



THE ALTERNATING HEMIPLEGIA OF CHILDHOOD FOUNDATION

Phone / Fax 650-365-5798

www.ahckids.org

"Our vision is to find the cause(s) and a cure for AHC while providing support to the children with AHC and the parents who care for them."

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WHAT A YEAR IT HAS BEEN?!?!

By Richard George

I'm going to try to give you an overall picture of what the Foundation has accomplished and look for answers from you on other issues.

GREAT NEWS!! Dr. Kathryn Swoboda's grant has been funded by the Foundation and we are looking for great things and many answers to come out of this project. This Grant is a renewing Grant for 2 more years so let's all say a prayer that Dr. Swoboda's research yields the answers we are all hoping for. This Grant was made possible by many good people who have either donated or raised funds for the Foundation. We are grateful to those who have worked so hard and who continue to strive to fund this research to help make curing our children a reality someday.

The Salt Lake City meeting held this past summer was a very interesting one. In particular, listening to Dr. Swoboda and Dr. Silver and how far they have advanced on acquiring information from all the families and how AHC is different in so many children. Getting to know all of the parents and listening to the stories of their children was enlightening to say the least and it made me feel as if no one is in this alone. I highly recommend if you have not been able to attend one of these meetings that you do so in the future.

As always, I must mention what makes all this possible. It's the hard work of all who volunteer and the monies raised to actually do the research, because the lifeline for our children is dollars. Without these dollars, could we have funded Dr. Swoboda's research??? NO WAY. And in order for us to continue renewing this research Grant, it's (oops -- it's that ugly word again) dollars. Please try to find it in your heart to do anything you can to help our children. There are many out there who know the pain but now they have the sweet sense of accomplishment because they have made the Grant possible.

We have only a handful of people running the Foundation and we need more committed and dedicated volunteers. A handful of people cannot run this whole Foundation. I know we are all extremely busy with our children, but guess what?? If we don't do it, no one else will. My e-Mail address is: richard7@ameritech.net and my phone number is: 1-888-557-5757. Please, to everyone out there, e-Mail me with your thoughts, your ideas, your suggestions, your criticism, and don't forget to pray daily so that we will continue on the right path.

Every day I am haunted by a phone call that I receive about 5 times a year. This call comes from one of our AHC children and she sometimes calls to just say hello; "What are you doing?" and "Thank you for having the Foundation to help me". The one big thing that haunts me the most is the question she asks me that I cannot answer. Her question is: "When is my cure coming"?? Please help me find this answer so that we can all tell her one day HERE IT IS!!

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Ordering Flunarizine

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Several families have been using Marks' for several years. Recently, four families' prescriptions ran out and they ordered and received their flunarizine in a timely manner. This will be a more direct and efficient way for each of you to order new prescriptions and maintain your refills.

If you have any questions or concerns, please feel free to call me at (toll free) 888-225-3353 or email me at laegan6@sbcglobal.net .

Insurance Pays for Flunarizine

by Lynn Egan

Recently we were able to get our insurance company, Blue Cross of California through my husband's union, to pay for flunarizine. We had been contemplating for several years about seeking coverage, just never got around to it. We wrote a letter explaining Kathleen's disorder and her need for flunarizine. We also had her neurologist write a letter to support ours.

We were turned down but given the option to appeal. So we did. We were granted a hearing. We had two choices; one was to mail in all the new supporting information or appeared in person. We decided to show our commitment in trying to get coverage and so we appeared in person with our supporting information; medical journal articles about flunarizine as well as our personal experience, Kathleen's history, our knowledge of AHC and flunarizine's efficacy for Kathleen.

We were notified two days later that they would make an exception for payment of flunarizine I believe that our appearance and appeal made the difference.

If you would like any further information regarding our process, please feel free to contact me.

Video Tapes Available

For those of you who were not able to attend the Salt Lake City family meeting, video tapes of the conference are available.

The video includes DNA Research Update, Dr. Kathryn Swoboda; Overview of AHC and Summary of the International AHC meeting in Paris, 2002, Dr. Kenneth Silver; Database Update, Dr. Mylynda Massart; Neuropsychology Presentation, Josh Magleby; Social Services for Children with Special Needs Holly Balken, RN, MSN; Utah Family Voices Coordinator, Gina Polamoney; and Physical Therapy, Lee Dibble, PT, PhD, ATC

The cost of the video tapes are : United States \$5.00; Canada \$6.00; International \$10.00 Please send checks to: Lynn Egan, 239 Nevada St., Redwood City, CA 94062

At a glance.....

