Help Find a Cure: Join the Patient Registry

IN THIS ISSUE

- I. HELP FIND A CURE: JOIN THE PATENT REGISTRY
- 2. INTERNATIONAL CAVERNOUS ANGIOMA PATIENT REGISTRY AND DNA/ TISSUE BANK
- 3. NEWS
- 5. STORIES
- 7. RESEARCH NEWS
- 8. CAVERNOMA ALLIANCE UK UPDATE
- 9. WELCOME TO CCM ITALIA/AIAC
- 10. NEWS FROM ANGIOMA ALLIANCE CANADA
- 11. ANGIOMA ALLIANCE DONORS
- 12. ABOUT ANGIOMA ALLIANCE

Note: In this newsletter, the terms "cavernous angioma," "cavernous malformation," and "CCM" are used interchangeably. Disease research requires more than just test tubes and laboratory equipment. Scientists need the help of the patient community to participate in research. To help researchers and speed the pace of research for a cure, Angioma Alliance has developed two programs: the International Cavernous Angioma Patient Registry and the DNA/Tissue bank. A side-by-side comparison of these two programs can be found on the next page of this newsletter. Here I'll focus on the Registry. people are similar to you, query the responses by age, type of lesion, etc.

Second, the people in the Registry become of pool of possible participants in research involving drug trials. We are getting closer and closer to having medications that may prevent or treat cavernous angiomas. To prove that drugs work, scientists have to give medications to people and study the results. By being in the Registry, researchers could contact you to let you know about studies that are happening. Importantly, you are in no way required

The International Cavernous Angioma Patient Registry

Patients, Researchers, Advocates and Physicians Partnering for a Cure

The Internal Cavernous Angioma Patient Registry was created for two purposes. First, information is gathered that researchers can use to better define the disease. When you sign up, you'll enter information about your experience with cavernous angiomas: when and how you were diagnosed, what problems you have had, and general information, such as your age and gender. Researchers can search this information (which is anonymous) to conduct what is called epidemiological research. And you, too, can be a researcher. Use the Explore function to browse the information in the Registry. For instance, if you want to see how many

to say yes to participation. But we know that researchers will need hundreds or even thousands of patients with cavernous angiomas to prove that drugs work. We hope you will consider participating if contacted.

We currently have about 450 participants in the Registry and are hoping for 1,200 by the end of 2012. Only with your help can we reach that goal. Join me in supporting Angioma Alliance by registering today. This is one small way that we can fight back against this frustrating, scary and, at times, devastating disease.

Remember, without you, there can be no cure!

Sara Sukalich

Angioma Alliance

International Cavernous Angioma Patient Registry

What is it?

The Patient Registry is a web-based database and communication tool designed to link patients and the scientific community. By creating a profile on the Patient Registry website, you will be notified about the most recent research studies for which you may be eligible to participate. Registering does not mean that you must participate in any study; it simply notifies you and gives you the option to participate. Angioma Alliance will e-mail you if you match the criteria for a study to give you the opportunity to contact the researcher and participate if you choose to do so.

Why do we need it?

Patient recruitment is one of the most difficult, time consuming and expensive elements of any research study. By having a large group of cavernous angioma patients who are interested in participating in research, and who are registered in the International Cavernous Angioma Patient Registry, Angioma Alliance is able to help researchers with the recruitment process.

For example, if a researcher is looking for 25 women between the ages of 30 and 45 who have a history of headaches, Angioma Alliance can search the Patient Registry to identify women who meet these criteria and contact them to inform them about the study. This direct approach to patient recruitment will help researchers complete their studies more quickly and efficiently.

Who can participate?

Everyone who is affected with cavernous angioma is eligible to participate. We currently have about 450 people registered in the Patient Registry; our goal for 2012 is to increase this number to 1,200 participants!

What is required of participants?

Create an online profile and answer the questionnaire about your current health and medical history. This may take about 30 minutes.

Update your online profile annually (you will receive a reminder by e-mail).

How can you sign up?

Create an online profile at **www.angioma.org**/ **registry**. Read the Terms and Conditions, register and complete the online questionnaire.

