



Angioma Alliance Newsletter

Editor-Cristina DeSalvo

Winter 2006
Volume 4, Issue 1

PATIENT REGISTRY AND BIOBANK TAKE OFF!

We've begun! Angioma Alliance has signed a contract to establish its own Tissue/DNA bank (Biobank) and Patient Registry. The Angioma Alliance Biobank and Registry will be a place where we collect tissue samples, blood samples, and medical and family history information from people with cavernous angiomas.

The beauty of a centralized Biobank and Registry is that the samples and information can be used by many studies rather than being restricted to just one lab and one experiment. A robust Biobank and Registry will save enormous amounts of time and money for researchers and will allow them to focus their resources on experiments that will lead to less invasive treatments and, eventually, a cure.

In addition, we should have more and better information than any individual lab could have, so the research that is conducted using our

samples and data will be even better than it would have been had a researcher been working on his or her own. Finally, we will be able to begin addressing some of the questions that all of us have – for example, are there circumstances that make a cavernous angioma more likely to bleed?

We are not yet ready to begin enrolling, but we would like you to think about whether you would be willing to participate. Initially, we will enroll individuals who have had surgery to remove a cavernous angioma. The surgery could have happened at any time in the past. We also will enroll those who are expecting to have surgery in the near future. Every time someone has a surgery, the hospital keeps a slide of the tissue that is removed. They will release this slide if a person requests it.

(continued on Page 3)

By: Connie Lee

Inside this issue:

<i>Family Conference 2006</i>	2
<i>Angioma Alliance In The News</i>	3
<i>Dipped Into Oblivion: Interview with Sacha Bonsor</i>	4
<i>Cognitive Rehabilitation Part II of II</i>	5-6
<i>Latest Research</i>	7
<i>2005 Annual Report & List of Donors</i>	8-11
<i>Medical Air Transport</i>	11
<i>*NEW Angioma Alliance Marketplace</i>	12

CALL FOR PAPERS...

If you would like to write a featured article for any one of Angioma Alliance's newsletters, please contact Cristina DeSalvo.

cmdesalvo@yahoo.com

Thank you!

EXPECTANT MANAGEMENT CHAT (or the "wait and see" approach")

Moderated by Michelle Hnath and Jack Hoch

Sunday, March 26

8:30 p.m. EST

7:30 p.m. CST

6:30 p.m. MST

5:30 p.m. PST

Monday, March 27

1:30 a.m. GMT

More Information on Page 7

ANGIOMA ALLIANCE RECEIVES \$10,000 GRANT

Angioma Alliance received a very generous unrestricted grant of \$10,000 from UCB Pharma. We have designated the funds to be used for the Angioma Alliance Biobank and Registry. We are very grateful for this support.

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

Board of Directors

Connie Lee, Psy.D., President
 Krestin Ryan, Treasurer
 Norma Villa, BSW, Secretary
 S. Anthony Gussio, CPA, MST,
 Assistant Treasurer
 Kristen Dehn, MS, Director
 Jack E. Hoch III, Director
 Amy Jagemann, Director

Scientific Advisory Board

Issam Awad, MD, MSc, FACS,
 Northwestern University
 Feinberg School of Medicine,
 Chair
 Jose Biller, MD, Loyola Univer-
 sity Chicago Stritch School of
 Medicine
 Eric Johnson, Ph.D., Prevention-
 Genetics
 Douglas Marchuk, Ph.D., Duke
 University Medical Center, Dept
 of Molecular Genetics and Mi-
 crobiology
 Leslie Morrison, MD, University
 of New Mexico Medical
 School
 Michael Scott, MD, Harvard Uni-
 versity Medical School

Family Conference 2006: Join Angioma Alliance in Sunny Santa Fe!

Save the date! The 2006 Angioma Alliance Annual Conference will be held on Friday and Saturday, June 23rd and 24th at the Hilton Santa Fe in beautiful Santa Fe, New Mexico. In addition to breakout sessions and discussions on the emotional and other impacts of cavernous angioma, the conference will feature the following expert speakers:

- ◆ Dr. Robert Spetzler of the Barrow Neurological Institute.
- ◆ Dr. Howard Yonas, who recently moved from the University of Pittsburgh to chair the neurosurgery department at the University of New Mexico.
- ◆ Dr. Leslie Morrison, a neurologist at the University of New Mexico
- ◆ Dr. Judy Gault, a leading cavernous angioma researcher who comes to us from the University of Colorado
- ◆ Dr. Eric Johnson of PreventionGenetics, and a genetics counselor

It's not too early to register! Information and registration forms for the family conference are now available online at:

<http://www.angiomaalliance.org/docs/2006InformationAndRegistration.pdf>

or by calling Angioma Alliance at 757-258-3355, or toll free at 866-HEAL-CCM.

DID YOU KNOW THAT...

- Santa Fe averages more than 300 days of sunshine per year?
- Santa Fe is located in the foothills of the Sangre de Cristo Mountains?
- Santa Fe has 200 restaurants, 250 art galleries, 50 Indian jewelry shops, 13 major museums, and a world-famous opera?
- Santa Fe is one of the largest art markets in the world?

