Do your friends and family really understand what a cavernous angioma is? Would you like to help us educate the world? This month is your opportunity to share the information you have with anyone who is interested. Here are some things you can do:

**On Social Media**
- Have you liked our Facebook page or followed us on Twitter? Do it, now, then ask your friends to like and follow us too.
- Write a two-paragraph version of your story and send it to us at info@angioma.org along with your picture so we can post it on our Facebook page this month.
- Share or retweet the cavernous angioma facts we’ll be posting to our Facebook page and Twitter feed throughout the month.
- Create a YouTube video, write a blog post, and exploit all the social media you can.
- Write the long version of your story and send it to us for the Member Stories section of our website.
- Tell us what you’re doing to raise awareness so we can share your ideas with others; and send us a picture if you can.

**In Public**
- Wear a red ribbon and ask your friends and family to wear one, too.
- Offer to tell your story at your place of worship, your school, the local nursing school, your hospital, the local charitable clubs, or anywhere people are willing to listen.
- Begin planning your October Anywhere Walk. It’s not too soon! We’ve just created a guide to help you organize a more ambitious walk. Download it at www.angioma.org/documents/walkguide.pdf.
- Angioma Alliance has also created a short booklet with patient stories. You can find the file at www.angioma.org/documents/inspiration.pdf after June 10, or contact us if you would like printed copies. Together, we can bring attention to our illness for improved diagnosis and better treatments.

**Traditional Media**
- Write a short letter to the editor of your local paper sharing your experience of the illness and letting your community know about Cavernous Angioma Awareness Month.
- Contact your local TV and radio news programs about your story.
- Write your government representatives to ask for increased research funding.

**Note:** In this newsletter, the terms “cavernous angioma,” “cavernous malformation,” and “CCM” are used interchangeably.
Deciding whether to test asymptomatic children is a very personal decision. No matter what choice a family makes, a person known to have multiple lesions would need to be tested first, as the “index patient.” Knowing the index patient’s exact mutation allows for specific testing of family members to determine if they are affected.

If the family mutation is known, there are a number of reasons to test asymptomatic children:

1. You will find out if your children don’t have a mutation, which will let you stop worrying about their disease status. Each child of a parent with a mutation has only a 50% chance of inheriting the mutation.

2. If a child who does have a mutation has ambiguous symptoms, doctors and, particularly, insurance companies, will be more driven to follow up with neurological testing. Children have died because they were not tested despite a known family mutation. They showed up in the ER and were sent home with diagnoses of migraine, or treated for flu instead of brain hemorrhage. Insurance companies have denied coverage for CT scans in undiagnosed children when the only symptom is headache. Less extreme, seizure disorders can be picked up sooner, before they cause developmental damage. ADHD can be understood in its context instead of being treated with stimulants.

3. You can take precautions for kids who have a mutation and you can eliminate the need to take precautions for kids who test negative. For example, it can be a burden to restrict ibuprofen but most doctors believe children with a mutation should stay away from this medication because of its blood-thinning properties. If parents don’t know whether their child has the illness, they should be treating them as if they do, just in case. This means all children of a parent with multiple cavernous angiomas, regardless of their mutation status, should be restricted from taking ibuprofen if they haven’t had genetic testing. That’s an unnecessary restriction on kids who don’t have a mutation but don’t know it.

4. An MRI isn’t enough. A negative MRI in a child doesn’t mean the child doesn’t have a mutation. It simply means the child has no lesions at that moment, or very small lesions that are undetectable. In people with a hereditary form of the illness, more cavernous angiomas develop over time. A child, particularly those with a CCM1 or CCM2 mutation, may not develop their first lesion until later in childhood. Only a genetic test can determine if a child doesn’t have the illness or simply hasn’t developed a lesion yet.

5. You may want to consider changes to your will. Some parents choose to establish trusts for children with positive genetic results to protect the child’s ability to receive benefits should the child become disabled at some point in their life. This is something to discuss with an estate planning attorney.

