February 2002
Newsletter

Volume 1
Issue 1

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."*

INSIDE THIS ISSUE:

AHCF
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AHC National Parents Meeting in Chicago, July 26-27, 2002

Chicago is the setting for our National meeting this year. It will take place July 26-27. It will be set up similar to previous years with arrival on Friday and the general meeting on Saturday.

Dr. Silver, Dr. Swoboda and two of her team members, Mylynda Schlesinger and Josh Magleby will be in attendance and will be speaking. In addition, they would like to hold Clinical Evaluations on Friday and again on Sunday morning, if needed. The Clinical Evaluations will include DNA background information, doctor review and a cognitive evaluation. They will take about 2 hours. Depending on the number of responses, each session will be approximately ½ hour apart.

If you plan to attend and would like to participate in the Clinical Evaluation, you can make an appointment with Mylynda Schlesinger at 801-585-9717 or by email at mschlesi@gentics.utah.edu. .

We are currently looking at accommodations close to the O'Hare airport. We will publish the hotel and price in the May newsletter, however we should have the information sometime in March. Please feel free to call or email Laurel Castanedo at 847-202-3907; laurel907@aol.com; or Lynn Egan at 650-365-5798; laegan6@sbcglobal.net.

Itinerary

Friday

Families with appointments will meet with Dr. Swoboda and others for evaluation. Friday night will be an informal reception for everyone.

Saturday

The meeting will be from 9:00-4:00 with a lunch break. Saturday night will be open.

Sunday

Families with appointments will meet with Dr. Swoboda and other for evaluation from 9:00 – 11:30.

Babysitting and activities will be planned for the children during meeting times.

AHC INTERNATIONAL MEETING IN SALT LAKE CITY, SUMMER 2003

Salt Lake City will host the next AHC International Meeting. It will take place some time in the summer of 2003.

Everyone is invited and as plans start to be made, we will inform you of the actual date and further plans.

Mark your calendar!

Update and New Directions, AHC Gene Project

Kathryn J. Swoboda M.D.

We would like to take this opportunity to update you regarding a number of exciting developments in the AHC gene project. The work on finding the gene or genes causing AHC has greatly expanded in the past year with the transition from Dr. Ptacek's laboratory to a completely independent laboratory effort focused primarily on AHC. This effort remains under the direction of Dr. Swoboda, but brings together a number of collaborative groups at the University of Utah, Eccles Institute of Human Genetics as well as laboratories elsewhere in the U.S. and internationally to expand the effort to uncover the genetic cause of AHC. We have added a number of new team members to the laboratory this year who are an integral part of this effort. A brief summary of the special attributes they bring to the project and their primary roles are listed below. These include Mylynda Schlesinger, Justine Milligan, Josh Magleby, Victoria McMeen and Luke Miller.

Mylynda Schlesinger Ph. D. is a medical student who recently received her doctoral degree in Biochemistry and Molecular Genetics at the University of Utah. She has played a critical role in expanding and analyzing the collection of important clinical data necessary to direct our work. She brings complementary expertise and experience in techniques integral to our effort in the laboratory effort as well, including our current cell culture and RNA work. We expect that she will be a longstanding champion and partner in the AHC gene project.

Justine Milligan is a laboratory specialist with extensive expertise in techniques involving the identification of genes and genetic mechanisms causing disease. She was recruited from a molecular biotech company in Boston, and gained much of her experience in research efforts at the Brigham and Women's Hospital and Dana Farber Cancer Institute. Her time and focus is primarily dedicated to finding the gene or genes causing AHC, and her dedication and expertise has improved the efficiency and productivity in evaluating candidate genes which are potentially implicated in the cause of this disorder. Over the past few months she has performed extensive evaluation of genes at the translocation breakpoint in the family with AHC and a chromosome abnormality, as well as evaluation of other "candidate genes" including brain expressed calcium channel genes. She is helping with our current linkage analysis effort, a complimentary approach to try to identify other regions in the genome (all the DNA found in a cell in that individual that makes up the chromosomes) that might have a role in causing the disorder.

Victoria McMeen is a clinical research coordinator working with us on this project. She assumed Catherine McKenna's position after Catherine moved to Denver several months ago. She brings special expertise, passion and dedication to the AHC effort with her nursing and medical school training in pediatrics in the Ukraine. She has proved extremely helpful in obtaining and organizing data in a timely fashion to complement our laboratory effort, grant funding efforts and plays a critical role in helping with our documentation and institutional review board requirements. She also helps with tissue culture and processing of DNA samples, and plays a critical role in maintaining and updating our computerized clinical database.

