
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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Editor's Note

Dear families,

As we approach the new Millennium, I am struck by just how far we have come in the last five years. Nine years ago, I knew none of you. Today, we are in touch with each other from around the world by the wonderful medium of the internet, as well as the traditional mediums of telephone and letters. I am thankful that our children were born in this part of the century because of the advancements in technology and medicine. And because of these advancements and because of your involvement, we are closer to attaining answers to AHC.

Dr. Ptacek is gathering our blood samples. Eighty families must participate to start the project. As of December 8, 1999, 73 families have returned their kits. Over 20 months have passed since this project was announced. How is it that we have allowed ourselves to become 'so busy' and complacent that we cannot make time for a simple blood draw?

After all of the tests we have put our children through, isn't it up to us to participate in this project that may make a difference in our children's life?

Please, if you have not participated, pick up the phone and order a blood kit from Dr. Ptacek's office or if you have the kit already, call and make an appointment today.

I want to thank many of you who e-mailed or called me to make sure everything was ok with Kathleen and my family when the June newsletter did not arrive and especially to Rosaria who wrote ".....But above all I hope that you have not lost the courage and the enthusiasm to support the families and fight against AHC, that would be a real loss for us all....."

CHANGE

We will be publishing the newsletter twice a year, May and November. Submission deadlines are the 10th of each month.

That was it! That is what woke me up! I realized that I still want to be involved. I still want to help, fight and continue to search for the answers to AHC.

We have families to raise and special children that need us. But also remember that you are each part of an "elite" group and that we are bonded together by our children. What you do for your child, you do for us all.

Please continue to correspond. Keep us all up to date on how and what is happening with your child(ren). We learn from each other.

I wish each of you the happiest of holidays and to a wonderful, healthy New Year!

Lynn Egan

This newsletter is sponsored by
Marino & Lorenza Vavassori
grandparents of
Alberto Di Naso
Sernovella, Italy
&
Martha MacKay,
In Loving Memory of her husband
John (Jack) MacKay, Uncle
of Jake Sproul
Gibsonia, PA, USA

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Foreign Affairs

A.F.H.A. - Association Francaise de l'Hemiplegie Alternante.
The french annual meeting of families, May 29, 1999.

This year, 10 families attended the meeting, as well as 5 guest (among them a professional teacher for disabled children and a journalist who wrote a large article about the meeting and the association in a regional newspaper).

No doctors came on this meeting, as they were too busy, and most probably because they have no major news to share with us.

Three professionals were invited to come in order to deal with the following topics:
* Savings accounts proposed for disabled people to prepare an additional income for their adult life.

* Different kinds of financial help for parents having a disabled child - list of specialized centres (or schools) for disabled people taking into account their age, intellectual and motor levels of development (as there are large differences among AHC children)

* A physiotherapist explained the best gestures and the useful precautions to take when moving, lifting up or down our kids during an hemiplegic or hypertonic attack, especially when they become teenagers or even adults. His presentation was interactive as he made families actively participate. This part of the meeting was particularly appreciated.

The next part of the meeting was devoted to proceed with the drawing of the winners of our first raffle in order to raise some money. The final result of the raffle was given by the children themselves to their parents, with a profit of \$8,000 (47.000 FFS). The first winner received a weekend in 'Center Parc Resort' for six people, the second winner received the telephone-fax, the third winner received four tickets for a day at 'Eurodisney Resort' and many other prizes were drawn.

We decided to use the money for three goals:

1. Distribute leaflets about AHC to many professionals in France.
2. Participate to the travel costs for the families who attended this year's meeting, and to help them to buy some specialized hardware like an armchair for example.
3. Provision a special account to be used for any AHC project.

The last part of the meeting was devoted to review our actions and goals for the next year; so we voted three main goals:

1. Participate in Dr. Ptacek's genetic study by sending our blood samples ASAP to complete the minimum number which is necessary to be able to start the study (around 20 French families, which means that 90% already returned their agreement sheets). We expect to have all kits returned to Dr. Ptacek's office by the end of September.
2. Keep on having very close contacts with the other European families; England, 19; Italy, 9; Germany, 15; Sweden, 1; The Netherlands, 2; Spain, 1 and France, 22.
3. Do our best to convince European doctors involved with AHC of the necessity to establish a European scientific board for AHC which could be able to define common projects to perform more studies on AHC. Moreover, we also spoke about the idea of organizing in France an international meeting to gather the most possible families. This project could take place for two days in April or May, 2001. Of course, doctors would be invited. On this occasion, they would be able to meet a lot of children and their families and share their projects or/and results.

Full version of the French meeting will be available on our Website: www.afha.org, by the end of September.

Take care,
Dominique Poncelin
President of A.F.H.A.

Midwest Gathering

Our first Midwest Gathering of AHC families was a huge success. Thirteen families attended including many grandparents. It was very heartwarming to see all the children together in one place. Even though they are all different in many ways, you can really see many common characteristics. It was especially nice to meet the two older children who attended Terra, 18 and Rob, 17, and see how well they get along. They are really great examples.

The blood draw for DNA testing was also very successful. We got samples from 5 families. The lab at Utah was very happy to receive so many. WE need to give a big thanks to the IFAHC for paying the cost of having the blood drawn.

Dr. Silver and his wife joined us for the day. He gave an interesting slide presentation and answered all questions. We are very grateful for all he does for AHC.

Richard George discussed the different grant proposals on the table and gave some fundraising ideas. We thank the AHF for paying for some of the refreshments and snacks and lunches for our guests.

Everyone in attendance agreed that we should meet again next year. We are trying for the same weekend, but to not have confirmation yet. We encourage families in other areas to organize a regional get together. Anyone who need help or advice, please call us at (815) 857-3585.

Your friends, Carol & Kevin Prunty

Families in attendance:

Carol, Kevin, Mary, Rachel Prunty, Amboy, IL
Cindy, Dave, Michael Rachel Ryan & grandparents, Winchester, IL
Carrie, Edward, Haley Dehn, Bluford, IL
Laurel, Robert, Rob Castanedo, Palatine, IL
Naomi Rodriguez, Stephen Mahoney, Jessica, Jackie Mahoney, Chicago, IL
Jackie, Craig, Conner, Neola, IA
Richard George, Livonia, MI
Pam, Terra Bowman, Portsmouth, OH
Ed, Michelle, Megan Schultz, Warren, OH

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Moving Out!

by Nancy Samson, Dave's Mom

I would like to share my experiences with Dave moving on to a group home.

When Dave turned 18 years old, he was determined to go out into the world like he envisioned 18 year old males doing. The first 'group home' I looked at was terrible. The clients (as they are called) were much lower functioning than Dave and only one of them was verbal (Dave's I.Q. is about 87 and he is very verbal, like his mom he likes to talk, sometimes a little to much, again just like his mom!) We looked at another home that was about a two hour drive from our home in Santa Barbara. We decided on this house because the care providers seemed very open, friendly and caring.

At first the transition was very hard for Dave and me. I worried every night about how he would feel going to sleep and waking up in a strange place. He called me everyday and there were a few tears although he was still determined to make his way in the world.

As the months passed it got easier and easier and I did realize that Dave and I had made the right decision for him to move. I am now 50 years old and I realize that this transition is going to be a process that takes many years. I don't want to grow old and perhaps ill myself and have Dave concerned about what will happen to him. When I am old, I hope that he will have already made the many necessary adjustments.

He has been at his new home for a little over a year now and I am amazed at his growth in terms of maturity and in not being dependent on me. Dave and I are considering another move for him for two reasons. I would like him to be in the same town as his family and his present roommates are all over 35 years old and the work center that he is at has only workers 45 years old and older!

I found a wonderful home in Santa Barbara that has 5 young (!) fellows in it

that are very highly functioning and very, very social. The agency that runs this residence also runs a work center. Dave and I visited the home twice this weekend. The first time we had a tour of the home, met the staff and some of the residents. Yesterday we went for a social visit. Dave played UNO with a couple of the fellows and one of the staff members present and although some of the residents are so independent as to go out and about by themselves, that would not be true for Dave, so there will always be someone to take him places and be with him on weekends.

At first, he was very hesitant and resistant to consider a new home although he wishes to move from his present one due to the age of the other residents. It took a little nudging on my part but once he saw the home and met the fellows he became quite excited about the move.

I would imagine that Dave will go through a few more moves before I am old and gone, so this is really a great experience for us. If you are considering a home in the future, I should warn you that it takes months and months of homework, i.e. looking at homes, getting the applications in, so you should plan at least six months to a year in advance. Don't be discouraged about the first home, if you don't like it...it is very similar to looking for a home to purchase, you won't like everything you see but there will be something out there, so just keep looking. Agencies might be better than a home owned by an individual because they have other sources of funding and are less likely to close.

All and all, Dave is in a better place in his life since he left his family...he has grown up and actually has less focus on his AH. The staff at his home and work take his episodes in stride and his illness is really no big deal for them. His family tended to be very emotionally caught up with his illness.

Now that Dave is in a work setting, I have taken time to reflect back on his

education and ask myself if we put the emphasis where it should have been all those years. My answer is no. As Dave is limited with what he can do with math and reading, the job market is going to be extremely limited for him. I wish that we would have had put more emphasis on people skills because that is what you need to be able to make it away from your family. Dave will do fine with that and I think I did do a great job in his growing up, i.e. friends, manners, etc. But I now see how very, very important that it is to any individual who is developmentally delayed.

If any of you ever want to come out here to Santa Barbara and see Dave's home and where he works, don't hesitate to call. We have a room in our home and of course, this being the resort town that it is, there are wonderful hotels/motels here. I would love to host a winter reprieve for some of you snowbound folks! Please email any questions or comments to me at samson6@silcom.com Hope this was of some help! Happy Holidays!



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

INTERNET CORNER

The Internet Corner is very long, 10 months worth of questions and answers and exchanges of information.

"My daughter Jenny is 11 years old and has AHC. When she was little, and before Flunarizine, she had many more severe attacks. Things quieted down after we started on Flunarizine which was over 3 years ago. Lately, we are seeing more and more migraines, paralysis in mostly the left leg, sometimes both legs, and a couple full body attacks with loss of speech and responsiveness. Has any one else been on Flunarizine for some time and started to see it lose its effectiveness? What next? She is spending more and more time in the nurses office at school. When Dr. Zupanc was here in Minnesota we saw her yearly (she is the one that diagnosed her after 6 years of misdiagnosis from other doctors) and she said that Jenny was one of the better cases she had seen. Now I am starting to see this change. Also, I was real spoiled having Dr. Zupanc here. What do others do that do not have a doctor that is real familiar with the disorder where they live? We do have a neurologist in Minneapolis that actually sees the two other families from Minnesota with AHC but I don't know when I should be seeking more of an expertise. I appreciate any ideas and input."

Marcia - Feb. 3-

"I am Nandana Vishwa's father. My son is the only case of AHC in Sri Lanka in a population of 17 million. Vishwa is 9 years old and we experienced the same problem after 1 or 2 years of Flunarizine. Then we talked to our doctor and at the same time wrote to Prof. Jean Aicardi (whose name appears in the medical advisory board of IFAHC) and explained to him giving the details of the episodes and how they progressed as time went by. Prof. Aicardi suggested that the dose Vishwa was receiving (2.5mg) at the time was insufficient. We then increased the dose to 5mg. and then after about 2 or 3 years increased it to 7.5 a day and he has been doing extremely well for the last 3 or

4 years. May I suggest that you first find out if Jenny is receiving the correct dose of Flunarizine?

One more thing that really improved Vishwa's condition was the introduction of Clobazam and since recently we have got extremely good results with Clonazepam. I read recently that Prof. Aicardi has also found Clonazepam to be effective in two cases. Well, as far as Vishwa is concerned he has improved so much after we started him on the combination of Flunarizine 7.5mg a day and Clonazepam 2 mg. a day in two divided doses. When I last contacted Prof. Aicardi he was attached to the Great Ormond Children's Hospital in London but unfortunately I do not know where he is now. Maybe you should talk to your doctor about it and maybe try to get in touch with Prof. Aicardi. Although Flunarizine has been named the drug of choice by the neurologist all over, Prof. Aicardi has reported in one of his research papers that the two drugs Clonazepam and Phenytoin has proved effective in occasional cases. So I think Vishwa can also be included in those "occasional cases".

Wish you all the best in search for the treatment"

Nandana - Feb. 4 -

"Jenny is presently taking 15mg. of Flunarizine per day. She weighs a little over 50lbs. We tried increasing her dose and she became so tired she could not function. I spoke with her neurologist today and we may try to introduce a drug for her migraines to see if we can cut down on those. I thought he told me Inderol but when I sent to the pharmacy to pick it up they had filled it with Periacitin. I know this was not correct so now I have to wait until tomorrow to try to straighten it out. Does your child get tired a lot? Jenny sleeps almost 12 hours a night and needs every minute of it. Many times at school she sleeps when she goes to the nurse. Thanks for your information, I will share it with the doctor when I call him."

Marcia - Feb. 4 -

"Our son is 12 and takes 15mg. of Flunarizine each day. We give it to him

at bedtime because when we gave it to him in the mornings he was tired all day and wanted to sleep a lot. But now he is active all day and sleeps good at night. You might try this with your daughter and see if it helps. Good luck..."

Donna Busby - Feb. 5 -

"My daughter Erika is 17 years old and she was diagnosed with AHC when she was 7 years old. We are living in Mexico and here nobody knows much about AHC. We think that she is the only case here. After the diagnosis Erika started to take 5mg. of Flunarizine every day and we observed that the crisis(attacks) decreased but her legs were paralyzed and rigid when she walked, we don't know if this was a consequence of the medicine. Actually Erika's weight is 105.lbs and she is taking 10 mg. of Flunarizine before sleep at night. In order to avoid the crisis during the day, Erika has to sleep 10 to 12 hours and be in a relax and quiet environment with no emotions or facts that cause Erika's exaltation. This is the reason why Erika is not going to the school and also because in Mexico there are no schools she can get help or special attention or privilege.

I just want to share my experience with you about Flunarizine and I hope you'll find the right doses for Jenny."

Leticia - Feb. 12 -

"I hope everyone is doing fine. I have been out of touch for a while because of relocation from California to Minnesota. I feel good to be in touch with everyone once again."

Nahid - Feb. 15 -

"Welcome to Minnesota, we have spoken on the phone a few times. How is Waleed? We have been battling many migraines and some larger attacks since we talked last. What is the vitamin that you said you give him that helps protect the brain? Has this been recommended by doctors and does anyone else use it?"

Marcia - Feb. 21 -

"I hope that this message finds you all in good health and peace of mind. I have been out of touch for sometime due to

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INTERNET CORNER

(Continued from page 5)

relocation. I can't tell you how alone I felt not to be in touch. I am thankful for my family but also for being in touch with people I have never met but yet share so much with them. Since I logged on, I have not received or seen any messages for at least two weeks. At first I thought I subscribed to the wrong mailing list and I had to re-subscribe. I hope that the silence is nothing serious. We need to keep in touch for the sake of our children who brought us together. I learned so much from reading your letters. Even if they seemed insignificant I still learned a lot. There are times when I felt sad and found comfort in reading your letters. In return I passed the comfort to my family. I miss all that we have shared. Please let us communicate to one another about how the children are doing. We are so few in this world and strength is always in numbers. I know that most of you are busy, but even a simple note once a week would be fine. Let's not lose what we have accomplished by finding one another. For now, I will say, talk to you soon. With the most sincere and warm greetings...."

Nahid

- Feb. 24 -

"I totally agree with you... it is a great chance to have the possibility to be in contact through the mailing list.

Aurelie is in good health these days so I have not so much to write these days....

You are right, I am so busy. I am currently working only for one boss. I thought I would have less work but the contrary happened as I have to collect a lot of information on our key clients. I have also several matters to deal with for the AFHA. Our latest newsletter is going to be posted soon on our Website. I have to finalize the translation Alex Cole forwarded to me a while ago."

Mirjana

- Feb. 25 -

"Yes, I agree that we should keep in touch. It means so much to hear that others are living similar lives to our own, even if in a small way.

