

❖ **INTERNATIONAL FOUNDATION FOR** ❖
ALTERNATING HEMIPLEGIA OF CHILDHOOD

Volume 1 Issue 2

March 1996

**Two Insurance Companies Pay for
Flunarizine**

Laurie Baker of Madison, Wisconsin was able to get her insurance company to pay for the flunarizine. The following letter was written by Laurie's physician to the insurance company.

May 15, 1995

Physicians Plus Insurance Corporation
 240 West Washington avenue
 Madison, Wisconsin 53703

RE: Allison Baker
 DOB: 6/13/90

To Whom It May Concern:

Allison Baker is a nearly five year old with a rare condition called alternating hemiplegia.

The only therapy that so far has shown some usefulness in this condition is an experimental drug called flunarizine. This is a calcium channel blocker which had been provided to Allison through a compassionate use program through Janssen. Janssen has now stopped providing this drug because it became difficult to prove through open label experience that this drug was effective and there are too few patients available to make a controlled trial practical. Therefore, Janssen decided not to attempt to register flunarizine for marketing in the United States. The drug is available in England, but it costs \$130.00 every three months. I am writing to ask Physicians Plus Insurance Company to cover this drug for Allison Baker.

Sincerely,

Fred Edelman, MD

In a letter dated June 14, 1995 Physicians Plus Insurance Corporation re-

sponded, "Our medical director has reviewed Allison's medical records and has agreed to make an exception to the drug benefit for her. This will be for a three month period."

"In order to reimburse you for Allison's prescription for flunarizine we will need your paid receipt and the drug information provided from your supplier."

My understanding from Laurie is that Allison will be seen every three months and the insurance will review the case. She is still being reimbursed at this date.

The Perkins family of Bloomington, MN was also able to get their insurance to pay for flunarizine. However, they were only able to get a one year supply.

Try writing a letter to your insurance company or enlist the help of your doctor. Include a copy of this newsletter. You may be pleasantly surprised at their response.

Good Luck!

**Getting to Detroit
thru the Help of
the Volunteer Pilot
Organizations**

I discovered the following ad in the August 1995 issue of Exceptional Parent Magazine. Since finances are always an issue for most of us, this ad was like a gift. I did call a few of these organizations and will list any information I can at the end of the article.

The following organizations provide free air transportation to eligible individuals and their families, for appointments with distant medical specialists. Travelers must be medically stable; no medical support is available on these flights. Eligibility is based on financial need; each organization has its own application procedure and criteria for "financial need." A few organizations may also require a medical referral.

Except where noted, flights may originate anywhere within the continental United States. As noted following some listings certain organizations have limits on the distance of single flight, but most of these groups will try to help families plan longer trips through relays with other organizations.

Air Care Alliance
 500-mile limit

Air Life Line
 500-Mile limit

Lifeline Pilots
 Flights must originate in Midwest;
 700-mile limit

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4-1-1, Ogawahigashi-cho
Kodaira, Tokyo 187 Japan

United Way

It is possible for individuals to direct contributions to the AHC Foundation through the United Way. In order to do so, two steps must take place.

First, the Foundation must be recognized by the local United Way. You need to contact your local United Way and indicate that you would like the Foundation assigned a code number to receive direct contributions. Give them the full name of the organization along with my name, address and phone number (listed below) and I will supply them with the rest of the information they require.

Second, you should complete a "contributors choice form" listing the Foundation as the destination of your United Way contributions. The form is submitted to the United Way along with your payroll pledge card, check or other donation forms. The form requires you to list the full name of the Foundation, its address (use mine) and code number. Once the Foundation is registered with the local United Way it stays registered, however, the contributors choice form must be completed annually by each donor. If the contributors request form was not submitted also with the payroll pledge card you can still submit one any time through January 15, of the next year.

United Way contributions can become an important source of funds for our organization. We already have code number 018457 for the United Way of Tristate (CT, NY, NJ) and code number 9157 in Pennsylvania. I encourage all families to get our organization registered by your local United Way and have friends, family, co-workers, etc. pledge to the Foundation.