The early registration fee for the conference is set at \$65 for affected adults and family members, \$45 for children in childcare, and \$90 for healthcare professionals. Early registration must be postmarked by June 1. The fees are \$80 for affected adults and family members, \$60 for children, and \$120 for healthcare professionals for registrations postmarked on or after June 1.

The Santa Fe Hilton is also accepting our room reservations. We have a discounted rate of \$139/night (the rooms typically run \$200+ for that time of year). Please check the conference registration form for reservation instructions. You must make your hotel reservation by May 22nd in order to be guaranteed the discount.



Angioma Alliance now 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 order, send a check or money order for \$5 to: Angioma Alliance, 107 Quaker Meeting House Road, Williamsburg, Virginia 23188

***or visit the NEW Angioma Alliance Marketplace and purchase all of your Angioma Alliance gear in one fast, easy transaction! (more information on Page 12)**

PATIENT REGISTRY AND BIOBANK TAKE OFF! (continued from Page 1)

By: Connie Lee

For the initial Biobank, we would like to ask for that pathology slide, for a blood sample from you, for medical records, and for a family history. We will provide the forms, blood kits, etc that would be needed to obtain these items.

If you enroll, the tissue on the slide would be divided into multiple pieces and DNA would be extracted from your blood sample. These would be sent, along with medical information, to research studies that are approved to receive them by our Biobank/Registry Scientific Advisory Board. All identifying information about you would be removed from the samples and data before they are sent out for research – this protects your privacy. We anticipate expanding the Biobank/Registry to include people who have not had surgery as we get additional funding (so keep those fundraisers going!).

If you think you would like to participate, please contact us at info@angiomaalliance.org and let us know.

Angioma Alliance In the News...

Kelly B. (indykelly on the community forum) and **Connie Lee** will be featured in an article about cavernous angioma in the March/April edition of Stroke Connection, the publication of the American Stroke Association. This magazine has a circulation of 90,000 and is sent to subscribers as well as to doctors' offices. To subscribe, visit the ASA site at: www.strokeassociation.org.

Riley Weinstein, a 13-year-old girl from Valencia, California, used her wish from Make A Wish to hire a film company to make a movie about her life to raise awareness of cavernous angioma and so that others with special needs "can learn about survival". Riley had multiple

brainstem cavernous angiomas that hemorrhaged when she was a toddler. She had surgery to remove them, and has had many subsequent surgeries. Her most noticeable deficit is facial paralysis that leaves her unable to blink or use one side of her mouth to speak. This powerful movie was shown at her local movie theater where she received the red carpet treatment, and the story was covered in the December 8 edition of the Los Angeles Daily News. We are working with the producers of the film to find ways to get broader distribution of Riley's story.

Joyce Gonzales was featured in an article in the Albuquerque Journal in November that high-

lighted her difficulty receiving a diagnosis as well as provided information about the common Hispanic mutation. The article received a great response and has directed many people with the illness to Angioma Alliance.

Tim and Sandra Gallegos were featured in an article in the Santa Fe New Mexican on January 8th. Tim and Sandra lost their 9-year-old daughter Jenae to a hemorrhaging cavernous angioma last year. They are helping to encourage those with familial CCM in the Santa Fe area to have all family members genetically tested and to have follow-up with MRI.

Dipped Into Oblivion: An Interview with Sacha Bonsor

By Cristina DeSalvo

Sacha Bonsor, member of Angioma Alliance UK and author, wrote a poignant memoir describing her struggle with cavernous angioma. I read Dipped Into Oblivion less than one year following my own brain surgery. Her emotions – initial shock and disbelief, confusion surrounding the decision to have surgery, fear and oddly, acceptance, just before surgery, frustration during recovery, and eventually relief – were real and honest. As someone who went through a very similar test, I found her openness and sincerity comforting.

Had I read Dipped Into Oblivion prior to my own surgery, I'm pretty sure it would not have changed my mind or made me more anxious about my impending surgery. Quite frankly, I'm not sure that would have been possible and I do not think that is the memoir's purpose. What I would have gained and appreciated is reassurance – not necessarily that I made the *right* decision, because that is the unknown, but that I had made one nonetheless. I would not have questioned my decision as much as I did, and I think I would have trusted myself more and been more at peace with my decision.

Reading the novel after surgery was not like reliving a terrible time in my life, rather, it helped me sort through some of my own feelings and look closely at my own experiences through someone else's lens. I found myself nodding in agreement as I read Sacha's memoir and acknowledging some of the feelings I failed to recognize while experiencing them. I asked Sacha some questions about the writing process and how she has used her experiences to help others.

1. *Can you briefly describe your history with CCM?*

I had my first haemorrhage from a cavernoma in my brainstem when I was 20, from which I fully recovered. I opted for surgery in May 2001, when I was twenty six, with an American surgeon, Dr Robert Spetzler in Phoenix, and the surgery went well. I was told that it had been removed. In April 2004, I experienced another haemorrhage and it turned out that a small part of the cavernoma had been left behind. I opted for surgery again, with Dr Spetzler again, in November 2005.