DNA/Tissue Bank

What is it?

The DNA/Tissue Bank is a research program where Angioma Alliance collects biological samples, including DNA and surgical tissue, as well as in-depth medical history information.

Why do we need it?

To better understand cavernous angiomas and work toward developing a cure, researchers need help from the patient community. DNA and surgically removed cavernous angioma tissue are valuable resources for researchers who are trying to answer critical questions about cavernous angioma behavior. Some of these questions are: Why do some cavernous angiomas bleed? Why do some grow? Why do some people develop more cavernous angiomas over time?

With the DNA/Tissue Bank program, Angioma Alliance collects and stores surgical tissue and provides it to researchers. To date, our DNA/Tissue Bank has supported the work of eight labs and led to the publication of several important papers.

The medical information collected is used to help us better understand the natural history of the disease. This helps us learn how cavernous angioma affects different people, and provides insight into the normal progression of the illness.

Who can participate?

Participation in the DNA/Tissue bank is limited to individuals affected by cavernous angioma who:

- have had surgery,
- are scheduled to have surgery, or
- who have multiple cavernous angiomas and/or a family history of the illness.

What is required of participants?

- Read and sign our information and consent form.
- Sign and return medical, imaging, and/or tissue release forms.
- Provide a blood sample.
- Complete a 90-minute phone interview with our nurse.
- Complete a 15-20 minute annual update phone interview with our nurse.

How can you sign up?

Complete and submit the interest form on our website at **www.angioma.org/DNA**. Amy Akers will then contact you to begin the enrollment process.

Amy Akers

News

MadoroM auction raises over \$100,000 for Angioma Alliance

Over 200 people attended this year's annual MadoroM wine auction charity in Bakersfield, California on February 25. The auction was the most successful yet, netting approximately \$115,000 for Angioma Alliance. Attendees went over the top in their generosity, bidding as much as \$35,000 for a single item. The organizers of this fundraiser, Liz Neuman and her family and friends, have chosen to restrict this year's auction proceeds for use by the CCM3 Action group. Our thanks to the many generous people of Bakersfield who consider Angioma Alliance their local charity. Our success Liz Neuman and Robin Foster, of Congressman Kevin support.



has everything to do with your McCarthy's staff, at the ModaroM Wine Auction.

Angioma Alliance has put together an outline and checklist that makes it easy to put on your own Fun

> Run in your city. We will also offer the support you need to make it happen! Please contact Savannah Hollis at shollis@angioma.org or Rachel Hart at rhart@angiomaalliance.org.

2012 CCM Scientific Meeting

On November 15-16, 2012, Angioma Alliance will be hosting the 8th annual CCM Scientific Meeting. This international scientific conference attracts experts in the field of CCM research to meet and discuss the latest scientific advances. All aspects of CCM research including molecular pharmacology, biology, animal research and human clinical trials will be discussed at this important meeting. No other national or international meetings attract the same group of scientists, all of whom

Angioma Alliance Fun Run/Walk

Angioma Alliance Board Members Rachel Hart and Savannah Hollis put on a very successful 3rd Annual Fun Run/Walk fundraiser on March 26th near Dallas, Texas. People traveled from all over the US to attend the fundraiser. T-shirts, wristbands and pins were given out and a raffle was held to benefit Angioma Alliance. Everybody had a wonderful time including the great people who volunteered to help make this fundraiser so successful. Event participation has more than doubled since the first event, and the funds raised have more than quadrupled. As Savannah said, "You'd be surprised how many people are willing to support a good cause especially if they know who they are helping!"

Special thanks to Board Member Gary Westcott, who walked in honor of the many members who could not personally attend the fundraiser, and Jessica Maynard-Noe for her hard work and contributions. Great job Rachel and Savannah!

are dedicated to fully understanding the biology of CCM and working toward developing a cure for the illness.

Expected attendance at the CCM Scientific Meeting is about 50 to 60 individuals who represent a international majority of the CCM research community. This includes investigators from the fields genetics, vascular biology, of pharmacology, neurology, radiology, neurosurgery, proteomics, cell biology, as well as biology of zebrafish, mouse and worm animal models. Also included in this meeting from the are representatives Federal Drug Administration and National Institutes of Health. Developing a treatment for CCM will require a global collaborative effort from researchers, clinicians, FDA, and importantly, NIH, industry the patient community. By hosting this meeting, Angioma Alliance aims to help to build these relationships and speed the pace of research for a cure.

