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.

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

Address Correction Requested

President's Letter

In the October 1997 issue we announced a proposed family gathering in the fall of 1999 at Disney World. By this time we were hoping to have some details as for dates, hotels, events, etc. Unfortunately, because of the lack of assistance, we are going to need to postpone/cancel this event. Very few of us work very hard to achieve foundation goals, however, its just not enough help. "Optional" items like this gathering need to be set aside in order to do other things.

In order to make arrangements for this type of event, many things must be put in place. We need to book hotel rooms, meeting space, food and beverages, events, attractions and other items. If someone would like to step forward to organize this event we would love to hear from you. Many families were looking forward to this and we would still like to make it a reality if possible.

On another note, based on my family, work and other commitments, I am planning to step down as President of the IFAHC effective December 31, 1999. This will mark two years as President and more than six years of active involvement with the organization. I have sacrificed a great deal of my personal time for this group and I feel it is time for someone else to step forward and make the same type of effort. Just as I am committed to a lifetime with my son Greg, I am committed to the goals of the IFAHC. I just need to have some of my time back so that I can attend to others matters that are equally deserving of my time.

Finally, I'll make one more plea for involvement from others. Order the blood kit from Dr. Ptacek's office and participate in the research project. Do a small fundraising project. Sponsor the next newsletter. Sign on to the bulletin board system and talk to each other. Please don't wait for someone else to do it.

Greg Wisyanski

CHANGE
We will be publishing the newsletter three times a year. February, June and October. Submission deadlines are the 10th of each month.

This newsletter is sponsored by Donna Egan, grandmother of Kathleen Egan of Redwood City, CA

Sponsorship

We need sponsors for the newsletters to help us defray the costs of copying and mailing. We are only asking for a $100 donation to be a sponsor. Please contact Lynn Egan if you are interested.

Inside This Issue

AHC Blood Cell & DNA Collection

In the April 1998 Alternating Hemiplegia Foundation (AHF) newsletter there was a very important article by Dr. Louis Ptacek regarding the creation of a blood cell bank that will allow for current and future genetic research. This project is extremely important so please make every effort to participate. The number of AHC patients is small, so we need a large response rate. There is also a minimum number that is needed before research can begin. It only takes a few minutes and everything can be done via Federal Express (which Dr. Ptacek pays for).

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

Dr. Louis Ptacek
Howard Hughes Medical Institute
University of Utah
Eccles Institute of Human Genetics
Bldg. 533 Room 4425
Salt Late City, UT 84112
1-800-444-8638, ext.5-9399
FAX: 1-801-585-5597
or e-mail to Catherine Mckenna at:
cmckenna@howard.genetics.utah.edu

CORRECTION
In the October 1998 issue the phone number for the DNA blood draw project at Eccles was incorrect. The correct number is 1-800-444-8638, ext. 5-9399. We apologize for any inconvenience or phone charges you may incurred when calling the incorrect number.

Flunarizine Update

by Dr. Kenneth Silver and Lynn Egan

Use of flunarizine for the treatment of AHC continues to be problematic for United States patients. The major difficulty is the medication is not available in the United States because it is not FDA approved. Families are forced to go to sources outside the United States to obtain flunarizine. The FDA requires that approved medications have demonstrated effectivness in a controlled-blinded study.

In the early 90's, Janssen did perform such a study on AHC. However, the information they obtained was insufficient to reach a definent conclusion.

On February 19th, we had a telephone conference call with the representatives from Janssen and FDA to discuss these issues.

The FDA is very sympathetic to our children's condition and need for medication to control these symptoms. There is a possibility they would support further studies of the usefulness of flunarizine. However, this would have to be investigated in a placebo controlled study involving our affected children.

To determine whether or not flunarizine is effective in treating AHC, many patients would have to enter into this study. Those patients using flunarizine, know it's effectiveness. However we need to prove this to the FDA. Only then could the FDA possibly approve flunarizine in the United States.

Please drop Lynn Egan a note by email or post whether or not you think your child would like to be included in such a study. Also, we would like to know who is on flunarizine, has it been effective and if not, why are you not using it. Thanking you in advance for your opinion and help.

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

Midwest Gathering

Guess What?! It is happening on June 11 and 12, 1999! Thanks to a lot of work from our friends the Prunty's, Kevin, Carol and Mary and Starnet's representative, Mary Smith. Thanks a million!

We would like to invite you to a "Midwest Gathering" family retreat! In coordination with Dr. Kenneth Silver of Loyola University, we have organized the following agenda. Please take time to look and study the agenda items. The Saturday morning meeting will be "taking care of business!" There will be a registered nurse at the meeting to take blood for any family that has not taken part in the DNA testing from Dr. Ptacek. You can get the DNA blood kits by calling 1-800-444-8638, ext. 59399, this is the University of Utah. You may bring the kits with you that day or we can arrange to get the kits for you. There will be a question about this on our information sheet. If you have any additions to the agenda you would like to include, feel free to contact us. Dr. Silver will be there to answer any questions that we might have. We are so blessed to have him in our midst!

