



Winter 2009

Angioma Alliance Newsletter

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The 2009 Family Conference

This year's family conference will be held April 3-5, 2009 at the Hilton Fisherman's Wharf in beautiful San Francisco. We'll start with a reception on Friday evening, a full day of sessions on Saturday and a half day on Sunday, and finally, a run/walk to benefit Angioma Alliance on Sunday.

Speakers include:

- Dr. Michael Lawton, Professor of Neurosurgery and Chief of the cerebrovascular and skull base surgery program at the University of California San Francisco
- Dr. Wade Smith, Neurologist and Director, UCSF Neurovascular Service
- Dr. Heather Fullerton, Pediatric Neurologist and Director, UCSF Pediatric Stroke and Vascular Disease Center
- Dr. Bill Young, Director, Center for Cerebrovascular Research, UCSF
- Dr. Helen Kim, Principal Investigator, Center for Cerebrovascular Research, UCSF
- Dr. Bob Stahl, Founder, Awareness and Relaxation Training (A.R.T.) and Mindful Living Program
- Dr. Kevin Whitehead, cavernous angioma researcher, University of Utah

Additional speakers to be determined, but we guarantee they'll be interesting.

We will also have ample opportunity for small group discussion and for socializing.

Sleeping rooms at the Hilton are \$159 for a single or double, \$179 for a triple and \$199 for a quad. To make your reservation call (415) 885-4700 and ask for the Angioma Alliance room block. You must make your reservation by March 3rd.

Registration forms for the family conference are available online: www.angiomaalliance.org/documents/2009Registration.pdf. The registration fee is \$95/person for early registration and \$120/person for registrations received after March 3rd. The registration fee includes receptions on Friday and Saturday evenings and a continental breakfast on Saturday and Sunday. Childcare will be available for children between the ages of 2-12 during the Saturday and Sunday sessions at a cost of \$50/child.

We hope to see you there!

Connie Lee

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

Angioma Alliance 2008 Annual Report

Angioma Alliance's fiscal year runs from October 1, 2007 through September 30, 2008 and we should receive the opinion from the audit firm of Cavanaugh, Nelson & Co., PLC, by the time this newsletter reaches your homes. In the mean time, we thought you might be interested in an unofficial look at the organization's finances.

Last year we were fortunate to receive grants that allowed us to purchase a medical freezer for the DNA/Tissue Bank, fund the scientific conference, produce family health history educational materials, and develop a registry database and begin sample processing. But it is still individual fundraising, contributions, and volunteers that allow us to uphold our mission to inform and support individuals affected by CCM. With these initiatives, we were able to hold a family conference, redesign our website, exhibit at medical conferences, provide quarterly newsletters, and keep the lights on.

Thank you all for your continued support,

Karen Asbury, Treasurer

STATEMENT OF FINANCIAL POSITION

SEPTEMBER 30, 2008

ASSETS

Cash	59,999
Equipment, Furniture & Registry Database	166,520
Less Accumulated Depreciation	(37,159)
Security Deposit	700
TOTAL ASSETS	\$ 190,060

LIABILITIES AND NET ASSETS

Accounts Payable and Accrued Liabilities	2,033
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TOTAL LIABILITIES 2,033

NET ASSETS

Unrestricted	
Board designated	183,511
Total Unrestricted Net Assets	183,511
Temporarily Restricted	4,516
Total Net Assets	188,027
TOTAL LIABILITIES AND NET ASSETS	\$ 190,060

STATEMENT OF ACTIVITIES For the Year Ended September 30, 2008

	Unrestricted	Temporarily Restricted	Total
PUBLIC SUPPORT AND REVENUE			
Contributions	\$ 48,782	28,088	\$ 76,869
Conference Registration Fees	4,305		4,305
Family Health History Project		9,280	9,280
Grants and Contracts	31,973	23,000	54,973
In-Kind Contributions	11,798		11,798
Special Events	15,678		15,678
Miscellaneous	3,084		3,084
TOTAL PUBLIC SUPPORT AND REVENUE	115,621	60,368	175,988
EXPENSES			
Program Services	82,231	43,302	125,533
General and Administrative	16,739		16,739
Fund Development	29,247		29,247
TOTAL EXPENSES	128,217	43,302	171,519
CHANGE IN NET ASSETS	(12,596)	17,066	4,469
NET ASSETS AT BEGINNING OF YEAR	48,159	135,400	183,558
NET ASSETS AT END OF YEAR	\$ 35,562	152,465	\$ 188,027

Research News

New Treatments are on the Way: Understanding Clinical Drug Studies

2009 will be a year of great excitement for the cavernous angioma community. We are going to see scientific discoveries that may trigger pilot trials for one, two, and perhaps as many as three medications for treatment of cavernous angiomas. This is the objective we've all been working toward, been dreaming of—a non-invasive way of preventing hemorrhage and the development of new lesions.