2. *Why did you choose to write a book about your CCM experience?*

I wanted to write a book that I wished I could have read. When I was ill I was looking for companionship and could not find a book that could offer it. There were a lot of books by older people on dealing with life threatening illnesses and choices but nothing written by someone in their twenties, with their life ahead of them. I also wrote it for myself, when recovering after my first surgery. It was very cathartic and helped me put a lot of ghosts to rest.

3. *How long did it take you? Did your writing help you recover emotionally from your experience?*

It took me a couple of months to get what I wanted to say out and then a year or so of it sitting in my top drawer and occasionally going back to it. The more time went on, the easier it was to pick out the important things, and to highlight how normal my life was outside of my illness.

4. *Who should read your book? Why?*

I would like to think that any person who suffers illness at a young age might get a little bit of solace from my book because it would help them to feel less alone.

6. *Is your memoir entirely non-fiction?*

Yes

7. *What is your favorite part of the book?*

I think the most enjoyable part to write was the end, when I could look back at the story and work out what I had learned from my experience - namely that it is the little things in life - the joy found in a sunset, or bees around lavender - that bring happiness.

8. *What was the hardest part of the writing process?*

I was very lucky in that I didn't find any of it hard. I think if words come from the heart, this is often the case.

Dipped Into Oblivion is available for order online at Amazon.

Cognitive Rehabilitation:

Help for Attention, Memory, and Other Problems with Thinking

Or “Why can’t I remember to pick up bread on the way home?”

Part II of II*

By: Connie Lee, Psy.D.

Executive Functions

Executive functions are those things we do that require a variety of processes, e.g. planning or time management. Often, these activities become difficult for individuals who have had a bleed or a surgery. Below, we’ll look at a few of these functions and talk about ways in which they may be addressed in cognitive rehabilitation.

Planning

We all carry out activities every day that require planning, even if we are not aware of it. Grocery shopping, paying bills, planting a garden, getting ready for work all include an element of planning. Some individuals have difficulty developing, organizing, and executing plans after a bleed or surgery.

The planning process can be broken down into six steps that can be addressed by cognitive rehabilitation.

Knowing the steps needed to complete a plan. To address this, a therapist would give you a task that requires planning skills such as applying for a credit card, preparing a meal, or finding a job and asking you to list all of the steps involved in the process in any order. You would be graded on how complete your list is.

Putting the steps in order (sequencing). You would be asked to take the list you developed above, and put the items in sequential order.

Initiating the plan. Taking the first step can be difficult for individuals with some types of brain injury. To improve this, a person must first become aware of the problem and then practice initiating in many different settings. For example, you could be asked to initiate a conversation, sit down with the checkbook, or write a paragraph on a topic you know well.

Carrying out the plan. Carrying out a plan often requires performing many steps and some may have multiple components. It may require higher level organizational skills to keep the plan moving along and it can be easy to become overwhelmed. To practice, a therapist could develop a list of errands to run and ask you to do them. The errands would be arranged from least to most complex. Happily, you’d be able to use your memory notebook if you have one, and there should be someone to come along with you.

Repair. Many times plans need to be changed because an obstacle develops that makes the original plan impossible to complete. A therapist can develop hypothetical situations that require you to think about how you would change a plan. For example, what if you needed Shitake mushrooms to complete a meal you were preparing for a special dinner party, but the grocery store was

out of them? Alternately, what if you needed to get to an appointment, but you walked out of your house and saw that you had a flat tire? Working out hypothetical situations can make coping with obstacles in real life easier.

Speed of Response. This means that you accomplish your goal in a reasonable amount of time. Practicing planning and carrying out plans should improve your efficiency over time.

Time Management

Brain injuries can result in difficulties with time management. It may become harder to judge time and to estimate how long it will take to perform a task. Good time management involves several steps.

Time estimation. Individuals with bleeds or surgery in the frontal lobe may have difficulty judging how much time has passed. You may start an activity and look up to discover that an hour has passed without your noticing. To improve this, a therapist may ask you to tell her when a certain amount of time has passed, e.g. 1 minute, 5 minutes, or 15 minutes. Sometimes you may just sit and wait for the time to pass or you may have a distracting activity in the interim. The task gets harder as the length of time increases.

Creating a time schedule. It’s important to be able to estimate how long it is going to take to complete tasks. You may practice creating realistic time schedules with a therapist for activities like getting ready in the morning (shower, dressing, breakfast, etc), cleaning the house, running errands, or performing work-related tasks. This requires both time management and planning skills.

Carrying out activities in the amount of time scheduled. Next, you may be asked to carry out the activities on your time schedule to see if your estimates were reasonable for you. To do this, you need to keep track of how long it actually took to complete the items on your schedule and compare this to your estimates. You may also need to look at whether you got stuck in an activity and kept at it too long without thinking about when your next task was supposed to start. For example, perhaps you needed to assemble a bike in the morning and then get to a doctor’s appointment in the early afternoon. If the bike assembly doesn’t go well, you will need to track the time and recognize that it may need to be left incomplete in order to make it to the appointment on time.

Repairing the schedule. Finally, it is important to be able to revise a schedule if it is not working. This can be done in the middle of a schedule by revising the time estimates for all of the subsequent activities. Or, it can be done once the entire schedule is completed.