The location is in Rockford, IL at the Bishop Lane Retreat. There will be a map forthcoming along with an information sheet to fill out to anyone who will be coming. There is lodging and meals provided at the Retreat for $45 a person. That includes two nights lodging and 5 meals for each person. You can contact the Prunty's for more information. We have also contacted the Holiday Inn in Rockford that has a lot to offer and they have quoted a price of $62 a night for two double beds but will allow up to 6 people per room. A roll-away bed can be reserved for $7. They have an indoor pool and putt-putt golf to mention a few. Their number is 1-800-383-7829 and tell them that you are an AHC family. Dr. Silver has agreed to stay at the Holiday Inn.

I encourage everyone to participate if at all possible. I am sending an application to all Illinois residents for Starnet that I mentioned earlier in my letter. The Starnet grant will only apply to families that have children 8 years old and

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Where Are We?

Did you ever wonder where other families are? To give you a sense of geographic location, the following is a listing of where we are in the United States, Canada and Worldwide.

UNITED STATES - 78

ALASKA
Fairbanks

ALABAMA
Cullman

ARIZONA
Phoenix*

CALIFORNIA
Redwood City
Brentwood
Santa Barbara
Canoga Park

CONNETICUT
Huntington

FLORIDA
Venice
Debary

GEORGIA
Dublin
Woodstock

IDAHO
Boise

ILLINOIS
Palatine
Winchester
Amboy
Chicago
Orland Park
Blueford

INDIANA
Indianapolis
LaPorte
Springport

IOWA
Perry
Neola

KANSAS
Wichita
Topeka

LOUISIANA
Kenner
Raceland

MARYLAND
Bethesda

MASSACHUETTS
Melrose
Newburyport

MICHIGAN
West Bloomfield
Sterling Heights

MINNESOTA
Brookland Park
Bloomington
Loretto
Inver Grove Heights

MISSISSIPPI
Natchez

MISSOURI
Joplin

MONTANA
Fairview

NEW HAMPSHIRE
Salem

NEW JERSEY
Orange
North Brunswick
Toms River
Montigue
Pennsauken

NEW MEXICO
Albequerque

NEW YORK
Port Byron
Cortland
Elmira
Liverpool
Lancaster

NORTH CAROLINA
Asheboro

OHIO
Portsmouth
Dayton
Warren
Columbus

PENNSYLVANIA
Middletown
Philadelphia
Lemoyne
Port Matilda
Stroudsburg
Gibsonia

TEXAS
Springtown
Garland
Angleton
Shepard
Dallas
Carrollton
Christoval

VIRGINIA
Vienna
Radford

WASHINGTON
Bellingham
Woodenville

WISCONSIN
Sturtevant
Madison
New London
Poynette

CANADA - 12

ALBERTA
Stoney Plain

BRITISH COLUMBIA
Revelstoke

NOVA SCOTIA
Wolfville
Sydney

ONTARIO
London
Welland
Sault St. Marie
Burlington
Hamilton
Brampton
Etobicoke

QUEBEC
Beaconfield

WORLDWIDE - 57

ROMANIA - 1
NEW ZEALAND - 2
AUSTRALIA - 2
CHILE - 2
MEXICO - 1
CROATIA 1
LEBENON - 1
SPAIN - 1
ITALY - 7
FRANCE - 18
SRI LANKA - 1
NETHERLANDS - 4
JAPAN - 7
SWEDEN - 1*
ENGLAND - 8

* - Two children w/AHC

Just Some Facts

DID YOU KNOW.........(at recent count and based on the information provided by families, the following statistics are available. This has no medical bearing)

Boys - 51 Girls - 68
Un-catorgarized - 30

Ages	# of Children
1	5
2	8
3	7
4	10
5	7
6	6
7	11
8	7
9	9
10	8
11	3
12	13
13	3
14	2
15	1
16	4
17	4
18	1
19	2
20	3
22	2
32	1
33	1
Un-catorgarized	31

INTERNET CORNER

The following are samples of what appears on the bulletin board. Only messages with permission are reprinted.

"It's me Mindy, Hailey's mom. I have 2 questions. First, does anyone know if your Dr. ever tried a medicine called SANDOGLOBULIN? Hailey's neuro is thinking of trying it. I don't know much about it yet. I have to look into it.
Next he was (Hailey's neuro) asking me if I could get a list of all the meds that were tried on AHC kids. So I thought if everyone wrote me maybe I could come up with a list. If there isn't one already...Thanks."
Mindy - Oct. 8 -

"Did anyone else see the report on the evening news in the last week or so about a new experimental surgical treatment for stoke victims? The goal of the surgery was to implant new neurons into the brain to help replace those lost to stroke.
I don't think anyone has definitely determined whether AHC episodes cause brain damage, however, every time I see something about strokes, I'm reminded about AHC and the paralysis. Maybe AHC and strokes work completely different and have completely different effects on a person.
Who knows, maybe if we can find a way to stop the episodes, there might be a way to repair any damage. I'm just rambling about this, but trying to be optimistic."
Greg - Oct. 8 -

