Angioma Alliance

Angioma Alliance Newsletter

Editor-Cristina DeSalvo

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COMING SOON...ANGIOMA ALLIANCE FAMILY CONFERENCE 2006!

It's not too late to register! The Angioma Alliance Annual Family Conference is being held in Santa Fe, New Mexico on June 22 and 23, and is shaping up to be our biggest and best conference yet. With outstanding speakers, including Dr. Robert Spetzler of the Barrow Neurological Institute, and many opportunities to learn from each other, this event will leave you with invaluable information and new friends. It is an event not to be missed!

In addition to breakout sessions and discussions on the emotional and other impacts of cavernous angioma, the conference will feature the following expert speakers:

- Dr. Robert Spetzler of the Barrow Neurological Institute.
- Dr. Howard Yonas, who recently moved from the University of Pittsburgh to chair the neurosurgery department at the University of New Mexico.
- Dr. Leslie Morrison, a neurologist at the University of New Mexico
- Dr. Judy Gault, a leading cavernous angioma researcher who comes to us from the University of Colorado
- Dr. Eric Johnson of PreventionGenetics

For more information on how to register and for details on how you can turn this event into fun for the whole family, see Page 2 of this newsletter.

ANGIOMA ALLIANCE NEUROLOGY RESIDENTS' AWARD

Angioma Alliance has established an award, for neurology residents in the United States, that will encourage residents to gain an in-depth knowledge of CCM before launching their careers. With the help of Dr. Jose Biller of our Scientific Advisory Board, we are distributing a series of case scenarios and general questions about CCM to medical school residency programs. Entrants will answer general questions and will provide a discussion of treatment issues relevant to the case scenarios. The entrant submitting the best paper will be awarded $1,000. Participating in this competition will place a resident in the position of knowing more about CCM than the vast majority of neurologists who are currently in clinical practice. If we are able to continue this as an annual competition, we will be able to create a growing referral base of new physicians who are well-versed in the treatment of CCM.

In this newsletter, the terms "cavernous angioma," "cavernous malformation," and "CCM" are used interchangeably.

Inside this issue:

CALL FOR PAPERS...

If you would like to write a featured article for any one of Angioma Alliance's newsletters, please contact Cristina DeSalvo.

cmdesalvo@yahoo.com

Thank you!

HOTEL INFORMATION

The conference is being held at the Santa Fe Hilton. We have a discounted rate of $139 pernight (the rooms typically run for $200+ for that time of year). Please check the conference registration form for reservation instructions. **You must make your hotel reservation by May 22nd in order to be guaranteed a room.**

Family Conference 2006: Join Angioma Alliance in Sunny Santa Fe!

HOW TO REGISTER

Registrations that we received postmarked before June 1st will get a registration discount (discounted registrations are $65). Adult registrations postmarked after June 1 are $80.

Information and registration forms for the family conference are now available online at:

http://www.angiomaalliance.org/docs/2006InformationAndRegistration.pdf

or by calling Angioma Alliance at 1-757-258-3355.

CHILDCARE

Childcare will be available from 8 am – 4 pm on both days for children who are between 3 and 13 years old. The kids will be taking a trip to the Children's Museum one afternoon and visiting a local park on another. There will be games, art activities, and videos planned as well. For children under 3, we can help to arrange individual childcare.

SANTA FE

Santa Fe offers plenty of fun for the whole family. In your free time , consider visiting Santa Fe's many museums, galleries, and restaurants. The downtown area near the Hilton of Santa Fe boasts the Palace of the Governors, which is the oldest public building in continuous use in the United States, and the Loretto Chapel with its miraculous staircase. You will also find the Georgia O'Keefe museum as well as museums of Indian arts and culture, international folk art, and fine arts. There are more galleries per square foot in Santa Fe than in any other city in the country. To order a free visitors guide, visit http://santafe.org/Visitors_Guide/index.html.

On the Importance of Being Informed By Kirk McElhearn

Those of us with cavernomas know that we face a (hopefully) long future during which we will see doctors often. Aside from any other health problems we may have, we will see general practitioners, neurologists, radiologists, and perhaps even neurosurgeons, regularly. For those who have operable cavernomas, and who opt for surgery, the brain surgeon will be the most important. For those whose cavernomas are inoperable, or who have chosen a "wait and see" approach, neurologists and radiologists will become familiar faces. And both types of patients will probably see general practitioners often. This familiarity with doctors is not something that anyone wants to develop, yet, in the case of any chronic illness, it is inevitable.

