faced with in our home life. These should never take the place of a trained professional, but you might want to give them a look. They are:

Steps to Follow: A guide to the Treatment of Adult Hemiplegia by Patricia Davies (this is the one we purchased)
Occupational Therapy in the Treatment of Adult Hemiplegia by Ortrud Eggers
Right in the Middle: The Importance of Trunk Activity in the Treatment of Adult Hemiplegia by Patricia Davies

If you can't find these publications in a bookstore, you may want to try the website www.amazon.com which is a large seller of books through the internet.

United Way Reminder

Don't forget that this is the time of year that United Way's throughout the country are conducting their annual solicitations. In most cases you can have your contributions to the United Way specifically designated to go to the IFAHC. We are already signed up in PA, CT, NY, NJ, New England (Boston) and most recently Minneapolis.
Full details for United Way qualification are contained on our website or contact Greg Wisyanski for additional details or assistance.

Fundraising tips

Tasting party - any food or beverage that you have an interest in or craving for can become a fun event to raise money. It can be beer, wine, cheese, chocolate, desserts, whatever. You can have it in your home or go big time and rent a room. Folks can bring items or you can get donations from vendors. Indulge yourself and support a good cause at the same time.
- Garage/tag sale - the next time you look around and decide you have accumulated too much stuff, have a garage or tag sale and donate the proceeds. Remember that your junk is someone else's treasure.

Handicap License Plates

In most states, children with AHC are considered "handicapped" and eligible for the special parking tags that hang from the rear view mirror. If you have not already obtained one, contact your Department of Motor Vehicles and ask for the form. Most require basic information (name, address, etc.), a diagnosis, and a doctor's signature. There is normally a little or no cost to obtain these tags.

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

Remember.....

-Disney World, Florida - We are still planning to have a family "Convention" in the fall of 1999. Many families have responded or inquired. We will have preliminary information in the January newsletter with the final agenda in April.
-Tapes of the 1997 Symposium, are still 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.
- 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

The e-mail address to send notes to the AFHA/AHC bulletin board has been changed to AHC@challengenet.com.
If you are not receiving messages from the bulletin board, you will need to subscribe again. Send an e-mail to pjourda@worldnet.fr
Also, when replying to the bulletin board, address TO or CC AHC@challengenet.com because otherwise your answer will only go to the person who posted the messge.

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