Cavernous Angioma Night at Great American Ball Park in Cincinnati

After two successful years of hosting the Dylan Mayer Rock & Bowl for Angioma Alliance, the Mayer family is taking a swing at a new event. Following a similar blueprint used in Boston for the Cavernous Angioma at Fenway, the Mayer family, Angioma Alliance, and the Cincinnati Reds have partnered to host Cavernous Angioma Night at Great American Ball Park. Sponsored by Zemas Madhouse Foods, this event takes place on Wednesday, September 9 at 7:10 pm, when the Cincinnati Reds play the Pittsburgh Pirates.

Four-year-old Dylan recently had his second successful brain surgery to remove three lesions. Like many other affected families, Dylan’s is striving to help find a treatment other than invasive brain surgery.

We are selling discounted tickets for the game at $15 each (normally $20), and $6 of every ticket will go to Angioma Alliance. Joining us at the festivities will be former Reds pitcher Joe Price and Mary Joyner. Both Joe and Mary have or had family affected. Joe is related to the Neuman family (Liz Neuman and two of her sons have the illness), and Mary is the daughter of Florence Griffith Joyner, also known as Flo-Jo, who passed away from a cavernous angioma-related seizure.

We will have two tables set up at the main entrance for a meet and greet with a raffle, starting at 5:00 pm. On-field festivities will start at approximately 6:45 pm. The pre-game ceremony will include a check presentation to Angioma Alliance, the National Anthem performed by Mary Joyner, and the first pitch by Joe Price, accompanied by the children of Angioma Alliance.

Please join us on September 9 for a memorable night for the Angioma Alliance community. To purchase tickets online please visit www.reds.com/angiomaalliance. If you are unable to join you can still participate by donating at www.Angioma.org/Donate and adding "Dylan" in the Message to Seller field.

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FEATURED ARTICLES:

This issue features events, past and future, including an upcoming event for everyone. Learn more about how you can participate in our Anywhere Walks on page 4.

In our interview on page 6, meet Angioma Alliance Board member Tracy Brown. Tracy is the mother of Zach Brown and the founder of the Zach Brown Virtual 5K for Angioma Alliance, now in its third year. She shares Zach’s story and her own motivation for organizing the 5K.

We are also excited to unveil our new book, Rare Kids: Living with Cavernous Angioma for ages 9-14. Find out more on page 4.
June 5th: Cavernous Angioma Night at the Boston Red Sox

June 5th was Cavernous Angioma Awareness Night at the Boston Red Sox. The evening honored Ryan Westmoreland, the Red Sox prospect who was forced to retire at the age of 21 because of brainstem hemorrhages caused by cavernous angioma. At the mention of his name, the stadium crowd became attentive, learning about an illness most had never heard of before. Our video was shown on the Jumbotron, and Mary Joyner, daughter of Florence Griffith-Joyner, sang the National Anthem. Ryan Westmoreland’s father threw the first pitch, accompanied by a group of our Angioma Alliance children. Ryan was interviewed by both NESN and WEEI, and shared his story with viewers and listeners in the Northeast.

The video of the pre-game ceremony is available on our YouTube channel at youtube.com/AngiomaAlliance.
The Angioma Alliance Family Conference in Chicago was an opportunity for more than 110 of our members, and a group of researchers, to gather to learn and support each other. For those who weren’t able to attend, live online streaming of presentations was available during the conference. You can view these videos on our YouTube Channel at Youtube.com/AngiomaAlliance.

We are looking forward to hosting a 2017 conference, date and venue to be announced.
Anywhere Walks

It’s almost fall, so it must be time for the Angioma Alliance Anywhere Walks! This year, we hope you will participate wherever you are: in the United States or around the world. In 2014, members in more than 40 cities and towns walked to raise awareness of cavernous angioma. Some walked alone as part of local parades; others organized walks of more than 200 participants; still others walked with their families in their neighborhoods.

This year we are using the EveryDayHero website for individual fundraising. Join the Angioma Alliance Team at give.everydayhero.com/us/team-angioma-alliance-anywhere-walks, and set up a page to share with your friends.