Greg Wisyanski, Treasurer
409 Buckingham Ave.
Milford, CT 06460
(203)-338-4006 work

Fundraising Efforts

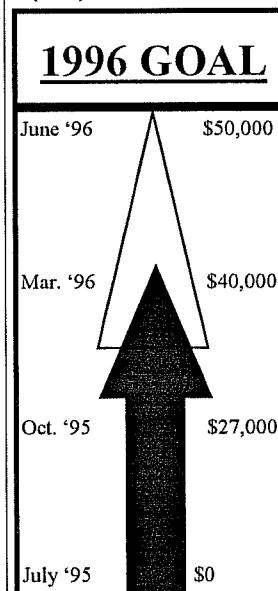
Richard and Rhonda George have been our main source of fundraising. In September 1995, the George's raised \$50,000 at a beer and wine tasting. In September 1996, they raised another \$27,000. And in December 1996, Miller Brewing Co. donated \$.04 per case of beer, in five counties to raise \$10,000.

On July 27th, the George's will again host a fundraiser. This time it is a Rock'n Blues Festival. Richard has the support of Budweiser and WRIF (local rock and blues station) as its sponsors. The concert is free to the public and will be held at Greenmead Park in Livonia, MI. The proceeds from the concessions and parking will go to AHC foundation. Contact Richard George, for information or if you know of any sponsors for this event.

The Wisyanski's and the Tasi's have worked together and have also raised over \$10,000 through an appeal letter to friends, relatives and businesses. Greg is willing to send you a copy, so that you too can help with the fundraising efforts.

It can be done!! Some suggestions from Richard are as simple as having a car wash or a bake sale. By contacting the school your child or children go to, many are willing to help. A portion of the monies goes to the school and then the rest goes to AHC. Call Richard for any information regarding fundraising. He is a source of information.

(313) 522-3706 .



Our goal for the fiscal year 1996 is \$50,000 and we are almost there. Next year we want to increase it. Please make an effort to help meet this goal. The more money we raise, the more research we can support.

Volunteer

(Continued from page 1)

Roads to Recovery

Donates deals on commercial flights originating in Maryland, Virginia or DC; also provides ground transportation, lodging and travel-related expenses.

Volunteer Pilots Association

500-mile limit

Wings for Children

500-mile limit

Wings of Mercy

500-mile limit

Organizations which offer commercial flights are:

- **Wings of Freedom** (407) 857-0727
- **Continental** (discount tickets) CARE-Force (713) 261-6626

Mercy Medical Airlift sent me the following information regarding **NPATH**, the **National Patient Air Transport Hotline** (800) 296-1217.

The mission and purpose of Mercy Medical Airlift (MMA) is to facilitate a charitable means of long-distance medical air transport for all low-income, "spend-down" and medically-indigent patients in our society thereby insuring equal access to distant specialized medical treatment or to appropriate facilities and settings for continuing care.

MMA operates the National Patient Air Transport Hotline (NPATH) which is the nation's only source of information on the total scope or spectrum of long-distance patient air transport options.

NPATH provides information and referral as follows:

1. For patients and patient families who must find a way to move loved one or themselves to distant locations for specialized treatment or recovery after illness or accident.

2. For health care industry personnel (doctors, nurses, social workers and discharge planners) and travel industry personnel who must find the most cost-effective means to move a patient and/or patient family member long-distance by

air.

3. For volunteer pilots and/or medical personnel who want to serve with one of the many volunteer pilot organizations that fly for the public benefit or with other charitable agencies that serve needy patients with charitably-assisted transport.

NPATH Information Specialists answer callers questions by explaining the various means through or by which patients can be helped. The Information Specialists have at their fingertips constantly updated directories and information on all known patient long-distance air transport options.

All known charitable patient transport options that can possible meet the need presented are carefully explained. These options include free outpatient transport by one or more of the active volunteer pilot groups, charitably-assisted air ambulance transport and a limited number of "ever changing" outpatient transport specials available from some airlines.

Various discount means and all known commercial services are also explained when no charitable means can meet the patient's needs.

Through the National Patient Air Transport Hotline all needy patients who call are helped - one by one - in a caring personal way.

Call **NPATH** at the above number for information and they will direct you to the agency that will best meet your needs in getting your child to Detroit for testing.

Regarding testing in Detroit

Dr. Chugani still needs AHC patients for the research so that he may be able to discover the cause of this condition and come up with a cure. The cost for testing is approximately \$3000 for each patient. Plan on staying for 3 to 5 days. Check with your insurance company for coverage. Dr. Chugani is willing to work with you in providing information that your insurance company may need.

