



# Angioma Alliance Newsletter

Editor-Cristina DeSalvo

Fall 2005  
Volume 3, Issue 4

## ANGIOMA ALLIANCE CO-HOSTS FIRST SCIENTIFIC WORKSHOP AT DUKE UNIVERSITY

By: Connie Lee

Angioma Alliance, with the assistance of Doug Marchuk who heads the Duke University laboratory, hosted the first Pathobiology of CCM scientific workshop on Friday, November 18, 2005 in Durham, NC. The workshop featured enthusiastic presentations of new data and lively discussion by members of every CCM laboratory in the US and Canada. All participants walked away expressing that they had learned new information that they could apply to their own work.

Several major developments resulted from this workshop:

I. A committee was formed to begin developing standards for collection of clinical data. This is being done in preparation for our patient registry. The committee will issue a series of standards and recommendations that will, at minimum, address the following:

- a. the type of MRI patients should be receiving so that MRIs can be compared over time
- b. indications for genetic testing
- c. standardizing criteria for what is considered a "bleed"
- d. developing a standardized list of the clinical data that should be collected for each individual in order to have a useful registry

2. The pharmacology industry will be approached to discuss the need for a drug that treats seizures that specifically are caused by blood or iron products in the brain.

3. Participating labs will pool their data to help determine the percentage of families with familial CCM that do not have the CCM1, CCM2, or CCM3 mutation. Then, they will generate a list of possibilities for discovering CCM4, if it exists, and divide the work of finding it.

4. The group will develop a "white paper" over the next 3-6 weeks to present to NIH to outline a major collaborative study that may include a number of the items above as well as additional biochemical and imaging experiments. We have been hoping for such a collaboration in order to increase the efficiency of this work and, potentially, make better use of research funding. We will need Angioma Alliance members to attend the meeting with NIH in Bethesda when it occurs. We will make an announcement when a date is selected.

Researchers agreed that a scientific workshop should be an annual event. The workshop was truly wonderful, and we are very grateful to be a part of this process.

Angioma Alliance now has its own magnetic car ribbon! These unique ribbons are the larger 3 1/2" x 8" size and are available at \$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



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

### Inside this issue:

<i>Family Conference 2006</i>	2
<i>Surgery Chat Details</i>	2
<i>Angioma Alliance UK Update</i>	3
<i>Board of Directors Announcements</i>	3
<i>Questions to Ask Your Doctor</i>	4
<i>Cognitive Rehabilitation:</i>	5-7
<i>Fundraising Update</i>	8
<i>How You Can Help...</i>	8

### IN THE NEXT ISSUE...

Don't miss the Winter 2006 Newsletter! It will feature an interview with Sacha Bonsor, author and member of Angioma Alliance UK, as well as a review of her memoir, [Dipped Into Oblivion](#)

### SURGERY CHAT

Co-moderated by Amy Jagemann and Kristen Dehn

Sunday, January 22, 2006

8:00 p.m. EST

7:00 p.m. CST

6:00 p.m. MST

5:00 p.m. PST

Monday, January 23, 2006

1:00 a.m. GMT

More Information on P. 2

## Family Conference 2006: Planning for Success!

Save the date! The 2006 Angioma Alliance Annual Conference will be held on Friday and Saturday, June 23<sup>rd</sup> and 24<sup>th</sup> at the Hilton Santa Fe in beautiful Santa Fe, New Mexico. The conference will feature:

- ◆ A keynote address by world-renowned neurosurgeon Dr. Robert Spetzler of the Barrow Neurological Institute.
- ◆ A presentation on the essentials of cavernous angioma as well as surgical considerations by Dr. Howard Yonas, who recently moved from the University of Pittsburgh to chair the neurosurgery department at the University of New Mexico.
- ◆ A presentation by Dr. Leslie Morrison, a neurologist at the University of New Mexico, on the “wait and see” approach to cavernous angioma management.
- ◆ Genetics information from 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.

