



Spring 2009

# Angioma Alliance Newsletter

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## Milestones in CCM Research

### **An Open Letter From the Angioma Alliance Scientific Advisory Board**

What a year of discovery and promise in Cerebral Cavernal Malformation (CCM) research!

A year ago, on March 14, 2008, the National Institute of Neurologic Disorders and Stroke hosted a symposium on the biology of vascular malformations of the brain, where 40 researchers and clinician invitees debated the state of current knowledge and gaps in our understanding about how these lesions form and progress. We discussed the immense possibilities in advancing our knowledge with ongoing research. This was a giant leap in putting CCM at the forefront of current research.

On November 20 and 21, 2008, CCM researchers met for our annual workshop in Washington, DC. We heard a summary of 20 basic science papers and 91 papers published in the previous year on CCMs. We exchanged information about what has been learned on how CCM genes affect molecular signals in cells and in animal models, to better understand how

lesions form, and how other factors might affect CCMs.

We know that the CCM lesions consist of dilated abnormal blood vessels that are lined on the inside by abnormal cells (called endothelial cells). These endothelial cells in CCMs are abnormally leaky and do not form the organized tubes of normal blood vessels. Mutations in any of the three known genes of CCM seem to cause similar problems in laboratory endothelial cell cultures and in animal models suggesting that the proteins produced by all three of these genes work in the same pathway. CCMs also exhibit a very strong immune response, involving inflammatory cells honed against a particular trigger which we still need to learn more about.

An exciting recent study showed that increased permeability (or leakage) in the blood vessels of the skin in an animal model with a CCM mutation is reversed by treatment of the animal by a statin, a common medication that is used to lower cholesterol in humans. The statins stabilize blood vessels and work on the same molecular

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

pathway involved in CCMs. This is of great interest because it raises the possibility that a factor in CCM disease could be reversed by a medication. However, translation of this animal experiment result into a treatment for people will require considerably more research.

With these exciting research discoveries, there is now the genuine hope of a medical treatment for CCM. Future research will focus on identifying the best drugs to use in people and how each of these works to prevent CCMs. It is especially important that studies be performed to ensure that such medications do not cause side effects that could harm those taking them.

During the next several years, people with CCMs may be asked to participate in research studies to help answer these questions. These studies will likely start with drugs that have been shown to be reasonably safe, such as the statins. Researchers are currently in the process of designing these human trials. Many issues need to be addressed when designing a trial of a treatment in humans, including determining who is

appropriate to include and exclude and what effect to measure (for example changes in the number and size of CCMs on several MRI scans). The work that goes into designing and performing a clinical trial in humans is vital to ensure that people are put at as little risk as possible and that treatments that really work are identified and that those treatments that do not work are rejected.

If a convincing effect is shown in the initial exploratory trials, additional larger studies will be needed including the gold-standard study known as a prospective double-blinded randomized controlled trial (Phase III) to prove that the treatment is safe and effective before it is adopted as a recommended treatment.

Other research might suggest additional therapeutic approaches in the future, including other permeability therapies, anti-inflammatory medications, and even blood vessel modifying (anti-angiogenesis) drugs. Enthusiasm or concern about each drug will need to be assessed based on potential risks and benefits of the individual therapy. More powerful

and potentially more risky therapies should have proof of effect and safety in animals before trials can proceed in humans.

We are all excited about the scientific promise of these advances, but proofs of benefit and safety on any aspect relevant to CCMs are not yet in hand. Thus, it is important that people with CCMs do not try unproven treatments on their own. Unfortunately, good research is a slow process and there may be a temptation for people not to wait and for instance to use available drugs like statins on their own before clinical trials are completed. Such uncontrolled and unobserved use of medications has a long history of resulting in harm to people and we strongly discourage the use of any unproven therapy outside the context of a clinical trial.

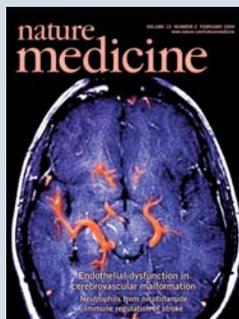
The Scientific Advisory Board of Angioma Alliance will continue to promote every aspect of CCM research including encouraging people to participate in appropriate clinical trials as they develop. We will work to inform people affected by CCMs and their families about scientific consensus and concerns as they arise in response to new discoveries. Much work is still needed, but there are glimmers of hope on the horizon, beyond our dreams even a decade ago.

