



# ANGIOMA ALLIANCE NEWSLETTER

because brains shouldn't bleed

## Let's Hear It For Research!

In this issue, many of our stories discuss findings of clinical and pre-clinical research. So much is happening, so quickly, that research news can feel disjointed and confusing. We'd like to offer you some ways to think about organizing research into tracks. Keeping up with research is easier if you understand some basic terms and the buckets into which projects fall.

We differentiate between clinical and pre-clinical research. Clinical research includes studies that enroll or look at people. These can be treatment trials, natural history studies that document how an illness affects people who are not treated, and studies of disease modifiers, e.g., the effect of blood thinners on hemorrhage in people with cavernous angiomas.

Pre-clinical research is the research that happens before we study people. This often involves tests in animal models of the illness. For cavernous angioma, our most-used animal models are nematodes (*C.elegans*), zebrafish, and mice. For many years, cavernous angioma research was conducted primarily at the pre-clinical stage. This has changed over the last two years.

Cavernous angioma clinical research is heading down multiple tracks at the same time. Major tracks include medications, surgical advances, and what we could call lifestyle and modifying factors. Here's an overview of each:

There are three **medications** currently in clinical trials with several more under consideration. Atorvastatin (first introduced under the brand name Lipitor) is being tested at the University of Chicago and the trial has begun its second year of recruiting. There will be a total of three years of recruiting and each patient will be on the medication for two years. This means that, if we do our part by participating in the trial to keep it on schedule, we should know whether this medication is effective in reducing hemorrhage in 2024 at the latest. More enrollment information and a webinar announcement can be found on page 3.

REC-994 (tempol) is a brand-new medication being developed by Recursion Pharmaceuticals

specifically for cavernous angioma. This medication is in Phase Ib trials. That means that healthy volunteers – people who do not have cavernous angioma – are taking the medicine to make sure it's safe before it's tried in our patients.

In addition to developing REC-994, Recursion is working with the University of Rochester and Angioma Alliance to create from scratch a validated patient-reported outcomes measure, hopefully to be approved for use by the FDA, also specifically for cavernous angioma. The CCM-Health Index will help patients report all the ways that our illness impacts lives. Many of you have already been part of the creation of the instrument. Fifteen members participated in interviews over the summer and, around Thanksgiving, 310 of you completed a long survey that allowed the researchers at the University of Rochester to narrow the questions that would be included. The next step will again be an interview, and we'll be putting out a call for 40 participants in the next few months.

Propranolol is a beta blocker medication that is in clinical trials in Italy. The first trial has completed recruiting. 79 people with familial cavernous angioma will now be taking the medication for two years. This study hopes to expand to other centers in Europe. In the United States and Europe, propranolol is also being tested in mouse models of the disease.

Progress is being made in both minimally-invasive and non-invasive **surgery**. Our article on page 5 discusses minimally-invasive stereotactic laser surgery, stereotactic radiosurgery, and non-invasive focused ultrasound. In addition, new technologies such as BrainPath give surgeons more options to operate safely to remove cavernous angioma lesions.

Finally, **lifestyle and modifying factors** have been an intense focus of research in the last few years. There are many videos on our YouTube channel that discuss relevant topics. You have read about the impact of gram-negative bacteria and of diet and a compromised gut lining in previous newsletter issues.

Microbiome research is ongoing and will continue to be for years to come. We've also told you about Vitamin D as a possible protective agent and about pilot research examining the relationship of sleep apnea to disease severity. On page 3, we also summarize a recent important paper on the use of blood thinners by people with cavernous angioma, and we'll be hosting a webinar on this topic in May or June. Many of you will be asked to participate in research on all of these fronts over the next few years. Please participate when and where you can.

Research continues in many other areas, including the development of new and better animal models of the illness, blood biomarkers that allow us to predict hemorrhage, and imaging biomarkers that allow us to measure even small changes in lesions. These are hopeful and exciting times.

