



ANGIOMA ALLIANCE NEWSLETTER

because brains shouldn't bleed

Free Genetic Testing for Angioma Alliance Members

Thanks to generous donors, Angioma Alliance is now able to offer free clinical diagnostic genetic testing to cavernous angioma patients in the United States and Canada to determine whether a change in the CCM1, CCM2, or CCM3 gene is causing their illness.

As part of our ongoing Genetic Testing Initiative, Angioma Alliance will begin offering free genetic testing to Americans and Canadians who:

- have multiple cavernous angiomas in the brain and/or spinal cord that can't be explained by a developmental venous anomaly or by brain radiation for cancer,
- have been denied insurance or Medicare coverage for genetic testing, or who do not have insurance, and
- are the first in their extended family to receive cavernous angioma genetic testing.

If you believe you qualify, and are interested in being tested, please register in the Angioma Alliance International Patient Registry at www.angioma.org/registry. If you are already registered, please update your registration by answering the Interest question. Also, please read the applicable page on the Angioma Alliance website: www.angioma.org/testing.

Once you have expressed your interest, we will contact you via email and send you an enrollment package. The program is first come/first serve for those who qualify, and will run as long as we have the necessary funding. Genetic tests are processed in batches of 20, so there may be some delay between the time you enroll and when you receive results. When testing is complete, results will be sent to your doctor.

Genetic testing is critical. Genetic testing will be a requirement for participation in clinical drug trials. It may be required later when medications become available to reduce hemorrhage risk and lesion proliferation. In other words, if you have multiple lesions and would like a non-surgical treatment, you will need testing.

Genetic testing can also assist in identifying other family members who may need monitoring and can tell you whether you have a more severe form of the illness caused by a mutation of the CCM3 gene that requires extra medical services.

Genetic testing currently costs \$1440 out-of-pocket. Everyone who is eligible should take advantage of this opportunity to receive this service free. Please spread the word to your doctors as well.



TABLE OF CONTENTS

1. FREE GENETIC TESTING FOR ANGIOMA ALLIANCE MEMBERS
2. ANGIOMA ALLIANCE NIGHT AT THE RED SOX
3. NEWS
5. ANGIOMA ALLIANCE FAMILY CONFERENCE
6. SPOTLIGHT: SHAWN MULVIHILL
8. RESEARCH UPDATE
12. INTERNATIONAL NEWS

FEATURED ARTICLES:

Please see page 5 for updated news about our first national family conference since 2011. We hope to see you there because it's going to provide information and experiences you can't get anywhere else.

Shawn Mulvihill is a cavernous angioma patient and father to a son with a dual diagnosis. Read an interview with him on page 6.

News

Angioma Alliance Night at the Red Sox: Updates

Angioma Alliance Night at the Boston Red Sox is almost here! On June 5th, the Boston Red Sox will honor Angioma Alliance in a pre-game ceremony. Mary Joyner, daughter of the late Olympic track star Florence Griffith Joyner, will be singing the National Anthem. Ryan Westmoreland, the young Red Sox player who retired after two cavernous angioma brainstem surgeries, will be on field with his family for the first pitch. You will even see some of our young members with Ryan.



More than 35,000 people will attend this game, and it will be covered on regional sports channels. We are using this opportunity to bring awareness of cavernous angioma to Boston and all of New England. You will find our volunteers in a booth in the concourse handing out information, and in the stands wearing t-shirts encouraging fans to text-to-donate.

Angioma Alliance has never had an opportunity like this, and we are grateful to the Red Sox for putting us on a national stage. If you are anywhere near the Boston area, please try to attend. As of this writing, list price tickets are still available at Redsox.com/AngiomaAlliance, and 250 Angioma Alliance supporters already have tickets. Aside from seats available through our link, this is a sold out game. Every ticket purchased through our link includes admission to a pre-game reception at the Marriott Residence Inn Back Bay starting at 5 pm where we'll be handing out t-shirts. We hope to see you there as well.

Angioma Alliance Night at the Cincinnati Reds

Not to be outdone by Boston, Cincinnati is hosting an Angioma Alliance Awareness Night. We feel very fortunate to have two huge events in one year. On Wednesday evening, September 9, we'd like to fill the Reds' stands with Angioma Alliance members. We have a large block of tickets available. To purchase tickets, email info@angioma.org or look for an upcoming announcement of an order page on the Reds website. If you or your company would like to support this awareness effort with a sponsorship, please contact cllee@angioma.org for opportunities. Ohio, Indiana, Kentucky: stay tuned. There will be more to come!