"Here's the list (of course, all unsuccessful) that I can remember: phenobarbitol, dilantin, tegritol, ativan, a calcium channel blocker other than flunarizine (don't remember the name), flunarizine (didn't work for my son)."
Greg - Oct. 8 -

"I would be interested to know if any children have experienced an increase in paralysis events while on Epilim. We believe that our daughter Ashliegh has had increased paralysis in the last 3 months and are wondering if it may be linked to her Epilim medication which she started at about the same time. Many thanks and I hope that your children are well."
Tim Powell - Oct. 8 -

"Jacob was on these medications when they thought that he had a seizure disorder, but it was really AHC. Phenobarb made him sleep, which helped the AHC slightly, but also really delayed his development. Tegritol and Depakote seemed to increase his episodes. Klonopin and ativan were used to try and induce sleep but usually didn't work. Periactin was used for a short time (I believe Dr. Chugani recommended this to Jake's neuro, it is a serotonin drug), no effect on episodes. He was on inderal for a while as this is an anti-migraine medication - no change. He is now on flunarizine which has helped decrease the duration of the attacks but not the frequency or intensity (which is worse)."
Becky - Oct. 8 -

"Aurelie's neurologist never tried this drug. I am collecting information in France on different treatments used. I am waiting for answers because nobody is connected to the E-mail except for Dominique and myself. Lynn or Greg requested few times ago information on this issue."
Mirjana - Oct. 8 -

I believe sandoglobulin is similar to IVIG (intravenous immunoglobulin). I have seen it many times at neurological sites. I know that it is used during neurological emergencies and immune-type diseases. When I have time, I'll do an intensive search."
Becky - Oct. 8 -

"I just realized that when I reply to the bulletin board that it is only going to the person who originated the email, not back to the bulletin board like it use to. I can see from today's emails that many of you have realized this as well as you are cc: the AHC bulletin board. I guess when the server changed, it was not able to stay the way it was.
Regarding drugs used, their dosages and their effectiveness, I am currently working with a couple of the doctors to get a data base together. It was discussed at the symposium and has just taken longer than expected.
As for us, Kathleen was on phenobarbitol, tegritol, veraphamil, nimodopine, and a couple of others that I just can't remember. We used these for 5-1/2 months, at levels higher than most adults and at times overlapping each other with NO effect or change in episodes. Since 13 months we have used flunarizine, ativan (since 1994), Co-Q10 (1 year) and vitamins."
Lynn - Oct. 8 -

" There are so many people that haven't given their blood yet for DNA testing... It's so easy, please look into it... WE NEED TO HELP OUR CHILDREN. THANK YOU."
Mindy - Oct. 20 -

".....I need advice. I want to try Baclofen drug. I have noticed that, after 3 years of flunarizine, the attacks are now much shorter as duration but more intense. Many times she has a bilateral attack or full body. Her attacks come along every 10 days.
If there is anyone who has tried this drug on their child, please let me know what your experience was.
My doctors need a confirmation that this drug is good in AHC, and if somebody used it with good results in AHC..."
Teddy - Oct. 28 -

"...as for Baclofen, when we meet in Detroit in 1995 with Dr. Chugani, Dr. Awaad talked about the use of Baclofen. At that time, I don't believe that he was using it, however was about to start on a new patient just diagnosed with AHC and not using flunarizine. He did not know at that time either, what the proper dosage would be and that he would continue to increase until there was change in the patient.
I don't recall the results of that patient nor do I know if anyone else has tried it. We did not want to try it because it would have meant taking Kathleen off flunarizine to use Baclofen.
As for Diana's episodes, we too went thru a period of full body episodes. In fact for about a year, that is the only kind we had,

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INTERNET CORNER

(Continued from page 5)

no left/right sided episodes just full body. I find that the episodes have changed so much over the years, with periods that are worse than others and also better.

I would be interested in knowing too, if anyone has tried and had good results with Baclofen..."

Lynn - Oct. 28 -

"On Monday I took Jayme to see the eye Dr. It was his first trip ever to get his eyes checked for glasses. The school where he goes felt it was time to have him checked. He is twelve and has AHC. Anyway his appointment was on Monday and he had just come out of an AHC episode the day before that has lasted four days so at the eye Dr. one of the procedures is getting his eyes dilated and lights shone into them to check for various things. He started another episode the next day!!! It is on the opposite side of his body but it was way too soon to start another episode. There should have been almost three weeks between, not two days. Do you think it came on early because of the eyes being dilated and the bright lights in his eyes? Any thoughts about this?"

Donna Busby - Nov. 6 -

"We have had this dilation procedure done to Greg's eyes 2 or 3 times now. He had minor episodes each time.