*Issam A. Awad, MD, MSc, FACs, MA (hon), on behalf of the Angioma Alliance Scientific Advisory Board*

*Connie Lee  
President, Angioma Alliance*

### Congratulations

Congratulations to Ben Kleaveland in Dr. Mark Kahn’s lab at the University of Pennsylvania and to Dr. Kevin Whitehead in Dr. Dean Li’s lab at the University of Utah. Their papers on CCM were chosen as the cover stories for the February 2009 issue of Nature Medicine, a much respected international science journal. This gives CCM a new prominence and is part of what another researcher has termed “an explosion of CCM basic research.”



## Family Conference 2009

The 5th Angioma Alliance Family Conference was held in San Francisco on the weekend of April 3rd. Highlights included a chance to learn from Dr. Bill Young and Dr. Kevin Whitehead about the latest research regarding the use of medications to treat cavernous angiomas, to learn about and experience mindfulness meditation with Dr. Bob Stahl, and to learn from each other in our small group discussions and during social times. We've captured the presentations from the conference on video and will be offering the DVDs on the website in the near future.

One concern that has arisen around the family conferences is the dwindling attendance. The Board of Directors is discussing alternatives to our conferences that will still address the need to get the most current information out to you, but will do so in a cost effective way. Alternatives that are being examined include making family conferences a component of scientific workshops rather than standalone events, holding smaller half-day local meetings such as Cavernoma Alliance UK does, and/or presenting experts via webcasts. Your opinions and ideas will be very valuable in guiding us to a format that will meet your needs.

## Senate Resolution to be introduced

Our champion in Congress, Senator Tom Udall, will be introducing a Senate Resolution calling for increased awareness, education, and research for cavernous angiomas. If you have received the mailed version of this newsletter, the introduction may have already taken place. As true preventive medical treatment rather than surgical intervention is becoming a reality, early diagnosis is even more of a priority than it was when then Congressman Udall introduced the House Resolution last year.

As of this writing, we are seeking Senate co-sponsors for the resolution. Ideally, a bipartisan approach would be best, so we are focusing on Republican Senators from southwestern states. We have already received the support of the National Council of La Raza, the largest Hispanic health lobby.

Once the Senate Resolution is introduced, we will need your help in contacting your Senators to support its moving from committee to the floor of the Senate for a vote. We will let you know exactly what to do and when to do it via our email mailing list and Community Forum. If you haven't already signed up for the mailing list, you can do so at <http://www.angiomaalliance.org/newsletter.htm>.

## It's Time to Plan Again

In 2006, Angioma Alliance developed a strategic plan for the years 2006-2009. It has been a guiding document that has encouraged us to stay focused on the most pressing priorities of our members. The document was created with a great deal of input from our members including the more than 200 individuals who responded to an online survey that we posted. It is time to start planning for the next three-year period, 2010-2012, and your input is needed again. We've set up a survey at <http://www.zoomerang.com/Survey/?p=WEB22945XLSUTT> where you can provide us with your hopes and dreams for the future of Angioma Alliance. We ask that you complete the survey as soon as possible as we will begin releasing and discussing results on May 17th. If you would like to be more intimately involved in the planning process by joining the Board of Director's conference calls on Sunday evenings, please let us know at [info@AngiomaAlliance.org](mailto:info@AngiomaAlliance.org).

## Call for Drug Study Participants

Dr. Kevin Whitehead of the University of Utah is currently seeking individuals with cavernous angiomas who are willing to release their medical records and imaging for an observational study of statins (Zocor, Lipitor, Crestor, Prevacol, Mevacor) as a treatment of cavernous angiomas. He is specifically seeking individuals who have had at least 2 MRIs and one of the following:

1. Who are currently taking statins,
2. Who have been advised by their physician that they should be taking a statin, but have not started taking one,
3. Who have an elevation in a blood test for c-reactive protein (CRP).

If you fall into one of these categories and would like to participate, please contact him at [kevin.whitehead@hsc.utah.edu](mailto:kevin.whitehead@hsc.utah.edu).