For more information on organizing walks both small and large, visit Angioma.org/walks. You can help cavernous angioma become an illness that steps out of the shadows.

Torrington Wine Tasting

On September 25, Ponte’s Package Store and the Binding Source will host the First Annual Wine Tasting event to benefit Angioma Alliance. Come and enjoy the fine wines and delectable cheeses and breads at the beautiful Torrington Country Club, at 250 Torrington Road in Goshen, Connecticut.

The country club offers magnificent views from its banquet facility overlooking its 18-hole golf course. Some of the finest distributors in the area will be offering their wines for tasting.

The VIP room will be offering fine scotches, bourbons, and liquors, as well as the chef’s best appetizers. There will be music by Torrington’s own Brian Mattiello to round out the evening. A raffle and silent auction will be sponsored by our local merchants and restaurants as well as vendors nationwide.

Tickets are $30 for regular admittance ($35 at the door) and $50 for VIP admission, and can be purchased at Ponte’s Package Store at 1270 East Main Street in Torrington, CT, or at www.bindingsource.com/angioma. For more information about this event or to find out how you can help, call Julia at 860-489-3333.

Free Genetic Testing Initiative

Our free genetic testing initiative continues. Angioma Alliance will pay for genetic testing if you meet the following criteria:

- You are a US or Canadian resident,
- You have multiple cavernous angioma lesions that can’t be explained by a DVA or a history of radiation for brain cancer,
- Your insurance will not cover testing, and
- You have a doctor who is willing to receive the results and share them with you.

To learn more, visit Angioma.org/testing. To let us know you are interested, please register in the Susan Sukalich Angioma Alliance International Patient Registry at angioma.org/registry.

Rare Kids: Living with Cavernous Angioma Now Available

Many kids who live with cavernous angioma don’t know another child with the illness. Rare Kids: Living with Cavernous Angioma breaks through the isolation. In these pages, affected children and their siblings talk about their challenges and triumphs with honesty, insight, and courage. Rare Kids is meant for any affected child and member of their support system. We hope the stories lead to discussion and connection.

Rare Kids contains the stories of 11 children between 10 and 15 years old who have a cavernous angioma, or an affected sibling. Their stories are told in their own words to help other kids understand the experience. This book is intended for children aged 9-14.

Buy your copy in the Angioma Alliance Awareness Store at angioma-alliance.myshopify.com.
Research Update

Genetic and molecular studies investigating the functional roles of CCM1, CCM2, and CCM3 continue to expand our knowledge of CCM biology, and identify potential new targets for future drug studies. New studies uncover a role for CCM1 in blood vessel support cells (pericytes); show that CCM2 is required in order to maintain structurally sound (non-leaky) vessels; and demonstrate that the loss of CCM3 in endothelial blood vessel cells not only causes the onset of CCM, but also influences glioblastoma brain tumors.

Cerebral Cavernous Malformation-1 Protein Controls DLL4-Notch3 Signaling Between the Endothelium and Pericytes

A European team of researchers studying blood vessel biology and molecular signaling in relation to CCM disease has recently identified a new contributing factor to the disease. Maintaining normal blood vessels requires complex and tightly regulated signaling that functions within a variety of cell types. The study team has shown that a signaling molecule called Delta-Like Ligand 4 (DLL-4) is involved in blood vessel growth and is regulated by the CCM1 gene. In this study, the researchers looked beyond blood vessel cells to investigate the role of other cell types, particularly pericytes, in this signaling system. Pericytes are cells that are normally found next to blood vessels and that help provide support and control vessel growth. Importantly, pericytes are not present in CCM lesions. The results of this study show that CCM1 gene mutations in blood vessel cells do cause downstream effects though DLL-4 in pericytes and that the altered signaling patterns in pericytes are likely to contribute to CCM disease state.


