



Angioma Alliance Newsletter

Spring Issue

May 12, 2005

Letter from the President

Dear Angioma Alliance members,

It is mid-May and preparations for the 2005 Angioma Alliance Family Conference in Baltimore are well underway. The Board and I are very excited about meeting everyone and being part of this special weekend. This year's conference is going to be even better than last year's - we will have a wider variety of speakers, more opportunities to get to know each other, and a working lab tour. My wish would be that everyone who has ever come in contact with Angioma Alliance would attend - it would be a little crowded, but we'd have a really wonderful time! A special word to East Coasters - the conference will not return to the East Coast until 2008, so it would be great to grab the opportunity this year if you can. Look for the articles in this issue that contain more information and updates on the conference (Pages 2-3).



Angioma Alliance President, Connie Lee, is pictured with her daughter Julia. Julia was diagnosed with multiple cerebral cavernous malformations.

This issue of the Angioma Alliance newsletter marks the first issue for our new Newsletter Editor, Cristina DeSalvo. I am grateful that Cristina has volunteered to take on this very important role. She has written a little about herself and her plans for the newsletter (Page 10). You will also find an interview with Mark Miller, a man who participated in quadrathlons after having surgery to remove a cavernous malformation from his medulla, the lowest part of the brainstem. Everyone who participates in Angioma Alliance has a story - we are happy to be able to share his with you. Finally, in this issue you will find the second installment of Jack Hoch's three-part series on imaging and diagnostics, and you will find information about our fundraising events and activities.

May 15th marks the three-year anniversary of Angioma Alliance's incorporation. It is fundraising that has allowed us to maintain our website, distribute print literature, exhibit at medical conventions, hold our conferences, and which will allow us to establish a patient registry. I want to thank each of you for participating in Angioma Alliance, and I particularly want to thank those of you who have taken the time to write letters to family and friends or to organize fundraising events. Your contributions help us to continue moving toward a future without CCM. At last year's family conference, Dr. Awad gave his historical perspective on CCM. To paraphrase him, he believed that the most significant contribution to understanding CCM, of the 1980s, was the MRI. He believed that the most significant contribution of the 1990s was genetic research. He predicted the most significant contribution of this decade would be Angioma Alliance and its role in supporting research, increasing public awareness, providing information to doctors and patients, and supporting one another. You are helping to prove him right.

Hope to see you in Baltimore.

Warmest wishes,
Connie Lee

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ANGIOMA ALLIANCE FAMILY CONFERENCE

June 24-26, 2005

Baltimore, MD

REGISTER ONLINE

FAMILY CONFERENCE 2005

The Angioma Alliance's second annual Family Conference is scheduled for the final weekend of June in Baltimore, Maryland. If you haven't already made arrangements to attend, time is running out! The conference will feature tours of facilities and research labs, expert speakers, and an opportunity to share stories with others whose lives have been affected by our disease. The complete schedule is on Page 3.

WHO: Patients, family members, doctors, neurosurgeons, researchers...

WHAT: Angioma Alliance Family Conference 2005

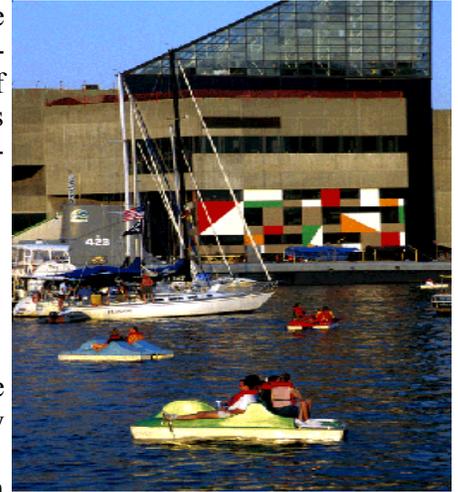
WHERE: Tremont Plaza Hotel, 222 Saint Paul Place, Baltimore, Maryland

WHEN: Friday, June 24, 2005 – Sunday, June 26, 2005

WHY: A unique opportunity to hear some of the nation's leading experts share their knowledge and to meet people whose lives also have been affected by CCM.