# Editorial

## Further Thoughts from the Cutting Edge

We are at a point in CCM research and technological development where decisions for patients are becoming increasingly difficult. Do I have brainstem surgery now, particularly since surgical techniques are advancing, or do I take a chance and wait for medications that may reduce my risk of another hemorrhage? There is no one correct answer to this question. Now, more than ever, it is important to seek a physician who is able to work with you to develop a decision-making algorithm. It is becoming increasingly clear that each life situation is unique and each cavernous angioma has its own personality. Good decision-making is a nuanced endeavor, not a cookie cutter activity. If your neurosurgeon or neurologist is not willing to talk with you about *all* possible approaches and their potential impact on your life, including those that are still in development, it is probably best to find another physician who will.

Imaging is another area that requires additional reflection. Recently, I received the following e-mail:

“Last week I had my annual MRI and after looking over my new MRI scan, the series done in Susceptibility Weighted Imaging are the most shocking views of my brain, since so many 'spots' of hemorrhage show up, making my brain look like 'Swiss Cheese,' or a war zone—it's quite frightening and sobering. Considering what I've been through and the appearance of my scan, I'm doing remarkably well. It amazes me that I don't have more deficits than I do... I have to wonder what the long-term effects of the many small bleeds will have on my brain as I age, such as Alzheimer's, etc. Have studies been done on 'us' yet regarding the long-term effects?”

Susceptibility weighted imaging (SWI) is a new software technology that allows radiologists to see the smallest blood vessel abnormalities, down to the 1 mm level. In the images, these abnormalities appear much larger than they are. For those with the hereditary form of CCM, with multiple lesions, these images can be horrific. For those with the sporadic form, particularly those with an accompanying venous anomaly (venous angioma), there may be a surprising finding of additional vessel abnormalities. These individuals may jump to the faulty conclusion that they have the hereditary form of the illness.

Right now, most radiologists are labeling these additional abnormalities as hemorrhaged cavernous angiomas (cavernous malformations), but it is not clear exactly what these tiny lesions are or what they might do. As far as we know, no one has removed one to examine it. From Dr. Blaine Hart, one of our leading neuroradiologists:

“I am not aware of any pathological correlation reported yet on small SWI-only lesions. I do not believe that we know that they definitely signify previous hemorrhage. It is possible that they could reflect malformations, or early stages of malformations, that have not bled, and we don't yet have good data on the risk of future hemorrhage for such small lesions. An analogy might be capillary telangiectasias, which are low-flow vascular malformations, most common in the pons, that are not thought to bleed at all but show up on susceptibility-sensitive sequences. They are thought to show up not because of hemosiderin but because of deoxygenated blood within sluggish capillaries. I suspect the same phenomenon could occur in cavernous malformations that have not bled, but we have no evidence yet one way or the other.”

Unfortunately, this explanation does not take away the indelible and traumatic image many patients are now holding of their or their child's “Swiss cheese” brain. The best we can do is reassure them that what really matters is how they feel, not what the pictures show. I would ask physicians to pause before ordering MRIs with an SWI sequence to think about whether this level of clarity is really necessary for treatment. It is possible that SWI will lead to a redefinition of the illness and may be helpful in development of treatments. However, patients whose imaging includes an SWI sequence should receive a great deal of compassionate explanation before they see the images themselves. For those of us who are patients being scheduled for an MRI, it may be helpful to ask ahead of time whether an SWI sequence is planned, whether there is any additional clinical benefit (perhaps for visualizing a venous anomaly without gadolinium contrast), and whether we can opt out if we would like. Forewarned is forearmed.

*Connie Lee*

# Fund Raising News

## Win a Smart Fourtwo Passion Coupe!

Looking for an extremely fuel efficient car to zip around town? Look no further: Angioma Alliance is raffling off a brand new Smart Fourtwo Passion Coupe. This isn't just any Smart car—it is metallic blue and upgraded with the Comfort Package. Wouldn't you love leather heated seats on cold winter mornings? Get more information about this model at <http://www.smartusa.com/smart-fourtwo-passion.aspx>.