Structure and Vascular Function of MEKK3-Cerebral Cavernous Malformations 2 Complex

The statins Simvastatin and Fasudil have both shown promising results for treating CCM. These drugs are believed to prevent and/or stop bleeding in lesions by targeting a chemical signal involving a molecule called Rho kinase. This complex signaling network is a focus point for CCM researchers who aim to understand the role of the CCM genes and how to best treat this illness.

In a recent study by researchers at Yale, the team identified a previously unknown role for CCM2 within the Rho kinase network. It has been known for quite some time that CCM2 interacts with a molecule called MEKK3. When molecules interact, this implies that there must be a biological function, but the precise purpose of the CCM2/MEKK3 interaction and how it relates to CCM disease remained unknown. This team sought to determine how a CCM2 gene mutation contributes to disease state. They discovered that the interaction of CCM2 and MEKK3 is required for proper Rho kinase signaling, and that, when this interaction is disrupted, blood vessels become leaky.


Loss of Endothelial Programmed Cell Death 10 Activates Glioblastoma Cells and Promotes Tumor Growth

The CCM3 gene is one of three genes known to cause familial cavernous angioma. However, when the gene was first identified, it was given the name Programmed Cell Death 10 (PDCD10) because it was found to be involved in the regulation of cell death, which is a normal process in the life of a cell. A hallmark of cancer cells is that they avoid the cell death process and grow out of control; CCM3 was thus originally thought to be a cancer gene.

A recent publication from a German team provides evidence that the CCM3 gene is also involved in the biology of an aggressive form of brain cancer called glioblastoma. Glioblastoma is challenging to treat with drugs and/or surgery, and has a very poor life expectancy; researchers are therefore actively looking for new ways to treat this cancer. This study showed that when CCM3 is lost in endothelial cells, they see an increase in cancer cell and blood vessel growth related to glioblastoma. These data suggest that CCM3 may also be a treatment target for glioblastoma.


Amy Akers
Connie Lee: I’m here now with Tracy Brown, founder of the Zach Brown 5K for Angioma Alliance. I’d just like to ask you a few questions. Can you tell me a little about your family’s experience with cavernous angioma; who’s affected and how it all happened?

Tracy Brown: Sure. My son Zach is 14 and he has a sporadic brainstem lesion. We had never even heard the word until four years ago. He was ten. He called home from school with a headache, and I said, “You don’t have a fever, you’re not throwing up. Go back to class.” A couple days later, he said he had some problems with his eye and his ear which I thought might have been allergies. Again, he wasn’t crying. It wasn’t the worst thing that I’d ever thought of.

We took him in to a local emergency room, and they did a CT. They said, “You have a lesion on your brainstem and there is a transfer unit on the way from Children’s National Hospital.” It took about three days, which, according to other people I’ve talked to, is a very quick diagnosis of an angioma. But, for us, three days seemed like an eternity waiting to hear what he had.

He was in the hospital for a week, came home for a day, and had a massive bleed. He was home literally 23 hours. He said he had a headache. Our instructions when he was sent home said he might have headaches. So, I gave him Tylenol and I was going to monitor him. But, within an hour of the onset of his headache, he said that he was no longer seeing. He lost his ability to speak clearly. He could not walk. He couldn’t hold his head up. That’s a major bleed. It was like something you see in a movie.

My husband carried him down the stairs and into the car. I held his head while he threw up because he couldn’t hold his own head up. We drove about 100 miles an hour to the hospital.

He was in ICU for 10 days and then on the regular neuro floor for about another 2 weeks. Then he spent a month at the National Rehab Hospital in DC. It affected the left side of his body and the right side of his face. He had facial paralysis, had to learn to walk again and learn fine motor skills on his left side.

CL: What’s been happening since then? It’s been four years, you said. How’s he been doing?

TB: He’s awesome. Literally hundreds of therapy sessions later, he runs, he plays basketball, and he goes to school in a normal setting. He’s had six eye surgeries, and his eye is pretty straight, pretty good. He’s had two major nerve surgeries trying to reanimate his face. So far, just minimal improvement, but we’re hopeful. And, knock on wood, no more bleeds. At this point, we consider it inoperable. Others will argue that; it’s a personal choice for all of us. When it’s in the brainstem, and other places I guess, but particularly in the brainstem, those are hard to get. We’re waiting on Angioma Alliance to help us find a treatment.