Josh Magleby is a graduate student pursuing his Ph.D. in psychology at the University of Utah. He and his advisor, Janiece Pompa, Ph. D., have agreed to spearhead the effort in a neuropsychological study of AHC patients. He and Mylynda Schlesinger have been working with one of our Utah AHC patients, Carly, to refine techniques which can be used to help clarify some of the specific strengths and learning problems our children with AHC face as they and their families cope with the sometimes unpredictable course of this illness. One targeted goal of this research will be to create specific guidelines for families and teachers about the ideal environment

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and strategies for maximizing outcome in terms of developmental abilities and skills in children with AHC.

Luke Miller is an undergraduate student with an interest in the biomedical sciences. He volunteers his time to help us with any number of tasks, making him an important asset to our efforts. This includes packing FEDEX kits, helping maintain our literature database, stocking supplies, helping with paperwork, and numerous other tasks that make our effort run more smoothly and efficiently.

Adam Craner, F.N.P. is a nurse practitioner working with Dr. Swoboda at Primary Children's Medical Center. He recently accompanied Dr. Swoboda and Justine Milligan to France, where they had they opportunity to meet 22 patients and families with AHC. His expertise in performing electrocardiograms, skin biopsies and blood draws was invaluable, and allowed Dr. Swoboda to focus on obtaining critical clinical information from the patients and families. His delight in interacting with and working with children, and his compassion and caring in his interactions with the families make him a special addition to the team.

In addition to the above laboratory and clinical team members, we have begun several collaborations with laboratories at the University of Utah and elsewhere to help speed our efforts, and make them more efficient. A few of these are outlined below, with a brief update regarding current status.

Candidate gene analysis: A gene which, when disrupted in any way, is considered to be a possible primary cause of AHC is considered a "candidate gene". Candidate genes for AHC are many, and include 1) genes that might be disrupted by the chromosome breakage in the family with AHC and a chromosome translocation – of course this has already been the source of extensive work in the laboratory, which is ongoing. 2) calcium channel genes – this hypothesis has been appealing for two reasons; a) flunarizine is the only medication to date that has any evidence showing benefit in at least a subset of AHC patients, and its predominant function is as a calcium channel blocker b) familial hemiplegic migraine, a neurologic disorder which shares many similarities to AHC has been found in some cases to be due to disruption of a calcium channel gene. 3) Other ion channel and receptor genes which play a role in initiating, maintaining or diminishing the electrical activity in certain cells in the brain – these are numerous.

As we continue to work on the chromosome breakage issue, and pursue other studies to help narrow down our region of focus to find the gene or genes involved, we have obtained the help of the High Throughput Sequencing Laboratory at the University of Utah, under the direction of **Robert Weiss, Ph.D**. His laboratory has played an integral role in providing rapidly acquired high throughput DNA sequence for the international human and mouse genome sequencing projects. With his laboratory's expertise, we are able to analyze calcium channel genes, which are typically very large, at a fraction of the time and cost it would otherwise entail. This would be much more difficult and time-consuming to do on our own, and we are incredibly grateful for their expertise and willingness to assist us in our efforts.

In a new effort to identify other mechanisms operative in AHC, and to expand our effort to uncover the biochemical basis of the disorder, we have decided to obtain skin biopsies in some patients. Skin cells can grow and reproduce in culture, and are widely used to measure a number of critical processes that occur in cells, including some aspects of energy metabolism. They can be easily sent from laboratory to laboratory. We are currently growing up skin cells from a number of patients we visited recently in France, and will use protein and RNA (ribonucleic acid, which is made from DNA in cells) to do microarray studies in collaboration with **James Metherall Ph.D**. These microarray studies will allow us to look downstream at what is being expressed in the cells of patients, and see if we can detect differences compared to children without AHC. This utilizes a new technology which allows us to look at hundreds of different products at once, and to try to pick out differences which might lead us in a new direction.

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:
Mylynda Schlesinger/
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
mschlesi@genetics.utah.edu
swoboda@genetics.utah.edu

Fundraising..................

