

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

Volume 2 Issue 4

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**Summary of Workshop**

**May 16-17, 1997**

**Seattle, Washington**

by Harry T. Chugani

**T**he AHC workshop held at the Chateau St. Michelle in the Columbia Valley just outside of Seattle on May 16-17, 1997 was the first such conference on AHC to be organized in the United States. Several years ago there was an AHC symposium held in Rome (organized by Prof. Federico Vigevano), the proceedings of which are published in a book. The aim of the Seattle workshop was not to repeat the discussions held in Rome but rather, to continue and extend the dialogue.

**GOALS OF THE WORKSHOP**

Our specific goals were:

- (1) to discuss the underlying cause (or pathophysiology) of AHC, and to hear from experts performing different types of research using various medical tools to determine how these might be applied to the study of AHC
- (2) to describe how neurologists in various countries were treating children with AHC and what types of medications they were using
- (3) to lay down the foundations for establishing national and international collaborations in the study and treatment of AHC
- (4) to discuss funding sources for AHC research and how the AHC foundations might facilitate research

A discussion for parents of children with AHC was held in parallel to the medical workshop and is summarized

separately. The medical workshop was a successful one and all our goals were met.

**CLINICAL FEATURES OF AHC**

The program began with Dr. Fred Andermann (Montreal, Canada) who summarized the outcome of the Rome workshop and emphasized his belief that the underlying cause of AHC is in some way related to those mechanisms which underlie migraine. Dr. Jean Aicardi (Paris, France & London, UK) gave a detailed summary of the disorder concerning his vast experience. He pointed out the various signs and symptoms and emphasized the reasons why he believed AHC is a distinct disorder which is not related to migraine. For example, migraine does not ever show paralysis on both sides of the body at the same time whereas this often occurs in AHC.

Dr. Renzo Guerrini (Pisa, Italy) showed some of his video-EEG recordings and

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**A Parent's Point of View,** by Sue McCutchan

On May 16, my husband Wayne and I were able to attend the AHC symposium in Seattle, WA. I've got to tell you, that we were pretty excited after 23 years on our own, that something like this could be made possible. Upon arrival, I was so impressed with the amount of organization that went into the symposium. Everything was planned down to the minute. Thank you to everyone involved especially Laura and Kim Cooper. The setting at the Chateau Ste. Michelle was absolutely beautiful. Sharing stories with the parents was so inspiring. I think each one touched my heart. But most exciting, was the team of doctors there for one on one questions. The doctors worked very hard for two days sharing and collecting information. I came away learning many new ideas about AHC.

For over 23 years, I've been searching for answers. Stacy was diagnosed at age 4 months. She was misdiagnosed most of her life. Stacy went to school with the assistance of a personal aide. After graduation from high school, we remodeled our downstairs into an apartment for her. This gave her some independence without leaving home. She presently sells Mary Kay Beauty Products from our home. With two brothers, a sister, a dog and a cat, she is always busy.

In closing, I want you to know, that sometimes Stacy's life can be so trying. Everything she has done, has taken twice as long to learn. Somedays were very hard to get through, but not once have I seen her give up hope. With research and time, I think there will be a cure. Please don't give up! Take one day at a time, make small goals, and love your child for who they are. *They're very special.*

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## Research Is Our Life-Line

Dear AH Families:

As a board member of the International Foundation for Alternating Hemiplegia and executive director of the Alternating Hemiplegia Foundation, I report with great pleasure that we are working towards a joint operating agreement. We have worked hand-in-hand over the past two years and now it is time to make it official.

Rhonda and I have been involved with the IFAHC since its inception. In fact, we planned the first IFAHC fundraiser in 1994. Since that time, we have raised 85% of all funds that are currently held for research.

With the addition of an AHF Chapter in Seattle, WA, we are even better positioned to meet the fundraising challenges of the future. The Coopers have already raised \$25,000 since their daughter's diagnosis in August 1996. In addition, the Coopers single-handedly planned and executed the research symposium, for which we all are grateful. If you have any questions, please don't hesitate to contact us:

- 1) Laura Cooper: family liaison  
(206) 486-3509
- 2) Kim Cooper: medical liaison  
(206) 486-3509
- 3) Richard George: fundraising  
toll free (888)557-5757 or  
(313) 522-3706

We both look forward to better serving your needs now and in the future.

On another note, there is some terrific information in this newsletter about the research symposium. Research directions have been charted for the future. Rhonda and I are extremely encouraged!! I had the pleasure of speaking with a few doctors about their funding needs. We must raise \$1 million over the next five years in order to adequately fund the research for our chil-

dren. Please don't be frightened by the \$1 million goal. If we work together, we can raise the money.