There also will be interactive breakout sessions focusing on:

- ◆ The emotional impact of having cavernous angioma.
- ◆ Rehabilitation of the cognitive impacts of cavernous angioma such as attention and memory deficits.
- ◆ The special issues involved in having the KRIT1 common Hispanic mutation.
- ◆ Multiple sessions during which you can get to know others whose experiences with cavernous angioma are similar to yours, e.g. brainstem angioma, parents of children with cavernous angioma, etc.

We also will have plenty of time for fun in town. Year after year, Santa Fe is rated by Condé Nast Traveler magazine as one of the top three places to visit in the United States. It features hundreds of years of history with many original buildings still standing (including portions of the hotel in which we will be staying). Downtown Santa Fe has more art galleries per square mile than any other city in the United States as well as dozens of interesting shops. The natural beauty of the area is unique; if you choose to stay longer, you will find great hiking and outdoor activities in the nearby mountains.

Please plan to join us for what will be a very informative and powerful weekend!

### Surgery Chat

Our first chat of the new year will be in January for anyone contemplating, facing, or recovering from surgery. Amy Jagemann and Kristen Dehn of the Angioma Alliance Board of Directors, both of whom underwent brain surgery for cavernous angioma, will co-moderate this chat. The Angioma Alliance chats are a wonderful opportunity to share information and support in real time with others who are living with the same concerns. We hope to see you there!

**When:** Sunday January 22<sup>nd</sup> at 8:00 pm EST (7:00 CST, 6:00 MST, 5:00 PST, and on 23 Jan at 0100 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](mailto:info@angiomaalliance.org) if you have difficulty accessing the link. You will need your screen name and password to login. When you enter, you will see the chat transcript appear at the top of the page and a textbox at the bottom to type your questions or responses. Click on “Send” or press “Enter” to have your message appear in the chat.

## ANGIOMA ALLIANCE UK CONTINUES TO GROW

Update by Kirk McElhearn and Ian Stuart

Angioma Alliance UK has been very active in the past few months, and has a great deal of news to share with sufferers of cavernomas and their loved ones. Membership is growing steadily, and the new website has been set up at: [www.angiomaalliance.org.uk](http://www.angiomaalliance.org.uk). For the moment, content is limited, but we will be expanding our website's offerings in the near future.

- ◆ We are pleased to announce that Mr. Neil Kitchen, Consultant Neurosurgeon and Associate Clinical Director, National Hospital of Neurology and Neurosurgery, London, is now the Medical Adviser to Angioma Alliance UK.
  - ◆ Following the superb efforts of Tim Loasby, Ian Stuart (coordinator, Angioma Alliance UK – not a cyclist!) David Dines, Toby Hammond, and Mark Hymas, who were sponsored by students, staff, friends and family to cycle 100 miles each in a day, Angioma Alliance UK received a generous cheque of over £1200.
  - ◆ To raise additional funds, Claire M. Taylor, a friend of the Alliance, is to do a sponsored sky dive for Angioma Alliance UK next year.
  - ◆ Angioma Alliance UK now has enough funds to produce its own posters and flyers for dissemination to regional neurological centres, with a goal of sensitizing neurologists and staff to the problems caused by cavernous angioma. These flyers will not only provide them with additional information, but also will help spread awareness of Angioma Alliance UK and its website, so doctors and patients can contact us.
  - ◆ Angioma Alliance UK has applied for a small grant of £500 from a South West foundation to enable us to invite a guest speaker to address our members.
  - ◆ Ian Stuart, coordinator of Angioma Alliance UK, appeared on BBC Radio to talk about the condition and the organization. To see an article and listen to a short recording, visit: [http://www.bbc.co.uk/dor-set/content/articles/2005/10/19/angioma\\_feature.shtml](http://www.bbc.co.uk/dor-set/content/articles/2005/10/19/angioma_feature.shtml)
  - ◆ Jack Hoch, from the Board of Directors of Angioma Alliance, hosted a web chat on brainstem cavernomas for UK members on Sunday November 6. About ten individuals were present. One person joined us from America along with an honorary member who lives in the French Alps.
- Stay tuned for more updates from Angioma Alliance UK.

