Angioma Alliance

Angioma Alliance Newsletter

Editor-Cristina DeSalvo

Fall 2006

Volume 4, Issue 3

Dear Angioma Alliance Friend,

Perhaps you have been wondering why there has been a longer break between newsletters than we typically have. It is not because there has been a lack of news – on the contrary, it is because there has been so much happening!

As I write this, I am sitting in our new home in Norfolk, Virginia, where we have moved in order to offer our daughter Julia the best educational setting possible in light of the challenges she faces from her experiences with CCM. I am surrounded by boxes labeled "Angioma Alliance" with no place to unpack them – yet. As you'll read in this issue, Angioma Alliance is taking the big step of moving into its own office (see Page 6). I am excited by the prospect of having a place to work with volunteers, offer a support group, and host visitors that come through town.

As well as moving, over the last weeks, I have been preparing for the second annual Angioma Alliance Pathobiology of CCM Scientific Workshop. As you will read on Page 6, this year's workshop will include every major scientist working on CCM in the world. I must say that I am seeing a light at the end of tunnel. The research into CCM is accelerating and researchers from other illnesses are finding connections between their work and ours. Who would have guessed that studying the heart of a zebrafish might yield answers that may lead to a cure for CCM? As our Board of Directors will attest, I have always hesitated to use the word "cure" in reference to CCM because I have felt that non-invasive treatment was the best we could hope for in my lifetime. But now, the field of genetics is moving so quickly, both for those with hereditary illness and for those with sporadic illness, that I am optimistic that a cure is possible and that we will see one much sooner than I had expected. It may not be this year or next, but it will happen. And it will be in no small part because of our efforts.

Please enjoy this issue. It is full of news of our very successful family conference, our new peer support program, our Neurology Resident's Award, our BioBank, our advocacy efforts, our United Kingdom branch, as well as a brief update of the latest in research. As always, I deeply appreciate your time, energy, and financial support – it is through your efforts that all of this is possible. Nowhere has this been made more concrete or more poignant than in the fundraising event held by Tim and Sandra Gallegos and Lillian Gonzales in memory of the young daughters they lost to CCM. Please take a few moments to read their story on Page 5 and share my awe at their strength and compassion. Their spirit and the spirit of the many who work to support us despite their own loss or adversity is what nurtures Angioma Alliance and what will carry us into our ever brighter future.

Connie Lee

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

Inside this issue:

IN THE NEWS...

Connie Lee, Angioma Alliance Founder and President, was featured in the August cover story of the Williamsburg Health Journal. The article can be found at: www.williamsburghealth.com. The story is titled "Heroes Among Us."

ANGIOMA ALLIANCE FAMILY CONFERENCE—A Success!

This year's family conference was attended by 110 people – more than double the number of the previous year's conference.

Attendees were treated to wonderful presentations including a tour de force overview of surgical technology by Dr. Robert Spetzler. We also met and enjoyed each other's company in small communication groups and during our social time.

The City of Santa Fe rolled out the red carpet for us. In addition to giving Angioma Alliance a $5,000 grant toward conference food expenses, the mayor issued a proclamation declaring June 23rd, 2006 to be Angioma Alliance Day in the city. The proclamation was read by Councilor Karen Heldmeyer who was instrumental in obtaining the city's support. Because of a founder mutation, the incidence of the familial form of cavernous angioma is higher in New Mexico than in any other place in the world. The city is beginning to see that this is truly a public health issue for them, in no small part because of the work of Angioma Alliance members Joyce Gonzales and Tim and Sandra Gallegos. This work is continuing as we are exploring ways to offer live or videotaped medical training to physicians and hospitals throughout New Mexico.

We want to thank all of the volunteers who helped to make the conference a success. The date and location of Angioma Alliance's 2007 Family Conference will be announced in the next newsletter. Stay tuned!

If you missed the conference, we videotaped the general session and DVDs are available for $40/set. You can order these online through the Angioma Alliance product store or by mailing a $40 check (US currency) to 107 Quaker Meeting House Rd, Williamsburg, VA 23188. Please include your return address and put in the memo line of your check that this is for DVDs.

