Winter 2011

Angioma Alliance Newsletter

Why We Reach Out to Special Populations: Are Some Patients More Equal Than Others?

IN THIS ISSUE

Angioma Alliance Patient Weekend
March 25-27, Dallas, Texas
See page 3 for info

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

I have been asked from time to time why researchers and Angioma Alliance focus on specific subgroups within the greater population of those affected by cavernous angiomas. Many of you know that we have worked for many years in New Mexico with individuals who have a hereditary form of the illness that is called the Common Hispanic Mutation on the CCM1 gene. In another article on page 3, you will see that we are establishing a center for those with the hereditary CCM3 mutation. Why are we not establishing research centers for those with the sporadic form of the illness since this form constitutes the majority of those who are affected?

There is a plan behind what might appear to be this narrow focus. New Mexico provides a unique opportunity for researchers to document the natural history of the illness and efficiently pilot test potential treatments. There are three reasons for this:

1: The hereditary form of the illness is typically characterized by multiple cavernous angiomas. Each cavernous angioma lesion is a standalone entity for research. This means that tracking the behavior of 10 lesions in one person with the Common Hispanic Mutation is equivalent to tracking 10 individuals who have one lesion each. By examining such patients, it is far easier to create studies that have sufficient statistical power to yield conclusions in a short period of time. Once a treatment has been documented as effective in those with the Common Hispanic Mutation, it can be tested on those with other hereditary forms and with sporadic lesions with the foreknowledge that it may indeed be able to help.

2: One of the challenges scientists have encountered with clinical drug testing is defining success. Is reducing leakiness of the cavernous angioma enough, or will this lead to lesions that grow in size and become even more tumor-like? Also, those with the hereditary form of the illness develop more lesions over time. How important is preventing this from happening in terms of a person's quality of life? These are questions that can be tested in a large sample of people with the hereditary form.

3: New Mexico has the densest population of affected individuals in the world so it is easier to find and enroll research participants.

(Continued on page 2.)

With the sporadic form of the illness, scientists are still trying to determine how these lesions form. Perhaps the same genetic mutation is involved, but in a specific cell rather than in a person's entire genetic make-up. The technology to test this has only recently been refined sufficiently to draw conclusions. This refinement was accomplished by examining cavernous angiomas donated by Angioma Alliance DNA/Tissue Bank members with the hereditary form of the illness. It would be good news if this hypothesis turns out to be true as it will allow for the creation of lab animals with the sporadic form of the illness, which will ultimately lead to treatments.

The CCM3 mutation has its own story. Research indicates that while people with the hereditary CCM3 mutation have cavernous angiomas, the overall function of the protein that is created by the CCM3 gene (PDCD10) is different from the proteins created by the CCM1 and CCM2 genes. The treatments that will work for CCM1 and CCM2 may not be sufficient to cover the spectrum of clinical symptoms for those with the CCM3 mutation. We know that people who have this mutation are more likely to have an aggressive presentation—50% of people with the mutation will have significant hemorrhages as children. We have evidence from the Angioma Alliance DNA/Tissue Bank that there may be other manifestations of this illness in addition to cavernous angiomas—in other kinds of tumors or in other body systems. Add to this the fact that the illness appears to be extremely rare—we believe that only 9 families in the United States have received a clinical diagnosis through genetic testing—and it becomes clear that having accurate documentation of each case is vital for understanding this form of the illness.

It will not be long before everyone with a cavernous angioma will be needed for research. This is the motivation behind our Patient Registry (www.angioma.org/registry). As I mentioned above, we will need to enroll ten times as many people with the sporadic form of the illness as those with hereditary forms in order to launch successful studies. If you have the sporadic form, please make it a point to register today.

Connie Lee

Angioma Alliance Patient Registry Starts Helping Researchers

In the next few weeks, participants in the Angioma Alliance Patient Registry will begin receiving notifications of research studies for which they may be eligible. Researchers at the University of New Mexico and the University of North Carolina at Chapel Hill have reached out to Angioma Alliance asking for research participants. These researchers know we have a Patient Registry and are looking forward to a good response.