The Ryan Challenge: Anonymous Donors Offer \$100,000 Matching Gift in honor of Angioma Alliance Night at the Red Sox

This year, all donations from *new donors* marked "in honor of Ryan" will be matched, up to a total of \$100,000! This is thanks to two extremely generous anonymous donors and in honor of Cavernous Angioma Night at the Red Sox. Please tell your friends and family that their \$100 donation will be worth \$200 to Angioma Alliance.

It's the perfect time to ask your circle to support Angioma Alliance and the work we do for patients and research. New matched donations will allow us to:

- Launch the newest effort in our genetic testing initiative.
- Host our family conference, including offering a limited number of scholarships.
- Begin establishing a network of clinical centers to support better care.
- Continue all of the work we do to drive research toward clinical drug trials.

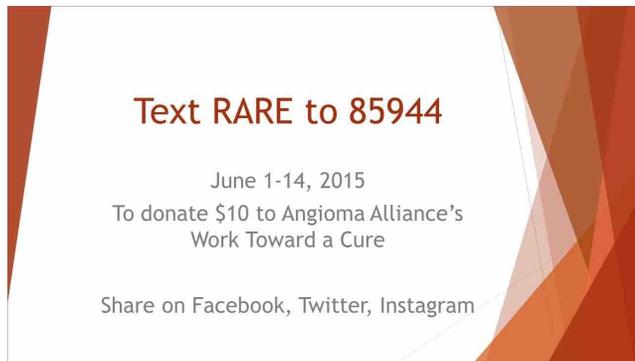
To contribute, visit our website at www.Angioma.org/Donate or mail your donation to Angioma Alliance, 520 W 21st Street, Suite G2-411, Norfolk, VA 23517. In online donations, "In honor of Ryan" can be marked in the "In memory of" box on the Review page under Purpose.

Helen Kim, MPH, PhD joins Angioma Alliance's Scientific Advisory Board



We are thrilled to announce that Dr. Helen Kim has accepted our invitation to join Angioma Alliance's Scientific Advisory board. Dr. Kim is a genetic epidemiologist at the University of California, San Francisco, who specializes in stroke and cardiovascular disease research. Dr. Kim works closely with Angioma Alliance and is a lead investigator on the Brain Vascular Malformations Consortium project where her team is looking for genetic changes (modifiers) responsible for CCM symptom variation within families. Learn more about Dr. Kim at profiles.ucsf.edu/helen.kim

Text-To-Donate to Angioma Alliance in June



Tell your friends! Tell your family! From June 1 through June 14 only, in honor of our Red Sox event and International Cavernous Angioma Awareness Month, United States residents can text the word RARE to 85944 to donate \$10 to Angioma Alliance. Share on Facebook, Twitter, and Instagram. It's an easy way to help support our work for a cure and bring attention to our illness and the events we have planned. The first 100 texts will be matched by the EveryLife Foundation who generously are allowing us to use their text-to-donate number.

Awareness Video and Challenge

We have a new video in which our members share the powerful truth of living with cavernous angioma in six-word stories. Please watch at www.tinyurl.com/AngiomaVideo. When you're finished, join the fight on Facebook, Twitter, and Instagram.



To participate: post a peace-sign selfie with the following text: I nominate [name 3 friends] to post a selfie with a peace sign, the hashtags #BrainsShouldntBleed #PeaceOfMind #Stroke, and the link tinyurl.com/AngiomaVideo, or they must make a \$10 donation to Angioma Alliance at angioma.org/donate.

Many of our members have begun to participate. We hope you will, too. It's time for cavernous angioma to become a household word, and we can do it with your help.

Biobank Update

Angioma Alliance's DNA/Tissue Bank is a research program that provides scientists with biological samples and medical history records for research projects. We are recruiting individuals who live in North America and who have recently had, or are scheduled to have surgery. To learn more, please visit www.angioma.org/dna. If you are interested in donating your surgical tissue for research, complete the form at the bottom of the page to begin the enrollment process.

October Anywhere Walks

It's not too early to begin planning your Anywhere Walk for the fall. Plans are underway for the 3rd annual Zach Brown Virtual 5K for Angioma Alliance. Last year, over 40 walks, large and small, were held in the United States and around the world in late September and October. We think of it as a "Where you are" fun run. We mean that both literally and metaphorically, as we want everyone with a cavernous angioma to learn to be happy where you are, even though it may not be where you had planned to be.