Currently, there is a wait of one year or more to buy a Smart Fourtwo in the United States from a dealer. You may have yours sooner. Our drawing will be on June 27, 2009 at the DeVargas Center in Santa Fe, New Mexico. You don't have to be present at the drawing to win—we will deliver the car to you anywhere in the continental United States. The winner of the car is responsible for tax, title, and registration.

Raffles tickets are \$50 each and we are limiting the number of tickets sold to only 1000. Proceeds from the raffle will be used to support next year's Scientific Workshop and to develop a continuing medical education program for healthcare providers.

We are accepting checks made out to Angioma Alliance and Visa or MasterCard for ticket purchase. Complete the entry form below and mail it with your payment to: Angioma Alliance, 142 W York St Suite 708, Norfolk, VA 23510, or fax it to 757-623-0616. We greatly appreciate your help in spreading the word and giving this form to your family, friends and coworkers.



Name: \_\_\_\_\_

Street address: \_\_\_\_\_  
\_\_\_\_\_

City: \_\_\_\_\_

State: \_\_\_\_\_ Zip: \_\_\_\_\_

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Number of tickets: \_\_\_\_\_

Visa/Mastercard Number: \_\_\_\_\_

Expiration Date: \_\_\_\_/\_\_\_\_

Signature: \_\_\_\_\_

**MadoroM Wine Auction a Stunning Success**

The 2009 MadoroM Charity Wine auction raised more than \$64,000 for Angioma Alliance this year. Andy and Marissa Amador and Shawn and Mike Blom have turned what started as the auction of one 18-liter bottle of MadoroM wine during their wine release in 2007 into a major fundraiser and social event in Bakersfield, CA. We are deeply grateful to the Amadors and Bloms and to the people of Bakersfield for their ongoing generosity. We can not emphasize enough how important this annual fundraiser is in helping Angioma Alliance carry out its activities. We'd also like to extend a special thanks to Brad Peters and his sister Liz Neuman who serve as inspirations to this community.

**14-year-old Donates Birthday Money to Angioma Alliance**

Grace Fleming of Bakersfield, CA, made a huge sacrifice for Angioma Alliance this year. She let her family and friends know that she would be donating her birthday money to Angioma Alliance. Through their generosity, Grace raised \$1,330 to help change the future for her affected aunt and cousins. Grace is a true hero!

**Colorado Elementary School Hosts a Wristband Fundraiser**

The Belmar Elementary School in Lakewood, Colorado, sponsored a sale of Angioma Alliance wristbands in honor of their student Calvin Broderick. The school raised \$117 in wristband sales and donations. Go Belmar! [picture of Calvin Broderick attached]

**Silpada Jewelry Party**

Linda Saenz of West Palm Beach, Florida, and Dawn Loscalzo of Lake Worth, Florida, hosted a Silpada home jewelry party that resulted in almost \$500 raised for the work of Angioma Alliance. Thanks Linda and Dawn!

**Angioma Alliance Run/Walk**

About 30 hardy people braved the sun and warm temperatures of an amazing San Francisco day to participate in the first Angioma Alliance 5K run/walk. Congratulations to Jim George for beating everyone to the finish and many thanks to those who helped organize, particularly Kandance Weems Norris. The event raised awareness and even received a mention on HLN's Nancy Grace show two nights in a row. This has resulted in numerous new members over the last two weeks. In addition, over \$1,000 was raised by participants. There's talk of running again next year, perhaps in Atlanta. We'll keep you posted.

**Blewer's Cinco de Mayo Fiesta**

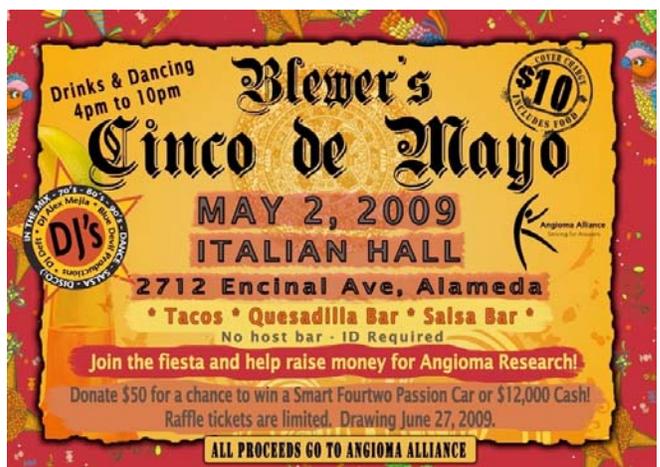
On May 2nd, Ronnie Bince's family and friends, including Brian Blewer, a popular bartender at McGee's Restaurant and DJ Alex Mejia, well-known for his work with KMEL radio, will host a Cinco de Mayo Fiesta to raise awareness of cavernous angiomas and to raise funds for research.