Jake has done well. He continues to have

one really bad day a month where he is unable to do anything. Almost everyday he has a dystonic attack, which can be short and mild or long and agonizing for him. He is learning to adapt, as are we. I just wish there was some way to make him understand that quiet will help an impending attack, but sometimes I think that he cannot help getting wound up. Sometimes he will cry inconsolably for a long time, and then I know that he is going to have a bad attack, and he does. His hemiplegic attacks are not that bad, it is the dystonic ones that bother him the most.

His speech has really improved lately and he really enjoys school."

Becky Sproul

- Feb. 25 -

"I've been appreciating all the information families have been providing on their experiences. Our son Alexander is now 21 months and has attacks every 11 days that last anywhere from two to five days. His last few have included full body attacks that can last for two days. These are the most difficult for us, especially ensuring he gets enough liquids. However on the good news front, Alexander still continues to develop with the help of early intervention. He is not yet walking but loves to climb. He has figured out animal sounds with the cow being his favorite sound and he doesn't hesitate to go after what he wants when another child has it. In other words, he is all boy."

Carol Presunka

- Feb. 25 -

"Thank you so much for your reply. I am so glad to hear from you. It must be very tiring to balance your work, home and AFHA. May god give you the strength. It is wonderful to hear that your daughter is doing well. Waleed has been steadily progressing. At this time of the year is very difficult because of the flu that is going around. He has his good and bad days but a lot of soups and fluids really help. I hope to always hear from you."

Nahid

- Feb. 26 -

"It is so wonderful to hear about Jake and his accomplishments. Your constant notes about him have always provided strength for me.

Waleed hasn't had a long episode for quite a while (thank GOD). However, he continues to have little episodes of eye movement and hemiplegia on either side but will only last for a few minutes until he goes to sleep. When his therapists see him in this condition, they feel so sad. I can see it in their eyes. I think that I have become used to seeing him this way. I try to stay as positive and cheerful as I can. That makes a big difference with him. He starts to smile and drift to sleep. When his eyes roll, I tell him 'Wow, Waleed, it must be hard for you to have your own roller coaster and he laughs. That makes me happy to know that I can communicate with him in his bad days too."

Nahid

- Feb. 26 -

"Alexander seems to act like my son. Waleed is 2 years and 4 months. He does a lot of climbing too. His greatest problem is balance. It is improving. He still doesn't walk independently. However he has the determination. He used to have a lot of full body attacks and we increased the Flunarizine by half a tablet. He takes 5mg each day for 3 days and then I skip a day and give him 5mg for 2 days and then skip, then back to 3 days. The slightest increase makes a difference for him. When he is having bad days I resort to feeding him pediasure. His appetite is not great and therefore I mostly depend on the pediasure."

Nahid

- Feb. 26 -

"Let me start off by saying that he is fine. The other day Waleed had some food in his mouth and got upset with his brother and then he started crying. Needless to say that he choked and we had to call 911. Immediately after that he had an episode. Of course, no one knew anything about AHC. Whenever he has a full blown episode his breathing pattern changes. The paramedics thought that they were losing him. I, of course, knew what the deal was and didn't panic. They found that WEIRD! When we got to the hospital, I could hear all the whispering 'did you ever hear of this before??' Now I was caught in the middle of explaining and putting him to sleep so that the

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INTERNET CORNER

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episode does not get worse. I couldn't do that because they thought that sleep is not a good idea. No matter how much I explained they didn't listen. Anyway, I probably should take the newsletter with me the next time we ever go anywhere. Sometimes I feel that the hardest part is the explaining. Looking back, the scene with the paramedics was like a scene from the movies."

Nahid

- Feb. 26 -

"Jayme is having a good stretch right now. He has gone 24 days without an episode at all. He doesn't usually go that long. We are enjoying the 'break'. I am sure he is too. He told me the other day the next time he is 'limp' on both sides to please scratch his nose once in a while. I couldn't believe it. I asked him if he itches any where else when he is 'limp?' and he said sometimes. How terrible to have an itch and can't scratch it. So now something else for me to worry about during an attack. He sure loves school. He is 12 and still in an elementary school setting. Which is were I feel he is the safest for now. He is real small for his age (about 45 lbs.) and not very tall. So I feel he isn't ready for middle school, which is fine since he is still doing third grade work and not ready for middle school. He only gets to stay one more school year in elementary though. He will be 14 when he goes to middle school so we are hoping for a growth spurt. Well I hope the rest of you are all fine."

Donna Busby

- Feb. 26 -

"We went yesterday to the swimming pool with Aurelie and after half an hour, she started a strong left episode. She was so happy to be there with us. After a while outside the water she was much better and went again in the water. She went to sleep very early that day. The day after she had no episode until mid morning. Then she had several attacks during the day. She is with my mother for the holidays. I hope she is going to recover soon."

Mirjana

- Mar. 1 -

"We too have had similar experiences with water. During the last few summers, we have attended a public pool and found that when Kathleen is in the water for five to ten minutes an episode will start. We take her out and as soon as her body temperature warms up the episode ends. And then when we visited the lake last year, I think that only one time did she get an episode??? I wonder if the 'stress' of body temperature sets it off. When she was little even a bath would set her off. Thank goodness that has changed.

For now we are doing very well. We increased her flunarizine to 12.5 (from 10mg.) daily and that seems to be a good dose. Her speech is improving, for which I am thankful. It still is hard to understand her at times, but over all I am feeling happy with where she is. School as always, agrees with her and as of this next school year, she will be going year round. She will have six weeks this summer and three-three week breaks during the year (October-December-April). I think it will be great for her, as summers have been long. We have her assessment(IEP) coming up the first week in April so I am anxious to see how the school evaluates her progress.

I have a few questions. Have you had the hepatitis series done for your child? Have you ever had flu or pneumonia shots? Did it prevent them from getting either of these? None of my kids have had the hepatitis series and it is mandatory for my son who is going into the seventh grade. As for Kathleen, I get nervous. The flu this year has been awful. We got lucky and Kathleen only got a twenty-four hour flu.

My other question is about teeth. Because of the flunarizine, Kathleen's gums are swollen, however more on one side than the other. The teeth on the more swollen side are also more crooked. Enough that I would possibly consider braces in the future. Anyone with similar teeth or have had braces? So far Kathleen has had all of her dental work without novocaine and her tolerance for pain(all kinds) is high. So we will see.."

Lynn

- Mar. 1 -

"Just read your note and thought I might answer. There should be a handbook

outlining all the things parents may expect at certain ages. Although it is recognized that each person is unique in her/his response to AHC, there are enough common things to help parents to better cope. My daughter, Juanita, who is 32 went through the same reactions with respect to baths and pools..., late language development etc. Her present biggest problem is not the paralysis but rather the seizure type activities, sometimes culminating in a total body seizure. Those total seizures can have long lasting after effects and should be suppressed if possible. The paralysis does not seem to have lasting effects."

Dick Van der Baaren - Mar. 1 -

"Jenny is due for her last shot in the hepatitis series and has not had a problem. I was quite worried as her very first attack came after her first DPT and any new shots bother me but no problem. She has also had braces, wore them for two years and now only wears a retainer at night. With everything she has gone through, they were a breeze. I honestly do not remember her complaining. It was a lot of work for me though, I did all the brushing so she would not have damage when they came off, you have to be very careful or the teeth can be stained or pitted if not kept clean. She now still likes me to brush her teeth so I have continued, seems weird to be brushing teeth for an 11 year old but I figure along with everything else, I still have to do for her, why not. She will only be better off for it. She will more than likely have to wear braces another round in the future. Her mouth was so small she had no room for her teeth."

Marcia

- Mar. 1 -

"I'm pretty sure that Abbie (age 9) will be a candidate for braces. But, like everything else, I'm sure she'll handle it like a trooper. I too have to brush Abbie's teeth for her to make sure the job gets done right. But, I do have her do it for herself each time for a few minutes and then I take over.

She had some dental work done last year where she had to go under general anesthesia — she just wouldn't cooperate

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with the dentist when we tried it without so, she was admitted for 'day surgery' and the dentist filled two cavities and did a thorough cleaning, x-rays, etc. all at once while she was asleep. I'm not sure I would recommend this as the way to go—she did not react well to the anesthesia and awoke very upset and terrified. Luckily, my sister-in-law is a hygienist, so we go to her now for all her cleaning and check-ups and Abbie has been doing fine."

Kathy

- Mar. 2 -

"My son Waleed (2yrs), will be having surgery by the end of the month on his teeth. He has lots of cavities and since he is very young,, he can't sit still for the dentist. I wonder if anyone has had a similar experience with their child at that age. I also wanted to know whether anyone has seen a difference with the shoe inserts that they recommend to our children at an early age."

Nahid

- Mar. 2 -

"Thank you so much...TJ is going to be seeing a specialist at the end of March (on his birthday no less) regarding being put under a general anesthetic to fill a cavity and take x-rays...what provoked this was not his age, it was the fact that he was having a bad day and went full blown in the dentist chair...should have seen the guys face when TJ did the posture thing..I always forget how scary it can look to someone the first time...

Anyways, he is having a much better week, and had a wonderful snowball fight at school today..He is so looking forward to his birthday (he will be 7) and has decided on a 'boys only' bowling party (including no mom)....."

Wendy

- Mar. 3 -

"It took me long enough to get back on the computer...I guess I don't have much time to spend on the computer and at night when Hailey finally goes to sleep I JUST WANT TO SLEEP you know that feeling...she still at 2 yrs does not sleep through the night..anyway of course

Hailey is having a bad episode today so maybe that's what brings me to the computer...but I do agree I miss not being able to turn on the computer and something being there...bear with me if this is messed up. I have Hailey in one arm...I think that is one of the things that makes it so hard to be totally dependent on me...sometimes I know it might sound mean but I just feel like give me a break ya know...about braces that's what I do for a living so if anyone has any questions just ask me...I also work for a children's dentist so you can ask me those questions too..and thank God when Hailey needs dental work done they are all friends of mine..that's a big help...so the poor kid I'm already crazy about keeping her teeth clean like she needs that on top of everything else...also about shots, Hailey is up to date with everything except we just started the Hep. B. She got one so far and will get the 2nd in 2 weeks...we also just did the DT instead of the DPT because Pertussis is know to cause seizures..other than that she even had the chicken pox vac. and everything is all right...Oh well sorry for chewing your ears off believe me I could go on and on...you know how you get when they are sick...

Mindy

- Mar. 4 -

"I just wanted to tell everyone that during Christmas I wrote a letter about Hailey and asked for donation...I didn't think much would come of it and it took all of me just to write it, but so far we have raised \$6,000.00 for the foundation...I'm only telling you this because it was so simple...I mailed it to a few friends and they mailed it and so on... Just a little thing to do to raise some money to help these kids...please lets save our children. Thanks."

Mindy

- Mar. 5 -

"Jenny was under general anesthesia for dental work this summer. She did just fine and came out of it fine so...just like any other kids, each one reacts differently.

Marcia

- Mar. 7 -

"Hello! My name is Yvonne Ockman. I have just recently logged on to the

bulletin board. I have been reading your letters and I think they are wonderful. I am the mother of a child with AHC. I learned about the bulletin board from Lynn Egan. Kristen is a 5 year old twin that was diagnosed with AHC when she was a year old. She had her first episode when she was 6 months old. She was being bathed by her godmother, and she noticed that her eyes were not right and that she was unresponsive. When I brought her to the doctor, they told me she was fine. Then a few weeks later she was in the swimming pool and it occurred again. This time her godmother knew something wasn't right. We brought her to a neurologist and they diagnosed her with a seizure disorder. We went along with this because we didn't know any better. These episodes occurred about 2 times a week. Kristen didn't develop like her twin, but every child develops differently. So we went along like this for 6 more months. As parents we felt helpless. The doctors couldn't explain why she would have no use of her limbs. Then we saw another doctor. This doctor, at the time was a fill-in for her regular doctor. He really blew our minds when he told us our daughter had a rare disorder called AHC. We were so afraid of this because at that time they didn't have much information about it.

We have come a long way since then. We have watched Kristen grow and do a lot of things they said she wouldn't do. I have had to fight to get her in school, and for her to be able to do many other things. We have had to fight mostly because people run away from the things they don't know about. Since AHC is not recognized as a common disorder, many people tend to be afraid of the unknown.

In February of 98 she was diagnosed with epilepsy after having a grand-mal seizure for an hour and a half. We now stop the seizures with Diastat rectal gel. For some reason they will not stop on their own. She is on flunarizine 5mgs twice a day, Tegretal 700mgs a day and Klonopin 5mgs once a day. We have finally gotten them under control. She has one about every 4 months. Her AHC episodes have gotten a lot better over the years. When she was young they would occur about 5 or 6 times a month. They were left and right sided.

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She wouldn't be able to eat or even speak for 3 to 5 days. The longest lasted 10 days. It would take her about 5 days to recover totally. She now has episodes about once every 4 weeks. Sometimes she will even go 2 or 3 months without one.

I enjoy all of your letters and hope you all continue sending them. They really help and encourage us all. I think it's great that we can communicate, after all we need to continue for ourselves as well as our children. Also our newsletters are a great enjoyment as well. Sorry for such a long letter, I tend to run off with things like this.

Hope all is well with all of you!"
Yvonne - Mar. 8 -

"I've been meaning to write for quite some time and finally got down to it. I am Carmelita, Vishwa's mother. Vishwa does not go to school now and is at home all the time. It's really stressful teaching your own kid, our expectations being too high, I guess. It affects our relationship and is not something I would advocate to any parent.

Vishwa is a very complex character. In some areas he is really very bright and intuitive, while at other times I cannot believe it's the same child. At any rate I think we have not been able to reach the maximum potential with him. All I really want is for us to help him to do the best he can. We're fortunate in that we seem to have reached a plateau with regard to AHC, the attacks are very much milder now. When I read some of the letters on the bulletin board, I remember how it was for us too, and I dread the thought of it recurring.

We're trying to start a school for kids with learning difficulties and it's really a challenging project.

Sri Lanka does not have any such academy to cater for children with specific needs, although there are many options available for the high handicapped. So this effort is specially for Vishwa and other children who have dyslexia.

Please write and tell me all about Jayme,

what he's like, things he likes to do and the problems he faces would really like to know."

Carmelita - Mar. 9 -

"Re: hepatitis shots -Our Margaret, who is 17, had the shots without any difficulties. Re: change in temperature bringing on episodes - Margaret has always had episodes shortly after getting in a pool. Even if the weather is warm, she seems to get chilled quickly, which brings on the episode. Same for going outside in winter to enjoy the snow. Re: teeth - Margaret has swollen gums, but we have always been told it was because of Dilantin. Maybe flunarizine is also to blame! Margaret needs braces on her teeth, but she has so many episodes these days, that it would be impossible for her to get to all the necessary appointments involved. Life is complicated enough.

Janet Kilpatrick - Mar. 11 -

"Hi, my name is Jenny Perkins. I am 11 years old and I have AHC. I was wondering if there was anyone out there my age that would like to write back and forth. Please write to me if you are interested. Also, if there are any parents with small children with AHC that would like to ask me a question about what it's like, I will answer your questions. Hope to hear from you."

Jenny - Mar. 17 -

"Hi Jenny, it's me Mohammed. How are you feeling? How does it feel to have AHC? What do you feel when you get sick? When I see Waleed sick I don't feel good. do you always feel sick? Do you have a brother or sister who help you? What can I do to my brother when he is not feeling well? When you are feeling well how do you feel? My brother has a very bad cold and he is not feeling very well. My brother is very cute and I wish he could become better and never get sick again. How does your medicine taste like and what do you feel after you take it? Do you get headaches? Does it feel painful? My brother sometimes gets into a laughing mood and he laughs without any reason. Do you feel that way sometimes? Anyway I wish we could meet soon."