It may be tempting to run to your doctor and get a prescription for any of the medications that will be tried, because as far as we know, those under consideration are already on the market. There are at least three reasons why this may not be a good idea:

1. The medications under consideration have been tested only in mice and fish that have been genetically engineered to have the hereditary form of cavernous angioma. They have not been tested in humans with cavernous angiomas. This means that they may not work or may indeed have a negative effect. To be as safe as possible, anyone taking a trial medication should be under the supervision of the researcher who is running the trial.
2. If you take a medication for the treatment of cavernous angiomas before it is shown to be effective in humans, you will become ineligible for participation in drug studies until you have been off the medication for a period of time. To prove that a medication works, we will initially need a small number of people to participate in pilot studies, then many people to participate in broader clinical trials. We need to help research move these possible treatments forward quickly and not muck up the studies with unsupervised use.
3. A study may actually be trying to compare the effectiveness of a particular medication on a variety of disorders. It may turn out that a medication works well for treating other vascular malformations but does not work for cavernous angiomas. Just because a medication is under study does not mean it is a good candidate for treating our specific lesions.

Angioma Alliance will publicize links to criteria for participation in drug studies as soon as they are available. You'll find the information on our site on a new page called Clinical Drug Trials in the Research section and in upcoming editions of this newsletter. For NIH funded studies, you can go to <http://clinicaltrials.gov> and search on "cavernous malformation" to get detailed information. At this time, there is one pilot study listed: <http://clinicaltrials.gov/ct2/show/NCT00783523>. We will also try to bring researchers in to discuss their work at the Family Conference in San Francisco in April.

Again, this is wonderful news, and we want to thank and help the researchers who have been working so hard to get us to this point!

Angioma Alliance Scientific Advisors Working on New Joint Paper

Just as the 2006 and 2007 Angioma Alliance Scientific Workshops led to the writing and publication of major papers defining cavernous angioma hemorrhage and setting standards for clinical data gathering, so the 2008 Scientific Workshop is leading to a jointly authored paper. The Angioma Alliance Scientific Advisors have begun work on suggested guidelines for the use of MRI with cavernous angioma patients. The paper has three objectives: 1) to provide minimum MRI standards for cavernous angiomas diagnosis and follow-up; 2) to suggest report language that is both accurate and sensitive to the patient; and 3) to suggest standards for MRI on patients who may be participating in research in order to provide consistent and sufficient information. We hope to see the result of their work by next year's conference.

Hand-Knit Scarves Raise Funds for Angioma Alliance

The scarf fundraiser begun by 11-year-old twins Kylie and Lauren Buck, who are affected by the CCM1 mutation, was featured in an article in the Allentown PA Morning Call. Lauren and Kylie's knitting club has raised more than \$800 to benefit Angioma Alliance by selling the scarves they make. To support their efforts, visit <http://www.scarves4ccm1.piczo.com>. Great work, girls!

Long-term seizure control after resection of supratentorial cavernomas: A retrospective single-center study in 53 patients

This Austrian group studied factors influencing the efficacy of the surgical resection of supratentorial (cerebral) CCMs. The efficacy of a resection was defined by the degree to which seizure activity ceased (or did not cease) post-surgery. The factors studied were the size and location of the CCM, the type and frequency of pre-surgical seizures, the number of years those seizures occurred, and whether damaged tissue was included in the resection.

The researchers found that the size, location, and seizure type and frequency had no significant effect on the success rate of the surgeries. However, whether or not damaged tissue was included in the resection and the number of years the seizures had occurred did impact the outcome of the surgery.

CCMs themselves do not have the capacity to generate seizures, but seizures result from damage to surrounding brain tissue. One means of tissue damage occurs through hemosiderosis resulting from a bleed. When blood leaves a ruptured blood vessel, the cells die, thereby causing the formation of iron deposits called hemosiderin, usually seen as rings around a CCM. When not contained within a cell, the iron is toxic.