While we currently have a pool of some 200 people enrolled in the Patient Registry, we need your help to expand and become a truly useful resource for research. Participating in the Angioma Alliance Patient Registry is an easy way for you to change the future for the better. The Registry is intended to be a way for us to notify you of research studies for which you might qualify. There is no obligation for you to participate in any given study—this is simply a way for us to let you know what is available. The Registry also provides us with a snapshot of the cavernous angioma community: how often folks are receiving MRIs, what the time lag is between first symptoms and diagnosis, etc. By visiting www.angioma.org/registry and spending 15 minutes entering your information, you are giving a precious gift to the cavernous angioma community. Your information is kept private; only Dr. Akers at Angioma Alliance has access to your contact information.

If you have questions or would like to discuss any concerns about the Registry, please contact Dr. Amy Akers at coordinator@angioma.org. We need to know if there have been any barriers to your participation. Based on our mailing list, there are many more of you who could be registered. Let us know if there is something we could change that would encourage your participation.

News

Angioma Alliance Patient Weekend

There is still time to register for the Angioma Alliance Patient Weekend in Dallas, Texas, on March 25-27. If you are considering attending, please register as soon as possible as we must cut registration off on March 22. We are also limited to 60 registrants. Here are the highlights:

Friday, March 25

Evening: Get-together at Savannah Hollis' home.

Saturday, March 26

Morning: Fun Run/Walk at T.W. Richardson Grove Park to benefit Angioma Alliance with lunch at the park. We expect citizens of the greater Dallas area to participate in the event. It would be wonderful to have a good turnout of Angioma Alliance members to raise awareness of the illness.

Afternoon: Presentations by Dr. Duke Samson, neurosurgeon, and Dr. Jessica Lee, neurologist, from the University of Texas Southwestern, and by Angioma Alliance President Dr. Connie Lee. These will be followed by smaller conversation groups organized by common experiences (e.g., brainstem cavernous angiomas, caretakers) to allow us to get to know each other. This portion of the meeting will be held at the Hyatt Place Dallas/Las Colinas.

Evening: On your own to rest or get out in the vibrant Las Colinas area.

Sunday, March 27

Morning: Presentations on the future of cavernous angioma treatment by Angioma Alliance Scientific Officer Dr. Amy Akers as well as the second half of Angioma Alliance President Dr. Connie Lee's presentation. This will be followed by a second round of conversation groups. These will again be held at Hyatt Place.

If you are planning to attend and have a request for a particular topic to be covered, please let us know.

The registration form can be found online at http://tinyurl.com/4qu7wfe. Registration for the entire weekend with the exception of the Fun Run/Walk will be $45 per adult. Registration for Fun Run/Walk participants is $15 and includes a t-shirt and the satisfaction of knowing you are helping Angioma Alliance drive research for a cure. We can help you to find a childcare provider while you are attending any of the conference activities.

We have not reserved a block of rooms at any particular hotel in order to allow the widest range of choices for attendees. At this time, Hyatt Place offers King, Double, and King wheelchair accessible suites with continental breakfast for $89/night with internet pre-purchase or for $98 with regular purchase. Hyatt Place offers a complimentary Dallas Fort Worth airport shuttle and a complimentary shuttle to anywhere within a 5-mile radius of the hotel, including Savannah Hollis' home for the Friday evening get together and the Saturday morning Fun Run/Walk. The hotel's website is http://lascolinas.place.hyatt.com.

CCM3 Consultation and Clinical Research Center

Angioma Alliance is pleased to announce the creation of a CCM3 Consultation and Clinical Research Center at the University of Chicago. Under the supervision of Dr. Issam Awad, the Center will serve as a centralized location to examine CCM3 patients and document the natural history of the illness. Dr. Awad's team will also report any significant findings to the individual's home physicians. While the Center is associated with Angioma Alliance, the cost for the Center will be covered by patients' medical insurance, supplemented by travel assistance and personal donations from a CCM3 family to cover excess medical costs.

Almost all individuals with the CCM3 mutation in the United States are enrolled in the Angioma Alliance DNA/Tissue Bank. Patients may release to the DNA/Tissue Bank the results of these examinations so that we can compare the natural history of the CCM3 mutation to that of the other genetic mutations that can cause hereditary cavernous angiomas.

The CCM3 mutation appears to be very rare – only 9 families in the United States have so far received a clinical diagnosis – and it is known to cause a more severe form of the illness than the CCM1 and CCM2 mutations.