Mohammed - Mar. 18 -

"Hi, Richard, thanks for writing to me. Before I have an attack I don't feel anything before it starts. When it starts I feel weak and usually my left leg quits working. Sometimes both of my legs quit working and my mom or dad has to carry me. Sometimes it happens at school and my teachers and school nurse take care of me. It doesn't hurt, it feels like it's asleep. When I have bigger attacks, I get sick to my stomach, get real sweaty and fall asleep. Sometimes I turn white and gray and can't talk. When I have migraines my head hurts A LOT! Sometimes I throw up. It always helps to sleep. Say hi to Nick and tell him I have a brother named Nick.

Jenny - Mar. 18 -

"Hello to everyone! Two days ago (March 17) it was my son Alberto's birthday: he is six years old now and I can hardly believe that we did it so well until now! It is a good period for Alberto, he has not had a complete attack for a whole month! Only some left hemiplegia which lasted no more than an hour.

Alberto was AHC diagnosed in April 1997, when he was four, and since then he has been taking flunarizine with great results.

He is now attending his third year of kindergarten in a special school inside a big medical and rehabilitation centre where he is also doing phisio kinesis and speech therapy. This should be his last year of kindergarten but we decided to have him attend another one before going to the elementary school.

Attending a special school didn't make life easier for us. The first year, when Alberto was three, we didn't even know what was his disorder. All the doctors were sure that it was epilepsy and didn't want to hear anything about making him relax and sleep...just rectal valium, EEG's and blood drawings which scared him to death. The second year we finally got the right diagnosis but still the doctors of the centre didn't know anything about AHC and thought we parents were crazy when we talked to Alberto while he was completely

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paralyzed and cheered him up by making faces at him and telling funny stories in order to make him relax. Result: Alberto kept on having bad and long lasting attacks at school almost every week and had to stay at home for many days to recover from them.

I began to bring all the information about AHC I was collecting from Internet and the news I was receiving from the foundations in the USA and France to the doctors and the teachers kept on insisting on their reading them.

And finally at the end of the second year the doctors and the pedagogists got to understand something about AHC and about physical and emotional efforts triggering the attacks so they proposed to us a reduced school time for the following year. Therefore this year Alberto stays at school from 9:00am to 1:30pm instead of 4:00pm and during the recreation time after lunch he sits with one of his teachers in a quiet corner reading books or playing with her.

And this seems to work: Alberto is attending the school regularly and this compensates abundantly the shorter school time. Until now he has not had any attacks during school time and all the teachers are enthusiastic about his improvements.

He can't walk independently yet but his physiotherapist has just started to work on it with encouraging results.

As for flunarizine, we didn't notice any meaningful side-effect for Alberto with the exception of a slight worsening of his tremors. But since last August he has been taking also 150mg of triptophane (a precursor of serotonin) each day in addition of flunarizine. According to us this drug is contributing a lot to further reduce the frequency and the duration of the attacks and is also relieving his movement disorders (tremors and lack of balance) a little so we are going on with it for another while.

Sorry for this long message of mine. I just wanted to share a piece of our story with you.

A big kiss to your children and greetings

to all of you."
Rosaria, Italy

- Mar. 19 -

"Even though my son is younger than your daughter, we still have the same problem. He would not go to sleep when he is uncomfortable with his surrounding. I also found out that when I am uncomfortable or stressed with something and he gets an episode, he does not sleep easily. I believe that he senses my frustration and fears to go to sleep. Once I discovered this I try to get myself into a relaxing mood and I don't concentrate in putting him to sleep so much. Instead I try to make him laugh or do something that he likes.

Sure enough I begin to feel him relax and drift off to sleep. When your daughter is at school and has the episodes, maybe he senses the uncomfortable atmosphere around her and of course wouldn't feel comfortable to go to sleep. My suggestion is to try to treat her as normal as possible even when she has an episode. Even if she doesn't go to sleep she will at least feel comfortable and less stressed. This has really made a difference with my son an ultimately with me. Our kids need to feel love and security all the time especially when they have an episode. I hope that I was helpful in some way."
Nahid

- Mar. 25 -

"My son is almost 13 and when he has an attack at school he has a quiet place he is laid down with a blanket and away from other children that might accidentally step on him. He lays there but he rarely even goes to sleep, especially into a deep enough sleep to help his attack. But he lays there and rests and a lot of the time that is enough to get him back on his feet for a little while anyway. If he cries though like he is uncomfortable the school calls me and I go get him. Thankfully my job allows me to be flexible, about 10 years ago I started my own house cleaning service so I could have my son with me when he can't go to school. I don't use chloral hydrate on him since for now he usually falls asleep pretty quickly if he is in the car or his own bed. If he doesn't fall asleep we sit him in the recliner in the living room with the rest of us so he doesn't feel isolated.

I think sometimes he gets tired of sleeping. If your daughter is feeling embarrassed or anxious at school about her attacks then that could explain why she can't sleep there. Also has she always had daily attacks at school or is this recent? Maybe there is something stressing her at school that is causing it daily, routine change or teacher change possibly. Good luck, I hope this helps."

Donna

- Mar. 25 -

"We are also having problems with Jake and his having attacks at school. Jake started flunarizine last March and his attacks have decreased a lot. Until last week, Jake had not had a major attack at school since going back in September. His attacks have been 20 minutes max and pretty mild. He got a sinus infection which really threw him for a loop. I have been called 5 days out of the last 6 because Jake had a bad attack at school. One time, they were ready to call an ambulance. I calmed them down over the phone and went to pick him up. By the time I got there, he was completely back to normal. I guess because we are used to it, we think that they should be able to handle it. Jake even attends a private school for handicapped children. One of their biggest concerns is sending Jake home on the bus. While it is frustrating for us (I certainly can't afford to leave work all the time), I think that it is pretty frightening for those who haven't witnessed it before. Also, this is someone else's child in their care, what if something went wrong?

Today, Jake again got very bad at school and they were afraid to send him home on the bus. His bus driver is very capable and I told the school that if she felt uncomfortable transporting him, then we would pick him up. As usual, he fell asleep on the bus and was fine by the time he got home. He had another bad attack that waxed and waned until he went to sleep about an hour ago.

We have found that with Jake it is best to try to divert his attention. He loves watching home movies and having books read to him. When it gets real bad, I take him into a room, close the door, turn out the light, play soft music and rock him in

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a rocking chair. Sometimes all it takes is some really quiet time to help relax him. As Nahid said, a relaxed attitude really helps. I have to forget about dinner and dishes and all the other things that need doing for a while. Sometimes just going for a ride or putting him in his chair and taking a walk helps him. I believe that you once said your daughter is small for her age but it must be awful hard lifting her all the time. I know that my back aches from all the lifting. While it is true that sleep makes it go away, Jake fights it so much that we have found that its best to try not to force it.

That seems like an extremely high dose of chloral hydrate. Do you give her suppositories? Another family that I know of uses rectal valium to help their daughter. That helps a lot with the 'twisting' or dystonic posturing. More than anything, that is what Jake hates the most (us too!) He screams when that happens and the sound just rips right through you. Drugs like valium, ativan, and Klonopin can help with the dystonic posturing but they also have a sedating effect. Jake has dystonic posturing almost everyday and it can occur without a hemiplegic attack. We are looking into starting medication to help lessen these attacks. Sometimes it can just affect an arm or a leg or both, but it is really uncomfortable for him.

Sorry this was so long. I hope I answered some of your questions, but feel free to email if you want to know anything else."
Becky - Mar. 25 -

"I would be interested to know exactly what steps care givers take when a child is having an episode. Our daughter, 17, is having episodes almost every day at school. During these attacks she is fearful, cannot walk, is weak on one or both sides of her body, has enlarged pupils, has slurred speech or no speech, always tried to get her to go to sleep, but this is getting harder to do. She is getting the maximum dose of chloral hydrate (2500mg if my math is correct) four or five times a week, just to

help her settle down to sleep. Even with this, she often does not sleep at school, so I am called to take her home. When she has attacks at home, she often wants us to sit with her until she can sleep. When she was younger, she seemed to be able to get to sleep faster and easier.

I know of one mother who has her AHC son remain in class, seated in a wheelchair, during episodes. Other writers to this bulletin board have mentioned that their child can carry on to a certain extent, when having an episode. Besides that fact that our daughter seems so miserable, I thought that since sleep is the only way episodes get stopped, and because episodes may cause cumulative deterioration, it was necessary to try to get her to sleep. However, I'm starting to wonder if there is some other way of dealing with it. I'm having to take a leave of absence from my job because the school does not want the responsibility of looking after her once the maximum chloral hydrate dose has been given and the episode has not ended. Does anyone else wonder if there are some psychological aspects to these episodes?"

kilpatri@worldchat.com

Don & Janet Kilpatrick

214 Hendrie Ave.

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- Mar. 25 -

"We do not use sedatives for Greg, just any relaxation method that works at the time. When we are trying to get him relaxed and he won't fall asleep we try to at least get his eyes closed either by holding him very close or even just lightly holding a hand over his eyes. He'll generally calm down then, but unfortunately it does seem like he has to go through a bit of posturing, etc. to get it out of his system. The longer its been since his last attack, the harder the next one is. It's like he stores it up or something and all the bad energy has to be released.

When he is starting to have an episode, for example, one side is affected and he is looking particularly shaky, we start making him comfortable with his favorite things. He has a favorite blanket and likes to hold small toys and fiddle with

them. Sometimes setting him up like this and leaving the room (and getting his brother out too) allows him to handle it in his own way. We can keep an eye on him from the doorway. Mostly he will calm down or sleep. We are lucky that the folks at school handle him and his episodes so well. We very rarely have to go get him (I think its been about 2 times this whole school year). We used to have to pick him up all the time. We all worry about our kids when they have these episodes but there really isn't anything that you can do that the folks at school also can't do. This is very much a challenge of dealing with AHC and I don't think that schools want to have to be bothered. If they send your child home all the time, aren't they interfering with their education? Don't you have a right to have your child at school and appropriately cared for? (Sorry, I'll get off the soap box — too many IEP's under our belts already!!)

Just to throw another question out, does anyone notice that their children do things that cause an episode? Lately, when Greg throws a tantrum it almost seems like he begins an episode. I don't think he starts the episode on purpose and it doesn't seem like he understands the effect the tantrum will have. Its tough dealing with these because we have the behavioral issue to begin with and the AHC thing at the end."

Greg

- Mar. 26 -

"Our son Kyle is 7-1/2 yrs old. We are fortunate in that the school is very supportive of him and dealing with his episodes. Kyle never leaves school even during his worst moments. In fact during the milder episodes, he seems to be more focused on his work and tries harder. Go figure. Kyle also has a wheelchair/stroller that he takes during his episodes to use if necessary. Often times he is less agitated by his episodes if he can watch other kids, even if he can't participate. The special ed classroom also has a bean bag chair, so if Kyle wants to sleep he is allowed to do so for as long as he needs, but he is not forced to.

We used to administer rectal valium to dissipate the severest attacks. As Kyle

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became older that seemed more awkward so we tried an oral dosage. It did not seem to help. We're not sure if the dose wasn't high enough or what, but we haven't pursued it in a couple of years. Almost embarrassing to admit, but a pacifier is our biggest ally right now. He is allowed to have it for the severest episodes and only at home and in the car. We really need to find something else because he is way to old and big for that, but we don't know how to make him relax other wise. Like someone else, we too put Kyle in a recliner or bean bag chair at home, so that he is physically supported and can participate with the family.

Best wishes to all. We continue to do well most of the time. However, the older the kids get the more difficult some things get."

DeAnne

- Mar. 27 -

"I would like to stay in contact with the family of 'Vishwa'. My brother's son has AHC and recently he started to get 'Clonazepam and first results are good. My brother is interested in how much of this medicine is best to give to his son depending on his body weight..

Please e-mail me at: promenada@hotmail.com. My brothers address is Dragomir Bozic, Dubovac d-4, 47000 Karlovac, Croatia"

Drazen Bozic

- Mar. 28 -

"Hi, everyone....this is my first time on the bulletin board..I finally got on the internet. David was in the hospital this past summer because he broke his back...he had surgery and was on blood thinner...for three weeks he didn't have any episodes. David usually has one a day. I am working with a neurologist who may agree to try David on an oral blood thinner. This might happen within the next month. I will let you know if we see any results."

Nancy Samson

- Mar. 29 -

"...I was reading the letters regarding our children having episodes while at school. Fortunately, Kristen's teachers

have only called once for me to go get her from school. They have been very good about keeping her there no matter how severe the episode tends to be. Her teachers are very understanding and supportive of her disorder. They are interested in learning whatever they can to better help her. When she does have an episode where she is unable to walk, they put her in a bean bag chair until she feels comfortable to participate again. She rides the bus to and from school everyday, but the school has provided her with a nurse who accompanies her to and from school on the bus. In the beginning, we used chloral hydrate to make her go to sleep, but after a year it quit working. As far as helping Kristen relax during an episode, she likes to lay in her bed and watch T.V. I have had to hire a lawyer to get Kristen in school and to make sure she gets the proper education and not to be sent home every day. The school provides the nurse. The nurse is equipped with a pager, two way radio, and a cell phone. She is at school all day. The school also has oxygen, etc. in case she has any affects which would require this equipment. This was not an easy task in the least. Once the school board saw that I was a persistent and determined mother, they provided what the law states they must provide for a child with disabilities to have an education.

On another note. Do any of the children (with AHC) suffer from epilepsy? I am very concerned for Kristen's health , because her seizures are so severe. If anyone can provide me with information, advice, etc. it would be greatly appreciated. We have an appointment Wednesday, unfortunately to try another medication to try to control the seizures."

Yvonne Ockman

- Mar. 30 -

"My son Alex is almost two and has had two seizures in his short life, about five months apart. We are hoping this is an exception not the rule. The first lasted about 1/2 hour after which the neurologist gave us a rectal valium in case of another attack. After five minutes of the second one we gave Alex the valium and he came out of it almost immediately. His arm stopped working temporarily but then he was back to normal. We also

upped Alex's phenobarbital level after the first attack. We're just waiting to see where this goes now."

Carol

- Mar. 30 -

"I am pretty sure with Jenny that the tantrum is the attack coming on. She seems to get irritated, sometimes for no reason, and very difficult to deal with. I always say in the back of my mind she is either going to have an attack or say she has a migraine soon and then it will be all over. So far I have always been right but who knows?"

Marcia

- Apr. 3 -

"Laura, I am just wondering whether you were referring to my letter of 3/25 when you mentioned that the 'laughing techniques seemed to abort the episode.' I have said that I try to make him laugh so that he can relax and finally go to sleep. I think that you have mentioned the same thing about the 'crazy tickling.' I will post the note I wrote once again so that if there is any misunderstanding, it will be cleared up (see 3/25)."

Nahid

- Apr. 3 -

"My son Alexander, 22 months, also responds favorable to laughter and tickling however he seems to get worse after the laughter episode. Relaxation also helps him recover occasionally however once he becomes active again the attack returns. This is such a complicated disorder, isn't it?"

Carol

- Apr. 5 -

"I have to agree with all of you! We have used laughter as a diversion to Kathleen's episodes since she was little. It does not make the episode go away by any means, however it changes, to be less intense. Also we change her 'environment'. When she was but 18 months, we were told by a therapist that by doing this, it diverted the attention of the episode to something else. Like going outside or even to another room in the house. As she has grown, this has become not as easy, so reading a book, or watching a favorite show or just putting on quiet music has helped.

Kathleen also will go through days of in

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and out, where she will stand up and tell me 'Its all done' and then moments later she is back in. I find these days much harder to deal with as I get very nervous that in her joy to be feeling well that she could fall and hurt herself.

Like all of you, we try to get Kathleen to sleep. But we gave up on giving her something because it didn't seem to work. The car still works the best for sleep but that is not always so easy. We are also trying to teach her to deal with them and relax on her own by deep breathing and closing her eyes. This too is not always easy or works, but we try. As for school, this year has been rough. In that I have had to pick her up many times from school because the episode will not release. They are very good about her staying but if it continues for more than two hours and she cannot eat, they call me. She is also working very hard and I wonder if the 'stress' of lessons just become too much. We are trying to come up with a happy medium....