I don't think his episodes were from the dilation as much as from the entire examination event. He was a few years younger (about 5 at the time) and very afraid of the doctor's office. It didn't matter that the exam didn't hurt or anything, he was just very afraid. When Greg becomes very frightened he can have episodes.

I also thought it may be the light that they shine in his eyes (we usually have sun glasses on his when its too bright outside) but he started the episode after they put the drops in his eyes while we were waiting for them to dilate.

I guess the bottom line with AHC is that anything can set off an episode for certain kids and then again other kids are fine. Makes you want to scream!!"

Greg - Nov. 9 -

"I need to speak with anyone who has had or knows about an Angiogram. Hailey's neurologist wants to do one and I don't know how to make that decision...Hailey is having an episode too so who can deal with anything right now (whole body)... I just need to vent...I hate this disease I could shoot somebody..."

Mindy - Nov. 20 -

"Thanks for this correspondence Donna and the reply from Greg Wisyanski. Alice was due to have this procedure done as part of her continual surveillance but since the standard examination with no dilation showed no problem and I do not have any concerns about the quality of her sight I have cancelled this test. Hope all is well with all of you."

Alex Cole - Nov. 27 -

"I lost a lot of my email and I was wondering if anyone remembers when the drug Diamox came up. I'm pretty sure someone wrote about it within the last two months or so.

The reason I ask is because I went to the Muscular Dystrophy site to read about periodic paralysis. These disorders are different than AHC but there are also some similarities. One of the treatments suggested was diamox.

If there is anyone whose child had been on diamox, I would be interested to hear if that was in any way effective or not.

Also, Jake has recently begun complaining of a headache prior to his attacks. Treating him with a small dose of tylenol seems to make him much more comfortable and twice has caused him to go to sleep, which stopped the attack. Any other children with complaints of headache, and what do you do for them? I hope that everyone has a happy and healthy holiday."

Becky - Dec. 6 -

"Well, TJ definitely gets headaches ...migraines actually and they are quite severe...sometimes the migraines do lead to episodes, but more often it just causes autonomic disturbances, like sweating, pupil dilation, skin tone changes and breathing changes...all we have found that helps is Motrin, since it isn't supposed to be a respiratory suppressant. Just a quick up date...TJ is doing wonderfully in grade one...the kids all help him out and even ask him to events outside of school...they love taking turns on TJ's bad days pushing his wheelchair around and doing hand over hand exercises..he is learning so much, even on his bad days..when he recovers, it is like he has absorbed everything that was going on around him. Be well all and lets hope Christmas isn't too bad."

Wendy - Dec. 6 -

"When our neurologist visited my son Alberto (5-1/2 years old) last July, he suggested that we use diamox, but we haven't tried it yet. Very likely we will do it sooner or later but we aren't in a hurry about it now because for Alberto this is a good period and we don't want to do anything that could alter it.

Anyway, Prof. Vigevano, in Rome, has just prescribed diamox to an AHC girl aged 12 and she has been taking it for three weeks, which is still a very short time and by now there are no evident effects. I will keep you informed about it.

As for migraines, I have just known a new AHC Italian family with a girl aged 22, Angela, who has been always suffering of AHC attacks but also of very painful headaches. Indeed recently the AHC attacks are getting less frequent (every 7-10 days) but headaches are almost daily with blindness and vomiting.

Here in Italy, none of the other eight known families (including mine) has ever reported of migraines associated to AHC, so I am asking all of you if there is anyone with the same problem and which drugs or any other kind of treatment or 'trick' have been tried to relieve the pain. Thank you very much to all of you, also on behalf of Angela's parents. CIAO from Italy."

Rosaria - Dec. 9 -

"My daughter Aurelie also complains sometimes of a headache prior to an attack. She only takes flunarizine (which is supposed to have an action on headaches...) and NOPRON when she has a bigger episode. It makes her sleep.

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INTERNET CORNER

(Continued from page 6)

a bigger episode. It makes her sleep.
She has currently much more episodes and we do not understand why. These are either soft only touching one side of the body or very painful like today. She is totally blocked...it drives us totally crazy.... We have to keep anyway and faith and fight. Our children better chance is the participation of all of us to the DNA project of Dr. Ptacek."
Mirjana *- Dec. 11 -*

"My son Jayme takes flunarizine everyday. He has had a chronic stuffy nose for years. He is 12 and he has had his tonsils and adenoids out. But still the stuffy nose. Does anyone else notice this with their child on flunarizine? I don't know if it is a side effect or not. The Dr. doesn't know why he has a stuffy nose everyday. Any ideas?
Donna *- Jan. 14 -*

"Greg is not on flunarizine, but he also is very stuffy and congested. For years we gave him benedryl elixir and for the last few months have been giving him Claritin for kids (reditabs that melt in his mouth in about 5 seconds). They help a lot. If he gets too stuffed he seems to have more episodes so we really try to keep him breathing as well as possible."
Greg *- Jan. 14 -*

