



ANGIOMA ALLIANCE NEWSLETTER

because brains shouldn't bleed

CCM-Health Index: A Critical Tool that Needs You

How do we know if a treatment—a medication, a dietary change, an activity change—is working? As we enter this exciting moment when we are testing treatments, this is a critical question that must be answered. It can only be answered by us.

First, we need to define what “working” means to us. Currently, researchers define “working” as reducing the number of lesions that develop in the hereditary form and reducing the incidence of hemorrhage for everyone. These two criteria are good, but they require expensive MRI for measurement. In addition to the cost, they may not be measuring everything that is important to those who are affected by cavernous angioma.

Hemorrhage is rare. At any given time, in our patient registry, which likely represents a more severely affected group than average, fewer than 10% of registrants report that they have had a hemorrhage in the last year. So, among 800 registrants, 720 have not had a recent hemorrhage. Some have never had a hemorrhage yet experience symptoms: seizure, headache, etc. Even among those who have had hemorrhage, recovery varies widely, with some returning to 100% of their pre-hemorrhage functioning while others remain severely disabled. Hemorrhage does not tell the whole story.

The number of lesions that develop is also a problematic measure. Among adults with the CCM1 and CCM2 hereditary form, new lesions develop very slowly. On average, a new lesion develops every 2 years, and new lesions are not necessarily symptomatic. We know individuals who have 100+ lesions and are barely symptomatic while one lesion by itself can have devastating effects for others.

What if we had a direct way to measure the impact of the illness on your life? What if we asked you? The idea seems obvious, but it has actually not been tried in a comprehensive way, in part because no one has figured out which questions to put on the survey. For example, should we ask only about obvious physical deficits and seizures, or do we need to ask about fatigue and anxiety? We have an idea of what matters,

what impairs our members, but we don't have the data to say for sure.

We finally have an opportunity to create a survey, a measurement tool, that will allow us to understand how the illness affects the health and quality of life of those affected by CCM. This is not a small undertaking. A psychometric team from the University of Rochester, funded by Recursion Pharmaceuticals who are developing REC-994 for the treatment of CCM, will research all the ways cavernous angioma affects our members in order to create a measurement tool to differentiate people with CCM from those without, and to differentiate those more severely affected from those who are less. It will tell us what the effects are.

The only way they can do this is by asking you. Our role, as Angioma Alliance, is to connect as many of our United States members with the project as possible. We will need at least 500 affected adults to test drive draft surveys. Our goal is to have this measurement tool, the CCM-Health Index, completed in one year.

Once we have a measure, it can be used to understand the impact of the illness among those affected as a whole and for any given individual. It will also allow us to determine changes in health and quality of life over time. A person could take the survey before starting treatment, and then take it again in six months or a year to see if the treatment has made a difference. This information can be used to evaluate treatments as they seek FDA approval and to compare treatments against each other. Having a realistic picture of the impact of treatment on your life, not just the limited information an MRI can provide, will allow for better evaluation and quicker approval of the treatments that make a difference.

Your participation is critical. The faster we can enroll, the faster we can create the final survey. The faster we complete it, the sooner we can get to treatments. When the time comes to complete surveys, we will be reaching out through our patient registry first. Please join the registry at www.AngiomaRegistry.org so we can find you. Your experience paves the path to a cure.

Connie Lee

News

Welcome New Employees

Please welcome Lindsay Ramirez and Darla Clayton to Angioma Alliance as our newest Community Engagement and Fundraising Specialists. Lindsay and Darla will work to develop our Community Alliances in the Western US and the Eastern US, respectively. Tracy Brown will shift her focus to the Community Alliances in the Central US.



Lindsay has been involved with Angioma Alliance the past three years as Co-Chair of the Orange County walk and founding Chair of the Southern California Community Alliance. She is a certified athletic trainer with 12 years of health and medical experience, as well as an educator of sports medicine and advisor for a sports medicine program. Lindsay has an affected husband and son.