## Angioma Alliance Board of Directors Announcements

Angioma Alliance Board of Directors is pleased to announce that **Norma Villa** has been elected to serve as Secretary. In 1992, Norma's daughter was diagnosed with multiple cavernous angiomas - the largest and most threatening on the pons of the brainstem. Although not medically confirmed, it is suspected to be the familial form of the disease. In 1994, her daughter underwent surgery that partially removed the brainstem angioma. Norma is particularly interested in the identification of a mutation founder gene responsible for familial cavernous angiomas in Mexican-Americans. Norma's educational background is in social work and human relations. She joined the board of Angioma Alliance to help with outreach projects, especially those extending to the Latino/Hispanic population.

Angioma Alliance Board of Directors is excited to introduce two new members:

**Tony Gussio, CPA, MS**, joins the Angioma Alliance Board of Directors to

serve as Assistant Treasurer. Tony has his own tax consulting business and he serves CPA firms in Maryland, Delaware, Philadelphia and New York City. He is also a contributing author for a national tax publication in Rockville, MD.

Tony was diagnosed, after the second bout of diplopia (resulting from hemorrhage), with a cavernous angioma in the mid-brain area of the brainstem in 1990. Although Tony suffers from minor neurological deficits, the lesion has not grown noticeably or bled since then. Because of the location of the lesion, Tony has maintained the "wait and see" approach.

Tony grew up in the suburbs of Baltimore in a large family, and now lives in the Canton neighborhood of Baltimore City.

**Krestin Ryan** joins the Angioma Alliance Board of Directors as our Treasurer. Krestin is an accountant who was born and raised in California. She is wife to Kevin and mother to 5-year-old Nathan and 3-year-old Ashley. Her

son, Nathan, was diagnosed with multiple cavernous malformations at 11 months of age through an incidental finding. In October, 2004, when Nathan was 4, two of the malformations hemorrhaged resulting in two separate brain surgeries. Since surgery, Nathan has developed two new malformations, bringing his current count to four. Krestin's husband, Kevin, was diagnosed in September 2005 with multiple cavernous angioma as well. His current count is six, with one in the left temporal lobe causing partial seizures and memory loss. Ashley has had an MRI done which did not reveal any cavernomas; however, she will be genetically tested. Krestin specializes in non-profit accounting and joins the Angioma Alliance in hopes of generating public awareness about the illness as well as assisting in generating contributions and the much-needed funding for the patient registry.

## Questions to Ask Your Doctor

Prepared by the Surgery Support Committee\*

When you are first diagnosed, it is likely you will feel overwhelmed by the sudden and many choices you must make. Which doctor? Which hospital? Surgery or not? What next? Sometimes it is hard to think clearly and get the answers you need to make informed decisions. Angioma Alliance's Surgery Support Committee has put together a list of questions you should ask your physician. You will probably want extra time to consider the information you receive, so make sure you or someone you trust takes thorough notes for your review later.

### General Questions

1. What size is the CCM?
2. How many CCMs do I have?
3. What is the exact location of the CCM?
4. What functions does this area of the brain perform?
5. Do there appear to be any venous or other malformations in the vicinity of the CCM?
6. Does it appear to have bled previously?
7. In your opinion, what are the conditions under which you recommend surgery to remove a CCM?
8. Are there any other treatments you consider?
9. What tests do you recommend? (MRI, functional MRI, MRA, angiogram, etc)
10. If I had another bleed, what deficits would you expect?
11. What symptoms warrant a call to you or a trip to the ER?
12. Should I have my children (or anyone else in my family) tested?
13. Is there a genetic test to diagnose CCM?
14. Should I be concerned about possible cavernous malformations in other areas of my body? Should my spine be scanned?
15. Is this a rare disorder?
16. How did I get/develop a CCM?
17. Are there any vitamins or supplements I should take to improve my situation?
18. Can I exercise?
19. Can I participate in sports? What about contact sports such as football or snowboarding that might include a blow to the head?
20. What restrictions in activities do you recommend?
21. Are you concerned about my blood pressure?
22. What medications, prescriptions and over the counter, do you recommend I avoid? Are there any vitamins or supplements to avoid?
23. Is travel to higher elevations safe?
24. May I drink caffeinated or alcoholic beverages?