By Carol Presunka

What's Been Done

It's been almost four years since my 4 ½ year old son Alex was diagnosed with AHC. After the initial shock and grief, we went looking for information on the disorder. We found the website with all kinds of links leading us to more information. I found Greg and Lynn who were always there with support and more information. Then came the chat site. Every time Alex did something weird I knew I could count on someone to share his or her experience with me. Then my question became "How can I help?"

We sent out Christmas letters to family and friends asking for donations to the foundation with not much success. We've written checks, not big ones. I got involved with the foundation, offering whatever assistance it might need. No matter where I looked the issue of money kept raising its head. How were we to fund research? How were we to pay for the newsletter? What about an AHC family gathering? How would we pay to bring doctors there?

How could we raise money without hitting on family and friends over and over again?

Then Lynn Egan went to an event at a racetrack. She suggested, since we live close together (about 30 minutes apart), we combine resources and put on an event of our own. In talking with the events coordinator we realized there was little risk. The minimum commitment was 12 people, the racetrack gave an excellent discount to non-profits and we could charge our guests whatever we liked. All we were left to do was to hand out invitations. The racetrack worked with us as numbers of invitees changed We ended up with 60 people at the event and a number of those who didn't come, sent donations. We arranged for a small raffle for a little extra cash. All in all, we raised over $2,000! We've decided to make it an annual event.

Richard George of the Michigan Chapter was happy to announce that the Sharkey T. George Golf Invitational was again a very fun and successful fundraiser for our Foundation. For four years the Melody Farms Family has done this Golf outing to benefit our children. Starting next year, they will be initiating their own foundation and the Golf Outing proceeds will be going to their new foundation to benefit other worthwhile causes. They are still in our corner for future fundraisers that we will undertake. We are very happy for the Melody Farms family and thank them profusely for their support and generosity throughout the years. We couldn't have kept our Foundation going without them!!

Mindy ...told me of her fundraising experiences. The first was like mine. She attached a picture of her daughter to a poem and included it in her Christmas cards. It was a success, raising $13,000 the first year. Another idea was a video they created that was shown to the student council at local high schools. Bake sales and hikes were carried out to raise money for the disorder after seeing the video. 50/50 raffles were another winning idea.

Now, How Can You Help?

Here's another letter idea that other families have done to raise money for our children. You can invite friends and family members to make a donation to the foundation in honor of a birthday, a baptism, an anniversary, a wedding, a religious holiday, or the passing of a loved one. What a wonderful way to honor a special person in your life!!

Another family suggested each AHC family set up a change jar. Every family member puts change in all year long. On March 30 of each year, the change is donated to the foundation. There are car washes, bake sales, donation boxes placed in local convenience stores. These are just a few ideas. What about a Murder Mystery Night? Have you heard about ESCRIP? If you subscribe, participating retailers will donate a percentage of your purchases to the organization of your choice. The AHCF will soon be registered. There are more ideas on the *www.ahckids.org* website fundraising page and other members are always willing to help. Perhaps you have an idea we can publish in the next newsletter?

Another year has ended and overall our fundraising is only "so-so". Although the fundraisers that have been undertaken have been very successful, they are too few and too far between. Melody Farms Family has been a fantastic support to our Foundation and with then now sharing their proceeds we need to step up our efforts. We want to show you the facts. The first fact is that only 3% of the families affected by AHC are helping raise money to help find a cure for our precious children. Another fact is that these 3% of families have raised 50% of the monies; the other 50% is being raised through the generosity of others that are not affected by this disease. Thank God for everyone, but our kids need <u>your help</u>.

If you need any help or just want to bounce an idea around, please just make a call to Cindy Ryan, 217-742-3253, email dcryan@wincoinet.com ; Laurie Pecchia, 888-557-5757; Greg Wisyanski, 814-234-4460, email gwisyanski@shanerhotels.com or Mindy Jonkoski, 732-929-9584, email MandM421@aol.com. The above was written to encourage, and perhaps inspire you to make an effort.

Remember all of us are volunteers and each one of us counts. <u>Please help!!</u>

What's New

By Carol Presunka

Hi Families

Did you know we send out 244 AHC newsletters every four months? These newsletters go all around the world. Having a four year old child with AHC, I know how important it is that we all keep informed on what's happening with the disorder and share experiences. That's why I volunteer my time in whatever way I can. Now I am about to ask you to do the same thing.

