



Spring 2007

# Angioma Alliance Newsletter

## IN THIS ISSUE

- 1 - MAJOR GRANT TO PURCHASE GENETIC TESTING EQUIPMENT
- 2 - ANGIOMA ALLIANCE 2006 ANNUAL REPORT
- 4 - Q&A: CONNIE LEE
- 5 - BIOBANK NEWS
- 6 - CALL TO STUDY CAVERNOUS ANGIOMAS IN NEW MEXICO
- 6 - NEUROLOGY RESIDENTS AWARD
- 7 - ANGIOMA ALLIANCE UK INTERNATIONAL FORUM
- 7 - ANGIOMA ALLIANCE AUSTRALIA UPDATE
- 8 - CALENDAR
- 8 - TAKE ACTION
- 10 - 2006 ANGIOMA ALLIANCE DONORS
- 12 - ABOUT ANGIOMA ALLIANCE

## Angioma Alliance Receives Major Grant for Genetic Testing Equipment

The HEDCO Foundation of San Ramon, California, has awarded a grant of \$143,522 to Angioma Alliance for the purchase of three pieces of genetic testing equipment, which will support our DNA/Tissue Bank and Patient Registry. The equipment will be housed at PreventionGenetics in Marshfield, Wisconsin, in the lab of our scientific advisory board member Dr. Eric Johnson, who currently performs CCM clinical diagnostic testing.

*What does this mean for the BioBank?*

This genetic testing equipment will be used to test DNA extracted from blood samples that are donated to the BioBank. In order to meet researchers'

requests for DNA and tissue samples that fit certain criteria—for example, samples with the common Hispanic mutation—we need to know whether a participant has a mutation and what the mutation is, if this can be determined. The ability to perform genetic testing and accommodate researchers' specific

requests will increase the usability of the BioBank in the research community.

*What does this mean for individual participants?*

Angioma Alliance's genetic testing will be at a research level of thoroughness rather than a clinical diagnosis level. This means that we will not be able to share specific research findings with participants. However, we will be able to let participants know if we believe they should consider follow-up confirmatory testing. If an individual

chooses to do this, the price of additional testing would be dramatically lower than it would be had they not participated in the BioBank. Rather than paying up to \$2,000 for testing (without insurance coverage), individuals would pay no more than \$200.

Angioma Alliance is grateful to the HEDCO Foundation for this generous grant. Not only will it make our BioBank a useful tool for research, it will also help us find a cure for CCM more quickly.

Angioma Alliance is grateful to the HEDCO Foundation for this generous grant. Not only will it make our BioBank a useful tool for research, it will also help us find a cure for CCM more quickly.

*Connie Lee*



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

## Angioma Alliance 2006 Annual Report

I would like to wish everyone a very Happy New Year and extend a heartfelt thanks to those who have contributed their time and/or financial resources to making this an amazing year for Angioma Alliance. We couldn't have done it without you.

The list is long, but I would like to recognize the following people who have put in countless hours to help each of us: Allison Ruggles, Joyce Gonzales, Michelle Hnath, Tim Gallegos, Liz Neuman, Cristina DeSalvo, our Scientific Advisors, and of course, our Board of Directors.

As a reminder, here are a few of the past year's highlights:

1. We opened the Angioma Alliance **DNA/Tissue bank** for business this year to help find a cure for CCM more quickly. We already have 57 participants and are preparing for many more.
2. We held our **largest family conference** to date in Santa Fe, New Mexico. Along with the surrounding fundraising events, this conference helped bring CCM to the attention of New Mexico state legislators, who are beginning to recognize the illness for the public health issue it represents in that state. They are considering a \$100,000 annual grant request made by Leslie Morrison and Joyce Gonzales for CCM medical education, genetic testing, patient education and research in New Mexico.
3. We sponsored our first **Neurology Residents' Award**. Seventeen new doctors now have a much more thorough understanding of CCM than they did at this time last year.
4. We sponsored our second annual **Scientific Workshop** which pushed us into the international realm with researchers from three continents. We are using this Angioma Alliance-inspired group of collaborators to approach NIH for additional resources to combat this illness. These researchers are already collaborating scientifically in ways that would not have occurred to them had these interactive meetings not taken place.

5. We launched a **peer support program** that now has more than 30 trained volunteers providing information and support to more than 40 newly diagnosed individuals. No one who reaches out to us has to struggle with this illness alone.