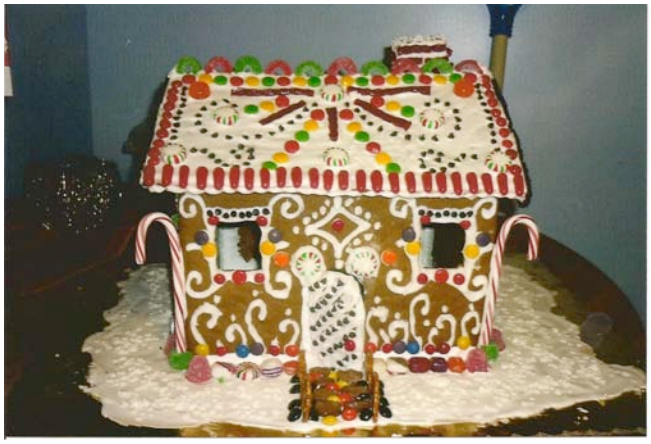
Benefit Auction in Durham, NC

Please mark your calendars for the second annual CCM Fashionable Event from 5-7 PM on Sunday, May 1, 2011. The Fashionable Event will be held at the beautiful Hamilton Hill Jewelers in Durham, North Carolina. It is sure to be an evening of fine food and drink combined with a very special silent auction of high end fashion and other items.

Gingerbread House Raffle

Sarah Westmoreland, older sister of Ryan Westmoreland, organized a small fundraiser in Portsmouth, Rhode Island, Ryan's home town, over the Christmas holiday. Ryan is a young baseball player who was signed by the Boston Red Sox where he was to begin playing in the 2010 season. In March, 2010, Ryan was diagnosed with a cavernous angioma in his brainstem. He subsequently underwent brain surgery to remove it and has since been determinedly working his way back into professional baseball. Ryan has been taking batting practice during spring training and is reported to be ahead of schedule in nearly all of his rehabilitation activities.

Ryan's sister Sarah works at a bakery in Portsmouth; her manager gave her a gingerbread house to decorate and raffle to benefit Angioma Alliance. She sold over $80 in tickets including fifteen tickets to Ryan. When the winner was picked, it turned out to be Ryan. We hope he enjoyed his sister's work. Thanks to Sarah and the Westmoreland family for their support.



Gardening for a Cure

For those of you in the Northeast and Midwest United States, it may be hard to believe, but winter will end one day. In the meantime, I encourage you to think warm thoughts by planning your garden.

Angioma Alliance has teamed with FlowerPower Fundraising to help make your garden beautiful. When you purchase tubers, bulbs, root clumps, and bare roots that will grow to become your flowers of summer, Angioma Alliance will receive 50% of each dollar you spend. Find the catalog here:

www.flowerpowerfundraising.com/campaign?campaign_id=4495

Click the green "Shop Now" button on the lower left and you can begin browsing and buying.

Wondering how to plant in frozen soil? You can go ahead and order now and the plants will not arrive until it is planting time in your area. The plants currently being sold on the website are planted in the spring, yielding summer and fall blooms. Orders placed through April 29 will be shipped between early April and late May, depending on when your order is submitted and the optimal planting time in your area.

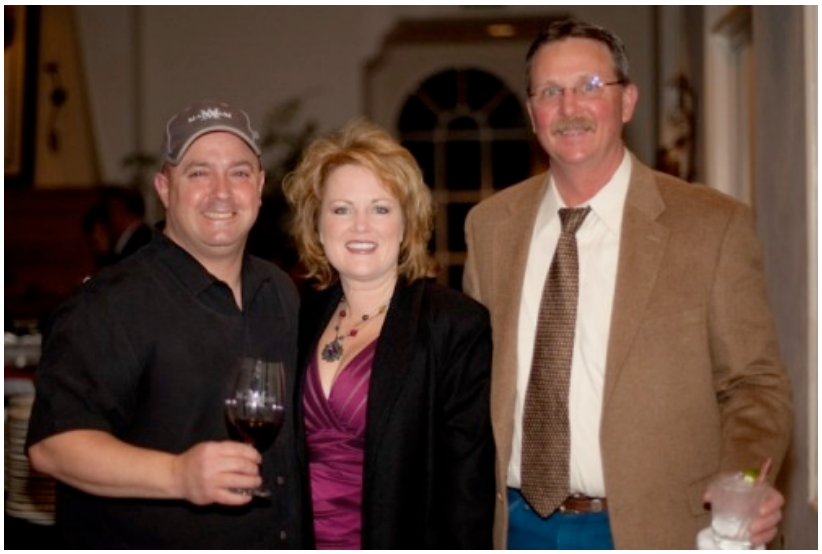
Don't just shop for yourself; please ask your family and friends to support us, too. You know what to do: Facebook it, tweet it, and email all your contacts. Everything helps.