However, there is also a negative side to testing asymptomatic children:

1. There is no denying that a positive genetic result changes childhood and family life. At a minimum, it adds MRIs, visits to a neurologist, and anxiety to the life of both the child and the parents. It can mean seeking out a therapist, at least temporarily, to help with the emotional adjustment. There may also be issues between siblings if some test positive for a mutation while others do not.

2. You take away the child’s choice of knowing if they have a mutation. Doctors often advise parents to wait on testing for diseases that have no treatment. They suggest waiting until an individual reaches an age of consent so they can make their own choice about whether or not they want to know. One could debate whether cavernous angiomas truly fall in the “no available treatment” category, since there can be childhood onset; surgery intervention is sometimes critical, and symptoms like seizure and headache do have treatments.

3. In the US, a positive genetic result can have a financial impact depending on your insurance coverage. The passage of the Affordable Care Act means that your insurance rates will no longer be affected, but adding an MRI and a specialist visit every year can be a strain because of co-insurance and co-pays. If testing isn’t covered by insurance, then the cost of testing each child will be approximately $250. (This is the price to test a family member where the index patient’s mutation is known. Testing of the index patient can cost a few thousand dollars).
4. In the US, children won’t have difficulty obtaining medical insurance and they can’t be discriminated against in employment as a result of a positive genetic test since the Genetic Information Nondiscrimination Act (GINA) was enacted. However, they may have difficulty buying life insurance if they start as adults. Children can be added to a parent’s life insurance policy even with a positive genetic test. When they are adults, the children will be able to separate to their own policy and add more coverage as needed.

There are some conditions where testing should be strongly considered. If a parent’s testing finds a mutation on the CCM3 gene, testing of children is necessary. At least 50% of people with a CCM3 mutation will have their first hemorrhage in childhood, lesions will bleed often, and such children will be at risk for a number of other disorders as part of what we’re coming to understand is a CCM3 syndrome. Second, once we have drug treatments, it could be considered negligent to withhold something that could prevent a brain or spinal hemorrhage. Not all kids will get medication; just the ones who test positive for a mutation. So, in a few years, it’s likely all kids of parents with the hereditary form of the illness will be tested as part of the standard of care.

If you do decide to go ahead with genetic testing for your children, you’ll find a letter that you can print out and take to your doctor or genetic counselor on pages 7-8 of this newsletter.

Connie Lee

Children’s Book about Cavernous Angioma in the Works

A group of Angioma Alliance members will be creating a book for children ages 8-13 who have cavernous angiomas. The book will explain the illness and help children understand the experiences they may have as a result of being diagnosed with cavernous angiomas.

The project committee includes Rebecca C. Jones, who has authored 16 children’s books, Myrna Sarowitz, a retired clinical psychologist and special education teacher, plus a group of Angioma Alliance parents. If you would like to help with this project, contact Connie Lee at clee@angioma.org.

Research Update

Over the past three months, there have been more than 25 publications describing CCM research findings. The studies are quite varied; some focus on care of human patients while others aim to understand the fundamental biology of the CCM disease genes and proteins. Below is a summary of a few selected publications.

Lesions from patients with sporadic cerebral cavernous malformations harbor somatic mutations in the CCM genes: evidence for a common biochemical pathway for CCM pathogenesis.

An important study from Duke University Medical Center investigated the genetic mechanism for sporadic CCM lesion development. It is known that familial CCM patients typically inherit one CCM gene mutation from a parent and acquire a second mutation specifically within the lesion tissue. This study team found evidence of a similar mechanism with sporadic CCM: CCM gene mutations were identified specifically (and only) within the lesion tissue in these sporadic cases. This supports the idea that sporadic lesions develop because of a similar genetic mechanism as familial CCM. Importantly, this study provides biological evidence that all forms of CCM may be able to be treated by the same drug therapy in the future.