### Our Mission

In 2007, we plan to increase our participation and expand in new areas, particularly in government advocacy in order to increase funding for research. To guide us, the board of directors and some key members of Angioma Alliance have constructed a new mission statement with related goals:

**It is the mission of Angioma Alliance to inform and support individuals affected by cerebral cavernous malformations while facilitating improved diagnosis and management of the illness through education and research. We envision a permanent cure for CCM.**

Our goals for the next three years are:

- *Information/Support:* To use all available means to disseminate information about CCM to those affected and their families, as well as to establish a caring community to provide support.
- *Research:* To advocate, facilitate and participate in CCM research in the pursuit of a complete understanding of the disease and, ultimately, a cure.
- *Physician Education:* To ensure that all appropriate physicians are aware of CCM and have ready access to the latest information to provide an accurate diagnosis and effective treatment.
- *Public Awareness:* To heighten public awareness of CCM to increase understanding, acceptance and funding for research and services.
- *Funding:* To build and sustain a broad base of diverse funding sources who will contribute the financial support needed to achieve our mission and goals.

**Looking Ahead**

In addition to continuing and expanding the work we are already doing, here are some new things you should look for in 2007:

- BioBank developments. See page 1 for information about the generous grant Angioma Alliance received from The HEDCO Foundation.
- Government advocacy to help fund our researchers. See this issue’s article about our upcoming meeting at NIH (page 6), plus Ken Ruggles’ letter to Senator Ted Kennedy (page 8-9).
- The publication of a scholarly article about CCM written for general practitioners, to be followed by the development of an interactive program to educate general practitioners throughout the country.
- A greatly expanded neurology resident competition funded by the generous donations of our members.
- Another family conference—date and location are TBD, but you can most likely expect it to take place in November in Washington, DC.

We are very excited about our growth and our planned activities. Your past support has allowed us to dream big, and we are moving forward to make these dreams come true.

*Connie Lee*

**Angioma Alliance  
Balance Sheet (preliminary)  
as of December 31, 2006**

<b>ASSETS</b>	
Total Current Assets	<b>\$76,068.56</b>
Total Fixed Assets	<b>\$4,471.10</b>
<b>TOTAL ASSETS</b>	<b>\$80,539.66</b>
 <b>LIABILITIES AND EQUITY</b>	
Total Liabilities	<b>\$784.88</b>
Total Equity	<b>\$79,754.78</b>
<b>TOTAL LIABILITIES AND EQUITY</b>	<b>\$80,539.66</b>

**Angioma Alliance  
Profit and Loss Statement  
January 1 to December 31, 2006  
(preliminary)**

<b>INCOME</b>	
<b>TOTAL INCOME</b>	<b>\$107,327.77</b>
 <b>EXPENSES</b>	
Administrative Expenses	<b>\$9,269.98</b>
Direct Service Expenses	<b>\$74,657.73</b>
Cost of goods sold	<b>\$301.01</b>
<b>TOTAL EXPENSES</b>	<b>\$84,228.72</b>
 <b>NET INCOME</b>	 <b>\$23,099.05</b>

Complete financial statements are available by download from [www.angiomaalliance.org/fs\\_2006.pdf](http://www.angiomaalliance.org/fs_2006.pdf).

**2006 Fundraisers**

We would like to extend our gratitude to the following people for their contributions in fundraiser organizing and/or writing letters to family and friends in 2006 to benefit Angioma Alliance:

- Tim and Sandra Gallegos and Lillian Gonzales: Bike-athon, silent auction and Frito pie fundraiser
- Mike and Shawn Blom and Andy and Marissa Amador: MadorAM wine release party and auction
- The City of Fresno: Charity poker tournament
- Heather Kurpiewski: Writing letters to family and friends
- Kalen Leave: Rock-a-thon
- Allison Ruggles: Writing letters to family and friends
- Lauren Ruggles, Michela North, and Lindsey Cobb: Lollipop fundraiser

## Q&A: Connie Lee

Connie Lee is the founder, president and—as of this year—first official employee of Angioma Alliance. She's also mother to Julia, an energetic six year old whose first cavernous angioma was discovered at four months after she suffered a major hemorrhage. Whether it's Connie's personal experience with the illness that has led to her incredible insight into dealing with CCMs, or her professional background in clinical psychology, one thing is certain: Connie knows how to navigate the emotional terrain of uncertainty and is a natural for articulating the concerns of those who come face to face with the illness.



Connie Lee and Julia

"It's identity-changing," Connie told me during a recent interview, "I think that everyone I've spoken with has an idea of who they were before the diagnosis that, for most people, was: 'I'm a healthy person with no limitations.' And then the diagnosis comes, surgery comes, and there are residual effects. Some of it is memory, fatigue, there are things that don't seem better or, they get better so slowly that people don't notice they're getting better. All of a sudden, their definition of who 'I am' becomes different: 'I am no longer unlimited,' 'I am a person with limitations' and 'I think that I might not be able to...' It's coming off of a dream for some people. It really is hard. It is a whole redefinition and reidentification process that has to go on."

I couldn't agree more, having recently been diagnosed with a CCM myself. I heard the term for the first time over the phone one April morning at work in 2006. The nurse told me the news was "reassuring" and that, by the way, my neurosurgeon wanted me to come in right away so I could begin my anti-epilepsy drug treatment, to be continued indefinitely. "Nobody I know of has heard of it before," Connie said, "unless it's the hereditary form and they've had a family member diagnosed."

