



ANGIOMA ALLIANCE NEWSLETTER

because brains shouldn't bleed

Drug Trials Are Here: Our Priorities Together

Since June, the first three clinical trials have been announced, and we couldn't be more excited. These trials represent hope, and, if they are to be successful, everyone involved with Angioma Alliance must play a role. We invite you to participate as you are able: in a Community Alliance, in our patient registry, at a conference, as a donor. The choices are endless. Some of our immediate priorities are:

Community Alliances

To be successful in filling trials, we need a strong, engaged patient community to help. Our Angioma Community Alliance grassroots program creates regional chapters offering patient support, public advocacy, and liaison to local medical providers. Community Alliances enable our members to carry out the mission of Angioma Alliance on a local level, educating our families about trials and assisting researchers in recruiting participants. We currently have five Community Alliances; our goal is to staff and grow this program to encompass all 50 states. This is our most critical need.

Centers of Excellence, Patient Registry, and Free Genetic Testing Program

In addition to educating our members and working with industry/academic researchers in trial design, Angioma Alliance has three programs that provide the backbone for clinical trials. First, the International Cavernous Angioma Patient Registry, the largest in the world, provides patients with information about research projects and provides researchers with the information they need for successful trial design. Second, our unique free genetic testing program allows individuals and their extended families to clear a large hurdle on their way to trial enrollment as they learn their family's specific genetic mutations. Finally, our growing network of CCM Centers of Excellence will become the sites for trials, as well as continuing to provide quality, coordinated care.

Engaging a Critical Population

The New Mexico Family Historical Project, launched in January of 2017, is dedicated to identifying and supporting individuals in New Mexico and the surrounding region who have the common Hispanic mutation, a genetic form of CCM. New Mexico is the state with the largest population of families affected by the genetic form of CCM in the world. In certain parts of the state, up to one person in 50 is affected. The project seeks to identify individuals who have inherited this mutation through community presentations, free genetic testing, and counseling, and to provide resources and support after their diagnosis. We encourage and facilitate participation in research studies that benefit all families affected by CCM and expect that a large contingent of clinical drug trial participants will arise from this group.

Connecting Researchers and Patients

The CCM Scientific Meeting is the only venue for researchers, clinicians, advocates, industry, and government agencies to assemble, and for international researchers and clinicians to share the latest CCM research data. The meeting is open to professionals in all scientific fields related to CCM research. This year, the National Family Conference, to be held in Silver Spring, MD, November 9 & 10, brings together these CCM experts and our families. The patient conference will feature clinical presentations, small group discussions, and opportunities for socializing. For many of us, this represents the first time we have met others who have the illness, a powerful experience. Clinical presentations are live-streamed and available on YouTube after the event, providing non-attendees an opportunity to learn about advances in care and opportunities for research participation.

We would love to have you more involved! Please reach out to us at info@angioma.org to learn more. With your help, real treatments will be just around the corner.

Connie Lee

The Road to Clinical Trials

The pathway to clinical trials has been a long and winding road. Years ago, misdiagnosis was common. It wasn't until the 1980s, when magnetic resonance imaging (MRI) became common practice, that cavernous angioma began to be properly recognized and diagnosed. At that time, we didn't understand the biology of the disease, how lesions form, or why they bleed.

In 1999, we had a huge breakthrough in the lab with the identification of the first causative gene for familial cavernous angioma. The gene was named CCM1, after the other common term for the illness, cerebral cavernous malformations. When it was discovered, the CCM1 gene had no known function. Because it was associated with the illness, we knew then that it had an important role in lesion development, but we didn't know why. Furthermore, CCM1 gene mutations did not explain all familial cases of the illness. Two more genes were later identified (both of which also had previously unknown functions): CCM2 was discovered in 2003, followed shortly thereafter with the finding of CCM3 in 2005.

The next decade of laboratory research focused on understanding the function of these three genes. What do they do? How do they do their job? And why, when they mutate, do they cause of the formation of blood vessel lesions? This work has been accomplished by academic and industry research teams across the world who investigate specific, hypothesis-driven questions, and use high-throughput screen platforms to identify key molecules associated with future drug targets.

Now, the University of Chicago is about to begin enrolling participants in the first clinical trial for symptomatic hemorrhage of cavernous angioma. We also anticipate a safety study to begin for a new drug REC-994 (Tempol), and in Europe, a multi-site study of propranolol has begun. (See the following pages for details on these studies.)