SPRING 2012

Connie Lee's Incredible Road Trip

I've been on the road with my daughter Julia for nearly three months, and we've been having a wonderful time meeting families throughout the country. Our journey has taken us across the southern United States, up and down the west coast and into the Midwest.

Our meetings have been powerful. For some people, this is the first time they've ever met anyone else with the illness. In Mississippi, we even brought together family members who had never met! The get-togethers have given folks a chance to share stories, compare doctors, and discuss the future. Some people are planning to organize other events in the future including fundraisers in their areas. Everyone has left committed to joining our patient registry and to encouraging affected family members to register.

We're picking up our trip in June when we travel to Canada for the first Angioma Alliance Canada family conference. If you'd like to participate in a get-together, please email me at clee@angioma.org. You can check our list of planned stops online at www.angioma.org/ roadtrip.

Photos clockwise from top-right: 1. Connie Lee (right), daughter Julia (front), and others at the Pasadena get-together. 2. The San Jose gettogether. 3. Julia Lee with AJ Buscemi and Charlie the Cavernous Angioma Traveling Awareness Bear. 4. The Phoenix get-together.









Stories

I Walked a Half Marathon

On March 25th, 2012, I walked the Dallas Rock-n-Roll Half Marathon (13.1 miles) and finished in 3 hours and 27 minutes.

Some might be say, "Big deal; lots of people participate in these events!" Others may think, "You walked—you didn't run?" I am 64 years old and I am a multiple cavernous angioma survivor. I've had five bleeds over the past twenty-five years; three of which were in my brainstem. I've had two craniotomies. Six years ago, following a bleed on Christmas Day, 2005, and subsequent brainstem surgery, I couldn't walk the three steps from my family room to our kitchen table without holding onto something or someone. So yes, this is a very BIG DEAL to me!



I was out there with 14,500 other people, but I would guess I was the only multiple hemorrhage brain survivor. Because it was the Rock-n-Roll Half Marathon. а different live rock and roll band blasted upbeat music at every mile point. Local high school cheerleaders lined the route, and Dallas С 0 w b 0

Cheerleaders cheered us across the finish line. All of these people—none of whom I knew—were spurring us on to completion. This reminded me of the thousands of folks who prayed for me and cheered me on following my bleeds and surgeries. And yes, even people I didn't know were rooting for me to get better.

Some things about the Marathon made me laugh out loud. One person was holding a banner that said "Pain is Temporary, but your finishing time will be posted on the Internet forever." Another guy held a banner that read, "Go Faster, My Arms are Getting Tired." I overheard one lady at the five-mile point say, "They routed us the long way out of downtown Dallas. Had we taken a more efficient route, we could have gotten to this point much quicker." Apparently she didn't understand that a marathon does not equal the shortest distance between two points. Through my multiple illnesses, I learned that my cavernous angioma bleed deficits were mostly temporary and that no matter how much I wanted to get better fast, healing was a slow process with no shortcuts. And, some days I just needed a good laugh!

I was also amused by some of my fellow participants. All the advice for preparation said to train hard for weeks, but to take the last five days or more off, to build up your endurance and prevent injury prior to the actual day of the event. In spite of this, I overheard a lady tell a first aid station volunteer (at around mile 9) that she was feeling really tired. The first aid volunteer asked if she had been keeping herself hydrated; drinking plenty of water. She replied, "Yes. I don't understand it. I walked 13 miles yesterday afternoon and felt fine, but today I am really tired." The volunteer patiently explained that she was likely just "out of gas." Again, this reminded me of my recoveries. Some days I overdid it in my attempt to rehabilitate, and it would take several days off to recover the stamina to start pushing myself to recovery again.