HOW: Registration Forms are available online (\$65/adult, \$35/child with childcare). Your registration fee includes the lab tour, all presentations, a Friday evening reception, Saturday morning breakfast, and childcare, if applicable.

Hotel rooms have been reserved at the Tremont Plaza Hotel in Baltimore's Inner Harbor (800-873-6668). Make your reservation **before May 26 to ensure that you get a room and receive our discounted rate** of \$135 per night. To help defray this cost, Angioma Alliance will pay \$20 per night for Thursday, Friday, and Saturday nights. This additional discount will be offered at checkout. If you are traveling to the conference alone and are interested in sharing a room to reduce costs, please send an email with your name, smoking preference, and dates of arrival and departure to Angioma Alliance. We will match as many people as we can. Rooms with two beds are available, and every room in the Tremont Plaza is a suite with a kitchenette and sitting area. We encourage everyone to stay at the Tremont Plaza if possible, but other, less expensive accommodations are available nearby. Please consult the Registration Form for more information on parking and transportation.



Baltimore's Inner Harbor offers family-oriented activities to make everyone's visit enjoyable.

ANNOUNCEMENT

We are pleased to announce the addition of two important speakers to our Family Conference schedule. Dr. Michel Berg is an associate professor of neurology and the Medical Director of the Strong Epilepsy Center at the University of Rochester Medical Center. He will discuss medication issues relevant to those with cavernous malformations, including epilepsy management, pain, attention disorders, sleep disorders, and fatigue. Dr. Mark Young is Chairman of the Department of Physical Medicine and Rehabilitation at the Maryland Rehabilitation Institute. Dr. Young will speak about vocational rehabilitation, assistive technology devices, and pain management.

Corporate Sponsors Still Needed

We are still seeking corporate assistance for this year's Family Conference. If you have contact with a corporation that might be interested in sponsoring this or any other event, we would appreciate your help soliciting support! Please contact the Angioma Alliance to learn about sponsorship opportunities and benefits.

VOLUNTEERS NEEDED!

If you plan to attend the Family Conference and are willing to help out, please let us know! We will need volunteers for:

Registration
Playroom setup and clean up
Photography
Many other tasks!

Please contact Connie Lee

If you are unable to attend *this* year's Family Conference, start planning ahead!

2006 – San Francisco

2007 – Midwest

2008 – East Coast

(all Family Conference locations are tentative)