Angioma Alliance works closely with our research teams to support and expedite movement of laboratory studies to our patient community. The first step in the process has been strong science and discovery. Now, successful clinical trials will require a unique set of tools. These tools include: an understanding of the natural history of the illness; an infrastructure network for trials;

and validated measurement tools (biomarkers and patient-reported outcomes).

Natural history

While every case of cavernous angioma is unique, understanding the overall typical disease course (natural history) is of critical importance for planning clinical trials and defining clinical endpoints (what we measure to decide if a drug treatment is effective). The Brain Vascular Malformations Consortium (BVMC) is an ongoing study that addresses this need. The BVMC has collected nearly ten years of clinical data and annual follow-ups (ongoing) for approximately 600 familial cavernous angioma patients. This tremendous data set can and has been used collaboratively to bridge the gap between animal studies and the human condition. For example, when the microbiome story was unfolding in mice, we wanted to know whether this was an animal-specific phenomenon, or if there might be a connection with the gut in humans as well. The BVMC team provided genetic data that supported investigating human microbiome samples in relation to clinical severity. This story continues to unfold; analysis of human microbiome composition is underway.

Building a network

Recruitment is among the most challenging aspects of all clinical trials, particularly those for rare conditions, like cavernous angioma, and/or in studies with limited focus, on a restricted age group, or a specific symptom. Phase III trials are large and will require coordination between multiple sites to achieve the required number of participants. Angioma Alliance continues to develop our network of recognized Clinical Centers that will function to provide excellence in care and research, and will also function as a network of clinical investigators who can contribute to multi-center studies in the future. Our growing network of Community Alliances is connecting our families to each other, to good information, and to local Clinical Centers and researchers.

Validating biomarkers

A new project, Trial Readiness in Cavernous Angiomas with Symptomatic Hemorrhage (CASH), will nurture the network of centers, better understand

the diversity of possible research participants, and validate measurement tools across the sites. The Trial Readiness project will assess potential patient groups at each site and hemorrhage rates in those groups to better understand the feasibility of designing and recruiting for a large trial focused on hemorrhage.

Hemorrhage is a devastating event, with severe clinical consequences. However, from a research statistical perspective, it is challenging to measure hemorrhage because the events occur infrequently. Instead of directly measuring hemorrhage frequency, researchers aim to use an advanced imaging tool to measure iron in and around cavernous angioma lesions. This iron measurement would function as a surrogate measure for hemorrhage. A focused aim of this project includes validating the reproducibility and reliability of imaging biomarkers at multiple institutions, in preparation for future multi-center trials.

There is still a place for basic research...

With a greater (but not yet complete) understanding of the biology of cavernous angioma, we have ten drugs or drug targets in our development pipeline. The cavernous angioma research community is full of talented and driven scientists who study the illness from all perspectives: at the level of the protein, cell, or complete animal model. Each year our investigators continue to refine and identify new drug targets.

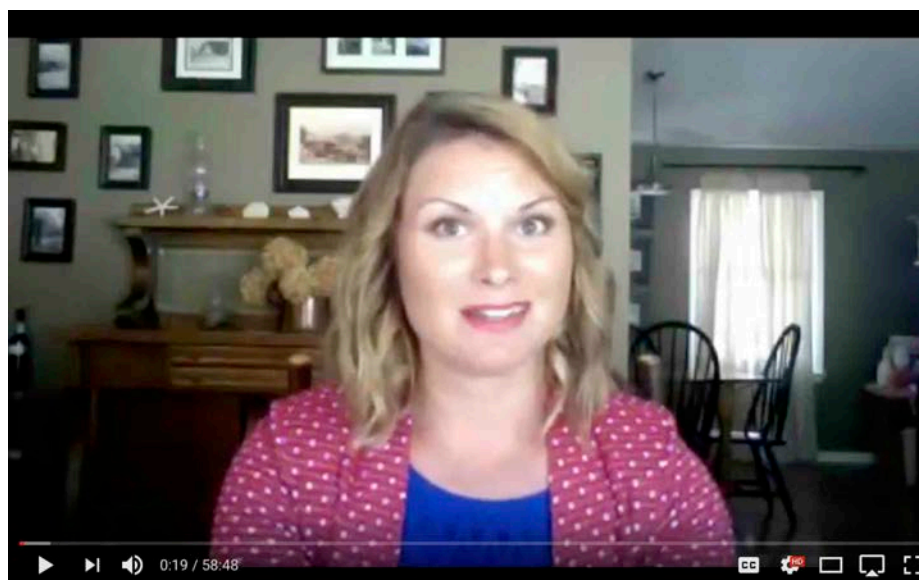
Before any new drug can reach a human for safety and efficacy testing, it must first pass muster in laboratory assays and animal models. Mice are the

featured animal model for cavernous angioma. Housed in academic institutions around the world, our researchers have access to *acute* and *chronic* disease mice. The acute mice are genetically engineered such that they develop a tremendous number of lesions within a few days of birth. These acute models are well-suited for studies that investigate the formation or earliest stages of lesion development. These studies can be completed within a few months. An acute mouse model was involved in the discovery of the possible microbiome connection to lesion development.