As discussed at the parents' meeting during the symposium, your hobbies are a potential fundraiser. Consider organizing a pledge walk, a bike tour, a car wash, a garage sale, or call Donna Cyr about hosting a Tupperware party. I would be happy to send you some fundraising ideas so please don't hesitate to call.

This is a critical juncture for all families with children who suffer with AH. Alternating Hemiplegia has captured the attention of the medical community. They are interested in conducting research to help our children. If we do not join forces and raise the money to fund the research, we will lose their interest. Research is our life-line! Please, let's team-up and feed off each others enthusiasm and strengths so we can rise up to meet our \$1 million challenge. Again, I am always available to answer your questions and help you with any of your fundraising ideas.

Warmest Regards,  
Richard George, President  
Alternating Hemiplegia Foundation  
**Temporary e-mail:**  
marc.george@worldnet.att.net

P.S. Rhonda and I would love to receive any correspondence at : 31250 Plymouth Road, Livonia, Mi 48150



### Letters to the Editor

Please send your ideas, suggestions and tips for any topic you would like to discuss i.e. insurance, day care, medicines, alternative methods. I will print them in the next newsletter as space allows. Send to: Lynn Egan, 239 Nevada St., Redwood City 94062; fax/phone (650) 365-5798; e-mail: Laegan@aol.com

## Symposium

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described his analysis of the clinical features of children during and between attacks. In addition, since Prof. Federico Vigevano (Rome, Italy) was not able to attend the workshop, Dr. Guerrini (Pisa, Italy) also showed some of Dr. Vigevano's video recordings of the attacks. Following this vivid demonstration, both the clinicians and basic scientists in the group became acquainted with how the attacks occur in children with AHC.

### SOME RESEARCH FINDINGS IN AHC

Dr. Kenneth Silver (Maywood, IL) has been using magnetic resonance spectroscopy (MRS), which uses the magnetic resonance imaging (MRI) machine to determine the concentrations of various chemicals in the brain, to study children with AHC and described the results he obtained when he was working in Montreal. He found that the muscles of children with AHC showed increased concentrations of inorganic phosphate and decreased phosphorylation potential. These findings suggested that AHC may be related to some disturbance in the functioning of mitochondria (structures within our cells which are responsible for generating energy to allow us to function). He also found a decrease of another chemical N-acetyl-aspartate (NAA) suggesting abnormal function (and perhaps damage) of brain cells. However, because the mitochondrial disorders are quite well studied, and these findings did not show all of the abnormalities seen in mitochondrial disorders, the participants agreed that AHC is probably not a primary disorder of mitochondria but rather, that the mitochondria are affected secondarily as a result of some other abnormality.

Dr. Gregory Moore (Detroit, MI) has also been using MRS to study children with AHC and reported his findings on 13 children. Interestingly, the most consistent abnormality was in a brain region called the cerebellum which is involved in posture, muscle tone, eye movements and some cognitive functions. Distur-

bances in these functions are typically seen in AHC. Dr. Moore also found an increase in the brain chemical glutamate which is closely linked to calcium channels where the medication flunarizine has its effect. He did not find elevated lactate in the brain, again supporting the consensus of the participants that AHC is probably not a primary disorder of mitochondria.

Dr. Mary Zupanc (Rochester, MN) cleared up a lot of confusion when she described her findings on AHC using SPECT scans which measure blood flow to the brain. The several papers published by various investigators appear to show conflicting results when using SPECT. Dr. Zupanc found decreased blood flow to the brain hemisphere opposite to the side of limb involvement during an attack, while others have reported an increased blood flow or no change at all. In reviewing the timing of the SPECT scan with relation to the onset of the attack, she found that the scans had been performed at various stages of the attack and thus could not be directly compared. She emphasized that a carefully controlled study using SPECT during different stages of the attack might provide useful information as to how the attack begins and spreads in the brain.