While these doctors are founts of knowledge, they are not omniscient, and can only help us if we help them. In my experience with a number of different doctors, I have seen how being informed, and being prepared, can make a big difference not only in the way doctors interact with me, but also in the type of information they provide.

When you go see the neurologist for the first time, you are probably scared, confused, and unsure of the future. This is understandable, and often the doctor will try to reassure you. Many doctors will simplify and understate things in order to do so, giving you incomplete and unhelpful information. Gone are the days when doctors would not tell the patients the truth about their conditions, assuming that they were better off not knowing what is wrong with them. Today, doctors owe it to patients to be up-front and honest, but patients also need to be proactive in order to develop a trusting, long-term relationship with their doctors and to get the best possible information.

The first thing to do is to be informed. Being informed about a medical condition such as a cavernoma is not simple. This is the brain, after all, a complicated organ that, in many cases, still perplexes doctors. My neurologist has told me, many times, that doctors just don't know certain things about the brain and about how cavernomas behave. Patients can get a fair amount of information from the Angioma Alliance website (www.angiomaalliance.org), as well as from other websites, so as not to enter the doctor's office unaware.

Make notes, ask questions on forums or mailing lists, print out articles about your condition, then ask your GP for help understanding them if necessary. You won't have much time with your neurologist, so it's better to be prepared for those appointments. Note your symptoms, their severity and frequency, and note every symptom that may be related to your cavernoma. Don't be afraid to go to the doctor's office with a list of questions you want answered, along with a list of symptoms to explain. Many people find it hard to remember everything they had planned to tell their doctor, and only think of some questions after leaving his or her office. It is better to approach a doctor's visit as a professional meeting, where both you and the doctor are on equal footing.

Curiously, I have found that, when seeing specialists, the mere fact that I use a few medical terms in discussing my condition ratchets the doctor's level of discourse up a few notches. They seemed to change their tone once they realized that I understood what they were talking about. But this assumes that I do understand, that I have informed myself before seeing them. The two go together, and I've found that spending time preparing for a doctor's appointment has gotten me much more useful and detailed information. In some cases, this detail won't get you any healthier, and it may even confuse you, but I've noticed that a simple "what does that mean?" gets a doctor to slow down, explain, then continue with an explanation.

Another important thing to do is take notes when seeing the doctor. Most doctors will be very understanding if you want to jot down some points. Notes can be very helpful if the doctor is prescribing new medications and you need to be aware of interactions or possible side effects. They can also help you remember any recommendations the doctor has made for lifestyle changes. Some may even allow you to bring a small tape recorder so you can play the tape back when you get home to make sure you understand all the fine points.

To sum up, it can be very helpful to approach a doctor's visit as though you were going to a meeting to discuss a project at the office. Plan ahead, make notes and prepare your questions. During the meeting, make notes, especially for any follow-up activities, and make sure you and the doctor are on the same page. While this is not an easy task--it requires that you learn enough about your condition to understand the doctor--it will pay off in the long run. Not only will the doctor be more honest, he likely will be more receptive to your questions.

This sort of approach is not for everyone. Many people are stressed out by their conditions, or simply cannot or do not want to understand the details. If this is your case, find a trusted friend or family member who can make a commitment to research your condition and accompany you to see the doctor. You can only benefit by being informed. Your doctor is likely to be more attentive, and you will probably be more receptive to his or her advice. In the long run, this is all we can do. As with any chronic medical condition, many of us are in it for the long haul, and it is better to be aware and informed than simply ignore the problem and expect it to go away.