By comparison, the chronic mouse models develop fewer lesions over a lifespan of several months. This is more comparable to the human condition as the lesions are composed of mature complex multi-cavernous vessels that are distributed throughout the brain. Studies with the chronic models require more time, up to a year or more, but address different questions. These mice are useful for research investigating the biology of the lesions themselves (how those blood vessel cells differ from other non-lesion vessels) and also for long-term treatment studies for hemorrhage or lesion shrinking, for example.

The pathway to clinical drug development is not short or straightforward; it takes a village, a coordinated and multidisciplinary village. I believe we have that village, and I look forward to working together to successfully fill these first few clinical trials and continue to learn about the biology and identify new drug targets.

Dr. Amy Akers



Dr. Amy Akers, Chief Scientific Officer, discussed the Trial Readiness Project and the upcoming atorvastatin trial with Dr. Issam Awad, University of Chicago, in a recent webinar. The webinar can be viewed at <https://youtu.be/P4TYBtAtieI>

Clinical Trial Announcements

A number of clinical trials are set to launch in the near future. We need as many people as possible to sign up for these trials, so look for one that is a fit for you to help find a cure!

Treatment Trial: Atorvastatin

The University of Chicago will begin recruiting participants this fall for the first clinical trial for cavernous angioma hemorrhage. They will be testing the medication atorvastatin.

Atorvastatin is a type of drug known as a statin. Statin drugs are commonly used in the United States for the treatment of high cholesterol and to prevent stroke and heart attack. In the general public, statins are safe and effective for these cardiovascular conditions.

Recent research of cavernous angioma has shown us that lesion blood vessels are leaky and unstable. In laboratory studies, statin drugs make these blood vessel cells stronger and more stable. Atorvastatin treatment is able to prevent hemorrhage in mouse models of cavernous angioma. It is not known whether the drug is safe and effective in human patients with cavernous angioma. This trial will begin the process of finding out.

What is being tested?

This clinical trial will test two things:

- Is atorvastatin safe for those with cavernous angioma?
- Can atorvastatin treatment stabilize cavernous angiomas that have recently bled?

Who can participate?

You may be able to participate if you meet the following conditions:

- You are an adult aged 18 to 80,
- You have at least one cavernous angioma lesion that has hemorrhaged within the last year,
- You have not had surgery, or do not plan to have surgery on the bleeding lesion,
- You have not taken any type of statin drug within the last year,
- You currently have primary medical care and health insurance.

Some individuals will not be allowed to participate for safety reasons. If you are pregnant, have had previous brain radiation, or suffer kidney, liver or muscle disease, you will not be able to participate.

What is expected of those who enroll in the study?

You will travel to the University of Chicago for three study visits during this two-year study.

Year One

During the first study visit you will:

- Have a physical and neurological exam,
- Talk about your current health and complete several questionnaires about your health and quality of life,
- Have an MRI,
- Receive your study medication.*

**This clinical trial is blinded and placebo-controlled. This means that some participants will take the study medication while others will take a placebo (a sugar pill that looks identical to the study medication). Neither you nor the study doctor will know whether you are taking the medicine or placebo. This information will be revealed at the end of the study.*

- Laboratory blood tests will need to be completed prior to beginning the drug trial and three months after your first study dose.
- You will speak with the study nurse by phone at three, six, and nine months after enrollment.

Year Two

Your second study visit will take place 12 months after you begin the study. At that time, you will travel to the University of Chicago for:

- Neurosurgical and neurological exam,
- Laboratory blood tests,
- MRI,
- Quality of life surveys.

During the second year, you will speak with the study nurse by phone at 15, 18 and 21-month timepoints.

End of study

A final visit to the University of Chicago will conclude the study. As with the 12-month visit, this final study visit will include:

- Neurosurgical and neurological evaluation,
- Laboratory blood tests,
- MRI,
- Quality of life surveys.

Will you get paid?