Hosts: Brian Blewer, Kathleen Bince, Alex Mejia

Location: The Italian Hall, 2712 Encinal Avenue, Alameda, CA 94501

When: Saturday, May 2, 2009, 4pm to 10pm

The fiesta will feature Mexican food, drinks and dancing. Cover charge is \$10 at door: includes food. (No Host Bar/ID required).



# International Updates



We have a lot of good news from Cavernoma Alliance UK. Joanne Smith, a member of Cavernoma Alliance UK, organized a sponsored walk which attracted more than 40 people, raising £2,450 (over \$3,000). Once Cavernoma Alliance UK have claimed "gift-aid"—the government contributes 28% of an individual's tax to the charity—the actual total will be over £3,000.

Cavernoma Alliance UK would like to thank Annabel Morrisey for her work in raising over £2,500 (about \$3,300) for our charity by running the Milton Keynes half marathon. Despite the icy wind Annabel managed to finish in 1:34 and said afterwards she "actually enjoyed it." Annabel was inspired by Finlay "Fighter" Freeman who was discharged from hospital only days after his 4th operation to remove a cavernoma from his brainstem. Annabel said that "As well as raising money for Cavernoma Alliance UK I am also hoping to have raised some awareness of this condition."

I attended the National Council for Voluntary Organisations Annual Conference 2009 on Wednesday 16th February in London. The advantage of this for the charity was "networking" during the breaks and at lunchtime. There were speeches by Sir Graham Melmoth and Baroness Pitkeathly, and I attended two workshops entitled, "Giving: A fundraising activity or act of citizenship?" and "Exploring international collaboration."

On Monday 23rd February, I went to Edinburgh, and met with the creative team of the The Edinburgh Charity Fashion Show, who are providing Cavernoma Alliance UK with one third of their profits (approximately £10,000, or \$14,000). One of Cavernoma Alliance UK's most recent members is a student at the University of Edinburgh, and without Eliza's encouragement, Joni Mackay's inspiration and an agreement by Dr. Rustam Al-Shahi Salman, Department of Clinical Neurosciences, Western General Hospital, Edinburgh, that we should have the funds towards our new information sheets (available in the "Downloads" section of our web site, [www.cavernoma.org.uk](http://www.cavernoma.org.uk)) and our London Forums, none of this would have happened. Check out their website: [www.edinburghcharityfashionshow.com](http://www.edinburghcharityfashionshow.com).

On February 28 it was Rare Diseases Day 2009 at the House of Commons in London, which I attended with Sharon Miller, a friend of Cavernoma Alliance

UK. A rare disease is a condition that affects 1 in 2,000 people (asymptomatic cavernomas are not a rare disease). Currently there are between 6,000 and 8,000 identified rare diseases. In the EU, rare diseases may affect up to 30 million EU citizens. This was a free event, hosted by The Genetic Interest Group

Cavernoma Alliance UK is also participating in some research studies, one of which is run by Dr. Roy Gilbar, who is looking at the family in relation to the decision-making process and how this works in practice as well as in relation to the current UK Law. The Genetic Interest Group, of which Cavernoma Alliance UK is a member, is supporting Dr. Gilbar in his research and some Cavernoma UK members will be contacting Dr. Gilbar to discuss decisions they have made regarding their health.