So where are those people who are like the "me" I hope to be? The people who have had a cavernous angioma removed (I got mine resected last November) and have resumed their place on the proverbial

greener side? Is surgery going to be my quick fix? "Those are the people who we tend not to hear from," Connie tells me, "Angioma Alliance is much more designed for the folks who are in it for the long haul for whatever reason—those are all people who gravitate toward us."

The folks that do gravitate find Angioma Alliance and Connie's vast network of selfless volunteers who donate support, raise awareness, write letters and corral communities for fundraising. But this action ensemble didn't fall out of the sky.

"In the beginning there was just a handful of us," Connie explained to me, "since then we've become a multilayered organization that's reaching out into different areas. Obviously we do member support, and provide information and opportunities for people to meet each other. But we're also working with researchers, and we do as much as we can for physician education."

Connie's ultimate goal for Angioma Alliance? To make it obsolete. In the meantime, there are more specific goals within her reach, and within the grasp of the organization, such as getting 100 people involved in the BioBank this year (there are currently just over 50) and starting the genetic testing component; beginning a family practice physician outreach program and getting an article published in a family practice journal; and creating a patient registry.

**"If we could just make them aware of the illness..."**

"We want to establish ourselves now as an advocate both with NIH and, to a certain extent, with Congress," she told me, thinking about the work ahead. "We have folks who are writing letters to different congresspeople who are involved in approving funding for NIH research—and we don't even initially need a great deal of money. If we could just make them aware of the illness..."

Read more about the goals and upcoming events of Angioma Alliance in this newsletter and online at [www.angiomaalliance.org](http://www.angiomaalliance.org), where you can read members' stories and discuss the illness with other users in the community forum.

*Rebecca Palmore*

# News

## Exciting News for the BioBank!

In addition to the grant from the HEDCO Foundation for the purchase of genetic testing equipment (see page 1), there is more news regarding the Angioma Alliance BioBank. Since February 1, the BioBank has been housed in the facilities of a company called Gene Logic.

From their web site: “Gene Logic is a leader in drug repositioning and genomics products, software, and services. Over 150 of the world's top pharmaceutical and biotechnology companies, research institutes, and government agencies have benefited from Gene Logic's diverse portfolio of drug development services, enabling them to make more informed, more reliable and more predictive decisions at each point in the highly complex and costly drug development process. Founded in 1994, Gene Logic is headquartered in Gaithersburg, Maryland, and conducts additional research and development in facilities in Cambridge, Massachusetts.”

Gene Logic will provide storage and processing services for biological samples as well as allow Angioma Alliance develop a clinical database to accompany our DNA/Tissue Bank.

We hope to have 100 participants in the BioBank by the end of 2007. In addition to increasing enrollment, we have six major tasks:

- To establish the genetic testing component of the BioBank using the equipment granted to us by the HECDO Foundation.
- To develop the infrastructure for the accompanying clinical data registry and to begin gathering

the information to fill this out. (We are working with the BioBank advisory committee and other members of the scientific community to determine what information would be most useful to collect.) The BioBank's move to Gene Logic means that we will have access to state of the art software to maintain our records.

- To develop literature to promote the BioBank among physicians, scientists and potential participants, and distribute that literature at conferences and directly to physicians.
- To file for institutional review board approval at a minimum of two major medical centers in order to receive tissue donations from patients that are treated there.
- To begin the process of sending our collected samples to researchers who will use them to further their work.
- To expand enrollment in the BioBank from those who are scheduled for surgery to people who have had surgery in the past and those with a family history of the illness.

The patient BioBank is now taking registrations! We are enrolling anyone who has an upcoming surgery and who is willing to donate their cavernous angioma(s) to research. If you would like to assist in the advancement of cavernous angioma research, please call the BioBank at:

**757-623-0615**

or toll-free at:

**866-432-5226**

## 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 Michelle 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).

## Call to Study Cavernous Angiomas in New Mexico

Following testimony by Joyce Gonzales and scientific advisor Dr. Leslie Morrison at a Health and Human Services committee meeting, Delegate Jim R. Trujillo of the New Mexico Legislature has recently requested that the Department of Health and Human Services and the Board of Regents of the University of New Mexico launch a study on cavernous angiomas, in an effort to raise awareness and increase funding for research in the state of New Mexico. Here is the text of his proposal:

HOUSE JOINT MEMORIAL 9  
48TH LEGISLATURE - STATE OF NEW MEXICO -  
FIRST SESSION, 2007

INTRODUCED BY Jim R. Trujillo

FOR THE LEGISLATIVE HEALTH AND HUMAN  
SERVICES COMMITTEE

A JOINT MEMORIAL URGING THE STATE  
TO SUPPORT RESEARCH ON  
CAVERNOUS ANGIOMA, A DISEASE THAT  
DISPROPORTIONATELY AFFECTS  
HISPANIC NEW MEXICANS.