Darla is a clinical psychologist and the head coach and “chief cook and bottle washer” for an adaptive track and field team she founded 8 years ago. She serves on the board for Adaptive Track and Field USA and

for Dralla. Darla and her two children have been diagnosed with a mutation of the CCM2 gene. She has been a member of Angioma Alliance since 2005 and has volunteered as a Peer Support Mentor for Angioma Alliance, supporting families of newly diagnosed children.

We are excited to welcome Lindsay and Darla to the Angioma Alliance family, and they are thrilled to take on their new roles and eager to work with you.

Baca Family Historical Project News

Because of a genetic founder mutation, New Mexico has more people affected by cavernous angioma than anywhere in the world.

Through the efforts of the Angioma Alliance Baca Family Historical Project and our advisors Dr. Atif Zafar and Dr. Javed Eliyas, the New Mexico legislature recently passed New Mexico House Joint Memorial 7.

The Memorial requests 1) more cavernous angioma research, 2) reporting of the number of cavernous angioma patients in New Mexico by primary care providers, 3) increased medical provider and public education, 4) increased genetic testing, and 5) a determination by the state's Health and Human Services department on whether genetic testing can be covered by Medicaid. To learn more, please read our op-ed in the *Albuquerque Journal*: hwww.abqjournal.com/1307783/30k-in-nm-need-this-blood-vessel-research.html

This legislation validates the work of the Baca Family Historical Project (BFHP), Angioma Alliance's effort in the state. Over the last two years, the BFHP has hosted dozens of public presentations with family tree workshops and genetic testing, and has trained hundreds of front-line medical providers. Our efforts to find families and expand access to care and participation in research will continue through the end of 2020.

Happenings Around the World

While Angioma Alliance is based in the United States, we love to share and support the work of our international sister organizations. Here are some exciting upcoming events:

June 7: The 1st European Patient Group Leaders meeting will bring together leaders of eight European cavernoma patient groups, along with their scientific advisors, to discuss the formation of a European patient consortium that can support research efforts.

June 8: The 13th annual Cavernoma Alliance UK forum will take place outside of London at the De Vere Horsley Estate. The forum will feature presentations by Dr. Helmut Bertalanffy, Dr. Jonathan Berg, and Dr. Connie Lee. For more information, visit www.cavernoma.org.uk.

August 12: Aliança Cavernoma Brasil (Cavernoma Alliance Brazil) will host its first national symposium, bringing together top scientists, clinicians, government officials, and patient advocates, including Dr. Connie Lee and Dr. Issam Awad, for a day of intense learning and discussion to improve care and speed research. For more information, visit www.cavernoma.org.br.

Community Alliance News

Over the past year, Angioma Alliance has been developing a network of regional Community Alliances that carry out the mission of Angioma Alliance in their areas. We already have eight Community Alliances up and running and more in the recruiting stage. Thank you to everyone who is doing such a tremendous job.

Western Region

Southern California: The newly formed Southern California Community Alliance is off to a running start! They will be hosting a webinar in June featuring neurosurgeon Dr. Anthony Wang from UCLA. Please keep an eye on our website and Facebook page for more details and registration. They also have two walks planned for the fall. This year's Orange County Walk will take place on September 15 and the Malibu Walk will be on October 13. You can contact them at socalangioma@gmail.com.

Pacific Northwest: The Pacific Northwest again participated in a Sand Flea Rally in April to raise awareness. Jeeps sporting Angioma Alliance logos raced through the dunes and the group raffled a basket of logo gear and rally supplies. You can contact them at nwangioma@gmail.com.

Colorado: The Colorado Community Alliance is looking forward to repeating their successful walk on September 21 in Denver with more details to follow. This year's walk will have a superhero theme. You can contact them at coangiomaalliance@gmail.com.

Northern California, Arizona, and Utah: Please reach out to Lindsay Ramirez at lindsay@angioma.org if you are interested in being part of newly forming Northern California, Arizona, and Utah Community Alliances. We have multiple interested members in each area and are just looking for a few more to complete the rosters.

Central Region

Michigan: Our newest Community Alliance is in Michigan. Their goals include assisting the University of Michigan in creating a CCM Clinical Center and hosting peer support and fundraising events. You can contact them at MIAngioma@gmail.com.