Enclosed in this newsletter is a request for contributions for the production of the newsletter. Now all we are asking for is $6 annually for a paper I find invaluable. For those of you who feel the same, is $6 too much to ask? Don't get me wrong. If you'd like to give more than that, we'd be more than happy to accept it. The majority of the funds raised go towards funding research, not into anyone's pockets. Instead of paying for postage and paper we'd rather put that money towards research.

In our last newsletter we wrote about the merger of the two AHC foundations. Because of our small numbers, it was felt that combining resources would maximize the impact of our group. In the newsletter was an insert asking for input for the new organization. We asked for volunteers, ideas and recommendations. We received a total of 8 replies. That's less than a 4% involvement. Did you also know that of all the money that's raised, less than 10% of our families contribute? The same people who get involved are the ones who answer the many questions posted on the AHC chat site, sharing their experiences to help others. I know they've helped me. Hopefully they've helped you too.

Now if you are anything like me you are now saying to yourselves, "I really want to get involved but I don't know how!" My personal phobia is asking people for money. Even I figured out a way to get people to open their wallets without feeling like I was imposing. Well, that's what this newsletter is all about. Included are stories of different families, and what they do to help. It's not all about raising money. It's being a contact person for new families, working with Kim Cooper as a liaison with our medical board or even just finding ways to get information out to the community about AHC. Perhaps your forte is publishing or writing. You might have a story for the newsletter. We have some amazing families who have volunteered to help in any way they can. If you feel you are stuck for ideas, call one of us.

Read the article about what it takes to fund research and realize we need all the help we can get. Alternating Hemiplegia of Childhood is not one of the "popular" disorders. Very few organizations volunteer resources, especially in these times. It's up to us.

For more information you can contact one of the following people:
Richard George
Lynn Egan
Carol Presunka
Mindy Jonkoski
Cindy Ryan

Medical Release Form

Just a reminder, <u>sign and return</u> the medical release form received from Dr. Swoboda.

Meet Kristen

By Yvonne Ockman

My daughter Kristen is seven years old and has AHC and Epilepsy. She has a fraternal twin sister named Erin and a brother named Austin who is four.

Kristen is very active and enjoys life. She loves to go to school and be with her peers. Camping, playing outside, and riding her Harley Davidson power wheel are just some of a few of her hobbies. She has a strong love of animals. We have two dogs that she loves to play with.

Kristen's developmental delays were noticed around six months. At first I thought she was just slower that her twin. When diagnosed with AHC at one year we realized why she wasn't doing the same things as her sister. Her development is between a 4 and 5 year old child.

She attends a regular school in what we call an inclusion setting. She loves school and is determined to keep up and do as the other children do. Her objectives are set up based on her needs and the goals I have set for her. She does very well and functions well with the other children.

We have learned to adjust our lives to help Kristen. When we go on an outing, we try to accommodate everyone. My husband or another family member will sit with Kristen while the other gives the other two children equal time.

We have always tried to treat Kristen the same as her siblings. But because of her disorder we tend to shelter her. As time passed, we realized that her spells could be triggered while sitting on the floor looking at a book or playing outside. We figured why not let her enjoy the most out of life by doing all of the things she loves to do. Kristen gets rewards and punishments the same as the others. We have taught her that she can do anything she sets her mind to, even if it means making changes to help her achieve them. Dealing with Kristen's disorder has, at times, been a struggle. We gather our strength from her. On her worst days, she will give 100%, therefore we feel we need to do the same.

I think Kristen has done so well because she doesn't see herself as different. **She loves life and will make you smile even on your worst day. There's no guarantee on how long we have them, therefore we should make the most of every moment.**

There are those days when all we can do is sit in front of a T. V. when she's down. Then there are those days where we can play ball in the yard. No matter which day today might be we take it as it comes. If I had the chance to live my life again, I would do it the same. There are many lessons in life. The most important to me is to play the hand I'm dealt. Everyday is a new one and I take it as it comes. No matter what the situation, I'm just thankful to be blessed with three beautiful children and the strength that God gives me to care for them.