WHEREAS, cavernous angioma is a devastating blood disease that has enormous consequences for those affected and their families; and

WHEREAS, cavernous angiomas are formations in the brain that cannot be detected easily except through very specific medical scans; and

WHEREAS, cavernous angiomas appear to be passed from one generation to the next; and

WHEREAS, those with a cavernous angioma should not take blood thinners or aspirin, but are rarely aware that they have the disease; and

WHEREAS, cavernous angiomas are more common in New Mexico than elsewhere because of the concentration of families; and

WHEREAS, a person with a cavernous angioma may go undiagnosed until sudden death or stroke;

NOW, THEREFORE, BE IT RESOLVED BY THE LEGISLATURE OF THE STATE OF NEW MEXICO that the Department of Health and Human services and the Board of Regents of the University of New Mexico be requested to appoint a

committee to study funding levels and new sources of funding to support research on cavernous angioma; and

BE IT FURTHER RESOLVED that the committee devise educational campaigns that use the resources available to government agencies and hospitals to inform New Mexicans of the dangers and warning signs of cavernous angioma; and

BE IT FURTHER RESOLVED that the committee report to the interim legislative health and human services committee about its findings and its educational efforts by November 2008; and

BE IT FURTHER RESOLVED that copies of this memorial be transmitted to the department of health, the human services department and the board of regents of the university of New Mexico.

## Announcement

### Neurology Residents' Award

Case studies for this year's Neurology Residents Award program have been sent to 1,400 neurology medical residents across the U.S. The program solicits responses to a cavernous angioma case study posed by a leading neurologist. Last year, we received 17 outstanding entries. This year, we're vigorously advertising the awards by sending out letters to each resident and offering the top prize winner the chance to submit his or her entry to the journal Neurology with a letter of support. Submissions for the award are due May 1; winners will be announced on June 20.

The 2007 Neurology Residents Award would not be possible without the generous support of the following Angioma Alliance members:

- Liz and John Neuman: \$1,000 Jake and Sam Neuman Award
- Lynnelle Corsi, sister of Allison Ruggles: \$500 Jenae Gallegos Award, \$500 Blue Haven Gonzales Award and several \$100 honorable mentions
- Kristen Davis: \$250 Riley Cerabona Award
- Michelle and Steve Hnath: \$250 Hope Award

We anticipate a great response to this year's contest because of your generosity.

# International Updates



## Angioma Alliance UK Announces First International Forum

Angioma Alliance UK will be organizing its first international forum in London on June 16, 2007. At this point, we are happy to welcome two of our companions from across the Atlantic: Connie Lee, president of Angioma Alliance, and geneticist Dr. Eric Johnson, whom many of you will remember from last year's family conference in Santa Fe, New Mexico. We recommend making reservations two months in advance so we can make the necessary arrangements with our caterer and provide plenty of food for all.

Regarding accommodations, a hotel very close to Conway Hall, the conference venue (25 Red Lion Square, London, WC1) is offering Angioma Alliance UK a very reasonable rate of £80 plus tax (17.5%) for a double room and buffet breakfast. (In high season, this hotel charges £200 a night, which is nearly \$400.) Please contact Ian Stuart when you decide to book: [info@angiomaalliance.org.uk](mailto:info@angiomaalliance.org.uk).

Get more information about the hotel: [www.grange-hotels.com](http://www.grange-hotels.com) and select Holborn; to read more about Conway Hall, where the forum will take place: [www.conwayhall.org.uk](http://www.conwayhall.org.uk).

Here is a preliminary list of speakers and their topics for the London forum:

- Dr. Rustam Al-Shahi Salman MA PhD MRCP (UK) MRC clinician scientist and honorary consultant neurologist.

Presentation: "Epidemiology, symptoms and prognosis"

- Mr. Neil Kitchen MD FRCS (SN) Consultant Neurosurgeon and Associate Clinical Director National Hospital for Neurology and Neurosurgery, Queen Square, London; Medical Adviser to Angioma Alliance UK.

Presentation: "Surgery for Cavernoma"

- Dr. Eric W. Johnson Director Molecular Diagnostics and BioBanking, Wisconsin, U.S.

Presentation: "Basic Genetics: An overview of CCM genetics and gene testing"

- Mr. Ian Sabin, BMSc FRCS FRCS (Ed) Consultant Neurosurgeon, Royal London Hospital, Whitechapel.

Presentation: "Star Wars: The Gamma Knife Strikes Back"

- Dr. Jonathan Berg, MSc MD FRCP (UK) Senior Lecturer and Honorary Consultant in Clinical Genetics, University of Dundee.

Presentation: "Cerebral Cavernous Malformations: If I have one, what does it mean for my family?"