Gliosis is the process by which a specific type of scar tissue is formed. When scar tissue forms, it suppresses further damage to an area. However, it can also have negative effects. A scar will often secrete molecules that inhibit the regeneration of new, healthy cells.

Individuals in whom damaged tissue was excised experienced greater success rates. The success rate was even higher in those individuals who had seizures for fewer than two years.

Stavrou, I, Baumgartner, C, Frischer, JM, Trattnig, S, and E. Knosp (2008) Long-term seizure control after resection of supratentorial cavernomas: a retrospective single-center study in 53 patients. *Neurosurgery*, 63(5), 888-897.

Lifetime Television Looks at Cavernous Angiomas

A program on Lifetime Television looked at cavernous angiomas, and featured Les Duncan (see p. 5). It aired on January 4, and will be broadcast again on March 8. For more info:

<http://healthcorner.walgreens.com/display/2132.htm>

Breakthroughs Presented at the 2008 Scientific Workshop

In November, thirty-five scientists from the United States, Canada, and various countries in Europe assembled in Washington for the 4th annual Pathobiology of Cerebral Cavernous Malformations Scientific Workshop sponsored by Angioma Alliance. This year's workshop was extended to a second day to accommodate the ever-increasing number of presentations. Scientists animatedly discussed their latest pre-published work, sharing information and opinions. Because this work is not yet published, we cannot discuss specifics here, but we can tell you that the progress has been significant.

Scientists are now pinpointing exactly which cells are compromised in the formation of cavernous angiomas. This knowledge, along with a deeper understanding of the function of the proteins involved in lesion formation, is allowing scientists to identify medications that may have promise in the treatment of cavernous angiomas. With this knowledge, researchers can begin to test these medications in animal models of the illness.



Drs Elizabeth Tournier-Lasserre and Issam Awad

Researchers also are beginning to understand that the genetic forms of the illness are systemic diseases that affect not just the brain and spine, but have an impact on the body's response to other illnesses. As these studies are published, we will include summaries in future newsletters. Obviously, we are excited about the possibility of medications to treat cavernous angioma; for more information about the role of Angioma Alliance members in this process, please see "New Treatments are on the Way: Understanding Clinical Drug Studies" on page 3 of this issue.

The 2009 Scientific Workshop will be held November 12-13 in Santa Fe, NM as part of the Cavernous Angioma Awareness Week activities.

News

Cavernous Angioma Awareness Week Was a Great Success!

From October 5-11, 2008, the City of Santa Fe, NM, hosted the first annual Cavernous Angioma Awareness Week. We had a wonderful time sharing information about the illness with the public and with health professionals. Highlights of the week included:

Two newspaper articles about the illness, one in the Albuquerque Journal North and one in the Santa Fe New Mexican.

Joyce Gonzales and Connie Lee were interviewed on the weekly medical program on KSWV 810, a local bilingual radio station with a listening audience of about 70,000. This was an opportunity to provide in-depth information to the greater community. The signal from the station carries all the way to the Colorado border, reaching the areas that have the highest number of affected people in New Mexico.

Dr. Leslie Morrison, a member of the Angioma Alliance Scientific Advisory Board, gave presentations to the medical staff at La Familia, the low fee clinic in Santa Fe, and to the public at a patient seminar hosted by St. Vincent's Hospital.

Borders hosted a book signing by Les Duncan for his latest book *Brain Storms*. Les reports that he spoke to a number of people who were very interested in learning more about the illness.



Joyce Gonzales, Les Duncan, and Laneia Gallegos, Marketing and Special Events Coordinator for the City of Santa Fe

Former City Councilor Karen Heldmeyer, Joyce Gonzales, and Connie Lee visited two local foundations that focus on supporting health

organizations to share information about the Common Hispanic Mutation and the work that Angioma Alliance is doing.

Congressman Tom Udall, who was represented by his wife Jill Cooper Udall, State Representative Jim Trujillo, and former City Councilor Karen Heldmeyer were honored at a well-attended public award ceremony and press conference. They each vowed to continue their efforts to bring more awareness and funding to the disease.



Jill Cooper Udall, New Mexico State Representative Jim Trujillo, and former Santa Fe City Councilor Karen Heldmeyer

As a result of Cavernous Angioma Awareness Week, we will be forming an official Northern New Mexico Chapter of Angioma Alliance based in Santa Fe. Joyce Gonzales will be its first President, and she will be working over the next months to form an advisory board and to establish goals for the chapter. We are very excited about the potential of this organization.