Yes, participating in a half marathon was similar to recovering from a cavernous angioma bleed. Both are easier when you have a brigade of supporters cheering your every step. Both are grueling events, where the pain and suffering is mostly temporary (even if temporary is measured in years, not days). Both take time and patience. And both burdens can be lightened by having an occasional chuckle.

Finally, the fact that I was able to competitively walk a half marathon proves that it is possible for a person to survive five brain hemorrhages and two craniotomies, and to overcome serious deficits, even if it takes six years.

Walking in this marathon was so rewarding, I might walk another one!

Les Duncan is the author of Brain Storms; Surviving Catastrophic Illness



Proceed north to the third traffic light and bear right to stay on Old Pecos Trail into town. Old Pecos Trail becomes Old Santa Fe Trail which dead ends into La Fonda at Water Street. Go around the hotel by turning left on Water, then making an immediate right. At the traffic light at San Francisco Street, turn right again – away from the Plaza and toward the St.

Francis Cathedral Basilica. Proceed to the hotel's parking garage at the end of the block, on the right side of the street.

6

Research News

First Clinical Study of Statin Drugs Begins at the University of New Mexico

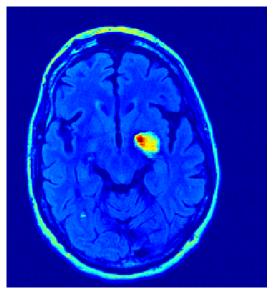
We are excited to announce that the University of New Mexico is currently recruiting participants to be involved in the first clinical trial for treatment of cavernous angioma.

Background

Individuals affected by cavernous angioma have clusters of enlarged blood vessels in the brain and/or spinal cord. Cavernous angioma blood vessels are abnormally permeable and may leak blood into the surrounding brain tissue. In studies of mice with cavernous angioma, use of statin medications (which are commonly prescribed to lower cholesterol) strengthened the blood vessels and prevented leakiness. This research project is looking at whether statin medication can also change the leakiness of the blood vessels in patients with cavernous angioma.

About this study

The research doctors will investigate the permeability of blood vessels using a magnetic resonance imaging (MRI) technique called dynamic contrast-enhanced MRI (DCEMRI). This technique measures leakiness but does not change it. Leaky vessels can be visualized by red, orange and yellow colors as shown below.



Example of DCEMRI on a cavernous angioma patient. Image courtesy of Dr. Blaine Hart and Dr. Leslie Morrison, University of New Mexico.

In this study, 30 participants will be randomly assigned to either simvastatin or no treatment for three months, and MRI will measure their blood vessel permeability at the beginning and end of the period. Importantly, this study is focused specifically on patients with a confirmed diagnosis of CCM1-CHM by DNA testing. The Common Hispanic Mutation (CCM1-CHM) is an inherited form of cavernous angioma frequently seen in Hispanic families of the southwestern United States. To be eligible for this study, participants must have elevated cholesterol levels necessitating statin treatment.

Goals of the project

This study is designed to help researchers learn more about the biology of cavernous angioma blood vessels and how drug treatment affects leakiness of those vessels. Importantly, this small study will help to guide plans for future larger-scale clinical trials.

For more information about the study, including who to contact about participation, please visit: http://rarediseasesnetwork.epi.usf.edu/BVMC/

Amy Akers & Beth Baca

Other Research News - Recent Publications

Sporadic CCM: An Italian research group published a study about the genetics of sporadic CCM. Sporadic CCM is not caused by mutations in any of the CCM genes; however, this group identified specific genetic variants that are more likely to be found in people with sporadic CCM than in the general population. (PMID: 22378217)

Conservative Management of CCM: Scottish researcher and Angioma Alliance Scientific Advisory Board member Rustam Al-Shahi Salman studied the untreated clinical course of cerebral cavernous malformations. This study looked at 139 individuals with at least one CCM who did not undergo surgical treatment. The findings show that within 5 years of experiencing a hemorrhage or neurological symptom, the risk of experiencing a recurrent symptom is higher than the risk of the initial symptom. However, after 5 years, the risk of experiencing additional symptoms begins to decline. (PMID: 22297119)

CCM3: While studying the function of the CCM3 protein, researchers in Spain identified that it plays an important role in protecting cells from damage caused by reactive oxygen species. Reactive oxygen species can damage cells and may have a role in other common diseases like heart disease and cancer. These molecules are also neutralized by antioxidants; compounds found in many foods including fruits and vegetables. (PMID: 22291017)

To read more about these studies, please use the pubmed.gov search engine and search for these papers by their PMID number listed above.

