

# ANGIOMA ALLIANCE NEWSLETTER

because brains shouldn't bleed

## June is Cavernous Angioma Awareness Month

Angioma Alliance is spearheading an international effort to increase awareness, further advocacy, and raise funds, and you can share your story as part of this event. We have a jam-packed month filled with lots of ways you can help spread awareness. The month's activities will coincide with our 2018 **CURE** theme. Each week, we will recognize a different group of people dedicated to supporting the mission of Angioma Alliance.

**C** represents our **CENTER OF EXCELLENCE** program. Throughout the week, we will recognize our Clinical Centers and Centers of Excellence, which provide high-quality interdisciplinary care for both sporadic and familial cavernous angioma patients.

**U** represents **YOU**, our Angioma Alliance community members. During this week, we will share your stories of courage and determination to persevere throughout your cavernous angioma journey.

**R** represents cavernous angioma **RESEARCHERS** who work tirelessly towards finding better treatments and a cure.

**E** represents **EVERYONE**. During this final week of appreciation, we will feature ways that our efforts collaboratively result in a nationwide community dedicated to empowering individuals affected by

cavernous angioma and driving research for better treatments and a cure.

How you can help support Awareness Month:

- Follow us on Facebook, Instagram, and Twitter, @AngiomaAlliance. Share our messages, post your own stories, and use the hashtag #BrainsShouldntBleed.
- Create a Facebook fundraiser or donate. It's easy; go to our Facebook page and click on Create a Fundraiser or Donate.
- Wear grey or maroon every Friday of the month and share on social media.
- Add our custom profile picture frame by visiting [www.facebook.com/profilepicframes](http://www.facebook.com/profilepicframes) and search for cavernous angioma, select our frame, and click Change Picture.
- Help us to spread the word and add the tag #BrainsShouldntBleed during the entire month of June!
- Find awareness kits and t-shirts for you and your loved ones in our online store at [shopangiomaalliance.bigcartel.com](http://shopangiomaalliance.bigcartel.com).

Without you, there can be no cure!

*Stephanie Alband*

### BREAKING NEWS: FIRST CLINICAL DRUG TRIAL FOR CAVERNOUS ANGIOMA HEMORRHAGE

The first clinical drug trial for cavernous angioma symptomatic hemorrhage has been approved by the National Institutes of Health (NIH) and will begin recruiting at the end of the summer. The University of Chicago Medicine will examine the effect of a widely-used and currently approved drug, atorvastatin, on stabilizing cavernous angiomas that have hemorrhaged.

Atorvastatin is a statin drug, commonly used for cholesterol lowering and stroke and heart attack prevention. While animal studies have been promising, it is currently not known if the drug is safe or helps prevent bleeding in cavernous angiomas in humans.

A description of the trial can be found at [clinicaltrials.gov/ct2/show/NCT02603328](https://clinicaltrials.gov/ct2/show/NCT02603328). Please stay tuned to our website and social media for more information in the next weeks.

## **4th Annual Cincinnati Reds Cavernous Angioma Night**

Join us for Cavernous Angioma Night at Great American Ball Park on Monday, August 13th at 7:10 p.m. as the Reds take on the Cleveland Indians. You can win a chance to throw out the first pitch! Go to [tinyurl.com/2018angiomaredsgame](http://tinyurl.com/2018angiomaredsgame) for more info. A free patient conference open to anyone affected by cavernous angioma will be held earlier in the day at Cincinnati Children's Hospital.

## **2nd Annual Art Auction**

Our 2nd Annual Art Auction was held on March 12-18, during Brain Awareness Week. Cavernoma Alliance UK also joined with their own event. Thank you, artists, for donating your beautiful artwork and Jana Bergholtz for your leadership. \$2,000 was raised!

## **Inaugural Houston Walk**

A huge thank you to Jonathan and Brandy Ott for hosting the Houston Walk on April 14 in honor of their son, Kelan! The event raised \$2,000! Despite the rain, many cavernous angioma families in the Houston area were able to connect. They plan to get together again soon to start planning next year's walk.

## **Angioma Alliance Canada Conference**

On Saturday, July 7, please join us at the Peter Gilgan Center for Research and Learning at the Hospital for Sick Children in Toronto. Look for registration information at [Angioma.ca](http://Angioma.ca).