LATEST RESEARCH

An Update on Cavernous Malformation Research

By: Connie Lee

Temporal Lobe Epilepsy

Two recent articles examined the issue of the effectiveness of surgery for temporal lobe epilepsy caused by cavernous malformations. The primary question was whether removal of the surrounding hemosiderin-stained brain tissue was necessary for a good outcome. An Italian study that included 163 patients who received temporal lobe lesionectomy (removal of only the cavernous angioma without the surrounding brain tissue) indicated that removing just the cavernous malformation was sufficient in cases where there had been only one seizure or very sporadic seizures. In their study, 63 of 64 patients who received lesionectomy very soon after their first sezure became seizure-free. The authors suspect that removing the cavernous angioma early prevents the buildup of hemosiderin in the surrounding brain tissue which they believe to be the actual cause of cavernous malformation related epilepsy. In the second article, the authors expand on this idea to assert that it's not the lesion itself that causes seizure, but the injury to neurons around the lesion by hemosiderin which leads to altered synaptic activity.

The second study examined 31 patients who had chronic epilepsy (more than 5 seizures for more than 12 months), had not had good seizure control using medication, and had undergone surgery. Those patients whose surgery included removing all of the surrounding hemosiderin-stained brain tissue fared better long term than those who had none or only part of the hemosiderin stained tissue removed. The table below indicates the **percentage of people who were seizure free** at three different points in time post-surgery:

	Complete Removal of Stained Tissue	Partial or No Removal of Stained Tissue
1 year post surgery	77%	65%
2 years post surgery	65%	41%
3 years post surgery	59%	24%

With both partial and complete hemosiderin removal, there was a deterioration of seizure control over the three-year period post surgery in a subset of patients. But the deterioration was much less severe in the group the had complete removal of stained tissue.

The take home message of the TLE articles is that if you have your lesion surgically removed after just one seizure or with only sporadic seizures, you can get by with just a simple lesionectomy with incredibly good results. However, if you wait until there is increased hemosiderin staining in surrounding brain tissue, the surgeon must get all the stained tissue if possible or you have worse outcome. Taken together, these authors would seem to be advocating a very aggressive approach toward surgery for temporal lobe seizures.

Spinal Cavernous Malformations

A spinal cavernous malformation article comes out of the Mayo Clinic in Rochester, MN. This group took a retrospective look at the 67 spinal cavernous malformation cases they had treated over an 8-year period. One thing that was noticed was that their patients tended to have a greater number of cavernous malformations in their brains and their spines than would be expected. They were finding a second cavernous malformation in the brain in at least 20% of the cases, even in many of those who did not have a family history of the illness. They suggest that it is a good idea to perform an intracranial (brain) MRI on anyone who is identified as having a spinal cavernous malformation to rule out additional lesions.

LATEST RESEARCH: An Update on Cerebral Cavernous Malformation Research (Continued from Page 4)

Genetics

The French group, led by Dr. Elizabeth Tournier-Lasserve, has published a paper examining the expression of the three known CCM genes in mice during different stages of their development from pre-natal to adult. Showing where a gene is expressed gives some indication to scientists of the role the genes may play. For example, the CCM2 and CCM3 genes were expressed in specific cortical vessels on day eight of the mouse's life, but were no longer detectable by day 19. That suggests that the proteins play a role in whatever developmental activity is happening around day eight; in this case, it appears to be a more intense time of angiogenesis (blood vessel creation) within the central nervous system.

Cohen-Gadol AA, Jacob JT, Edwards DA, Krauss WE. Coexistence of intracranial and spinal cavernous malformations: a study of prevalence and natural history. J Neurosurg. 2006 Mar;104(3):376-81.

Baumann CR, Schuknecht B, Lo Russo G, Cossu M, Citterio A, Andermann F, Siegel AM. Seizure outcome after resection of cavernous malformations is better when surrounding hemosiderin-stained brain also is removed. Epilepsia. 2006 Mar;47 (3):563-6.

Ferroli P, Casazza M, Marras C, Mendola C, Franzini A, Broggi G. Cerebral cavernomas and seizures: a retrospective study on 163 patients who underwent pure lesionectomy. Neurol Sci. 2006 Feb;26(6):390-4.

Petit N, Blecon A, Denier C, Tournier-Lasserve E. Patterns of expression of the three cerebral cavernous malformation (CCM) genes during embryonic and postnatal brain development. Gene Expr Patterns. 2006 Jan 30.