Cognitive Rehabilitation: Help for Attention, Memory, and Other Problems with Thinking (continued)

Self-Regulation

Self-awareness is the ability to use internal and external feedback to control and change your behavior. Often with frontal lobe damage, this ability may be compromised.

Becoming self-aware requires three primary skills:

Awareness. This means that you are able to make statements about your own behavior that indicates you understand what you are doing and the impact it has on others.

Ability to respond to this feedback. This means that you are able to change your behavior, if needed, in response to your awareness.

Impulse control. Self-regulation also requires impulse control. This means that you are able to think before acting. Having good impulse control helps in controlling inappropriate behavior.

The key to addressing these issues is improving awareness. A therapist may design an exercise in which you are asked to put a hash mark on a piece of paper every time you do something, such as interrupt another person while they are talking. The therapist will give you a specific period of time during which you observe yourself, and the therapist will track the behavior as well. At the end of the time, you and the therapist will compare notes. The behavior does not have to be something you need to change – the point of the exercise is simply to become aware of what you do. Increasing awareness is often the best way to change a behavior over time, and can go a long way toward improving self control.

Treatment By Compensating

Some people continue to have executive function impairments even after a great deal of cognitive rehabilitation. For these individuals, developing a very set schedule and routine may help in compensating for the deficit. The individual may need to change professions to a job with more structure, less responsibility, and reduced social interaction in order to function more successfully.

Other Areas Addressed by Cognitive Rehabilitation

Cognitive rehabilitation can be used to address other types of cognitive impairment as well. For example, a therapist may be able to help with visual processing. The work would focus on how you understand what you see and how you respond to what you see. This is different from a vision therapist or ophthalmologist who would concentrate on the actual muscles and nerves of your eye.

A therapist may address the use of language. Unlike speech therapy, the focus of cognitive rehabilitation is to learn how to use the right language at the right time. For example, after a bleed or surgery, a person may experience increased difficulty initiating a conversation and making small talk. Or, a person may not think about asking for help when needed. Cognitive rehabilitation therapists work on the practical use of everyday speech.

A therapist may address directly issues of problem solving. Some problem solving is involved in planning, time management, and self-regulation training, but it can become the focus of the treatment if needed.

Finally, a cognitive rehabilitation therapist may address abstract reasoning. Some types of reasoning include logical reasoning, creative reasoning, and social reasoning. A typical example of logical reasoning is an exercise in which you are asked to design a seating chart for a dinner party but have many identified guests who have special seating needs, i.e. Jane will not sit next to Sandy, Sandy must sit to the right of Ben, etc. The challenge is to figure out how to arrange the seats so that everyone is happy. An example of creative reasoning is brainstorming – generating as many ideas on a topic as you can. For example, you could be asked to come up with as many ways of using a piece of paper as possible (write on it, use it as a fan, make a paper airplane, start a fire, line your birdcage, etc). Finally, social reasoning involves understanding why some behaviors are or are not appropriate. For example, what are two good reasons why most people call ahead before visiting an out-of-town friend? Or, when would it be a good idea to send flowers to someone? When would it be a bad idea?

Cognitive rehabilitation can be enormously helpful in regaining some of the mental abilities you had before your bleed or surgery. The easiest way to find a neuropsychologist in your area is to ask your neurologist. Or, call a local rehabilitation hospital with a stroke and brain injury unit or your State's psychological association for a referral.

References

Cigna Health Corporation. "Cigna Healthcare Coverage Position: Cognitive Rehabilitation," July 15, 2005.

National Academy of Neuropsychology. "What is a Neuropsychological Evaluation?" Brochure, 2001.

Sohlberg, M. and Mateer, C. Introduction to Cognitive Rehabilitation: Theory and Practice. New York: Guilford Press, 2001.

**Part I of II of this article was featured in the Fall 2005 Newsletter and appears online (www.angiomaalliance.org).*

Your Help Is Needed: Complete a Survey for Angioma Alliance!

We need your input! Angioma Alliance is in the process of developing its strategic plan for the next 3-5 years. As part of this planning process, we would very much like to hear your thoughts on the ways in which we should expand our services. Please take 5-10 minutes to visit our home page and follow the link to the member survey. Or, call us at 1-866-HEAL-CCM, and we will mail a copy of the survey to you. Thank you in advance!

LATEST RESEARCH

An Update on Cerebral Cavernous Malformation Research

By: Connie Lee

Spinal Cord Cavernous Malformations

In a paper published by the neurosurgical group at the Barrow Neurological Institute, the authors went back through the records to examine the outcome of 53 cases in which spinal cavernous malformations were removed with traditional surgery. Specifically, they were trying to determine if surgery improved patients' pain symptoms. Of the 53 cases, 21 were experiencing pain related to their spinal cavernous malformation before surgery. The authors found that only 52% of those who had surgery saw long-term pain improvement (11 patients). Nine (43%) reported the same level of pain as before their surgery and 1 patient reported pain that became worse after surgery. Patients appeared to fare better immediately after surgery when 78% experienced less pain. It is not clear why pain symptoms increased for many patients an average of 10 months after surgery. While the sample size for this study is small, it may indicate that surgery is less effective at reducing pain related to spinal cord cavernous malformations than previously thought.