Family Conference 2006
"A Picture is Worth A Thousand Words…"

Connie Lee and Jack Hoch. (right)

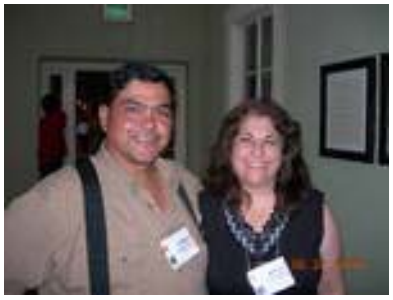
Allison and Ken Ruggles (below)

Dr. Robert Spetzler (left) presents at the Angioma Alliance Family Conference.

Sisters Kandance Weems Norris and Kim Weems. (right)

Joyce and Greg Gonzales (right)

Dr. Spetzler with Ian Stuart, of Angioma Alliance UK, and Hazel Romero. (right)



Peer Support Program Begins

Many times individuals or family members of individuals who are newly diagnosed or facing a turning point in their illness would like to develop a one-on-one relationship with another person who has had similar experiences. With the help of Angioma Alliance's Michelle Hnath and Kristen Dehn, we have begun a peer-matching program to fill this need. Peer support is based on the philosophy that the person who can really understand you is a person who has been there. Over the last several months, Kristen and Michelle have been training a variety of experienced members who have offered their time to serve as peer support volunteers.

What is a Peer Support Volunteer?

A Peer Support Volunteer offers a unique and valuable service to others struggling to learn to live with one or more cavernous angiomas. The Volunteer is directly affected by cavernous angiomas and wants to share his or her experiences with others. By offering a friendly ear, the Volunteer can help ease the fear and isolation that may come with a diagnosis of cavernous angioma(s).

How does the relationship work?

The goal of peer support is to link people who have experienced the challenges of living with a cavernous angioma(s) with others facing similar difficulties. To be matched with a Peer Support Volunteer, you will complete a Peer Support Request form or provide the required information over the phone. The form asks for information about you and your current situation that will allow us to provide the best match. You will receive an acknowledgment that your form has been received, and we will attempt to make a match within 1-2 weeks. Your assigned Peer Support Volunteer will contact you once the match has been made.

Depending on the situation, a match may involve a single exchange or follow-up contacts over an extended period of time. Contacts may be by phone, email or in person should you and your Peer Support Volunteer be geographically close.

What are the limits of the relationship?

Peer support does not replace professional help. Peer Support Volunteers do not attempt to provide psychotherapy or take the place of a physician. The peer supporters know that, even for individuals affected by the same genetic condition, everyone's medical needs are unique.

The Peer Support Volunteer does not:

- Provide counseling or therapy
- Lend money
- Give medical advice
- Do personal favors
- Provide transportation
- Come up with all the answers

Although we have screened and provided training to all peer support volunteers, Angioma Alliance assumes no responsibility for any injury caused by the relationship. Please contact us immediately at 1-866-432-5226 if you believe a Peer Support Volunteer has acted inappropriately or if you have other concerns about the relationship. Peer Support Volunteers have been asked to keep all information in the strictest confidence but there is no absolute guarantee of this.

How do I obtain a match?

If you have access to the internet, we have a page on our site, http://www.angiomaalliance.org/support.html, which provides links to Peer Support Request Forms. Simply complete the form and it will go to our Peer Support Coordinator who will use the information to make a match. If you do not have internet access, call 1-866-432-5226 and we will gather the same information or mail a form to you to complete

LATEST RESEARCH

An Update on Cavernous Malformation Research

By: Connie Lee

Several developments have occurred in cavernous angioma research since our last newsletter:

CCM2 gene is more often the cause of familial cavernous malformations than thought

Just announced at the American Society of Human Genetics conference poster session on October 9th, Dr. Doug Marchuk's lab at Duke University has discovered that the CCM2 gene may be the cause of up to 40% of cases of familial cavernous malformations rather than the 20% once believed. A large number of individuals that were identified as having a familial mutation, but whose gene was not yet identified, turned out to have what is known as a "deletion" on the CCM2 gene. A deletion is when part or all of a gene is missing. Typical genetic testing does not look for deletions, just for changes in a gene (mutations). This finding means that labs may be able to identify up to 90% of individuals with the familial form of the illness. It is suspected that a fourth gene may be responsible for the remaining 10%.

Retinal Cavernous Malformations and Familial CCM

A multi-disciplinary group in France determined that 5% of individuals with familial cavernous angiomas, regardless of the specific mutation, also have retinal cavernous angiomas.