Family Conference 2005-Schedule of Events



Friday June 24, 2005	Saturday June 25, 2005
<i>Tour of Johns Hopkins lab and research presentation</i> [no child care provided] 9:00-11:30	<i>Breakfast</i> 7:00– 8:00 (Plaza C)
<i>Lunch</i> [on your own] 11:30-12:30	<i>Registration and childcare check-in</i> 7:30-8:00
<i>Registration and child care check-in</i> 12:30-1:00	<i>Welcome from Angioma Alliance President, Connie Lee</i> 8:00-8:15 (Plaza B)
<i>Welcome from Angioma Alliance President, Connie Lee</i> 1:00-1:15 (Plaza B)	<i>Treatment Options</i> -Dr. Issam Awad, Professor of Nuerological Surgery at Northwestern University 8:15-9:00 (Plaza B)
<i>CCM Overview</i> -Dr. Richard Clatterbuck, Director of Cerebrovascular Research, Johns Hopkins University 1:15-1:50 (Plaza B)	<i>Surgery Technology and Options</i> —Dr. Daniele Rigamonti, Professor of Neurosurgery and Radiology at Johns Hopkins University 9:00-9:45 (Plaza B)
<i>Genetics Presentation</i> —Dr. Eric Johnson, Prevention Genetics 1:50-2:30 (Plaza B)	<i>Medication Issues</i> – Dr. Michel Berg, University of Rochester 10:00-10:45 (Plaza B)
<i>Questions & Answers with Drs. Clatterbuck and Johnson</i> 2:30-2:45 (Plaza B)	<i>Pediatric Treatment Options</i> – Dr. Leslie Morrison, Pediatric Neurologist at the University of New Mexico 10:45-11:30 (Plaza B)
<i>Disability and Insurance Presentation</i> , Alan Becke of MetLife MetDesk 3:00-3:30 (Plaza B)	<i>Questions and Answers</i> 11:30-12:00 (Plaza B)
<i>Social Security Disability Presentation</i> , Vicky Deruggiero, Public Affairs Specialist for the Social Security Administration 3:30-4:00 (Plaza B)	<i>Lunch</i> [on your own, no childcare provided during this time] 12:00-1:30
<i>Vocational Rehabilitation and Pain Management Presentation</i> , Dr. Mark Young, Maryland Rehabilitation Institute 4:00-4:30 (Plaza B)	<i>Experiences with CCM</i> -Angioma Alliance members share their own experiences and answer questions 1:30-2:15 (Plaza B)
<i>Question & Answers with Dr. Young, Mr. Becke, and Ms. Deruggiero</i> 4:30-5:00 (Plaza B)	<i>Your Experiences with CCM</i> -an opportunity to meet other attendees 2:15-3:15 (Plaza B)
<i>Dinner and break</i> [on your own] 5:30-8:00	<i>Announcements and Questions</i> 3:15-3:45 (Plaza B)
<i>Hospitality Suite</i> —Informal Reception Tremont Plaza Hotel 8:30-10:00	

This schedule is tentative and all events are subject to change-please consult website for the most up-to-date information!

If enough people express interest, we will plan a group outing to the **Baltimore National Aquarium** on **Sunday, June 26**. Please note your interest in this event on your registration form!

Children in childcare will take a field trip to Port Discovery, Baltimore's children's museum, on Saturday, from 9:45 a.m. to 12:00 p.m. Read more about this activity on the Registration Form!



CCM in the News: Interview with Mark Miller

Each February, athletes assemble at the starting line of a grueling race known as the Mt. Taylor Quadrathlon, in Grants, New Mexico. Teams (or soloists) compete in four events – bike, run, cross-country ski, and snowshoe – to climb 5,000 feet up Mt. Taylor before beginning the equally steep descent to the finish, an astounding 44-mile roundtrip.

For this issue, we spoke with Mark Miller, whose tremendous story of recovery we believe you will find uplifting and inspiring. At the age of 45, Mark was diagnosed with a cavernous malformation in the base of his brainstem, just below the medulla, and underwent surgery three months later. Now, six years post-surgery, he has participated in the Mt. Taylor Quadrathlon four times, and he continues to challenge himself to improve mentally and physically. In 2005, he participated for what he claims may be the final time. This is his story.

Angioma Alliance: How was your cavernous malformation diagnosed?

Mark Miller: Looking back now, I started to experience some symptoms about two years before my diagnosis. I had difficulty singing and I found out later that my right vocal chord was paralyzed. A couple months later, I woke up feeling a numbness in my face, and I had persisting ‘buzzing’ sensations. Also, I was beginning to lose balance and, as a result, my body adopted a more rigid posture. There was a lot of pain associated with this, which I mistook for arthritis. Ultimately, after many false leads were explored, I wrote down all of my seemingly unrelated symptoms for my doctor and, in retrospect, that was the key to the correct diagnosis.

“It was not a matter of making speed, it was a matter of having a challenge and facing that challenge.” - Mark Miller on his post-surgery goals.



Mark Miller (center), pictured with his family.

AA: How did you struggle with the decision to have surgery? What role did your family play?