Newsletter– Editor

Laura Cooper
(888) 263-2454
Email: Lauracooper@bigplanet.com
Washington State, USA

Lynn Egan
Phone/fax (650)365-5798
Email: laegan6@sbcglobal.net
California, USA

Informational/Website
Robin Klein
robin.klein@stanfordalumni.org

Parent Support
Lynn Egan —— Laura Cooper
Sheri DeLuke
(518) 373-8141
sherideluke@yahoo.com

Medical Liaison:
Kim E. Cooper
(425)895-9942; Fax (661) 825-9547
kcoop@gte.net
Please feel free to contact Kim with questions pertaining to the current or upcoming research projects

Fundraising/Donations:
Greg Wisyanski, 201 Ira Lane,
Port Matilda, PA 16870
(814) 234-4460 days; (814) 234-3880 fax
email: gwisyanski@shanerhotels.com

Richard George
11700 Merriman Rd.
Livonia, Michigan 48150
(888)557-5757
email: richard7@ameritech.net

Carol Prunty
202 W. Wasson Rd.
Amboy, IL 61310
(815) 857-3585
email: prunty58@essext.com

MEMORIES OF A SPECIAL FRIEND

One of our precious AHC children recently lost her uncle, Jim Dehn, at a very young age. Uncle Jim died on October 19, 2001 and left behind Haley, his niece, who held a special place in his heart. On behalf of all the AHC families, our deepest, heartfelt sympathies and prayers go out to the entire Dehn family. Uncle Jim has always supported the Foundation in every way. His family has chosen the Foundation as the recipient of memorial donations in his honor. What a wonderful way to remember such a special person.

Uncle Jim: You will be missed and always loved, Haley

Internet News

By Lynn Egan

ahc_kids_only new

A bulletin board has been started for AHC children. This allows them to correspond with each other.

To subscribe, send an email to: ahc_kids_only@yahoogroups.com

Once you have signed up, you can view all postings since the beginning. Thank you Rachel Prunty for setting this up!

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www.ahckids.org

Please take a look at the website. It has been revised and we will continue to update and make changes. We have added a new page 'Families Worldwide'. The thought was for families to know where other families are. I also thought that families could be contacts around the world. I can get more specific by listing your city and make a link to your email address. For those of you who are not on email but would like to be a contact, I could list your phone number. Let me know if you would like to be a family contact.

P.S.—On the questionnaire that Carol Presunka sent out, someone offered to be a Parent Support. We would love to know who you are, so please contact Carol at sunplace@pacbell.net or (408) 626-8506.

Internet Corner

As much as we would like to continue with the Internet Corner, we have decided to discontinue it. There have been so many postings and to try and reprint them all takes a lot of room.

I will from time to time, list topics that were discussed for those of you not internet connected. Then if there is a particular topic you are interested in, you can contact another parent for the information.

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

To subscribe send an email to http://groups.yahoo.com/group/afha/ you will be signed up. You can then view all the previous postings.

From the Vice President

Dear families,

As we begin this new year, we have much to be thankful for. The events of September 11, 2001 puts in perspective that life is short and we must enjoy and cherish each day.

Last year was a productive year. With the joining of the Alternating Hemiplegia Foundation and the International Foundation for Alternating Hemiplegia of Childhood, we have begun to pool our resources and have drawn on the strengths of many.

We will again have a 'Midwest Meeting'. Chicago seems a logical choice, as it is a hub for flying and many families are in the surrounding states. We hope to see many of you there! Then begins a year of planning for the International Meeting. I for one am very excited. The format will be similar to the symposium in Seattle, WA in 1997. I will be creating a web page for both meetings with information as it becomes available. Check periodically for updates. If your are not connected to the internet, please feel free to call if your interested in attending either or both meetings.

Research by Dr. Kathy Swoboda (DNA) and Dr. Johannes F. M. van Brederode (flunarizine) continue to progress. Like all things, it takes time and funding.

We are entering our third year of research. We can help further the research by funding another post doc. That means we all need to get involved. This newsletter focuses on involvement, fundraising that has been done and fundraising that can be done.

Make 2002 the year that each one of us finds a way to contribute to our foundation. We are our children's advocates.

I wish all of you a wonderful and healthy New Year! I look forward to seeing you.

Take care, Lynn Egan

Foreign Affairs..................

A. F. H. A.— France

This is a short sum up of the two main events here in France during the last year :

Meeting of families (28-29 April 2001 near Paris

Up to now, 32 families belong to the French group, the youngest child is 1 year old and the oldest one is 32 years old. We met for two days , near Paris, with our children. This is for everybody the time to share experience (education – treatment and so on), and to talk about different topics, in relation with AHC or handicap. This time, the two main topics were :

1/ relaxation by massage , so as to help our kids to recover faster from their hemiplegic or distonic episodes (light but not severe episodes). A professional woman came to explain different methods to the families, and help the parents to try these methods on themselves , then on their children.