Once a year, we bring together the brilliant minds who are working on these hard questions and making critical discoveries. The Angioma Alliance International Scientific Meeting, which just celebrated its 15th year, is the venue where findings are shared, new ideas are sparked, and collaborations are formed. Highlights of the 2019 meeting can be found on page 6. We are privileged to be the trusted hosts of the global research community and could not do this without your support.

**Angioma Alliance's ongoing support of research** is deep and multi-fold. In addition to the scientific meeting and our role communicating science to the patient community, we host an International Patient Registry ([www.AngiomaRegistry.org](http://www.AngiomaRegistry.org)), a critical tool for understanding the patient community, communicating research news, and recruiting for studies. We also host a DNA and Tissue Bank that provides tissue to university labs around the world. Our free genetic testing program provides valuable information to our families and also prepares these families for clinical research participation. Our genealogy and outreach programs in New Mexico, in the Southeast, and now, among those who carry the CCM2 Ashkenazi founder mutation increase the number of cavernous angioma patients that we know, as well as increasing the visibility of the illness in states and nationally. Angioma Alliance staff are well

known at both the National Institutes of Health and at the Food and Drug Administration where we advocate for increased research funding and understanding of the patient experience. Again, your support has made these activities possible.

Members like you support research with your participation. You enroll in our patient registry and in clinical research. You share your story on social media and with the press. You join a Community Alliance that offers outreach to local medical providers who can refer patients to our group and to studies. Your Community Alliance participation also offers support and hope to the newly diagnosed in your area. Every event you host and every meetup you attend makes a difference. Please continue to stay involved: because brains shouldn't bleed.

## **2019 Angioma Alliance Annual Report**

As an organization, Angioma Alliance is an excellent steward of your gifts and donations, and we strive for financial transparency. Our 2019 audited financial statement and our IRS Form 990 filing are available on our website at [angioma.org/pages.aspx?content=619](http://angioma.org/pages.aspx?content=619). Our fiscal year runs from October 1 through September 30.

### **Summary**

Because of your generous support, our fiscal year 2019 gross income was \$739,712, an 8% increase from the previous year. Our expenses were \$653,317, and our net assets at the end of the year were \$407,179.

Best practices encourage non-profits to spend no more than 20% of their income on fundraising expenses. In fiscal year 2019, Angioma Alliance spent 16% of its income on fundraising expenses. We spent an additional 4% on management and overhead expenses. Fully 80% of our income was dedicated to program expenses.

Please see [www.angioma.org/documents/AngiomaAllianceProgramsNov2019.pdf](http://www.angioma.org/documents/AngiomaAllianceProgramsNov2019.pdf) for a list of programs your donations support.

## Research Update

### Antithrombotics (Blood Thinners) and Cavernous Angioma

Antithrombotic therapy includes drugs used for the prevention and treatment of blood clots (such as aspirin or other blood thinners). There is a question in the medical community about the safety of using these types of drugs in patients who need them for a cardiovascular condition and who also have a cavernous angioma.

Does having one or multiple cavernous angiomas make it unsafe for the patient to take antithrombotic therapy (increase the risk of hemorrhage, for example)?

A new study from an international collaborative team representing the Scottish Audit of Intracranial Vascular Malformations Steering Committee aimed to determine the effects these drugs have on cavernous angioma patients. To address the question of safety, the study team monitored 300 cavernous angioma patients for an average of 11.6 years after diagnosis.

The authors report that no safety issues were detected related to cavernous angioma. Their findings indicate that the use of antithrombotic therapy in the sampled cavernous angioma patients did not appear to increase the risk of hemorrhage or focal neurological deficit.

It is important to note that this study is *not* a clinical treatment trial for cavernous angioma. The purpose of this study was not to test whether antithrombotics prevent CCM hemorrhage. Instead, the study observed people with cavernous angioma and another condition that required antithrombotic therapy. The goal was to determine if those drugs posed a safety risk to the cavernous angioma community.