"I never noticed something like that with Aurelie."
Mirjana *- Jan. 14 -*

"I didn't realize that your son Greg is not on flunarizine. Does he take something else for his AH? Just curious....."
Donna *- Jan. 14 -*

"Kyle is not currently taking flunarizine. While on the medication (approx. 2 years) he did not experience any stuffy nose symptoms other than the time he actually was sick with a cold."
David McGinley *- Jan. 14 -*

"My son Alberto is almost six now and he has been taking flunarizine since he was four.
But since he was born he has always had a stuffy nose and congested so I don't think that it is a side effect of flunarizine.
Last September he had his adenoids out, and indeed the situation is a little better now, I even if not as much as we would have like. He can sleep more peacefully, which I guess is helping a little in reducing the frequency of the attacks, but during the day, he keeps on breathing with him mouth and loosing a lot of saliva...
He is not yet well trained to blow his nose by himself and he doesn't like to be helped either so this isn't contributing to solve the problem...
Best wishes to all of you."
Rosaria *- Jan. 18 -*

"I am the father of a boy who is suffering from AHC. We are from Sri Lanka but were fortunate enough to have diagnosed the condition at a fairly early age. My son Vishwa is receiving flunarizine 7.5mg in combination with Rivotril 2mg a day and since the introduction of Rivotrol (Clonazepam) Vishwa has improved considerably. I have written the details of the improvement to Lynn with who I have been communication. May be some parents have already tried this drug and not got any results but I can't resist the temptation to cry out loud after what we have been through. Except for the problems in his behavior and education (which were there right from the beginning) his medical condition has improved since Rivotril was given. Maybe some parents are interested in this. I would like to subscribe to the AHC bulletin board so that I can read about the progress of the other children.
My email addresses are nandanap@slt.lk or perera100@hotmail.com
Nandana Perera *- Jan. 25 -*

(Continued from page 3)

younger, but there is also another grant, Clearinghouse, that I will also be sending. I will be sending Starnet our agenda so that they can respond as promptly as possible. When we were approved by Starnet in 1997, we had to show copies of our receipts to be reimbursed and received a check promptly.
I want all of you to know how much our small community has fought for all of us. Since Michael's diagnosis in February, 1997, there has been $36,000 raised for our children's research from 2 concerts and recordings and I want you to know that you can do it too! Bring your ideas and items, if you have sold anything, so that we can fund all the needed grants for a CURE for AHC!
I am so excited about meeting other families and I think this will be a blessing to be encouraged instead of discouraged. This weekend is about fun and bonding!
Good Bless and Keep Smiling!
The Ryans and Pruntys

AGENDA

Friday, June 11, 1999
6:00pm Meal at the Bishop Lane Retreat
7:00pm Family Greetings and Introduction

Saturday, June 12, 1999
8:30am Breakfast
9:30am Family Interests
  DNA Testing (feedback on the testing and registered nurse will be here for those who haven't participated)
  Grant Proposals (what's happening
10:30am Dr. Kenneth Silver
  Definition
  Research
  Family Concerns
11:30am Other Guests
Lunch
Afternoon Family Fun and Games
  Entertainment provided by Starnet
Supper

Sunday, June 13, 1999
8:30am Breakfast
9:30am Wrap Up

Reprinted with permission from ARC.

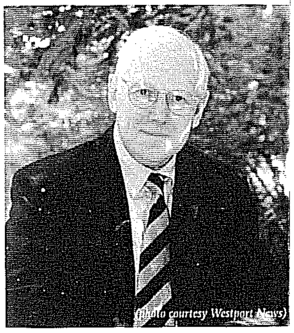
A Medical Mystery Story

Emily Sofia's condition has a name. It's called Alternating Hemiplegia. But its origins and treatment remain a medical mystery.

At Summit Park Elementary School with teacher Renee Cappiello

Sometimes Dr. Sidney Baker thinks of himself as a medical detective. He takes on cases that no one else seems able to solve, chronic illnesses for which there appear to be no obvious explanations. Emily Sofia's case presented him with a unique challenge.

The six-year-old has been having strange 'episodes' ever since she was born. At any moment, without warning, some part of her body suddenly becomes paralyzed. It may be an arm one day, or a leg the next. The paralysis may last a few minutes, or a few days.


(Photo courtesy Westport News)

Dr. Sidney Baker

"It's like a sneeze of the nervous system," says Dr. Baker. "One moment she's able to sit up and use all her limbs, then suddenly an arm will go completely limp. It's a startling thing to see. There's absolutely no motion in one limb, as though it had turned into a piece of spaghetti. It's almost as if she had a stroke, but she hasn't."

The official name for Emily's condition is 'Alternating Hemiplegia' (hemi=half; plegia=stroke or paralysis), a form of partial paralysis which alternately affects one side of the body and then the other. The problem, however, is that nobody knows exactly what causes this condition, or how to cure it.

Even pinpointing this diagnosis wasn't easy. As Emily's mother Lee Sofia explains, her daughter's symptoms stumped many members of the medical community.