Kim LJ, Klopfenstein JD, Zabramski JM, Sonntag VKH, Spetzler RF. Analysis of pain resolution after surgical resection of intramedullary spinal cord cavernous malformations. *Neurosurgery* 58:106-111, 2006.

CCM2

The laboratory at Duke University has developed a mouse model that has a mutation of the CCM2 gene (called Ccm2 in mice). The development of a mouse model is an important step

in understanding this illness and provides a platform for many tests that could not otherwise be performed on humans.

Plummer NW, Squire TL, Srinivasan S, Huang E, Zawistowski JS, Matsunami H, Hale LP, Marchuk DA. Neuronal expression of the Ccm2 gene in a new mouse model of cerebral cavernous malformations. *Mamm Genome*. 2006 Feb;17(2):119-28. Epub 2006 Feb 7.

CCM3

Three labs published reports indicating that CCM3 is a far more uncommon genetic mutation than was previously expected. Papers coming from Duke University, Yale University, and McGill University in Montreal all point to the idea that less than 10% of cases of familial cavernous malformation can be attributed to the CCM3 (PDCD10) gene. This gives rise to the speculation that there may be a CCM4 gene or some other undiscovered mechanism causing some familial cavernous malformations.

Guclu B, Ozturk AK, Pricola KL, Bilguvar K, Shin D, O'Roak BJ, Gunel M. Mutations in apoptosis-related gene, PDCD10, cause cerebral cavernous malformation 3. *Neurosurgery*. 2005 Nov;57(5):1008-13.

Liquori CL, Berg MJ, Squitieri F, Ottenbacher M, Sorlie M, Leedom TP, Cannella M, Maglione V, Ptacek L, Johnson EW, Marchuk DA. Low frequency of PDCD10 mutations in a panel of CCM3 probands: potential for a fourth CCM locus. *Hum Mutat*. 2006 Jan;27(1):118.

Verlaan DJ, Roussel J, Laurent SB, Elger CE, Siegel AM, Rouleau GA. CCM3 mutations are uncommon in cerebral cavernous malformations. *Neurology*. 2005 Dec 27;65(12):1982-3.

EXPECTANT MANAGEMENT CHAT

The next Angioma Alliance chat will focus on the "wait and see" approach to treatment. This chat is for those who are living with cavernous angioma, but for whom surgery is not an option or who have chosen not to have surgery. The chat will focus on sharing and support. It will be hosted by Michelle Hnath (Michelle on the Community Forum) and Jack Hoch, Angioma Alliance Board Member, both of whom have been living with brainstem cavernous angiomas.

When: Sunday March 26th at 8:30 pm EST (7:30 CST, 6:30 MST, 5:30 PST, and on 27 March at 0130 GMT).

Where: On the day of the chat, we will post a link to the chat on our Community Forum, email listserv, and on the Chats page of our website. Please check the link earlier in the day and contact us at info@angiomaalliance.org if you have difficulty accessing the link. For instructions on participating in a chat, please visit our Chat Announcements page at <http://www.angiomaalliance.org/chat.html>.

ANGIOMA ALLIANCE 2005 ANNUAL REPORT

Our income in 2005 greatly surpassed our expectations. We are very grateful for the support of all our donors and volunteers and for those who held special events to benefit Angioma Alliance.

Our balance sheet represents our total liabilities and equity as of December 31, 2005. What is most impressive about this is that we tripled our bottom line since December 31, 2004 moving from \$20,110 to \$62,143. The bulk of this increase is the result of funds that were raised that have been board-designated or restricted for our patient registry. Our patient registry fund has grown from \$8400 at the end of 2004 to \$42,139 at the end of 2005. Additionally, we acquired an HP Color LaserJet printer through the generosity of Greg and Kelly B. from Indiana and the Hewlett Packard Gifts in Kind program, increasing our fixed assets from \$1525 at year's end 2004 to \$4353 in 2005.