Tantrums are something that go in spurts. But they always precede an episode! We try to stop those as soon as possible because it definitely makes a difference in how severe the episode is. But again, only sometimes we are successful. I believe it depends just how irritated Kathleen's system is. I try to think of myself and how I feel when I'm off and can't put my finger on it. I think for Kathleen, she can't express just what she is feeling and so the tantrum.

As our children become older, we are faced with a whole new set of issues. I wish there were a set of guidelines to follow...."

Lynn

- Apr. 5 -

"When Alberto (age 6) is going to have an attack, he becomes hyperactive, restless, even frantic. In the past I thought that it was all this intense activity that caused the attack and I always tried to block him, to force him to stop; on the contrary, I am now convinced that it is his own reaction when he feels that an attack is coming. Usually any brusque attempt to stop him

and make him calm down is self-defeating because he gets even more furious and upset and the attack seems to come more severe. Thus recently we have learnt to let him do his own way during these moments; sometimes we try to suggest a different activity, more quiet but equally amusing and interesting and we never force him to do anything that he doesn't want to. Many times this seems to work.

Recently he informs us even before the attack actually begins: he shows us his arms when it still seems to work well and indeed after ten minutes it gradually blocks.

Also when he has a bilateral attack and is completely blocked he strongly reacts to any attempt to make him do something he doesn't like. If he is relaxed and calm, for example when we read him a book or make him watch a home movie, he is completely floppy but he smiles, he follows with his eyes and he is willing to participate. On the contrary if he doesn't like the situation, for example because we don't pay enough attention to him or, even worse, we try to make him sleep taking him to the bedroom in the darkness, he immediately becomes completely stiff and shakes violently until we give up and find a more interesting activity. Making a trip by car or in the stroller sometimes works too. Anyway after two hours at most, he is so tired and worn out by the attack that he finally gets to sleep spontaneously.

Thus we don't yearn to make him sleep immediately anymore, like we did in the past. We also tried with drugs, rectal valium and Nopron (Niaprazine), but they didn't work at all, on the contrary they made him even more scared and upset and less willing to sleep. Now we just try to make him feel as comfortable as possible and turn his attention away from the attack."

Rosaria, Italy

- Apr. 8 -

"I tried to sign the guest book on the web-site but I don't think it worked. My e-mail is samson6@silcom.com. I am working with Dave's neuro to see if being on a blood-thinner will help his episodes. If any of you want to take a vacation in sea-side Santa Barbara you are welcome to stay at my home, you may even consider

going out to dinner while I care for your child(ren)! I e-mailed here last week and to Lynn. I didn't get a reply so I don't know if either mail was received. I would like the Kilpatrick's e-mail address. I'll keep you in touch about the blood thinner."

Nancy

- Apr. 8 -

"Hello my name is Betty Jo, my daughter Danyelle 8 yrs. was just diagnosed with AHC 6 months ago. This is my first time on the chat line as well as my first time typing on our first computer. Danyelle's new found AHC has pushed us into the modern age. I am very interested in meeting parents of AHC children. I am so very glad I finally understand what is going on with my child!! I have a new beginning and a new understanding."

Betty Jo

- Apr. 14 -

"My name is Donna & I have a 12 yr. old son with AHC. We was diagnosed at about 18 months to 2 years old. I want to welcome you to the AHC chat. If Danyelle would ever like to email Jayme (my son) he would love to hear from her."

- Apr. 14 -

"I'm Carol and we have a son 22 months with AHC. We've really found this chat line helpful and I'm sure you will too."

- Apr. 14 -

"My name is Becky and my son Jake is 7 yrs old and was diagnosed with AHC 2 years ago. You can really learn a lot from the people on this list, not just the medical stuff but the day to day things too. Since most of us do not live near other families, this is a great way to keep in touch.

Although it gets quiet on the list at times, we are always ready to offer our experiences or just be a sounding board."

- Apr. 14 -

"I'm so glad that you were able to get hooked up! I received your letter and permission form a few weeks ago, but with spring break...you know how it goes! You will really enjoy talking with everyone. Since we are so spread out, it is a great way to communicate. There are a few

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families close to you which I believe I have given you names and phone #'s. Let me know if you need them again."

Lynn

- Apr. 14 -

"...I understand your daughter Abigail was diagnosed at 2 yrs.. I really wish Danyelle was diagnosed earlier. For 8 and 1/2 yrs, she has been on anti convulsion medication. That I believe has slowed her mentally. She is 9, functioning at 3 yrs., but to all of our amazement since she has been off them, for 6 months. Now she is learning at a great and amazing speed. People who don't even know her very well have noticed. Just a few days ago a check-out clerk at the grocery store said 'Wow, I have never heard her say so much!'

I don't really know how this is supposed to work. I kind of thought it was going to be a chat line? As you well know every little bit of support helps. I am very thankful to the AHC and IFAHC, they are truly beautiful people."

Betty Jo & Danyelle

- Apr. 17 -

"...I just looked up your letter and to answer your question of two days ago, our family resides in Wisconsin in the town of Sturtevant, 20 mi. south of Milwaukee. I have been in contact with Lynnshe helped me get in contact with Dr. Silver in Chicago who Danyelle has been under his care for 6 months..... I am so very thankful to everyone who is out there willing to give me info and help me finally understand....."

Betty Jo

- Apr. 18 -

"Two weeks ago, Early Childhood Education had a fundraiser and we decided to go. They had a concert, a loud concert. So far Waleed was doing fine. I was very concerned about the loud noise but I decided to stay anyway because Waled was doing fine. Up until that day he had had no major episode for at least 3 months. Anyway, two days after the concert, Waleed woke up in the morning crying and very nervous. He was very agitated. Later on that day he lost his

right side and that continued on and off for two days. Then he had a full body attack for two days. He was very agitated as if he is in pain. He wants to move around but he can't. For a whole week he wasn't feeling well but then he was gradually coming out of it.

Not long ago, when Waleed has his episodes I would have an overwhelming feeling of sadness and despair. I didn't want to look outside the window to see other kids his age play outside. A week with his episode felt like a year. Everyone around the house would be uptight. Even though I am a religious person and I pray a lot, I still couldn't overcome the feeling. However this time was different. I was finally comfortable. We went for long drives because he loves that, and I love it too. We did a lot of reading. I bought a fish tank, a small one near the bed so that he can stare at the fish. That was very relaxing. I feel very light. Letting go of the sadness release a lot of energy. I still feel bad when I see other kids playing outside and he can't play, but the overwhelming feeling has left for now. I just thought to share my feelings with all of you. Thank you for listening...."

Nahid

- Apr. 18 -

"I received your letter around 8pm had a real long day at work! I have received the most amazing amount of hello and welcome from so many parents. I am so thankful, I can't even imagine what I must have been like for those in the not so far past? I am so thankful I understand what exactly is going on with Danyelle now, even though we don't have many answers its nice to know we are not alone. Danyelle and I are going to the gathering in Rockford, Ill., and are very excited to meet other families. In Oct. 98, I met the Dehn and Prunty families through Dr. Silver in his office at Loyola Univ..... Thank you all for receiving us with open arms!"

Betty Jo

- Apr. 19 -

"Following Nandana's letter on the internet corner we approached our GP and asked for a trial. Claire has had AH since two years old and is now 14. During this period she has one or two

episodes daily for around half an hour, has speech problems learning, mobility etc., etc. Since the first day of taking Clonazepam, Claire has HAD NO EPISODES AT ALL, IS WALKING UNAIDED 3K PER DAY AND IS NOW INTO HER 18TH DAY. This has not happened before, the longest relief being six days on the introduction of Sanomigrane when she was 9.

We are cautious as she has lived with this for so long, but we do see real signs of speech improvement, coordination and muscle control. Plus the fact that she can exercise an hour each day means that her unused muscles are finally getting the chance to work and build.

We are far from being the evangelical types with regard to dramatic effects from medication, but our cynical stance is being eroded with each day that passes. Please feel free to publish this and invite any contact on scottar@xtra.co.nz.

Andrew Scott, New Zealand - Apr. 22 -

"...I am very excited about what you have written about this new medication. My son has AHC and has been on flunarizine for 2 and 1/2 yrs. The medication has helped but he still has quite a number of episodes. He still doesn't walk. Can I know more about this medication so that I can approach my doctor and see what he has to say. Is your daughter taking any other medication? Has she ever been on flunarizine? I would appreciate any answers from you. Thank you."

Nahid

- Apr. 23 -

"Thank you for your email. Claire is 14 and we have tried flunarizine about six years ago but to be truthful we found no benefit and stopped taking the drug. The only previous drug that managed to stop Claire's episodes was Sanomigrane (I think this is a brand name and not the medical name - I will find the medical name for you), which halted the seizures for six days after which they returned. She still takes this drug, which is a migraine treatment. As she is getting older the amount of episodes had decreased but she was still having two weeks out of every month being very distant and on the verge of an episode.

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We are very cautious, as I said in my original email, as she has had AHC since two years old and we don't believe there is a 'wonder' cure, but as each day passes (20 today) she is definitely stronger, her speech is better, she seems more 'awake' and she still undertakes an hour of walking to the beach and back which we would never attempt three weeks ago without taking her wheelchair, and you could guarantee a floppy episode.

I understand Clonazepam is innocuous and causes no side effects but we would be interested to hear what your doctor's opinion is as we are always wary of long term side effects outweighing any gains made.

Overall, Nahid, we have made more gains in the last twenty days than in the last twelve years and if she reverts tomorrow to previous condition we would still call it a success."

Andrew Scott

- Apr. 22 -

"Out daughter Margaret, 17, has been on Clonazepam, 9mg per day, for about 6 years. At first, we noticed a great improvement; her episodes, which had been getting quite severe, became less so. Unfortunately, things have got worse again as time has gone by. I hope you are luckier!"

Janet Kilpatrick, Canada

- Apr. 22 -

"Thanks so much for this update and information. After receiving your info today, I did a follow-up and research on the internet. Since both you and Nandana have seen the same good results, I wanted to check from our end.

Clonazepam (trade name Klonopin in the US; Rivotril in Canada) is an antianxiety agent and is available in both countries. In fact, I know that several of our families have mentioned trying/using Klonopin over the years.

I just happened to talk to one family today and their daughter is on Clonazepam and flunarizine with very good results. We have used Ativan for years for our daughter, but I wonder just how effective it is after continuing use. I

have been told that a 'drug holiday' sometimes needs to be done for certain drugs to be effective again, as the body becomes used to them. Ativan and Clonazepam are both of the valium family. I did call my pharmacy and while ativan is generally used for antianxiety, Klonopin is used as an anti-seizure agent. Another search I did produced the following on Clonazepam: available in tablets 0.5mg, 1.0mg and 2.0mg; treatment: effective against generalized tonic clonic and partial seizures, absences and myoclonic jerks; possible side effects include drowsiness and sedation are quite common but these may wear off, and tolerance(decline in effectiveness with time) tends to develop. Nihid forwarded me your reply, as we happened to talk and had the same questions. We go to the neurologist on Monday and I plan to question him about the drug.

Both you and Nandana have given us some insightful information. If there are any other families using or who have tried Clonazepam, please let us know how effective it is.

As you say, it is not a 'wonder cure' but if it keeps the episodes at bay for longer periods of time, our children are so much better off.

Please keep us up to date on your Claire's progress..."

Lynn

- Apr. 22 -

"Just for reference, Amanda (7) has used the Klonopin for about 2 weeks and her episodes went from about one a month to everyday (this was about 3 years ago). We went back to the Ativan and generic Ativan monthly switch and stabilized within 2 weeks."

Catherine Mathews

- Apr. 23 -

"I completely sympathize with you and your attitude. When I think back to two years ago, of the bad days when we didn't know how to cope with Alberto's (6) attacks. I start shivering. We lived in the terror while waiting for the next attack: Alberto can't do this and that or else he may have an attack. Alberto must be kept quiet, he can't get too tired or otherwise he will be sick. You can get the picture. In practice, we didn't let him live, and we

couldn't live too.

But fortunately now we have understood that we can't prevent Alberto from making all the experiences and the efforts he feels like doing. We now enjoy every good day as if it should last forever and try not to worry about the future and the possible attacks. Then, when he has an attack we try to take it normally, as part of Alberto's life, we just relax and spend the time as quiet and comfortable as possible. This is helping him a lot, and us too!

Of course this is enormously easier not that, after two years of Sibelium (Flunarizine) and 10 months of triptophane, the attacks have remarkably decreased, from two-three weeks each month to few hours every ten-fifteen days. But especially knowing so many other families has been very helpful in this respect.

In particular my mother, whose message I posted on the list few days ago, is enthusiastic of hearing about the experiences of the other children. By knowing their names, ages and places she can better figure how they live and keep them in her heart together with her beloved nephew. Indeed she was the very first person who strongly pushed me to search for other families, in Italy and abroad, when I was still to concentrated and distressed for Alberto's disorder and its rarity.

In Italy we are now nine families ranging from a very severe case, with bad complications, to a very light case with no motor problems at all and very little speech difficulties. We talk on the phone almost every week and this gives a great strength to all of us. Unfortunately we don't live close to one another but we all met for the first time the last year and we are going to meet again at the end of April.

But also the messages from the list are very helpful and I can easily understand the newcomers' enthusiasm. Welcome to you all! And many useful news are coming from it recently: Nandana, Andrew, I am very interested in the results you are having with Clonazepam and I am going to ask about it to my doctor too. Please keep us updated.

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P.S. - I have done it again, in spite of all my theoretical speeches! This evening we were in the court yard of my father's firm and Alberto was getting over excited because of the many people there, workers, customers...He kept on turning from one to another like a top and couldn't stop so I took him abruptly inside and tried to hold him in my arms and make him take a rest and relax for a while. He didn't like the thing at all and while he was trying to get free the left side began to slow down. Nothing particularly serious, just a left hemiplegia, it was already 7:30pm and in an hour he was already sleeping quietly. Very likely the attack would have come anyway but now I wouldn't feel so furious with myself for interfering with his life once again. But I can't afford such thoughts or else I can get crazy very soon...tomorrow it will surely go better. CIAO!"

Rosaria

- Apr. 24 -

"I am so glad some have started using Clonazepam. When we first tried Clonazepam we did not have any knowledge about its effectiveness in AHC. However as time went by, as people started questioning about it, I went through the articles that I had and to my amazement, I found that a paper published by Dr. Aicardi and two other doctors mentions that Clonazepam was effective in two cases out of 22 they studied. I have already sent a copy of this paper to Donna Busby and informed Lynn about it. Maybe we should ask Dr. Aicardi or some other doctor to take an interest on this? After all Clonazepam is an anti-epileptic agent and the results we have seen so far points to the fact that the views of some Japanese doctors that AHC is of epileptic origin may be correct? It is worth getting some doctors involved in this.

I also want to say that we tried Clonazepam some years ago without Flunarizine but it had no effect whatsoever. It was only when we tried it in combination with Flunarizine it worked. Vishwa is on Clonazepam for the last year and the dose that he responded to was 2mg

in two divided doses. I wish everybody luck with their attempts to find the correct combination of correct drugs!

Nandana

- Apr. 25 -

"I have not written for a long time. I am sorry about this. I am glad to read that there is a positive experience with this combination of drugs.

When I spoke about Clonazepam to Dr. Goutieres (NECKER, Paris), she told us that she already tried it a few years ago without success and that she was afraid about the side effect of this drug..., we did not try it. Also, because Aurelie(5) was in a good period. She only takes 10mg Flunarizine and when she has stronger episodes some Nopron which helps her to relax and seems to shorten the episode.

Anyway, I am going to send her Andrew Scott and your e-mails. I hope she is going to revise her position and check further. I sent her a letter to know if she would accept to help us to obtain MEMENTINE in France. During our last year meeting, she spoke about a very positive effect of this drug on a German boy. I will keep you all updated as soon as I receive further news.

Mirjana

- Apr. 26 -

"It's been awhile since I have written. I have just gotten a new computer. I am very excited about having this list right at my finger tips. Before I would have to go across town to my in-laws to log on. Now I have it right here. I feel relieved, because now I can check my mail everyday.