## **Other Upcoming Events**

Go to our website or our Facebook page for information about these upcoming fundraising events:

- Saberseminar, Fri-Sat, August 4-5, Boston, MA.
- Torrington Wine Tasting, Friday, September 14, Torrington Country Club, Goshen, CT.
- Angioma Alliance Walk & 5K Honoring Florence Joyner, Sunday, September 23, Flo Jo Park, Mission Viejo, CA.
- Zach Brown 5K, Sunday, October 7, YMCA Camp Letts, Edgewater, MD.
- Malibu Angioma Alliance Walk, Sunday, October 21, Zuma Beach, Malibu, CA.

## **Cincinnati Children's Hospital Medical Center Recognized as Center of Excellence**

On April 17, Cincinnati Children's Hospital Medical Center was recognized as a pediatric Clinical Center of Excellence by Angioma Alliance. The designation is awarded to clinical centers that provide expert multidisciplinary care for patients with cavernous angiomas and engage in cavernous angioma research. Angioma Alliance Board Chair Tony Mayer awarded the certificate of recognition, together with his son Dylan, who has had two brain surgeries at CCHMC.



"We are proud to be honored with this designation," says Dr. Sudhakar Vadivelu, Director of the Cincinnati Children's Cerebrovascular Disease Center and the Center of Excellence. "Our team is committed to providing outstanding care to families affected by cerebral cavernous malformations. We look forward to deepening our relationship with Angioma Alliance and the national patient community."

"We are pleased to recognize the Center of Excellence team at Cincinnati Children's Hospital Medical Center for the outstanding care they have been providing to our families," says Connie Lee, Psy.D., president and CEO, Angioma Alliance. "We also appreciate the investment they have made in researching cavernous angioma, paving the way for better treatments in the future."

At Cincinnati Children's, patients receive care from a collaborative, highly experienced team, including a pediatric neurosurgeon and clinicians with expertise in childhood neurology, diagnostic neuroradiology, stroke, genetics, vascular anomalies, and blood disorders. The goal is to provide a seamless, team-based, patient-focused approach.

## Baca Family Historical Project Updates

The Baca Family Historical Project is an initiative of Angioma Alliance in the Southwest, primarily in New Mexico. We connect members of the extended Baca family, the original Hispanic family that settled in the area in 1600, because it is in this family that the Common Hispanic Mutation, one of the familial forms of cavernous angioma, began. By connecting this family, we build a supportive community and are able to identify more individuals who are at risk. As part of our work, we offer genetic testing to those who can trace their family line to Cristobal Baca II, born in New Mexico in the early 1600s.

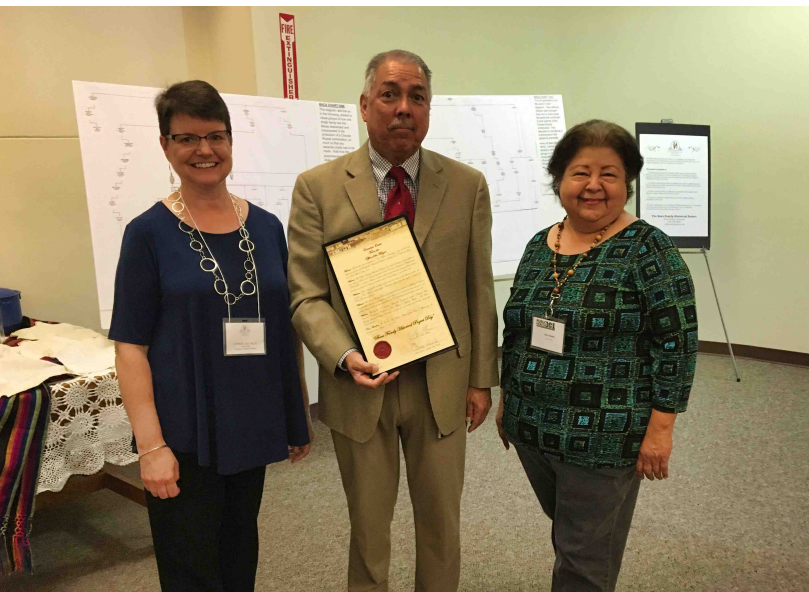
Our first year, 2017, we partnered with genealogical expert Henrietta Christmas to offer a number of conferences in northern New Mexico, attended by over 200 Baca family members. The conferences offer presentations on Baca family history, the genealogy of the Common Hispanic Mutation, and the clinical features of hereditary cavernous angioma. The presentations are followed by a family tree workshop in which professional genealogists work with attendees to flesh out their ancestry. Finally, free genetic testing is offered to those who qualify. Between conferences, Baca family members may contact Joyce Gonzales, our staff genealogist to go through the same process remotely.