Author and Angioma Alliance UK member Sacha Bonsor hopes to attend. She wrote "Dipped into Oblivion," the first book by a lay-person in the UK describing personal difficulties with brainstem cavernomas. Sacha is the health editor of *The Times*, and hopes to cover the event for the newspaper.

The forum is free. We look forward to your attendance and participation.

*Ian Stuart and Kirk McElhearn*

## Angioma Alliance Australia

A questionnaire was sent out last year to Australians who have shown an interest in forming Angioma Alliance Australia. Responses to this survey will be collated and summarized, then distributed among the participants to share key areas of interest and consider how Angioma Alliance Australia will take form.

Thus far, two key issues have surfaced: funding, and setting up a local Australian web site.

We are taking one small step at a time and I am sure that those who have shown interest in the formation of Angioma Alliance Australia will hold great hope and anticipation to see it up and running in the very near future.

If you live in Australia and are interested in the formation of Angioma Alliance Australia, please email Caroline Cheung: [ccheung919@yahoo.com.au](mailto:ccheung919@yahoo.com.au), coordinator of AA Australia.

*Caroline Cheung*

## Calendar

**February 24, 2007:** MadoraM, a Napa Valley vineyard, will again host a release party and wine auction to benefit Angioma Alliance and another charity, Small Miracles. Last year's auction raised over \$18,000 for Angioma Alliance. This year, the party and auction will be held on February 24 at the Bakersfield Country Club in Bakersfield, California—a much larger venue. We are very grateful to the vineyard owners and to all those who participate for their generous support of Angioma Alliance.



**March 2, 2007:** Angioma Alliance President Connie Lee and Doug Marchuk of the scientific advisory board will attend an open house workshop hosted by the Center for Scientific Review (CSR) at the National Institute of Health (NIH) in Bethesda, Md. This marks a new opportunity for dialogue between CCM experts like Lee and Marchuk and the CSR's peer review groups, who evaluate the majority of the NIH grant requests (which total more than \$20 billion a year for biomedical research). At the workshop, they will help realign and reinvent the grant review process so that research on CCM is reviewed more fairly. The end goal for this workshop is to secure greater funding for CCM research from NIH. Read the full news release about open house workshops at NIH online: [www.nih.gov/news/pr/jan2007/csr-22.htm](http://www.nih.gov/news/pr/jan2007/csr-22.htm).

**March 8, 2007:** Kristen Dehn, Angioma Alliance Board of Directors member, will attend the American Society for Experimental NeuroTherapeutics Sixth Annual Advocacy Program in Washington DC. Each year, the ASENT Advocacy Forum presents an opportunity for an in-depth discussion of hot topics in neurotherapeutics development as identified by patient advocate groups.

From their web site: “The American Society for Experimental NeuroTherapeutics (ASENT) is an independent non-profit organization established in 1997 by leaders in academia, government, advocacy and industry to facilitate the process by which new therapies are made available to patients with neurological disorders. Its primary goal is to encourage and advance the development of improved therapies for diseases and disorders of the nervous system.”

Kristen is hoping to bring CCM to the attention of those in the neurotherapeutics industry. We wish her luck as she advocates for increased industry focus.

## Take Action

Angioma Alliance chair Ken Ruggles recently wrote a letter to Senator Ted Kennedy in an effort to increase awareness of cavernous angiomas and raise support for research that could lead to a cure for this illness that affects more than a million Americans.

Find a template letter online at [www.angiomaalliance.org/advocacy.html](http://www.angiomaalliance.org/advocacy.html) to personalize and send to Senate and Congress members by fax (when possible), e-mail or postal mail. Or, take Ken's lead and write your own.

You can find contact information for your representatives online. For the U.S. Senate: [www.senate.gov/general/contact\\_information/senators\\_cfm.cfm](http://www.senate.gov/general/contact_information/senators_cfm.cfm), and the U.S. Congress: [www.house.gov/house/MemberWWW.shtml](http://www.house.gov/house/MemberWWW.shtml).

See Ken's letter on the following page.

Dear Senator Kennedy,

I want to take this opportunity to request your assistance in promoting research into cerebral vascular malformations. As you know, Senator Tim Johnson recently suffered a debilitating brain hemorrhage caused by an AVM. This story struck a nerve with my family because my wife experienced strokes in her late 30's from a related condition, cerebral cavernous malformation (CCM). My wife is just one of more than one million Americans who are at a dramatically increased risk of cerebral hemorrhage, epilepsy, and neurological deficits from this illness. One famous individual to be affected by CCM was the star track athlete Florence Griffith Joyner who passed away from a CCM-related seizure in 1998. Many more prominent and less prominent individuals are affected, but because there is a stigma attached to diseases of the brain, they are not publicly known. I have attached pages from the Angioma Alliance website with additional information about the illness.