BALANCE SHEET AS OF 12/31/2005		PROFIT AND LOSS 2005	
ASSETS	TOTAL	REVENUE	
<u>Current Assets</u>		<u>Contributions</u>	
Bank Accounts		Board Designated for Patient Registry	\$24,506
Paypal	\$ 2,280	Unrestricted	\$14,147
SunTrust Checking	\$42,664	Restricted for Patient Registry	\$ 9,470
Undeposited Cash	<u>\$12,870</u>	<u>Family Conference Income</u>	\$ 3,470
Total Bank Accounts	<u>\$57,814</u>	<u>Unrestricted Grants</u>	
Total Current Assets	<u>\$57,814</u>	Corporate	\$ 4,451
<u>Fixed Assets</u>		Foundation	\$ 3,000
Equipment	\$ 4,353	<u>Logo Item and Brochure Sales</u>	\$ 1,520
Total Fixed Assets	<u>\$ 4,353</u>	<u>Other Special Events</u>	\$ 101
TOTAL ASSETS	<u>\$62,167</u>	TOTAL REVENUE	<u>\$60,665</u>
LIABILITIES AND EQUITY		EXPENSES	% of total
<u>Liabilities</u>		<u>Bank Charges and Credit Card Processing</u>	\$ 88 < 1%
Current Liabilities		<u>Direct Service</u>	
Credit Cards		Family Conference	\$ 8,403
Advanta Mastercard	\$ 2,792	Scientific Meeting	\$ 2,871
Total Credit Cards	<u>\$ 2,792</u>	Physician Awareness/Education	\$ 2,455
Total Current Liabilities	<u>\$ 2,792</u>	Printing	\$ 1,173
Total Liabilities	<u>\$ 2,792</u>	Public Awareness	\$ 887
		Telephone (toll free number)	\$ 802
		Postage	\$ 557
		Website	\$ 423
		Patient Registry	<u>\$ 67</u>
		Total Direct Service	\$ 17,638 88%
<u>Equity</u>		<u>Dues and Subscriptions</u>	\$ 100 < 1%
Retained Earnings	\$18,821	<u>Fundraising</u>	\$ 852 4%
Net Income	<u>\$40,554</u>	<u>Legal/ Accounting Fees</u>	\$ 711 3.5%
Total Equity	<u>\$59,375</u>	<u>Licenses and Permits</u>	\$ 741 3.7%
TOTAL LIABILITIES AND EQUITY	<u>\$62,167</u>	<u>Office Supplies</u>	\$ 17 < 1%
		<u>Tax Refund</u>	(\$ 38) (<1%)
		TOTAL EXPENSES	<u>\$20,109</u>
		Net Operating Income	<u>\$40,554</u>
		Net Income	<u>\$40,554</u>

ANGIOMA ALLIANCE 2005 ANNUAL REPORT

We ended the year within \$242 of our planned 2005 budget. There were two large unanticipated expenses in 2005. First was the expense of the scientific meeting that was held in November. We were very fortunate to have the additional funds available to host this event. Second, we are in the process of registering as a charity in each state in which we fundraise; this is a very costly and time-consuming process. The total expense incurred for this process in 2005 was \$1,253 in legal and application fees. We will continue this process in 2006. Even with this administrative expense, we continue to spend 88% of our income on direct service.

Below is our proposed budget for 2006. While it reflects a very large increase in expected income, most of this is anticipated to be received as corporate contributions toward our Tissue/DNA Bank and Patient Registry.

ANGIOMA ALLIANCE 2006 BUDGET

REVENUE

Contributions

Unrestricted Individual	\$18,000
Unrestricted Corporate	\$ 3,000
Unrestricted Foundation	\$ 3,000

Unrestricted Special Events \$ 4,000

Logo item/brochure sales \$ 1,700

Family conference registrations \$ 5,200

Total Unrestricted \$34,900

Restricted/Designated

Individual	\$10,000
Corporate	\$60,000
Foundation	\$ 2,000
Special Events	\$ 2,000

Total Restricted/Designated \$74,000

TOTAL REVENUE \$108,900

EXPENSES

Family Conference \$13,500

Scientific Meeting \$3,200

Exhibiting \$3,500

Legal/Accounting/License/Permits \$3,800

Publications/Postage \$2,300

Public Awareness \$1,500

Toll-free Line \$ 860

Website \$2,840

Fund-raising \$1,400

Capital Equipment \$2,000

TOTAL EXPENSES \$34,900

LIST OF DONORS

Beacons 5000+

UCB Pharma, Inc.

Leaders 1000-4999

Lynnelle Corsi
 Connie and Dave Costa
 Joyce and Greg Gonzales
 John and Connie Lee
 Tom W. Price Family Trust
 The Tony Stewart Foundation
 The Wert Family Foundation
 on behalf of Josi and Steve
 Javinsky

Benefactors – 500-999

George and Trudy Barron
 Howard Bonde
 Cephalon
 Joseph and Anna Ferrando
 Forest Pharmaceuticals
 Lee and Paula Hougen
 Anita and Steve Matejka
 Tom and Nancy McHugh
 Walter and Linda Sarwatka
 Krista Zug

Community Builders 250-499

Anonymous
 Batesville Products
 Laura and Kurt Bridgman
 Sally and Mike Derrig
 Diana and James George
 Tony Gussio
 Ed and Barbara Hart
 Mary Anne Iannetta

Tammy and Joe Lovrich

Milestone Contractors

Bob and Nancy Mueller

James and Helen Neuman

Liz and John Neuman

Sandy Neuman

Virginia Peter

Nola Price

Richmar Farms

Allison and Ken Ruggles

Mike and Cathy Ryan

Sara Sukalich

3D Energy Service

Town Planner Calendar

Laura and Tom White

Partners 100-249

Don and Tina Allen

AnyDoc Software

Bev and Roger Baldwin

Carl and Chelsea Beffa

Beth Kennedy and John Bense

Diane and Jim Bowser

Karen Smith and Paul
 DeMarco

Bill and Pat DeSalvo

Ruta Gedmintas

Richard Gonzales

The Kids at Heritage YMCA

Michelle and Steve Hnath

David and Ruth Hopkinson

Igve.com

Deborah Kaeser

Linda and Tony LaMarca

Sheila McIntosh

Preferred Medical, LLC

ANGIOMA ALLIANCE 2005 ANNUAL REPORT— LIST OF DONORS (continued)