MM: I wasn't in a panic, but after the diagnosis I saw no sense in agonizing over the next step. The local neurosurgeon advised me that angiomas are somewhat unpredictable and that, in my case, there might not be a *great* urgency, but another bleed could be fatal because of the critical location. He did recommend that I seek a specialist rather than have the surgery done locally. The biggest anxiety was wondering what was wrong before the diagnosis and, after that, the chance for fatal consequences made it an easy choice. Take it out! My wife and family gave me their whole support. They made it clear that the decision was mine to make and that they would be behind me whichever path I chose.

AA: Who performed your surgery?

MM: Dr. Robert Spetzler, of the Barrow Neurological Institute in Phoenix, Arizona. He was very matter-of-fact about my chances, and told me that there was a risk for a devastating surgical experience, the worst case, of course, being that I might not survive. It could have been bad, but I had a great doctor. My advice to others facing a similar situation would be to find a super-specialist.

AA: Which were the most difficult setbacks to overcome?

MM: I had no idea of the effects that surgery would have on my well being. After surgery I could not walk at all and I had no stamina. I participated in physical, speech and occupational therapies, but the hardest part for me was regaining my cognitive skills. I was sweating bullets trying to make my mind work. To this day, I can't multi-task nearly as well, so I resort to writing notes to remember certain things that I formerly would remember to do. You just learn to compensate accordingly.

(Continued on page 5)



(Continued from page 4)

AA: How did you begin to regain your physical strength?

MM: After surgery, I started taking tai chi to get my balance back to normal. It involves a lot of gentle motion and left-right shifting of body weight. Also about two years ago, I started doing yoga. Both exercises have been great for generating body awareness and increasing balance and stability.

AA: How did you become involved in quadrathlons?

MM: Prior to surgery, I was reasonably athletic and worked out regularly, though I had never participated in a quadrathlon. A few weeks after surgery, I vowed to participate in one the following year, as a way to help speed up my recovery. Unbeknownst to me, it was a nearly impossible goal that I had set for myself. On the one hand, I had a lot more recovering to do than I initially thought and a lot of stamina to regain, but, on the other hand, it was a challenging goal and something to work toward. I participated in my first quadrathlon 13 months later, in February 2000, as a skier. There was little snow that year, so really I just ‘walked’ up the ski segment of the race!

For the 2005 quadrathlon, my colleagues and I formed the quad Three Gimps and a Geek. I was one of the gimps, with brain surgery, another had overcome leg cancer, and the third was a stroke victim. We couldn’t find a fourth ‘gimp’, so we settled for another friend as the geek. I was the bicyclist.

AA: Do you view the quadrathlon as a mental or a physical challenge?

MM: Both. Physically, surgery is pretty devastating, and it would be really easy to let yourself off the hook and not challenge yourself. For me, it was not a matter of making speed, it was a matter of having a challenge and facing that challenge. It really was a mental goal, and what comes along with the package is physical rehabilitation.

AA: What effects did your quadrathlon training and performance have on your recovery?

MM: I think the whole experience sped up my recovery. If we let ourselves coast as long as we feel like coasting, I’d still be coasting today. Instead, by setting a goal, I felt I had to satisfy myself and not let my teammates down. But that’s the mental aspect, and that’s why you put yourself through anything like this, to do what 90% of people don’t do, and to think at the end that ‘I did it, I survived.’

AA: Do you have plans to compete in another quadrathlon?