Unfortunately, the National Institutes of Health (NIH) focus and funding for CCM has been minimal. While a disease like multiple sclerosis, one that often has a similar course but is 4 times less frequent than CCM, receives upwards of \$90 million a year in public funding for research, CCM receives less than \$5 million. This is particularly troubling for several reasons. First, CCM is a virtual paradigm disease that results from a failure of angiogenesis. Understanding the mechanisms behind CCM may help us to treat other illnesses such as cancer, epilepsy, and the broader range of stroke. Secondly, the densest population of CCM in the world can be found among the Hispanic population in the American Southwest. The hereditary form of the illness has existed there for hundreds of years, and there are currently thousands of affected individuals. If any country can solve the mysteries of CCM, it should be the US. The affected residents in the American Southwest, and other affected patients and families throughout our country, are willing and able to participate in research if only there were funded studies. Finally, a large amount of fundamental research was assembled during the NIH Decade of the Brain in the 1990's on how blood vessels form (and malform) in the human brain, but the increasingly difficult NIH funding of new research in recent years has prevented the translation of this information for better understanding and management of this disease. This could change.

There are a number of ways that CCM can receive an increased focus at NIH, and not all require additional overall expenditure. First, Congress can request that CCM research be specifically identified in the upcoming National Institute of Neurological Disorders and Stroke (NINDS) Program Announcement on Angiogenesis. Second, as part of the NIH budgeting process, Congress may request that NIH/NINDS report back to Congress the amount of funding allocated for CCM research. Finally and most ideally, Congress may request that NINDS sponsor CCM research with an ample budgetary "set aside".

I am a Massachusetts resident and also chairman of the board of directors of Angioma Alliance, the international patient advocacy organization for this illness. Our organization has been doing its part to expedite the search for a cure for CCM. As part of this, we have organized an international consortium of collegial, collaborative researchers who are eager to coordinate their efforts. Already, their synergistic work has led to the discovery of three different genes that cause this disease. Much more is at the threshold of discovery based on this preliminary work, and, if given the proper support, we believe this will rapidly translate to patient benefit.

I would like to encourage you to provide your support to the efforts of CCM researchers. More than a million Americans will benefit from your actions. I would like to meet with you or your staff in Massachusetts or Washington on behalf of the Angioma Alliance; I will be contacting your office shortly to set up an appointment.

Thank you very much,

Ken Ruggles  
Chairman, Angioma Alliance Board of Directors

**Members of the Senate Health, Education, Labor, and Pensions Committee:**

Democrats by Rank	Republicans by Rank
Edward Kennedy (MA)	Michael B. Enzi (WY)
Christopher Dodd (CT)	Judd Gregg (NH)
Tom Harkin (IA)	Lamar Alexander (TN)
Barbara A. Mikulski (MD)	Richard Burr (NC)
Jeff Bingaman (NM)	Johnny Isakson (GA)
Patty Murray (WA)	Lisa Murkowski (AK)
Jack Reed (RI)	Orrin G. Hatch (UT)
Hillary Rodham Clinton (NY)	Pat Roberts (KS)
Barack Obama (IL)	Wayne Allard (CO)
Bernard Sanders (I) (VT)	Tom Coburn, M.D. (OK)
Sherrod Brown (OH)	

## 2006 Angioma Alliance Donors

### Beacons, \$5,000+

Anonymous  
City of Santa Fe, New Mexico  
Daniel H. Lawlor Charitable  
Foundation  
Camille Lee

### Leaders, \$1,000-\$4,999

Greg and Kelly Battas  
Greg Burwell  
City of Fresno, California  
Fraternal Order of Eagles  
Hewlett Packard Employee  
Charitable Gifts Program  
The Key Foundation  
Little Neck Circle of the Kings  
Daughters  
Tom and Nancy McHugh  
Alex and Monique Rogers  
Santa Fe Community Foundation  
Jeff Townsend  
Steve and Lori Williams

### Benefactors, \$500-\$999

Greg Bynum  
Daniel Engle  
Lee and Paula Hougen  
Newport News Medical Society  
Alliance  
Michael and Sandra Schulte  
Sara Sukalich and Matthew  
Mingione  
The Wert Family Foundation

### Community Builders, \$250-\$499

Gary Burwell  
Libby Davis  
Ruta Gedmintas  
Igive.com  
Bernie LeBeau  
Bruce Lynn  
Stan and Mabel Matsumoto  
Brad Peters  
Lee and Michael Rashkind  
The Rashkind Family Foundation  
Santa Fe Mazda Volvo  
Tom and Laura White

### Partners, \$100-\$249

Donald Adams  
Anonymous  
AnyDoc Software  
Roger and Bev Baldwin  
Benevolink Foundation  
Howard Bonde  
Diane and Jim Bowser  
Coronado Paint  
Tom and Robin Feher  
Tony Gussio  
Tracy Hougham