Clinical course of untreated pediatric brainstem cavernous malformations: hemorrhage risk and functional recovery.

A Chinese medical team investigated the clinical outcome for CCM patients who suffer from brainstem lesions during childhood. They reviewed records of 85 pediatric patients followed up for a total of 5 years. Their findings show that without surgical intervention, 80% of patients had experienced prior hemorrhage, but that individual hemorrhage risk decreased after two years. At the end of the study, 23% of participants had worsened, while complete recovery was experienced by nearly 50% of participants. Larger lesion size and the presence of edema (swelling) appeared to be related to a greater risk of hemorrhage.

Beyond the lesion: The epileptogenic networks around cavernous angiomas.

The researchers of this study sought to investigate how much of the brain that surrounds a CCM lesion contributes to seizures (the epileptic zone). This study is specifically focused on those patients who experience focal drug-resistant epilepsy. Surgical removal of the lesion and hemosiderin ring is typical to treat these cases, but it is not always curative. Using a specialized electrode technology called stereoelectroencephalography (SEEG), this team discovered that a patient’s epileptic zone may extend beyond the region directly adjacent to the lesion, and the pattern of tissue involved in that zone can be complex and irregularly shaped. This small, six-patient study is intriguing and needs to be repeated on a larger scale, but the authors suggest that patients with drug-resistant epilepsy consider having their unique epileptic zone defined prior to surgery.


Long-term natural history of incidentally discovered cavernous malformations in a single-center cohort.

A research team at the Mayo Clinic in Rochester, MN, aimed to investigate the clinical course of incidentally discovered intracerebral CCM lesions. Incidental findings are those that are discovered by accident, and are therefore presumed not to be associated with clinical symptoms. The study group consisted of 107 participants with an average age of 52 years (+/- 20). The team found that, of this group, only two patients experienced hemorrhage after their angiomas were identified. Furthermore, no patients experienced seizures during the follow-up period (median 12.5 years). The study concluded that the hemorrhage rate of incidentally found lesions is very low. This data is most relevant for clinical management of adults with single, incidentally found lesions; in these cases, risk of bleeding is likely to be less than the risks associated with brain surgery.


Are there effective alternatives to surgery for the treatment of symptomatic brainstem cavernous malformation?

Brainstem CCM lesions occur fairly commonly and present unique challenges to medical management because they have a higher bleeding rate and are more difficult to reach surgically, as compared to lesions in other parts of the brain. In this expert opinion paper, a team of Italian surgeons recommends surgery for brainstem lesions that have previously bled and that are causing neurological symptoms. However, conservative management (MRI monitoring without surgery) may be appropriate for those whose brainstem lesions are not actively bleeding, and/or are located near the fourth ventricle, or deep within the brainstem. It is the opinion of these authors that radiosurgery should only be considered for those lesions that are aggressively and actively bleeding and are otherwise inaccessible for traditional surgical removal.


CCM3, a gene associated with cerebral cavernous malformations, is required for neuronal migration.

A Yale research team further investigated the function of the CCM3 protein and discovered an important role for the development of neurons that is beyond the scope of CCM disease. This team showed that in addition to its cellular function in endothelia cells, the CCM3 protein is required for developing neurons to properly migrate to their proper location. If CCM3 is mutated or otherwise not functional in neurons, those developing cells will not become properly positioned or not have the correct shape/structural formation. Moreover, it was shown that a loss of CCM3 function causes an increase in Rho Kinase activity in the brain. Rho Kinase is the drug target for both Fasudil and statins, which are currently under investigation for CCM therapy.


“Like” Dr. Amy Akers’ page on Facebook to stay on top of the latest cavernous angioma science news. You can find her at https://www.facebook.com/AmyAkersPhD.
**What I’m Working On: Director Tracy Brown**

I’m Tracy Brown, and I’ve been on the Board of Directors for Angioma Alliance for about a year. I found Angioma Alliance two years ago, after my son Zach had 2 hemorrhages from a brainstem cavernous angioma. Since that time, I’ve done all I can to help further research and awareness.