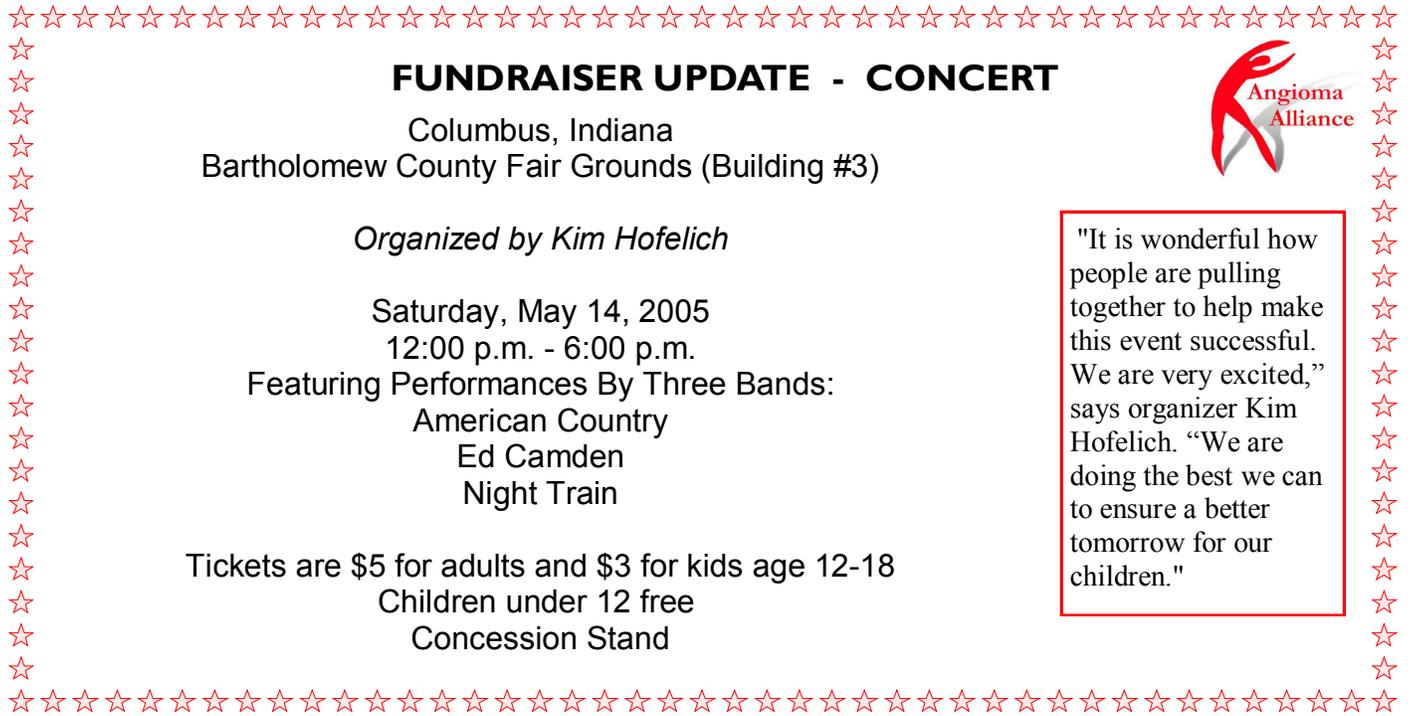
MM: My wife and I like to hike and camp, and hiking is about as arduous as I want to get right now. I don’t plan to initiate another quadrathlon team, and I hope I have sense enough to decline another opportunity to compete, if someone asks me to.

AA: How do you feel about being an inspiration to others?

MM: I hope to be always an inspiration to someone else. We sometimes don’t choose the paths set before us, but how we deal with the challenges is what makes life worth living. It is important for people to know that there are others out there who have been through the same thing, so here I am!

Despite obvious limitations, Three Gimps and a Geek finished the exhausting course in seven hours, a time commendable by any standards. As for Mark’s rehabilitation, he continues to struggle with some permanent deficits but, as he puts it, “nothing he can’t live with”. By maintaining a positive attitude and challenging himself in all aspects of his life, Mark continues to make a truly remarkable and inspirational recovery.

DON'T FORGET TO REGISTER FOR THE ANGIOMA ALLIANCE FAMILY CONFERENCE!!! SEE PAGES 2-3 OF THIS NEWSLETTER, OR VISIT WWW.ANGIOMAALLIANCE.ORG, FOR MORE INFORMATION.