Also as a result of the week, we will be working with the University of New Mexico to develop a presentation targeted at healthcare providers in New Mexico that will qualify for continuing medical education credits. Depending on the funding we receive, we may be able to provide the presentation in a number of formats: online and live workshops, and possibly DVD. Offering continuing medical education credits should make it much easier for us to reach the medical community in New Mexico.

The 2009 Santa Fe Cavernous Angioma Awareness Week is planned for November 8th-14th. We will announce the activities as the week approaches.

Fund Raising

Win a Smart Fortwo 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 Fortwo 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-fortwo-passion.aspx>.

Currently, there is a wait of one year or more to buy a Smart Fortwo 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.



Name: _____

Street address: _____

City: _____

State: _____ Zip: _____

Phone: _____

E-mail: _____

Number of tickets: _____

Visa/Mastercard Number: _____

Expiration Date: ____/____

Signature: _____

International Updates



A great deal seems to have happened in just a few months on this side of the pond.

We are in the midst of changing our name on the Charity Commission's register from Angioma Alliance UK to Cavernoma Alliance UK. Once this change has been completed, mid- January 2009, our website and e-mail will be www.cavernoma.org.uk and info@cavernoma.org.uk. Mr. Kitchen, consultant neurosurgeon, National Hospital of Neurology and Neurosurgery, and our senior medical adviser, suggested that as cavernoma is the term used for our condition in Europe, our group should use the term "cavernoma" rather than angioma, the common term in the US. By keeping "Alliance" it is hoped that our strong bond with the main organization in the USA is evident. Thanks to Mark Seymour, a member of Angioma Alliance in North America, and now an honorary member of Cavernoma Alliance UK, and Paul Oldham, webmaster of Cavernoma Alliance UK, we have a new logo. (For the Angioma Alliance newsletter we have added the optional "tag" line to be used for banners and promotional material.)

Angioma Alliance UK was awarded £9000 (\$14,500) by Awards for All, part of the UK lottery, for establishing ten regional hubs in communities across the UK. These "caverhubs" will be talks given by regional professionals and an opportunity to interface with them and meet others affected by this condition.

I have just returned from the excellent CaverHub in Sheffield, South Yorkshire, about 150 miles North of London. (I will attend the inaugural meeting of each CaverHub.) Sheffield is a former steel town surrounded by beautiful landscapes—Yorkshire Dales are staggering. It is also where, some thirty years ago, the country's first Gamma Knife unit was set up at the Royal Hallamshire Hospital. Mr. J. Rowe, a consultant neurosurgeon on the Gamma Knife Unit, spoke to us at length about craniotomy and Gamma Knife surgery. Mr Rowe uses both approaches but mainly traditional surgery for complete removal of the cavernoma. Following questions from the fifteen members that were assembled, Mr. Cranmer, a radiographer from the Gamma Knife Unit in

Sheffield, guided us through the whole process from the fitting of the stereotactic frame to the after-care provided by his staff. The meeting lasted a total of three hours. My fear was that these Hubs dilute interest in the London Forum. But this initial meeting proved my fears to be unfounded as many members were inspired to discover and understand more.

A third of the lottery grant is dedicated to the London Forum, which will take place on June 13, 2009. We will again be using the excellent facilities of the Grange Holborn Hotel, Southampton Row. Our American friends must make the London Forum this year. The \$/£ rate is good and we have an exciting line-up of speakers including Dr. Bertalanffy from Switzerland described by Dr. Spetzler in Arizona, as "possibly the best vascular neurosurgeon in Europe."

Angioma Alliance UK regrets the death of Alistair William MacQueen. A strong supporter of our organisation, Mr. MacQueen had two children, Katie and Ali MacQueen, both of whom have had lives disrupted by cavernomas. With the kind help of his widow Jan, Angioma Alliance UK acquired part of the retiring collection from his funeral, giving us the ability to establish the Alistair William MacQueen Memorial Lecture 2009 at the London Forum.

The British Medical Authority agreed to pay £500 more towards the cost of new information sheets bringing the total to £1250. The text for these has been written for us by one of our medical advisers Dr. Rustam Al-Shahi Salman.