In 2018, we continue these conferences. On May 18th, at the 2nd annual Albuquerque Baca Family Historical Project conference, the City of Albuquerque proclaimed the day to be Baca Family Historical Project Day. We are honored to have this citywide recognition.

We have also added a new partner. The New Mexico Board of Health has organized multiple conferences targeting Community Health Workers, known in New Mexico as *promotoras*, to educate these front-line providers about the genealogical connection and the illness. The Board of Health has approved our presentation for continuing education credits awarded to attendees. The Baca Family Historical Project has only one full-time and one part-time staff member; our reach is limited. The hundreds of community health workers who can now educate their constituents will make an enormous difference in how many New Mexicans we can reach. Our community health worker conferences have also expanded to include community health workers from the El Paso area of Texas and from Juarez, Mexico.

In an unusual partnership, we are working with a voluntary organization called Statistics Without Borders. This is an international group of mathematicians who assist non-profits with statistical projects. We often are asked to quote the number of people affected by the Common Hispanic Mutation in New Mexico. Our best estimate is 30,000, but we have not had this level of experts applying their knowledge to the project. Now, Statistics Without Borders is working with Joyce Gonzales and Dr. Leslie Morrison to arrive at a more definitive answer. Having this answer will help us to understand the extent of the work needed in New Mexico to reach families and medical professionals and to assist researchers.

Please help us continue this critical project by contributing to meet the match offered by the Julian Grace Foundation. The first \$20,000 in new donations we receive in 2018 toward the Baca Family Historical Project will be matched dollar-for-dollar by the foundation. Our work helps not just those in New Mexico, but also helps researchers everywhere who are trying to gain an understanding of cavernous angioma so that better treatments can be found.



Connie Lee, Alan Armijo, Albuquerque Director of Constituent Services, and Nora Chavez, Baca Family Historical Project Community Outreach Specialist.



## Four Angioma Community Alliances Form

Since announcing our Angioma Community Alliance initiative in the last newsletter, we are proud to announce the formation of four volunteer Community Alliances, carrying out the mission of Angioma Alliance on a local level.

We now have Angioma Community Alliances that represent Greater Washington DC, the Pacific Northwest, Florida, and Colorado.

Each group was founded with five volunteers serving in the roles of Chair, Vice-Chair, Treasurer, Event Co-Chair, and Peer Support Co-Chair. These positions serve as core roles, helping to keep a larger group organized and moving forward.

The Pacific Northwest Community Alliance raced out of the gate by raising awareness and riding for a reason at the 2018 Sand Flea Rally in April. Members and their friends wrapped Jeeps with a modified version of the Angioma Alliance logo and spread the word at the event. The event also served as the NW Community Alliance's first in-person meetup, as the event was attended by multiple Angioma Alliance families. On May 20th, the group held an online meetup via video conferencing. On July 18, Angela Johnson, Chair of the Northwest Community Alliance will be a guest speaker regarding mental health access at the Oregon Museum of Science and Industry. She will speak on how mental health care is imperative with CCM.

The other new Community Alliances are creating formal action plans that will serve as roadmaps for the upcoming year. The Greater Washington DC Alliance has submitted theirs, and it includes:

- Hosting a Meet and Greet on June 10th for the greater DC Alliance community.
- Creating a Welcome Packet for new members.
- Expanding the Zach Brown 5K event in October with a goal of raising \$10,000.
- Serving as the volunteer base at the National Patient Conference being held in Silver Spring, MD, in November.
- Educating medical professionals at two universities or hospitals by conducting a presentation and distributing literature.

Our Florida Community Alliance has made plans for two events, Boating for Brains and Bowling for Brains. They are also planning to create a list of local medical resources and to distribute cavernous angioma information to these facilities.