Texas: The Texas group held a very well-attended meetup in Dallas in early March. Attendees included neurosurgeon Dr. Jan-Karl Burkhardt from Baylor in Houston who gave a short presentation. You can contact them at txangioma@gmail.com.

Missouri, Eastern Kansas, and Northern Arkansas: Please contact Tracy Brown at tracy@angioma.org if you are interested in being part of a newly forming Community Alliance covering this area.

Ohio: Ohio does not yet have a Community Alliance, but they have an event. The 5th annual Angioma Alliance Night at the Cincinnati Reds will be held on Father's Day this year. More information can be found in the Upcoming Events section of this newsletter or by contacting Tracy Brown at tracy@angioma.org.

Eastern Region

Tri-State area: The Tri-State area boasts three upcoming events. On June 29, please visit A&J Cycles in Hillburn, NY, for their open house and a raffle for Angioma Alliance. On July 3, please join us at Citi Field Stadium as the Mets face the Yankees (more info in the Upcoming Events section). Finally, on September 27, the DeMichiel and Ponte families host the annual Torrington Wine Tasting event. Motorcycles, baseball, and wine: something for everyone! To learn more and participate, please reach out to TristateAngioma@gmail.com.

Greater Washington DC: There will be a meet-up on June 2, from 11-1:30 at Hains Point picnic area. In addition to Community Alliance leadership, in attendance will be Angioma Alliance staff Connie Lee, Darla Clayton, and Tracy Brown. The Greater DC group is planning their next public event and will be providing support for the national family conference in November. You can contact them at dcangioma@gmail.com.

Florida: Florida has taken a national role, hosting quarterly webinars with Dr. Issam Awad and his team that update our community on the atorvastatin trial at the University of Chicago. If you live in Florida, they would love your help in planning their next events. You can contact them at flangioma@gmail.com.

New England: There isn't a formal Community Alliance here, but there should be! Two major events are held in Massachusetts – the Brains Shouldn't Bleed Benefit Concert and Saber Seminar - and there is a CCM Center of Excellence at Boston Children's Hospital. Please contact Darla Clayton at darla@angioma.org if you are interested in being part of a new alliance to support and expand these efforts.

Eastern Pennsylvania, Delaware, and South Jersey: We are planning a get-together on either July 6 or 7 in the Philadelphia area to share stories and make plans. Please keep an eye on our Facebook page or Upcoming Events page for details or reach out to Darla Clayton at darla@angioma.org.

If you are interested in learning more about Community Alliances, visit our website or attend our webinars, scheduled the last Monday of each month at 4:30 pm PT, 7:30 pm ET. Learn more and register using the link at www.angioma.org/local.

Recent Events

Two recent, very fun, fundraising events were held to benefit Angioma Alliance: one on the West Coast and one on the East Coast. In Hillsborough, California, Isaac and Jodi Babbs hosted a Western Barbecue and Pig Roast that raised almost \$40,000. The event included musical entertainment by Jake Neuman, son of our Board member Liz Neuman who is himself affected with a mutation of the CCM3 gene. There was a pig on a spit and chickens who pooped for prizes. John Wayne was in attendance and lots of people were bad enough to warrant a Wanted poster. Wine and spirits tastings topped off a memorable evening.

Tyler Fairbank hosted a benefit concert in Pittsfield, Massachusetts that raised \$20,000. His band T-Bone Daddy entertained the crowd at the Garage, part of the historic Colonial Theater. Tyler had a brainstem cavernous angioma hemorrhage two years ago with subsequent surgery in Boston. He retaught himself guitar, his passion, and was thrilled to be able to share his talent to support our work.

Thanks to both for their outstanding efforts!



Upcoming Events

International Cavernous Angioma Awareness Month

June is International Cavernous Angioma Awareness Month, the month we set aside to share information about the illness with family, friends, and the general public. This year, we have two extra opportunities:

1. A group of generous donors has offered to match all donations made to our members' Facebook fundraisers in June up to \$6,000 (www.facebook.com/fund/AngiomaAlliance/). If we work together, we can meet this match!

2. We are working with Sen. Tom Udall's office to introduce federal legislation that will be called the CCM-CARE Bill of 2019. When you see our announcement in June, please take the time to call your Senators and Congressional Representatives and ask them to co-sponsor the legislation.