Michael and Anne Ranallo	Oriana Aguilar	In honor of Jay, Churchill, Billy and Paris	Tom and Andrea Price	John and Julie Griffen
Mary and Ken Reeb	George Bailey	Lee Rashkind	Tom W. Price Family Trust	Marie Griswold
Diana Rodionov	Pamela Brunner		Richmar Farms	Kevin and Deborah Hamilton
Ron Schechter	Mary Jane Cartmill	In honor of Julia Lee	Erin Samman	David and Jennifer Hammel
Roger and Carol Sherman	Kelly and Scott Cedarquist	Elizabeth and Thomas Koerner	Sandy Souza	Bill and Kathy Hanlon
David Silver	Tim and Leslie Connelly		J.P. Walsh	Gary and Janice Hanrahan
Karen Smith	Cristina DeSalvo	In memory of James LaPorte	In Honor of Allison Ruggles	Deidre and James Hansman
Martin and Joan Smith	Les Dubnick	Fay and Althea Pettigrew	Greg and Ellen Bauer	Tara and Stephen Healy
Roy and Liz Snyder	Judy Farris		Kim Beaudoin	John and Kerry Ann Herlihy
Michael Styles	Letty Flatt	In honor of Jake and Sam Neuman	Joann and Kurt Benson	Dolly Hightower
Dick and Nancy Taylor	Kit Fournier	3D Energy Service	Kathy and Paul Bittrich	Homesite Group
Han von Baeyer and Barbara Watkinson	Ruth Fraser	Grace Buonavita-Sevilla	Melissa Booth	Julian and Susan Huang
George and Jan Youngdahl	David and Karen Fuss	Bugni Hardware and Feed	Elaine Bouchie	Mary Anne Iannetta
Supporters 50-99	Bill and Susan Geary	Nestor Cardenas	Suzanne Brant	Edward and Dawn Johns
Fred and Joan Adair	Lisa Hayden	Child and Family Psychology	Kerin Caieiro	Andrew and Kelly Johnson
Henry Anawaty	Jeffrey Jin	Valerie Cox	Kevin and Libby Carr	George and Ann Marie Juliano
Jennifer Bartels	Jim and Phoebe Kent	Cueva Chiropractic	Donna Zackey Cazeault	Deborah Kaeser
Katherine and David Barto	Sandra Lautenschlager	Elva Cueva	Certa Propainters	Johanna and Joseph Kelly
Irene Beauvais	John Martin	Kim and Rick Gerdes	Sandra Cheverie	Eugene Kennedy
Elena Cruz	John and Jackie McCabe	Bella Gitter-Stubbs	John Congdon and Mary Dunne Congdon	Charissa Kerr
Jeffrey Demichiel	Cheri McNeely	Darlene Gotcher	Sharon Conger	Diane Lansing
Ruth Ecker	Mark McPherson	Patty Grubbs	Andrew and Julie Connolly	Laura Lifland
Jan and Michael Fitzpatrick	Christina Meddaugh	John and Sherrie Gruber	James and Midge Corsi	Tamara and Michael Lovuolo
Cynthia Gaboury	Dorinda Miller	Keith Peters Painting	John and Linda Corsi	Greg and Lisa Mackin
Marie and Robert Gussio	Erin Roach	Rodney Knittel	Lynnelle Corsi	Gary and Sarah Magnuson
Herbert and Clara Hagen	Tania Ryan	Nancy Macian-Hernandez	Marc and Aileen Crespi	Marlene Maltese
John Hofelich	Linda Saenz	Anita and Steve Matejka	Maureen and William Daly	Philip and Lisa Markella
Innovative Mortgage Service	Chuck and Nancy Sheppard	Lauren Mathews-Hill	Margaret and Kenneth Dickinson	Barry McAloney
Lil Lieverman	Lisa Silletti	Dan McMahan Automobiles	Carolyn and Michael DiFilipo	Douglas McAloney
Lisa Neuman	David and Donna Stanford	Cecilia Mendoza	Patricia and Christopher Donato	Wayne and Pamela McArdle
Ned Perry	Ian Stuart	James and Helen Neuman	Brian and Kathy Duddy	Joseph and Leslie McCarthy
Kimberly Randall	Mary Templeton	Liz and John Neuman	Anne and Edward Errasti	Kevin and Patty McHugh
Sharon Robinson	Marie Wattles	Katherine Parker	Cheryl Foote	Karen McLaughlin
Karen Schweigl	Sylvia Wee	Brad Peters	Kenneth Gibson	Dennis and Karen McLeod
Susan and Paul Sukalich	Wells Fargo	Dorothy Peters	Michelle Glick	Eric and Elizabeth Moskowitz
Saskia van Dijl	Kathy and Buzz Wincheski	Mary Peters	Annemarie and Thomas Goode	Mulrenin Building Company
Norma Villa	Lisa Wixson	Ollie Peters	Gordon Brothers Group	Robert and Traci Najarian
Ivelina Zlatev	In memory of Jenae Gallegos	Penelope Powers		Laurel and Joseph Nardone
Friends 0-49	Tim and Sandra Gallegos	Nola Price		Kevin and Robin Nolan
Donald Adams	Andrea Pacheco			Bob and Cathy O'Brien
	Eloise Valverde			