This year's Zach Brown Virtual 5K will be held in Edgewater, Maryland, on Sunday, September 27, at Camp Letts. If you are on Facebook, follow the Zach Brown Virtual 5k for Angioma Alliance page to keep up with details of this particular walk. If you'd like to sponsor, email Tracy Brown at tracy@angioma.org. All donations go directly to Angioma Alliance.

If you don't live near Edgewater, it's a good time to set your date and reserve a spot for your walk. If your venue requires insurance, please contact us at info@angioma.org so we may provide you with a certificate. We've had members set up walks at parks, schools, and simply in their neighborhoods. If you walked last year, do it again and make it even more fun by adding a 50/50 raffle or entertainment. Throughout the summer, we'll be posting updates on how to set up a donation page to benefit Angioma Alliance and suggestions on how to make your walk the best it can be. We'd love to keep building each year!

CCM3 Indy Updates

CCM3 Indy is dedicated to furthering awareness of the ultra-rare CCM3 mutation that causes a more severe form of cavernous angioma illness, as well as supporting the Angioma Alliance mission. Year round, we work to host opportunities, take part in events, and fundraise to reach our goal.

Late February brought success with another great year of candle sales at the Indianapolis Boat, Sport, and Travel Show, and March provided fun and opportunity as we joined with the Zack Brown 5K and their supporters for Angioma Alliance night at the Indiana Pacers game, as well as announcing the second annual Cavernous Cure Movement. April showered us with an outstanding response to our need for increased support including a registration opportunity, the opening of our t-shirt design contest, and a smaller fundraiser.



Looking forward, we plan to take part in area community events, host additional registration opportunities, create exciting options for potential team participants to become further involved, and host another community awareness fundraising event in September. To learn more and keep up, visit us at www.Facebook.com/CCM3Indy.

Heather Sanders

LEGISLATION

Look for an announcement coming soon regarding new cavernous angioma legislation being introduced into the Senate and House of Representatives. To prepare, it's a great time to find out who is representing you in Congress.

Join us in Chicago for the 2015 Family Conference

The Angioma Alliance Family Conference is being held this summer in Oakbrook, IL, on July 24-26. This conference is going to be fantastic. Come to the conference and learn about:

- cavernous angioma basics; what they are and what they do
- management of cavernous angiomas including how decisions are made about surgery, and special pregnancy considerations
- how to read an MRI
- medications under consideration to treat cavernous angioma, and where they are in the process
- managing epilepsy
- the latest rehabilitation options
- neuro-ophthalmology
- coping with cavernous angioma as a patient, as a caregiver, and during transitions
- the role of patients in moving research forward

One of our main goals is to provide attendees with cutting-edge information. Our rare assemblage of invited speakers includes world experts in their respective fields: scientists who are doing research, and those who are bringing their findings to patients. There is nowhere else a patient or caregiver could receive this level of information. Speakers include:

- Dr. Issam Awad, chair of our Scientific Advisory Board and Director of Neurovascular Surgery at University of Chicago Medicine
- Dr. Elliott Roth, chair of Northwestern University Feinberg School of Medicine Department of Physical Medicine and Rehabilitation
- Dr. Gregory Christoforidis, Section Chief of Neuroradiology at University of Chicago Medicine
- Dr. James Tao, Neurologist and Epileptologist at University of Chicago Medicine
- Dr. Susan Ksiazek, Neuro-Ophthalmologist at University of Chicago Medicine

In addition to medical professionals, attendees will be hearing from experts in managing the life changes of the illness:

- Eileen Benthall, mother of a teenage daughter with multiple cavernous angiomas and author of *Breathing Underwater: A Caregiver's Journey of Hope*
- Dr. Myrna Sarowitz, Clinical Psychologist, professional Life Coach, and cavernous angioma patient
- Dr. Connie Lee, Founding President of Angioma Alliance and clinical psychologist

There will be time for conversation groups, during which attendees can share their experiences. We will also have informal time to socialize.



Children are invited to participate in our children's program. Artist and Angioma Alliance member Crystal Shaulis will be creating art with the kids. Older kids can also participate in a video project. Childcare will be provided by nursing students.