FUNDRAISER UPDATE - CONCERT

Columbus, Indiana
 Bartholomew County Fair Grounds (Building #3)



Organized by Kim Hofelich

Saturday, May 14, 2005
 12:00 p.m. - 6:00 p.m.
 Featuring Performances By Three Bands:
 American Country
 Ed Camden
 Night Train

Tickets are \$5 for adults and \$3 for kids age 12-18
 Children under 12 free
 Concession Stand

"It is wonderful how people are pulling together to help make this event successful. We are very excited," says organizer Kim Hofelich. "We are doing the best we can to ensure a better tomorrow for our children."

Introduction to Fundraising Committee Chairperson, Liz Neuman

Dear Everyone,

My name is Liz Neuman, and I am the Chair of the Angioma Alliance Fundraising Committee. My job has several features:

- 1.) I have been encouraging people who are interested in helping Angioma Alliance to write letters to family and friends by personalizing a template letter we provide. This is a really simple, quick, and effective way to raise funds. For example, Joyce Gonzales, a member from New Mexico, raised \$700 last Fall this way.
- 2) I have been giving support and information to others who would like to organize events. One wonderful benefit of organizing a public event is that, in addition to raising money, it raises public awareness of CCM and Angioma Alliance. You can read about Kim Hofelich's benefit concert in this issue of the newsletter (above). We have folks who will be participating in walks and runs on our behalf, and others who are interested in hosting softball or other sports tournaments. Others have expressed interested in using their talents, such as jewelry making, to raise funds for Angioma Alliance.
- 3.) I have organized fundraising events (a large rummage sale and benefit dinner parties) and have pursued my own letter-writing campaign to family and friends to support our future patient registry. These efforts have raised almost \$12,000 since last summer. With a little creativity you can turn almost any one of your hobbies or interests into a fundraising event. I have even turned an evening with friends into a successful fundraiser simply by showing a copy of the Angioma Alliance's fundraising video. It is only six minutes, but it is very effective.



Fundraising Chair Liz Neuman is pictured with her sons, Jake and Sam. Both Jake and Sam have been diagnosed with cerebral cavernous malformations.

If you are interested in organizing a benefit event or writing letters, please feel free to contact me at theneumans@hotmail.com or through Angioma Alliance (info@angiomaalliance.org).

I appreciate your continued support!

Sincerely, Liz

Diagnostic Imaging Primer – Part II: Angiography

By: Jack Hoch

This is the second of three medical imaging articles aimed at covering the nuts and bolts of procedures available to patients for diagnosing brain lesions.

An angiogram (also known as an arteriogram) is a diagnostic test used to gauge the integrity of blood vessels within the body. It is an indispensable element in determining the root cause of a problem, either by positive identification or by ruling out certain possibilities. An angiogram will only “see” areas where there is blood flow above a threshold rate. As such, it cannot image cavernous malformations directly, but it may help to do so by process of elimination. When used in conjunction with an MRI, an angiogram provides an invaluable look at blood vessel irregularities previously viewable only through surgery or at autopsy. The combination of the two generally results in a diagnosis of high confidence.

Of course, nothing in life is ever easy, and that is the case with angiography. Technological advances have yielded additional angiography choices that can complicate the decision-making process, potentially adding stress or anxiety to an already confusing situation. Even so, it is nice to have alternatives, especially non-invasive ones, which were not available 20 years ago.

The remainder of this article will provide some details on the three different types of angiography commonly used in today’s medical facilities: CTA, MRA, and conventional angiography.

Computed Tomography Angiography (CTA)

CTA is the least accurate, yet least expensive, angiography alternative. In essence, its strengths and weaknesses are similar to the CT vs. MRI comparison discussed in the first diagnostic imaging article. Basically, its availability is more widespread than MRA, it costs less, and there are fewer restrictions since CTA can be used on patients with metal in their bodies (pacemakers, screws, rods, plates, etc.). Unfortunately, like its CT cousin, the precision is not as high as with MRI, and it requires an iodine-based contrast injection, which can be detrimental to some at-risk patients.