Cavernoma Alliance UK Update

Health UnLocked

Cavernoma Alliance UK has recently become a member of Health UnLocked, a community that offers online polls which can be accessed by all (http://cavernoma.healthunlocked.com).

All members are encouraged to participate in the polls, which ask questions such as whether you were misdiagnosed by your GP, what age you had diagnosis of cavernoma, as well as questions on the location of your cavernoma. Health UnLocked is free to participate. Please participate and check into the Health UnLocked site regularly because this will give health professionals an accurate picture of your response to the polls' questions.

Research

The Guidelines for Clinical Management of CCM are now available to read or as a PDF download for free on our site, www.cavernoma.org.uk. These CA UK-funded guidelines would not have been possible without the generous support of Genetic Alliance UK and members especially Frank Gent and LAC.

CCM Italia

Ian Stuart, the founder-member and co-ordinator attended the opening ceremony of our affiliated organisation, CCM Italia at the University of Torino, Italy on Friday 23 March 2012. Friday 23 March saw the birth of this important association, and on Saturday Ian gave a presentation on the work of CA UK. Professor Francesco Retta and the students of the "CCM Dream Team" are working hard in Professor Retta's lab on the genetics of cavernous malformations.



Brain Awareness Week

Brain Awareness Week, on Saturday 17 March 2012, was attended by over 30 members who listened to Arlene Wilkie, CEO, Neurological Alliance, provide updates on the parliamentary process of neurology, details of which can be found on our website. Members also heard Mr Richard Kerry, consultant neurosurgeon, John Radcliffe Hospital, Oxford, deliver a talk entitled Cavernoma, The Past, The Present and The Future. In this talk, Mr Kerr discussed what we now know as cavernous malformations, their present treatment and provided projections of neurosurgery in the future.



Jumping for CA UK

Lee Smith is boldly going where many men and women have gone before (but you won't catch me doing it—my cavernoma, of course). Lee and friends are jumping from a plane to raise some much needed funding for CA UK. Please go to his JustGiving page and sponsor him (www.justgiving.com/jumpforzane). Lee's jump for Zane (his son with multiple cavernomas) occurs on June 16.

The Forum

This year's Forum will be held on 16 June 2012 at The Grange Holborn Hotel, from 9 am to 5 pm. Our keynote speaker is Mr Owen Sparrow, consultant neurosurgeon, Southampton University Hospital. Members' Workshops will follow morning coffee. We then have lunch, followed by speakers from the National Hospital for Neurology and Neurosurgery, Queen Square, London, on epilepsy and physiotherapy after a bleed. I'm looking forward to seeing many of you at our annual conference.

Ian Stuart



Welcome to CCM Italia/AIAC

On March 23-24, 2012 a new patient-researcher organization affiliated with Angioma Alliance was born at the Faculty of Medicine and Surgery "San Luigi Gonzaga" of the University of Torino, Italy: CCM Italia—Associazione Italiana Angiomi Cavernosi (AIAC).

The idea dates back to November, 2010, when I attended the Angioma Alliance annual Pathobiology of Cerebral Cavernous Malformations Scientific Workshops, held in Washington, DC. Impressed by Angioma Alliance's successful experience in uniting CCM patients and scientists with interests in different aspects of the CCM disease, I became convinced of the need to create a patient-researcher association in Italy.

The CCM Italia/AIAC association was formed with the advice and support of the Telethon Foundation, and follows the establishment of the CCM Italia website (www.ccmitalia.unito.it), the first Italian portal for CCM patients and family members, in June, 2011. Because of this dedicated website, Italian CCM families have the opportunity to get to know each other and interact with people providing information and support. In addition to providing an informative and supportive platform for Italian CCM patients, the CCM Italia/AIAC organization aims to meet an existing need for increased awareness and



understanding of CCM (even among medical doctors), as well as at building an Italian multidisciplinary research network for information sharing and cooperation among clinicians and researchers with complementary expertise and interests related to diverse aspects of the CCM disease.