Dear AHC Families and Friends

Dr. Swoboda and I would like to share with you a summary of our research efforts over the past year and give you some early insights on the upcoming year.

In addition to the full time laboratory effort to identify the gene responsible for AHC, we spent a large part of 2002 expanding our clinical database. The clinical database includes relevant information from medical records, laboratory data, neurological evaluations of the children, neuropsychological evaluations and his stories of disease onset and progression for each child. We also began documenting all medications that each child has taken and any of the positive or negative effects observed on these medications. The goal of collecting this information is to further understand the clinical history of AHC and determine key trends shared among all of the AHC children that can be readily analyzed and interpreted.

In June of 2002 we held a small Northeast meeting with 16 families. We met for one very power packed day at the Embassy Suites in Manhattan. We began the day with a presentation from Dr. Swoboda over viewing the current status of the genetic research that is ongoing in our Utah lab. Then each family took a turn meeting with Dr. Swoboda for a neurological evaluation and private interview. Each of the parents also completed several questionnaires for our clinical database. Additionally, each child had an EKG taken of which there were no abnormal results found.

In July of 2002, we repeated this meeting formula at the Midwest Gathering of AHC families in Chicago. Here we had the opportunity to evaluate 30 more children and collect clinical information, and individual neurological exams with Dr. Swoboda. Dr. Janiece Pompa and graduate student Josh Magelby joined us and collected a significant amount of neuropsychological and cognitive information from each of the children. Analysis of this data has allowed them to postulate several cognitive trends associated with AHC that they hope to study further.

Recently, Dr. Swoboda and myself

joined Dr. Kenneth Silver in Paris France to present at the European Society of Pediatric Neurology Association Satellite Symposium on AHC. The data collected from the NY and Chicago meetings was presented in the context of this international meeting. We also had the opportunity to hear from the other physicians around the world who are working on AHC. This meeting generated much excitement and interest regarding further international collaboration of physicians and scientists to advance the research efforts focused on AHC.

In March, a handful of physicians and scientists will met in Italy in conjunction with the Italian AHC association annual meeting. This was our first opportunity to evaluate the Italian children and meet the numerous Italian doctors studying AHC. While we were there, the international team of doctors and parents met to discuss the specific research goals for the next year and how to design a new international clinical database which has been written up as a European Union Funded project by AHC parent Sveta Litharska.

Finally, this summer, many of the US families came to Salt Lake City, Utah to be evaluated by Dr. Swoboda and Dr. Silver and our team of Neuropsychologists. This was a very successful meeting where we were able to collect data on several new patients as well as patients that we had not previously evaluated. Families came from all over the US, many making it their summer driving vacation, and one family came all the way from Australia.

Since this summer meeting, I have moved on to the Oregon Health and Sciences University in Portland, OR, however, Mark Wride will be continuing to assist Dr. Swoboda on the AHC projects at the University of Utah. I hope to remain as involved as possible in the continuing research on AHC. Please don't hesitate to contact me for any questions regarding participation in our research or to update your children's files.

Sincerely,
Mylynda B. Schlesinger-Massart, Ph.D.
massartm@ohsu.edu

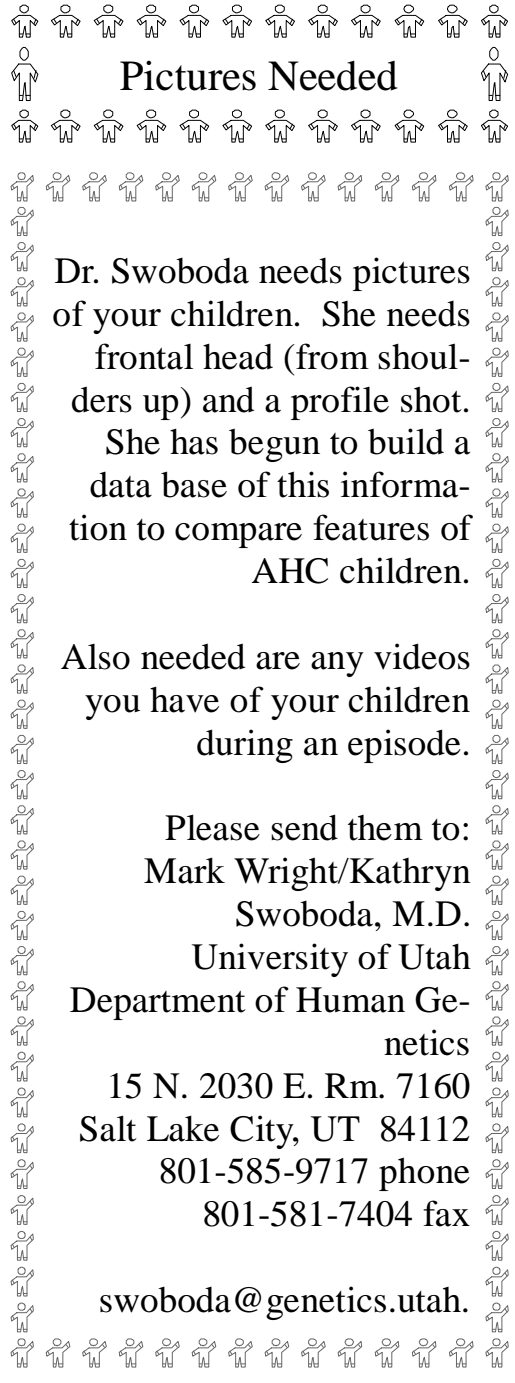
Alternating Hemiplegia of Childhood Research Update, 2003