Last year we held our first Zach Brown 5K for Angioma Alliance, which grew into the Angioma Alliance Anywhere Walk. People participated in over 30 cities and six countries, and we had about 300 local participants. All of the money raised goes to the Angioma Alliance. I felt it was important to attach Zach’s name to the event because so many people saw what he had gone through the last couple of years, but wouldn’t know the disease by name.

I am currently working on this year’s 5K, which will be held in Edgewater, MD, at YMCA Camp Letts on October 5. Again, we’re encouraging people around the world to join us by walking with loved ones wherever they are. T-shirts, bracelets, and bibs are great at getting people used to seeing the word “angioma,” and if we are going to find a treatment and eventual cure we need people to know we exist.

I also organize smaller fundraising events like an evening at Sweet Frog frozen yogurt (June 11, in Edgewater, MD) and a dinner/dance on July 19. We are a small organization compared to those of other illnesses, and you can be certain that the dollars you raise or donate directly impact the future care and treatment of cavernous angioma patients.

I am very open to ideas and suggestions for fundraising, and I’m willing to help others who are planning their own events. I am so grateful for the support we received thus far, and I know the second annual Zach Brown 5K for Angioma Alliance will be bigger and better than last year!

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**2014 Dylan Mayer Rock & Bowl for Angioma Alliance**

The 2nd Annual Dylan Mayer Rock & Bowl for the Angioma Alliance was held on April 12th in Hamilton, Ohio (just outside Cincinnati). It was another successful event as the Rock & Bowl raised a little over $16,000. The proceeds went directly to Angioma Alliance. In their first year (2013), the Mayer family and their volunteers raised a little over $11,000. They not only topped their first year number, but they beat it by an astounding 45%. Tony and Cari Mayer attributed the additional success to a few additions: adding lane sponsors, more silent auction items, a closest to the pin/longest drive golf simulator contest and a photo booth.

Dylan Mayer (3 years old) has CCM1 and had surgery in July 2012 to remove a bleeding lesion from his right frontal lobe that caused seizures. He currently has other lesions. Dylan’s mother (Cari) and grandmother (Debbie) both have CCM1 but are currently asymptomatic.

Tony and Cari want to again thank family, friends, volunteers, Angioma Alliance, Alley’s on the River, the generous sponsors, and everyone who attended and donated. It was another fun, memorable evening, and we look forward to holding another event next year.

**CCM3 in Indy Walks On**

On May 16, the CCM3 in Indy group held their first 5K walk and family fun day at Greenwood Community High School in the Indianapolis area. The crowd, and especially the kids, enjoyed balloon animals, inflatables, face-painting and a DJ.

CCM3 in Indy, led by Heather Sanders and Jessica Morrison, in support of CCM3 patient Lexi Sanders, has raised over $5,000 toward the work of the Angioma Alliance CCM3 Action group in the past year.
New Board Members

Ryan Lisiak

Ryan has been involved with Angioma Alliance for several months, and recently joined the Board of Directors. He currently lives near Hartford, CT, with his wife and two young boys. He manages a Business Unit for Danaher Corporation, a $20B diversified manufacturing company. His first CCM was found in 1999 in his brainstem, at which time he was treated with stereotactic radiosurgery. In 2011, he was diagnosed with his second CCM in the left thalamus.

Ryan is currently assisting Angioma Alliance in a few ways. Along with Connie Lee, Dr Amy Akers and fellow board member Kristen Lewis, he is helping to affordably advance our genetic testing initiative. The goal is to collect genetic information of a large sample of individuals who likely possess the CCM1-CCM3 mutations. We are working in parallel with scientists and drug companies to establish a plan to use this information for human drug trials. Ryan is also working with other members of the Angioma Alliance community to coordinate fundraising activities in the Boston area. If you would like to support these efforts with your time or ideas, please reach out to Ryan at rlisiak@gmail.com.