FlowerPower can ship only to the contiguous United States because of agricultural and shipping restrictions.

Thanks for your support and happy gardening!

2011 MadoroM Wine Auction Sets New Records

The final numbers are still being tallied, but it appears that Angioma Alliance will receive $100,000 through the generosity of donors at what has become an annual Bakersfield, California, event. Wine Release attendees were introduced to cavernous angiomas and Angioma Alliance by Liz Neuman, Angioma Alliance member and mother of Jake and Sam Neuman. Liz gave a speech entitled "Uninterrupted," in which she explained the ongoing need for the work of Angioma Alliance so children with cavernous angiomas could one day have childhoods that remained uninterrupted by bleeds and brain surgeries. An interview with Liz appears on pages 6-7 of this issue.



Andy Amador, Shannon Grove and Rick Grove

This year's bidders had a wonderful program of experiences and items from which to choose. For the second time, Representative Kevin McCarthy, now House Majority Whip, donated a "Capitol Hill Experience," which included lunch with the Congressman in the Congressional Dining Room. In the same vein, this year saw the addition of a "Sacramento Experience" with newly elected Assemblywoman Shannon Grove.

The traditional 18-liter bottle of MadoroM wine was auctioned as well as two barrels of MadoroM Camouflage and a number of rare cult wines. We are very grateful to Andy and Marissa Amador and Mike and Shawn Blom for hosting this event now for the 6th year. It just keeps getting better.

Tom Fowler

Liz Neuman and Marissa Amador

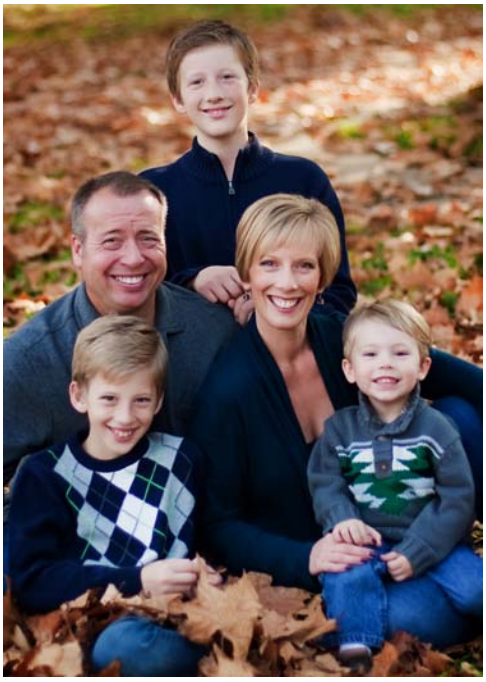
Stories

A Mother's Love and a Caring Community Combine to Drive Cavernous Angioma Research

There is one family that ties together a number of stories in this issue. Liz Neuman, and her children Jake and Sam, have been part of Angioma Alliance since its early days in 2002. All three are affected by the CCM3 mutation, and their family is the reason for Angioma Alliance's involvement in the annual MadoroM Benefit Wine Auction, which has raised nearly $300,000 over the last 6 years. I talked to Liz before this year's MadoroM Wine Auction.

Liz explained that her journey with cavernous angiomas started when her son Jake was 2. "He had a period of about 4 to 6 weeks of being generally unwell, but we didn't know what was wrong. On New Year's Eve, 1999, when I went to wake him up from his nap, I found him sitting up in bed making guttural noises. He was conscious but he didn't respond."