Unlike SPECT scans, PET scans provide more clear images of the brain and are used to measure a variety of biochemical functions. Dr. Ednea da Silva (Detroit, MI) reported findings from 11 children with AHC. She found that PET scans of glucose metabolism (an indicator of the degree of activity in various regions of the brain) often showed one or more areas of decreased glucose consumption suggesting that they had been damaged. Other children were more likely to show more discrete regions of damage compared to younger children with AHC. A single child studied with PET scanning of benzodiazepine receptors (those sites on the surface of brain cells that are stimulated by medications such as ativan, klonopin or val-

ium) during an attack showed increase activity of this receptor site opposite to the side of limb paralysis; following the attack, the glucose PET scan showed decrease activity in the same area of the brain. A third type of PET scan which measures how fast the chemical serotonin is being made in various regions of the brain has just been developed. Serotonin is increased in migraine and treatment of migraine is designed to block serotonin effects in the brain. The Detroit group has scheduled one AHC patient to undergo this test and plans to study more children in an effort to determine the relationship of AHC to migraine. It is possible that migraine medications might be useful in treating AHC.

### SOME NEW IDEAS ABOUT WHAT MIGHT CAUSE AHC

Dr. Philip Schwartzkroin (Seattle, WA), a basic scientist and past president of the American Epilepsy Society outlined the lessons learned from epilepsy research and applied them to the study of AHC. He suggested that one process in the brain called 'spreading cortical depression', which is believed to play a role in migraine, may also be worthy of study in children with AHC. This would be consistent with the observation that flunarizine helps alleviate the attacks in some children with AHC. Dr. Schwartzkroin then went on to present several possible mechanisms which might explain the signs and symptoms of AHC and suggested that we should take a broad and objective view and consider all of these hypotheses.

A highlight of the meeting was the presentation by Dr. Louis Ptacek (Salt Lake City, UT) whose work on 'channelopathies' is well known. A 'channel' is a pore on the surface of brain cells allowing certain 'ions' (such as sodium, potassium, calcium, chloride and magnesium) to pass in and out of the cells under controlled circumstances. A 'channelopathy' is a disorder (typically genetic) in which there is abnormal functions of a type of channel leading to an imbalance of ions inside and outside of

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## Symposium

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the brain cells and an alteration of the excitability of the cells. Dr. Ptacek's suggestion that AHC may be a type of 'channelopathy' was very well received by the participants who felt that the signs and symptoms of AHC were quite consistent with this idea. Several of the other 'channelopathies' have been well studied and effective treatments are available for some of them. Dr. Ptacek would like to collect blood samples from children with AHC as well as their parents and possibly close relatives as well in order to develop a 'bank' of blood cells which can then be used for further testing as more and more techniques become available to study these disorders.

Dr. Michael Johnston (Baltimore, MD), an expert on calcium channels (which are blocked by flunarizine), explored the relationship between the chemical glutamate (which is closely linked to calcium channels) and the production of another chemical nitric oxide which may be associated with the progressive damage to the brain in children with AHC. He suggested that one way of determining whether such a mechanism may be important in AHC is to perform spinal taps and look for a chemical called citrulline in the spinal fluid. In addition, it may be worthwhile trying to block the production of nitric oxide, but at present no such blocking agents are clinically available.

It was interesting that Dr. Diane Chugani (Detroit, MI), a neuropharmacologist who had never previously met Dr. Johnston, also suggested that abnormal production of nitric oxide in the brain might be related to progressive brain damage in children with AHC. She attempted to link these mechanisms with previous observations that AHC might affect the mitochondria secondarily (discussed above). She described how alterations in the chemical pathway for the synthesis of serotonin as well as disturbances in nitric oxide pathways can both lead to impaired energy production in the brain and resemble mitochondrial disorders. She suggested measuring blood and spinal fluid levels of tryptophan and

quinolinic acid in order to further study these possible mechanisms. With regard to treatment, Dr. Diane Chugani suggested that using the agent Coenzyme Q-10 may have protective effect on the brain.

### GENETIC APPROACHES TO AHC

Dr. Eva Andermann (Montreal, Canada), a well-known geneticist on neurological disorders, described her patients with a benign form of AHC with attacks occurring only at night. These patients clearly have a condition that is related to migraine. She found that 88% of her patients had one or more first or second degree relatives with migraine. She also pointed out that the condition CADASIL in which affected individuals have small strokes beginning during adulthood have a genetic defect on chromosome 19. Approximately 50% of individuals with familial hemiplegic migraine also have genetic defect on the same chromosome. Furthermore, one form of episodic ataxia (a 'channelopathy') also has a defect on the same chromosome. Therefore, she suggested that a reasonable place to look for a genetic abnormality in AHC would be chromosome 19.