Jeff Jin

Jeff was first diagnosed with a cavernous angioma in his brainstem in 1992 while in college. He underwent several surgeries and extensive inpatient and outpatient rehabilitation. He was able to return to the University of Pennsylvania the following year, and went on to graduate with a BA in Anthropology and then a Masters of Social Work. Jeff became a member of Angioma Alliance in 2004 before undergoing a gamma knife procedure, and has not suffered a reoccurrence since 2001.

He currently works at the Kennedy Health System dialysis center, where he also serves on their Executive Diversity Council. He is active as a volunteer with the Animal Adoption Center in New Jersey, and at the University of Pennsylvania Alumni Secondary School committee interviewing high school applicants. He is also an international lecturer and educator on LGBT issues with the National Kidney Foundation. Jeff will be working with Kristen Lewis to identify and apply for grants to support Angioma Alliance’s clinical drug trial initiatives.

Crystal Shaulis

In 2010, at age 25, Crystal was diagnosed with an inoperable brainstem lesion following a large bleed in the medulla. Once home, with some coordination and feeling returning to her hands, she nervously looked for blogs authored by others who were going through the same ordeal. She quickly realized how small the angioma community really was, and, in response, created the blog Girl with a Pearl-Sized Cavernous Angioma (http://calabresellas.blogspot.com), documenting her struggle with diagnosis, recovery and life beyond.

Soon after, she became a part of the Angioma Alliance community and attended family conferences in the United States, Canada and the United Kingdom. During this time, Crystal also continued with her studies and recently graduated summa cum laude from Western Michigan University’s Gwen Frostic School of Art and the Lee Honors College. She is currently an instructor, intern coordinator, and volunteer for the Kalamazoo Book Arts Center.

Crystal will be organizing fundraising events, spreading awareness about cavernous angioma, and managing Angioma Alliance’s website content and Facebook page.

Are you interested in a leadership role with Angioma Alliance? We are currently expanding our Board of Directors and are seeking applicants. We are looking for individuals who have had managerial experience in communications/media, event planning, fundraising, and/or grassroots organizing.

We ask that you dedicate an average of 3-5 hours/week to Angioma Alliance work, including a monthly Board conference call (usually on Sunday evening), and that you attend our International Scientific Meeting in November (this year November 6-7) in Washington, DC.

On the Board of Directors, you will be the first to find out about initiatives and advances in research, and you will be a member of the premier body shaping our path toward a cure. For more information, or to express your interest, contact Connie Lee at clee@angioma.org.
Dear Physician or Genetic Counselor:

As the Chief Scientific Officer and clinician members of the Angioma Alliance Scientific Advisory Board, we write to endorse the critical importance of pursuing clinical genetic testing for cavernous angioma (cerebral cavernous malformations, CCM, cavernoma) patients who have a family history of the illness and/or multiple cavernous angiomas. This is an autosomal dominant disease with one of three gene loci and nearly complete clinical penetrance during a patient's lifetime. We ask that you help your patients obtain clinical genetic testing, by referral to one of the laboratories listed below, or by consulting a genetics professional or neurologist for this purpose. Identifying a patient's genotype, which may have immediate clinical implications for the patients and their kindred, is important for clinical monitoring as well as for future research endeavors, as described below.

- CCM follows an autosomal dominant inheritance pattern and therefore can affect many members of a patient's multi-generational family. First degree relatives have a 50% likelihood of sharing the disease, yet clinical screening by MRI is expensive, may require IV contrast or sedation, and may have occasional false negative results. Delay in obtaining a specific diagnosis may result in unnecessary and sometimes risky diagnostic procedures, such as angiograms or unnecessary surgery. Identifying your patients' genetic mutations will enable family screening with greater confidence, and will allow MRI screening to be targeted to other family members at risk. Once the family gene is known, a negative genetic test result for a relative is reassuring not only to that individual, but for all of that individual's descendants and will alleviate the burden and costs of imaging of unaffected relatives and their offspring.