TISSUE/DNA BANK AND PATIENT REGISTRY UPDATE

As you may have read in our last newsletter, Angioma Alliance is in the process of creating a Tissue/DNA bank and Patient Registry for those affected by cavernous malformations. At this time, we are working to develop our procedures in preparation for Institutional Review Board approval. We are hoping to have this process completed by the end of June and begin enrolling our first participants in July. Stay tuned for more news about the BioBank and Registry in the next issue of the newsletter.

ANGIOMA ALLIANCE DEVELOPING PEER SUPPORT PROGRAM

By: Kristen Dehn

Angioma Alliance is excited to announce that it is in the process of developing a peer support program. The recent member survey indicated that members wanted a peer support program and now Angioma Alliance is gearing up to give it to you!

The program will closely match cavernous angioma patients who would like one-on-one support with other cavernous angioma patients who are facing similar experiences. The goal of peer support is to match people who have experienced the challenges of living with cavernous angioma(s) with others in similar situations, with the hope that they will become a source of support.

Angioma Alliance is in the process of developing the training aspects of the program to be given to potential peer supporters. Training will be offered to peer supporters to assist them in developing the listening and communication skills needed to become the best possible support for the patient in need. We're hoping that our members will find this program to be very helpful and useful.

We are in the final stages of putting this program together and additional information will be on our website shortly.

FUNDRAISING UPDATE

On May 30th of 2005 we lost our 9-year-old daughter, Janae, to complications with cavernous angioma.

Our family was deeply troubled by how little was known at our local hospital and surrounding cities about the illness. Eight months later our youngest son, Joel, showed the same symptoms as our daughter. You would have thought that the hospital had learned from my daughter's experience, but the ER doctors were even less knowledgeable than before. We have decided that something needs to be done!

In memory of our daughter and the one year anniversary of her passing, we plan to have a memorial and fundraiser on June 3rd, 2006. We are striving to increase awareness by handling out flyers about this illness all over New Mexico. Proceeds will be given to Angioma Alliance to continue building awareness and in the hope of greatly increasing support for education and research. Our family does not want another family to experience the loss and grief we have gone through. If through this effort even one life is saved, it will be worth it. You can be a part of this event even if it is by sending in a small donation to the Angioma Alliance. Please put down in the comment: **Jenae and Blue Memorial**. Blue is another young girl who passed away at age six and whose life could have been saved if her doctor had known about cavernous angioma. This event is dedicated to her memory also. More information about the event can be found at http://jenae.gallegos.home.att.net. Click on the fundraiser link. Thank you in advance.

- Tim Gallegos

Wine Auction Raises More Than $15,000 for Angioma Alliance!

MadoroM, a Napa Valley vineyard, hosted a wine auction to benefit Angioma Alliance and another charity. The owners of MadoroM, **Andy and Marissa Amador** and **Mike and Shawn Blom**, donated an 18-liter bottle of their new release cabernet sauvignon. Other attendees joined in and spontaneously donated valuable wines from their own collections. By the end of the evening, over $30,000 was raised and divided between the two organizations. It was a great time for everyone and there are plans to hold this event again next year. Thanks to the Amadors and the Bloms!

Charity Poker for Angioma Alliance

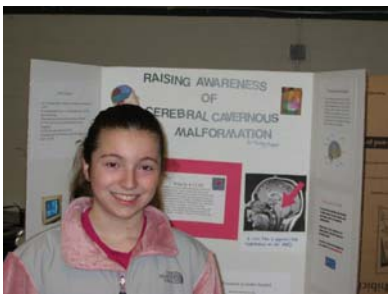
Ted Stobie, **Jeremy Neuman**, and **Andrea Smalley** played for Angioma Alliance in a charity poker tournament hosted by the Club One Casino in Fresno, California. Ted Stobie's expert play won $1,750 for our organization. Thanks to everyone who participated!

Rock-a-Thon Benefits Angioma Alliance

Kalen Leive, a high school senior in Columbus, Indiana, organized a Rock-a-Thon which raised more than $800 for Angioma Alliance. Way to go, Kalen!

In Other News...