Help spread the word online and in your community!

It's game time!
5TH ANNUAL
Cavernous Angioma Awareness Game!
 COME WITH DAD FOR THIS FATHER'S DAY GAME VS. THE RANGERS!
 JOE PRICE, FORMER REDS PITCHER (1980-86), WILL BE THERE!
 HOSTED BY CARI & TONY MAYER IN HONOR OF THEIR SON, DYLAN
crowdrise.com/2019angiomareds

JUNE 16 2019	GREAT AMERICAN BALLPARK \$20 OUTER MEZZANINE TICKETS Section 412-414 on 3rd baseline \$11/tix benefits Angioma Alliance ?s email mayeraj44@yahoo.com	SUNDAY 1:00 PM
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Angioma Alliance is a 501c3 organization dedicated to informing, supporting, & empowering individuals affected by cavernous angioma and drive research for better treatments and a cure.



Save The Date!

National Patient Conference
 November 8-9, 2019
 Silver Spring, Maryland

Meet our Scientists!
 Keynote: Dr. Issam Awad



WWW.CROWDRISE.COM/2019ANGIOMAGAME

FUNDS RAISED SUPPORT THOSE AFFECTED BY CAVERNOUS ANGIOMA!

METS VS. YANKEES
WEDNESDAY, JULY 3

First 100 tix sold receive an on-field photo opp at 6pm
 \$70 - Sect. 535 (Promenade Outfield) \$18 tax ded.
 \$125 - Sect. 141 (Big Apple Reserved) \$22 tax ded.
 \$210 - Sect. 126 (Field Box w/ access to Porsche, Foxwoods, Jim Beam clubs) \$35 tax ded.

7:10 GAME
 AT CITI FIELD

?S CONTACT: KRISTEN @ TRISTATEANGIOMA@GMAIL.COM
 HOSTED BY THE TRISTATE ANGIOMA COMMUNITY ALLIANCE

Proceeds benefit Angioma Alliance, a 501c3 organization dedicated to informing, supporting & empowering individuals affected by cavernous angioma and driving research for better treatments and a cure.

angioma.org

Research Update

State of the Science

There has been a lot of progress recently in cavernous angioma research, and this is a good time to present an overview of the clinical trials, new laboratory findings, and the development of new tools for clinical research.

Ongoing Clinical Trials

Phase I Safety Study for REC-994 (tempol)

According to the team at Recursion Pharmaceuticals, "Recursion continues to develop its compound REC-994 for CCM. The first of two Phase I studies in healthy volunteers is complete with the second Phase I due to begin in Q3, 2019." (Phase I studies focus on healthy volunteers to assess drug safety.) "The company is currently designing a Phase II study that would be conducted in CCM patients and plans to meet with the FDA early next year to discuss proposed plans for the continued development of the drug."

Phase I/II Atorvastatin for Cavernous Angioma with Symptomatic Hemorrhage

Atorvastatin is a drug currently approved for use as a cholesterol-reducing medication. The University of Chicago is running a study to determine if the drug is also an effective treatment for cavernous angioma with symptomatic hemorrhage (CASH). This study is termed phase I/II as it is studying whether the drug is safe for those diagnosed with cavernous angioma and whether the drug is effective in treating the illness. According to Dr. Issam Awad, lead investigator, the atorvastatin trial is on track in study recruitment, with 16 (of 80) individuals recruited and enrolled thus far.

To be eligible for this study, participants must be adults who have experienced a clinical hemorrhage within the last 12 months and who are willing to travel to the University of Chicago three times over a period of two years. Travel stipends are provided. For more information and to learn if you may be eligible to participate, please visit: angioma.org/pages.aspx?content=586

Phase II Treat CCM: Propranolol in Cerebral Cavernous Malformations

Propranolol is a beta-blocker drug often prescribed for blood pressure, social anxiety, and other conditions. This drug is also known to be effective in shrinking infantile hemangioma and has been used anecdotally to treat several cavernous angioma patients with particularly aggressive lesions.