Clinical research with human participants is challenging for a variety of reasons, and is often limited by practicalities such as sample size and clinical care. Limitations of this study include the relatively small sample size and the lack of randomization of participants to treatment versus no treatment. Because of sample size limitations, it remains unclear how this class of drug may affect

those who have experienced past hemorrhage and are therefore at the greatest risk of re-hemorrhage. The findings are intriguing and follow up studies should be interesting.

So, what do these findings mean for our community now?

According to senior author Dr. Rustam Al-Shahi Salman, "the findings of our study allow me to continue to reassure other physicians about the use of these drugs in people with a cerebral cavernous malformation who have another medical condition – like an irregular heartbeat – where we already know that these drugs are beneficial for reducing the risk of clotting problems."

Furthermore, recommendations from Dr. Kelly Flemming include:

- **Do not start aspirin daily or blood thinner unless your doctor has recommended it.**
- If you have a condition that may require a blood thinner, your doctor or a specialist should make the determination of risk and benefit in your individual situation.
- More studies are likely to investigate the protective effect of aspirin and other blood thinners and whether these findings apply to sporadic, familial, [those with or without prior hemorrhage], or all patients with cavernous malformation.

Angioma Alliance is planning a webinar on this topic scheduled for May. Please watch our website and Facebook page for an announcement.

[www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(19\)30231-5/](http://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(19)30231-5/)

*Amy Akers, PhD, Chief Scientific Officer*

### Atorvastatin Clinical Trial

The University of Chicago atorvastatin clinical trial continues to recruit. The trial looks at the effect of atorvastatin on reducing the risk of future bleeds from cavernous angiomas. Dr. Issam Awad has been updating the Angioma Alliance community on the trial through quarterly webinars. His next webinar is scheduled for April 9 at 7 pm Eastern, 4 pm Pacific. Registration is required: [www.bit.ly/AprilATWebinar](http://www.bit.ly/AprilATWebinar).

To participate in the atorvastatin clinical trial, you must be a United States adult, not on statins, with a

documented symptomatic hemorrhage in the last year. Additional information about trial enrollment and participation is available on our website and in the trial brochure at [www.angioma.org/documents/ATTrialBrochure.pdf](http://www.angioma.org/documents/ATTrialBrochure.pdf).

The atorvastatin trial is a two-year commitment that includes three high quality MRIs at no cost to the participant. A travel stipend is provided for those traveling to Chicago from out of state. Participants are free to exit the trial at any time.

Finding out whether atorvastatin is beneficial in reducing recurrence of symptomatic hemorrhage is of critical importance to our community. Atorvastatin is a well-tolerated, inexpensive medication that has been effective in reducing hemorrhage in mice bred with a CCM mutation. Now, with your participation, we can determine whether it can help our families, too.

## **New Mouse Models May Help Answer New Questions**

Mouse models of human disease can be great tools for understanding the biology of an illness and for early phase drug studies. CCM researchers use two different types of mouse models that we term, “chronic” or “acute.” Acute models are developed using genetic tricks that turn off both copies of one of the CCM genes within *all* the blood vessel cells of the body. This strategy results in a robust model where lots of brain lesions develop at a very early age. The benefit of such a model is that it allows for fast studies, but the mice are very sick and only short-term treatment trials are possible.

Chronic models more closely represent the human condition: they develop lesions over time, and those lesions mature and hemorrhage. These types of chronic models are best for long term drug studies.

A French research team recently developed a new chronic model in which the CCM2 gene is turned off only in the brain blood vessel cells. The result is that mice develop brain lesions but do not suffer the additional side effects and poor health that is common in acute models or older generation chronic models. The team at Duke University created a chronic CCM3 model that develop mature multi-cavernous lesions that are prone to hemorrhage and closely resemble the

human condition. These mice are ideal for testing the effects of drugs on pre-existing mature lesions. New generation chronic mouse models will likely be important tools for our researchers as we continue to understand better the biology and identify new possible treatments for cavernous angioma.