CL: Tell me about the Zach Brown 5K.

TB: We started that about a year after his bleed. I mentioned that he was unable to walk, and he relearned to walk. That was part of the reason for the 5K, because he couldn’t and then he could. We wanted everyone to be included, and that’s the virtual part of it. Those who can’t walk can cheer on those who can. Or, if you walk slowly, if you run, wherever you were, you could be with us physically at the location or wherever you were as a person.
I met other people online who were very isolated with this illness. I don’t know if I could call it lucky, but Zach is “lucky” to be a kid and have it, because he has a lot of support. A lot of older people don’t have the support that he has, and that was part of it, too, to make them feel a part of it.

CL: You’re coming up on the third year of this event. How has it changed? Is there anything different your attendees are going to see?

TB: Way to put the pressure on me! It’s continuing to grow, and that’s great. He’s entering the high school in a week. He has a habit of making friends very quickly. I’m hoping we’ll have a surge of younger kids there this year, because there’s 2,000 kids at his high school. I would love it if we could get a really huge turnout and I won’t be a bit surprised when that happens.

CL: How many people had attended before?

TB: In the past, it’s been between 200 and 300 depending on the year. And then it evolved into the Anywhere Walk through Angioma Alliance. There were people walking in 30 states, I think, and 8 other countries.

CL: I’ve been fortunate enough to attend the past few. I know that you’ve had entertainment: a DJ. Wasn’t there a bounce house? You had some raffle items the first year. What’s the name of the organization that provided the food for you?

TB: Unfortunately, they can’t this year, but they did the past two years. It’s called Fired Up to Help. It’s a great organization. I’m working to find someone else. There should still be food, and a DJ, and lots of people.

CL: Is there anything else you’d like folks to know, that you’d like to share?

TB: I’m, of course, grateful for everyone that’s supported us. I always like to say that, because I don’t ever want a day to go where people don’t know how thankful I am. If you have an angioma, get involved in finding the treatments that we need. If everyone got involved and brought their people onboard, we could do this faster.

My hope and my wish would be for people that have angiomas to just have normal problems and not have the “is my brain going to bleed” problem. Just take away that one problem; normal problems we can deal with.

CL: Thank you.

You can see the video of this interview at youtu.be/jZmY2B6O7h4.

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<th>Take Action!</th>
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<td>On May 20th, Senator Tom Udall and the New Mexico Congressional delegation introduced legislation called the CCM-CARE Act. In the Senate, it’s known as S.1391. In the House, it is known as H.R.2480. We need you to call your legislators to let them know how important this legislation is to you. We particularly need those of you represented by members of the Senate HELP Committee and the House Energy and Commerce Committee to ask your legislator to cosponsor the bill.</td>
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<td>The CCM-CARE Act calls for the development of three Clinical Coordinating Centers to organize and oversee multi-center drug trials and multiple Centers of Excellence where patients could go to participate. Money would be available for training of doctors and support staff in these Centers. Additionally, the act asks for increased research funding and for better monitoring of disease incidence.</td>
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<td>This is the time to call your legislators to let them know why this bill is important to your family. For more information about the bill and a script for a phone call, please visit our website at angioma.org/pages.aspx?content=123.</td>
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International News

Cavernoma Alliance UK

Has it really been ten years since Ian Stuart received from Dr. Connie Lee his “little red guy”, Angioma Alliance’s symbol at the time, and an introduction to the world of cavernoma support and research?

During its first year, Angioma Alliance UK, as the group was called back then, had a total of 34 members. Now, CAUK has almost a thousand. Supported by an excellent board of voluntary trustees, a Big Lottery Grant, and five full and part-time staff, CAUK is currently planning its first free introductory pack for the newly-diagnosed, which will include a DVD on cavernoma made by its medical advisers and some of its members.