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Miscellaneous News

We would like to extend a special “thank you!” to Kelly and Greg B. from Indiana and the Hewlett Packard Gifts-In-Kind Program for donating a HP 4650 Color Laserjet Printer to Angioma Alliance. Already, it has made an enormous difference in our productivity. Thank you for your generosity!

American Academy of Neurology Convention

In April, Board Members Norma Villa and Connie Lee spent a few days in Miami, exhibiting at the American Academy of Neurology annual convention. They were impressed by the variety of doctors who visited the booth. Doctors from all over the world, medical students, and neurologists with varying levels of knowledge dropped by to chat and learn. The photo (right) shows Connie Lee in front of the Angioma Alliance exhibit.



***The April 27, 2005, issue of Prensa Hispana, Arizona’s largest Spanish newspaper, featured a full-page article about Norma Villa, her daughter, CCM, and Angioma Alliance. Congratulations, Norma! ***



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Magnetic Resonance Angiography (MRA)

MRA is rapidly becoming the diagnostic test of choice for blood vessel imaging. It can detect blood vessels that are either bulging (aneurism) or narrowing (stenosis). Likewise, it can pick up high blood flow lesions such as arteriovenous malformations (AVMs). CTA can accomplish this as well, but not with the degree of precision found in MRA. The degree of precision is what gives MRA a big advantage over CTA in terms of early detection.

MRA also offers important advantages over conventional angiography. Unlike the latter, MRA is non-invasive and is much quicker. While the risks with an invasive procedure are relatively small, those risks are still present. MRA completely removes this concern.

Regardless, some of the more intransigent medical facilities consider MRA (and CTA) somewhat experimental and prefer to use conventional angiography.

A comprehensive guide covering what one can expect prior to and during the procedure may be found on WebMD.

Conventional Angiography

Long the gold standard for blood vessel diagnostics, conventional angiography has been around a very long time. One can think of it as an X-ray of one's blood vessels. The procedure is more involved than that for MRA or CTA in that it requires an incision, normally in the femoral artery near the groin area (local anesthesia). Once this incision is made, a catheter is inserted into the artery and "snaked" into the blood vessel of concern. To image blood vessels in the brain, this requires the catheter to be guided through the torso and neck and into the head. Once the catheter is in place, contrast material is injected and images are taken of the affected area.

The advantage of conventional angiography is that the images are taken with close proximity perspective. Of all the imaging methods, it is the most precise. This precision, however, comes with a higher relative risk of complications, such as infection, hemorrhage from the catheter damaging a blood vessel or even stroke. Also, there is a recovery time associated with the operation of at least four hours, which requires keeping one's leg immobilized for that period of time.

What is the Best Procedure?

No doubt, the ambiguous answer of "it depends". In reality, most general cases can probably be handled by MRA as long as the hospital staff is well trained on the latest technology and diagnostic procedures. If one doctor recommends a conventional angiogram, ask, "Why not an MRA?" Good engineering practice always stipulates that one chooses the simplest and safest of two procedures if the expected results are the same. Make the physician explain to you why conventional angiography should be used in lieu of MRA.

Be aware that when discussing the darker side of medicine and inherent conflicts of interest, conventional angiography procedures receive a higher insurance reimbursement rate than do MRAs. All other factors being equal, some unscrupulous doctors may choose conventional angiography over MRA to grab that higher reimbursement rate.

Also, don't lambaste emergency medical room staff if they order a CTA. In many cases, a CTA is a great first look at an emerging problem where time is of the essence.

The real downside, after having read all of this, is that if one's angiography is "negative" (normal), that only rules out high flow lesions such as AVMs. If a lesion imaged by MRI is suspected as the underlying cause of symptoms, then the absence of anything unusual on an angiogram heightens the possibility that the lesion may be an angiographically occult vascular malformation (AOVM), such as a cavernous malformation, which by nature is low flow.