The problems began almost the moment Emily came into the world. She was born with torticollis, a stiff neck resulting from spasmodic contraction of the neck muscles which caused her to draw her head to one side. A head and neck sonogram revealed no tumors or brain swelling, no bone or muscle malformations. "They said it was just a result of her being born transverse and that she would be fine," recalls Ms. Sofia.

But Emily wasn't fine. "She was colicky for about three weeks. She had constant severe diarrhea and was screaming every waking moment," says Ms. Sofia. "She was about two months old when we first noticed that she was having strange spasm-like episodes. Her eyes would do strange things, she would turn all red and sweaty as if she were holding her breath, but she wasn't."

The Sofias immediately took Emily to the pediatrician. "He said that an infant's neurological system isn't fully developed. He said we should 'wait and see'." The same thing happened at Emily's four-month check-up. This time Ms. Sofia was more insistent. "I told the doctor that I wanted to bring the baby to a neurologist, but he didn't take me seriously. He thought I was just a nervous mother. So I took things into my own hands. The next day I went to another pediatrician."

With "Grandma" Gina de la Cruz, Foster Grandparent Program

The second pediatrician tried weaning Emily off nursing and putting her on formula. That only made things worse. They tried putting her on soya rather than milk. That stopped the colic, but not the diarrhea or the spasms. "We had to make what we called 'swamp mud'–it was our own formula made from fresh vegetables and vitamin supplements. We were concerned that Emily wasn't getting the proper nutrition and that she was being dehydrated because of the constant diarrhea," explains Ms. Sofia.

Emily examining pretty flowers with her mom Lee Sofia

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What is Alternating Hemiplegia of Childhood?

The following information is adapted with permission from a brochure prepared and distributed by the International Foundation for Alternating Hemiplegia of Childhood (IFAHC). IFAHC is a voluntary, non-profit foundation established to support children who are afflicted with AHC and their parents. It does not provide medical advice. The following material is provided for informational purposes only.

*Alternating Hemiplegia of Childhood (AHC) is a rare neurological disorder in which repeated, transient attacks of hemiplegia (paralysis of a portion of the body) occur, affecting either side or both sides of the body.

*The hemiplegia can range from simple numbness in an extremity to full loss of feeling and movement. The attacks may last for minutes, hours, days or weeks and are normally relieved by sleep.

*Children with AHC exhibit a

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wide range of symptoms including tonic attacks (lack of muscle tone), dystonic posturing (stiffening of extremities), nystagmus and other oculomotor abnormalities (eye disorders), developmental delays, mental retardation and seizures. Not all children suffer from all of these associated symptoms.

*The causes of hemiplegic attacks differ in each child. High stress activities as well as the presence of a cold or upper respiratory problems have been known to cause attacks. Some children are affected by bright lights, wind, temperature changes, exposure to water or to certain foods or chemicals.

*There is no evidence to suggest that children 'grow out of' AHC as they age. Many exhibit a greater degree of ability to handle the attacks or to avoid factors that cause the attacks as they get older, but this is not always the case.

*There is no proof that the disease is fatal or shortens life expectancy, but sufficient documentation is not available at this time. There is developing evidence that AHC may cause ongoing and progressive mental and neurological deficits.

*The cause of AHC is unknown and there is no known cure for the disorder. The drug flunarizine (trade name Sibelium) has been used successfully in many cases to lessen the effects of AHC. Other drugs that induce sleep have also been used to reduce the severity and length of attacks. Because the effects of AHC are thought to be cumulative in relation to neurological damage, reducing the severity of attacks may have significant positive long-term benefits.

*Many children are initially diagnosed with epilepsy or other seizure disorders and prescribed anticonvulsant medications. While some do suffer from seizures, the use of these drugs is generally unwarranted and produces no benefit. Unfortunately, diagnosis cannot be accomplished through a single test and involves the ruling out of other similar disorders.

*The number of children known to have been diagnosed with AHC in the United States is less than 100 and less than 250 worldwide. However, due to misdiagnosis, it is difficult to determine how many children actually have AHC.

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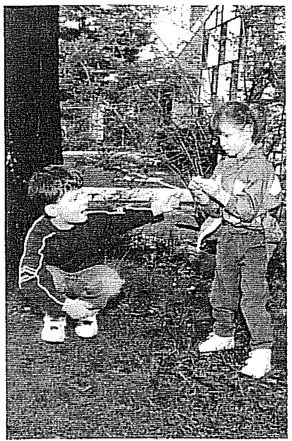
Over the next few months the Sofias tried an endless round of nutritionists, allergists, even a homeopath. No one could give them any solid answers.

At the age of 8 1/2 months Emily developed an upper respiratory infection. Antibiotics were prescribed and within 24 hours she had her first quadriplegic episode. She was completely paralyzed. "We brought her to the emergency room at Nyack hospital where they tested her for meningitis. They did a spinal tap. They did EEG's and MRI's. At that point, they decided she had epilepsy, even though the tests didn't show any signs of epilepsy," Ms. Sofia recalls. "But she did have these spasms and her muscles were very flaccid."