Neurosurgical Focus features CCM

The July issue of *Neurosurgical Focus*, a publication produced by the American Association of Neurological Surgeons, was dedicated to cavernous angioma treatment and research. These 14 articles were reviews of the literature allowing neurosurgeons not familiar with the illness an efficient way to get a broad overview without wading through hundreds of individual studies. We are very grateful for AANS taking the time to produce this issue and hope that it will be widely read by the neurosurgical community.

Animal models of CCM

Research on the animal version of the KRIT1 mutation was published using both the zebrafish and c.elegans (a type of worm commonly used in genetic disorders). Animal models are very important in helping scientists understand what specific proteins are doing and which parts of a gene are the most essential. It is likely through animal models that treatments for CCM will be developed. This will be facilitated further by the Angioma Alliance scientific workshop where these animal model researchers will be presenting their work and discussing collaborations.

References

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Labauge P, Krivosic V, Denier C, Tournier-Lasserve E, Gaudric A. Frequency of retinal cavernomas in 60 patients with familial cerebral cavernomas: a clinical and genetic study. Arch Ophthalmol. 2006 Jun;124(6):885-6.

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FUNDRAISER NETS OVER $26,000 FOR ANGIOMA ALLIANCE

Tim and Sandra Gallegos and Lillian Gonzales held a fundraiser in Santa Fe, New Mexico in memory of their daughters who passed away from cavernous angioma hemorrhages. The bike-athon, silent auction, and Frito pie sale raised more than $26,000 for our work. Tim Gallegos presented the proceeds of the event to Connie Lee during the family conference. There was not a dry eye in the room as Tim read his presentation statement:

Jenae Jasmine Gallegos
7/16/1995 - 5/30/2005

> I would like to donate the proceeds from our fundraising effort to help impact and save lives by furthering research and spreading awareness. This effort was done in memory of my daughter Jenae Jasmine Gallegos, age 9, whose life was taken on May 30th, 2005 and also in memory of Blue Haven Gonzales, age 6, whose life was taken on October 5th, 2001.

Blue Haven Gonzales
1/7/1995 - 10/5/2001

> I am sad to say that these girls' lives were taken short due to complications from cavernous angioma. Jenae and Blue never even had a chance of being diagnosed with cavernous angioma while they were alive. Awareness and testing is key. This illness is not rare; what is rare is awareness and knowledge about this illness. We need to find out what makes these lesions bleed.
>
> With much help from close family and friends, together we were able to raise money toward the cause in hope that other families will not be impacted by this illness the way we have. Much more money is needed, so I challenge you to do the same type of effort in your communities. If we can do it, you can do it. Jointly we can minimize the effects of cavernous angioma and maybe even neutralize it all together. But in order to make cavernous angioma an illness of the past, it will take thousands of us pulling together toward a common goal. It will never get done if we lay idle thinking someone else will do it. We all need to get involved. This donation represents: Blood, Sweat and Tears.
>
> Connie, I present the amount of $26,003.50 from our fundraiser initiatives to go toward research. Thank you for allowing me the honor of presenting this to you this day.

We are so very grateful to Tim, Sandra, Lillian and all of the volunteers who made this event so successful. This was the largest fundraiser in our history and is supporting many of the activities you are reading about in this newsletter.

BioBank Enrolls First Participants!

The Angioma Alliance Tissue/DNA bank and Patient Registry enrolled its first participants at the family conference in Santa Fe. Fifty blood kits were shipped out of the conference to the storage facility in Marshfield, Wisconsin. We are not yet ready for general enrollment as we are still processing those who enrolled at the conference, but we can accept new participants who are expecting surgery. If you have a surgery scheduled (or will be having one in the future) and would like to participate in the BioBank, please let us know as early as possible. We are looking forward to quickly filling our BioBank with surgically removed tissue that can be used to advance cavernous angioma research. In the future, as we have our systems in place, we will be able to accept new participants at a faster pace. Thanks for all of your financial and personal support for this important work.

COMING SOON: SECOND ANNUAL SCIENTIFIC CONFERENCE

In 2005, a group of cavernous malformation researchers met in Durham, North Carolina for the first ever Angioma Alliance Scientific Conference. An opportunity for researchers to share ideas on cavernous malformations, the conference was a turning point for the Angioma Alliance and cavernous malformation research around the world.