The next four days brought more questions than answers. Liz called 911, but "the paramedics thought he looked fine. They told me that if we still thought there was something wrong we should take him to Urgent Care." Following her intuition, she and her husband John took Jake to Urgent Care where he had a full seizure. He was rushed to the hospital and had a CT scan that didn't lead to a definitive diagnosis. Liz explained, "They found the lesion but they didn't know what it was. They thought he might be injured or that his lesion might be caused by an infectious illness. He was transferred to LA Children's Hospital. Because of the New Year's holiday, we were there four days before we found out what he had. It turned out to be a golf-ball-sized cavernous angioma in his left frontal lobe. He had brain surgery to remove it the very next day."



Jake; John and Liz; Sam and Will Neuman.

Liz went on, "Jake had a rough recovery. He had a lot of pain, but at the time it seemed that he had recovered everything pretty well. We understood that we would not know what would be affected for some time… Now that he is thirteen, it is obvious that he has attention and impulse control deficits from the damage to his frontal lobe. Jake was also found to have another cavernous angioma in his parietal lobe."

Liz's experience with cavernous angiomas continued with her son Sam. Liz said, "When Jake was diagnosed, my second son Sam was three months old. He was born with what we were told was a hemangioma on top of his foot. When Jake was still in the hospital, we asked if Sam's hemangioma was related to what Jake had. They told us that it absolutely was not and that the illness was genetic only in Hispanic families from the Southwest." This is incorrect. Although there is a founder mutation that leads to more people with the familial form of the illness among this specific Hispanic population, it can be genetic in any family.

Liz' persistence was again needed, this time to get Sam diagnosed. Liz had contacted a doctor at Boston Children's Hospital to discuss possible treatment options for Jake. He could not help, but he did suggest that Sam likely did not have a simple hemangioma. He encouraged Liz to request an MRI for Sam. "They found four cavernous angiomas in his brain as well as three in his leg and one in his foot. He wound up having surgery on his foot because the cavernous angioma grew so much that he couldn't wear shoes. A year later, he had his first bleed and had brain surgery to remove a right parietal lobe cavernous angioma."

When Sam was 5, he had a hemorrhage in a frontal lobe lesion. Liz had a suspicion that something had happened because Sam had started stuttering. Within four years, Sam had three brain surgeries with three different surgeons to remove this same lesion. Despite each surgeon believing the entire lesion had been removed, it continued to grow back. The first time it recurred,

the lesion regrew to egg size without any warning. Sam had to be helicoptered for emergency surgery. Although he was quite ill, Sam appreciated this experience. Sam's last surgery on this lesion was in 2008, and it has not recurred.

In the last month, Sam has had a significant hemorrhage in the temporal lobe. Liz says that this bleed "has taken even more of a toll on his speech and his word control. Also, because it's in the temporal lobe, his mood is very bad. Loud noises are intolerable. Things that used to be easy for him in school have been very hard." Liz homeschools both Jake and Sam, and she witnesses this frustration firsthand. Liz and her husband will find out in early March whether Sam will need yet another brain surgery.

Until 2006, the exact mutation that was causing Jake and Sam's illness had not been identified. To help with this effort, the entire Neuman family had been donating blood to studies whenever possible. In 2006, the answer came; Jake and Sam were among the first group in the United States to be diagnosed with the CCM3 genetic mutation. At the same time, Liz also tested positive for the CCM3 mutation. An MRI showed that Liz has three lesions, but she has not had symptoms.

Liz has been active in Angioma Alliance almost since the beginning of the organization. She has allowed us to use her family's story in all of our promotional material including our video "Cavernous Angioma and Children" that can be seen on YouTube. (www.youtube.com/watch?v=7seV4jzcbmE)

Just as significantly, Liz and her family have raised the funds that have supported so many of our activities. Previous to the MadoroM Wine Auction, Liz organized a rummage sale sponsored by her children's school, and she solicited thousands of dollars in donations from her circle of family and friends. The MadoroM wine auction is her primary focus at this time and has made a more significant contribution to our organization than any other event or grant.