Dr. James Garbern (Detroit, MI) discussed the family with AHC reported by Mikati several years ago. The affected members in this family have a defect in their chromosomes where a portion of chromosome 3 is attached in chromosome 9, and a portion of chromosome 9 is attached in chromosome 3. This is known as a 'translocation' defect in the chromosomes, and can provide important clues as to the location of genetic defects in the more typical AHC patients who do not show translocation between chromosomes 3 and 9. Dr. Garbern suggested that the neighboring regions of chromosomes 3 and 9 in their family should be scrutinized for genetic errors in AHC patients, and wants to collect blood from both Mikati's reported family as well as other AHC patients. Dr. Garbern listed a number of genetic probes currently available to detect possible genetic defects in these two chromosomes.

### TREATMENT OF AHC

Dr. Steven Roach (Dallas, TX), has published a book on diseases of blood vessels in the brain, and is also involved in several family support organizations for neurological disorders. He discussed some aspects of a database for AHC patients and emphasized the need for a release signed by the family which will allow interested researchers to contact the family without liability.

Dr. Giuseppe Gobbi (Reggio Emilia, Italy), summarized the Italian experience in the treatment of AHC. He divided treatment strategies into chronic treatment designed to minimize the number of attacks, and acute treatment designed to abort an attack once it had already begun. Flunarizine was the most useful chronic treatment and was effective in 60% of patients, but only rarely was the benefit sustained over a long period of time. With regard to acute treatment, he reported the interesting observation that a new medication called niaprazine seemed to be effective in aborting an attack without inducing sleep. This was of particular interest to the participants who realized that the most widely used method to abort an attack at present is to use ativan or chloral hydrate, both of which will cause the child to sleep.

The final formal speaker, Dr. Jong Rho (Seattle, WA), gave a very scholarly presentation on the properties of flunarizine as studied in the laboratory on cell cultures. The point was made that flunarizine has a number of effects in addition to blocking calcium channels, and it is possible that its usefulness in the treatment of AHC may be the result of some of these other properties. Flunarizine remains the treatment of choice in AHC, and the second most widely used group of medications is the benzodiazepines, which include ativan, valium and klonopin.

### RECOMMENDATIONS FOR THE FUTURE

We encouraged discussions following each of the presentations and many ideas were discussed. Following the formal

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## Symposium

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presentations, there were further discussion regarding the direction that we, as a group, should pursue in order to elucidate the underlying cause of AHC. Several conclusions and recommendations were reached and these are listed as follows:

(1) The participants unanimously agreed that there should not be two separate organizations for AHC. The fact that the disorder is relatively rare already limits access to patients for study, and the existing split into two organizations further limits accessibility to a degree that cannot and should not be tolerated. We strongly urge the organizations, for the sake of the children and the best chances for progress, to put aside their egos and differences in order to merge into one organization with international chapters.

(2) There should be an international database of AHC patients, and that database should be available to any researcher who wants to study this disorder. At present, there are several small databases belonging to various investigators and probable overlap, so that an individual patient may be included in more than one database. A subcommittee was set up to discuss and design the most suitable types of data to be included in the database. Input from investigators interested in AHC, but not present in the workshop (for example, Dr. Vigevano, Dr. Mikati and others) will be sought. The final database should be coded in order to protect the privacy of the patients and families, but should be accessible on the internet.

(3) In addition to the blood cell bank which Dr. Louis Ptacek would like to initiate, there would be the awareness that when patients with AHC expire, the brain and body tissue is a valuable resource for research and should be stored in one of the number of tissue banks in various parts of the USA and other countries.

(4) Genetic studies aimed at searching for a chromosomal abnormality should be given the highest priority for research

funding, and the work should begin as soon as possible. A genetics task force including Dr. Ptacek, Dr. Garbern and Dr. Eva Andermann was appointed, and it was emphasized that these investigators should collaborate with each other in the genetic project. The skills required for the genetics studies are not easily available to the other participants of the workshop who should serve as facilitators of this project by making patients and blood specimens available.

(5) There has to be some organized efforts to test the efficacy of new medications in the treatment of AHC. Dr. Mary Zupanc is very interested in drug trials and volunteered to organize the trials. The specific protocols can be followed locally by various participants and the results reported to Dr. Zupanc for analysis. There are many medications which have been tried and found not to be effective in the treatment of AHC, but these 'failures' are rarely reported in the neurology journals. The AHC organization should send a questionnaire to all pediatric neurologists asking them which medications they have tried on their AHC patients and which have not been effective or have actually made the children worse. This information is extremely important to obtain so that the children will not have to be subjected to drugs that are not effective for their symptoms and that cause side effects. This will prevent unnecessary suffering and false hopes.