Don't forget about the International Cavernoma Alliance UK Forum on Saturday 13th June 2009, in London. The forum will have a range of speakers: Rustam Al-Shahi Salman, Honorary consultant neurologist, Department of Clinical Neurosciences, Western General Hospital, Edinburgh and one of Cavernoma Alliance UK's medical advisers; Dr. Jonathan Berg, Senior Lecturer and Researcher from the University of Dundee, will speak on genetics; your very own Dr. Eric Johnson, from the Angioma Scientific Advisory Board, will make a brief appearance as will Dr. Connie Lee, President of Angioma Alliance, who will update those from the Old World about advances that have been made in the New World. And, at midday, the recipient of the 2009 Alistair William MacQueen Memorial Lecture. Dr. Helmut Bertalanffy, described by Dr. Spetzler from Arizona, USA, as "probably the best vascular neurosurgeon in Europe," will speak and answer questions.

Following a free lunch at 1 p.m., members can meet at 2 p.m. for structured but informal workshops, and you, our American friends, are invited to discuss the Forum with us at the 2009/10 Annual General Meeting at 4 p.m..

Reduced-rate accommodation is available at the five-star Grange Holborn Hotel; you'll find more information on our website. I hope to see plenty of you there!

*Ian Stuart*

# Stories

## Rolling With the Punches

A few weeks ago I had a cavernous angioma bleed. This was not my first bleed—it was my fifth.

It was Friday the 13th; what an omen. I had just finished my daily 5-mile walk (fortunately I had bypassed the big, strenuous hill that day) and poured myself a glass of cold water. As I began to drink, I noticed that my upper lip was numb. It was like I had been to the dentist and the Novocain hadn't quite worn off.

I immediately checked out the rest of my body, looking for any other neurological symptoms. I had none. So I went through the litany of options. One, I could carry on with my daily activities, because it was probably nothing. Two, I could lie down for a while to see if things got better or worse: why bother the emergency room over a numb lip? Three, I could go to the hospital; get it checked out, just in case. That would put my mind at ease.

Fortunately, I chose option three—I went to the emergency room. Once there, I announced that I might be having a brain bleed. I explained that I had a history of this sort of thing and suspected it could be happening again. I was abruptly moved to the head of the line. The emergency room doctor ordered a CT scan. At this point I was feeling pretty good and I thought I might have sounded a false alarm. I was fully expecting the doctor to say, "I've looked at your CT scan and saw no sign of bleeding."

That is not what he said.

Instead, he told me there was bleeding on the right side of my brain stem. "No, not again," I said to myself. I was moved into neurological ICU and told to stay in bed. All of this over some minor numbness on my upper lip?

Well, not for long. Two hours later I had double vision, weakness, vertigo, and I became extremely tired. The numbness had also spread to most of the right side of my face. I spent the next several days in

the hospital. By the time I was released, my condition had worsened and I spent a couple of weeks at home in bed.

My neurosurgeon told me, "I'm surprised your symptoms aren't much worse." Given the location and size of the bleed they certainly could have been.

So I've learned some new things about cavernous angioma bleeds.

Initial symptoms for a bleed can be quick and severe, but they can also be mild and slow.

Don't wait for major symptoms to arise before getting checked out.



I am glad I chose option three, going to the emergency room. Had I carried on with my daily life, my next stop would have been the golf course. I certainly felt like playing golf at the time. I would have been pounding golf balls while my brain was bleeding. This could have made the bleed worse and the resulting damage to my body more severe.

Could the numbness in my upper lip have been nothing? Sure. But the worst that could have happened was that I would have been embarrassed that I had bothered the doctors and nurses and been told to go back home and resume life. No, wait a minute; that is the best thing that could have happened.

Cavernous angioma is a nasty illness. Take care of yourself and pay attention to the small stuff. Because when it comes to a bleed, there is no such thing as small stuff.

My prognosis is good. The double vision is already gone. The numbness has improved. My vertigo will go away with time—it always has before. And my stamina is coming back a little bit at a time. My neurosurgeon wants to take this cavernous angioma out, because if it bleeds again, I might not be so lucky.

*Les Duncan is the author of Brain Storms; Surviving Catastrophic Illness.*

## Two Years After Bleeding in Brainstem, UT-Arlington Student Still Struggling

Savannah Hollis was at her computer doing physics homework when her right foot went numb.

"So numb that someone could hit it with a hammer and I wouldn't feel it," she said.

The numbness spread up her calf, to her hand and finally to her armpit.