Colorado is planning a walk-a-thon. They are also planning to hold 2-3 peer support group meetings in 2018 and would like to reach out to neurosurgeons and their offices to distribute information and make connections.

We are excited to see these groups taking shape and making plans. If you would like to help form an Angioma Community Alliance near you, contact Stephanie Alband at [salband@angioma.org](mailto:salband@angioma.org). We have interested individuals around the country and only need a critical mass of five people in an area to start. To learn more about our program, visit [Angioma.org/Local](http://Angioma.org/Local).



## Erin Woodall: Overcoming Obstacles

Nothing keeps Erin Woodall down. In her early 30s, Erin began experiencing cavernous angioma symptoms from a hemorrhaging lesion that lay at the junction of her cervical spine and the base of her brainstem. This is one of the most difficult locations for a cavernous angioma to be, both in terms of symptoms and treatment. Over the next five years, Erin suffered 6 additional bleeds, and, by 2014, was having difficulty with speech and with her left arm and leg. It was clear this was a very active lesion, but four neurosurgeons turned down her request for surgical intervention, telling her that surgery in that location could leave her quadriplegic. However, leaving the lesion in place left her at risk for the same.

Finally, Erin consulted Dr. Robert Spetzler, now retired, who agreed to operate. When she emerged from surgery, Erin had lost additional significant function. In her blog, *Dizzyland* ([erinsdizzyland.blogspot.com](http://erinsdizzyland.blogspot.com)), Erin described the challenges she faced a month after surgery. These challenges are common to many of our brainstem surgery survivors.

Her list of symptoms and deficits, in her words:

Nausea: I have medications for this, but there are some days it is horrible.

Speech/tongue: my tongue is very weak and that is why my speech is messed up. The right side of my tongue cannot hold the correct placement for my words to be correct.

Left side insanity: my left side hurts, is numb, shoots pain, feels weak, and is sensitive to the wind against my skin, and on and on. This side had been paralyzed briefly after the surgery.

Stiffness in my left arm and leg: My left arm and leg will become completely rigid, usually in my sleep. The muscles are so tight that it hurts to the point the pain wakes me up. Sometimes I wake Mike [Erin's fiancé] if I hit him, depending on how I'm lying. I find this much funnier than he does.

Apraxia: this is newly diagnosed. Apraxia is the "inability to execute learned purposeful movements, despite having the desire and the physical capacity to perform the movements." An example would be: I want to reach out for something, but I can't just do that. I have to almost tell my body step-by-step, move shoulder, straighten elbow, open hand, etc.

Exhaustion: I started to write "tired," but that's not the correct word. They told me in the hospital that I would be tired and need extra sleep and they were right. Simple things like taking a shower are exhausting to me, and I almost need a nap from that. Even something like sitting in church is tiring and requires a nap.

Forgetful: Mike added this one. If I'm forgetful, I don't remember it!

Freakish sound sensitivity: in my right ear, my hearing for high-pitched sounds is insane. I heard a sound that people kept saying I could not hear, but it was hurting my head. Mike could hear it and then somebody else that had a stroke heard it and asked what that horrible sound was.

Balance: My balance is still off, and I still have some problems with dizziness. I do not use my cane all the time, but I do take my rollator if I know there is a lot of walking. I stumble now even when standing still. [Erin has since acquired a power wheelchair that she uses because of dizziness.]

Confusion: when I am in a group with lots of different conversations or background noise I have a hard time concentrating. I cannot play computer games and talk on the phone like I use to either. Anything that requires me to focus on more than one thing is very difficult. I will usually stop talking in these situations and just pretend to pay attention.

Ice pick headaches: I get these headaches that feel like you have stabbed me in the head with an ice pick and a few seconds later pull it back out. These headaches are extremely painful, but thankfully only last a short time.

Pressure headaches: these are different than the ice pick; with these it feels as if something is pressing against my head for an unlimited amount of time and not as severe as the ice pick. These headaches can last for a couple of hours or an entire day.

Numbness—wow—this one is entertaining. Around the surgery site, it is still numb, but I'm getting some feeling. At the edges of the numbness, it is very painful. The numb places will itch, but I can't feel to scratch, so it drives me crazy.

Missing things: I really hate this the most. I miss things all the time and it makes me feel so unreliable. I have had to miss things Mike and I really wanted to do because of any of the above things.