Participants will receive funds to help offset travel costs. For those living in the Chicago area, you will receive \$50 per visit. If you live more than 200 miles from Chicago, you will receive \$500 per visit.

To stretch this travel stipend so it can come close to covering the actual cost of travel, Angioma Alliance has a listing of Airbnb accommodations that are lower-cost than traditional hotels on our website. We are working with Angel Flight to provide free air transportation within 1,000 miles of Chicago.

How do you get started?

Contact the study staff at the University of Chicago. Kristina Piedad is Dr. Awad’s study nurse who can answer any questions you may have and get you started with the enrollment process. Kristina can be reached by phone or email:

773-834-5210

Kristina.Piedad@uchospitals.edu

Treatment Trial: Propranolol

A multi-center Phase II treatment trial of propranolol is currently recruiting participants in Italy. At this time, you must live in Italy to participate, but the study team is hoping to expand the study to other EU countries. A similar but unrelated trial is planned and seeking funding in the United States.

Propranolol is a type of beta-blocker drug. Beta-blockers are typically prescribed for lowering blood pressure, managing heart attacks, and improving blood flow. Case studies in the medical literature have reported on the treatment of a small number of cavernous angioma patients with propranolol. These cases involved aggressive and/or large lesions. During the time the individuals in the case studies were taking propranolol, the large lesion became smaller and the lesions with prior aggressive bleeding did not

hemorrhage. However, we cannot draw a conclusion from just a few cases.

To study the effects of this drug in a controlled environment, the study team aims to explore the long-term (two-year) effects of propranolol treatment.

Specifically, they will assess whether propranolol is able to:

- Reduce the number of lesions
- Reduce clinical events and symptoms

Can you participate?

You may be a candidate to participate if you meet the following conditions:

- You live in Italy,
- You are an adult, 18 or older,
- You have familial (inherited) cavernous angioma,
- You have a history of clinical symptoms that may include: hemorrhage, stroke, seizures, etc.

You may not be able to participate in the study if you have recently undergone brain surgery, are pregnant, are unable to have an MRI, or are diagnosed with severe asthma, unstable diabetes, or liver and/or renal failure.

Participation will include travel to a study site in Italy.

For a full list of eligibility criteria, please visit: clinicaltrials.gov/ct2/show/NCT03589014.

REC-994 Safety Study

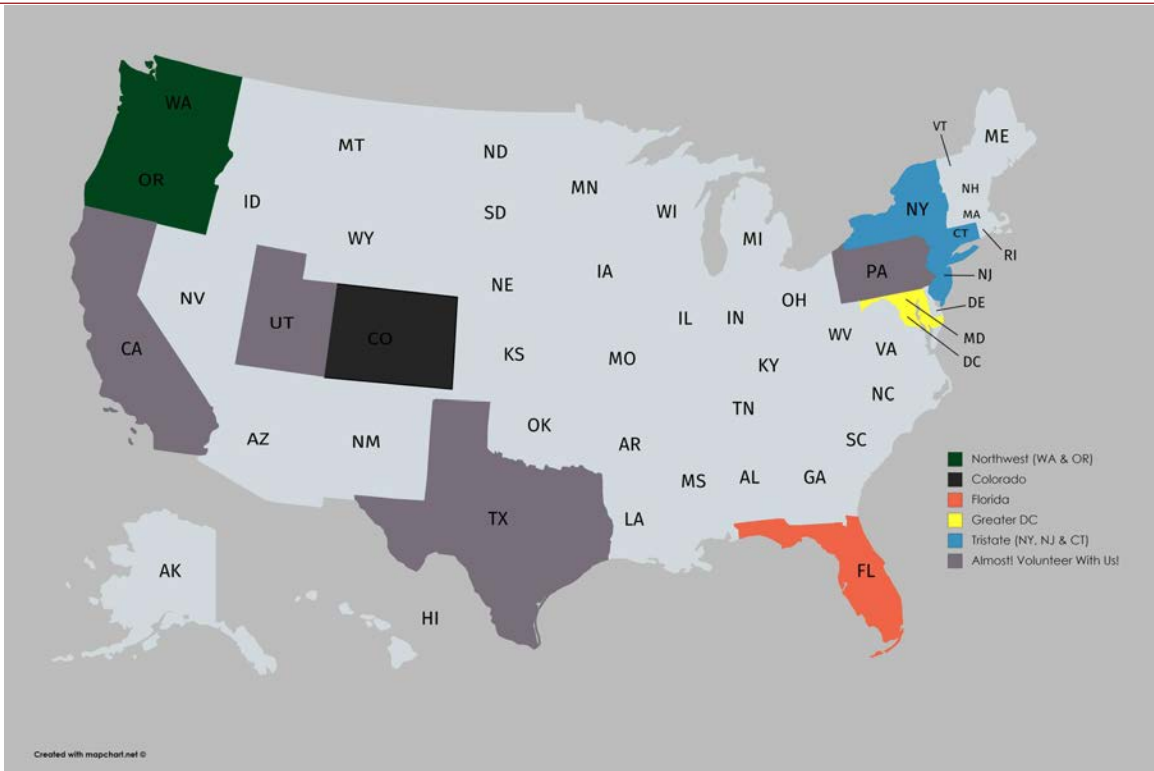
Recursion Pharmaceuticals recently announced they have received FDA approval to test their study molecule, REC-994 (Tempol), in humans. This study team has previously shown REC-994 to be effective in mouse models of cavernous angioma. In the mice, treatment with the study drug strengthens blood vessels and makes the cavernous angioma lesions less likely to leak blood into the surrounding brain.