Following the great success of last year's event, Angioma Alliance is geared up to hold the Second Annual Angioma Alliance Scientific Conference in Washington, D.C., on November 17th. This year, representatives from every major lab in the world will attend and, once again, we hope to foster intense discussion and opportunities for future collaboration among leading cavernous malformation researchers.

As of the printing of this newsletter, the attendee list includes:

From the US - Issam Awad*, Bob Shenkar, Judy Gault, Doug Marchuk* and two members of his lab, Gary Johnson and four members of his lab, Eric Johnson*, John Mably, Murat Gunel, Daniele Rigamonti*, Siddharth Kharkar, Leslie Morrison*, Jun Zhang, Dean Li, and Kevin Whitehead

From Canada - Brent Derry and Shu Ito

From France - Elizabeth Tournier-Lasserve

From Italy - Eugenio Pozzatti

From Brazil - Jorge Marcondes de Souza

From Scotland - Rustam Al-Shahi*

From NIH - Gabrielle LeBlanc

* Denotes members of the Angioma Alliance Scientific Advisory Board and/or Angioma Alliance BioBank Advisory Committee.

ANGIOMA ALLIANCE HAS NEW OFFICE

Angioma Alliance will be moving out of President Connie Lee's home into its own office in downtown Norfolk, Virginia. Beginning November 1st, the new address for Angioma Alliance will be:

142 West York Street, Suite 708

Norfolk, Virginia 23510

Any mail sent to the Williamsburg address will forward, so please feel free to continue to send donations and orders to the old address. While our toll-free line will stay the same, we will have a new direct phone line and will publicize this when it becomes available. Having a real office in an urban area means that Angioma Alliance can grow to include more local volunteers and offer a patient support group. The office is located a few blocks from Eastern Virginia Medical School, and we anticipate forming relationships with area neurologists and neurosurgeons. If you live in the Hampton Roads area and would like to help or participate, please call us at 1-866-HEAL-CCM (866-432-5226). This move out into the world represents a major step in the development of Angioma Alliance as we work toward our mission of informing and supporting individuals affected by CCM while facilitating improved diagnosis and management of the illness through education and research.

ANGIOMA ALLIANCE UK UPDATE

By Ian Stuart

Angioma Alliance UK is pleased to announce the First International Angioma Alliance UK Forum. Speakers will be:

Mr. Neil Kitchen, Consultant Neurosurgeon and Associate Clinical Director, National Hospital for Neurology and Neurosurgery, Queen Square, London

Dr. Rustam Al-Shahi, Senior Lecturer in Neurology, Western General Hospital

Dr. Eric W. Johnson, Director, PreventionGenetics

Dr. Jonathan Berg, Senior Lecturer and Honorary Consultant in Clinical Genetics, University of Dundee; and

Mr. Ian Sabin, Consultant Neurosurgeon at the Royal London Hospital, Whitechapel.

The forum will be held in the Brockway Room, Conway Hall, Red Lion Square, London, WC1, 9-5.30pm, Saturday 16 June 2007. We have already received £2000 in funding from the National Lottery (article at right). Now Angioma Alliance UK will be able to defray some members' costs; pay the hall hire expenses at Conway Hall; have the event catered and off-set some of the expenses of our speakers who are traveling from the other end of the country.


£2,000 windfall to help the sufferers of angioma

Angioma Alliance UK hopes that anyone touched by cerebral cavernous malformations, anyone who has or had this illness, and all of those individuals interested in the condition from all over the world, will attend. Admission is free.

For further information, contact Ian Stuart:

info@angiomaalliance.org.uk

ANGIOMA ALLIANCE GRANTS FIRST NEUROLOGY AWARD

Congratulations to the first recipients of Angioma Alliance's Neurology Residents Award! Dr. Geetha Bhavani Kandimala, from the University of Texas Southwestern won the first place prize. Second and third place prizes went to Dr. Amit Mahesh Shelat, from the Albert Einstein College of Medicine Program at the North Shore-Long Island Jewish Health System, and Dr. Meredith Broderick from the University Hospitals of Cleveland/Case Western Reserve, respectively. With the help of Dr. Joseph Biller, Angioma Alliance established this award to encourage residents to gain an in-depth understanding of cavernous malformations. Case studies and questions were distributed to residency programs and 17 great entries were received. Angioma Alliance would like to offer this award annually to promote the study of CCM and create a growing referral base of physicians who are well-versed in the diagnosis and treatment of CCM.