Fast forward four years since her surgery, and Erin has made gradual improvements but still struggles with many of the same deficits. She can walk but can't lift her leg to, for example, get into an SUV. She lives in rural northwest North Carolina, but only drives on good days, which can be less than once a week. Her sensitivity to sound and her dizziness still keep her from church.



Erin and Mike at a 2015 Color Run

Erin lives with her fiancé Mike, who uses a wheelchair because he was born with paraplegia and has also lost the use of his right arm. Mike serves as an inspiration and a teacher for Erin, helping her learn new ways to live life with one working arm.

"Mike goes deer hunting and fills our freezer," Erin shared. "We went camping, and he put our tent together by himself. He's always surprising me."

Erin has been frustrated by her limitations at times, but she has remained determined to challenge herself. Starting a blog was a challenge. Taking on an aggressive reading list was a challenge. Increasing her exercising and planting a garden was a challenge. This April, Erin took on her biggest challenge yet. She shared with our Angioma Alliance Facebook group:

"Last weekend I decided to be daring! I competed in an obstacle course race. 16 strangers joined me in Tennessee to help me. With them pushing, pulling, and tugging, I climbed a 16-foot wall, walked through part of

a lake and up on a platform, and crawled under barbed wire. For crawling, I used one arm and dragged myself, because I lost the use of my left arm and most of the use on my left leg when I had a cavernous malformation removed from my brainstem in 2014. I did not finish because I exhaust so fast, but I'm so excited for what I did and for the people who joined me and got to learn about cavernous malformations."

Warrior Dash's Team Erin provided Erin with the physical and emotional support she needed to perform the obstacle tasks. Erin learned from her team that sometimes a person could use a "Spartan handshake" (the term was borrowed from Spartan Race) to get through a challenge.

"My Spartan handshake was 4 people pushing up on my butt to get me over the wall," she laughs.

Erin has a genetic form of the illness, which can cause multiple lesions to form, so she remains at risk for additional cavernous angioma hemorrhages. Her neurologist has told her that her MRI "looks like a can of peas has been dumped" into her brain because of the number of lesions. But, that's not going to stop Erin from participating in the obstacle course again next year. And next year, she again plans to show her new obstacle course helpers what it means to be living and thriving with cavernous angioma, Erin-style.



Photo credit: R. Glenndon

## What is a clinical trial?

*"Behind most every treatment, medicine, therapy & medical device...are millions of people who have volunteered to take part in clinical trials."*

*The Impact Clinical Trials Have on All of Us - CISCRP*

Clinical trials are research studies that rely on volunteers in order to answer questions about safety and efficacy of new drug (or device) treatments. There are several phases of clinical trials that must be completed before the drug can come to market, termed phases I-III.

Phase I trials focus on drug safety. These studies are typically small in number (20-100 participants), short in time, and enroll healthy volunteers.

Phase II trials test drug efficacy. These studies are often longer in duration (months to years, depending on trial design) and may enroll several hundred volunteers who have the illness under investigation. The trial is seeking to determine whether a drug works on the condition, is safe and what doses are most appropriate.

Phase III trials are similar to phase II in design, but typically follow a larger cohort of study participants for a longer duration of time. These trials determine whether the new drug is more effective and/or safer than the current standard of care. With positive Phase III results, the study investigator or pharmaceutical company running the trial will seek FDA approval for the drug.

Testing for efficacy (does the drug work to treat the condition?) requires a comparison of a treated group to a non-treated group. Commonly used study design is that of a randomized controlled trial (aka placebo-controlled trial). Following this study design, participants are randomly assigned to take either the study medication or a placebo. In a blinded study, the information is coded so that neither the participant nor the study doctor knows if the pill is the study drug or placebo. This information is only revealed at the end of the study during analysis.

Who qualifies for trial participation? Well, that depends on what the drug does and how the trial is designed. For example, a drug designed to prevent hemorrhage will focus on cavernous angioma patients who have recently hemorrhaged, as this group is most likely to hemorrhage again. A drug that aims to shrink lesion size would be the most inclusive, while a drug

that prevents new lesion formation would need to be tested on those with familial cavernous angioma and multiple lesions. Inclusion criteria may also include age restrictions, lab values, and current and recent medication use, for example. Each study will have a unique and well-defined set of inclusion criteria.