Kathryn J. Swoboda, M.D.

The past year has been a busy one for AHC research. We are very excited to have received a generous grant from the AHC Foundation that has allowed us to speed up our efforts to uncover a genetic cause for AHC. Our database continues to expand, and more importantly, interest among our international and national scientific and medical colleagues continues to grow. We have established collaborative ties and research agreements with physicians in Italy and Spain in addition to well established ones in France and Canada to help spur these efforts on. AHC meetings this year in Italy and in Salt Lake City allowed us the opportunity to meet a number of new families and children and to see old friends, and collect additional valuable information for the clinical database to increase our understanding of the range of medical issues in AHC, and to help guide our scientific efforts. In conjunction with efforts to find the causative genetic mechanisms in AHC, such efforts are no less important in helping to guide other physicians in the care of AHC children, and to guide our hypotheses in finding a cause.

On the laboratory front, the continued collection of patients and families, particularly those with more than one affected child continues to be an extremely valuable and important focus and an ongoing critical research resource for genetic studies on AHC. With the help of colleagues around the world, we have now identified eight such families, and have available DNA and cell lines on seven of these families. We are currently undertaking yet another genome wide screening linkage study using the additional families who joined our efforts in 2003 to help look for shared clues that may provide answers to our many questions regard the genetic etiology. We continue to learn continually of new sporadic cases as well, and have more than 130 such children and families in the database who are actively included in our ongoing candidate gene analysis studies. However, these cases represent only a fraction of the many cases around the globe that we are aware of via contact from physicians and families.

We are in the process of completing work to refine a more efficient way of screening for gene deletion events using quantitative PCR technology, which we hope to implement for screening large candidate ion channels and other genes in early 2004. This should make our efforts more efficient, since southern blot studies, which we had previously been using for such screening, are extremely labor intensive. We have analyzed more than 20 candidate genes or loci over the past year via both linkage analysis and sequencing studies, and sequencing of gene candidates continues on a weekly basis. In collaboration with scientists at our institution and others, we hope to test a new gene chip technology in 2004 designed to screen for small deletions across the entire genome. While expensive, the benefit of this technology is that we can examine a much larger number of genetic regions in an extremely efficient fashion. We are extremely grateful and excited about the support of the AHC Foundation, and the tremendous trust that allows families and physicians from around the world to work together to find an answer to the many questions still unanswered regarding the cause of AHC.



Pictures Needed

Dr. Swoboda needs pictures of your children. She needs frontal head (from shoulders up) and a profile shot. She has begun to build a data base of this information to compare features of AHC children.

Also needed are any videos you have of your children during an episode.

Please send them to:
 Mark Wright/Kathryn Swoboda, M.D.
 University of Utah
 Department of Human Genetics
 15 N. 2030 E. Rm. 7160
 Salt Lake City, UT 84112
 801-585-9717 phone
 801-581-7404 fax

swoboda@genetics.utah.

Letting Go

By Deanna Huizing

Contemplating the many things that have been occurring in my family life, I realized that from the moment of our children's birth, we as parents must learn how to let them go. Loving our children unconditionally is not a question. The fact is, we must also teach our children, with or without disabilities, what they need to know to remain as independent as they can be when they reach adulthood.