- The different genotypes of CCM are not alike. All patients with familial CCM require monitoring and follow-up care. However, patients with CCM3 gene mutations require additional specialized care and monitoring. These patients are known to have a particularly severe and multi-systemic disease course including early age of symptom onset, high lesion burden, high hemorrhage rates and an association with meningiomas (Riant et. al 2013, PMID: 23801932). A low threshold is appropriate in these cases for aggressive screening of vascular, tumor and other pathologies in association with subtle symptoms.

- Genotypic information will be important for expediting and facilitating recruitment for future clinical trials. Identifying a drug treatment for this illness will dramatically impact the prognosis for CCM patients as well as greatly reduce the lifetime healthcare cost. Genetic information will help to define the patient population for a trial and to determine whether a given drug treatment will be effective in all forms of the illness. Early trials will likely focus on cases with a defined genotype.

Recent publications report that as many as 95% of familial CCM patients will harbor a mutation in CCM1, CCM2 or CCM3. Mutations are identified following a tiered approach of standard gene sequencing to be followed with deletion testing, where appropriate. For reference, please see Riant et. al 2013 (PMID: 23595507) and Schroder et. al, 2013 (PMID: 23722637). A template letter of medical necessity for insurance providers is available at: www.angioma.org/documents/ccmLMN.docx. Clinical diagnostic genetic testing can be ordered from a variety of for-profit companies including PreventionGenetics, GeneDX, Athena Diagnostics, and ARUP Laboratories.

Angioma Alliance is a 501(c)3 non-profit organization. All donations are tax deductible.
Thank you very much for your support and assistance as we strive to increase awareness of the importance of genetic testing for our patients and their families. Please feel free to call Dr. Amy Akers at 757-818-0403 with any questions. She can also be reached via email at amy.akers@angioma.org.

Patients, families and health care providers are encouraged to review updated scientific information about this disease, on the Angioma Alliance website at www.angioma.org.

Sincerely yours, on behalf of Angioma Alliance,

Amy Akers, PhD
Chief Scientific Officer
Angioma Alliance

Issam Awad MD, MSc, FACS, MA (hon)
Chair, Scientific Advisory Board
University of Chicago

Kelly Flemming, MD
Mayo Clinic

Leslie Morrison, MD
University of New Mexico

Kevin Whitehead, MD
University of Utah

Angioma Alliance is a 501(c)3 tax exempt organization. All contributions are tax-deductible.
International News

Cavernoma Alliance UK

Our charity has been busy the last few months. We have been organising CaverHubs throughout the country; these events began with Professor Paul Marks giving a talk on neurovascular surgery and cavernoma to the Yorkshire CaverHub in early May. And during the following weeks, Mr Richard Kerr and Mr. Owen Sparrow, consultant neurosurgeons in Oxford and Southampton respectively, presented talks on cavernoma.

Angela Yeomans and Ian Stuart have been raising awareness amongst young, recently-qualified neurosurgeons. A three-day conference was held in early May at the Royal College of Surgeons in London, where CAUK had a notable presence.

As written about in previous newsletters, the Big Lottery have been extraordinary generous. But our grant does not cover all of CAUK’s activities. Consequently, CAUK had to launch an appeal to fund the first step in identifying the correct way to treat and manage cavernoma, review what is known about cavernoma, and identify the priorities for research. As mentioned in the Spring Newsletter, this will cost £25,000 (about $40,000) and provide CAUK with the information needed to carry out the research.