You can find more information on our website. Registration is \$40 for adults and \$20 for children. To register, visit tinyurl.com/AngiomaConference. Our room block has sold out in the hotel, but there are numerous nearby hotels with availability. Some are in walking distance and some have shuttles. A list is on our website. We are still accepting sponsors and vendors for the conference. Please contact us at info@angioma.org for more sponsor/vendor information.

Spotlight: Shawn Mulvihill

Connie Lee: I'm here today with Shawn Mulvihill. Shawn, can you tell me a little about your family's history with cavernous angioma?

Shawn Mulvihill: Sure, no problem. Thanks, Connie. I'm very happy to meet with you today.

So, my history, I didn't know a whole lot about cavernous malformations until about 2007. Around 2006, I had a headache for just about a full year, and I had no idea why. Around September, I passed out and I wasn't sure exactly what happened. I went to the hospital and they said it could just be a fainting episode, so they ran some tests. I had to do an MRI, which was actually the day before my wedding. Talk about stress, right?

We went on our honeymoon and came back a few weeks later, and I went and chatted with the doctor, and he said, "Well, you have something called..." And he passed me a piece of paper. "It's called cavernous malformations." And I said, "What is that and what can happen?" And so he briefly explained what it is, and he said, "Either nothing can happen, or you can die." Unfortunately, that was my first introduction to cavernous malformations.

Prior to that, in the late '90s, my mom had brain surgery and we didn't know exactly why. At that time, we thought it could have been an aneurysm. But, looking back, it would have been a cavernous malformation because I have CCM1 which is the familial version of the gene. Now we have, including myself, seven people in my family that have the cavernomas.

I had three bigger cavernous malformations in the brain and, in 2009, I was having a pretty rough time. I had on-and-off headaches and I also had another seizure. I went to the hospital and they said, "You know what? It's bleeding. One of yours has to come out." To my surprise, it was one that was in my third ventricle which is quite deep. It was one that they had said they would never touch, but they decided, "You

know what? This is blocking the flow of cerebrospinal fluid so we need to take it out." April Fools, 2009, I had brain surgery to remove one of my cavernomas. It was at the Toronto Western Hospital performed by Dr. Wallace, a fantastic person. Now I'm doing great. I still have some cavernomas in there, so I still live with that concern daily, that perhaps something might happen. But, something might not happen, right?

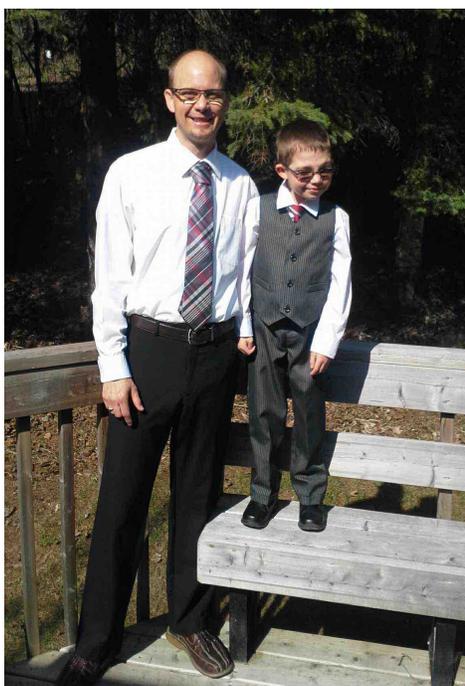
In 2007, we had a son, so we decided to get him tested to see if he did have the gene or not. It turns out that, yes, he tested positive for the gene. He's had subsequent MRIs, and there's nothing in there to indicate anything has formed, so we thank God for that fact that he's still healthy and there's nothing there.

CL: Your son Jaxon has a second diagnosis as well. Can you tell us what that is and if it has any effect on how you manage his cavernous malformations?

SM: Sure, of course. He has something called 22q gene deletion. They are two totally separate genetic disorders. One has nothing to do with the other. The 22q, essentially, it's a tiny little piece of the chromosome that's missing. The way it affects him is through his gross motor skills. He didn't walk until he was about two and a half, and he still wears supports on his legs to help him walk. A lot of people who have 22q, they also could

be diagnosed with autism. A lot of them wear glasses, which he does. They could often have seizures, and we don't know why. In the past year or so, my son has had a few seizures.