By the time Hollis' boyfriend got her to an emergency room in Lafayette, La., her left eye was darting wildly in all directions. She tried to sip some Sprite but could not swallow. When she opened her mouth to speak, no one understood her.

Hollis, a pre-med major, had looked up her symptoms on the Internet and suspected a stroke. But for a 21-year-old, she figured, that couldn't be right. As the hours ticked away, Hollis never lost consciousness. She understood that something was terribly wrong, but she couldn't grasp what was happening to her.

About 10:30 p.m. an emergency room doctor called her mother, who was driving to Lafayette from her home in Hurst. An MRI had revealed bleeding in Hollis' brainstem, and there was no way to stop it.

"How far away are you," the doctor asked.

"Maybe four hours," Gwen Perkins replied.

"You need to hurry."

### The ordeal

When Perkins arrived at the hospital, her daughter was slumped to one side in the bed and her eyes were rolling around so much that it was hard to look at her without getting dizzy. Over the next three days, however, Hollis' condition stabilized as the bleeding stopped on its own.

She had survived, but she was left with the effects of a hemorrhagic stroke.

"I couldn't sit up, swallow, see, talk or walk," she said.

The bleeding in her brain began Aug. 26, 2006. But nearly a month went by before Hollis learned what had caused it.

By then she was already entrenched in physical therapy at Baylor Institute for Rehabilitation in Dallas. Hollis thought that the bleeding had been an isolated incident and that her greatest challenge would be learning to walk, talk and swallow again.

Then she learned that an MRI had revealed a cranial cavernous malformation in her brainstem, a vital area that controls breathing, heart rate and blood

pressure. It was the worst possible place for something like this to occur.

Now that a cluster of blood vessels had bled, it would likely happen again—and the next time could be fatal. If she did nothing, Hollis faced significant impairment and the scary possibility of death.

"She would not be able to exercise, have children or even overexert herself," Perkins said. "And there was no telling when it would bleed again."

The malformation had to come out. But finding a neurosurgeon to perform the delicate surgery was difficult.

"The first doctor said that since it was on her brainstem, there was no way he'd touch it and we'd be hard-pressed to find someone who would," Perkins said.

Hollis' family kept looking until they found someone willing to do the surgery. Dr. Duke Samson, chairman of neurosurgery at UT Southwestern Medical Center at Dallas, agreed to take Hollis' case.

There is no effective treatment other than surgery, he said.

"But the brainstem is a forbidden city as far as surgery is considered," Samson said.

Hollis did not hesitate.

"If this was what I had to do to get on with the rest of my life, then I had to do it," she said.



**The disorder**

Cerebral cavernous malformations occur in about 0.5 percent of the general population. Only about 10 percent occur on the brainstem.

On an MRI, they look like big pieces of popcorn in the brain, Samson said.

About 25 percent of people with a CCM never experience symptoms, according to the National Institute of Neurological Disorders and Stroke. The CCM never grows, bleeds or causes seizures, headaches or paralysis.

"Some will remain almost like they're in limbo forever, he said. "There's no reason to take one out if it is not active."

During Hollis' surgery, an incision was made from behind her ear to the back of her head. Another CCM in a different part of a brain was left untouched because it posed no risk.

After surgery, Hollis took a year to recover before enrolling at the University of Texas at Arlington.

She also got involved with the Angioma Alliance, a nonprofit organization that supports education and research. She plans to start a support group to help others facing similar health problems.

After spending so much time in hospitals, Hollis said, she decided against medical school and instead plans to teach science.

**The future**

She has tried to get on with a life that has its limitations. Despite therapy, she still cannot swallow, she said, except for tiny sips of chocolate milk or strawberry shakes. For more than two years she has depended on a feeding tube for all of her nourishment. But she keeps trying.

Once a runner, she has yet to regain her stamina, and she goes to bed early. It's not exactly the lifestyle of the typical college student, but Hollis is not complaining. She just hopes that others who experience CCM symptoms do something about it.

"I kept thinking it was really nothing," she said. "It wasn't."

The experience has given Hollis an extraordinary perspective on life that even she seems unaware of, Perkins said. But clearly she feels she has a purpose.

"It's not to be a martyr or an inspiration but to show people there is no obstacle in life that can't be overcome," she said. "I don't think she even realizes this gift she has walked away with, but everybody else does."