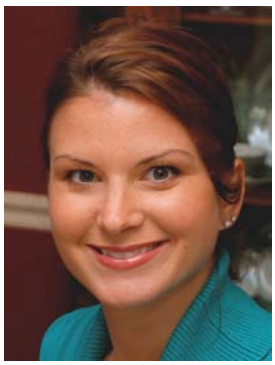
I asked Liz how the event started. She explained, "My brother Brad was at a wine release in Napa and met Andy Amador who owns the MadoroM vineyard. Brad and Andy became fast friends. I was planning a benefit dinner for Angioma Alliance and asked Andy if he would be willing to donate wine for the event. Andy suggested that he could do even better by auctioning wine at the annual MadoroM wine release party. In 2006, Andy had a special 18-liter bottle of MadoroM wine created. This was auctioned and raised $6,000. Spontaneously, other attendees at the wine release offered bottles of wine from their own wine cellars for auction." When it was totaled, the first year raised $34,000 which was split between Angioma Alliance and a second charity, Small Miracles.

The auction has grown each year. You will read in this issue about this year's event (see page 5). Liz spoke about the reasons for the auction's success. "I think that first year when I talked to the attendees and told them about our situation people felt sympathetic and wanted to help. But they also knew there was something concrete they could help to accomplish—they knew we were trying to create the DNA/Tissue Bank and how we were going to go about it. The fact that our disease is relatively rare is really helpful. People can see that they can make a difference in this illness. Trying to cure breast cancer feels like an overwhelming task, but in six years of fundraisers for cavernous angiomas, we've gone from nothing to testing medications. We're moving research by leaps and bounds using money from the people at this event. I think the real reason, though, is that people in Bakersfield are just incredibly generous and kind. I left Bakersfield for a few years but I had to come back. For me, there's no place like home."

Liz's hopes for the future are simple. "I would like to see a non-surgical treatment for cavernous angiomas. The theme of my speech at the wine auction is 'My children need a childhood that is uninterrupted.' My brother Brad asked my son Sam recently if he would like to go fishing next month. Sam answered by saying, 'I want to go, Uncle Brad, but I may be having brain surgery.' I would like my kids to be able to make plans to go fishing without the possibility of hemorrhage or brain surgery hanging over them. This is an illness with volunteers and donors that can change this. We can change the future for cavernous angioma patients."

Connie Lee

Cavernous Angiomas and Surgery: Common Questions



Amy Akers, Angioma Alliance Chief Scientific Officer

Many people affected by cavernous angioma have questions regarding surgery. This article addresses the most common questions, with answers based on the published clinical literature cited at the end of the online version of this article. (www.angiomacommunity.org /blog/?p=344) For information specific to you or your family, please consult your physician.

Some key terms

Hemorrhage: The medical term for "bleeding."
Resection: The surgical removal of a lesion.
Lesion: A medical term for an abnormality on or in a body part caused by disease or injury.
Seizure: Uncontrolled electrical activity in the brain, which may cause cognitive or physical symptoms.
Brainstem: The part of the brain between the cortex (the white matter) and the spinal cord.

What is a clinical hemorrhage?

A hemorrhage is when there is a bleed in your brain. Clinically, the definition of a hemorrhage is an event that includes both the onset of symptoms (e.g. headache, seizure, etc) *and* radiological or physical evidence of a vascular bleed.

Bleeding from a cavernous angioma can cause symptoms in two ways. The first is when blood leaks from a lesion and makes contact with brain tissue. It is also thought that an increased amount of bleed inside a lesion can cause pressure on the surrounding tissue.

When is surgery recommended for brainstem lesions?

Brainstem lesions may cause particular concern because they are more likely to develop clinical hemorrhage (bleeding together with neurological symptoms) than lesions located in other parts of the brain. The brainstem is the location of many cranial nerves as well as those for essential motor and sensory capacities, thus this represents a particularly sensitive brain region. Brainstem lesions are therefore often treated more aggressively than lesions in other parts of the brain. The decision to undergo brain surgery is certainly difficult; one must weigh the risk of potential harm from surgery and one's current clinical status compared to the risk of additional bleeds.

Surgery on a surgically accessible brainstem lesion may be recommended if:

- The lesion has hemorrhaged multiple times and shows to be causing worsening neurological deficits (including motor or sensory deficits, headaches, double vision, vertigo, etc.), or
- The lesion has hemorrhaged and blood has extended into the surrounding brain.

In general, surgery may be recommended if the risk of brain surgery is outweighed by possible negative consequences of new hemorrhages.

When is surgery not recommended for brainstem lesions?

In a recent report from the Barrow Neurological Institute at St. Joseph's Hospital in Phoenix, Arizona, roughly half of all patients with brainstem lesions in the past 15 years have been recommended for surgery.