Knowing that he has the cavernomas and the 22q, we brought him directly to the Sickkids Hospital to have a look and check him out. Knowing he has the cavernous malformations, I get a little bit more concerned. My anxiety might spike up a little bit more. But we just kind of follow him in that respect. There was nothing there as far as cavernous malformations were concerned so it could have been something



totally unrelated to the CCM1, right? It could have just been low iron, something like that. We just keep an eye on him and he continues to live a happy positive life.

CL: You're in Canada and you're now the President of Angioma Alliance Canada. I was wondering if you could tell me a little about the organization, what it's doing, and what you're looking forward to?

SM: We started the Angioma Alliance Canada in 2011 when you put the word out there asking other people to step up. So, myself and a few other people that met via a forum that Angioma Alliance in the US has, we decided to work together and to form the Canadian Alliance. And, as you said, I am now the President, proud President. In the past few months we've been going through organizational change and things are going extremely well for us. We have a good following. There wasn't any representation in Canada so people didn't know where to turn.

Saturday, June 6th, we're having our fourth annual Canadian conference. We have a good amount of people that have registered for that. We have Dr. Loch McDonald - he works with St. Michael's Hospital in Toronto as a neurosurgeon there - as well as Dr. Brent Derry. He is a senior scientist researcher at the Sickkids Hospital in Toronto. He's going to be speaking to us as well, talking about the worm models and how they work toward a cure. He's been one of our biggest supporters. He helps us out every step of the way. I met with them last week and he's pretty excited for the conference as well.

CL: Beyond June 6th, what is it that Angioma Alliance Canada has up its sleeve? What are you planning?

SM: I know Dr. Derry wants to get a lot of Canadians together so he can sequence the genes and do a lot of work towards a cure. One of the things we'll be doing is collecting a lot of people and getting them information so we can work with the Sickkids Hospital.

Essentially, in Canada, we're growing the organization. We have representation in Ontario and we have some on the West Coast and

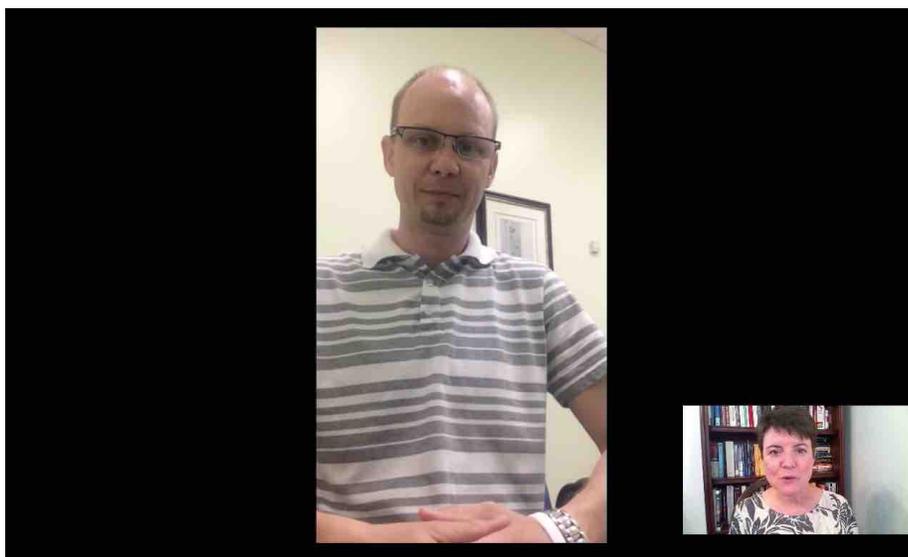
some in Quebec. We are also chatting with someone in the East, in Halifax, to join our organization. One of the things we've been talking about is potentially having a conference in other parts of Canada. Dr. Derry has said he's more than willing to travel with me and we can go across Canada and hold conferences in different provinces. People in our group are very excited about that. We're a very tightly knit group now, and everyone is working together for a common cure.

CL: Is there anything else you'd like to share that you haven't covered already, that you want to make sure people know?

SM: I know when I was first diagnosed, I was scared. I didn't know anything about it. And especially if you start researching it, googling it, you see all of these danger warning signs. I was pretty concerned and that was all I ever thought about. But, you know what? It does get easier. You get to understand that it's not something that's going to explode one day, and you're not going to make it. You have time. There's a lot of great medical professionals out there. I found that as time gets further apart that I think about it, about the cavernous malformations and what could happen, it gets a lot easier to live with the disease.