Raising a Child with or at Risk for Cavernous Malformations

Frequently Asked Questions, Part II 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.

Should my child have any activity restrictions?

If your child has seizures as a result of cavernous malformations, she or he may be advised about a number of activity restrictions. The following table lists the comparative risks of activities for children with epilepsy and can be found in "A Guide for Parents of Children with Epilepsy" produced by Shire Richwood, a pharmaceutical company. We have adapted some entries to make this table appropriate for children with cavernous malformations whether or not they have epilepsy.

No or Very Little Risk – No extra supervision needed	Moderate Risk – May need supervision or help during a seizure	High Risk - Avoid
Jogging	Climbing a tree or jungle gym – Always have a spotter underneath; avoid being upside down	Mountain or rock climbing
Aerobics	Swimming – Always swim with a buddy and/or lifeguard	Bungee jumping
Cross-country skiing	Horseback riding – Wear a helmet	Scuba diving
Dancing	Bike and scooter riding – Wear a helmet	Skydiving
Hiking	Canoeing – Wear a life vest and helmet	Caving
Golf	Ice-skating or hockey – Wear a helmet	Boxing
Ping-pong	Tennis	Hang gliding or surfing/windsurfing
Bowling	Gymnastics – Always have a spotter underneath; avoid being upside down	Solo flying
Baseball – wear a helmet	Rollerblading, skate boarding – Wear a helmet	
Field hockey – wear a helmet	Football – There is concern about the level of contact those with cavernous malformations	
Most track and field events	Soccer - restrict "heading" the ball	

Although head trauma has not been shown to be associated with cavernous malformation hemorrhage, most physicians recommend that children with cavernous malformations stay away from contact sports. Children should also be diligent about wearing a helmet in other situations in which there is an increased chance of head injury, such as skateboarding, biking, scooter riding, or inline skating. Many physicians also encourage helmet use while snowboarding or skiing. It is unwise to allow your child to spend extended periods upside down. This can increase blood volume and venous pressure in the brain. Following this restriction may limit participation in gymnastics or in the use of some playground equipment. (continued on Page 9)

Raising a Child...Continued from Page 8.

Cavernous malformations run in our family. When should I have my child tested for the illness?

This is a very individual decision, but physicians often recommend to their patients that children be screened before school age. Some parents have their children screened in infancy because sedation is sometimes easier with babies, babies won't remember the MRI, and parents can be relieved of the worry if the child doesn't have the illness. Some parents wait until their child is old enough to lie still for the MRI without sedation. Others never have their child screened unless there are symptoms because they want their kids to have as "normal" a childhood as possible.

Screening as early as possible and at minimum before school age is recommended for several reasons. First, children who are identified with cavernous malformations can be monitored, and in some cases, a cavernous malformation can be removed before it causes irreparable damage or death. Second, early identification can allow parents to work with a school system to create a plan in case of a medical emergency. Also, cavernous malformations may play a role in learning or behavior problems a child might experience. Knowing whether a child has the condition can help in making decisions about how to address these problems. Third, parents are better prepared to make informed decisions about a child's participation in activities such as contact sports. Fourth, teachers may notice symptoms of neurological deficit before parents notice them. Knowing the diagnosis and what to watch for can help a teacher to become an extra set of eyes for your family.

Clinical diagnostic blood testing is available for three genetic mutations that can cause the illness. This means that a family will be able to submit a child's blood or cheek swab sample to a lab rather than have the child undergo an MRI to determine if there is a mutation. The affected parent should have genetic testing first to determine the specific mutation before submitting the child's sample. More information can be found under "Genetic Testing" on our website.

How is an MRI for a child different from that for an adult?

Children who are unable to remain still for the 30-60 minutes required for an MRI will require some kind of sedation before the procedure. Your child will either be sedated to the level of sedation analgesia, also known as conscious sedation or twilight sleep, or to the deeper level induced by general anesthesia. Most hospitals will try sedation analgesia first, but some children become agitated by or are unable to tolerate the medications used for sedation analgesia. If this is the case, subsequent MRIs are performed using general anesthesia. The following information is from a pamphlet published by The American Society of Anesthesiologists entitled "Anesthesia and You: Sedation Analgesia":

Although once referred to as "twilight sleep," over the past few years the term "conscious sedation" has become popular to describe a semi-conscious state that allows patients to be comfortable during certain surgical or medical procedures.