[www.ahajournals.org/doi/abs/10.1161/STROKEAHA.119.027207](http://www.ahajournals.org/doi/abs/10.1161/STROKEAHA.119.027207)

[www.biorxiv.org/content/10.1101/2020.02.12.944421v1](http://www.biorxiv.org/content/10.1101/2020.02.12.944421v1)

## **Protecting Your Gut Lining**

In our Fall 2019 newsletter, we shared new research from Dr. Mark Kahn's lab on the connection between the integrity of the gut and its potential impact on cavernous angioma. Dr. Kahn spoke at our patient conference in November to discuss his lab's recent findings with our community.

From his research, we learned that one of the ways we could actively participate in protecting our gut lining is by avoiding emulsifiers, which are mostly found in processed foods ([angioma.org/documents/EmulsifierList.pdf](http://angioma.org/documents/EmulsifierList.pdf)). Keep in mind that the more processed an item is, the more likely it will contain emulsifiers and other harmful ingredients. Chemically processed emulsifiers, like polysorbate 80, are more harmful than other emulsifiers found naturally in food, like eggs. Damage is dose-dependent. A small amount of an emulsifier, even a chemically processed emulsifier, once in a while is not going to destroy your gut lining. We should be more concerned about regular use.

For more information about following a CCM-healthy diet, check out the presentation from our Patient Conference by Diane Darcy, RD on our YouTube channel. Here are some short tips:

- Try adding in one new healthy food item per week; over time these will crowd out the more processed foods in your pantry.
- Aim for a grocery cart with fruits and veggies representing all the colors of the rainbow; more fiber and color equals a healthier gut and beneficial nutrients to combat inflammation.
- See our cookbook at [bit.ly/AACookbook](http://bit.ly/AACookbook) for emulsifier free recipe ideas.

*Kristen Dahlem, RN, NBC-HWC*

## **Stereotactic Laser Ablation, Stereotactic Radiosurgery, and Focused Ultrasound**

There has been a great deal of discussion, and some confusion, in our Facebook groups recently about the use of laser surgery for cavernous angiomas in the brain. We're hoping to clarify some of the basic concepts here.

Stereotactic is a general term that refers to how a brain is positioned and mapped for any kind of intervention. It uses MRI with a 3-dimensional coordinate system to precisely locate small targets in the brain. Stereotactic procedures are used in traditional surgery (open resection), laser surgery, and radiosurgery.

Stereotactic laser ablation (SLA), also known as magnetic resonance (MR) thermography-guided laser interstitial thermal therapy (LITT), is a technique in which a small opening is made in the skull to allow a laser device to be inserted into the brain via a cannula. Laser is used to destroy the cavernous angioma tissue. SLA uses real-time MR thermography to measure temperatures and visualize surrounding tissue. Most often, SLA is used to treat lesions that cause epilepsy. The most recent article documenting the safety and effectiveness of the technique for cavernous angioma that cause epilepsy was published in early 2019 and can be found at <http://bit.ly/CCMLaser>. Although the number of treated patients is still small, SLA use is becoming widespread around the United States as an alternative to open resection. When SLA is not successful at controlling seizure, it can be followed by open resection.

Stereotactic radiosurgery (SRS) is a non-invasive technique in which a focused beam of radiation, accurate to 1-2 mm, targets a lesion. Stereotactic radiosurgery is also known as gamma knife or Cyberknife, and it does not require an opening in the skull. This technology has been in use for many years but with a great deal of controversy. SRS does not remove the cavernous angioma. Instead, it damages the DNA of cavernous angioma cells which makes them unable to reproduce. This is a process that occurs over time, and it is believed that it requires up to 2 years to reduce the risk of hemorrhage from a lesion that has received SRS.