### Management

1. How often will I have follow-up tests (and which ones)?
2. How often will I follow up with you?
3. What will you be looking for while monitoring me? What changes are you looking for?
4. Is there anything I can do to minimize the risk of a bleed (or re-bleed)?
5. What is the risk of re-bleed?
6. Is this risk cumulative?
7. How would I know if I had another bleed? (i.e. what symptoms should I expect to see?)

### Surgery Recommendation

1. How long would you estimate the surgery to take?
2. How long would you estimate for recovery from surgery?
3. How long will I be in the hospital?
4. When do you expect I would be able to return to work and /or daily responsibilities?
5. What, if any, additional deficits would be possible as a result of the surgery?
6. Would you anticipate any of the deficits to be permanent?
7. Can my CCM come back after surgery?
8. What happens if you don't get it all out the first time?

### Surgeon's Background

1. How many of these have you seen?
2. Do you have a cerebrovascular specialization?
3. How many CCMs have you removed surgically?
4. (If you have a brainstem CCM) How many of these were brainstem CCMs?
5. What medical school did you attend?
6. Where did you perform your residency and fellowship?

\* The Surgery Support Committee is dedicated to providing information and emotional support to those affected by cerebral cavernous malformations. If you are interested in seeking support for your surgery-related concerns, please contact the Angioma Alliance. Also, we invite you to participate in a surgery chat, which will take place in January 2006. Please see page 2 of this newsletter for more information and instructions on how to log in.

# 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 I of II\*

By: Connie Lee, Psy.D.

Brain injury of any sort, including that from cavernous malformations, can cause a variety of cognitive impairments. For example, after a bleed or surgery, individuals often complain of difficulty with attention, short term memory, and multi-tasking, even if they have no visible physical deficits. Neuropsychology is the discipline that is designed to assess and treat these cognitive problems. It is surprising how infrequently patients are referred for neuropsychological evaluation and treatment – it is certainly something to request if you believe that you could benefit. Most major US insurance companies will cover the cost of an evaluation and follow-up treatment.

The National Academy of Neuropsychology provides clear explanations of neuropsychological testing and the role of the neuropsychologist:

#### WHAT IS A NEUROPSYCHOLOGICAL EVALUATION?

A neuropsychological evaluation involves testing that is sensitive to problems in brain functioning. Unlike CT or MRI scans, which show what the structure of the brain looks like, neuropsychological testing examines how well the brain is working when it performs certain functions (for example, remembering). The type of tests that you will take depends upon the questions you and your doctor have. The tests may assess the following areas: *attention and memory, reasoning and problem-solving, visual-spatial functions, language functions, sensory/perceptual functions, motor functions, academic skills, and emotional functioning*. The tests are not invasive; that is, they do not involve machines or X-rays. Most of the tests will involve questions-and-answers, or working with materials on a table. Some tests may use a computer. The testing may be performed by the neuropsychologist or a trained staff member. The neuropsychologist or a staff member will also spend some time talking with you about your medical, personal, and school history. The total time involved in your evaluation will depend upon the questions you and your doctor have.

#### WHAT IS A NEUROPSYCHOLOGIST?

A neuropsychologist is a licensed psychologist specializing in the area of brain-behavior relationships. Although a neuropsychologist has a doctoral degree in psychology, he or she does not just focus on emotional or psychological problems. The neuropsychologist has additional training in the specialty field of clinical neuropsychology. That means a neuropsychologist is educated in brain anatomy, brain function, and brain injury or disease. The neuropsychologist also has specialized training in administering and interpreting the specific kind of tests included in your neuro-

psychological evaluation. As a part of the required education, a neuropsychologist also has years of practical experience working with people who have had problems involving the brain.