2/ emergencies, so as to teach parents how to cope with an emergency situation which may happen to our kids during severe attacks , for example with respiratory difficulties.

At the end of the meeting, a journalist joined us to write an article published in the local newspaper, during our raffle for "fund raising for AHC research", with the final result of 11 900 euros (78 000 FF).

Meeting between French families and Dr. Kathryn Swoboda

As we took the decision , a few month ago, to help the American research for the genetic origin of AHC, we organized a meeting in France with Dr Swoboda on 17 – 18 October (We did 2 meetings one in Paris and one in Bordeaux). 26 French families (out of 32), agreed to participate to the data collection, and Dr Swoboda could be able to see and do exams to the children and their family. She did , with the help of her technical assistant, blood drawings - skin biopsies - ECG - videos and photos.) She also asked a lot of questions to the parents about the first months of their child's life. In addition of that, she did a conference to the families to explain the purposes of her study.

As far as the main conclusions of this meeting are concerned, we pointed out :

1/ finding the gene or genes responsible for AHC may take several years (but less than 5 years)
2/ This will not recover our kids from their affection, but it may help to try new treatments in order to allow a better development.

3/ Collecting the clinical data's from families and from doctors who follow the AHC children is very important for the study

4/ It should also be very interesting to do more MRI - Petscan to older children, in order to verify the supposed progressive deterioration due to AHC.

5/ It's important to make parents aware of the fact that, in case of seizures or convulsions, they should stop it as soon as possible (either with valium or anything else), as a convulsion which lasts more than 30 minutes may damage the brain.

Best wishes to all of you
Dominique Poncelin
(president of A.F.H. A.)

A.I.S.EA. — Italy

Last October 6-7 2001 the Italian Association for Alternating Hemiplegia, A.I.S.EA, organized a meeting for the AHC families and the doctors members of its Medical Board. We were 14 families with 11 children, four doctors, among which Prof Vigevano and Doctor Gobbi, and Dr Albanese and Dr Moalli from the University of Psychology in Padova.

We met in a country house near Perugia, in the center of Italy, near the most famous artistic and historical places of Italy (Assisi, Orvieto, Spoleto, Florence, Rome). The place was fantastic, in the greenery and peace of the hills of the Umbria region; it was particularly appreciated by our children who were able to relax, play, talk to one another and above all feel acknowledged as members of a whole great family.

During the morning of Saturday October 6, the doctors of the Medical Board met and defined the details of a research project to start immediately after the meeting. They also listened to Dr Albanese's presentation of the study she carried out in the early last year about the neuropsychological features of AHC. As President of A. I.S.EA I was present at such meeting together with Laura, our Vice President.

our doctors and psychologists made the following decisions:
1. The creation of a research team to carry out a clinical study of the neurological and neuropsychological features of AHC and the creation of an Italian database; through the comparative analysis of the collected data further research will be planned, for example neuroimaging, metabolic and genetic studies.
2. The creation of a specialized center in Padova for the complete psychological and intellective evaluation of all our children and an individual support, in par-

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ticular about the educational and learning problems.

All these activities are to be funded mainly by A.I.S.EA and partially by the Italian Health Department. The doctors also committed themselves to make AHC and their work well known among the Italian doctors during all the medical events they will happen to organize this year, also in order to find other AHC cases to be studied.

After the lunch, during which our doctors were able to meet us parents and in particular our children, they presented us the decisions taken in the morning and answered all our questions. It was a very special moment and also the doctors were satisfied of such an important opportunity to face directly with the AHC people's problems. Also the oldest AHC guys took part in this meeting with meaningful questions and remarks.

The morning of the following day, Sunday October 7, the psychologists of Padova told us about the results of their study and about their proposal not only for further research but especially for an individual support to our children. All of us were very interested in such a chance to help our children and accepted with enthusiasm to go to Padova for at least two days every year to meet the psychologists. Finally we had an associative meeting to make the point about our activities; we also spoke about the situation abroad, with the help of the reports sent to me by the Presidents of the French and American Associations. After the lunch, people started to leave: it was an extraordinary experience and all of us look forward to repeat it this year.