Volunteer Opportunities



The Angioma Alliance is growing and so is our need for volunteers! We are trying to fill the following volunteer positions, and would greatly appreciate your dedication and expertise. Thank you for your continued support!

Attorney – Responsible for reviewing contracts (particularly our upcoming contract with Genetic Alliance Biobank), answering general questions and providing legal advice. We desire someone with experience in non-profit law.

Coordinator of Physician Directory – Responsible for (1) creation of e-mail and direct mail lists of surgeons (we will provide information for this purpose) (2) follow-up correspondence with doctors and (3) database maintenance, including entry and updating of doctor information and patient feedback, and collecting additional data, as needed.

Corporate Sponsor- We urgently need corporate sponsors for the upcoming Family Conference and would like your help in soliciting them! There are many levels of sponsorship (ranging from \$500-\$25,000), and many opportunities for benefits. Please contact the Angioma Alliance for more information.

Fundraiser- Our new Fundraising Committee Chair (see Page 6) is hard at work, but she needs your help organizing philanthropic events in your area! Consider planning a charity run, benefit dinner party, or rummage sale. Contact Fundraising Chair Liz Neuman at theneumans@hotmail.com to discuss your fundraising ideas.

Researcher- Responsible for performing web-based research to expand our "Links and Resources" page and to identify books for inclusion on our "Bookstore" page.

Website Administrator- Responsible for maintaining our Portuguese website. Knowledge of Portuguese is helpful, but not necessary. The staff in Dr. Jorge Marcondes's CCM research lab in Rio de Janeiro will provide assistance.

Volunteering is an act of heroism on a grand scale. And it matters profoundly. It does more than help people beat the odds; it *changes* the odds.
-Former President
Bill Clinton

Please contact the Angioma Alliance
to discuss these and other volunteer possibilities.
info@angiomaalliance.org or 1-866-HEAL-CCM

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NEW ON OUR WEBSITE

Look for a new page titled “Rehabilitation” in the Surgery Support section of the website. It provides an introduction to the various therapies that are available to those who are post-surgery or post-bleed and gives helpful insight from members of the surgery support committee who have tested such therapies.

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.

How You Can Help...

You may send donations via regular mail or you may use the “Make a Donation” link on our homepage.

All donations to Angioma Alliance are tax deductible.

Public awareness can lead to increased research funding and improved quality of life for those affected by CCM. Our CCM pins (right) are a popular fashion accessory AND a great way to increase awareness of CCM. We’re offering the pin to thank you for any donation of \$10 or more. Each pin comes with 5 information cards. Show your support with our newest accessory!



COMING SOON...
ANGIOMA ALLIANCE WRISTBANDS AND T-SHIRTS

Letter from the Editor

Dear Readers,

This issue marks my introduction as Newsletter Editor, and I am excited to be a part of Angioma Alliance’s important outreach and educational efforts. Over the course of the next several issues, we will be experimenting with ways to make the newsletter more visually appealing, readable, and informative for Angioma Alliance members and the greater community.

Our longer-term goals are to expand circulation to include doctors’ offices and new patients, and to be recognized by other medical organizations and publications. In other words, we intend to utilize this newsletter to increase our presence in the medical and not-for-profit communities. You can assist in these efforts by sharing the newsletter with family and friends, or by printing and distributing copies at fundraising events.

Our goals are attainable with your input, so we appreciate your suggestions and comments, and we encourage you to submit articles and stories that you would like to see published in the newsletter.

You will notice that we are using new software to layout the newsletter. We recommend that you install free Adobe Acrobat® Reader®, if you do not already have it, which will allow you to view the newsletter’s graphics and designs in pdf form. Until this transition is complete, we will continue to offer a text-only version of the document.

I look forward to working with Angioma Alliance members to ensure that our newsletter becomes the primary source for research articles, stories, and event information for those affected by cerebral cavernous malformations.

Sincerely,
Cristina DeSalvo