We applied for funding from a number of bodies. All of our proposals were unsuccessful except £5,000 ($8,000) from the Hospital Saturday Fund. However, the leaders of this research project, Mr Neil Kitchen, National Hospital for Neurology and Neurosurgery, and Professor Rustam Al-Shahi Salman, University of Edinburgh, managed to secure combined funds of £6,000 ($10,000). This still left CAUK with a shortfall of £14,000 ($22,000). The Trustees committed themselves to matching £7,000 ($11,000) from CAUK reserves if members also raised £7,000.

CAUK emailed all of its members on 24 April and created a dedicated site on JustGiving. Members were fantastic in their response. Within the week we had almost reached our target, and, as I write this to you, three weeks after our initial appeal, the JustGiving page stands at £7377, or more than $11,000! In addition to our UK residents, there was an outpouring of generosity from our overseas members in America, Australia, New Zealand, Spain, Sweden, and Ireland, including many members who chose to remain anonymous. On behalf of the staff and Trustees, thank you for an incredibly successful appeal. CAUK now has sufficient funds to apply to the James Lind Alliance.

The 8th International Cavernoma Alliance UK Forum will be held at the Grange Holborn Hotel, Saturday 14 June 2014. Last year, members attended from Canada, America, Sweden and Spain to hear, amongst others, Dr. Bertalanffy. CAUK hopes that there will be a similar worldwide spread this year.

Ian Stuart
**Aliança Cavernoma Brasil: A Dream Come True**

The Aliança Cavernoma Brasil had its real beginning back in June 1993, on the day I found out that my 7-year-old daughter had cavernous angioma.

For years, I had looked for knowledge and help for my daughter and all those people who, by virtue of the disease, had contacted me. It was hard to find doctors who could better explain the meaning of having and living with cavernous malformations.

I knew I would somehow find the right answer. In 2008, I was finally in contact with Connie Lee and Angioma Alliance, and I realized that I had found the right path. The contact with Connie led me to Dr. Jorge Marcondes, a Brazilian neurosurgeon who is dedicated to neurovascular diseases and especially cerebral cavernomas.

Brazil has a population of 250 million; the more I was getting these e-mails and contact from people and families harboring cerebral cavernomas and anxiously looking for answers, the more I realized that we could do more. I finally decided to create a Brazilian association to help those people, and I was glad to count on the support of Dr. Marcondes to help me out on the first steps.

In February, 2014, we organized a multidisciplinary pilot seminar entitled Cerebral Cavernomas: Advances and Perspectives, at the Universidade Federal do Rio de Janeiro, in order to reach out to scientists, health professionals and students who might want to get involved in such a project. The Aliança Cavernoma Brasil Project was introduced there. We were fortunate to have presentations from our gifted neuroradiologists, Dr. Emerson Gasparetto and Fernanda Moll, already involved in human and animal model research. In addition to having neuropharmacologists dedicated to epilepsy, such as Dr. Soniza Leon, from the same University. To our great surprise, there was a full amphitheater of post-graduate students, eager to understand this little-known disease.

The Aliança Cavernoma Brasil was born on May 3, 2014, in Brasilia, and we are proud to have on our Scientific Board Dr. Issam Awad, Professor of Neurosurgery at the University of Chicago, who graciously accepted to help us on this new project.

Our scientific advisors are Dr. Marcondes de Souza, Dr. Gasparetto and Dr. Soniza Leon, along with the renowned Brazilian neuropathologist, Professor Leila Chimelli.

Connie Lee has been tremendously supportive all these years, and we must mention how much we appreciate all the help we have gotten from her and Angioma Alliance so far.

The Aliança Cavernoma Brasil is a non-governmental, non-profit organization whose objectives are: reaching out to patients and families with cerebral cavernous malformations; creating a baseline registry of people with the disease; supporting research and clinical studies and the development of new treatments; and producing and distributing information about the disease throughout the country.

We have taken the first steps toward the dream we had back in 1993, and that we will be greatly rewarded by helping people of this huge country to understand and live better with the disease.