Joanne Smith, one of our members, lives in Garforth near Leeds in Yorkshire. She had one cavernoma removed fifteen years ago but another was discovered earlier this year when she was pregnant with her second son. She recently organized a five mile sponsored walk to Parlington Woods and back to raise money for our charity. About 40 people took part in the walk.

Next time I write, I hope that it will be from Cavernoma Towers and that my entry in the newsletter will not all be about money.

Ian Stuart



Stories

“A Father-Son Respect Thing”

David Picchietti grasped his cane with one hand, his other firmly planted on the leather armrest of the couch, and eased himself upright.

Nolan, David’s eldest son, stood protectively next to him, never taking his eyes off his father and holding David’s left elbow in his hand to help David keep his balance. Once standing, one hand clutching his cane, the other tucked inside the left pocket of his jeans, David grinned.

“A few years ago,” David said, “this would have been unheard of.”

Nolan, a senior at Marian Central, nodded.

“Standing up with a cane was something we weren’t sure we’d ever do.”

David Picchietti, four years after enduring brain surgery to remove a cavernous malformation that had settled at the base of his brain stem, puts the cane slowly in front of him and begins to walk out of the Picchietti family’s living room toward the front door.

It’s about a 60-foot journey. It used to take David more than an hour to get from his chair in the family’s living room to the front door and back.

Thanks to Nolan and the tireless therapy he has helped his father through, the two have managed to shave David’s time down to six minutes.

“We still have a lot of work to do,” said Nolan, as he held out his arm toward his father, who continued the walk back toward his chair without needing his son for balance.

“But to say we’ve come a long way is an understatement.”

In between soccer matches, practices and making himself a solid student at Marian, Nolan has found time every day to help his father with therapy and spend time helping mold the person that his father has become post-surgery.

It’s a different person than the man who coached Nolan when he first discovered he wanted to be a goalie. But Nolan also is different.

“It made me more mature,” Nolan said, as he watched his father move back toward the living room. “I go to school now and I see kids who are so different than I am toward their parents, and a lot of them are kind of mean toward them, and I just think about how wrong that is and how you should never take your parents for granted.”

“I knew I’d have to grow up really fast”

In 2004, when Nolan was finishing eighth-grade and busy with sports, school and friends, David sought

medical attention for headaches he had put up with for more than a year.

When doctors diagnosed David as having a cavernous malformation—a hereditary and non-cancerous cluster of abnormal dilated blood vessels in the brain—the Picchietti family’s world turned upside down.

David underwent immediate surgery. Afterward, he could no longer walk, speak or see clearly, or write.

Nolan was at a soccer camp in Iowa when his father had surgery. He had been told not to worry and that everything would be fine.

Doctors initially said recovery would take six to eight weeks.

“We’re still waiting for six to eight weeks,” Nolan said.

The surgery and David’s subsequent condition meant many changes to the life to which Nolan and his younger brother, Connor, had become accustomed. Their mother, Deirdre, went back to work because David’s work as a carpenter was done. Nolan had to help as the family went through therapy programs with David, including speech and physical therapy.

Doctors warned Deirdre her boys might rebel, but the opposite happened to Nolan—he grew up immediately.

“Everyone told me ‘You’ll see big changes in your kids,’” Deirdre said. “But we were very blessed. All we really did, especially the first year after David’s surgery ... was tell them all the time ‘Family is all we have.’ And these boys really listened, especially Nolan, which was encouraging, because he was at such a critical age.”

For the first year after surgery, David went to therapy in Northbrook every day. In April 2005, the family started taking David to Centegra Health System in Crystal Lake. Through Centegra, Nolan began to learn how to help his father at home: Walking next to him or behind him with either a cane or walker for balance, keeping track of how long it took to walk certain distances and counting how many times David reached out to touch Nolan for balance.

Every weekend, in between soccer practices and games, and every evening after school, Nolan would spend at least an hour doing therapy with his father.

Therapists at Centegra were astounded by David’s progress, Deirdre said.

“The therapists got to see the relationship the boys had with their father, and especially Nolan,” Deirdre said. “They could see that Nolan could really help David.”

Typically two to three years after surgery, therapy ends, Deirdre said, and insurance will not cover it any more.

“Nolan simply refuses to believe that,” Deirdre said. “He’ll talk about how when he’s at college, he’ll come home on the weekends and help his dad. He wants to get Connor ready to do the therapy so that when he’s gone, Connor will be able to take over. He’s turned into a leader, but instead of directing or telling you what to do, he’s just incredibly compassionate.”