#### Cognitive Rehabilitation

Treatment for cognitive impairments is called “cognitive rehabilitation”. The neuropsychological test battery can feel very long, but it is important for the neuropsychologist to have as much information as possible about your functioning before she develops a cognitive rehabilitation plan. Like any rehabilitation therapy, cognitive therapy has two parts: 1) improving your ability to perform the impaired function through therapy techniques and at home practice and 2) developing strategies for compensating for any residual deficits. Also, like other rehabilitation therapies, neuropsychological assessment and cognitive rehabilitation break down functions into their individual components so that the broken links can be found and addressed. In physical therapy, walking is assessed by looking at a variety of factors including muscle strength, range of motion, and balance. It doesn’t make sense to focus on strength when the real issue is balance. This is also true for cognitive rehabilitation.

Let’s examine some of the common cognitive functions and see how neuropsychologists understand and address them.

#### Attention

What is attention? Do any of the following apply to you?

“I try to watch TV but I just drift off. I can’t seem to stay focused on anything even when I’m relaxed and there are no distractions.”

“I can’t cook while there is noisy construction work happening next door. I get too distracted.”

“I can’t listen to the lecture and take notes at the same time. I can’t switch back and forth quickly enough.”

“I can’t brush my daughter’s hair while I talk on the phone. I can’t do two things at once anymore.”

For the neuropsychologist, all of these are problems with attention, but the kind of attention required varies from task to task. As a result, the rehabilitation exercises vary depending on the problem.

#### Sustained attention

“I try to watch TV, but I just drift off. I can’t seem to stay focused on anything even when I’m relaxed and there are no distractions.”

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

Drifting off is a problem with *focused or sustained attention*. Although it can happen on occasion to anyone, this is most often a continuing problem for those with brainstem bleeds or surgeries.

Cognitive rehabilitation offers several types of exercises to address this issue. For the most basic exercises, you would listen to a tape and hear a series of numbers. You are asked to push a button every time you hear a specific number, for example "4". You practice increasing the amount of time that you can continue the task without errors. The task can be made much more difficult by changing the rules for responding. For example, you could be asked to press the button every time you see a number that is 2 fewer than the number that came before it: (\* = push button) 10, 12, 8, 6\*, 4\*, 9, 7\*. The task could use letters or words rather than numbers. In a second type of task, you are asked to count backwards from 100 by 3s, 4s etc. This also can be made more difficult by adding more rules. For example, counting backward by 3 then adding 1: 100, 97, 98, 95, 96....

### Selective attention

"I can't cook while there is noisy construction work happening next door. I get too distracted."

Getting distracted by background noise is an issue of *selective attention*. Selective attention is the ability to focus on the important or relevant stimuli in the presence of distracting stimuli.

To treat selective attention, you would perform exercises like those above, but add background noise, often on tape. Ideally, the background noise should be the same type as that which is a problem for you in your daily activities. Many individuals are distracted by internal stimuli such as thoughts or worries. For this, neuropsychologists may encourage writing down thoughts and worries before beginning the task. Being distracted by internal stimuli also can be a sign of depression or an anxiety disorder. Therapy or medication to treat these underlying causes may be in order.

### Alternating attention

"I can't listen to the lecture and take notes at the same time. I can't switch back and forth quickly enough."

Not being able to switch back and forth is a problem of *alternating attention*. Alternating attention is required for any two tasks that require thought and that are performed at the same time.