One controversy with the use of SRS is the risk of increased symptoms or disability, which may occur

through edema after the procedure or through necrosis of surrounding brain tissue 6-9 months later. The use of smaller radiation doses has reduced the incidence of this. Additionally, it is believed that SRS can cause the formation of additional lesions in those with the hereditary form of CCM illness. Finally, because cavernous angiomas that have hemorrhaged generally re-hemorrhage less after 2 years of being hemorrhage-free, it's difficult to determine whether the reduced hemorrhage rate two years after SRS is due to radiosurgery or whether it's simply what would have happened with no intervention.

In the United States, SRS is reserved for lesions that are highly symptomatic and for which there are no other options. The Angioma Alliance Clinical Care Consensus Guidelines ([www.angioma.org/ccmguidelines](http://www.angioma.org/ccmguidelines)) discuss recommended use in more detail. In the UK and Europe, the technique is used more frequently. A long-term randomized study is beginning in the United Kingdom.

Focused ultrasound (FUS) is a non-invasive technique in which a focused beam of ultrasound targets a lesion. The skull is not opened and there is no radiation involved. Focused ultrasound has several mechanisms of action. Like laser surgery, it can work through ablation by heating and destroying tissue. It can also be used in combination with a substance that becomes caustic when its exposed to focused ultrasound. This is called sonodynamic therapy and requires minimal increase in temperature. FUS is also being researched as a way to deliver medications directly to the brain by increasing vascular permeability; without FUS, the blood-brain barrier would prevent this.

As of this writing, focused ultrasound has been used to treat approximately 2,000 patients with brain disorders, primarily brain tumors and tremor. It's not yet in human trials for cavernous angioma, but it is under investigation in mouse models at the University of Virginia, funded by the Focused Ultrasound Foundation. This is very exciting technology that may hold a great deal of promise for our patients. Angioma Alliance is working closely with the Focused Ultrasound Foundation and UVA to advance their work. More information about the technology can be found on the Focused Ultrasound Foundation website ([www.fusfoundation.org](http://www.fusfoundation.org)).

## CCM Scientific Meeting 2019

This fall, Angioma Alliance hosted our 15th annual CCM Scientific Meeting and National Patient Conference in Washington, DC. The Scientific Meeting is open to scientists and clinicians with a research interest in all areas of CCM science. Again this year, the attendance exceeded 100 individuals from across the United States as well as from eight countries in Europe, South America, and Australia. Representatives from the National Institutes of Health (NIH), two advocacy organizations (Angioma Alliance and Cavernoma Alliance UK), and three pharmaceutical companies (Biogen, Cervello, and Recursion Pharmaceuticals) were also in attendance.

The Scientific Meeting agenda includes two different presentation platforms: talks and posters. The poster session offers an opportunity for in-depth discussions of new projects, ideas, and scientific techniques/technologies. With sponsorship from the FEBS Journal, an award for the most outstanding poster is provided to the trainee with the best presentation. A committee of judges awarded Sam Krempel, a graduate student from the SickKids Hospital, the best poster award for his research using the nematode worm entitled, "CCM1 and CCM3 cooperate to maintain intestinal function in *C.elegans*." The judging committee also recognized Alexandra Fitser, who works in a fish lab at the NIH campus studying blood vessel development, as the runner-up. The judges were particularly impressed by

Alexandra's work because she is a very early career scientist who completed her undergraduate education last year. The title of her poster was "nfatc1 deficiency causes thoracic duct dilation during vascular development."



Amy Aker and Sam Krempel, winner of the 2020 FEBS Journal Poster Prize.



The family conference kicked off with a Plenary Session, where both Scientific Meeting and Patient Conference attendees were treated to a keynote presentation by Dr. Issam Awad. Dr. Awad is the Chair of our Scientific Advisory Board and a world-renowned neurosurgeon and researcher at the University of Chicago. His talk described the significant progress of research over the last two decades and how the body of work has led us to initiate our first clinical trials for the treatment of CCM. After the plenary session, the meetings run separately, except for meals and breaks, when patients and researchers have opportunities for informal conversations.