I have been reading the last three letters (my father-in-law transferred what I haven't read) and I am glad to hear that the Klonopin is working for some of you. Kristen (5) was on Klonopin for about 3 years. we did see a lot of improvement over time. Just recently she was changed to Ativan. We noticed her spells were beginning to increase. Also her seizures were increasing. She was having a seizure about every 2 weeks. Her spells were almost everyday. She was changed from Tegretol to Depekote. The spells and seizures have not appeared in the last 2 weeks. But she has really changed. She went from eating 3 meals a day to not eating hardly any. Her behavior has

gotten unbelievable. We can't reason with her, she's had to go to the principal's office 3 times this week. Is there anyone that can offer some advice on this. We are hoping this is just an adjustment time for her. But I'm really worried that it's the medication. Hope all is well with everyone. Hope to hear from someone!"

Yvonne

- Apr. 30 -

"I'm sorry to hear that Kristen has been having a rough time. When Jake was still diagnosed as having a seizure disorder, he was on Tegretol and Depakote together. He lost all appetite and really began losing weight. He also would have vomiting. We were worried that he would need a feeding tube. Luckily, we found out that the medicine wasn't effective for his AHC because he began refusing all medicine. It took him a while to recover. He was on extremely high doses of both meds.

We used Klonopin on an as needed basis for a short time to try to induce sleep. I noticed a big change in Jake's behavior when he was taking it. He would get kind of mean. I'm not certain though that it was just from the Klonopin, it could have been from the combination of all the drugs he was on. As a matter of fact, we have been thinking of trying him on it on a regular daily basis, especially after hearing of others success."

Becky

- Apr. 30 -

"Two months ago Waleed choked on some food and I believed I told you about his experience. Anyway from then on he had an ongoing wheezing and they thought that it was just a bad cold. They took all sorts of xrays and they all came out clean. Finally we saw a specialist and he said that he will have to go in there and see what is going on. They found that he had small piece of food surrounded by mucus. He said that they got there just in time otherwise his lung would have collapsed. I can't tell you how relieved we are. That just shows you that all these equipments couldn't pick up this piece of food or detect any abnormality. I wonder what our kids have and the equipments can't pick up..... Anyway I will write another time to update you on what my neurologist

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said about the Clonazepam. Stay tuned and take care for now."

Nahid - May 3 -

"CLONAZEPAM - Ok Cinderella - times up! After a stunning 42 days with no episodes, the inevitable has happened, a return to one a day and a period of being 'distant' - if you follow my description.

I would thank Nandana Perera for alerting us to this drug and allowing Claire (our 13 yr. old daughter) the clearest period since she started AHC episodes at two years old. We made the most of it by walking on the beach for an hour every day, reading, sailing on the American's Cup course, cinema - cramming in all the things we know she enjoys but ultimately trigger an episode. She has emerged stronger from this period and we hope more equipped to deal with AHC.

The question is WHY did it work?

In New Zealand we have a modern medical service, but with the population so small there is no explanation or theory emerging as to what actually happened to Claire during this period. We will continue to administer Clonazepam - possible with the addition of a 'drug holiday' in the hope that the re-introduction will trigger another clear period. Clonazepam is no wonder cure, but it must be determined what part it played, and is it a component towards a solution?

Andrew Scott - May 18 -

"Amazing to say the least that she went so long with no episodes!!! I would truly like to see a scientist take the drugs that have an 'effectiveness' on AHC and look at what they are made up of and what part of the brain they affect.

We just started Clonazepam on Saturday. Kathleen has been on Ativan (same family as Clonazepam) for three plus years. Initially we saw fantastic results, but like so many drugs, I believe her system became use to it. As of the last few months, she had been having episodes every week lasting one and two days. I

have had to take her out of school much of the time as well.

We increased the Flunarizine in January and really saw no change. One thing we have noticed since starting the Clonazepam is that Kathleen is very 'sloppy' in walking and at school, her aide commented that she seemed very tired. Sleepiness being a side effect, we will continue for a few weeks and see. I remember that when we started Ativan, it took three weeks for her to 'adjust' to the use of the drug.

All we can do is try! I am thankful to have other families to talk with and share experiences with. And for Claire, it must have been wonderful to not have an episode for so long.

Keep us all posted on how things are going and I will do the same.

Lynn - May 18 -

We too just started Alexander on Clonazepam last Monday. The previous two episodes were the worst Alexander has experienced lasting 5 days one time and 7 the next. His usual episodes are 4-5 days with 9-11 good days in between. The oddest thing happened the last time. Alex wouldn't go to sleep. Even giving him rectal chloral hydrate, he just lay there almost catatonic. Considering he is only two and still takes naps this was very unsettling. He just had another episode since the Clonazepam, but it only lasted two days. Hopefully this is a sign of things to come!

Carol - May 18 -

"As so many of you are trying Clonazepam I thought I should give you the dosages we used for Claire: Clonazepam for Claire (age 13, 52kg, 5ft.7in), 1x0.5mg twice daily - tried 2x 0.5mg but withdrew after very doze day at school. Claire already taking Sanomigraine, 2x0.5mg at night before bed. Tried Flunarizine six or seven years ago with no real effect. I believe the common denominator between the Clonazepam and Sanomigraine is Valium (Lynn am I right?) maybe this is the 'active' ingredient.

Andrew Scott - May 18 -

"Nandana and I am very glad that so

many of you are trying Clonazepam and have been getting results. I thought you all would be interested in hearing a little more about our experience with it.

We first gave Clonazepam to Vishwa quite some years ago before he was diagnosed as AHC. Our doctor prescribed it thinking he was suffering from some form of epilepsy. It was not in the least effective. Last January '98 we went to our doctor in some desperation to get some help about Vishwa's behavioral problems. The doctor then prescribed 1.75mg of Clonazepam in combination with the 7.5 Flunarizine that Vishwa was getting at that time.

The effect was almost immediate and can be only described as sheer magic! Behavior improved, Vishwa's speech which has always been a problem because he stammers got very fluent with absolutely no stammer, and overall alertness improved as well.

As for the attacks they became virtually nonexistent. Up to the time before we started on Clonazepam Vishwa was getting hemiplegic attacks about every 6-9 days each lasting 2-3 days with the occasional paraplegia attacks. What attacks he did get was in the form of a stiffening of the fingers which passed off after some time - 10-15 minutes. Unless he told us we were unable to even detect when Vishwa was having an attack. This period lasted for about 3 months, after a while speech gradually got a little worse as did the other good effects.

We have tried increasing the dose of Clonazepam and then reduced it again after noticing tiredness and unsteady walking. In fact Vishwa had quite a few falls during this time with no visible improvement in speech and alertness etc. We have now settled on an O.K. medium of 2mg given in divided doses of 1mg twice a day together with 10mg Flunarizine. His body weight is 27kg, and he is 9yrs and 9months old.

While we never reached the 'high' we first did, the combination continues to be effective. Now when Vishwa gets an attack it either passes away after 10-15 minutes on its own or it passes off after a nap. It has never continued for a whole day. We don't remember the bad times

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now, when Vishwa was more sick than well. When we do, it really sends a chill through us as it does when we read some of the letters on the bulletin board. We've been down all these same roads. Since recently Vishwa has been constantly complaining of nausea and bad headaches. Have any of your kids experienced this and how do you treat it? It seems to be a new manifestation of the disease which has been constantly changing over the years. I hope our experience will prove useful to you all."
Carmelita & Nandana - May 19 -

"Drazen....We received your email telling us about your brother's son Matija. Firstly, the chemical name of the drug is Clonazepam and this is sold in Sri Lanka under the trade name 'Rivotril'. Before you start treatment you have to consult a doctor about the dose. According to the manufacturer's instructions, the maintenance dose for children up to 10 years (or up to 30kg of body weight) the dose is .05mg to .1mg per Kg of body weight daily. (This means if your child's weight is 10kg you can give a dose of .5mg to 1mg a day).

We received your email asking us for some information some time ago and we answered it in detail. Did you get it? However about our experience with Clonazepam, we have just written a letter to the bulletin board. Please read it. If you require any further information, please feel free to write again and ask. Clonazepam changed many things for us and we would like it if it can work for the others."

Nandana - May 19 -

We also tried Clonazepam with Jake during the time they thought he had seizures. I had told the doctor that Jake got much better if he went to sleep so he gave me a bottle of it and told us to try it when Jake got bad. At first it did seem to help but it seemed to cause some behavior problems. I think that the problem was taking it when needed instead of regularly. When you talk of

your son 'What attacks he did get was in the form of stiffening of the fingers which passed off after some time 10-15 minutes'. Do you mean that your son has a clenched fist that is so tight you cannot unwind his fingers? This is one of Jake's major problems. However it doesn't just involve his hand, it usually involves his arm and a leg. This is known as dystonia. I have found that hardly anyone talks about this or else their child does not experience this. Jake hates this more than the hemiplegia. It is very painful for him. Drugs like Valium, Ativan, and Clonazepam are used to help dystonia. For that reason, we are will to try the Clonazepam again.

Jake (age 7), has recently begun really complaining about NOISE. Everything is TOO NOISY or TOO LOUD. He will walk around with his hands over his ears. If I ask him if his head hurts, he usually says yes. I have started giving him a very low dose of tylenol which does seem to help somewhat. Yesterday at school, he had a rather bad attack. They said that he had an episode lasting 15 minutes just before lunch. He ate his lunch as though he were starving (very rare for him) and then had an attack that began so 'violently' that he fell off his chair onto the floor, striking his head on the table. He was bad off and on the rest of the day. Oh well, this is too long. Keep in touch!"
Becky - May 20 -

"Please don't feel that Jake is the only one with this form of dystonia. It too is the major issue for our son Kyle (age 7-1/2). He experiences his most severely on his left side with his arm bending upward at the elbow and the fist clenching. When the experiences it on the right side, the arm stiffens outward and the fist occurs. Kyle also experiences the stiffness in the legs.

We are currently administering no medications at this time. We weaned Kyle off of Flunarizine last summer. I can't say that our episodes are any worse for it. We are just watching the results that the rest of you have before rushing into the medication issue again.

Kyle has had a terrific school year and he has really blossomed in the classroom. He continues to be significantly behind his

age level peers. But he continues to make leaps and bounds of progress in his own right. We are looking forward to fun and adventures during summer vacation."

DeAnne McGinley - May 20 -

"I am so glad to hear that the change of Clonazepam is working for those of you who have started using it. Kristen had been on it for 2-1/2 yrs. She really did well. She would go without a spell for about 2-3 weeks. But in April her doctor changed her to Ativan. Kristen started having seizures again. She's hoping that this along with the change to Depakote will help control the seizures. She told me that the spells hopefully wouldn't increase. We saw a slight increase for about a week. Since then she has gone about 2 weeks. Also no seizures since the change to Depakote!!! I hope you all have great results with the Clonazepam. I believe it really helps. Best of luck."

Ockman Family - May 20 -

"I was reading the information from Becky and Joe. Our Kristen (age 5) with AHC/ Epilepsy has dystonia when she has her spells. Sometimes will have the stiffening of the arm and leg, other times its just her arm and hand. She had a bad episode today. We noticed the right arm and leg were really stiff. She made a small crying sound and her eyes would roll and twitch. We haven't seen much of these spells lately. I guess its time for one. We have been really blessed. She doesn't have very many of these. Now that she is on Ativan, I find she is having more.

If anyone can offer some advice on potty training, I would love to hear some feedback. Sometimes I think she's ready, and sometimes not. Any advice would be greatly appreciated."

Yvonne - May 22 -

"I was most interested to read about Kristen's doing so well on Clonazepam. Our son Vishwa who is nine now has been on it for over a year, with good results. Why did your doctor change over to Ativan? Was it because Kristen was not doing so well on Clonazepam any more? I would also like to know if she is on both

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Ativan and Depakote and whether you give these drugs in combination with Flunarizine. Did you also give Flunarizine while giving Clonazepam?

As for potty training, I'm afraid that is one area in which we are still struggling with! Vishwa has found it easier to learn to read and write than be toilet trained. This is something that really disturbs us very much."

Carmelita - May 23 -

"Carmelita - sorry its' taken me so long to return your letter. I am in the middle of moving. Between two girls in school, a two year old at home, and two infants I baby-sit for, it's pretty tough.

I was really glad to hear from you. Kristen's doctor changed her from Clonazepam to Ativan, because she (Kristen) started to have more frequent episodes. Little did I know we should have left well enough alone. Since the change to Ativan, I find she's having even more. I will be speaking with her soon about this. We might have to go back to the Clonazepam. Kristen would go sometimes for about four to five weeks without having any signs of weakness.. In fact her spells would come and go so quickly that we were so surprised. I guess I should have given her a little more time.

Kristen is getting Ativan 2mg at bedtime and Depakote 250mg twice a day. Also Flunarizine 5mg twice a day. She has been on flunarizine since she was a little over one yr. old. We saw a 100% improvement. While she was on Clonazepam she took the Flunarizine. I really believe myself the two work well together. At least they did for Kristen. In the beginning Kristen was really delayed. She was having 2 to 3 spells a week. I mean full blown attacks. Once we started the flunarizine she did better. But later when we added the Clonazepam she really did well. Her therapists couldn't believe the improvement. It was like day and night. I'm hoping it will help the others like it did for her.

As for potty training, well I don't know if its Kristen being hard headed or if the

AHC has something to do with it. I'll try taking her and nothing happens. then the next thing I know she's wet. We have been luck, because the school is really trying to help. But they understand and have a lot of patience.

Hopefully this will help with the questions you had. If there is anything else, please let me know."

Yvonne - May 25 -

"We are looking forward to meeting everyone at Rockford! Hope everyone is well enough to make the trip. Here is an update on Hailey - she now is taking Flunarizine, Topamax, and Ativan and seems to be doing well. She has made some great improvements in her speech and ability to retain information that she is learning at school. We are hopeful that this 'good spell' lasts for a while. See you all in June."

Carrie Dehn - May 26 -

"I hope that you and your families are all having a great summer. I was just wondering how the weekend in Rockford went? Was there a good turnout? I wish that we had been able to go. I would appreciate it if someone who went there would write and let us all know how it turned out.

Also, did anyone else get an email about egroups for AHC and a bulletin board? Any ideas as to what that is about?"

Becky - June 28 -

"I don't know about Rockford however I did get the message about the new bulletin board. I was wondering about that myself. Does that mean chanllengenet is no more?"

Carol - June 28 -

"Hello...I'm Mindy..my daughter Hailey is 29 months and has AHC just for those of you who don't know me already..I just wanted to tell everyone something...on Sunday June 27, my aunt got married and in her invitation she asked that no gifts be given but instead to donate to the AHC foundation...I can't tell you how thankful I am to her and what a thing to do at your own wedding. I was just sharing this with all of you because it is not only my daughter's life she is hoping

to make a difference in, it is all of your children's too."

Mindy - June 29 -

"What a wonderful thing for your aunt to do. Please thank her for all of us parents of children with AHC."

Charlotte - June 30 -

"Mindy - thank you so much to you and to your aunt for this wonderful thought of yours. This kind of support is helping us a lot and means our daily struggle against AHC less hard. Thank you also on behalf of Alberto, my son, who is six and has AHC."

Rosaria - July 3 -

"We have exciting news! Jenny has been granted a wish through Make-A-Wish of Minnesota. Our whole family is going to Disneyworld. This is something she has wanted to do for many years. She is so excited, she wants to leave now. Has anyone else gone through Make-A-Wish for their children?"

Marcia - July 28 -

"...Thanks very much for the message about the Midwestern meeting especially since it has been the only one I have seen and has been generally available. I would be very interested in any more details the organizers or attendees could put out such as who was there, what was successful and not so about the meeting. Also is there a resume official or unofficial of Dr. Silver's address? Could one be made? Our family were fortunate to attend the French family meeting last May when other nationalities were invited and Dr. Goutieres gave a most interesting talk including some personal views and observations. It is on the AFHA website in French and perhaps in English. I found this fascinating. I understand that Dr. Silver has been supportive of numerous families and would like to have heard him. Please can someone help?"