The next step for this research is testing whether the drug is safe for human use. A safety trial will test REC-994 on healthy volunteers. This is common practice for new drugs and will help determine if the study drug is suitable for testing in cavernous angioma patients. The safety trial is planned to begin recruitment late this year. Read Recursion’s trial announcement: tinyurl.com/REC994.

Dr. Amy Akers



Medications currently in the pipeline for clinical trials.



Community Alliance Program

Since we launched the Community Alliance Initiative in January, we now have five groups across the nation! Community Alliances are tasked with organizing grassroots fundraising, support, education, and awareness initiatives in their local communities to support the Angioma Alliance mission.

There are other areas where we are close to starting a group, but we need a few more volunteers to get things going. For more information on the Community Alliance program, please go to www.angioma.org/local or reach out to salband@angioma.org.

Upcoming Events

4th Annual Torrington Wine Tasting, Torrington, CT

On September 14, hundreds will attend the 4th Annual Torrington Wine Tasting in Torrington, CT. The event, organized by Julie DeMichiel and Terry Ponte, raises over \$40,000 annually. Highlights include wine, beer, chocolate tasting, a silent auction, and live music.

www.tinyurl.com/2018angiomawinetasting

Bags for Brains, Sharon, MA

This fun-filled cornhole competition, on October 6, is hosted by Regina Hill, Angioma Alliance member. Highlights include cash prizes, a cookout, and a raffle.

www.tinyurl.com/2018angiomabagsforbrains

Inaugural Colorado Zombie Walk, Morrison, CO

Come on out for this spooky, kooky Zombie Walk on Saturday, September 22, at Bear Creek Lake Park in Morrison, CO. Hosted by the Colorado Angioma Community Alliance, this family-friendly fundraising and awareness event will feature ghoulish games, prizes, refreshments, a raffle and more!

www.tinyurl.com/2018angiomazombiewalk

2nd Annual Orange County Walk and 5K

Calling all superheroes! The 2nd Annual Orange County Walk honoring Florence Griffith Joyner will take place on Sunday, September 23, at Flo Jo Park in Mission Viejo, CA. All CCM superheroes and heroines will be asked to strike their best superhero pose to show their strength against cavernous angioma! Mrs. Incredible and Batman will also make an appearance.

www.tinyurl.com/2018ocangiomawalk

6th Annual Zach Brown 5K, Edgewater, MD

The 6th Annual Zach Brown 5K will be held at Camp Letts YMCA on Sunday, October 7. The walk is hosted by 16-year-old Zach Brown, who has had two brainstem cavernous angioma bleeds, and the Greater DC Community Alliance. This annual fundraising and awareness event is attended by hundreds every year.

www.tinyurl.com/2018zachbrown5k

Event Wrap-up

Saber Seminar, Boston, MA

On the first weekend of August, 200 scientists, mathematicians, and baseball experts gathered at Boston University for the Sabermetrics, Scouting, and the Science of Baseball seminar. Organized by Dan Brooks and Chuck Korb, this meeting is about more than baseball. It's also about supporting the mission of Angioma Alliance. This is a major fundraiser and all proceeds from ticket sales are donated to Angioma Alliance. We are very grateful!

Art for Angioma Alliance, Online Auction

Throughout the summer, talented artists auctioned off their artwork to benefit the Baca Family Historical Project. The virtual event hosted on Facebook at Art for Angioma Alliance (@artforangiomaalliance) by Jana Bergholtz features amazing artwork using various mediums. Because of a generous matching gift by the Julian Grace Foundation, the auction raised over \$7,500 for the New Mexico project!