ANGIOMA ALLIANCE 2005 ANNUAL REPORT— LIST OF DONORS (continued)

Daniel and Joann Passeri
 Pat and Marilyn Quilty
 Timothy and Paige Riddle
 Irene and Ronald Ruggles
 Deborah Salaun
 Mary Alice and David Scanlan
 Anthony and Susan Scavongelli
 Ann Smith
 Johanna Southworth
 Sarah and Michael Stinebiser
 Suzuki Strings
 Jennifer Tobias
 Donna and John Tobin
 Barbara Tomasian and Stephen Erwin
 Paul and Dorothy Toselli
 Jeffrey and Mary Jane Turner
 Mary and Wallace Varonko
 Vehicle Procurement Services
 James and Donna Walsh
 Brian and Aileen Zec

In Honor of Krestin Ryan

John and Janet Aqius
 Howard Bonde
 Phyllis Bonde
 R.C. and Molly Bonde
 The Brewer Family
 Laura and Kurt Bridgman
 Ed and Sandy Conner
 Connie and Dave Costa
 Michelle Enes
 John Ferrando
 Joseph and Anna Ferrando
 Victor and Lourde Galande
 Donald and Marge Gray
 Ed and Barbara Hart
 Richard and Tana Laura
 Sandra and Dennis Lema
 Leslie and Grant London
 Kim and John Lyons
 Carole Marsala

Stan and Mabel Matsumoto
 Sis Milon
 Bob and Nancy Mueller
 Charley and Cappy Novello
 Gary Padilla
 James and Judy Pettigrew
 Rosalie Proulx
 Gary and Janet Reynolds
 Mike and Cathy Ryan
 Karyn and Jim Scaduto
 Gary Williams
 Loretta Williams

Gifts in Kind

American Country
 Greg and Kelly B.
 Benchwarmers
 Brian's Barber Shop
 Certa ProPainters
 Citizen's Bank (Duxbury, MA)
 The Clothes Line
 Empire Wine and Spirits
 Expressions
 The Finished Window
 Flowerland (Kingston, MA)
 Cheryl Foote
 Hanniford Brothers
 The Hansman Family
 Hewlett Packard Gifts In Kind
 Jett Foundation
 Johanna Kelly
 KA Ricco Inc
 John and Connie Lee
 The Magnuson Family
 The McSherry Family
 Mill Wharf
 Adrian Morris Salon
 Nana and Uncle Barry
 Night Train
 Papa Johns Pizza, Columbus, IN
 Plimouth Plantation
 Ports & Company

Shawn Harris Enterprises
 The Sun Tavern
 Three Pines Enterprises
 Tin Mints
 USA Health & Fitness
 Wilson Hair Design
 Windsor House

We would also like to thank Kim Hofelich, Liz Neuman, Andrea Price, Allison Ruggles, and the kids of the Heritage YMCA summer program for raising money to benefit Angioma Alliance through special events.

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



Charitable Medical Air Transportation

Do you have a family member needing long-distance travel for specialized medical evaluation, diagnosis or treatment? If so, you can call the National Patient Travel Center, a 501(c)(3) charity specializing in helping patients find free or low-cost travel and hospital hospitality for family members in distant cities far from home.

The National Patient Air Transportation Helpline is the only service of its kind in America. It can be reached every day of the year. It has been in operation for 15 years and helps thousands of patient families annually. Call them at 800-296-1217 east coast time from 9AM to 5PM. There is no charge for this referral service.

The NPATH Helpline is operated by Mercy Medical Airlift in support of Angel Flight America (which does 90% of long-distance charitable medical air transportation in the U.S.), Joe's House, the National Association of Hospital Hospitality Houses, and the American Cancer Society.

*Mercy Medical Airlift
 National Patient Travel Center
 4620 Haygood Road, Suite 1
 Virginia Beach, VA 23455
 mercymedical@erols.com*

Note: If you have any questions about this service, call Steve Patterson, Executive Vice President, Mercy Medical Airlift at 757-318-9174.

Editor-Cristina DeSalvo

Angioma Alliance
107 Quaker Meeting House Rd
Williamsburg, VA 23188

Phone: 757-258-3355
Toll Free: 866-HEAL-CCM

info@angiomaalliance.org
www.angiomaalliance.org

VOLUNTEER INFORMATION

Angioma Alliance is always in need of volunteers. Whatever your skills and time commitment, we can use your help! Contact Angioma Alliance at the telephone number or e-mail address above to learn how you can contribute. Together, we can make a difference.

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 MARKETPLACE

Have you visited the new Angioma Alliance marketplace? Follow the link from our main menu or type in: <http://stores.homestead.com/AngiomaAlliance/default.htm>, to order wristbands, car magnets, and brochures all in one easy transaction. Your purchases support the work we do and help us to expand our programs.



Angioma Alliance
107 Quaker Meeting House Rd
Williamsburg, VA 23188