Alex Cole, UK - July 29 -

"Marcia - This is MaryKay Riley over in Loretto. Congratulations for Jenny and the rest of you. I just called Make-A-

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Wish last week to find out what we needed to do to have Nick considered. How long did it take?

My husband and I were there BC(before children) and I know you will have a great time."

MaryKay - July 29 -

"It was only a matter of 1-2 weeks before we got paperwork and then only about 2 weeks later they were out to the house. I couldn't believe how fast it all went! None of us have ever been there so it will be quite an experience."

Marcia - July 29 -

"We had a wish granted last year and went to Disney in October. It was a wonderful trip. They have greeters at the airport, rental car counter and everywhere else to help you out. The best part was all the attention Greg got as he went around Disney. He had a Make-A-Wish badge on and all the workers at Disney look for them. We never had to stand in line, they took us back stage and we met every character at the parks. It is really a once in a lifetime experience."

Greg - July 30 -

"I'm glad to hear you had such a good time. Is October a good time to go? Jenny can't stand the heat and humidity so we were hoping it would be a little cooler."

Marcia - Aug. 1 -

"How do you go about getting your child into the Make-A-Wish foundation?"

Mindy - Aug. 3 -

"I was wondering that myself. I would like to know how too....."

Donna - Aug. 3 -

" I thought that I sent this info to the group but I must have just answered someone personally. First of all, Make-A-Wish has a website www.Make-A-Wish.org. It has all the information you need about who is eligible and how to contact them. Any child between the ages

of 2-1/2 and 18 with a life-threatening or terminal illness may be eligible. You can call them yourself to refer your child or someone involved with your child's health or care can refer them. They will ask for your child's doctors name and number and check with them about your child's health. Then they will set up a meeting at your home. The two volunteers who came to my home couldn't been any nicer. They brought a bunch of goodies for Jake and his brother Luke. One of them even made chocolate cookies for Jake. Then they talk to your child and you about what they would like for a wish. We talked about several things that we thought that Jake would like (of course he wanted them all). Our other top contender was a horse for Jake. They said no problem - they would get him a horse and provide for room and board for a whole year. It was a hard decision because Jake loves horses so much and loves to ride, but we thought that the Disneyworld trip would be wonderful for him. We also worked out a side trip to my in-laws in Jacksonville while we are there. They make all the arrangements. If you go to their website, you can read about some of the other wishes that they have granted. It is just an amazing organization, the wonderful things that they do for children.

If anyone has questions, please don't hesitate to write. By the way, we are going October 9-16."

Becky - Aug. 3 -

"Just a really quick question...when did AHC get classified as a life-threatening, or terminal illness...as far as I have known, even with those recent deaths we have heard of, that our kids should be able to live long lives...when did this change?"

Wendy - Aug. 4 -

"I think that it is a Doctor's call type of thing. They don't include things like diabetes or epilepsy. A child with a treatable cancer can be granted a wish. It doesn't necessarily mean that the child will die, just that their life has been threatened or is threatened by their illness. I know of another child who, during an episode, wasn't breathing well

enough and had to be placed on a ventilator. I would consider that life-threatening."

Becky - Aug. 5 -

"Hope this email finds all of you doing fine. We are doing okay.

Are there anyone of the children with AHC that might be taking Limictol? Has anyone ever tried this? I know its used for seizures. Kristen has been put on this hoping that it will make them stop. I was just curious that maybe some of you might know something."

Yvonne - Aug. 29 -

"Our Disneyworld trip date has been changed to October 23-30. Was anyone else going to be there at that time?"

Marcia - Aug. 31 -

"I'm wondering if there is anyone out there. I haven't see anyone write in what seems to be a long time. I know everyone is busy Hope back to school was an easy time for the kids. We are still adjusting. Jenny had a double ear infection by the end of the second week of school which makes everything else challenging. Hope to see some activity in my email account."

Marcia - Sept. 14 -

"Marcia, I noticed that it has been quiet too. I hope that means that everyone is doing well. Jake has adjusted to his new school pretty well. Jake goes to a private special ed school and he really seems to like it. We tried to send him to public schools but it was terrible (I think that our school system is terrible). Luckily he hasn't had any really bad attacks yet. His speech is coming along very nicely and he is really showing an interest in school work. A problem for him is that he has to catch a bus at 7am and has a long bus ride.

Are you guys excited about Disneyworld yet? All this hurricane business is making me nervous. My in-laws live in Florida too and are moving out for now. Make-A-Wish sent us a really cool book about Disneyworld and Jake looks through it every night. He can't wait to go to Mickey's House."

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Becky - Sept. 14 -

"Yes, I too agree it has been quiet around here. I also hope that means all is well.

Back to school was crazy for us also. This is Kristen's first year of kindergarten. Last year she was in pre-k. She didn't do to well at first. But now she seems to be settling in. We are also lowering her dose of Depakote. I'm sure that has a lot to do with it. Because her behavior has improved at home as well.

We are going to Disney in October. That is if Floyd leaves it alone!. Keep in touch, it's really to quiet around here. Hope to hear from anyone soon."

Yvonne - Sept. 14 -

" We are in the process of moving and it has been hectic here. We put Alex (age 2) on Clonopin as well this summer and first it seemed to really reduce the severity and length of the attacks, however they seemed to occur more often. He seems to be reverting back to the more severe attacks lately. He is not yet walking but he loves to climb and pull himself up on whatever he can. However he is really trying to communicate more using sign language. He probably has about 10 signs he uses now.

We have decided to scale back the flunarizine to see how he does without it. Has anyone else tried removing their child off flunarizine? If so, what was the result?"

Carol - Sept. 15 -

" I agree it has been really quiet lately. We have all settled back into our school routine around here now. It always takes a while to adjust after being off all summer. But Jayme is loving school. This is his eighth year of school. He is learning pretty good but still at about a first or second grade level. He is thirteen now, so we wonder like the teachers, how much further he will go. His speech is really coming along great all of a sudden. He is talking a lot more clearly. We started him on Klonopin (Clonazepam)

this summer and we feel it has really helped his attacks of AH to not be so often. He takes it with the Flunarizine. We were able to reduce his Flunarizine by half also when he started the Clonazepam. So we are hoping he has a better school year this year with less attacks. We will see....We hope you are doing well. And hope to hear from more of you...."

Donna - Sept. 15 -

"Is it really true that there are four families going to Disneyworld in October?? We are going the week of the 9th. I had talked with Lynn Egan about a month ago and she thought that they might go at the end of October. Let's hope that the hurricane season blows itself out soon."

Becky - Sept. 15 -

"We are also off to another great and busy school year. Kyle is doing wonderfully so far at school. He has the same special education teacher and para again but a new regular ed teacher for 2nd grade. The bulk of his 'academics' is in special ed but his para is terrific in adapting discovery centers used in regular ed for him.

Kyle's most exciting news at this point is that he has joined a soccer team and played his first game last Saturday. He plays through the VIP program through AYSO soccer. He was having a really tough time on Saturday physically but we decided to go get his uniform and to meet and watch the other kids. When we got there, he was so excited that he insisted he could play. They allow parents or special helpers to be on the field with the players, so I held his arm and helped him move from place to place on the field. His arms never worked the entire game but the legs held up fairly reasonable. I asked him a couple of times if he would like to rest or keep playing but he refused to quit (and the smile never quit as well!!). It was a great experience for him and the coaches made sure everyone got their fair share of time with their foot on the ball. I can't wait until this week when he should be feeling at his best.

Kyle continues to not take any medications whatsoever for AHC.

Someone asked about taking kids off flunarizine. Kyle took flunarizine for about two years. Like most there appeared to be some help for the attacks initially, but later we couldn't document any real benefits. Under the guidance of our neuro, we slowly weaned him from the drug. He has been 'drug-free' for about a year now. I can't say we are any worse off than we were before. Our experiences with AHC seem to be clinical. For many months it will be so predictable and then there will be a slight change. We haven't seen any real changes, good or bad, in almost two years. We have seen however Kyle's overall attitude and behavior return to being much more pleasant like he was when he was younger. He has even returned to more social play with others. We went through about a year long period where behavior was a real issue especially at home. I'm sure most of the change is due to some maturing.

Kyle continues to love life to the fullest - school, playground time with friends, church, swimming, roller coasters, soccer, television, computer and the likes. We don't shelter him from too much even if it brings on attacks; we simply adapt the activity. I can't refuse him any activity (like swimming with a life jacket of course) if he seems to be having fun. He often seems more upset if we make him quit. Sorry to go on like this, but I am so proud of my son."

DeAnne McGinley - Sept. 15 -

"I might as well chime in about Abbie. We just moved from Melrose, MA to Plymouth, MA. I thought the special ed program in the Melrose schools was great. Boy, am I so pleased to learn that Plymouth schools are even better! Steve & I just met with the special ed team this morning and I am so impressed with them and with all that their program has to offer. I'm so happy that Abbie will get the very best — she deserves nothing less! Abbie has been going great. She did have a very mild spell over the weekend, but other than that hasn't experienced anything for probably close to six months now. We are so fortunate! Hope everybody is well and that the new school year brings great things for all of our

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children.”

Kathy - Sept. 16 -

“We tried stopping Flunarizine two years ago for Vishwa and the result was very unpleasant. In fact we were advised to stop it by a doctor but it brought in more and more attacks. May be you should re-consider your decision.”

Nandana - Sept. 17 -

“We have a 6-1/2 year old boy who most likely has AHC. Originally it was though he had intractable epilepsy. Some of his seizures were followed by Todds paralysis. Gregory has been on the ketogenic diet since the age of 4. Along with his meds, Dilantin & Clonopin, his seizures have been well controlled. In July '98 he had a seizure which left him with a left sided hemiplegia that lasted 8 weeks. The following November he had a brief attack of hemiplegia without seizure that lasted 30 minutes. This past July he suffered a right sided hemiplegia and is still recovering. Gregory has autistic features and has severe developmental delays. We have a million questions.

We see a lot of people are using Klonopin. Gregory has been on it for years by the time the hemiplegia attacks occurred. Has anyone every tried Haldol for the attacks? I am wondering why many people are trying to take their kids off of Flunarizine. What side effects have been observed? How long do most children take to recover from the paralyzes? Are any children on Co-Q10? Does anyone know if the ketogenic diet is contraindicated for children with AHC? We appreciate any info that can be shared.”

Kathy & Gerard - Sept. 18 -

“In response as to why take a child off Flunarizine, my response is why have a child take a drug if it has no positive benefits? We hadn't experienced the potential side effects associated with Flunarizine but the fact that it didn't seem to have any helping effects for AHC in our case was our primary reason. Best

of luck in your medication decisions.”
DeAnne - Sept. 19 -

Welcome to the list! Your son's story sounds so much like my son's that I just had to write. Jake is now 8 yrs. At the age of 18 months, he started having episodes that appeared to be seizures. He was first treated with phenobarbital which has a sedating effect that helped to prevent further attacks. However, we had to put him on such high dose to prevent the 'seizures' that he was like a zombie. Jake's EEG's never showed epilepsy, but we never got an EEG on him during an attack until he was over 5 yrs. This made the neurologist finally realize that we were dealing with something other than epilepsy. Some children do have both epilepsy and AHC, though. We too thought Jake had Todd's paralysis, although his usually lasted only about a week to 10 days after an attack. By the time we realized that it wasn't seizures, he had been on Tegretol, Depakote, and Klonopin without success. He was getting sick from all the medication. We went to see Dr. Chugani in Detroit and he confirmed that Jake had AHC. We placed Jake on Flunarizine and noticed a change in his attacks within weeks. Jake is also severely developmentally delayed but he has really improved since he has come off all the medication. Right now, he only takes Flunarizine. I think that parents are considering taking their child off of Flunarizine because they don't see much benefit for their child. Some children do not improve, while others do. Flunarizine has relatively few side effects. especially when compared to anti-seizure medication. I know of some families that use Valium or Ativan, but I can't say I have heard of anyone using Haldol.

I just have a few questions for you. Does your son get better after sleeping for a while? Does you child have epilepsy or are they saying it is something else now? For most children (al least from what I have read on this list) the attacks appear to change as they get older. Jake's attacks really involved his eyes a lot when he was younger, but now he mainly just gets very large pupils when he has an

attack of hemiplegia. Where they really resembled seizures when he was younger, now they don't.

I hope that I have helped you some. If you have any questions that I can answer for you, please don't hesitate to write.”

Becky - Sept. 19 -

“Our nine yr. old daughter (in two weeks!) has been on Flunarizine since she was 13 months old. By 18 months she was on 15mg daily. We have tried to take her off/reduce Flunarizine three times in the last five years. The first time, she started having increased episodes after just two weeks of decreasing to 10mg daily. We put her back up to 15mg and she was better. A year and a half later, we decided to try again. We reduced again to 10mg and for the next three weeks she was the best she ever was. She seemed brighter, more with it...not to say she was 'drugged' by the dosage of 15mg, maybe her senses were slightly dull...Anyway, our Flunarizine got stuck in customs from England and we ran out. One week after no Flunarizine we ended up in the hospital for seven days, the episode lasted for 10 days. No speech, no walking, trouble with swallowing so only soft foods. It was awful. It also left her weaker on the right side, lower tone. It took four months to get her back up to where she was before this disaster. I know we had this kind of an episode because we ran out and Flunarizine was stopped cold turkey. Flunarizine is one that needs to be decreased slowly. While we were waiting for the Flunarizine, we tried her on a different calcium channel blocker called Nimodipine. After two months, with no changes we went back to Flunarizine and once again, her episodes improved. We left things alone for the next 22 months and again reduced to 10mg of Flunarizine. Those three brief weeks we had seen previously, we saw again for the next eight months. Then the episodes started to increase. Episodes that were every 3-4 weeks, lasting hours to a day, increase to every two weeks, lasting 1 to 2 days (always on the weekend). Several months ago there was much discussion about many of the children having episodes on weekends.

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As always with this disorder, you ask yourself all those questions. Is she getting sick? Is she having a growing spurt? Are the episodes just changing pattern? Etc., etc.?????. Well, after almost four months of this, we increased the Flunarizine back to 15mg (so a year at 10mg). There was no improvement. In fact after another two months, the episodes increased to once a week! We were very upset.

About this time, there was much discussion about the use of Klonopin (Clonazepam) and the wonderful results a few parents were having. Klonopin is a benzodiazepine, same family as Ativan which we had been using for 4-1/2 yrs., successfully.

However I had been wondering for some time whether or not it was effective or not. Since we were not seeing any changes from the Flunarizine, and after checking with our neuro, we switched from Ativan to Klonopin. The episodes immediately got better!! We went 2-1/2 weeks before another episode! But with the switch we had significant side effects of lower tone, which affected everything, more drooling, difficulty with speech, walking was unstable...We stayed on Klonopin for two months. My hope was that switching would be considered a 'drug holiday' from Ativan and that we would again see the same wonderful results of Ativan as we did when we started it almost five years ago. It worked!!! In the ten weeks since we switched back to Ativan, she has only had two major episodes, lasting a day and the most recent was brought on by the flu. She does continue to have those little ones, lasting a few minutes a few times a week, but I just don't count them anymore.

Flunarizine does not work for everyone. In fact we have many families not using any drug for AHC. For now Flunarizine works for us. We will continue until something better is discovered to work. You asked about Haldol. Several years ago, we discussed this with our neurologist. Families were using it in England with some success. After looking into the drug, we decided against it

because of the possible side effects. We have been using Co-Q10 for two years. We have not noticed any changes because of it, however we continue to use it with hope it will help in the long run. Several families have/are on the ketogenic diet for seizures and have improved. As for treating AHC with the diet, several years ago, three to four children tried the diet for AHC with no success.

Our daughter continue to progress. Third grade is challenging. Math continues to be tough, but we are focusing on money and time and have started to use a calculator. Reading is almost second grade level. She is starting to use two hands for typing on her computer. We are working on writing skills (still very hard) lots of hand over hand and tracing. We too, started hippo therapy (horse therapy) last week. She got a little to excited and had to stop early.