Bowling for Brains, Tampa, FL

On July 14, the Florida Angioma Community Alliance hosted its first event, a bowlathon. Chaired by Amy Brooks, the event allowed families to connect and have fun. Over \$1,000 was raised. The Florida Community Alliance is planning its second event, Cruising for a Cure—a casino night on a cruise ship—later this fall. Stay tuned to our website and Facebook page for more information about the cruise and all of our other events.



UVA CCM Clinical Center team. Left to right: Dr. Min Park, Susan Rannigan, Chelsea Chambers, Dr. Connie Lee, Dr. Yashar Kalani, Julia Lee, Dr. Andrew Southerland. Not pictured: Drs. Barrett Zlotoff, Mark Shaffrey, Bradford Worrall. Photo credit: UVA Health System.

Cavernous Angioma Night at Great American Ballpark, Cincinnati, OH: On August 13, over 250 Angioma Alliance friends and family attended the 4th Annual Cavernous Angioma Night as the Reds played the Indians. Tony Mayer, Chair of the Board of Directors, recognized Joe Price, former Reds pitcher, with a certificate of appreciation for his enduring dedication to the mission of Angioma Alliance. The event raised over \$8,000. A patient conference was held before the game at Cincinnati Children's Hospital, an Angioma Alliance designated Center of Excellence.



Two CCM Centers Recognized

University of California San Francisco

Angioma Alliance has recognized the University of California San Francisco as a CCM Center of Excellence. Under the guidance of Medical Co-Directors Drs. Nerissa Ko and Adib Abl, UCSF is currently the only Center of Excellence on the West Coast. Learn more at tinyurl.com/y89seuwz.

University of Virginia Health System

We have recognized University of Virginia Health System as a CCM Clinical Center. A CCM Clinical Center meets many of the same standards as a Center of Excellence but may not yet have the same volume of patients. Directed by Dr. Yashar Kalani, the UVA team will be featured at our National Patient Conference in November. Learn more about UVA's program at tinyurl.com/y96ypze2.

Member Profile: Determined, resilient, persistent... that is Tania!

Our journey began in 2005, when Tania was just four years old. We were living in southern Spain when, one day, Tania's left pupil was dilated. We took her to the ER, and, after an MRI, the doctors dropped a bomb. She had cavernous angiomas (CCM), and the one on her brainstem had bled. You all know what happens next: devastation, sadness, hopelessness, fear, anger, etc. Then you find the strength to do the best you can for your loved one. That's it, there is no other choice.

After consulting with various doctors and specialists we decided to have the cavernous angioma removed in the US. However, it was too deep. Rather than cause Tania harm, the doctor decided to back off. After five days, Tania was out of the hospital with no deficits. Now it was wait and see, and pray it never bleeds again. We decided to move to the Washington-Baltimore area later that year, in 2006. The only plan was annual MRIs.

For the next seven years, all was well, no evidence of bleeding. Tania and her older sister, Adriana, enjoyed staying active with yearly trips to Spain (their mom is from Madrid), playing in a soccer league, learning to play musical instruments, dance recitals, fishing, camping, amusement parks, etc. Tania excelled in school, taking the most challenging classes, joining the drama club, and she consistently made the honor roll.

In 2013, Tania had a bleed causing double vision and weakness on her right side. After a few months of rehab, she recovered about 80%. After subsequent bleeds in 2015 and 2016, we couldn't "wait and see" any longer. Each bleed was causing Tania more harm.

In October 2017, after much prayer and reaching out to various doctors, we decided to move forward with surgery at the University of Chicago. Most of the CCM was removed, however a small amount could not be safely resected. After surgery, Tania couldn't walk and most of her right side was paralyzed. Both eyes were closed, she had limited movement, and difficulty swallowing and speaking.

Tania stayed in the hospital for almost two weeks. Then she was transferred to a rehab center in downtown Chicago. After a month, Tania was well enough to go back home where she continued daily

occupational, physical, and speech therapy, and, later, home schooling. In June 2017, Tania was discharged from the therapy programs. She could walk, and her speech and cognitive skills improved. So, she was able to once again spend the summer in Spain.

Throughout her entire recovery, Tania never once complained about the hard workouts. When her therapists asked her if she wanted to take a break, she never stopped, she just kept on going. They were all constantly amazed by her motivation. As a parent, you never want to see your child go through this situation. It's an emotional roller coaster for all, but in the end, we found strength through Tania. Every day she was a bit better. She always did what her doctors and therapists told her to do in an effort to get back to "normal."