And then there comes a point where you can help other people like we do. I just want people to know you can certainly live a happy, healthy life and still have the disease.

The Angioma Alliance Canada website, angioma.ca, is under renovation and should be running well very soon.



Research Update

Important research has been published since our last issue. A clinical study from the Mayo Clinic suggests that CCM patients are more likely to present with symptomatic hemorrhage during the fall and winter. In basic science research, two studies identify an important role for the CCM3 protein related to biological tube formation; and, the physical interaction of the CCM2 and CCM3 molecules is found to be necessary to maintain proper protein levels and vessel structure.

Seasonal variation in hemorrhage and focal neurologic deficit due to intracerebral cavernous malformations

In a study published in the June issue of the Journal of Clinical Neuroscience, Mayo Clinic researchers investigated whether onset of CCM symptoms are affected by seasonal variation and/or flu season. Ten years of medical records were studied for nearly 300 CCM patients seen at the Mayo Clinic from 1989-1999. Indeed, more patients were treated for intracerebral hemorrhage during the fall and winter compared to spring and summer. The research team hypothesized this seasonality may be linked in part to vitamin D levels, which naturally decline during the winter months. Inflammation levels increase during flu season and may also contribute to the increase in cold weather-related hemorrhage symptoms.

<http://www.ncbi.nlm.nih.gov/pubmed/25769259>

CCM-3/STRIPAK promotes seamless tube extension through endocytic recycling.

In a paper published by Nature Communications, Dr. Brent Derry's team, at the Hospital for Sick Children and University of Toronto, describes the way in which the CCM3 protein is critically involved in tube formation. Tube formation is an important process

in the developing body: tubes make up our blood vessels and lung gas exchange system, for example. This team investigated the molecular mechanism of excretory canal (gut) formation in the *c. Elegans* worm model and discovered how the CCM3 molecule is needed for tube growth. The study uncovered a previously unknown role for CCM3 and identified new molecules with which it interacts. By better understanding the role of CCM3, this team may have also identified targets for future CCM drug therapy studies.

<http://www.ncbi.nlm.nih.gov/pubmed/25743393>

CCM2-CCM3 interaction stabilizes their protein expression and permits endothelial network formation

Protein molecules interact with each other to send and receive signals to maintain or change something within the cell or neighboring cells. A recent study published by researchers at Yale University aimed to investigate the CCM2-CCM3 protein interaction. It is known that these two molecules physically interact within blood vessel cells, but how and why were not well understood. This research team used x-ray crystallography to map the interaction at a molecular level (the precise location on the protein where they bind to one another). Furthermore, this team showed that the purpose of this interaction is to stabilize and maintain the levels of both proteins within the cell. Without binding to one another, these proteins are susceptible to breaking down, which leads to a variety of effects including improper vessel development.

<http://www.ncbi.nlm.nih.gov/pubmed/25825518>

Amy Akers, Chief Scientific Officer

Awareness Items Now Available

You've been asking for awareness items with the new Angioma Alliance logo, and we have them for you. There are two websites offering a variety of items.

At Shopify (angioma-alliance.myshopify.com), you will find Awareness Kits and t-shirts. The current Awareness Kits include a removable bumper sticker, two reusable cellphone screen cleaners (they stick to the back of your phone), a tote bag, and an optional cap. We also offer a "Because Brains Shouldn't Bleed" t-shirt. These items are available for a limited time, so stock up now!

We have a full range of items, including mugs, jewelry, and cellphone and tablet skins, at Zazzle (www.zazzle.com/angiomaalliance). These are somewhat more expensive because they are made to order.

We hope you'll raise awareness in whatever way fits you, because brains shouldn't bleed.

International News

Cavernoma Alliance UK

The last few months have seen a great deal of activity for CAUK.

In February, Paul Cooper (our new fundraising and development manager), Tim Millward (treasurer and trustee), and Ian Stuart (founder and co-ordinator), travelled to attend Rare Disease Day UK (RDUK), organised at the Houses of Parliament. RDUK was an excellent opportunity for CAUK to raise awareness.

March saw CAUK travel far and wide for Brain Awareness Week, and this was a busy time for volunteers, members, and trustees. Simon Temple (trustee) travelled to Newcastle to raise awareness amongst neurological students before listening to talks by a neurosurgeon and a neurologist at the Royal Hallamshire Hospital in Sheffield. David White (chair), and a small group of members, visited a hospital in Birmingham and listened to a consultant neurologist and a specialist in neurorehabilitation. The final event of the week was a lecture entitled 'Cavernoma Bleeding – What Does It Really Mean?' by Professor Dr Helmut Bertalanffy, Director of the Vascular Institute in Hanover, Germany.