I hope this has answered some of your questions. Having just been diagnosed you have millions of questions, we still have them..... please feel free to write back if you have more.

Lynn - Sept. 20 -

"Does anyone have any experience with using Diastat (rectal Valium) to abort an attack as it is getting underway?

Our 9 yr. old daughter is currently taking Tegretol to prevent seizures that may accompany attacks and we also have Diastat on hand to administer in case of an attack. Fortunately, her attacks are relatively infrequent, and so we have not needed to test the Diastat to see if it works, but the thought is that the Diastat would abort an attack and simply put her to sleep, thus avoiding the hemiplegia and other symptoms that have sometimes persisted for days."

Ben Jungreis - Sept. 21 -

"We used to use rectal Valium when Kyle was a toddler and pre-schooler. It was one of the few things that helped abort an episode. However it only would help for a short period of time. Mainly helping him to rest. We tried switching to an oral form when he was 5/6 years of age but that didn't seem to have any impact at all. We've not administered rectal Valium in probably two years now. It became quite

awkward as he has gotten older and as I stated earlier, it only provided temporary relief (mainly in the form of sleep). We now just make Kyle rest or take a nap during his most difficult episodes if we see he is really cranky. If we can get him to relax and not be so agitated or frustrated with his severest episodes he manages quite well without meds."

DeAnne - Sept. 21 -

"...Yes, Abbie's worst episodes do occur in the wee hours of the morning while she's still asleep. She wakes up with the paralysis or dystonia usually around 5:00am and gradually gets better as the morning wears on. She is usually able to take little cat naps during that period to get some relief, but even when given Valium is not able to sleep long enough to make the spell completely disappear. She experiences vomiting during this period as well and is very groggy and spacy, etc. As soon as she requests something to eat we know its all over and that she's returned to her normal self. Once the spell is over, she's as happy as can be and it's as if it never happened.

She has been on Ativan since she was about 3 or 4. During the first 4 yrs. or so we were increasing the dosages to keep up with her growth, but have kept it at the same dose as it was when she was about 7. This is our way of very gradually weaning her off it. When we started her on Ativan it was more due to her behavior than anything. She was exhibiting periods of extreme anxiousness and would get very, very whiny — We had heard about Ativan as a treatment for AHC and also learned that it is used to curb anxiousness, so we decided to give it a try. It did seem to calm her down— whether or not it made a difference in the episodes, I don't know. She continues to get better and better, going greater periods of time without episodes as the years were on. It's hard to say whether the Ativan has anything to do with it or if she's just 'growing out of it'. I would like to think the later."

Kathy - Sept. 21 -

"We have used chloral hydrate to put Alex, 2-1/2, to sleep when he is in a

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severe attack. However we found it was a temporary measure and once he woke up he went back into an episode so we don't use it anymore. We do have rectal Valium in case of a seizure. Alex has had two seizures, both of which lasted quite awhile, one over 45 minutes, the other we used the Valium after the first 10 minutes and he came out of it right away. He is on Phenobarbital for seizures."

Carol

- Sept. 21 -

"...My name is Dick van der Baaren. I am the father of Juanita. She is 32 and has AHC. I met many of the parents years ago at the AHC conference in Seattle. Juanita is doing reasonable well. Her bouts of paralysis come about weekly but do not last very long. Our biggest concern is to keep the epileptic seizures under control. She is presently on a combination of Phenobarbital and Dilantin. Through the years we tried most everything including Flunarizine. The neurologist suggested to try another anti-epileptic drug called Torimaz (or Topirimate). This drug seems not only to be a very effective anti-epileptic drug, but there are some indications that it has some anti-migraine properties. I wonder if anyone has any experience with this drug for AHC patients.

In reading through the many message on the internet, I am struck that the diagnosis of AHC is still causing so many problems. I found the article Alternating Hemiplegia of Childhood by Prof. Jean Aicardi in 1987, extremely helpful. Although there must be good literature on clinical diagnostic tools, for those who still have difficulties the above article may be of help. It was published in International Pediatrics/vol 2/April-June 1987.

Through her 32 years, Juanita has tried many drugs including Benadril, Zarontin/Valium, Phenobarbital, Dilantin, Mysoline, Nicotinamide, Clonazepam, Diamox, Tegretol, Sandomigrain, Adalat, Elavil, Propanolol, Depakene, Persantin, Sansert, Celontin, Ritalin, Inderol,

Bellegral, Neurontin, Flunarizine and some more. Some like Sandomigrain and Neurontin, seem to have some temporary results, some made things worse.

Up till age 12, Juanita did not have epileptic type seizures. After that age, the seizure activity became evident. Maybe they were suppressed by her medication till that time.

Her bouts of paralysis have changed character through the years. As a baby, it was every 18 days, for about four days, switching from left to right, usually with total body in between. Thank pattern has disappeared completely. Also, it was always completely left or right. Now it can be an arm or a leg only. We have not observed any clear evidence that the bouts of paralysis had any after effects. In contrast the epileptic type of seizure activity, when they become a total body event, may create weeks of decreased mobility and/or cognitive effects."

Dick

- Sept. 22 -

"Well, I guess we were the first to go but we just got home from Disney and Floyd...well we took our daughter Hailey 32 months in a full blown attack and all.. It was a hard decision to make ...last year in Oct. we were heading to the Bahamas and the night before we were leaving she started with an episode so we didn't go..and now this trip the night before we were leaving she started again and it couldn't be a little one right..so we didn't know what to do and we decided that if we didn't go we would never do anything...so we went..we left on Sat. Sept. 11 and Hailey had an attack full blown until Thurs...Sept. 16...then on Sat, Sept. 18 she got a cold. We stayed until Mon. the 20th..we did have a good time though I'm happy we went...we got a special pass and Hailey got to see the characters about 50 times...and here I am not knowing if she knows what is going on when she has attacks...well as soon as she came out of it, she asked for more Goofy the first one we saw on Sat. I was amazed...it was hot and we only did the slow moving rides because the others cause attacks..anyway she LOVED IT....."

Mindy

- Sept. 24 -

"I have a concern. My son Jayme is having an attack right now on his right side. He started it last Thursday morning and it is still with him (7 days). He hasn't had an attack last so long in all the years he has been on medication. He is 13 so he has been on med's for 11 years or so...His attacks always last a couple days or less and then they're gone for two weeks or more. He is very alert with this attack and able to play and dress but he just can't use his right arm...A lot of dystonia with this too... It hasn't even gone to intermittent throughout the day just constant paralysis...No signs of ending soon..Has this happened to anyone else? I hope Jayme isn't starting a new pattern with his attacks. This is a very long attack..Any ideas???"

Donna

- Sept. 29 -

"Jake had a really bad attack when he was about 4 years old. He had inadvertently received an overdose of Dilantin in the ER of a local Children's Hospital and lost consciousness. They did a CT scan which was ok and an MRI and several EEGs. This was before we knew it was AHC. He couldn't walk for several days. He slowly regained strength in his right leg, but it took over a month before he was back to normal. It wasn't completely paralyzed after about 4 days, but he had a severe weakness for a long time. We find that Jake's dystonia is much worse during really bad attacks.

Becky

- Sept. 30 -

"I need to know all the info anyone can give me on Haldol???? Hailey's neuro...it's in his mind now."

Mindy

- Sept. 30 -

"My nephew has been diagnosed with AHC. We do not have very much information about the disorder. We are very interested in learning more about it and finding some doctors that have treated children with this disorder. Please e-mail me with some information."

Stephanie

- Oct. 1 -

"I can remember the same type of thing happening with Jenny when she was younger. She always amazed us how she

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continued on no matter what was happening. She is now 12, attacks are much less each year she gets older."

Marcia - Oct. 1 -

"...Vishwa has had attacks similar to what you described about twice. Very slight but lasted several days. He in fact just recovered after a 4 day attack. Once his attack lasted 13 days!

However I think sometimes a sedative like Valium in a higher dose has helped him recover sooner. I also think the key factors are sleep and rest....."

Nandana - Oct. 2 -

Note: Maria Helle posted to the bulletin board in french. I have had it translated.

"We are the parents of Vincent, age 29, and we were very happy to read your message as we searching for adults with AHC to find out how the disorder progress over time. Vincent has had AHC since birth. His attacks of paralysis sometimes affect the right side, sometimes the left but more often the left side. He also had occasional attacks of bilateral. His attacks last several hours, recurring over 2-3 days. His periods of remission have never lasted more than 8 days. Since the age of 10, he has had epileptic seizures, of which the number varies: last year eight, this year seven. The seizures occur particularly between June and October. No treatment has really helped and he does take Neurotin, Tegretol and Gardnal but nothing for AHC. He works at a workshop for the handicap and has no independence because of his AHC. He lives with us and depends a lot on us. How is Juanita life? Is she independent? Does she work? How does she deal with her periods of paralysis? Does she have any behavior problems? Is she sometimes aggressive? Does she attend psychotherapy sessions? And you the parents, how do you organize your life to remain available and in good health? Thanking you in advance for your reply".

Maria - Oct. 2 -

".....It seems that Vincent and Juanita have many things in common. Nita's medication is also primarily to suppress her epilepsy. If it does anything to suppress AHC remains to be seen. We tried Neurontin and Tegretol with some success. However, Dilantin has played the dominant role. This week we started on a relatively new anti-epileptic drug, Topamax. ... she has had several bouts of AHC with limited seizure activity. Her problem is the increasing problems with balance. She starts falling a lot. We are also in contact with a family in Montreal with a daughter of 35, who has AHC. She is we believe the oldest know case. The progress of her AHC is also causing decreased mobility. She now has to use the wheelchair. Seizures are also a problem.

Juanita does not see a psychiatrist as her behavior is not that troublesome. She is very social and likes to talk. She attends a workshop like your son. She is unable to go on her own for physical reason. She lives with one other young woman with a handicap in a five bedroom unit next to my house. Two part time attendants (care takers) live with them. My family is also closely involved.

Some nine years ago we started an organization (cooperative) with people with disabilities and their families and friends. The aim is to allow the persons with disabilities as much freedom and choices as possible while providing the supports where and when needed. It has worked out well. The organization now has 60 persons with disabilities living where they choose with the assistance of staffing they hire. The government is funding them....."

Dick van der Baaren - Oct. 3 -

"...I have a daughter Amanda (8) who has experienced something similar. Since going on the Flunarizine at 13 months she has been pretty consistent at an episode every month to six weeks in the evening lasting until she goes to sleep (about 2 hours). Last September 1998, Amanda had an episode that started in the afternoon and lasted about 3 weeks. Unable to use one or both arms, legs, loss of sight, etc. After that she came out of the episode sloooooowly. She is still not as

strong or balanced. The biggest change was her emotional state. She is very aggressive, lack of attention and uncooperative. We have put her on an anti-depressant in January '99 and have had positive results with attention and cooperation. Aggressive behavior was still a BIG problem. Last month we changed her to Prozac and it seems to be addressing all three, we'll know better in about a month. In addition, Amanda has not had an episode since, almost 13 months. I guess I'm trying to say her episode that lasted so long and was out of character did indicate a change in the disease for her, what this means in the long run, I don't know."

Catherine - Oct. 4 -

"...I have a feeling Jayme's patterns must be changing too. He is on day 12 now. I hope his attacks quit like Amanda's did after this attack is over...Jayme does still take Flunarizine and we recently put him on Clonazepam. I don't think the second must be helping..."

Donna - Oct. 5 -

"We are parents of a girl 3 yrs. old. Celine, who is AH."

Pascal & Marie - Oct. 5 -

"It's Mindy, Hailey's mom...just writing to share my feeling...we are thinking about having another baby...Hailey will be 3 in Jan. and of course she is our only child...but of course I am scared to death of having another child with AHC...I'm sure others feel the way I do!! It's silly but I just wish someone had the right answer for me, ye know?????....."

Mindy - Oct. 19 -

"...I know what you are going thru. When I learned I was pregnant again (when Abbie was 4 yrs.), I was petrified. I was so afraid that the baby would be born with similar problems. Even though I got all kinds of assurances from the doctors. I was also concerned that I wouldn't be able to continue to devote enough time and energy into caring for Abbie as well as her two older sisters. I almost drove myself crazy with worry. Well, my beautiful fourth daughter, Maggie, was

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born as perfectly healthy as could be. And as it turned out, she has been the most wonderful gift our family could have received. she is Abbie's best friend and sometimes I wonder what Abbie would ever have done without her! Abbie is now 10 and Maggie is 6. Maggie has surpassed Abbie in all developmental areas, but she is still the little sister. It has been all of Maggie's incredible strengths and gifts that have been such a good example for Abbie. I honestly don't think Abbie would be as far along mentally and physically as she is having to keep up with our very rambunctious, very precocious, very very special gift, Maggie. I wish you the very best of luck."
Kathy - Oct. 19 -

"Our Ann, with AHC, is eleven yrs. We had the same fears as you about having another baby after Ann. We let ten years pass before we were ready for another baby. Although pregnancy is living hell because we thought of the possible repeated outcome, we kept our courage. We now have a beautiful, healthy baby boy who is now 21 months old. Ann's disorder has made us appreciate many things, especially health. We cherish this little boy's every move and word...things that most parents take for granted. We continue to test fate since we are now expecting our fourth child in the next two months.

We had always been advised that the chances of AHC to occur again, was very slim, no worse than any other possible disease, disorder, etc."

John Richards - Oct. 20 -

"Recently I was phoned by a family in the North East of England, Liz and Stuart Hall in Co. Durham who are not on the internet.

They have a son Jack with AHC who we met at last year's UK meeting. He is now 3 yrs. (They also have a younger son without AHC and have sent sample of all their blood to the genetic project in Utah).

Jack had been having regular AHC

episodes and often accompanied by pain and extreme discomfort so that originally he was diagnosed with epilepsy. However as is typical of AHC, his episodes were relieved by sleep. The consultant in Newcastle suggested the family try Triclofos, a sedative, to help Jack to sleep. The family have found that if they give Jack Triclofos at the onset of an attack and he goes to sleep, when he wakes up again the attack has gone i.e. it does not resume after a short while and the effects of sleep have worn off. This is a great relief to this family where the child had suffered great deal on a regular basis. They try to give Triclofos now at the beginning of every attack; it appears important to give the medication and induce sleep very early in the attack to ensure the attack does not resume when Jack wakes up. Liz reports that the onset of attacks is more frequent with this regime but they have been able to avoid Jack having a painful episode for some months. The family were anxious to pass on this good experience. Since they are not on the internet, you can call them in the US on 1388-810604.

Through the hospital pharmacy information service, I found out that in the UK, Triclofos does not have licence for use in children but is prescribed for adult insomnia. It is produced by Norton Health Care and the patent on the product has expired. According to the pharmacist this medication is related to chloral hydrate and acts through the same active metabolite.

The experience of the Hall family appears similar to that reported last year for some children in France and Italy taking Niaprazine.

Any comments or replies to this message I will send on to the Hall family...."

Alex - Oct. 21 -

"We just got back from Disney on Sunday, what a great time. The Give Kids the World Village was truly a nice place to stay and they really make everything easy for you. The people there were so nice. If anyone is going to Disneyworld, I would highly recommend stopping at their Guest Relations. They have a great pamphlet called Guidebook for Guests with Disabilities. It tells you

how to get around Disney if you or your child is in a wheelchair, what rides accommodate wheelchairs, and how to go in the back way. We used a park wheelchair the first two days because we were afraid of losing ours, but when we found out how attentive all of the park employees were, we used Jake's chair from then on. Most of the time they would take it to the exit so that it was there when we got off the rides. If your children really enjoy rides and are 48 inches tall, I would recommend going to the new Universal Studios Island of Adventure. What a blast!! The Spiderman ride was really fun. Jake's favorite was to meet all the Disney characters. When the employees saw Jake's Give Kids the World badge, they took him in the back way and he got to meet all the characters by himself. Boy did he love that. If anyone is interested in hearing more about the parks or the Give Kids the World Village, please let me know."