Tania Casaus, shown here in Segovia, Spain, is a high school senior who has had three brain surgeries. Tania is a proud supporter of the annual Zach Brown 5K fundraiser for Angioma Alliance. This will be Tania's third walk/run. On October 7, in Edgewater, Maryland, please join Tania, Zach and others impacted by CCM by registering or donating at: www.tinyurl.com/2018zachbrown5k.

We are thankful for the support of our families who are in New Mexico and Spain, our friends in the DC area, and the Angioma Alliance community. After Tania's bleed in 2016, we called Dr. Connie Lee and told her our story. She told us about the Zach Brown 5K Angioma Alliance fundraiser in nearby Edgewater, Maryland. We attended and met Zach and other families that were going through the same thing. We weren't alone anymore. We were instantly connected, and we provided support to one another. Before Tania's surgery in 2017, she set a goal: that she will run/walk at the Zach Brown 5K in 2018. We will be there, Zach!

Tania's strength is her indelible zest for life. She wants to travel the world, experience new things, meet new people, take on new challenges; she is fearless! Despite what Tania went through this past year, she returned to a full class schedule to complete her senior high school year on time. If you ask Tania what she wants to do one day, she will say she hasn't figured it out yet, and she is just focused on this year, taking it one day at a time. She still has challenges to overcome with deficits to her right side and eye movement, but one thing is certain, Tania will continue to be determined, resilient, persistent!

Carlos Casaus

Carlos Casaus (Tania's Dad) has tested positive for CCM1 but has been asymptomatic. Carlos is also the Chair of the Greater DC Community Alliance (GDCCA). Community Alliances are tasked with organizing grassroots fundraising, support, education, and awareness initiatives in their local communities to support the Angioma Alliance mission. For more information or to join the GDCCA contact them at dcangioma@gmail.com.

National Patient Conference, November 9-10, Silver Spring, MD

Please join us at the DoubleTree Silver Spring for two days of presentations and conversations about cavernous angioma research and treatment. This meeting is being held concurrently with the International Scientific Meeting, and there will be a shared session and other opportunities to interact with the researchers.

At the conference, you will:

- Attend a keynote presentation by Dr. Rustam Al-Shahi Salman, along with the researchers,
- Hear presentations geared toward patients and their families from leading clinicians and researchers including Dr. Issam Awad, Dr. Yashar Kalani, Dr. Stacy Suskauer, Dr. Andrew Southerland, Dr. Amy Akers, Dr. Robin Brickel, and Dr. Connie Lee,
- Have an opportunity to meet Scientific Meeting attendees over lunch,
- Meet other Angioma Alliance members and share stories and tools.

This is a unique opportunity to interact with the research community and to learn about the patient and family role in advancing the search for better treatments. Our International Scientific Meeting attracts every major research laboratory in the world, as well as many leading clinicians.

Early registration through October 7 is \$70/first registrant, \$45/each additional registrant.

Registration from October 8-31 is \$80/first registrant, \$55/each additional registrant.

Late registration from November 1-6 is \$100/first registrant, \$75 each additional registrant. Learn more and register at www.tinyurl.com/Angioma2018.

Online Peer Support Meeting: Spinal Cavernous Angioma

Please join us on Sunday, September 23 at 6 pm ET (5 pm CT, 4 pm MT, 3 pm PT) in an online peer support meeting for those affected by spinal cavernous angioma. Facilitated by Myrna Sarowitz, longtime member, life coach, and spinal cavernous angioma survivor, the meeting will use the Zoom platform to allow participants

to share stories and support. Zoom allows participants to see and hear each other, or you may dial in by phone. Remember to register ahead of time; you'll be sent a link via email that will get you to the meeting. Please go to www.tinyurl.com/AASpineMeeting to register.

International News

Cavernoma Alliance UK

In the last newsletter Cavernoma Alliance UK (CAUK) paid tribute to the leadership of its retiring Chair, David White. As co-ordinator I have watched the charity's membership and impact grow rapidly. So the Board of Trustees and I agreed that a leader was required to provide shape to the charity that I had founded in 2005.