Kelsey Ruggles (right) entered the Duxbury Science fair in April with her project "Raising Awareness of Cerebral Cavernous Malformations". With a goal of educating students, teachers, and parents, Kelsey included information on symptoms, facts about the condition, the role of genetics, and how individuals can help. She also included a binder of personal stories from families affected by CCMs. Kelsey researched material on the internet and used information from the Angioma Alliance website as well as medical information presented at last year's family conference. She did an amazing job and we are very proud.—Allison Ruggles



ANGIOMA ALLIANCE UK UPDATE

By Ian Stuart

- Angioma Alliance UK recently was approved by the charity commission and has officially received its charity status. Now that Angioma Alliance UK is approved as a charity, the advantage is tremendous. Among other things, charity status provides a much-needed tax exemption (17.5% VAT is added in the UK on top of the price of goods and services). The granting of this charity number also allows Angioma Alliance UK to print and distribute information sheets and posters to doctors' offices (at the moment this literature is only available for download through the website at www.angiomaalliance.org.uk). The charity number also gives Angioma Alliance UK the status needed to apply for grants exclusively awarded to registered charities.
- Angioma Alliance UK also is preparing documents for the "Awards for All" scheme funded by the UK lottery. AA UK is writing the grant specifically to assist in hosting its first conference. Neil Kitchen, consultant neurosurgeon and associate clinical director, National Hospital for Neurology and Neurosurgery, Queen Square, London, has kindly agreed to be the keynote speaker. Mr. Kitchen (surgeons in the UK embrace this title rather than "Doctor") has said that a neurologist should also be able to give a talk. The exact date and location are to be arranged. Ian Stuart, coordinator of Angioma Alliance UK, plans to travel to New Mexico at his own expense to attend the Angioma Alliance Family Conference 2006.
- Angioma Alliance UK hopes to invade members' public libraries, set up booths and talk to readers about cavernous angiomas. Further educational plans are to visit local schools and inform young people about this condition.
- Membership is growing. Among the members of Angioma Alliance UK are two doctors who did not previously know about this condition. Angioma Alliance UK also has honorary members who live throughout Europe.
- Angioma Alliance UK is still on the hunt for a patron. If anyone has any contacts in the UK or Europe, please let Kirk McElhearn and Ian Stuart know by emailing them at: info@angiomaalliance.org.uk.

Submitted by: Kirk McElhearn, Honorary Member, Angioma Alliance UK, and Ian Stuart, Member and Coordinator, Angioma Alliance UK

ANGIOMA ALLIANCE PLANS AUSTRALIAN BRANCH

Do you suffer from CCM and/or do you know of a friend or family member who suffers from CCM? Do you reside in Australia?

If you answered yes to both of the questions above, we would like you to become involved in our effort to extend the international awareness of this condition. We are forming a voluntary action group which aims at establishing the Australian branch of Angioma Alliance. Initially, we will service the Australians and, further down the track, the Asian-Pacific population affected by CCM.

Together, we can bring greater support for CCM sufferers and an increase in public awareness of this potentially debilitating condition in the Australian and Asian-Pacific Region. Interested persons, please email Caroline Cheung at ccheung919@yahoo.com.au

THE RESULTS ARE IN!

Angioma Alliance Member Survey

By Connie Lee

Since our last newsletter, we have been running an online member survey to help us identify our priorities for the next 3-5 years. We received 218 responses and have compiled the results.

We asked about what areas members consider to be our most important functions. The three areas identified by members with the percentage of respondents who endorsed them are: Patient/Family Information (81%), Research and Promotion of Research (72%), and Patient/Family Support (51%). The remaining items ranked as follows: Physician Education (35%), Public Awareness (24%), Patient Financial Support (10%), and International Outreach (5%).

When asked about individual activities that we could add to what we already do, our members suggested several priorities, which are listed on Page 9.

When asked how often our family conference should be held, 52% of respondents thought that the right timing is to hold the conference once a year as we are doing now. Twenty percent (20%) thought we should hold the conference more than once a year while 14% thought that every two years would be sufficient.

The questions that asked about how we proportion our budget were apparently not well designed. Respondents indicated that every single area in our budget, with the exception of research, should receive a greater percentage of the total budget, while the research budget should remain the same. We wish we had more than 100% with which to work, but that's not quite mathematically possible.