Becky - Oct. 20 -

"...my name is Isabel and my cousin Erika has AHC. She is 18 yrs. and I just want to share my aunts situation with you. Erika is the oldest in her family and my aunt did not know what kind of illness Erika had until maybe four years ago (they live in Mexico and the situation there is very different). So, she gets pregnant two years later and Fernando was born in perfect health. He is 16 now and is a big support for the family as a brother and as a son. It helps to keep an emotional balance in the family...."

Isabel - Oct. 20 -

"I am Nandana - Vishwa's father who is living in Sri Lanka. Vishwa is 10 years old and hardly gets any attacks now. Vishwa is the only kid with AHC in Sri Lanka and we feel quite isolated here as we have no contacts with any person even in the Asian continent.

I want to get some information to take a big decision on his education and I will be grateful if you can please take a little time to answer me. My e-mail is nandanap@slt.lk Could you please write a few lines and send me the following information about your AHC kid?

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1. Does your AHC child get special payments or other benefits from the government by reason of him/her being AHC?

2. After diagnosing your child as AHC, how many times was he/she hospitalized for AHC episodes or seizures connected to AHC?

3. If anyone of you have obtained medical insurance for your AHC kid, how much is the premium (annual) that you pay? (is it the normal premium or do you pay an extra amount by reason of AHC?)

4. Your mailing address (if you don't mind). Thanks."

Nandana

- Oct. 29 -

"I am the president of the French group of families concerned by AHC. We are for the time being 24 families in the association (out of 35 cases of AHC known in France). Some of you already know our group thanks to our website: www.afha.org.

As each of you, I received every message sent on the forum "challengenet" which is so useful for sharing our experiences with our kids. As I am too busy due to my personal job and my 'free job' as president of the French association, I have never sent any message by challengenet, except this one about the blood collection for the American genetic project of Dr. Ptacek.

I took the decision to send you this message after having received the updated situation of the blood collection from Dr. Ptacek's secretary, and I must recognize that I am not happy of what I've read.

1. Do you know that one of the decision of the last symposium about AHC organized by the Alternating Hemiplegia Foundation A.H.F. (Seattle 1997) was an American genetic project from Dr. Ptacek (Utah) in order to have a better knowledge of the origin of AHC.

2. Do you know that before starting this genetic study, Dr. Ptacek needs at least 80 blood samples?

3. Do you know that more than one year after starting the blood collection in USA,

only 45 blood kits have been returned, and that the genetic study HAS NOT STARTED UP TO NOW!!!

4. As soon as we have been aware of this situation in France, we decided to ask French families to participate to the American blood collection. 21 families (out of 24) accepted immediately and 16 blood samples have already been sent back to Dr. Ptacek's office (the others will be returned within one month).

5. In spite of the French participation, the number of 80 blood samples is still not reached, and we are going to ask other European families to do so, but they are very few.

So PLEASE, American families, contact Dr. Ptacek's secretary to receive at home your kit, the email is: jkimball@howard.genetics.utah.edu It's so easy...If you are in contact with other families concerned by AHC, not connected to the internet, give them this message.

I do believe that each family must be aware that this genetic study is the only one which exists, and it is our responsibility and duty to make it STARTING by sending blood kits; yes indeed, how could we require more involvement from scientists in AHC and at the same time not being able to provide 80 blood samples when one project exists???

I'm sorry for the this long message, but I am sure most of you agree with me, and what is sure is that our AHC children, which are our common point, are waiting for a better life, and better treatment, and we must help the doctors for that, don't we????

Thanks a lot for having read this message, feel free to answer to me either by challengenet, or if you had rather a personal answer with my email: dponcelin@aol.com

My best regards to all of you, with a special thought for our AHC children."

Dominique Poncelin - Oct. 29 -

"Thank you for your letter - you are absolutely correct - we are so fortunate that Dr. Ptacek and his staff are will to undertake this study, and yet we, the ones who have the most to benefit, are delinquent in our participation.

However, allow me to relate the great difficulties that our family has encountered in attempting to have our blood drawn following the receipt of our kits - all of the medical laboratories that I spoke to completely refused to draw blood for this project, despite my offer to pay a fee; most of them said that they do not draw blood unless they are performing a blood test in their lab. The medical office in my company has also refused, citing legal liability concerns. Our pediatrician is also very reluctant - he says that he does not do this sort of thing! Finally, we were able to have my daughter's sample taken, because he has to take another blood test and the medical laboratory agreed to fill some extra vials for Dr. Ptacek's study, However, my wife, myself, and our daughter's siblings' samples have yet to be taken. I hope to prevail upon our pediatrician and overcome his reluctance to draw the samples, but if that does not work I do not know of other options.

Have other families encountered these sort of difficulties from the medical establishment? Does anyone have some suggestions as to how to get these blood samples drawn?"

Ben Jungreis

- Oct. 29 -

"I am sorry you have had such difficulties finding someone to draw blood for the research project . This happens occasionally and it always amazes me because the procedure is very simple and all the materials needed are included in the kits. If you would please forward the name and phone number of the physicians office that is most convenient for you, I will give them a call and help arrange things. I can fax them a prescription to have the blood drawn if needed. Thank you for your response."

Jenny Kimball(Dr. Ptacek's office)

- Oct. 29 -

"We also wondered how to get the blood. Our problem was trying to get everyone together at the same time to give blood since it need to be sent out soon afterward. I am a nurse and I don't really have much experience in drawing blood (just giving it) and felt uncomfortable

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about taking it from my children. After the kit sat here for about a month, I decided to do it myself. I wouldn't recommend it for anyone else, unless they had experience. Actually, it went pretty well and the kit has everything you need. My advice is to ask your neighbors or friends if they know anyone who would be willing to take the blood. I know that if someone asked me to do it, I would be willing. We gave the kits lollipops to suck on (and divert their attention) while taking the blood and they did great."

Becky - Oct. 31 -

"Mr. Poncelin's message is an eye opener to all of us. We are all using Flunarizine (and some other drugs in combination) but we all know the results are very limited. Our children continue with AHC and their problems. The question remains, how many of our children will be able to live independent lives?

As Dominique very correctly says, genetic project is the only research available at the moment. No body has ventured to do any other clinical trails or research on new drugs. We must be thankful to Dr. Ptacek and his staff who has been very prompt to our requests.

Have we taken AHC for granted i.e. that my son has to live with it and nothing will happen to change it. To be very honest I felt ashamed. The genetic study may not find a cure for AHC but will certainly help the doctors understand the causes better and then...who knows? I want to share my experience with the blood kits. I live in Sri Lanka - a development country in South Asia where medical facilities are not very pleasant. Medical professionals (even the nurses) have no regard whatsoever for what a layman says. You wouldn't imagine how their eyes went up when I went to them and talked about drawing my family's blood for research. Fortunately, I knew some doctors and I was able to convince them (the doctor who diagnosed my son Vishwa as AHC is in Brunai now). No other doctor knows about AHC here and

nobody cares to learn about it!

When we finally got down to it, we realized that the quantity of blood required for research is more than what is needed for normal tests. It was hectic for Vishwa and we thought that he would get an attack when blood was being drawn. He was so pale and scared. It sure was very traumatic for him. I think we drew a little less than the syringe would hold (from Vishwa). I must mention that the staff at Dr. Ptacek's office was extremely helpful and very prompt in their response to my questions. It is time that we should take even an extra effort and cooperate by sending the blood samples.

In addition, may I also suggest the following steps.

1. To appoint a team (parents who are suitably located) to work on a proposal to invite the attention of the neurologists or neurological institutes to do research on other aspects of AHC (aspects discussed at the 1997 Seattle symposium) I think it is important to have one coordinating body (or person) for the IFAHC and APEHA to liaise with the medical professional because this will prevent duplication of correspondence and other work.

2. To appoint some doctor (who is interested to compile the knowledge and experience of parents who have tried various drugs in the treatment of AHC. We all know that different drugs and combinations have worked for different kids. Maybe the future AHC cases could then be treated with less experimentation and the best combination could be found quickly. Why should every parent go through the same process of trial and error? I am a lawyer and work for the Sri Lanka Customs Dept. I will be please to contribute in any limited way I could from Sri Lanka. Sorry about the long message. Wish you all the best in your child's situation. Let us not lose hope...and sleep over it!

Nandana - Oct. 31 -

"There are never guarantees when having a child. If you have planned to have more than one, I wouldn't think twice. Another child, AHC or not, would still be a blessing. Just my feelings!"

Marcia

- Nov. 1 -

"We returned from Disneyworld on Sat. Oct. 30th. We also stayed at Give Kids the World Village and had a truly wonderful time. I never expected so much but it made actually dealing with the vacation much easier. The Village was great and we never waited in a line at the parks. Jennifer will never forget her trip and neither will we."

Marcia

- Nov. 1 -

"Hello, can anyone help me? I usually get my Flunarizine from Mexico. My friend who travels to Mexico came back with less than usual, and time has seemed to go by faster than usual this month, so now Dave only had a little bit left. Can I borrow some (a couple of week's worth) until I secure my supply from Mexico. (by the end of this month)? I am a single mother (widow) of Dave and his four sisters so I find myself to be a little busier than is probably efficient and I find myself short of time and medicine. Let me know if you can help..I will gladly reimburse any postage expense. My e-mail is samson6@silcom.com and my address is 3105 Calle Fresno, Santa Barbara, CA 93015; tel.#805-682-3205.

This weekend I am going to find time to sit down and write about Dave's experience moving into a group home (it has been very successful) and about the difficulties we have had in the past with behavioral problems (which seem to be tremendously improved since Dave has 'moved out on his own' as he likes to say!) He is doing better than my wildest dreams and I will share this success story with you this weekend. Please let me know if you can help with the Flunarizine. Thanks"

Nancy

- Nov. 6 -

"Looking at the larger picture of Claire and the use of Clonazepam we have seen major benefits in terms of the reduction of incidence of episodes. Claire takes 0.5mg x1 morning and 0.5 x 1 before bed, night doses have made her very 'distant'.

Overall, we are regularly seeing periods of 10-16 days entirely free of 'floppy episodes', and a much quicker recovery from these episodes when they happen.

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The times where Claire is completely incapacitated i.e. both arms, legs, speech etc. have gone for the moment.

Yesterday, we walked to the beach (about 10 minutes), went swimming (very high risk of a floppy), and then played with the dog on the beach for half an hour with only a slight (one leg) floppy which went away in 15 mins. So, in summary the frequency and the severity have both shown a marked decrease since the April introduction.

Claire also takes Pizotifen 0.5mg x 2 at night and has done for 3-4 years. Hope some of this helps.

Andrew - Nov. 7 -

"We need your help! There is a family whose six year old daughter developed seizures last year. On Friday night, she had a grand mal seizure that lasted two hours. They are about at the end of the road, as they have tried many different drugs with little long term effects.

If your child has seizures, what drugs have been used to keep the seizures in check? What was the dose? Are the seizures under control now? I know that several of the children have been on the Ketogenic diet with success. Could you please let me know when your child was on it (how old)? Was it successful? Thank you so much for your help.

Lynn - Nov. 8 -

"Although my daughter, Juanita (32), has suffered from seizure activities they have only been severe on one occasion. She has been on 175mg Dilantin and 60mg Phenobarbital which controlled seizure activity fairly well. The same combination in slightly higher dose is used by a young lady (34) in Montreal with good success. This lady suffered from severe seizures which are now reasonably well controlled. (she also has AHC). Since about 1 month, Juanita has replaced her Phenobarbital with Topamax (Topiramax) Till now the results are hopeful. But it is too early to say if it really helps. We have not reached the therapeutic level yet. Topamax was

recommended by the neurologist because there were some indication that this drug also had anti-migraine properties. He thought it might be worth trying for AHC patients."

Dick van der Baaren - Nov. 9 -

"We have had success with introducing Lamictil together with Epilum and Frisium which Gabrielle was already on. Gab has been on Lamictil for nearly a year now and no hospital emergency admissions so far. Any seizures which have occurred have abated or been subdued with rectal Valium administered by us."

Paul & Carmel Shannon - Nov. 9 -

"We have found that the most effective therapy for aborting a seizure once it has started is Ativan."

Ben - Nov. 10 -

"Ann, our daughter, is now eleven yrs. old. She had her first grand mal seizure at the age of three and she has had one or two each year since with the exception of the last year and a half. We have tried many anti-convulsants, with no success. In fact, they would increase the chances and intensity of any hemiplegia spells. Our only prevention is .025mg of Clonazepam (Klonopin) each day (Ann is around 70 lbs), which is a minimal dose. Any increase in this medication or the prolonged use of Ativan has created major behavior problems.

We also have an injection (injected in the leg) of Ativan ready at all times in the event that Ann appears to be starting a seizure. The sooner we intervene, the more likely we are to stop the seizure and prevent any hospitalization. Also, Ann's life is very controlled...She does not go outside very often or for very long (10 to 15 minutes) and we try to be very low keyed during the holidays or special events.

Ann has had seizures that have lasted up to one and a half hours. It is very frightening. It is key that you are assertive in the emergency room in order to get medication into your child ASAP. The longer they wait to put the medication into your child, the longer the seizure will last and the more medication

that is required to stop the seizure. Check with your doctor about the Ativan injection. It may prevent some visits to the hospital."

John Richards - Nov. 9 -

"It's Mindy, Hailey's mom....Does anyone know about Diamox...why some kids are on it and if it works...please let me know. Thanks."

Mindy - Nov. 30 -

"I have heard about a positive effect of this drug but Aurelie is not yet treated with it. When we met Dr. Goutieres in July she told us that some doctors are using it. Our next visit is planned for January and we plan to ask some precision. I will keep you informed.

You may be wondering why we have not yet tried this drug with Aurelie. It is mainly because she is currently quite well with her actual treatment (10mg Flunarizine and a maximum of 7.5ml Niaprazine 3 times/day when she is having an important access).

A friend of mine (a doctor) suggested to give her a lower dose of Niaprazine (2.5ml for instance) as soon as we notice she is becoming aggressive or when we can predict she is going to feel a particularly intense positive emotion she wouldn't be able to contain in order to avoid some episodes. We have not tried yet as we first wanted to discuss it with Aurelie's neuro pediatrician but the suggestion sounds interesting for some episodes especially those triggered off by an intense positive emotion (when seeing her uncle after a certain time or when receiving a new toy particularly expected, or when going to the swimming pool for instance)."

Mirjana - Dec. 1 -

Note: If you would like more information or would like to respond to any of the emails in Internet Corner, please email or write or call Lynn Egan.

"Friends are angels who lift us to our feet when our wings have trouble remembering how to fly." -- Anonymous

Midwest Gathering

(Continued from page 3)

Laurie, Ray, Allison, Rachel Baker, Madison, WI
 Brenda, Scott, Torrie, Kelsie Dailey & grandparents, New London, WI
 Betty Jo and Danyelle McGhee, Sturtevant, WI
 Khalid Adblerahim, Nahid Ahmed, Waleed, Mohammed, Brooklyn Park, MN
 Dr. & Mrs. Silver, Maywood, IL
 Mary Smith from StarNet & Daughter, Amboy, IL

Y2K, Does It Affect You?

There has been so much talk about "What if?....." Just as a reminder, be sure to have enough of your child's medication on hand in the event there are some Y2K glitches.

For those of you in the U.S. who get Flunarizine from other countries, think about ordering extra, just in case.

If you have any problems, please call Yvonne Ockman at (504) 537-7147 or Lynn Egan at (650) 365-5798.

NEW IFAHC Website Address

The new website address is:
www.ahckids.org

We will be changing the look of our site. If you have any suggestions and would like to contribute, please send e-mail laegan@aol.com

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

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. 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 Lake City, UT 84112
 1-800-444-8638, ext.5-9399
 FAX: 1-801-585-5597
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AFHA/AHF website

The e-mail address to post messages to the AFHA/AHF bulletin board is AHC@challengenet.com. If you are not receiving messages from the bulletin board, you will need to subscribe again.

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