It is too early to offer a specific timeline for cavernous angioma clinical trials, but with at least a dozen therapeutic approaches under study ([www.angioma.org/pipeline](http://www.angioma.org/pipeline)), the research is moving faster than ever. Stay tuned for study announcements and don't forget to register for the patient registry ([www.angioma.org/registry](http://www.angioma.org/registry)).

## Study shows chemical signatures in the blood can predict CCM hemorrhage within the next year

One of the many challenges in caring for CCM patients is that clinical symptoms are often highly variable and unpredictable. Even within families where affected individuals have the same mutation, clinical course varies, and we are unable to predict if and when lesions will hemorrhage. That is, until now...

Dr. Awad's group from the University of Chicago asked the question, how can we predict future CCM lesion activity (growth and/or hemorrhage)? We have learned previously that chemical markers in our blood, known as serum biomarkers, are related to CCM disease biology and/or brain hemorrhage. The team analyzed blood samples from a group of CCM patients, measured the biomarkers, and followed up with the study participants the following year. As a result of the study, the team developed a model in which a weighted combination of four specific serum biomarkers can predict future hemorrhage activity within the next 12 months.

These exciting findings are not quite ready for clinical use. The next step is to compare the biomarker levels in non-CCM individuals to those with aggressive and stable CCM. These relative measurements will make the plasma biomarker findings clinically relevant to identify those CCM patients at risk of hemorrhage over the next year.

Validation of these findings at multiple sites is part of the new Clinical Trials Readiness Project. Validation will facilitate moving serum biomarker measurement from the laboratory to clinical practice.

*Amy Akers*

## What Would You Like Your Doctors to Know?

*We asked those who interact with us on Facebook to tell us what they would most like their doctors to know about their experience with cavernous angioma. We were surprised by the quantity, thoughtfulness, and diversity of responses. Below is a small sample of the 115 comments posted. Do they echo your experience?*

*A large number of responses addressed the issue of validating and addressing the unique experience of the cavernous angioma patient and their loved ones with compassion.*

General Notes: take a deep breath before opening the door. Exhale. Open it, walk in. Smile and greet me warmly. Say hello to my wife. We are nervous. Yes, it's been 20 years for me, but it's been 10 difficult years for my wife. She feels my pain as acutely as I do and bears much of the weight of my condition. I look normal, Doc, but I am a pianist who can no longer use his right hand well enough. I can no longer run like I used to. Sure, I'm not dead. Awesome. But the psychological effort required to overcome physical deficits, push through fear of breakthrough seizures, and do this all while being a full-time teacher is, at times, suffocating. So, Dr. So-And-So, slow your roll. Be gentle. I'm just your 11:00, but what you say in the next 10 minutes at this "routine" check-up might as well be coming from a burning bush for how important it is to me. Every word crashes against my central nervous system. And again, my wife. I apologize for having gotten an "internet degree" in Neurology for Dummies. But, I'm curious. I want to be proactive. I want to understand. I want control. You can see that, right? So, Doctor, I know you can't fix this today, but please, I'm begging you, be patient and kind. That's literally all I want because, damn, I also just spent \$27 to park. Thanks.

Validate this disease with us. Be knowledgeable and compassionate. We are not looking for a friend; we want our conditions and symptoms acknowledged. "You're fine" doesn't work. We all know 'fine' left the first surgery day or stroke day.

If I could say anything, it's that the doctors need to learn to listen, really listen, to those of us that have this disease. We are the ones that are living with this

disease. We are the ones that learn more about it, and some of us actually document and record information about it.

That a main symptom, e.g., seizure, is not the ONLY symptom they need to consider when looking at how our day-to-day lives are affected.

*Commenters also shared their experience of being told that symptoms they experience are not related to cavernous angioma but being offered no alternative explanations.*

Don't say, "There is still so much we don't know about the brain" and then turn around and be dismissive and say, "none of your CCMs are causing said symptom(s)" even though everything else has been ruled out as a cause.

I would like them to know and understand that just because a symptom isn't common doesn't mean that it is not a symptom!

The symptoms are not imagined or "in my head" but they exist and are literally in my head.