Tom Hoyt and Carolyn Zawacki  
David and Susan Kelley  
Beth Kennedy and John Bensel  
Heather Kurpiewski  
Linda LaMarca  
Tammy and Joe Lovrich  
Nichole Martinez  
Al and Evelyn McKenney  
Wayne and Delores Moyer  
Beverly Nash  
Virginia Peter  
Charles and Ollie Peters  
Sharon Robinson  
Diana Rodionov  
Ron Schechter  
David Silver  
Softmart  
Virginia Spadoni  
State Employees Credit Union, New  
Mexico  
Brad VanderMeer

### Friends, \$1-\$99

Nancy Abruzzo  
Joan and Fred Adair  
Don and Tina Allen  
Matt Archuleta  
Arquello Services  
Davide Bacci  
Leanne and Stephen Barker  
Barnes & Noble  
Peter and Karen Barnett  
Katherine and David Barto  
Irene Beauvais  
John Becker  
Carl and Chelsea Beffa  
The Brewer Family  
Phillip and Jane Bush  
Sean Canavan  
Corrin Chang  
Beverly and Louis Cunningham  
Les Dubnick  
Ruth Ecker  
Elegant Nails  
Estep & Co., Inc.  
Michael and Jan Fitzpatrick  
Kit Fournier  
Ruth Fraser  
Margie Garcia  
Bill and Susan Geary  
Joyce and Greg Gonzales  
Dan Gurule  
Tony Hoffman  
Ron Holt  
Tamara Jonas  
Sally Kellen  
Kim Kelly  
Thomas and Mary Kendrick  
C.J. Kitterman  
Mabel Leyba

Lil Lieverman  
Jim and Sieg Linde  
Rose Lopez  
Tessie Lopez  
Andrea Lord  
Christine Lovato  
Anita and Steve Matejka  
John and Jackie McCabe  
J.M. Melita  
MGM Mirage Voice Foundation  
Gerald and Diane Mihay  
Catherine Nix  
Lisa Nurre  
Virginia Oczkowski  
Mary Ortiz  
Ned Perry  
Evy Pierson  
Kimberly Randall  
Philip and Teresa Raubinger  
Richardson Home Improvements  
Janet Rivera  
Shelly Rohe  
Cynthia and Charles Romero  
Jessica Romero  
Pamela Roth  
Julia Rush  
Marcella Salazar  
Santa Fe Car Wash  
Jeroen Smeets  
Roy and Liz Snyder  
Sandy Souza  
Maureen Sparrow  
David and Donna Stanford  
Robert Stites  
Susan and Paul Sukalich  
T.A. Gibbs Co. General Builders  
Ray and Patricia Tapia  
Louise Taylor  
UBS  
Saskia van Dijn  
Norma Villa  
Jennifer Wallace  
Kandance Weems Norris  
Carl and Teresa Weichman  
Lisa Wixson  
Menda and Keith Wright

### Honoraria and Memorials:

*In honor of Don Adams*  
Judy Farris

*In memory of Simon Anderson*  
Steve and Peter Antonopulos  
Greg and Kelly Battas  
Lisa Blundell  
Orlando DaSilva  
Patricia Dobec  
Fred Tortorella  
Peter Gardanis

Leslie Hayes  
 John and Maureen Kisel  
 Jane Kramer  
 Jennifer Lewis  
 Ralph and Elaine Loveland  
 Dianne and Hugh Macdonald  
 Mike Phillips  
 Shannon Ross  
 Peter Sienkowski  
 Carol Syred  
 Mati Vassos

*In honor of Misha Beck*

Shirley Grahn  
 Matthew and Gina White

*In honor of Jerry and Charlene Bowlin*

Bettina Bendzłowicz

*In honor of Riley Cerabona*

Janice Cerabona  
 Kristen Davis

*In honor of Lynnelle Corsi*

Laura Lifland

*In memory of Jenae Gallegos*

Mark and Veronica Campos  
 Elena Esmeralda Cruz  
 Tim and Sandra Gallegos  
 Andrea Pacheco  
 Plaza II Executive Center, Inc.  
 Cheryl Whitman

*In memory of Blue Haven Gonzales*

Rebecca Pence  
 Dolores Tafoya

*In honor of Stephanie Kennedy*

Thomas and Shauna Connelly

*In memory of John Knowles*

June Rochedieu

*In honor of Heather Kurpiewski*

Andy and Lyz Cooper  
 Ted and Paula Driscoll  
 Thomas and Rosemary Kurpiewski  
 Christine Martinez  
 Julie Morris  
 Visual Photography  
 Ted and Carol Weaton