Members and non-members alike participated in sponsored events. In March, Ryan Atwell took part in a sponsored climb of Mount Snowdon, to raise money for CAUK, and obtained match funding from Barclays

Bank. Ryan advised "Before the climb I was particularly worried due to a number of reasons. Most noticeably the fact that I was only diagnosed with a cavernoma less than 12 months ago. The physical challenge came from the fact that I have never climbed a mountain before or completed anything strenuous in terms of long periods of cardio exercise." Ryan completed his climb and descent in 5 hours. There were several more fundraising events including the London Marathon, Silverstone Half Marathon, cycling and even a Pupils Wear a Hat Day!

The Society of British Neurological Surgeons held their spring meeting at Southampton Football Stadium in April. This unlikely venue turned out to be fantastic event, allowing CAUK to raise awareness to over 300 medical professionals, and to establish new contacts for future events and meetings.

On Saturday 13 June, CAUK holds its 9th International Annual Forum at the Grange Hotel in Holborn. This Forum will launch the beginning of the exciting 10th anniversary celebrations that include a new logo and website. (Further information: www.cavernoma.org.uk/opus865)

Past forums have seen members from the worldwide international cavernoma community attending this important event. We look forward to welcoming you to London.

Angela Yeomans



Ian Stuart (founder-member and co-ordinator), Angela Yeomans (community worker) and Paul Cooper (fundraising and development manager).

Angioma Alliance Philippines

On March 7, Angioma Alliance Philippines held its very first meet-up of members in Manila. It was an overwhelming experience for everyone. Stories and experiences were shared, and it was a comforting and empowering event to see everyone declaring support for each other.

Angioma Alliance Philippines will hold more gatherings going forward to discuss how the collective effort of the group may help in increasing awareness and providing support to all other cavernoma patients.

Oj Mina III

CCM Italia

On April 23rd, CCM Italia organized the 2015 Italian Cerebral Cavernous Malformation Scientific Meeting. The distinguished venue was the Aula Magna of the Torino University School of Medicine, located in the Lingotto Conference Center, Torino, Italy. The initiative was promoted and supported by the Associazione Italiana Angiomi Cavernosi (AIAC) and the University of Torino School of Medicine, as well as by the most relevant Italian Scientific Societies in clinical and basic research fields related to Cerebrovascular Diseases.

The scientific organizers, Professor Francesco Retta (University of Torino), Lorenza Trabalzini (University of Siena), and Marco Fontanella (University of Brescia), hosted nearly 100 attendees, including 40 speakers and moderators who presented and discussed the state of the art and future perspectives in the field of CCM disease.

The meeting aimed to provide an opportunity to increase knowledge among physicians and MD/PhD post-graduate trainees in medical disciplines. It also allowed Italian clinical and basic researchers to share and discuss the latest clinical data and research findings, and to develop new hypotheses and collaborations. The multidisciplinary nature of the meeting offered a unique opportunity for the various participating scientists to understand the multifaceted aspect of CCM disease, its full spectrum, and to provide new scientific insights through innovative and integrated research approaches.

Among the most interesting features of the 2015 Italian CCM Scientific Meeting were complementary and comprehensive presentations describing recent advances in diagnosis and clinical management of CCM disease. These included advances in neurological, neuroradiological and genetic diagnosis, neurosurgery procedures, as well as recent progress into the understanding of pathogenic mechanisms and the identification of risk factors of prognostic value associated with disease onset, progression and severity. Since the most severe clinical features of CCM disease, including intra-cerebral hemorrhage, vary greatly among individuals, a major current research challenge is the prediction of disease outcome, in order to develop better options for disease prevention and treatment. This could ultimately match patients with individualized treatment.

The full meeting agenda, complete with talk titles and presenter information can be found on the CCM Italia website.

Eliana Trapani and Francesco Retta

Angioma Alliance Canada

This year's Angioma Alliance Canada conference is just around the corner. It will be held at the Peter Gilgan Centre for Research and Learning Directions Research Institute in Toronto, on June 6, from 8:30 am to 4:40 pm. We will be able to hear expert speakers and share experiences with each other. Featured this year are neurosurgeon Dr. Loch Macdonald who will speak on the "A-Z of Cavernous Malformation," and researcher Dr. Brent Derry who will discuss research methods.