Several types of exercises can begin to treat this. In one, you are presented with a list of numbers. You cross out odd numbers until the therapist says "change". You would then begin to cross out even numbers. The task becomes more difficult as the length of time between changes shortens. Alternately, you could be presented with pairs of numbers and be asked to change back and forth between adding and subtracting when cued. Finally, you may look at words that are printed differently from the meaning of the word: BIG little LITTLE BIG LITTLE big little LITTLE. You would be asked first to read the words and then to say the size of each word. In this example, the response should be "big little little big

little big little little" and then the size of each word "big little big big little little big." There are many other exercises that work along this same principle. These types of exercises are very difficult even for most people without any type of brain injury.

### Divided attention

"I can't brush my daughter's hair while I talk on the phone. I can't do two things at once anymore."

Not being able to do two things at once is a problem with *divided attention*. In divided attention, an individual is asked to perform two tasks at once, but one task should be something that a person can do without thinking or with very little thought. In the example of brushing a child's hair while talking on the phone, brushing hair should be an automatic task performed with some attention but little thought. To address this issue, you may be asked to perform the task of pushing a buzzer in response to a specific number as in the sustained attention example above. The difference here is that you will both hear numbers through a headset and see number flashed individually on a screen. They will not be the same numbers. You must push the buzzer if either tape or screen has the specific number. Alternately, you may be asked to perform sorting exercises. For example, you may be presented with a deck of cards and asked to sort the cards by suit. During the sorting, you also are supposed to turn over any card that contains a specific letter, such as the letter "n" (one, seven, nine, ten, Queen, King). Again, this is quite a challenge, even for those without brain injury.

### **Processing Speed**

Reduced processing speed, how long it takes to move through a task, is often a problem for those with brain injury. All of the exercises above are designed to address this issue as well. Individuals can try to increase their speed at performing each task with practice.

### **Memory**

Memory is a multi-step process and a problem can occur at any step along the way. It is helpful for a neuropsychologist to explore where in the process your memory is being affected, particularly since what seem like memory issues may instead be problems with attention or with visual or auditory processing. For problems that are caused directly by memory deficits, the most common and most effective way to manage the situation is to develop "compensatory techniques", external things that can help you stay organized and remember. Let's look at the stages of memory.

### Attention

This is the first stage. You can't process something and store it if you haven't paid attention to it in the first place. All of the exercises above are intended to address this part of the memory process.

### Encoding

In encoding, a person links information to something that is already known. In other words, a piece of information is categorized. How well you are able to do this plays a large role in whether you are able to store information. For example, suppose you are just learning what a pot is. It is much more effective to categorize it as

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

cookware than as something that rhymes with “spot”. Problems in encoding can arise in several ways. It may not be a categorization problem, but could be the result of a problem with the language center of the brain or with visual or auditory processing areas. In this case, addressing those other issues may help with encoding. Damage to the frontal lobes or in the dorsomedial thalamus can result directly in problems with categorization and organization. We’ll talk about some ideas for treating these and other memory stage issues below.

### Storage

Individuals, particularly those with hippocampal damage and associated mesial temporal lobe damage can be left with a limited ability to store new information. Encoded information does make it to long term memory, but the memory deteriorates quickly and the information can’t be retrieved. You may have categorized a pot correctly as cookware and have stored this information, but your brain just isn’t able to keep the information for long. The next time you see a pot, you won’t remember what it is.

### Consolidation

Consolidation happens when you integrate your new knowledge – a pot is cookware – with more detailed information that you already know. For example, when you have consolidated, you have figured out how it fits into the class of cookware: that a pot is different from a pan, that you can use it to boil water, etc.

### Retrieval

Retrieval is the ability to get information out of memory without cues. Retrieval problems can be the result of damage to a language area (aphasia), or can occur directly with damage to many different areas of the brain. A person with a retrieval problem often has the tip of the tongue phenomena: “Dorothy came from...oh, the name of the town is on the tip of my tongue. Just name a few towns in Kansas. I’ll recognize it when I hear it.” If the memory problem happens before the retrieval stage, a person will not be able to recognize the right name from a list.

### Treatment for memory problems

There are many ideas about the most effective methods for improving memory after brain injury. Below, I’ve listed a couple of methods by McKay Moore Sohlberg and Catherine Mateer.