If your insurance company does not pay for these tests, then you will be responsible. The foundation cannot pay for these tests

at this time.

If you are interested in having your child participate in this research, please call or write Dr. Chugani at:

Dr. Harry T. Chugani, M.D.
 Director of the Pet Center
 Children's Hospital of Michigan
 3901 Beaubien Blvd.
 Detroit, Michigan 48201-2196
 (313) 993-2867



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

International Foundation of Alternating Hemiplegia of Childhood
 29 Leonard Rd., Melrose, MA 02176
 (617) 665-8906

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Membership Contributions

AHC is a volunteer organization. Donations are the main source of funding for research and the newsletter. AHC is a tax exempt organization under 501 (c) (3) of the internal revenue code, so your donations are tax deductible. Why not make AHC your annual charity or maybe you could ask your place of employment to make AHC their charity. Please fill out the form below and return it to: AHC, Greg Wisyanski, Treasurer, 409 Buckingham Ave., Milford, CT 06460

PARENTS

Name _____
 Address _____
 City _____ State _____
 Zip _____ Phone _____

PROFESSIONALS

Name _____
 Title/Position _____

 Address _____

 City _____ State _____
 Zip _____ Phone _____
 Fax _____

Enclosed is a donation of \$ _____
 which is for: (please check one)

- Family donations to help AHC \$5-25
- Donor \$50
- Sponsor \$75
- Professional subscription fee \$75
- Patron \$100
- Contributor \$500-\$1000

I cannot afford to donate at this time, but please keep me on the AHC newsletter mailings.

For donations of \$100 and over:

- You may mention my donation in the newsletter.
- I prefer you not mention my donation.

From the Editor

A digit has been added to the overseas prefix. The fax number for John Bell & Croyden is now 011-44-171-935-9605.

If you have not sent in your permission form recently sent to you, please send it to me so I can update the files.

If you hear from a new family, please remember to let me know so that I can send them a New Family Packet.

I now have a fax. The number is (415) 365-5798.

Dr. Chugani has tested 8 children for the research program. He will be providing us with data from these patients in the next newsletter. (see page 3 - Regarding testing...)

Send me an article about your child for the next newsletter. Include a photo with the article, so that we may put a name with a face.



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

Last April, Rhinda Arnold of Odessa, Texas took it upon herself the task of educating the people around her. Rhinda Arnold contacted her local newspaper and the following article appeared the following week in the ODESSA AMERICAN newspaper. Then Rhinda was contacted by the local television station and interviewed. The interview was on the evening news. The wire service picked up the article, but unfortunately for us, that was as far as it went.

CARING FOR A \$1 MILLION BABY

Rare disease keeps family seeking cure

By Kristie Hayward
Odessa American

It has taken an Odessa family numerous doctor visits, frequent jaunts across the Mexico border for medicine and about \$1 million in medical bills to alleviate their 5-year-old daughter's headaches and learn she is suffering a rare syndrome about which doctors know very little.

Two years ago, Hollie Arnold was diagnosed with alternating hemiplegia of childhood, a syndrome only 67 other Americans are known to suffer, said Rhinda Arnold, Hollie's mother.

"We call her our million-dollar baby because that's what she cost us her first year," she said. "My mother calls (children with the ailment) unicorns because they're so rare."

Dr. Harry Chugani of the Children's Hospital at Detroit Medical Center said he believes there are many more cases that have been misdiagnosed because so little is known about AHC.

Chugani joined the International Foundation of Alternating Hemiplegia of Children last spring and is conducting research on the syndrome.

"It's such a challenging and interesting condition," he said. "It's like they had a stroke, but they recover from it."

Scott and Rhinda Arnold noticed the problem when Hollie was 3 months old.

"Her attacks, she goes limp on one side or another or completely limp," she said. "One day she could feel great, and the next day she could be completely limp and not moving."

The episodes begin with a migraine headache. Hollie will point to the center of her forehead and say that it hurts, Arnold said.

Before too long, her body will begin to go limp, she said. Hollie then will point toward the side of her body that's going numb and say that it tickles, Arnold said.

The episodes that lasted from 10 minutes to three days were diagnosed as seizures, she said.

"The doctors really don't know what causes it or why they get it," she said. "A lot of doctors know of this, they've heard of this. But they do not know about it. Knowing of it and knowing about it are two different things."