Sedation analgesia can provide pain relief as well as relief of anxiety that may accompany some treatments or diagnostic tests. It involves using medications for many types of procedures without using general anesthesia, which causes complete unconsciousness.

Sedation analgesia is usually administered through an intravenous catheter, or "I.V.," to relax you and to minimize any discomfort that you might experience... Oftentimes, sedation analgesia can have fewer side effects than may occur with general anesthesia. Frequently, there is less nausea from sedation techniques, and patients generally recover faster after the procedures. (continued on Page 10)

Raising a Child...Continued from Page 9.

LEVELS OF SEDATION

Although the effects of sedation are better described in terms of "stages" or being part of a "continuum," sedation is usually divided into three categories:

1) Minimal sedation or anxiolysis

2) Moderate sedation

3) Deep sedation

During ***minimal sedation***, you will feel relaxed, and you may be awake. You can understand and answer questions and will be able to follow your physician's instructions. When receiving ***moderate sedation***, you will feel drowsy and may even sleep through much of the procedure, but will be easily awakened when spoken to or touched. You may or may not remember being in the procedure room. During ***deep sedation***, you will sleep through the procedure with little or no memory of the procedure room. Your breathing can slow, and you might be sleeping until the medications wear off. With deep sedation, supplemental oxygen is often given.

For both general anesthesia and sedation analgesia, your child will not be allowed to eat or drink for a number of hours before the procedure.

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

Cavernous Angioma Advocacy

In late September, Dr. Leslie Morrison of the Angioma Alliance scientific advisory board and Joyce Gonzales, Angioma Alliance New Mexico Coordinator, spoke before the New Mexico Health and Human Services Committee. Their goal was both to educate the committee about the prevalence of cavernous angiomas in the Hispanic population and to request assistance in patient/physician education, patient diagnosis and research in the state. Dr. Morrison and Joyce were warmly received by the committee and will be submitting a grant proposal to address the many needs of those with cavernous angiomas in New Mexico. Their work can also provide a model that members from other states or countries may use as they approach their own legislatures.

Also in late September, Angioma Alliance President Connie Lee was part of a non-profit forum at the National Institute of Neurological Disorders and Stroke – this is the part of NIH that gives grant money to our researchers. At the forum, she was able to make clear to the head of NINDS and the applicable program managers of the need for additional funding for CCM research. She also asked for suggestions as to what we could do as an organization to increase the likelihood that our researchers will get funded. Currently, NINDS is able to fund only 10% of grant requests it receives. NINDS members suggested that, in addition to creating as robust a patient registry and BioBank as possible, we explore the possibility of creating an annual Young Investigator's Award to give incentive for pilot projects that could be used as the basis for applying for full NINDS grants. Other organizations who have offered such an award have had good success in expanding research into their diseases. The typical Young Investigator's Award given by other organizations ranges from $15,000 to $75,000. The Angioma Alliance Board of Directors will be discussing the possibility of offering such an award and would encourage anyone interested in fundraising for this to contact us.

VOLUNTEER OPPORTUNITIES

We know that you've wanted to get more involved with Angioma Alliance but weren't sure how. We have many needs for volunteers right now, particularly as we are expanding our programs. Never knowing when a bleed may happen can leave one feeling helpless; volunteering is a great way to feel empowered. In helping yourself and others with cavernous angiomas through Angioma Alliance, you are making a difference.

Board of Directors

We would like to expand our Board of Directors to include members or friends who have additional skills/experience that will bring us into the future. Our Board is a working board that meets monthly via chat, typically on a Sunday evening, and is in frequent email contact throughout the month. Each board member takes responsibility for projects or a specific area of our program. The amount of time required varies depending on the project or area and often commitments wax and wane over the course of the year. The new Board Members do not need to be affected directly by cavernous angiomas. However, we understand that Board Members who are affected by cavernous angiomas or are caretakers may need to pull back at times because of illness. Our bylaws indicate that Board Members are elected for three-year terms, but obviously, one may resign earlier if circumstances warrant. The positions we would like to add include:

1. **Development** – we are in the midst of developing a strategic plan that will carry us through the next 3-5 years. We need an individual who can help us develop the relationships with funders that we will need to bring our plans to fruition. Ideally, this would be a person who has previous experience in the non-profit sector obtaining grants (foundation, corporate, and government), developing annual campaigns, and guiding volunteers through the process of planning fundraising events. While we would love to have someone with experience in all of these areas, realistically, we would be happy to work with someone who has any one of these experiences. This person should not feel that they need to do all of the grantwriting/fundraising themselves, but should be active in encouraging and identifying volunteers who can take roles in these activities. This would mean writing articles for the newsletter and making announcements on our Community Forum and listserv as well as making personal contact with volunteers.