Acting locally, cooperating globally is the slogan of CCM Italia/AIAC. Indeed, while acting on a nationwide scale, this organization is also interacting with CCM-focused organizations active worldwide, including Angioma Alliance and Cavernoma Alliance UK.

Francesco Retta



The first meeting of CCM Italia/AIAC. If you look closely, you can see Cavernoma Alliance's Ian Stuart to the left of center...

SPRING 2012

News from Angioma Alliance Canada

Since the inception of Angioma Alliance Canada last year, our group has been hard at work getting more organized. Using online media we were able to complete the writing of our constitution and have submitted our



application to become an official charitable organization under Canadian Law. Once approved, we will be able to write tax receipts for donations, which will allow us to begin major fund raising later this year.

Besides writing our constitution, our organization was also able to produce its first brochure about Cavernous Angioma. Using the brochures of the Angioma Alliance and the Cavernoma Alliance UK as templates, we were able to write our brochure with the Canadian patient in mind. Our goal is to make every neurologist and neurosurgeon in Canada aware of this brochure, hoping they will be willing to distribute it to their cavernous angioma patients. The president of the Angioma Alliance Canada, Henk van der Wilt, was able to increase awareness on Cavernous Angioma in his community, by having the township he resides in, Wainfleet, declare February 28, 2012 as "Cavernous Angioma Awareness Day." On top of this wonderful accomplishment he managed to get his story published in a regional newspaper. (http://bit.ly/I5IBN9)

To coincide with Connie Lee's road trip (see page 4 of this newsletter), Angioma Alliance Canada will be hosting its first ever Family Conference on Saturday June 2, 2012 at McMaster University in Hamilton, Ontario. Connie Lee will be there as guest and speaker. Dr. Brent Derry, from the Toronto Hospital for Sick Children, will also be a speaker. He will address the audience on cavernous angioma research. It promises to be an exciting day. Any interested Canadians, as well as international guests, are more than welcome to attend. Kindly register online at www.angioma.ca.

Henk van der Wilt

Brian Morris Runs Goofy Marathon to Raise Money for Angioma Alliance

Who would run a half marathon on one day and just turn around and run a full marathon the next? Yes, we're talking 39.3 miles in two days! Some may call it a race fit for "Goofy," but others, like Brian Morris, call it a duty motivated by a friend and running buddy.

It was 2010 when his running partner Stephanie was forced to hang up her running shoes after being diagnosed with cerebral cavernous malformations. So moved by his friend, Brian decided to challenge his feet and endurance to run Goofy's Race and a Half Challenge—a combination of the Walt Disney World half Marathon and the Walt Disney World Marathon—to raise money for Angioma Alliance.

Brian contacted all of his friends by email and explained the situation. He asked for their financial support if he would run this marathon. Brian raised over \$6,000 in a couple of months through his friends and the matching program offered by his employer, Bank of America. He found us when searching the Internet to learn more about Stephanie's disease and decided he could do something to help find a cure for Stephanie. Hats off to Brian and all of his dedication to supporting our cause!



About Angioma Alliance

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

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How You Can Help

Your contributions will help fund conferences and forums, increase research, and enhance outreach and support efforts. Our pins, car decals and wristbands support the mission and growth of Angioma Alliance. Share these meaningful gifts with your friends and family.

Each donation of \$10 or more will come with a CCM lapel pin as a thank you gift. Our "little red guy" pin is a wonderful way to increase awareness of cerebral cavernous malformation (CCM). Increasing public awareness can go a long way toward increasing research funding and improving quality of life for those with cavernous angioma. Each pin comes with cavernous angioma business-size information cards that can be handed to anyone who might have questions.





Angioma Alliance also offers a wide range of apparel and other items featuring the Angioma Alliance logo. There are t-shirts, sweatshirts, hoodies, mugs, stickers and much more available. You can find these items in our Café Press store. To purchase Angioma Alliance merchandise, go to our web site and click the Store link at the top of the page.

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

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

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