The areas you focus on will be different in some situations, but the goal is the same, Independence, or as much as is possible. Some children, such as my youngest son, may never reach total independence, but they will learn to do many things for themselves, if we teach them.

Now that my son, David, is in his early teens I can see how similar he is to others his age. He has the same drive to be his own person as other teens. David wants to be allowed to do things apart from his family, even though he still needs someone with him. He wants to make his own choices whenever he can. David wants to be out and around friends more than with his family. These are the same things my other four children struggled with at this age.

Our struggle is finding ways to allow him to do these things, keeping his safety and limitations in mind. One thing we have found helpful is to give him control of the little things, which seem to be big things to him. For instance, he is able to choose: what he wants for breakfast, what he wants in his lunch, and what he will wear. The meals may not be totally balanced or healthy and the clothes may not match, but when I look at what my other teens would eat or wear, there

is not much difference, and they



survived.

We've learned not to make issues out of things that don't matter and learned where to draw the line on things that do matter. For example, our son used to love to wear his pajamas all the time, so we made a rule, "he could wear pajamas whenever he wanted, in the house, but he must put clothes on before going out". This worked for him because he could be in control, yet he still learned where and when pajamas were acceptable. He is now going through an opposite phase and wants to wear his clothes to bed! Now the rule is, "that is OK as long as they are clean!" If we were to fight over these things we would always be in battle.

As parents of a child with a disability we've had to let go in other ways as well. Reality kicked in, and we've had to let go of our dreams. There were times when we grieved over the things he would never do and finally there came a point where we could accept him just the way he is. When we could finally say "God doesn't make mistakes and God hold's his future" we were able to focus on what he could do and what things we needed to do to ensure that he could be all that "He could be."

Another way we had to let go was in learning to accept help. We used to think we had to do everything for our child. We had to be realistic, for example, when he was in the hospital someone had to be with him day and night, but that

person didn't have to be us. We needed to accept the help of family and friends and service providers, and get some sleep. This way we were refreshed and much more able to handle the long days.

Our son has grown physically and in strength, and we have had to let go even more, allowing others to help with his care much of his day. This was hard at first, but the benefits have been tremendous. Not only are we less stressed, but he is much happier. His needs are addressed more thoroughly and he is out in the community with other kids his age.

We are still in process of letting David go. We know that he will "grow up" and leave home to "live on his own", even though he will need assistance. This too is a normal phase of life. We have already seen two of our children leave home to become independent adults, and our goal with David is to let him become as independent as is possible.

I once read a poem when our son was in the hospital that really touched my heart and really made me think, Although I can't remember it the part which was installed in my memory was that our children are not our own, but are lent to us for a little while. They belong to God and He will want them back one day, our job is to love them and then let them go.

*The hard part is
learning to let go.*

Reflections

There are many of us who go through the same ordeal everyday. With a kid who has AHC, we often sacrifice to accommodate his or her medical, educational and emotional needs. Some of us ask the question, "Why us?" "Why me?". Most of us find relief in the belief that God has a plan for everyone in this world, or with our strong faith in God, leave it to Him. Many parents whom I personally met, and whose thoughts I read on AHC chat board, inspired me to be more courageous, patient and content. Coming from Sri Lanka, a predominantly Buddhist country, I take relief in this old Sri Lankan saying; *life is like a river. The river always travels looking for lower ground, seeking to rest in the calmness of the valley. But it has to crash and fall around rocks before it can hope to reach the valley.* This is what makes me go on. Our son has AHC and is 14 now. I have learned things, I would never have learnt if not for his existence. I am convinced that the majority of AHC parents will say the same. We fall, crash and sometimes break. Each time we break, we learn, become stronger and wiser.

Life still goes on. Like the river.

No matter what our explanation is, we still have the same problems to cope with everyday, and, when one problem seems to be solved another surfaces. We still worry about what the future holds for our AHC kid. I used to wonder too, what and how we should shape our AHC son's present, future and, more importantly, what lies ahead for us battling this strange, mysterious condition that baffles even the most prominent neurologists.