Additionally, patient Crystal Shaulis will share her experiences living with an inoperable cavernous malformation, and Nikki Mulvihill will discuss financial planning. As always, we will have time in the schedule for group discussions and informal socializing. For more information, visit workingtowardsacure.ca/node/17.



Aliança Cavernoma Brasil

Although not yet 6 months old, Aliança Cavernoma Brasil has achieved prominence on the national scene. Our website has had more than 8,200 visits from 280 cities in Brazil and abroad. This shows that we are visible and are fulfilling one of our goals, which is to reach people with information about cavernoma.

On May 6, 2015, congresswoman Mara Gabrielli filed Proposition INC 382/2015 in the House suggesting the registration of cavernoma as part of the National Network of Research on Neglected Diseases. The document highlights the importance of Aliança Cavernoma Brasil as an association that aims to clarify aspects of the disease nationwide. In concluding her statement, congresswoman Gabrielli said "By including cavernoma as a priority disease for studies of the National Network of Research on Neglected Diseases, we can produce knowledge about this disease that quietly has made victims in Brazil, many of whom suffered for lack of information."

In other news, our Scientific Advisor, Dr. Jorge Marcondes, wrote a grant proposal, submitted to the Ministry of Health, to research the profile of the disease in Brazil. Today this illness is neglected in Ministry of Health statistics. For this project, we have the support of senator Romario Faria, whose team has followed the process step-by-step. At this point, we are waiting to schedule a meeting at the Ministry of Health.

In addition to these two major projects, the Aliança Cavernoma participated in the Seminar on Rare Diseases in the House to discuss the creation of a Rare Diseases Clinical Centre for the Federal District. Also, Aliança Cavernoma was recently invited by the President of Amavi - Maria Victoria Association, a non-governmental organization created in order to support



Congresswoman Mara Gabrielli with Selva Chaves, president and founder of Aliança Cavernoma Brasil.

people with rare diseases, to compete for one of the chairs of the Health Council in the Federal District.

We are happy with these achievements, but certain that we still have a lot to accomplish. We want to thank all who are on our side for their support in this fight for life.

Selva Chaves

INTERNATIONAL CAVERNOUS ANGIOMA MONTH

June is International Cavernous Angioma Awareness Month, and the increasing number of cavernous angioma patient groups around the world make this year particularly special. In the last 12 months, we've added Aliança Cavernoma Brasil, Angioma Alliance Philippines, a second patient group in Italy called Associazione Nazionale Angioma Cavernoso Cerebrale (ANACC), and a group is forming in Australia. As you read in the International News section of our newsletter, our patients groups are not just supporting patients; they are supporting researchers and becoming involved in government policy.

To celebrate the month, our three oldest groups are holding special events. As you can read on page 2, Angioma Alliance in the US is working with a baseball team to host a Cavernous Angioma Awareness Night in front of more than 35,000 people. Angioma Alliance Canada and Cavernoma Alliance UK will be holding their annual patient conferences. We hope that everyone uses this month to share your personal stories with your social circles, the press, government officials, and each other.

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 treatments and 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
Fax: 757-623-0616
info@angioma.org
www.angioma.org
www.facebook.com/AngiomaAlliance
Twitter: @AngiomaAlliance

Angioma Alliance Board of Directors

- Connie Lee, President
- Karen Asbury, Treasurer
- Tony Mayer, Director
- Kristen Lewis, Director
- Tracy Brown, Director
- Jeffrey Jin, Director
- Ryan Lisiak, Director
- Liz Neuman, Director

Scientific Advisory Board

- Issam Awad, MD, MSc, FACS, University of Chicago Pritzker School of Medicine
- Brent Derry, Ph.D., The Hospital for Sick Children, University of Toronto
- Kelly Flemming, MD, Mayo Clinic, Rochester, MN
- Douglas Marchuk, Ph.D., Duke University Medical Center
- Leslie Morrison, MD, University of New Mexico Medical School
- Rustam Al-Shahi Salman, MA, PhD, MRCP, Western General Hospital, Edinburgh, Scotland
- Kevin Whitehead, MD, University of Utah
- Dr. Helen Kim, University of California, San Francisco

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

A 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.