We have already begun to address some of the highest priority items. We are in the process of developing a physician directory that will initially include self-selected cerebrovascular surgeons. There will also be an opportunity for members to provide public feedback for these physicians. We do not yet have a plan to add neurologists primarily because we have no way of ensuring that a self-selected neurologist provides appropriate care for those with CCM. One thought we have is that we will add neurologists by invitation only based on your recommendations. Please let us know what you think of this.

To increase knowledge of the illness among neurologists, we are initially targeting medical residents and their supervisors through the Angioma Alliance Neurology Residents' Award. There is more information about this new program in this newsletter (see Page 1). We hope to nurture a new generation of physicians who will have a detailed understanding of the course and treatment of this illness.

We are also in the process of creating a peer support program. See the related article in this newsletter on Page 5.

Lobbying for increased research spending, creating treatment guidelines, and continuing medical education programs are larger long-term projects that will require participation from more than our membership. These will be included in our strategic plan, and we welcome anyone who may want to participate in turning these dreams into reality.

We have begun fostering relationships with international researchers by inviting four international researchers to our next scientific workshop in November. Two of the four invitees, Dr. Eugenio Pozzati from Italy and Dr. Jorge Marcondes de Souza from Brazil, have already agreed to attend.

We would like to encourage anyone who has a particularly strong feeling about an item from the list to contact us if they would like to be involved in developing the program. Also, I'd personally like to invite Canadian members to contact me regarding developing an Angioma Alliance chapter in Canada. As Ian Stuart in the UK has shown, this is very possible and worthwhile. The UK chapter already has 40 members and is growing weekly.

I want to thank everyone who took the time to participate in the survey. The Angioma Alliance Board of Directors will be meeting over the next several months to develop a comprehensive, detailed strategic plan that will guide our way as we grow into our next chapter.

MEMBER SURVEY RESULTS (continued)

Create a physician directory for referrals	62%
Develop a list of support contacts – folks who have been there and who can be called by new visitors or the newly diagnosed (peer-to-peer support).	62%
Work with our clinical and scientific advisors to create guidelines for treating CCM and develop a section of our website just for medical professionals	61%
Lobby NIH and congress for increased research spending	58%
Develop continuing education programs for physicians and nurses	52%
Create a tissue/DNA bank and patient registry	46%
Foster international relationships between researchers	46%
Bring in experts to join a chat or a forum or listserv discussion	44%
Expand information on our website	44%
Sponsor annual scientific workshops for researchers	42%
Exhibit at more medical conventions	40%
Offer grants to researchers	39%
Offer free or discounted genetic testing	38%
Distribute patient literature more widely (to family doctors for example)	37%
Develop information packets to be mailed to new patients and new visitors to the site	36%
Develop information packets targeted at specific audiences like schools, health clinics, etc.	34%
Establish Angioma Alliance chapters in countries outside of the United States and United Kingdom	34%
Organize public fundraisers	33%
Organize a letter writing campaign to media outlets (TV, radio, magazines)	30%
Increase our efforts toward developing face-to-face local support networks	30%
Encourage and assist members to contact their local press with their story	28%
Offer financial assistance to members for medical expenses	26%
Exhibit at health fairs throughout the country	26%
Increase surgery support through member hospital visits	25%
Offer financial support to members for medical travel	25%
Buy advertising space in health magazines or other print media, billboards, radio, TV	24%
Add more website support: expanded forum, more chats	22%
Exhibit at international medical conventions	22%
Organize an opportunity for kids with CCM to meet and get to know each other that is separate from the family conference – for example, at a camp or at Disneyworld	22%
Develop more Angioma Alliance products in addition to our wristbands and car magnets	21%
Sponsor international patients to help them come to the US or other major medical centers around the world for treatment	21%
Buy advertising space in medical magazines	20%
Translate our patient information into additional languages (we currently offer Spanish and a limited amount of Portuguese information)	17%
Improve the appearance of our website	2%

Raising a Child with or at Risk for Cavernous Malformations

Frequently Asked Questions, Part I of III

This material is intended for informational purposes only and does not replace consultation with a knowledgeable physician.

By: Connie Lee

Note: We use the term "cavernous malformation" as a synonym for cavernous angioma, cavernous hemangioma, and cavernoma. Venous malformations (venous angioma, DVAs) and arterio-venous malformations (AVMs) are different types of vascular malformations and information for these conditions is not included here.