Not to discount headaches/migraines. *(This comment was repeated many times over by numerous commenters and echoed by those who experience other pain.)*

Too many doctors rely on imaging alone, and don't listen.

*For many, the anxiety and uncertainty of the illness was the most important message to convey.*

How unsettling the uncertainty is. Will I have another bleed? Will I lose my independence? Will I become a burden or lose a loved one? Will I always be able to do the things I enjoy doing? Every day, I wake up and am grateful for the ability to walk, talk, see, smell, taste, touch. I hope I never have to one day say I took something for granted.

We should NEVER be told, "it's no big deal." That's an opinion, not a fact. The fact is that things could change at any time. I remember walking away thinking "at least cancer has options." I only have symptom management. It was very hard.

The uncertainty is unsettling. Telling a patient, "Don't worry, it will probably never bleed again" isn't really helpful.



From a parent's perspective, being told that we as parents were being "too optimistic" for our child's recovery after his hemorrhage. Is there such thing? I don't believe so. Once you take away hope, there's not much left.

*Some wanted doctors to understand the frustration of living with cavernous angioma and the need for flexibility/creativity in treating the whole person.*

I smile because it's another visit that I have hope for but know will probably end up being an expensive and quick same old thing. I smile because my husband is frustrated and I'm calming him while trying to hide my own frustrations. I smile because I hurt and am dizzy every single day and hope that one day, you'll tell me that there might be a way to help. I smile because I have four girls to raise and know that surgery still isn't an option for me, so let's try something natural. Please tell me what I can and can't take, so I don't worry every time I need some relief from a horrible cold or allergies and decide to go without.

I often feel that there is no chair for me in the doctor's room. It's a tumor, but it's not cancerous and not "dangerous" or rapidly growing. So, I don't fit in the dramatic "brain cancer chair." It may bleed, but sometimes not enough to cause big deficits and I'm told that I'm lucky. So, I don't fit in the dramatic "big brain hemorrhage chair." Then for the headaches and pain... not able to sit in this chair either because cavernoma has some restrictions on what medicine to use, and I don't respond to normal migraine treatment. Then the fatigue, dizziness, constantly feeling off but no two days are the same. I can have a few weeks with progress but all of a sudden, I have a setback. I look at the ME [myalgic encephalomyelitis, also known as chronic fatigue syndrome] chair, but cannot sit down. The doctors don't have a cavernoma chair. And I feel lost. My situation is a little of this and a little of that, but as a whole my life has changed as much as any brain cancer or hemorrhage patient.

Everyday life is a struggle. People don't understand how hard it is to do normal things, work, and have enough stamina to make it through. No matter how much they preach about eating and

exercise, it doesn't go away! Quality of life doesn't come easy.

Every day is a rollercoaster, and healing isn't linear.

That not only does everyone have different symptoms and reactions, they also heal and recover completely differently too. We don't fit in a box.

*Finally, the other side, from a young physician who is also a cavernous angioma patient:*

Unfortunately, because it's a rare disease there is truth to this. But think of a high schooler living in a social media age and in this culture; they know more about the challenges of being a teenager than their parents. Yet the parents have the experience to view things with a broader perspective and provide needed wisdom, guidance and discipline. Physicians are vigorously educated, harshly worked, and often know more than you realize. They are not miracle workers and they're prone to imperfection like any other human. Yet it's people who sacrifice a *minimum* of 15 years of their life and 90 to 100-hour work weeks including weekends and holidays before being able to call themselves neurosurgeons; it's those people who cure us. Their sacrifice is brutal; there are few people who are even able to make it to their level, and I see it first-hand.

#### Monthly Gifts

Your monthly donation will allow you to give more on an annual basis, but the distribution of payments across the year makes the commitment more manageable. In addition, a monthly donation allows Angioma Alliance to sustain and grow by having a clear financial forecast for the future.

**\$10**



Per Month

Provides patient information booklets to 40 newly-diagnosed families.

**\$25**



Per Month

Funds enrollment of two people in the CCM Microbiome Project.

**\$50**



Per Month

Provides four young researchers the opportunity to attend our annual Scientific Meeting, nurturing the next generation of cavernous angioma researchers.

#### CALL TO ACTION



To sign up for monthly donations, fill out and return the enclosed donation envelope or sign up at [angioma.org/donate](http://angioma.org/donate).