The goal of the Treat CCM Propranolol study is to determine whether long term treatment with the medication will reduce the number of lesions and clinical symptoms in patients. The study is currently recruiting participants at multiple centers across Italy. As of this writing, 37 participants are enrolled and have been randomized to treatment or placebo. Enrollment is anticipated to close in June of 2019, with continued drug treatment and monitoring for two years.

Laboratory Findings

In the lab, several groups have recently reported new findings related to understanding the biology of cavernous angioma and identifying new targets for drug development.

New Targets

A recent publication from Dr. Brent Derry's lab at the University of Toronto describes several new findings:

They found the worm versions of the CCM2 and ICAP genes (ICAP is another gene that codes for a protein involved in CCM1 signaling). These genes were previously not known to exist in worms, and their identification opens doors to expand upon studies of CCM2 and ICAP in this animal model.

The team also discovered a novel function of CCM1 related to zinc and the control of the molecule's transportation and distribution. They found that in worms, mice, and humans, across all three species, there seems to be a connection of CCM1 function and zinc regulation. Proper regulation of zinc is important for normal cell turnover. How zinc impacts cavernous angioma disease biology remains unknown, however, and warrants further investigation.

Another strategy to identify new possible druggable targets is to look at whether the genes are uniquely active in the cells that make up CCM lesions. The University of Chicago team addressed this question by isolating RNA from lesion tissue and analyzing those messages. (RNAs are the chemical messages that follow the directions coded by genes to create proteins.) They then compared messages from human lesions (both familial and sporadic) as well as mouse and worm models of cavernous angioma. The result is an extensive library of data that can be used for hypothesis generation and/or to complement and confirm laboratory findings.

Mouse Drug Study

As discussed above, atorvastatin is a one of the group of cholesterol-reducing medications that are anticipated as a possible therapy for cavernous angioma. A mouse study supporting this hypothesis was recently published. In mouse models of cavernous angioma, treatment with atorvastatin reduced lesion burden (number and size of lesions) as well as bleeding.

For more detailed summaries of these studies and a link to the original publication, please visit my Facebook page: www.facebook.com/AmyAkersPhD

Amy Akers

Getting Ready for Trials

CASH Trial Readiness

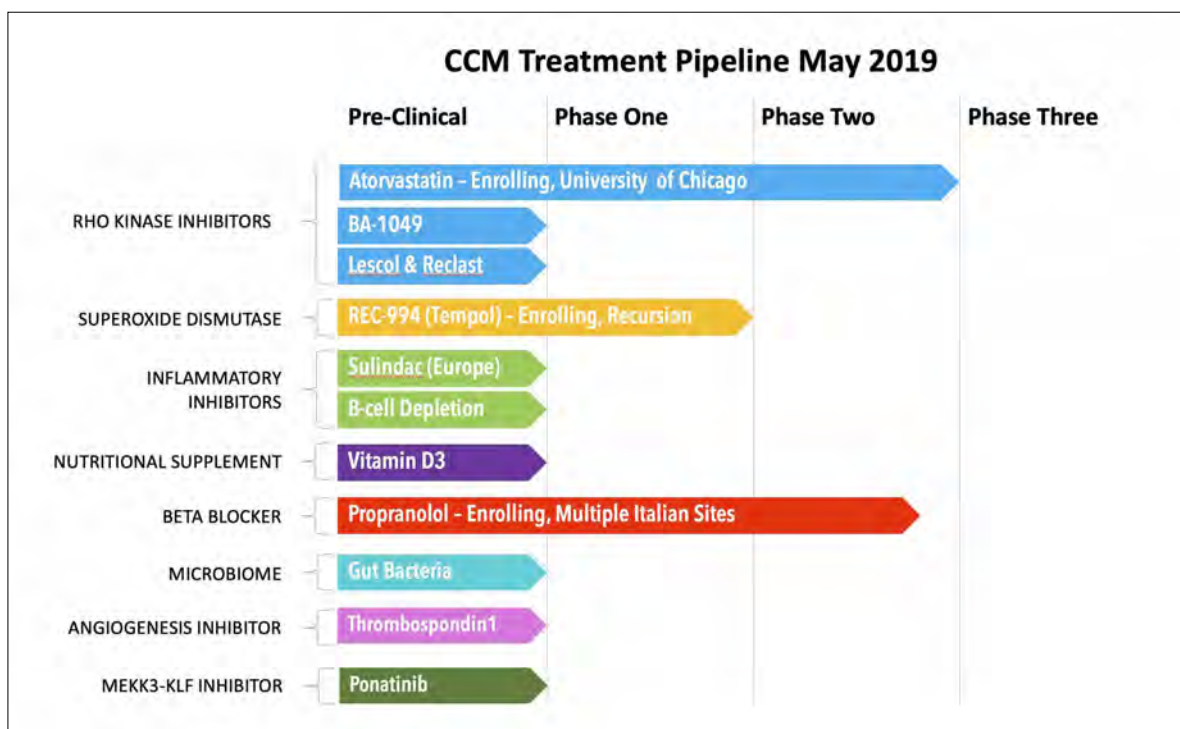
The Cavernous Angioma with Symptomatic Hemorrhage (CASH) Trial Readiness project is a multi-center study. As the name implies, the study is designed to prepare our researchers for clinical trials. Two primary goals are to determine the number of participants who may be eligible to join future clinical trials and, to validate the functionality of imaging biomarkers at multiple clinical sites.