For patients not undergoing surgical excision of the lesion (from this study and others), conservative management and observation was recommended for one or more of the following reasons:

- The patient experienced few or no symptoms,
- The lesion was small and/or inaccessible,
- The lesion had minor hemorrhages in the past that showed rapid improvement, or
- The lesion was asymptomatic and located in an area below the 4th ventricle—surgery through this region tends to cause the most severe deficits.

Each of these conditions was considered to be less risky to the patient than surgery.

What are some statistics for surgical outcomes?

Brain surgery involves serious risks; however, individuals who choose surgery often believe that the risks are worth taking, as surgical removal of a cavernous angioma can significantly reduce future risk of hemorrhage.

Two recent reports examined the surgical outcomes from large series of patients; the results are summarized below.

In a series of 260 adult patients who were treated between 1985 and 2009 at the Barrow Neurological Institute at St. Joseph's Hospital in Phoenix, Arizona, the following outcomes were observed:

- 89% of patients had the entirety of their lesion removed.
- 45% of patients showed an improvement in symptoms after surgery.
- 36% of patients showed new, permanent deficits, or worsening symptoms including motor or sensory disabilities, cognitive impairment, ataxia, pain and/or behavioral changes.
- 7% of patients experienced a re-hemorrhage.
- 5% of patients required additional surgeries.

Another publication, compiling data from 45 studies published between 1970 and 2008, reported similar results. In total, 745 patients sought treatment for their brainstem cavernous angioma. In this group:

- 92% of patients had a complete resection of their lesion.
- Of those with partial resections, about 50% of the patients experienced a re-hemorrhage of the remaining lesion.

For those patients with complete resection of their lesion:

- 85% of patients were the same or showed improvement post-surgery.
- 14% of patients were worse following surgery.
- 1.9% of patients died due to long-term surgery related outcomes.

While these results highlight the risks associated with surgery, the overall success for these groups of patients is illustrated by a reduction in the individual rate of hemorrhage.

What if a developmental venous anomaly is present?

A developmental venous anomaly (DVA or venous angioma) is a large vein structure that is often found near a cavernous angioma. During surgical removal of the cavernous angioma, it is generally recommended to leave the DVA intact. It may have an important role for normal venous drainage, and removal of a DVA may cause an unnecessary risk of venous infarction, or a blockage of blood flow.

Can surgery be useful for CCM-related epilepsy treatment?

Seizures and epilepsy (recurring seizures) are among the most common symptoms associated with cavernous angioma. It is not known why cavernous angiomas cause seizures. One hypothesis may be that bleeding from the lesions causes seizures; however, research suggests that bleeding is not the primary factor involved. In one study, clinical hemorrhage was more often observed in patients who did not experience seizures. This same study shows that location of lesions is more predictive of one's risk of epilepsy: those with cavernous angiomas in the temporal lobe are more likely to have seizures.

Seizures and epilepsy can be controlled with anti-seizure medications and/or surgical removal of lesions that cause seizures. In a series of 44 patients with epilepsy that was not controllable with medication, 72% of patients undergoing resection became seizure-free. The remaining patients who underwent surgery had rare seizures, some improvement or no improvement from pre-surgical conditions. In summary, surgical options may be an effective option for reducing seizures in cavernous angioma patients who suffer from epilepsy.

How can natural history studies help better answer these questions?

The decision to undergo surgery is personal, medical and scientific. One of the largest criticisms to studies such as those discussed here is that it remains unknown how surgical outcomes compare to conservative management of lesions (i.e. observation without surgical intervention). There is a need for a large-scale natural history study (a study that follows a group of people over time to see how their condition evolves) to better understand the normal progression of cavernous angioma patients through time. This is difficult because patients are treated in different countries, states or hospitals.

Angioma Alliance is working to help with this effort though our research initiatives including the Patient Registry and the DNA & Tissue Bank. To learn more about these programs and consider participating please visit: www.angioma.org/dna. Without you, there can be no cure!

Amy Akers

Cavernoma Alliance UK Update

I have found that the secret to having strong, well-attended Cavernoma Alliance UK events is rather like cooking—it's all in the preparation. And so this winter I have sat at my desk plotting for spring. Albeit infrequently, I did venture outside; here is some of what CA UK achieved.