Last week, I saw a mentally handicapped child in the swimming pool. He was so care free and happy and playing with himself in the pool. He didn't look around to see if everybody approves of his behavior. He was making some noises, laughing, playing with the water. We all know what we think of a person with Downs Syndrome. We feel sorry. I know of some people who are uncomfortable with them. It is difficult to "admire" a mentally handicapped person. Then I suddenly realized, I too have always pitied mentally handicapped people. After watching this child play for a while, I asked myself, "when did I feel like that last time?" I couldn't think of any time I

felt just like the way he was feeling. He was so cheerful and happy. He had no reservations about living his happiness. This reminded me of the way how my own son plays in the bath tub. This reminded me of the way he plays with water – with the garden hose, water gun or just splashing water or whatever object that he has in his hands. Then I remembered with a sharp tingle of guilt, that we hardly admire or encourage that. We don't allow him to have that kind of fun – mostly because it is not the type of activity we expect from a teenager. We keep pushing for "age appropriate" behavior. We are very happy when we see such behavior in him. Then it struck me, why we have these expectations even from our AHC kids. It is the accepted social standard, what the society expects to see in an individual of a certain age. We are so entangled in this social standards and expectations, (many of you will think it is unrealistic to breakaway from them) we sometimes forget to ask ourselves the simple question, "what is happiness?" If only we could say "happiness is being happy" I thought we could change much in our children's lives. I was amazed how simple it looked.

I mean happiness.

That day, I came home and our son was playing in the backyard, throwing a stick and a lid of a tin at a tree. When it struck the tree, making a loud noise, he too made some triumphant noises. As if to proclaim, "I did it!"

I asked, "Are you having fun?" He didn't answer, but looked flabbergasted. He surely felt guilty. He nodded, happily. He probably expected me to say, "That is not something you should be doing. Don't make those noises. Play quietly. Take some of your toys in the house, and be quiet."

I reassured him, "Have fun, and play safe." That night, I found him to be very relaxed. I felt that strong bond that we seldom experienced since he became a teenager. Our family had a very pleasant and relaxed conversation at the dinner table. My son was more talkative than usual. I felt that he was also more receptive and respectful towards what others said. He was happy.

Now I keep reminding myself, happiness is simply, *being happy*. I will do what makes him happy rather than what makes *me* happy.

Nandana Perera.

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Call Dave or Cindy Ryan to Purchase tickets or for more information (217)742-3253

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Fundraising in Boston

By Karen Venti

We had our 2nd annual Addie Rose Family Fun Day fundraiser for AHC. Despite a damp and rainy day, many friends and family joined us for a wonderful time. We had cookie decorating, ice cream sundaes, cotton candy, moonwalk, music, BBQ and a terrific silent auction.

Many local businesses participated in the silent auction this year...from restaurants to clothing and sports stores; from rock climbing birthday parties to ski passes and gift baskets; from a famous local artist's prints to an autographed Cam Neely Boston

Bruins hockey jersey and much more! There really was something for everyone.

Some friends at local Boston radio stations gave us some public service announcement time and someone said the local news station mentioned the event on their noon news program.

The fundraiser raised as much as last year, somewhere around \$9-10,000 with more donations still coming in.

We look forward to bigger and better and more streamlined next year!

New Toll-Free Number

Lynn Egan now has a toll-free number that you can reach her at **888-225-3353**.

Call backs will be within 24 hours of receiving your call.

Italian Update

Hello, I am Rosaria Vavassori, Alberto's mother, a 10 years old boy affected by AHC. I am also the President of A.I.S.EA, the Italian association for AHC which at present counts 26 families.

After the international AHC workshop in Paris (1° December 2002), in collaboration with the French association AFHA, we organized a Working Session in Italy (Foligno, 28 March 2003) . We invited doctors and researchers interested in AHC in order to define new research projects and their funding. The Working Session was added to the Meeting of the Italian families (Foligno, 29-30 Marzo 2003).

In addition to all the Italian doctors of our Scientific Committee, Dr Swoboda and Dr Schlesinger took part in the Working Session, together with Dr Alexis Arzimanoglou and Pr Jean Aicardi from France and Dr Tsveta Schyns from Austria.

Some interesting proposals for research were presented by the Italian doctors: clinic studies with Functional MRI and Evoked Potentials and a genetic screening proposed by Dr Casari (Milan) of a gene on chromosome 1, the same gene which has been recently discovered as responsible of the Hemiplegic Migraine, a neurological disorder similar, in some clinic manifestations, to AHC.

Dr Gobbi and his collaborator Dr Giannotta presented the Italian Clinic Database, a grant project funded by A.I.S.EA. As a conclusion of the working session, our doctors signed an agreement with doctor Swoboda in order to unify the Italian and American Databases and share the clinical data and blood samples of their respective cases.