Also well attended, the National Patient Conference hosted 40 individuals who traveled from all corners of the United States, and even New Zealand, to listen to expert talks on the latest from the clinic and research and to participate in support groups. Videos of the presentations are available on the Angioma Alliance YouTube channel at [www.Youtube.com/user/AngiomaAlliance](http://www.Youtube.com/user/AngiomaAlliance).

Save the date! The 2020 Scientific Meeting and National Patient Conference are scheduled for November 12-14, 2020, at the Bethesda Hotel in Bethesda, Maryland. While the Scientific Meeting is open only to researchers, the patient meeting on November 13-14 is open to everyone.



### Awareness Items

Our Angioma Alliance online store is stocked with new awareness items for you. We now have T-shirts with this year's Believe theme, our CCM-Healthy Cookbook with recipes from our members and professional chefs, Ladies' Bangle Bracelets, and Waterproof Stickers. Visit our store at [shopangiomaalliance.bigcartel.com](http://shopangiomaalliance.bigcartel.com) to see these and more.



## Events

### Ski Event in Northwest Massachusetts

Come join us at Jiminy Peak in northwest Massachusetts on March 26th for The Brains Shouldn't Bleed Ski and Fundraiser Event hosted by Tyler Fairbank. The event will include skiing and a live concert, with Jack Waldheim performing from 4-6 pm at Christiansen's Tavern. Concert tickets and more info are available here: [tinyurl.com/rlskvfg](https://tinyurl.com/rlskvfg)

In addition, net proceeds from lift ticket sales on March 26th will be donated to Angioma Alliance. Please visit the Jiminy Peak website to purchase lift tickets. Thank you so much, Tyler, for your support!

You can watch Tyler's road to recovery from his brainstem surgery on our YouTube channel at [www.youtube.com/XCH3AMgRB3g](https://www.youtube.com/XCH3AMgRB3g).



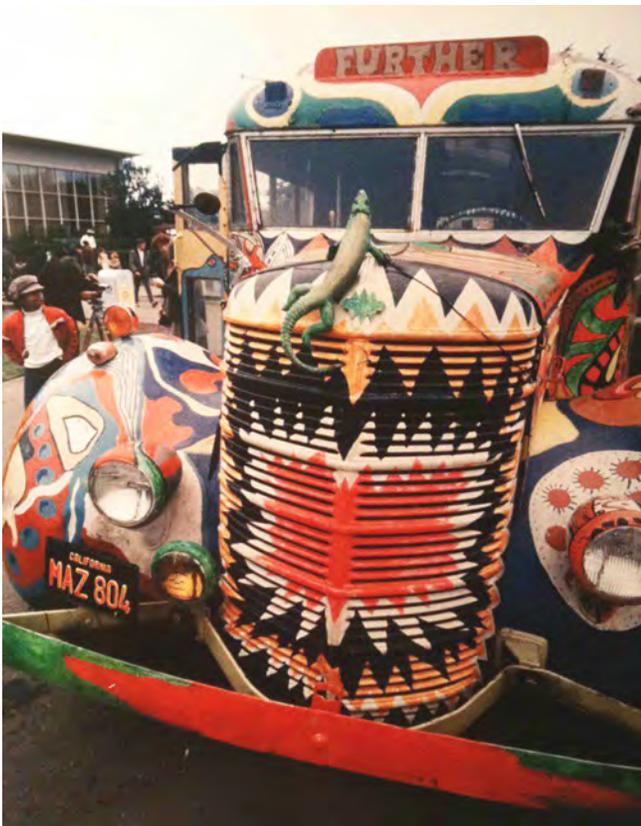
### 60s Party and Book Reading in Hillsborough California

On May 16th, Isaac Babbs and his family are throwing a 60s Counter-Cultural Party/Literary Event featuring Isaac's father, Ken Babbs, reading from his soon-to-be-published book "Cronies," about his escapades with Ken Kesey, Neal Cassady, and the Merry Pranksters.