*In honor of Julia Lee*

Sally Derrig  
 Ken and Mary Reeb  
 Hanni Sherman

*In memory of Cydney Lynn Mahoney*

Joseph and Anna Ferrando

*In honor of Jake and Sam Neuman*

Brad and Rebecca Hogue

James and Helen Neuman  
 Sandy Neuman  
 Nola Price

*In memory of Caroline Nunes*

Joseph and Anna Ferrando

*In memory of Steve Paulson*

Joseph and Anna Ferrando

*In memory of Lillian Reichl and in honor of Erma Levisen*

Lorna Reichl

*In honor of Shelly Rohe and Heather Hudson*

Jason Marsden

*In honor of Allison Ruggles*

Sharon Conger  
 John and Linda Corsi  
 Kathy Corsi  
 Marlene and William Daly  
 Carolyn and Michael DiFillipo  
 Diane Lansing  
 Tamara and Michael Lovuolo  
 Joseph and Leslie McCarthy  
 Laurel and Joseph Nardone  
 Daniel and Joann Passeri  
 Karen and Chuck Pillsbury  
 Irene and Ronald Ruggles  
 Barbara Tomasian  
 Brian and Edie Tonis  
 Sylvia Wee

*In honor of the Ryan family*

Monae Hooks  
 Richard and Tana Laura  
 Mike and Cathy Ryan

*In honor of Mark Seymour*

William Calloway  
 Christine Castellano

*In honor of Cristina DeSalvo Stevenson*

William and Patricia DeSalvo

*In honor of Samantha Weber*

Batesville Products

*In memory of Craig Yoder*

Thomas Brown  
 Sophie Chou  
 Delta Lambda Phi Fraternity  
 Indiana University/Purdue  
 University Department of  
 Chemistry and Chemical Biology  
 Pete and Becky Doll  
 Dan and Marilyn Evans  
 Jackie Haines  
 Susan and Ron Heath  
 Rhoda Israelov  
 Joan Moss

Nancy and William Peat  
 Adrienne Quill  
 Carolyn Savill  
 Cathy Siler  
 Mike and Shelley Tracy  
 Samuel and Jane Wendel  
 Joni and Bill Wilson

**Gifts in Kind:**

Andy and Marissa Amador  
 Hewlett Packard Gifts in Kind  
 International  
 John and Connie Lee  
 Bruce Lynn  
 MadoroM  
 Carl and Sue Sciandri  
 Kevin Small  
 Jeff Townsend

*From the city of Santa Fe, New Mexico:*

Beauty First/Danielle V. Richards  
 Beaver Toyota  
 Big Jo Hardware  
 Roberta Cheek  
 Blue Corn  
 Esme Cruz  
 Bumble Bees  
 Capitol Ford  
 Joyce Gonzales  
 Nina Gonzales  
 Card Rageous  
 Carl & Sandra's  
 Castro's  
 Chavez Jewelers  
 Christine's Bridal  
 David's Salon  
 Diego's  
 Elegant Nails  
 Embassy Suites  
 Fanzz  
 Francesca Ciani  
 Gameco  
 Jackalope  
 JC Penney  
 Kiva Pharmacy  
 Leather Works  
 Nail Time  
 Nature's Way  
 Outback Steakhouse  
 The Outdoorsman  
 PC's Restaurant and Lounge  
 Piccolino  
 Red Lobster  
 Regis  
 Rob and Charlies  
 Soap Opera  
 Tomasita's  
 Trade Secret  
 Traditions  
 Universal Fine Jewelry  
 Western Warehouse

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, volunteer-run health organization created by people affected by cerebral cavernous malformations (CCM). Our mission is to improve the quality of life for those affected by CCM through education, support, and promotion of research. We are monitored closely in our educational efforts by a Scientific Advisory Board comprised of leading cerebrovascular neurosurgeons, neurogeneticists, and neurologists.

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

866-HEAL-CCM (Toll free)  
757-623-0615  
[info@angiomaalliance.org](mailto:info@angiomaalliance.org)  
[www.angiomaalliance.org](http://www.angiomaalliance.org)

## Angioma Alliance Board of Directors

- Connie Lee, Psy.D, President
- Ken Ruggles, Chair
- Krestin Ryan, Treasurer
- Norma Villa, BSW, Secretary
- Kristen Dehn, MS, Director
- Amy Jagemann, MBA, Director

## Scientific Advisory Board

- Issam Awad, MD, MSc, FACS—Northwestern University Feinberg School of Medicine, Chair
- Jose Biller, MD—Loyola University Chicago Stritch School of Medicine
- Eric Johnson, Ph.D.—PreventionGenetics
- Douglas Marchuk, Ph.D.—Duke University Medical Center, Dept. of Molecular Genetics and Microbiology
- Leslie Morrison, MD—University of New Mexico Medical School

## 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.

**The Angioma Alliance Newsletter is a quarterly publication of Angioma Alliance**

Editor: Rebecca Palmore, [rkpalmore@yahoo.com](mailto:rkpalmore@yahoo.com)  
Layout: Kirk McElhearn, [kirk@mcelhearn.com](mailto:kirk@mcelhearn.com)

Photo credits: Page 1: Applied Biosystems, Page 4:  
Brian M. Freer, Page 8: Copyright Miro Schaap