2. **Advocacy** – we are anticipating creating and expanding our relationships with government. As you read in the "Advocacy" article in this issue, we are already beginning to work with NINDS and with the New Mexico state government. We also have invitations to teach the biotech industry and the pharmaceutical industry about our illness through their advocacy organizations BIOS and PHRMA. We are looking for one or more individuals with advocacy experience and/or a strong marketing background who can help us to develop relationships with government and industry to increase both research into treatments for CCM and services for those affected. Again, this would involve developing a volunteer base as much as making actual contacts with government/industry leaders.

3. **Science** – as our involvement in research grows, we are looking for someone who can help us to identify the best course for us to take to expedite the search for a cure. We are looking for someone who has knowledge of the steps necessary for drug development, who can keep up with the literature of molecular biology, and who can help us identify researchers or young investigators in related fields with whom we should try to form relationships. This person may become involved in evaluating BioBank requests from researchers and in evaluating researcher grant requests should we be in a position to offer such.

4. **Public Relations** – we are looking for an individual who can increase visibility of our illness and organization among the public through the media and other awareness campaigns.

5. **Relationships with the medical community** – we are looking for someone who can work with volunteers to develop programs of outreach to the medical community so that they become familiar with our illness, with our organization as a resource, and with our BioBank. This could include participation in medical conventions, developing a section of our website for clinicians, producing/distributing literature, and helping to organize grand rounds. Ideally, this individual would have a medical background.

Editor-Cristina DeSalvo

NEW ADDRESS
(as of Nov. 1)

Angioma Alliance
142 West York Street, Suite 708
Norfolk, Virginia 23510

Toll Free: 866-HEAL-CCM

info@angiomaalliance.org
www.angiomaalliance.org

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.

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.

Volunteer Opportunities (Continued from Page 11)

6. **Event planner** – our family conference is a major undertaking each year, but many of the tasks can be done from a distance and do not vary much from year to year. We are seeking someone with event planning experience who can coordinate, with local volunteers, national family conferences and any future regional conferences we may plan.

7. **Volunteer coordinator** – this individual would help develop our volunteer base, keep track of volunteers, and connect individuals with the appropriate coordinator for the activity they have chosen.

Other Volunteer Opportunities

Perhaps a Board of Directors position is a little much for you take on right now. We have many other opportunities. As you read above, almost every new board position will require a group of volunteers to support the activity. Please consider volunteering in any of above categories. In addition, we have the following needs:

1. **Simple fundraising** – one of our most effective fundraising tools has been to have members send a letter to their family and friends letting them know about Angioma Alliance and the illness and including a donation return envelope. Friends and family are often looking for a way to help but don't know how. This can be particularly effective during the holidays when many individuals are making their end of year charity donations. We can provide a sample letter and donation return envelopes for your use. Other individuals have applied to their local private foundations for grants and have always been successful. This may involve sending only a letter and following up with a phone call. While local foundations do require a local individual to spearhead the request, we can help you to identify foundations in your area and compose the request letter.

2. **Peer Support Volunteers** – as you read in this issue, we have begun a peer support program. We are seeking volunteers to serve as peer support volunteers. Volunteers must have been living with a diagnosis of cavernous angioma or been the caretaker of someone with cavernous angioma for at least 2 years. Peer support volunteers should have about 2 hours a week to give to this activity. We are in particular need of: 1) individuals who are caretakers of individuals with cavernous angiomas (spouses/partners, parents of affected adults or children); 2) people who have had a longer term recovery from surgery or a bleed that have experienced physical and/or occupational therapy; and 3) people with the common Hispanic mutation.

Additional volunteer opportunities will be posted online at www.angiomaalliance.org. If you are interested in any of these tasks or have another idea for how you would like to help Angioma Alliance, please contact us at 1-866-432-5226 or at info@AngiomaAlliance.org. I believe another organization uses this slogan, but it is equally true for us – together, we can make a difference.