The event is being held in Hillsborough, CA at Isaac's home. Tickets are \$175/person and are available at <http://bit.ly/BabbsEvent>. Northern California Angioma Alliance members should contact Lindsay Ramirez at [lindsay@angioma.org](mailto:lindsay@angioma.org) for attendance information. A signed copy of Ken Babbs' prior book "Who Shot the Water Buffalo" is included with the donation/event.

In addition to the reading and question/answer session, highlights include hors d'oeuvres, wine tasting, a silent auction, and a catered dinner. Come in optional 60s attire (it's a great chance to get that tie-dye out), and there will be groovy photo opportunities.

Isaac's youngest son, Lukas, 22, has a cavernous angioma. Lukas had a hemorrhage and is, fortunately, fully recovered but still lives with the disease.



## Rare Disease Day 2020

February 29th was Global Rare Disease Day, a day where we raise awareness of the 300 million people worldwide who are affected by rare disease. Our members chose this occasion to host meetups and attend events around the country. These photos are a sample of the wonderful ways our Community Alliances showed their rare. More information about our Community Alliance program is available on our website at [www.angioma.org/local](http://www.angioma.org/local).





## Angioma Alliance Bracket Buster Challenge

Monday March 16th 2020 • 6:00 am

[ENTER PRIZE POOL](#) [DONATE ONLY](#)

### About the Event

Get in on the March Madness excitement with our first "Angioma Alliance Bracket Buster Challenge"! Join our team on ESPN, create your bracket, and cheer on your favorite teams. You don't need to know anything about basketball to enjoy a good challenge and anyone can win, so why not join the fun!

To enter the Angioma Alliance Bracket Buster Challenge, visit [www.give.classy.org/bracket-challenge](http://www.give.classy.org/bracket-challenge).



# ANGIOMA ALLIANCE DAY AT THE BALL PARK

Join us in support of Angioma Alliance and our Arizona Patient Community

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

Camelback Ranch  
10710 W. Camelback Rd  
Phoenix, AZ 85037  
March 22 | 12PM

RESERVE YOUR TICKETS HERE

[HTTPS://GROUPMATICS.EVENTS/S/OTHER/ANGIOMAALLIANCE](https://groupmatics.events/s/other/angiomaalliance)



## Trent Clayton: National Paralympics Record-Holder

In 2003, my son Trent was born. He was adorable; absolutely perfect and most importantly, healthy. He was, however, a fussy baby. He would become hysterical if we laid him down, so he slept in a swing most of the time. We were told he was colicky; we were told he had reflux; or maybe an ear infection. We thought we were just really bad at this parenting thing. What were we doing wrong? At his 9-month appointment, his pediatrician blew off our concerns that he wasn't using his right hand and suggested that he was just a lefty. But when I mentioned my concerns to my neuropsychology professor, she was clearly concerned. She insisted that babies don't have a preference. That was when we really started to worry.

We finally got the pediatrician to take our concerns seriously, and Trent was referred to see a neurologist, then sent for an MRI.

While he was in the MRI, we started hearing urgent overhead pages for this doctor to come to the MRI suite STAT. I wondered how many MRI suites they had and assured myself that none of these specialists could be on their way to see my baby. Meanwhile, the scan planned for 45 minutes dragged on to two hours, until finally we were directed back to sit with my still sleeping little guy. When the doctor came in, he told me he had some troubling news, that the scan showed a "mass" in my son's brain. They planned emergency surgery for the next day. The surgeon, who believed it

was a tumor, was quite surprised when the large mass in my son's brain was actually filled with blood.