The Board of Trustees, CA UK, continue their quarterly meetings in the Old Boardroom, National Hospital for Neurology and Neurosurgery, Queen Square, London. Indeed the ranks now include Alison Garwood, a former Registered Nurse with a personal interest in cavernomas, particularly those in the spine. I first "met" Alison over Skype whilst she was working in Australia and needed some support. After relocating to the UK, and being appointed a Trustee, Alison has already proven herself. Last year Alison and I produced a three-fold patient information leaflet which "Indispensable Iris," CA UK's secretary, sent to all vascular neurosurgeons in the UK. This mail shot is in advance of their March conference which CA UK will attend. Next to be targeted are the geneticists and the neurologists.

Thanks to the generosity of Mr. Kitchen, consultant neurosurgeon, and Dr. Salman, consultant neurologist, CA UK's medical advisers, the free CaverClinics seem to be functioning rather well. Members have reported their visits have been useful and Mr. Kitchen has informed me that a steady stream of affected people with cavernomas have been seen.

Whilst asymptomatic cavernomas are known in the UK to affect 1 in 600 individuals, symptomatic cavernoma are classified as a "rare" condition. So together with Frank Gent, CA UK is participating in Rare Diseases Day, 28 February 2011 in the Houses of Parliament. Alison is representing us in the Welsh Assembly, and the Scottish Co-ordinator, Nicola Godsal, in the Scottish Parliament. (This is the first time CA UK has been represented in three of the four parliaments. By next year I hope to have found a member to represent us in Northern Ireland.) Nicola Godsal is also running the first-ever CA UK CaverHub in Glasgow, 12 March, with Dr. Salman and Mr. Jerome St. George, consultant neurosurgeon, participating.

International Brain Awareness Week (www.dana.org/brainweek) occurs 14-20 March. CA UK is participating with a CaverHub at the National Hospital for Neurology and Neurosurgery, Queen Square, London. Presentations by the Brain and Spine Foundation and the Neurological Alliance culminate with a lecture entitled "Why Surgical Removal of a Cavernoma May Not Always be a Good Idea" given by CA UK's senior medical adviser Mr. Neil Kitchen.

In March I also materialise at the Angioma Alliance Patient Weekend in Dallas, Texas, where I look forward to seeing old friends, making new ones, and buying a Stetson. My visit is to encourage American attendance at the 5th Annual International Cavernoma Alliance UK Forum, to he held in London on 4 June 2011. An impressive line up of speakers this year includes a neuroradiologist, a neuropsychologist, and our keynote speaker Mr. Mohsen Javadpour MB, BCh, FRCS(SN), consultant neurosurgeon, The Walton Centre for Neurology and Neurosurgery. Mr. Javadpour's neurovascular training was completed in Toronto, Canada, with Dr. Gentili. Mr. Javadpour's talk is entitled "Cavernomas - What are they, how do they affect people, and how can they be treated?" Mr. Javadpour's talk will be followed by members' questions. See cavernoma.org/305 for further details of this year's Forum. Attendance is a must.

And so whatever the weather, if there are Americans in attendance at the Forum, I promise to wear my Stetson.

Ian Stuart

About Angioma Alliance

Angioma Alliance is a non-profit, international, patient-directed health organization created by people affected by cerebral cavernous angiomas (also known as cavernous malformations or CCM). Our mission is to inform, support, and empower individuals affected by cavernous angioma and drive research for a cure. We are monitored closely in our educational efforts by a Scientific Advisory Board comprised of leading cerebrovascular neurosurgeons, neurogeneticists, and neurologists.

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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 as a thank you gift. Our "little red guy" pin is a wonderful way to increase awareness of cerebral cavernous malformation (CCM). 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 also offers a wide range of apparel and other items featuring the Angioma Alliance logo. There are t-shirts, sweatshirts, hoodies, mugs, stickers and much more available. You can find these items in our Café Press store. To purchase Angioma Alliance merchandise, go to our web site and click the Store link at the top of the page.

To donate to Angioma Alliance, send a check or money order (using the enclosed envelope) or visit www.angioma.org. You can also donate on line using a credit card with our Paypal connection.

We Need You: Angioma Alliance needs volunteers in many areas. If you have time to give, please visit www.angioma.org/volunteer

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