The doctors started Emily on a regimen of phenobarbital. As a result, she was sleeping 20 hours a day and went down to 18 pounds. So the Sofia's took Emily to yet another neurologist. He put her on an anti-seizure medication. It didn't help.

At 12 months, the second neurologist signed Emily into Montefiore Hospital's special epilepsy unit. There, she was monitored 24-hours-a-day. In the first four days, she had 96 episodes. They ran her through a battery of tests and finally concluded that whatever Emily had, it was definitely NOT epilepsy. That would explain why the anti-seizure medication wasn't working. After ruling out everything else, they finally concluded that Emily had Alternating Hemiplegia, a very rare neurological disorder. "She was the 60th reported case in the entire world," says Emily's mother. "The neurologist would only treat her with flunarizine, a calcium channel blocker that is the only known treatment for this condition, and has been shown to decrease the episodes. But there were horror stories about this drug's side effects to the kidneys and heart muscle. We wanted to try something else." The Sofias would not give up.



Emily enjoying play time with classmate Matthew Yaciuk

The homeopath they had visited months before had suggested that Emily's problems may be aggravated by food allergies and advised that they remove eggs, wheat and soy from her diet. "We were skeptical then, but now we decided to go back to that homeopath and try out his theories. He turned out not to be so crazy after all. Once we eliminated the wrong foods, the diarrhea stopped and Emily was able to hold down nutrients and get stronger."

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Emily needed all the strength she could muster to deal with her 'episodes'. Based on her mother's description, it is hard to imagine how Emily could survive these on an ongoing basis.

"Emily starts with a crying drone, almost like a siren, and at the top of the scream she draws her arms in, arches her back, turns flush red and sweaty, and white around the mouth. She holds that for about one to two minutes. Then she winds down and starts to cough. Her eyes open and she looks at me, but by then she has some feeling missing, some limb that has gone numb. She may then start the cycle all over again, and when she comes out of it she may have the feeling back, or the numbness may be on a new side." Amazingly, in those early years Emily would go through a full cycle every five to seven minutes. The only relief would come when she was asleep.

The homeopath's theory of food allergies set the Sofias on a new road. "We would take certain foods away and then return them to her diet in small amounts to see the reaction. We started logging in what she ate and what her reactions were."

The Sofias also began tracking down every bit of information available about Alternating Hemiplegia and about allergies. It was during this search that they came across the name of Dr. Sidney McDonald Baker.

A graduate of Yale University School of Medicine, Dr. Baker has a special interest in the nutritional, biochemical and environmental aspects of chronic illness. While an Assistant Professor of Medical Computer Sciences at Yale's School of Medicine, he learned much about collecting medical history data and information handling. He also learned the importance of looking at the individual patient rather than the broad diagnosis. "My approach is a kind of medical tailoring, cut and measure until you find a treatment that fits in each individual case," he explains. Dr. Baker served as Director of Research at the Gesell Institute of Human Development, a non-profit diagnostic, treatment and research center, and then as Senior Clinician and Director of Research at the Princeton Biocenter in Princeton, New Jersey. That's where the Sofias caught up with him.

"The first thing I did was to see if there was a pattern to Emily's reactions," says Dr. Baker. "Could it be something in her diet, or her environment? Maybe it's something she needs to get more of, or something she needs to avoid."

By process of trial and error, they found that Emily is extremely sensitive to molds in the air and to certain chemicals. For example, the scent of perfume will immediately trigger an episode. Dr. Baker has now begun a process of desensitization with Emily. "By controlling her exposure to some of these allergens, and by desensitizing her with a particular kind of injection, we hope to make some progress," he says.

The progress is already evident. Instead of every few minutes, Emily's episodes now occur only every seven-to-ten days and usually only involve a weakness of an arm or leg. Both Emily and her parents have become more aware of those things in the environment which may trigger an episode. "When she goes for a blood test, the combination of stress and the smell of the alcohol pad brings on an episode," says Ms. Sofia. "I learn something new every day about how the body functions. I now know how close the olfactory nerves are to the front of the brain. That's why fragrances affect Emily much faster than foods, which can take a few days to cause a reaction. Her immune system is over-defensive so that anything she comes in contact with on a regular basis becomes the enemy and triggers an immune reaction," she continues. "That means we have to change foods and toothpastes frequently. She can't eat the same thing every day. She's also very sensitive to molds. Little things like that can make a big difference in her environment."

Ms. Sofia is especially thankful to Prime Time for Kids where Emily was enrolled from the age of 14 months until her graduation in June of 1997. "They're great because they're so flexible. Emily had one bad week during a summer session. We wondered what was going on. When I went to the school, I found that there was a hamster cage sitting below an air conditioning unit, and the dander was blowing through the room. When the cage was moved, Emily's problem disappeared."