When he was 2 years old, the bleeding started again, and we were sent to Boston Children's Hospital. This was the first time we would hear the words cerebral cavernous malformations. This is a hugely important part of our story because it helped us get connected with Angioma Alliance. We joined the online forum and we read everything we could. Our little guy had his second surgery in Boston when

he was 2 years old. When he was 4 years old, he had genetic testing that determined that he has a CCM2 mutation. My husband and I were tested, and we found that I also have the CCM2 mutation. When my daughter was born shortly thereafter, we had her cord blood tested and learned that she also carries the mutation.

Of the three of us, Trent has had the most difficulties, experiencing multiple bleeds over the years. He had his third brain surgery when he was 12 years old. A couple of days before his surgery, Connie Lee reached out and asked if we wanted to attend a hockey game with Angioma Alliance in New Jersey and if Trent would be interested in a special honor, the privilege of riding the Zamboni during intermission. Would he? Yes! This is such a wonderful memory

during a really difficult time. The third time is the charm as they say, and they are pretty sure they got the entire problematic lesion out at that surgery. He still has 10 more CCMs in his brain so he is followed by regular MRIs.

My daughter has 2 CCMs and one has bled. I have one in my brainstem. Trent will always have some deficits from the damage to his brain: he has right-sided hemiparesis, and he needs more time to process information. But, he has a really fantastic, positive outlook. He wants to compete in the Paralympics one day in track and field. Discus is his best event and he currently holds the national

record in his age and disability classification. He's in 10th grade in high school and thinks he might want to go into graphic design as a career field. He is a baritone in the chorus, and he enjoys cooking, and spends too much time video gaming. I'm thrilled to be part of the Angioma Alliance team because our mission is so incredibly important to me! My kids need a cure!

*Darla Clayton, Community Engagement Specialist*



## Introduction to the European Cavernoma Alliance

Our friends in Europe have been working hard to create a federation of cavernous angioma patient organizations. European Cavernoma Alliance launched a webpage at [www.cavernoma-europe.org](http://www.cavernoma-europe.org) where you can learn more and connect with its member organizations. It is only by working together that we will achieve a cure.

The European Cavernoma Alliance is an alliance of six officially registered non-profit organisations:

- Association sur Les Cavernomes Cérébraux (ACC), France
- Cavernoma Alliance UK
- Associazione Nazionale Angioma Cavernoso Cerebrale (ANACC Onlus), Italy
- Federal Association of Congenital Vascular Malformations (FACVM), Germany
- Asociación Española de Cavernomas (AECCM), Spain
- Cavernöst Angiom Sverige (CASE), Sweden

and 3 patient advocacy groups:

- Cavernoma Ireland
- Kavernøs Angiom Norge (KAN), Norway
- Kavernooma Finland

### Our Vision

We envision a future in which every cavernoma patient in Europe will easily find access to specialist doctors who are well-informed about the disease AND about ongoing research, and where researchers, doctors, and patients have joined forces to improve care and find a cure.

### Our Mission

As a European federation, it's our mission to empower cavernoma patients in Europe by providing them with high-quality information, resources, tools, and emotional support. We promote creative, yet strategic interventions and stimulate productive collaborations between researchers, patients, and clinicians in order to accelerate better care, treatment options and ultimately to find a cure for cavernoma.



### Our Values

The values of ECA are to be collaborative, informative, high quality, empowering, supportive, and trustworthy.

### Our Goals

The European Cavernoma Alliance is a federation of cavernoma patient advocacy groups that are working together to improve the lives and prospects of cavernoma patients (and their carers) by adopting the following goals:

- To promote the creation of CCM centres of expertise across Europe
- To promote therapeutic care pathways at European level and national emergency guidelines for better early intervention after a haemorrhage stroke caused by a cavernoma
- To stimulate research and development of treatments by increasing the communication between patients, researchers, and clinicians
- To help countries without a local cavernoma patient association to form their own association
- To raise awareness of cavernoma among the medical community, and public.

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

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[www.facebook.com/AngiomaAlliance](https://www.facebook.com/AngiomaAlliance)  
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because brains shouldn't bleed® is a registered trademark of Angioma Alliance.

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.