A common complaint among folks with memory problems is difficulty remembering to do things they were supposed to do. In one exercise, you are given a task to perform, but are asked to wait a specific period of time before doing it. During the wait time, the exercise can be set up so that you either just sit or you perform an alternate activity (a “distracter” task). You do have access to a clock. The exercise becomes more difficult by increasing the amount of time between being assigned the task and having to perform it.

Another way in which memory problems are treated is through the development of a memory notebook system with very detailed instruction and a great deal of practice in using it. A mem-

ory notebook is a binder or planner filled with forms and divided by categories. It is much like a Daytimer® but with sections tailored to address the individual’s memory deficit. Possible sections could include:

- Orientation: A script that you can use to give people pertinent information about yourself, your medical history and any other relevant information.
- Memory log: Forms for charting information about what you have done. You are asked to make a note every time you change your activity during the day. On average, you will be making a note hourly. As time consuming as this may seem, the memory log is usually part of everyone’s memory notebook. Keeping the log helps memory by forcing you to think about what you have done for that period of time. Writing it down further increases the likelihood that you will remember what you have done later. And, if your memory does fail, you have a reference to look at.
- Calendar: The calendar should have dates and times that you can use for scheduling appointments and other activities.
- Things to do: This section has forms for listing errands and other future tasks. It would also contain a space for the due date and completion date.
- Transportation: If you have trouble remembering how to get places, this may contain maps and/or bus information to get you to the places you most commonly go.
- Feelings log: This section has forms to record your feelings about events, etc.
- Names: Contains forms to record names and identifying information of new people.
- Today at work: These are forms that are adapted for your specific job that allow you to record all the necessary information you need to perform your work.

As you are using the memory notebook, you will find that some things that occur fall into multiple sections. For example, if you are invited to a potluck on Sunday night and asked to bring an entrée, you will need to put a note on both the calendar and in the Things to Do section (make an entrée). You may also need to note receiving the invitation in your Memory log, put directions in the Transportation section, or put the host’s information in the Names section. Although this can be somewhat tedious, with practice it will become second nature. The memory notebook is a way of developing better categorization and organization skills that will lead to better encoding even without the notebook.

*\*Part II of II of this article, with references, will be featured in the Winter 2006 Newsletter and appears online ([www.angiomaalliance.org](http://www.angiomaalliance.org)).*

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#### **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.

#### **How You Can Help...**

You may send donations via regular mail or you may use the "Make a Donation" link on our homepage.

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



#### **FUNDRAISING UPDATE**

**Allison Ruggles** and her sister **Lynnelle Corsi** held a charity Halloween party for 80 that included a DJ, food, and a silent auction. We are very pleased to announce that a great time was had by all and that their event, and the donations that resulted from it, raised more than \$10,000 for the Angioma Alliance patient registry. Way to go Allison and Lynnelle!

**Ron Schechter** took the opportunity of his daughter's bat mitzvah to educate the reception attendees about cavernous angioma and Angioma Alliance. During the event, he made available Angioma Alliance wristbands and raised \$252 through sales and donations. What a great idea!

NASCAR driver **Tony Stewart's** foundation made a \$1,000 unrestricted gift to Angioma Alliance. Thank you, Tony. We greatly appreciate your generosity. Thanks also to **Kim Hofelich** whose work made this gift possible.

#### **NOW HERE...**

**Angioma Alliance wristbands *and* car magnets.**

#### **GREAT STOCKING STUFFERS!**

Like the wristbands and car magnets associated with so many other causes, we now have our own. If you have been looking for just the right cause to wear a wristband or display a magnet on your car, or if you want to add to your collection of Angioma Alliance gear, this is the time to order. Angioma Alliance wristbands and car magnets are \$5 each including shipping. You can order by sending a check made out to Angioma Alliance to: Angioma Alliance, 107 Quaker Meeting House Road, Williamsburg, VA 23188, or by using Paypal via the Angioma Alliance link on the website.