When Emily was ready to move to elementary school, Ms. Sofia went from school to school, checking out buildings. "We couldn't have her in an old building smelling of mold and mildew. And carpeting is a problem because of dust mites." Emily is now in the Special Education kindergarten at Summit Park Elementary School in New City.

A degenerative neurological disorder, Alternating Hemiplegia has affected Emily's motor functions. She sometimes uses a walker and has an awkward gait. Her muscles are not fully developed and she is small for her age. She has therefore been placed in the Special Education K-1 class for the multiply handicapped. But she is much more advanced in her cognitive skills. She can work on a computer and has been studying math and English with the second and third grade Special Education classes. "She has had some episodes in class, but the other children don't even seem to notice," says her teacher, Renee Cappiello. "The students here appreciate each other's abilities."

"Emily is aware of her problems and knows what she can and can't eat, what she can and can't do," says ARC Service Coordinator Alyson Brenner. "She receives physical therapy, occupational therapy to help develop fine motor skills for such tasks as writing or doing puzzles, and speech therapy for articulation. Her parents are involved. They're good advocates for Emily. Her mother signed her up as a "Daisy Girl Scout", the youngest division of the Girl Scouts. She encourages Emily to try as many different kinds of activities as she can."

Dr. Baker, too, credits both Emily and her parents for her amazing progress. "Emily has a remarkable personality. She has the capacity to ignore her paralysis episodes when they happen. She just bounces along and uses whatever limbs are functioning to accomplish what needs to be done. She's a resilient child." Dr. Baker, who just released his second book (*Detoxification & Healing*, Keats Publishing, Inc.), is not accepting any new patients, though he has sometimes acted as a resource to other physicians. He advises parents with children "who have something that is not working right" to keep asking questions, and to find doctors who are willing to keep trying until they find the answers. "Most of what I've learned, I learned from listening to my patients," he says. "We have to treat the individual, not the disease."

"Go with your instincts," advises Emily's mother. "If you don't believe in a doctor, find a new one. Don't give up."

Toy Catalogs for Children with Disabilities

Toys R Us analyzes skill building in off-the-shelf products in its "Toy Guide for Diffferently-Abled Children." A clutch ball for $3.99 develops eye tracking skills and positive social relations. Olympic Barbies ($12.99) help children develop gross and fine motor skills, personal satisfaction and language skills.

A soft rocking cow ($49.99) teaches cause and effect.

The Toys "R" Us catalogs are available through stores, with additional information from the Lekotek Toy Resource Helpline at (800) 366-7529.

Toys For Special Children has a catalog of adapted or specially created toys that range from sensory bead chains to battery-powered drivable cars.

For information, call (800) 832-8697.

"The Guide To Toys for Children Who are Blind or Visually Impaired" is available by calling (800) 851-9955, or visit them at the Toy Manufactures of America Website: www.toy-tma.org.

The Intermediate Unit also has some catalogs and instructions on adapting battery-operated toys.

For information, contact Moses or Repka at (724) 836-2460.

ARC Services

In most communities there is a chapter of the Association of Retarded Citizens (ARC). Depending on your child's status, you may qualify to receive benefits from the ARC. They perform support group functions, print publications about living with mental retardation and hold seminars on pertinent topics (for example, financial planning for parents of special needs children). Another service that may be available to you through ARC is their Family Driven Support Services in which they provide small amounts of money towards items that aren't covered by insurance or other means. The money isn't a lot but its nice to have towards things such as respite care, special equipment, medical co-payments, extra therapy, etc. The local ARC's also tend to be well connected with other organizations providing services to special needs children. We encourage you to look in your local phone book under ARC and see what they can do for you.

Special Thanks

The IFAHC would like to extend a special thanks to the family of Daniela Sanchez for their recent fundraising efforts. We are especially grateful to her grandmother, Evelyn Rosado, who helped orchestrate this effort and who has been kind enough to get donations from her employer the last several years.

Their project was quite straight forward. They had a birthday party for Daniela and asked that in lieu of gifts, people make donations to the IFAHC. They supplied a form letter that friends and relatives could write their name and address on and send in a pre-addressed envelope with the check. By doing this they were able to identify who donated and then thank them.

Again, thank you very much. It is greatly appreciated.

Remember......

- We received several more stories from families for our booklet about Living with AHC. We would like a few more, so please , take a few minutes and share your story. Let us know if you wish to remain anonymous or want your name, address, etc., published. You can send all information to Lynn Egan.
- For those of you receiving the newsletter for the first time, previous copies are available through Lynn Egan or they are posted on the IFAHC website at www.c-com.net/~ifahc.

IFAHC Website

Some of you have expressed trouble accessing the IFAHC website. The website address is:
www.c-com.net/~ifahc

Language Translators

Do we have any families who know Spanish and would like to correspond with our Spanish families? Please contact me, so that I can make this connection between you. Thank you.

AFHA/AHF website

The e-mail address to post messages to the AFHA/AHC 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.