All those who attended the workshop were impressed at the progress achieved over the two days. A medical summary of the proceeding will be prepared by Dr. Jong Rho and Dr. Harry Chugani, and this will then be submitted to one of the pediatric neurology journals for publication. Reprints will be available, and the AHC organization should purchase these for widespread distribution. For the time being, the recommendations to the parents and foundations have been made. Let us begin the work!

## Medical Update

### Overview, by Kim Cooper

As a follow up to the recent AHC Symposium held in May, there are several exciting things on the medical front that are currently taking shape. Although these items are currently in the developmental stages, in the coming weeks we hope to have a lot more details to pass along. They are as follows:

1) As outlined in the symposium summary, we are having ongoing discussions with Dr. Louis Ptacek regarding the collection of blood samples from AHC children and their families. The purpose of this collection effort would be to develop a 'bank' of blood cells which would be used for continued testing as new techniques and information become available. We hope to have most of the details worked out and distributed to AHC families by the end of August.

2) Also discussed in the symposium summary, there are indications that elevated levels of nitric oxide in the brain may be responsible for the progressive damage that seems to occur in most children with AHC. The best way to further investigate this theory is through the testing of cerebral spinal fluid (CSF), collected via a spinal tap. In conducting a test of this nature, CSF samples would need to be collected from a minimum of twelve AHC patients. We will have more details to report on this by the end of August as well.

3) A request for research proposals is currently being drafted. Once finalized, it will be sent to symposium participants and other medical professionals wanting to conduct specific research in areas considered to be beneficial in learning more about the pathophysiology of, and the possible treatment and/or cure for AHC.

On a related note, copies of the audio and video tapes of the symposium will be available soon to those of you who would like to purchase them. The price will be based on the original cost of record and the subsequent duplication fees. If you are interested please contact Richard George @ (888) 557-5757.

## From the President

Dear Parents,

I hope that all is well in your household and that your children have been having fun this summer. As parents we know that stress is one of the major contributors to the onset of a hemiplegic attack and that is difficult to keep the stress levels down to a minimum when kids are playing. To me it always seems to take away the fun from a child with Alternating Hemiplegia, however we must do what we can to enhance the lives of our children.

On a more personal note I would like you to know what we are doing for our son Colin who will be five (5) in September. He has been sleeping on a Magnetic Mattress Pad for approximately one year. From our observations we have seen improvements in his energy levels and his speech. He sleeps very soundly and awakes with much enthusiasm. He speaks in sentences up to 10 words and has been a regular chatterbox the last few months. In addition to 10 mg. of Flunarizine daily we supplement his diet with Vitamin C, Multivitamins, CoEnzyme Q, Ginkgo Biloba and a special herbal tea. Colin has a hemiplegic attack approximately once a week, however the intensity and duration is minimal. Sometimes the attacks last for several minutes, he sleeps for one to five minutes, and then he has an attack on the opposite side. This may occur over several hours, however this is the exception rather than the rule with his attacks. The expressed pain and dystonic posturing have been minimal since the use of the magnetic mattress pad. He still has minor attacks when subjected to high stress situations such as playing intensely with his two brothers, Ian (age 8) and Nicholas (age 6). Playing in the sandbox or in the baby pool for 10-15 minutes also brings on an attack.

My wife, Karen, is currently in Portland, Oregon with Colin where we are trying experimental Acupuncture over the next three weeks. We will inform you as to the results as soon as we know whether the treatment is helpful or has any negative

side effects. We can only hope that this procedure will have some positive aspects and improve his condition.

For those parents who are using the magnetic mattress pads for their children, we hope that you have seen some improvement in their condition. The preliminary reports we have had from some of you is very promising. We believe that anything that we can do which helps the children, that is non-invasive and non-drug associated is a plus. Unfortunately there are no cure-alls and we do not have the answers as to the cause(s) or cure for AHC, however new directions in research may give us new insight into the disorder and provide new avenues for therapy.

Research is important yet costly and may or may not provide the solutions in the near term to the problems associated with AHC, we as parents most desperately seek for our children. However, we must make every effort to support the doctors and scientists in their search for answers and solutions and this takes money. Fundraising activities are very important no matter how large or small they may be. Please make an effort to assist in this activity and inform your community about AHC. You may be surprised.

On a business note, the IFAHC is currently in negotiations with the Alternating Hemiplegia Foundation (AHF) to establish a Joint Operating Agreement (JOA). Additional information from AHF is provided in an article from their President, Richard George, in this newsletter. Please do not be alarmed by the fact that there are two organizations. We have been working with the AHF since its inception and have cooperatively funded the research activities to date without any significant problems. The roles and responsibilities of these organizations will be defined in the JOA such that there is no duplication of efforts in supporting parents and the children with AHC.