IFAH currently has doctors like Chugani researching the syndrome, Arnold said.

"I don't feel like there's enough funding for the doctors to do their research," she said. "I want the doctors to find out what's



The Odessa American: Darwin Welgol

Hollie Arnold, 5, suffers from a rare illness that causes to Mexico for medicine and treatments unavailable in the United States. Her parents have been taking her

going on. I want a doctor who will dedicate himself to this and not take five or six years to figure it out."

After three years of trips to a variety of doctors, a neurologist who spent a few months in Odessa a couple of years ago referred the Arnolds to a doctor at the Children's Hospital in Galveston who worked with AHC patients, she said.

Dr. Jay Cook, a pediatric neurologist at The University of Texas Medical Branch in Galveston, diagnosed Hollie as having AHC, Arnold said.

Another Houston-area neurologist, Dr. Tina Narayan, who has since moved out of state, recommended the drug Flunarizine, Arnold said.

The drug, however, has not received approval by the Federal Drug Administration for treatment of AHC and is not manufactured in the United States, she said.

"This medication was used by the people in Belgium and it seems to work — not in all cases," Chugani said. "But it's the best available drug. It's not a cure by any means.

It decreases the number of attacks."

One reason Flunarizine has not been FDA approved is because so few people have AHC — it would not be cost effective to mass produce a drug used in less than 67 cases, Chugani said.

The Arnold's pay about \$100 for eight boxes of Flunarizine, about a four-month supply Arnold said. Hollie must take two capsules daily, she said.

It is not illegal for people to bring the drug to the United States, said Ivy Kupec, a spokeswoman for the FDA.

"But there's no guarantee it's safe," she added.

A drug produced outside the United States is not required to meet the same standards as drugs produced here, Kupec said.

But the cost of the drug and the trips to Mexico appear to be paying off so far, Arnold said.

"I've seen a remarkable change in her (since) we put her on this medicine," she said.

Other drugs that have been used to treat AHC sufferers include valium, ativan and baclofen, Chugani said.

With Flunarizine, Hollie's episodes do not last as long or occur as often, Arnold said.

"Her going completely limp, she hasn't done that," Arnold said.

And during the past year she's become more active and is talking more, Arnold said.

Hollie continues to see Cook in Galveston every six months for check-ups and so he can monitor her dosage of Flunarizine, Arnold said.

"It sure would help to have a doctor close," she said. "I also want for us to get this drug here. Why are they depriving our kids?"

Other than the a few episodes each month, Hollie appears to be a normal 5-year-old girl, Arnold said.

Other tests, such as electroencephalograms and computerized atrial tomogra-

Diagnosing alternating hemiplegia

By Kristie Hayward
Odessa American

Alternating hemiplegia of childhood was identified in 1971 as a rare syndrome characterized by many different symptoms, said Stephen Hurley of Melrose, Mass., founder of the International Foundation of Alternating Hemiplegia of Childhood.

"Children with AHC usually live a nightmare of varying lengths before they're diagnosed properly," he said.

Sufferers of AHC may show episodes of paralysis, abnormalities of motor movement control, epilepsy, mental retardation to varying degrees and developmental delays, according to information released by the foundation.

Most AHC sufferers are diagnosed with a myriad of ailments before being properly diagnosed with AHC because so little research has been conducted, he said.

"There's no place to go for funding; there's no place to go for support," Hurley said. "There's no place to go for anything."

Families of AHC sufferers have organized fund raisers to help finance research, and Dr. Harry Chugani of Children's Hospital at Detroit Medical Center recently agreed to join the foundation and study AHC, Hurley said.

A 1993 study by Drs. Kenneth Silver and Frederick Andermann states the mechanism of AHC remains unknown but an association to migraine is suspected.

Patients treated with Flunarizine, a drug manufactured by Janssen and used experimentally until about a year ago, showed a reduction in the duration of attacks, according to the 1993 study.

The Food and Drug Administration would not approve the drug for AHC patients, he said.

Problems with liver and kidney ailments began to show up in patients taking Flunarizine, and subsequently Janssen no longer produced or distributed it in states, Hurley said.

About 75 cases of AHC have been diagnosed in the United States since the syndrome was identified.