*Jan Jarvis, Star-Telegram.com*

*Savannah Hollis has become an advocate for cavernous angioma awareness. In addition to this piece in the Dallas/Fort Worth Star Telegram, her story has appeared in Cosmo magazine and she has been a featured guest on "The Doctors," a daytime medical information television program. We would like to thank Savannah for all she is doing to help others with cavernous angiomas.*

**Angioma Alliance DNA/Tissue Bank**

The Angioma Alliance DNA/Tissue Bank and Clinical Database is now being accessed by five different research laboratories! We have become a valuable resource, and we want to thank everyone who has given their time to enroll. We continue to look for more folks to join. Right now, we are enrolling individuals who have an upcoming surgery scheduled, individuals who have had a past surgery (particularly at St. Joseph's in Phoenix, Arizona), and individuals with the hereditary form of the illness. If you'd like more information, please visit <http://www.angiomaalliance.org/registry.aspx?content=99>.

**Peer support program seeks additional volunteers**

The peer support program is more successful than we imagined it would be. As of this writing, 30 volunteers are providing support to more than 40 peers. In order to fill the growing demand, we are in need of more volunteers—specifically, individuals with brainstem cavernous angiomas and spouses of those with cavernous angiomas. All volunteers should be at least two years beyond their diagnosis and have one or two hours a week to share with a newly diagnosed individual by phone or email. Experience is not required; training is provided.

If you would like to volunteer, please contact Norma at [support@angiomaalliance.org](mailto:support@angiomaalliance.org), or complete the peer support volunteer form that can be found in the Support Contacts section of our website, [www.angiomaalliance.org](http://www.angiomaalliance.org).

## Angioma Alliance Donors January 1 – March 31, 2009

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## Two more ways to help Angioma Alliance

### Café Press Store

We have opened an online store through Café Press, offering a wide range of high-quality Angioma Alliance logo items. Look for it at [www.cafepress.com/AngiomaAlliance](http://www.cafepress.com/AngiomaAlliance).

Our original store offering brochures, DVDs, wristbands, and car magnets remains open at <http://stores.homestead.com/AngiomaAlliance/Categories.bok>. The original store will have new offerings—2009 conference DVDs, materials for the newly diagnosed—in the near future.

### Red Swan

Have any old gold or silver jewelry that you no longer wear? Use Red Swan to turn it into a donation to Angioma Alliance. Visit <http://www.redswan.com> or get in touch with Christine Castellano at [castellano@proofmark.org](mailto:castellano@proofmark.org) for information and a starter kit. Simply write the Authorized Charity Code 45 for Angioma Alliance on your inventory sheet, and your Red Swan payment will be sent directly to us. You can even host a Red Swan party and encourage your friends to empty their jewelry boxes for charity! We have tested Red Swan and believe they offer fair prices for the jewelry that you send.

We have tried to present as complete a list of donors as possible and apologize for any omissions. Please let us know if we have inadvertently left off your name and we will make the correction.

**Who We Are...**

Angioma Alliance is a non-profit, international, patient-directed health organization created by people affected by cerebral cavernous malformations (CCM). Our mission is to inform and support individuals affected by CCM while facilitating improved diagnosis and management of the illness through education and research. We are monitored closely in our educational efforts by a Scientific Advisory Board comprised of leading cerebrovascular neurosurgeons, neurogeneticists, and neurologists.

Angioma Alliance  
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**How You Can Help**

Your contributions will help fund conferences and forums, increase research, and enhance outreach and support efforts. Our pins, car decals and wristbands support the mission and growth of Angioma Alliance. Share these meaningful gifts with your friends and family.

Each donation of \$10 or more will come with a CCM lapel pin thank you gift. 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.



Angioma Alliance has its own magnetic car ribbon! These unique ribbons are the larger 3 1/2” x 8” size and are available for \$5 each, including shipping. Educate while you travel!

To donate or order Angioma Alliance merchandise, send a check or money order (using the enclosed envelope) or visit [www.angiomaalliance.org](http://www.angiomaalliance.org) and purchase all of your Angioma Alliance gear in one fast, easy transaction! You can donate and purchase using a credit card with our Paypal connection.

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