My infant can't tell me when she has a headache. What are the symptoms of a cavernous malformation hemorrhage in an infant?

It is difficult to determine when an infant is having trouble with cavernous malformations versus when they are having a normal childhood illness. Those of us who have experienced raising an infant with this illness can identify with the anxiety this engenders. In general, there are several ways to distinguish whether a behavior warrants a trip to the pediatrician versus a trip to the ER or the neurosurgeon.

If your baby starts to demonstrate unusual irritability and a new onset sleep problem without fever, this may be a first sign. The baby may be having a normal reaction to teething, may have a virus, an earache, or any number of other childhood illnesses. However, pressure from a cavernous malformation bleed is greater when a baby is sleeping because gravity is not helping to move blood away from the head, making frequent awakenings common. Babies also become irritable while a cavernous malformation is bleeding much as an adult would. Although not a reason to panic, a trip to the pediatrician would be a good choice to help identify the source of the baby's symptoms.

There are more serious signs of hemorrhage that warrant a call to the neurosurgeon and perhaps a trip to the ER. Signs to watch include:

-Your baby loses a function that she could once perform such as rolling over, holding up her head, crawling, or babbling.

-Changes in your baby's eyes: Keeping tabs on your baby's eyes is important – look for a pupil that is suddenly larger in one eye than the other (unequal pupils), eyes "jumping" left to right or up and down when the baby is trying to look straight ahead (nystagmus), or both eyes no longer looking in the same direction (strabismus).

-A first tonic-clonic seizure (see below for description) not related to fever.

-If the fontanel (soft spot) becomes raised above where it normally is, this may be a sign of increased pressure in the brain. Feeling your baby's soft spot (fontanel) and becoming familiar with how raised it is can help you monitor her.

-If your baby experiences projectile vomiting, particularly along with any of the other signs, it is important to call the neurosurgeon. Projectile vomiting is vomiting with some force behind it. For example, if your baby is in her rear-facing car seat and vomits, it's probably not projectile vomiting if she's only soiled the front of her clothes. If she's soiled anything beyond her car seat you would want to suspect projectile vomiting. Also, if your baby vomits in her bed and does not have other symptoms of illness, this would warrant a call to the doctor.

-If your baby holds her head to one side or the other and appears to be unable to straighten her neck, this is called torticollis and may indicate a hemorrhage in the area of the brain called the posterior fossa.

Finally, if your child loses consciousness, you will want to call the neurosurgeon and emergency services.

What are the symptoms of a cavernous malformation hemorrhage in a child over 2?

Please read the symptoms for children above, because many of these continue to apply to older children. Addi-

tionally, preschool age and older children may be able to communicate headache pain associated with a cavernous malformation. Some people experience a pain they describe as brief, cold, and sharp going through their head. Others have intense ongoing pain. Headache, like seizure, often accompanies cavernous malformation even if there is no new bleeding.

Your child may exhibit new and unusual irritability, similar to what you might notice when they are becoming ill with influenza or other more serious contagious illness. The irritability may go on for days without evidence of other symptoms. In the absence of any of the other warning signs, this may not indicate a hemorrhage, but it is something to note.

Your child may have a new onset sleep disturbance, waking up with head discomfort or projectile vomiting. A preschool age child may not be able to tell you about head discomfort, but may wake up multiple times over the night. Pressure from a cavernous malformation bleed is greater when a child is sleeping because gravity is not helping to move blood away from the head, making frequent awakenings common.

A child who had previously not experienced seizure may have a seizure or those with seizure disorders may experience a worsening that can't be attributed to outgrowing medication doses.

Many people who have cavernous malformation hemorrhages experience vision problems or dizziness as an initial symptom. Your child may complain of seeing double or having blurry vision. They may become so dizzy that they can not walk. Some anti-seizure medications have these symptoms as side effects. It is important to rule this out.

A child may be able to communicate to you that they are experiencing tingling or numbness in a part of their body, most often in arms or legs. You may also notice speech problems – difficulty finding words, slurred speech, or difficulty understanding oral instructions.

Should my child have any medication restrictions?