See RARE on Page 2B

Susan Loudon of Fairbanks, Alaska sent me the following article published in the Quillum Ikaiyucarcia (Yupik translation for "How Can I Help?")... a newsletter of information and stories from the Alaska Family Resource Project. The article was written by Christa Loudon, who is afflicted with AHC. Christa and her mom also just returned from a trip to Detroit, where Christa had the testing done as part of the research program.

My Story

by Christa Loudon,
as read to the Joint House and Senate
Finance Committee, Juneau, March,
1995

Hello, my name is Christa Loudon. This month, on March 28, I am going to be nineteen years old and I am a happy camper!

And now I want to tell you guys about myself. I have disabilities like C.P. (it means cerebral palsy) and I also have alternating hemiplegia, and a seizure disorder, but I also have feelings. Some of my friends do not understand that I have feelings about being a person that is in a wheelchair. And I do understand, because I am in a wheelchair sometimes.

I have a body that does not always want to work right. Sometimes my body shuts down and then nothing will move. For that reason I have to have a wheelchair. When my body shuts down and won't work I cannot do anything. I can hear and see but can't move. I can feel things inside my body but I can't do anything about it. For example, sometimes I have an itch and can't scratch it. And I can hear and see people



laughing and talking and having fun but I can't have fun with them, I have to just sit there.

Sometimes I also have seizures and I do hate them. I know when I am having a seizure because I get really hot and start seeing double. It's like all I can see is spots. My head feels like it goes 'round and 'round, falling and falling. The first thing I have after my seizure is a bad headache. I feel woozy and my stomach feels sick. I have to lay still and quiet until I feel better.

Sometimes when people die their lips turn blue but after I have a seizure my lips turn white. It's hard having a life like this. People call me names sometimes,

and are not nice to me, and this really hurts my feelings.

But when I move out of my house and get a job I will need wheelchair accessible housing and a roommate that is also my best friend. I just hope to have good housing and a good roommate. Someday I will get a job and a house, but I will need somebody to help me find a house and to get a job working with little children. I can do a lot for myself, but I just hope somebody will be there to help me do everything.

I receive SSI and Medicaid. I can go to my doctor five times in one month, but I must pay for my eye checkups, my glasses, and for my dental expenses.

I have my own checking account. I pay my bills, I buy my clothes, my personal items, and I have a budget. My parents help me learn.

I also have a computer and a fancy wheelchair and I also have my own phone line with my own phone number and I am H-A-P-P-Y to have something like this. One other thing I have is an electric powered three wheeler. I can pedal it and when I run out of strength, I can get myself back home.

When I'm at home my brother helps me a lot. One time I could feel a cramp in my foot but couldn't move it. I could feel the pain. My brother massaged it until it was better.

And now if you see me like that you will know what I am going through. People like me just want the help we need to enjoy life like anyone else. We have feelings like you do, and want to make something of ourselves.

Thank you for letting me share my story with you.



(continued from other side)

Rare

phies, have shown no evident problems, she said.

"Which thrills me," Arnold said. Preventing the episodes has been a guessing game for the Arnolds, she said.

They have figured out that bright lights and static electricity can trigger the migraines, Arnold said. And at one point, they thought eating too much tomato sauce could cause an episode, Arnold said.

But now chocolate appears to trigger them, while pizza and spaghetti cause no effects, she said.

"I don't know what it is or why it affects her, but it does," Arnold said.

Hollie's future is uncertain because so little is known about AHC.

Only once has she stopped breathing from an episode, and there is no known case of someone dying from the syndrome, Arnold said.

"It's not fatal, but it's awful for the kids that have it," Chugani said.

But he said not enough research has been done to say for certain what happens as the children diagnosed with AHC age.

Arnold said the children she is aware of with AHC appear to be prone to other ailments.

Hollie has been hospitalized three times with pneumonia, she said.

Some doctors have said Hollie

will grow out of it; others say it will worsen during puberty, Arnold said.

And some doctors say she'll eventually go into an episode and never come out, she said.

"Sometimes it's like having two different kids," Arnold said. "She changes every day. It amazes me that she's so much like a normal child, but she has this handicap that will bring her down. And she's not the same child."

Chugani said he is hopeful more research about AHC will ultimately lead to a cure, or at least a better understanding about what is happening so that proper treatment can be prescribed.

"Nobody understands what's going on in the brain when this kind of attack comes," he said.