CAUK is planning birthday celebrations from June 2015 through June 2016. Here are some of the events CAUK has planned.

• A reception on 30 October 2015 in Dorset.
• A Christmas appeal to be launched in November.
• CaverNews – a CaverZine – published for the first time in 2015, to generate interest in the cavernoma community.
• CAUK is naming March 2016 as Cavernoma Alliance UK month, together with Brain Awareness Week Events throughout England.
• A 10th Anniversary reception (with birthday cake), Friday 10 June 2016.
• The 10th International Forum, Saturday 11 June 2016.

CAUK would like to thank all its UK and International members, some of whom have been with the charity from the beginning, and those who have joined the community as recently as this month. Without you there is no CAUK; please keep sharing and raising awareness of cavernoma.

To coincide with the launch of the Tenth Anniversary celebrations, CAUK is pleased to officially introduce our new logo and website.

The updated logo is still recognisable as CAUK, and it will gradually be applied to all new merchandise and literature over the next few months.

Helping the Cavernoma Community

We have produced a website with a fresher look, while still retaining aspects of our original identity. We hope our members will find it engaging and supportive. CAUK hopes that the site will be launched in September. Visit www.cavernoma.org.uk.

The Ninth International Cavernoma Alliance UK Forum

The Ninth International Cavernoma Alliance UK (CAUK) Forum was exciting for a number of reasons. The Forum brought together members from all over the country, enabling them to exchange valuable information and ideas in a unique and safe environment. The Forum hosted a range of important speakers. Our keynote speaker was a leader in clinical genetics from Dundee, Dr. Jonathan Berg, who discussed, in easily-understood terms, the complex role of genetics in clinical management. Dr Berg was a guest speaker at our very first Forum in 2007.

For the first time this year, CAUK ran two parallel sessions: on “PGD, Pregnancy and Cavernoma” and “The Psychological Effects of Living with a Cavernoma”.

After lunch, CAUK members participated in a number of workshops with topics including mindfulness, cavernoma surgery, and a talk on the UK’s Expert Patient Programme. The final talk was by Dr Tim Wehner, a consultant neurologist, specialising in cavernoma and epilepsy.

Ian Stuart and Angela Yeomans
Angioma Alliance Newsletter Fall 2015

Angioma Alliance Canada

On June 6, we held our 4th annual conference. We would like to thank the presenters: Dr. Derry from the Sick Kids Hospital, Dr. Macdonald from St. Michael’s Hospital, Crystal Shaulis, Nikki Mulvihill, and Shawn Mulvihill, President of Angioma Alliance Canada. Attendees came from the West coast to the East coast of Canada, and many provinces between, as well as from the United States and Australia.

A recording of the conference is available for sale along with merchandise such as water bottles, coffee mugs, hats, t-shirts, and drink cozies. Email us at angiomaalliancecanada@gmail for more information.

We traveled to Chicago to attend the Angioma Alliance Family Conference, where we made some great connections and friendships. We would like to thank Connie Lee for her continued leadership and support in this journey. I am confident that our collective groups will find a cure for this disease in our lifetime.

I’d like to recognize a big supporter of the Angioma Alliance Canada. Please see Natalie Poirier’s story below.

Helping Angiomas Take a Hike

Imagine living with a ticking time bomb inside your head. You don’t know when it will go off or what damage it will cause. It could happen tomorrow, next year, or never. It could cause seizures, numbness, or bleeding. In the worst cases, it can take your life. There’s nothing you can do to stop it.

This is what it’s like for people living with a cavernous malformation or angioma. A cavernous malformation is an abnormal collection of blood vessels in the brain that can bleed due to defects in the vessel walls. It can either be hereditary or sporadic in its formation. Leaks also occur occasionally and in many people do not occur at all.

My sister has a cavernous malformation in her medulla. She has had two episodes of bleeding, the second of which left her temporarily unable to walk or feel the left side of her body, among many other symptoms. A third episode would be sufficient cause to attempt a removal of the malformation but it's not without risks. She is 27 years old.