The two following days, the meeting of the Italian families was held with the participation of 16 families and 15 children. There were also Raquel's (12) parents from Spain and Dominique Poncelin, president of AFHA, who presented the activities of the French association.

Dr Swoboda and Dr Schlesinger presented their genetic project and the American Clinic Database to the families and answered all their questions.

At present, some of the proposed projects have already started; the remaining and new ones are scheduled for the next year. In the meanwhile, in order to facilitate Dr Casari's research and any other new genetic project, even international, we are completing the Italian Blood Bank by the end of this year.

Let's hope that good news will result from all these activities, thanks mainly to the collaboration between doctors and the associations of families, at an international level.

I want to thank Dr Swoboda and Dr Schlesinger for their coming to Italy and for their deep involvement in the research for AHC. A special thank also to Lynn, she has always helped and supported me since the beginning, when I had just received the AHC diagnosis for my son and was looking not only for information but, above all, for a friend who could understand me and my difficulties with the disorder.

My best wishes to you all. Rosaria

Bulletin Board

The AFHA hosts a bulletin board. Everyone can subscribe. Families post their questions, concerns and ideas regarding AHC and their children.

To sign up, go to www.yahoo.com. Click on 'Groups' on the left hand side under Connect. Type 'AFHA' in the box under Join a Group. Follow the direction and subscribe.

French Update

Workshop on AHC in Paris – December 1st, 2002

by Dominique Poncelin (president of AFHA – French Organization for AHC)

It was a very important moment that the international workshop in Paris gathered 24 international scientists, all involved in AHC, from various countries (North America – Europe – Middle East.)

It was important because it was the third world international meeting on alternating Hemiplegia. The criteria of diagnosis was clearly identified and the differences with other "nearby" syndromes were clearly analyzed at the first meeting held in Roma in 1992. New tracks of research, notably in genetics were decided at the second meeting held in Seattle in 1997. In addition, this workshop attempted to do a comparative point of the clinical observations of the disease and its evolution; the various treatments tried, their efficiency; the current state of the genetic researches; as well as a conference on the topic of "chanellopathies", which may have a link with the observed dysfunction in alternating Hemiplegia..

Important also because our French association, who number 37 French AHC cases, had financed this workshop .

I made the introductions at the request of Dr. Arzimanoglou, the organizer of the workshop. I acknowledge being impressed in front of this amphitheatre full with famous scientists for their knowledge of AHC. I then expressed my observations and wishes of the families. The words came out easily because I was thinking of our children.

Observation: The knowledge of the origins of Alternating Hemiplegia and its treatment has improved very little in the last 10 years. That is due on the one hand to the fact that it is in itself a very rare disease and difficult to study. On the other hand because of a lack of effectiveness in the collection of information and results obtained between the various specialists who are interested in it.

Wishes of the families: To establish, with the assistance and the support of associations of parents, a true international collaboration between specialists involved in clinical and genetic research for this disease.

I finished by saying that we must make this happen in order to give a positive response to the sufferings of our children affected by AHC, and also to do it in the memory of those who, unfortunately , already left us.

Personal conclusions of the workshop :

Some positive points :

1. First of all, "the nice surprise" was the number of participants in this international meeting on Alternating Hemiplegia. There were 29 speakers, coming from North America, from Europe and from the Middle-East and we were expected a "public of professionals" with approximately 80; Eventually, there were a little more than 200 people, specialists, scientists, coming there to listen to the talks. It was the evidence that this disease was not « so » ignored by the medical profession.
2. The quality of Dr. Swoboda's report on the "point stage" of the genetic study in USA. The specialists attending the meeting were impressed by the amount of work carried out in hardly 2 years. Nevertheless, for the moment « no result in sight », the genetic research goes on..... .
3. Positive too, the fact that the speakers present agreed well that the important thing was to engage the research on AHC at the international level, with the direct participation of associations of families. We organized a meeting the following day which gathered the representatives of associations from France and Italy, and it has been decided to organize a first " working session" over one day in Italy in March 2003, which will gather 4 or 5 specialists and the representatives in associations of families. The objective will be to discuss and make a presentation to associations of written and quantified projects,

Some « disappointing points » :

1. Even if it is not really a surprise, the talks of the various specialists clearly confirmed that we have not progressed very much in the knowledge of this disease for 10 years.
2. Disappointing also, the results announced as for a really positive effect of sibélium on the crises: seems to be effective at only 40% of the children on average. Nevertheless, this drug is the only one to have nevertheless a certain success and it does not present known side effects.

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Address Correction Requested