After a nationwide search we are very pleased to announce the appointment of Helen Evans to be the new and first Chief Executive of CAUK. Helen starts on Monday 17th September. Helen is part-time and will work from her home in south Oxfordshire, south eastern England. Until recently Helen

was Chief Executive of Getting Heard, an Oxfordshire based advocacy charity. Under her leadership, the charity was awarded the prestigious Quality Performance Mark, secured multi-year Big Lottery funding and was one of the first providers of Care Act advocacy in the UK. Before working with Getting Heard, Helen was Head of Safeguarding for a global aid agency, following a 10-year career in international human resources. She is an alumnus of the Jo Cox Women in Leadership Programme, and currently an Oxfordshire County Councillor.

I will continue my role as co-ordinator and work with Helen to take us forward. Running CAUK from its beginnings in 2005 until we received Big Lottery funding in 2013 marked the first phase in the charity's development. The second phase began with our successful bid to the Big Lottery where part-time staff, volunteers along with the tireless work of David White and the trustees increased our visibility and support tremendously.

Without a doubt this is a very exciting time for CAUK and Helen as she assumes her role in shaping CAUK's vision. Helen's previous experience in the charity sector, both large and small, provides a wonderful background for CAUK as we move into the third phase of our existence.

Ian Stuart

Cavernöst Angiom Sverige (CASE)

On August 26, 2018, Jonas Dahlsten (treasurer), Anne Johnen Dahlsten (secretary), and Jana Bergholtz (president) officially started a new charity in Sweden with the name Cavernöst Angiom Sverige (CASE). This charity will operate under the umbrella organization Sällsynta Diagnoser; Rare Diseases Sweden.

Its mission is to raise awareness for cavernous angioma, cavernoma, cavernous malformations (CCM) in Sweden, to provide support to patients and their families, connect to researchers and specialists who have an interest in CCM, and to connect to other CCM patient organizations (especially within Europe, to be able to approach the European Reference Networks together). If you live in Europe, come and join our closed Europe support group: www.facebook.com/groups/1435794749827227/. If your country doesn't have a CCM patient organization; maybe we can inspire some of you to start one?



Jana Bergholtz (left), Jonas Dahlsten, Anne Johnen Dahlsten (right) and their sons Emil and Aaron.

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:

Scientific Meeting - \$35,000 to \$1,000

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

Newsletter - \$10,000 to \$5,000/year

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 - \$10,000 to \$1,000/year

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 - Range of opportunities

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.

DNA/Tissue Bank and Genetic Testing - \$20,000/year

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 Stephanie Alband at salband@angioma.org to learn more about these opportunities and valuable benefits for your company.



**ANGIOMA
ALLIANCE**

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
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A copy of the latest financial report, registration filed by this organization and a description of our programs and activities may be obtained by contacting us at: Angioma Alliance, 520 W 21st St STE G2-411, Norfolk, VA 23517, info@angioma.org. If you are a resident of one of the following states, you may obtain financial information directly from the state agency.

- Florida – A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE, WITHIN THE STATES, 800-435-7352 (800-HELP-FLA) OR BY VISITING www.800helpfla.com. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL OR RECOMMENDATION BY THE STATE. Florida Registration CH20096
- Georgia – A full and fair description of our programs and our financial statement summary is available upon request at our office and email indicated above.
- Colorado – Colorado residents may obtain copies of registration and financial documents from the office of the Secretary of State, 303-894-2860, www.sos.state.co.us/ Reg. No. 20063003635.
- Maryland – For the cost of copies and postage, from the Office of the Secretary of State, State House, Annapolis, MD 21401.
- Michigan – MICS # 35000
- New Jersey – INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FOR THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING 973-504-6215 AND IS AVAILABLE ON THE INTERNET AT: <http://www.state.nj.us/lps/ca/charfrm.htm>. REGISTRATION WITH THE ATTORNEY GENERAL DOES NOT IMPLY ENDORSEMENT.
- New York – Upon Request, Attorney General Charities Bureau, 102 Broadway, New York, NY 10271
- North Carolina – Financial information about this organization and a copy of its license are available for the State Solicitation Licensing Branch at 919-807-2214. This is not an endorsement by the state.
- Pennsylvania – The official registration and financial information of Angioma Alliance may be obtained from the Pennsylvania Department of State by calling toll-free within Pennsylvania 800-732-0999. Registration does not imply endorsement.
- Virginia – State Division of Consumer Affairs, Department of Agriculture and Consumer Services, PO Box 1163, Richmond, VA 23218.
- Washington – Secretary of State at 800-332-4483 or <http://www.sos.wa.gov/charities/>. REGISTRATION WITH A STATE AGENCY DOES NOT CONSTITUTE OR IMPLY ENDORSEMENT, APPROVAL OR RECOMMENDATION BY THAT STATE.