As with adults, children with cavernous malformations should not be given aspirin or other NSAIDs such as ibuprofen or naprosyn products. These products reduce the ability of blood to clot, worsening any bleed that might occur. For aspirin, this effect lasts long after the aspirin has left the child's system. For the same reason, some physicians advise against the use of valproic acid (Depakote or Depakene) as an anti-seizure medication for patients with cavernous malformations. Other drugs that have drug thinning properties such as warfarin (Coumadin) or heparin should never be used.

Some controversy exists regarding the safety of many of the medications used to treat ADHD because most increase blood pressure and heart rate, if only slightly. High blood pressure is thought to be associated with increased cavernous malformation bleeding, but the impact of the small blood pressure increase caused by prescription stimulant use is not known.

What are the symptoms of a seizure disorder?

While most of us think of a seizure as a very dramatic event in which a person becomes unconscious, falls to the ground, and engages in a few minutes of jerking movements, a seizure can be quite subtle. There are two classes of seizure – general and focal. All seizures caused by cavernous malformations begin as focal seizures, but some may generalize from there.

A focal seizure can be either a partial motor or partial complex seizure. With either, there is no loss of consciousness. A child may have jerking in a single body part that is not in their conscious control, may have odd mouth movements like lip smacking, may pick at clothing, or may have odd movements. In some cases, a child may be overwhelmed by a sudden strong feeling that comes on without explanation.

Generalized seizures include tonic-clonic seizures (also known as grand mal) and absence seizures. With tonic-clonic seizure, there is a loss of consciousness and a loss of body control. The child will not be able to stand, will exhibit strong jerking movements, and may lose bladder control. With absence seizure, there is a loss of consciousness, but no loss of body control. These are often called "stop and stare" seizures because a child may simply stop his or her activity and stare into space for thirty seconds or more. (continued on Page 12)

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VOLUNTEER INFORMATION

Angioma Alliance is always in need of volunteers. Whatever your skills and time commitment, we can use your help! Contact Angioma Alliance at the telephone number or e-mail address above to learn how you can contribute. Together, we can make a difference.

Each donation of $10 or more will come with a CCM lapel pin thank you gift. Like the ribbons associated with other illnesses, our "little red guy" pin is a wonderful way to increase awareness of cerebral cavernous malformation (CCM), our little known illness. Increasing public awareness can go a long way toward increasing research funding and improving quality of life for those with cavernous angioma. Each pin comes with cavernous angioma business-size information cards that can be handed to anyone who might have questions.

Who We Are...

Angioma Alliance is a non-profit, international, volunteer-run health organization created by people affected by cerebral cavernous malformations (CCM). Our mission is to improve the quality of life for those affected by CCM through education, support, and promotion of research. We are monitored closely in our educational efforts by a Scientific Advisory Board comprised of leading cerebrovascular neurosurgeons, neurogeneticists, and neurologists.

Raising a Child...Continued from Page 11.

Can my child be treated with anti-seizure medication?

Yes, children are treated with anti-seizure medication. A number of common anti-seizure medications are approved for use in children and are available in liquid, sprinkle or chewable form.

Most anti-seizure medications are designed to be most effective for one or two specific types of seizure. Your child's doctor should discuss with you the medication options for your child. Every anti-seizure medication has side effects. Your child may need to try several medications before finding the one that is effective and has a tolerable number of side effects. Side effects tend to be worst when first starting a medication, during periods when the dosage is being increased, and during the times of the day when the blood concentration of the medication is at its peak. Common side effects include sedation, nausea and stomach distress, dizziness, vision problems, attention problems, mood disturbance, and balance/coordination problems. Not every anti-epileptic medication causes every side effect. Other more severe side effects are possible. It is important to discuss the possibility of side effects, both minor and severe, with your child's doctor before beginning treatment.

Parts II and III of this article will explore many subjects, including the following: activity limitations, MRI and CT scans, deficits and emotional and behavioral issues, emergency plans, and insurance. Please stay tuned to the next newsletter for the second installment of this article. If you would like to read the article in its entirety, please visit www.angiomaalliance.org.

Angioma Alliance now has its own magnetic car ribbon! These unique ribbons are the larger 3 ½" x 8" size and are available for $5 each, including shipping. Educate while you travel!

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