Last December the doctors of our medical board met again on the occasion of a Medical Congress to talk about the construction of the AHC database and refine the questionnaire to be filled in order to collect the data of each case. Dr Gobbi is directing the project and A.I.S.EA has just donated 13000 Euro (little more than 1.000 US $) to pay one of his assistant to carry it out.
All the results of such studies will be eventually shared with the international AHC community, in particular with Dr. Swoboda and her group, probably during the International AHC Meeting next year. A.I.S.EA is willing to cooperate in any way with the American association and doctors in order to organize it at best.

My best regards to you all.
Rosaria Vavassori,
Alberto's (9) mum,
President of A.I.S.EA

AHC people present at the meeting:
Alberto, 9 next march, LECCO
Francesca, 15, SAVONA
Germana, 15, ROMA
Alice, 12, ROMA,
Tiziano, 2, ROMA,
Andrea, 9, PERUGIA
Andrea, 30, ROMA,
Stefania, 17, TARANTO,
Stefania, 37, NAPOLI,
Saverio, 11, CASERTA
Angela, 23, CATANZARO

Netherlands

Families in the Netherlands have been meeting about every six months. Their most recent meeting was January 13, 2002. Harm Straathof was kind enough to write about their day.

"Yes we had a nice day together and it was amazing to see how all the three kids played together".

"Willem and Marion Zorge (the new family) were also there. It was clear that it was a very comforting day for them. They had indeed all the questions we ourselves had, a few years ago. They were a bit disappointed about the way they have to go. We will help them all we can....".

"But we, the three families (the Bollens, the van der Drifts and us) are all very positive thinking people that don't let this disease take away the happiness of our lives. We all give are children the best. I think that is what gave the Zorges a bit of hope. However I can imagine what it means when you see three handicapped children especially when you don't have any idea about the future of the disease, and still hoping it will pass".

"At the end of the afternoon we all went for dinner at a Pancake restaurant. This restaurant wasn't very 'wheelchair friendly'.
It was fun because all three of us had a wheelchair and all three children got out of them and were walking into the restaurant. It's funny to see all the people looking when three children get out of their chairs and walk almost normally".

"All three (Sebastian van der Drift, Alice Straathof, and Anabel Bollen) did not have seizures that day. We laughed about it.
Unfortunately Sebastian was sick. No, he did NOT have a seizure, but a cold. Yes, even AHC-kids can get the flu, and the van der Drifts had to go home. Sebastian's younger brother, Christopher was disappointed about it".

"Although we did not have much news about AHC we discussed the medicine because the older kids (Sebastian 9 years and Annabel 13 years) have more epileptic seizures then in their younger years. Alice (6 years) is stable at the moment, two to three times a week she has seizures and is completely weak, but only for a few hours. No heavy epileptic seizures anymore".

AHCF Addresses

Foundation Headquarters
Richard George
11700 Merriman Rd.
Livonia, Michigan 48150
(888) 557-5757

Lynn Egan
239 Nevada St.
Redwood City, CA 94062
(650) 365-5798

Mindy Jonkoski
P.O. Box 109
Toms River, New Jersey 08754
(732) 929-9584

Cindy Ryan
R# 1, Box 31
Winchester, Illinois 62694
(217) 742-3253

Laura Cooper
P.O. Box 2621
Woodinville, Washington 98072
(888) 263-2454

Foreign Contacts

United Kingdom
Sama, Osborne Lane
Warfield, Bracknell Berks
England, RG426DY
44-01 344-420640

Germany
Schhopenhauerstr.5
66346 Puttlingen
Deutschland

Australia
37 Forester Street
Essendon, Australia 3040

AHC Associations

France
AFHA—Association Francaise de l'Hemiplegie Alternate
Dominique Poncelin, President
4 Chemin de la Sabiere
91180 - St. Germain les Arpajon
France
www.afha.org

Italy
A.I. S.EA— Associazione Italiana per la Sindrome di Emiplegia Alternante
Rosaria Vavassori, President
Via Sernovella, 37
23878 Verderio Superiore
(LECCO) Italy
www.aisea.com

If you have a change of address or would like this newsletter sent to others, please contact Lynn Egan at 650-365-5798 email: laegan6@sbcglobal.net or Laura Cooper at 888-263-2454, email: Laura-

Board of Trustees

Alternating Hemiplegia of Childhood Foundation
239 Nevada St.
Redwood City, CA 94062
U. S. A.

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