At the beginning of August, 2015, I will be setting out on a journey through provincial and national parks across Ontario to hike for this cause. Through this fundraiser, my hope is to bring awareness to this hidden illness and raise money for medical research so that one day surgery will have reduced risks and episodes may be foreseeable or even preventable. My big sister is my idol, my hero, my confidante, and my friend. She has supported (and put up with me!) my whole life, and I want nothing more than to help her in return.

For more information about the hike, or if you’re interested in joining me for a section of it, feel free to contact me via Facebook or email at taliepoirier@gmail.com. You can also like my Facebook page at www.facebook.com/thebrainventure for updates on my trek.

Natalie Poirier
CCM Italia

Last July, the Italian Telethon Foundation communicated the outcomes of the 2015 Telethon call for research projects on genetic diseases, which resulted in the selection and funding of 33 research projects among 273 presented by researchers from all over Italy.

Among the selected projects and grant winners there is a multi-center research project focused on Cerebral Cavernous Malformation (CCM) disease, coordinated by Prof. Francesco Retta at the Department of Clinical and Biological Sciences of the University of Torino. This project aims at further characterizing CCM disease mechanisms and exploring novel therapeutic strategies through multidisciplinary and integrated research approaches.

This multi-center project also involves two major partners of the CCM Italia research network, Prof. Lorenza Trabalzini at the Department of Biotechnology, Chemistry and Pharmacy of the University of Siena, and Prof. Paolo Pinton at the Department of Morphology, Surgery and Experimental Medicine of the University of Ferrara.

The three research units involved in the project will take also advantage of collaboration and resources from other CCM Italia Units, as well as from international research collaborators and CCM-focused organizations. The project focused on CCM disease will be supported for three years with a grant of €419,000. In addition, building on the success of the first Italian CCM Scientific Meeting held in Torino on April 23, 2015, an annual Italian CCM Scientific Meeting will be organized to better share information and ideas, and to increase collaboration among investigators with distinct but complementary knowledge and expertise.

Hopefully, a better understanding of CCM pathogenesis will soon lead to novel therapeutic options to prevent or reverse adverse clinical outcomes in CCM patients.

Francesco Retta

Brain Vascular Malformations Consortium Is Recruiting CCM1 Patients

In collaboration with two other disease foundations (The Sturge-Weber Foundation and Cure HHT), Angioma Alliance has partnered with researchers and received a Rare Disease Clinical Research Network Consortium Grant. The Brain Vascular Malformations Consortium is a study team investigating three rare diseases that cause brain vascular malformations including Hereditary Hemorrhagic Telangiectasia, Sturge-Weber Syndrome, and Cerebral Cavernous Malformation (CCM).

We are currently recruiting participants for a study called “Brain Vascular Malformation Consortium: Predictors of Clinical Course. Project 1: Modifiers of Disease Severity and Progression in Cerebral Cavernous Malformations (CCM).”

Why Is This Important?

The goal of this study is to investigate the genetic factors that contribute to CCM disease severity and progression. To address this question, researchers are looking specifically at the genetic variations in individuals with CCM1 gene mutations.

In this study, clinical, genetic and environmental information will be collected from people with the CCM1 mutation to look for risk factors affecting CCM disease severity.

Any potential risk factors that are identified may have implications for all forms of CCM, including those with other genetic mutations or the sporadic form of the illness.

To participate:
- Join the Susan Sukalich-Angioma Alliance Patient Registry www.angioma.org/registry, or,
- Contact the Study Scientist Amy Akers, PhD, Principal Investigator, by email at amy.akers@angioma.org.
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.

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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 our support for 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 information for the cavernous angioma community. If you would like to reach this community and 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.

Events
Angioma Alliance members host multiple events throughout the year, from Cavernous Angioma Awareness Night at major league sporting events to smaller Fun Runs and tournaments. Sponsorship opportunities are always available with varying levels of public exposure depending on the event.

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.