Mutual respect and pride

Nolan led the Hurricanes to a second-place finish in the Suburban Catholic Conference this season and titles in both the Class 2A regional and sectional matches before bowing out to Chicago Lake View in the supersectional, one match shy of a berth in the Class 2A state soccer tournament.

It was an exciting year, and college interest and scholarship opportunities are both coming in.

The surgery might have changed many things in David’s life, but watching his son play soccer was one thing he didn’t have to give up.

From his wheelchair on the sidelines, David watched as Nolan saved many opponents’ shots at critical times during matches, including a 21-save performance in the sectional title match against Lakes.

And after every match, Nolan greeted his father before anyone else.

“I would tell him ‘Good job,’ ” David said, “and when he’d let one go by, even if they’d win, 7-1, I’d say ‘What happened there?!’ ”

“It’s a father-son respect thing,” Nolan said. “I probably wouldn’t be an athlete if it weren’t for my dad. And we’re as close as you’ll see a son and a father get.”

The compassion Nolan has developed over the years shows in his dealings with his soccer teammates, and the relationships he has on the field. He is one of the first to shake hands with officials before and after matches. He does not lead as much by words as he does by example. Marian coach Mike Golda said several times throughout the season that Nolan’s leadership, both as a player and as a person, carried the team in many situations.

“He puts a lot of care and compassion into everything he does,” Deirdre said. “He has made me so proud of him; he has such a big heart.”

A place to belong

Along with the adjustments of having his father in therapy, Nolan began his first year of high school at Huntley.

After feeling like he didn’t quite fit in there, Deirdre looked into the work study program at Marian. When the family qualified, Nolan began his sophomore year there.

It was an instant fit.

“He attributes a lot of how he is to being at Marian,” Deirdre said. “He feels like he’s part of a family there and that he’s really at home.”

The entire Picchietti family felt as though the Marian community reached out to them as well.

“I’ll come to these soccer games and I’ll be pushing David in the wheelchair and coaches and dads and fans will come and help me,” Deirdre said. “It’s truly been such a blessing to have both our boys at Marian. They know us very well and it is like a family.”

“If you get no help, you go nowhere.”

Nolan helped as his father sat back down on the leather couch in the family’s living room.

He tucked the cane behind a chair and sat at David’s side.

“They used to tell us that he might not ever walk,” Nolan said. “At least they never thought it would be without a rolling walker.”

David’s writing is returning as well, and his speech, although slow, is articulate. He still has two cavernous malformations—one on his left frontal lobe and another on the right.

Since they are not cancerous and are not at risk of bursting, David will never have them removed.

His sons have about a 50 percent chance of developing cavernous malformations.

Nolan’s only concern is helping his father cope.

And for that, David is grateful.

“If you get no help, you go nowhere,” David said. “I’ve got so much help, from my wife, to my son, my doctors.

“And for Nolan, I have a lot of pride.”

Maureen Lynch

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Angioma Alliance Donors July 1—December 31, 2008

Beacons (\$5000+)

HEDCO Foundation

Leaders (\$1000-\$4999)

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Ronnie Bince
Diana and James George
Friends and Family of Michelle
Hnath
Roger Peters and Lorna Reichl
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Deirdre Picchiatti
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PreventionGenetics

In honor of Connie Lee

Friends and Family of Christine
Castellano and Mark Seymour

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celebration of life*
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Kansadie Weems

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The Impact of the Economy on Angioma Alliance

Some of you may be wondering how Angioma Alliance has been affected by these difficult economic times. The major impact has been on grants to help fund this year's activities. While 2008 saw more than \$64,000 in unrestricted and restricted grants from corporations and foundations, we have not been able to secure a single grant for 2009. We have been told by a number of corporations and other funding organizations that they have suspended all grantmaking for the time being.

What does this mean for Angioma Alliance? It means we really need our members and friends to organize fundraising events to help make up the difference. With the news that there are potential medications in the pipeline, this is not a time for us to cut back. Angioma Alliance is heavily involved in supporting the work of these researchers—our efforts have been an essential part of developing these options and will become even more so over time. Our individual donors were very generous in our end-of-year appeal, and we would like to thank each of you for your support. What we now need are folks who are willing to reach out to their larger circle of friends and family and to their community to raise the funds needed to offset the loss of grants. If you are able to host a fundraiser, no matter how small, please let us know so that we can support your efforts.

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.

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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 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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