## Cavernoma Alliance UK News

As June approaches so does Cavernous Angioma month. This year Cavernoma Alliance UK (CAUK) celebrate on 2 June 2018 in Manchester, a city some 160 miles to the northwest of London where CAUK is hosting its annual Forum. With a distinctly pediatric feel but with relevance too for the wider cavernoma community, speakers include Drs Ronan Burke, a neuropsychologist, and Ed Smith, a pediatric neurosurgeon, from Boston Children's Hospital who gave an excellent talk to CAUK some years ago. Instead of formal workshops CAUK will trial a new series of afternoon "pods," most of which will be hosted by clinicians and nurses from the Royal Manchester Children's Hospital, who have provided wonderful support to us for several years. Constructed as informal drop-in sessions, CaverFamily members (parents of children with cavernoma) as well as adult members of the community will be able to discuss their concerns within a protected and understanding environment.

Our new CaverFamilies program mentioned above is funded by a major two-year grant to CAUK from Global's Make Some Noise awarded in April. GMSN is the charitable arm of a consortium of radio stations in the UK and the grant was secured by Simona Stankovska who now leads our CaverFamilies. The grant will support a dedicated Community Worker and an ambitious program of events for both children and young adults up to the age of 26.

While Cavernous Angioma month is the culmination of our year, CAUK has been engaged in pushing back the physical, emotional and intellectual challenges faced by those with or caring for those with cavernoma. For example, Ailsa Crowe, our community worker in the north, organized three events during Brain Awareness Week involving medical professionals. There was also a London Brain Awareness Week event, this year featuring Lesley Foulkes, an advanced nurse practitioner, and Dr Sofia Eriksson, an epilepsy specialist. Consultant neurosurgeon Mr Peter Whitfield also spoke at an event lead by trustee Roxanna Dixon.

As with every charity, the tremendous fundraising of our members continues to be at its core. Gavin Crowe, Ailsa's father, has undertaken to visit all of his law offices throughout Scotland and England on two

wheels. The funds raised will go towards the law firm's chosen charities for 2018: MND Scotland (ALS) and CAUK. Ailsa has a cavernoma, and Gavin chose CAUK because of the support we have been able to give her. Ailsa's cavernoma bled a few years ago and she was forced to give up work and live at home supported by Gavin and his wife. CAUK is fortunate that she now works with us. Gavin's ride will begin at the firm's Newcastle office on Monday 4th June and will then travel north to Scotland taking a circuitous route to visit the offices in the major cities and towns of Scotland, finishing in Aberdeen the following Friday.

In September, David Overy will cycle from one end of the UK to the other to raise money for CAUK. This challenge consists of cycling 969 miles over 9 days. David has decided to take on this cycling challenge in aid of his daughter Poppy, who was diagnosed with multiple cavernomas in 2011 at just 14 months old. According to David, after trying to understand all the information, they came across CAUK. "We gained information to help us have an idea of what was to be expected in the future for our daughter. After gaining more knowledge we were able to ask more questions to help us too. Over time we learnt of other families with children who have cavernomas, and we have become members of the CaverFamilies." A few years later they also discovered that Hayley, Poppy's mother, had the CCM1 gene, and subsequently, it was discovered that Hayley also has cavernomas. After suffering with severe headaches, dizziness and tinnitus, an MRI showed multiple cavernomas, none of which had bled. Therefore, David's challenge is now no longer just for his daughter, but also for his wife.



David White, who has been Chair of the trustees since 2013, is retiring as Chair at the June Forum. During the time that he has been Chair, CAUK has grown from 600 members to almost 2,000, ensuring that cavernoma is firmly on the medical map. He has been adviser, colleague and friend. With his boundless optimism and rational insights, David will leave a gaping hole at the very centre of CAUK that will be impossible to fill.

*David White & Ian Stuart*

## SPECIAL THANKS TO OUR MAJOR DONORS

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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](http://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](mailto: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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[www.angioma.org](http://www.angioma.org)

[www.facebook.com/AngiomaAlliance](https://www.facebook.com/AngiomaAlliance)

[info@angioma.org](mailto:info@angioma.org)

Twitter: @AngiomaAlliance

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](mailto: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](http://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/](http://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.