The IFAHC will continue to provide information and support to the IFAHC membership through its Administration and Medical Advisory Board. However,

this board may be a combined board between the AHF and the IFAHC since there are so few doctors and scientists interested in supporting research into AHC. More information will be forthcoming after negotiations with AHF are formalized.

In the near future representatives from the IFAHC will be attending the annual Child Neurology Society meeting and the annual Family Conference of the National Organization of Rare Disorders (NORD). Members who are interested in attending and providing support during these meetings should contact Lynn Egan as soon as possible.

Thank all of you for your time and your patience. We wish the best for you and your children and may the Good Lord be with you and protect you.

Neal Jackson

### *More on the magnetic mattress pads:*

In speaking with the families that are using the magnetic mattress pads, almost all have had positive results. The amount of time before positive results are observed by the parents or other professionals treating the child appears to be directly related to the age of the child. The younger children seem to be responding quicker and with a greater positive impact.

I will be gathering data from the 10 families who are participating in the study and will have the information available for the next newsletter.

Karen Jackson



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



## Kids Helping Kids

Dear Friends:

I am so glad that we have had the opportunity to get acquainted. I wish it was under different circumstances, but we have a common bond, none the less! I have been blessed with so many parents I met in Seattle and on the internet, I must let you know that you have made the difference on how we have dealt with Michael and AHC. The support we have found keeps every day looking brighter... thank you and I know the good Lord is watching out after our children and our fundraising efforts!

We had our first meeting on our project in the big city of Alsey, IL! The population in Alsey is 250 people, so don't think your town is too small to make a difference. We are planning to make a audio and video for AHC...all His children. I told some of you about my idea in Seattle and looks like there's no stopping us now! We are requesting kids from all over the area to participate in a "kids choir", and most expect around 200 kids in this choir! That's practically our population... but why not! I need the AHC kids help, also. I need video footage from all our children, our families, schools, hobbies, etc. I want to combine the AHC kids and the kids singing on a video to be sold world wide for research funding! We are also planning a concert sometime in November, 1997 and hope to have the audio and video complete so I need your videos now! Our next meeting is on August 7, 1997, so if I could get your videos by then or no later than the end of August, it would be fantastic! Also, I would like permission to give the kids choir your child's address to maybe become pen pals...kids for kids! I hope this project is two-fold; one to get the public aware and help our children and two, get the kids involved in the area churches, and I think if they become pen pals that would make their efforts even more personal! Hope to hear from all of you real soon and please keep a rainbow in mind when making your videos, because that

was my original idea...picture a rainbow and God's promise to AHC...all His children. Send your videos as soon as possible to the address below and if you have any questions, by all means send me email. On bad days, it keeps us going. Remember, we are determined and with God's help, we can find a cure!

Keep smiling,

Dave, Cindy, Rachel and Michael Ryan  
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## Other Events

### Fundraising

Carol and Kevin Prunty from Rockford, IL, are having a moonlight bowling fundraiser at Cherry Bowl on Saturday, September 13 at 9:00 p.m. We hope to fill the place with bowlers and have some other activities going on as well.

### Conferences

*The 1997 NORD conference* is being held in conjunction with "Exceptional Parents" in Washington, D.C. on October 30-November 2. The conference is designed for patients, families and voluntary organizational leaders. Workshops directed to patients and families:

- Participate in discussions on issues affecting the special health care needs and children with disabilities.
- Take advantage of networking opportunities with other family members who share your concerns.
- Learn about important resources that are available.

*The Child Neurology Society* meeting is being held October 30 - Nov. 1 at the Pointe Hilton Resort, South Mountain in Phoenix, Arizona. Lynn Egan will be receiving a packet from the Child Neurology Society the first week of August, for those who may be interested in attending.

## Updates

In our letter dated February 19, 1997, we wrote that the U.S. Web Site was to be ready by March 1. Because of many circumstances this has not happened, however Catherine Mathews is now working on it and also investigating, along with Kim Cooper, a proprietary server that will best serve our needs for disseminating information. The individual e-mail addresses have changed also. Please look below for those changes.

The foundation fax/phone area code has changed from 415 to 650. Please make a note.

**International Foundation for  
Alternating Hemiplegia of Childhood**  
201 Ira Lane, Port Matilda, PA 16870  
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### **Board of Trustees**

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