_Selva Chaves de Sousa_

**SOS Angioma**

In order to provide better support to the Italian community of CCM patients and their families, CCM Italia has recently launched a mobile application for Android, SOS Angioma. This is a free service available for both smartphones and tablets that focuses specifically on biomedical research and health and social care regarding Cerebral Cavernous Malformations (CCM).

SOS Angioma complements and extends the services offered by the websites of CCM Italia, the Italian network for multidisciplinary and integrated research on CCM disease, and the Associazione Italiana Angiomi Cavernosi (AIAC). These groups have already created a platform focused on the CCM disease for Italian patients, doctors and researchers. This joint platform facilitates productive cooperation between basic researchers and clinicians engaged in better understanding CCM disease pathogenesis for the development of novel, safe and effective treatments. It has also compensated for the lack of coordinated territorial support and assistance. It contributes significantly to dissemination of knowledge of the disease and alleviates the isolation in
which CCM affected people and their families often find themselves.

Through advanced geolocation systems, the SOS Angioma app allows users to locate hospital departments and clinical centers specializing in the diagnosis (clinical, neuroradiological and genetic) and medical and surgical treatment of CCM disease, as well as clinical and basic research centers interested in CCM biomedical topics. SOS Angioma also provides phone numbers of useful hospital facilities and services, including telephone switchboards, health information services and appointment booking for specialist visits and exams, as well as phone numbers and e-mail addresses for contacting hospital wards and specialists.

It also contains information on how to get to the center of interest (including site maps and information on local public transportation services), gives guidance to reach specific hospital departments and wards, and provides ward information and visiting times. The app helps the user find and contact physiotherapy, rehabilitation and social care services as well as clinical and basic research centers. Finally, the app has Videos, News and Publications sections so users can stay up to date on general information and research developments in the CCM field.

It will be possible to view feedback left by other users and leave your own, thus exchanging information and experiences and helping other people find the best solution for their needs.


Saverio Francesco Retta

**Johanna in the Movies**

Johanna is 17 years old and recently underwent her 90th brain surgery. After her last surgery one of her wounds didn’t heal properly and left her skull exposed. Johanna needed plastic surgery to replace the eroded skin leaving her with large bandaging on her head. To make Johanna’s bandage more fun her photographer brother, David Benthal, helped her recreate famous images. (http://johannainthemovies.tumblr.com)

Even in her pain Johanna’s humor has always been her best medicine.
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.

Angioma Alliance
520 W 21st Street, Suite G2-411
Norfolk, Virginia 23517
Phone: 571-306-2873
Fax: 757-623-0616
info@angioma.org
www.angioma.org

How You Can Help

Your contributions help fund our research initiatives toward a cure and our patient support programs. To donate, please send a check or money order in the enclosed envelope or visit our website at www.angioma.org to donate with a credit card.

Sponsorships can maintain essential programs or help us expand the way we support the patient and research community. Sponsors are acknowledged with logo placement, naming opportunities, or appropriate other recognition. Sponsorships are available for the following:

- **Newsletter**
  This newsletter reaches thousands of patients and donors both in print and online. It is the only patient-directed source of news and information for the cavernous angioma community. If you have an interest in reaching this community to support our efforts, please contact us.

- **Website**
  Our website has a global reach, and is always in the top three search results for cavernous angioma. It is the first place newly diagnosed patients look for information and support. In addition to being a patient resource, the website provides information to medical support staff, researchers and the general public.

  - **Children’s Book**
    Sponsored printing of the children’s book under development would allow us to give the book to our families for free.

  - **Scientific Meeting**
    Our scientific meeting offers a variety of opportunities to support and reach the research community, including travel awards and sponsored speakers, breaks, and meals.

  - **DNA and Tissue Bank and Genetic Testing**
    The DNA and Tissue Bank is the major source of cavernous angioma biological samples for labs around the world, and we have provided the raw materials for several major published studies.
    Contact us at info@angioma.org to discuss any of these sponsorship opportunities.

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