As with the atorvastatin trial, this readiness project is also recruiting at its predicted rate, with more than 40 cases enrolled and with coordinated data collected across sites.

CCM-Health Index

As you read in our lead story, this survey-based tool will assess the quality of life of our patient community; the resulting score of the survey can then be used as an outcome measure for clinical trials.

We will need your help to participate in the study to design and develop this tool. Recruitment aims to begin shortly. Be sure to sign up for the Patient Registry to stay informed about this, and other ongoing studies.



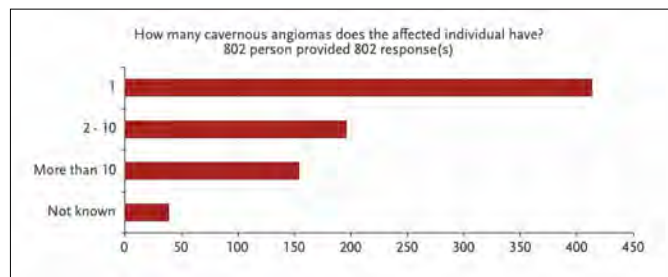
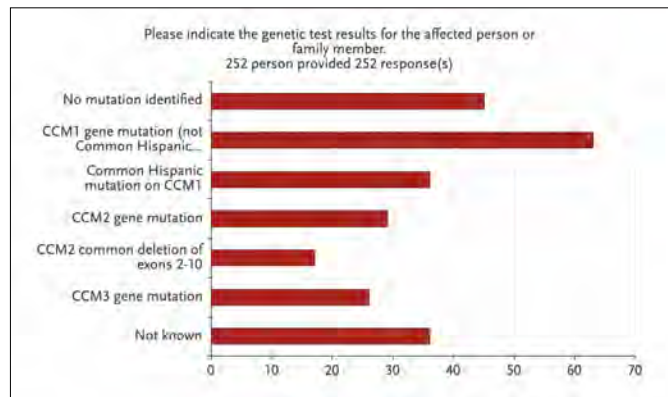
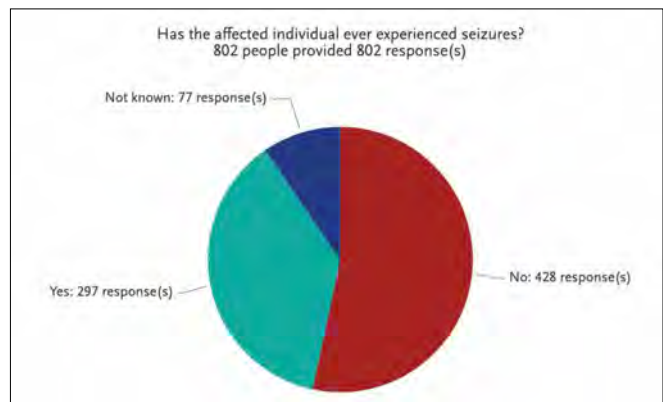
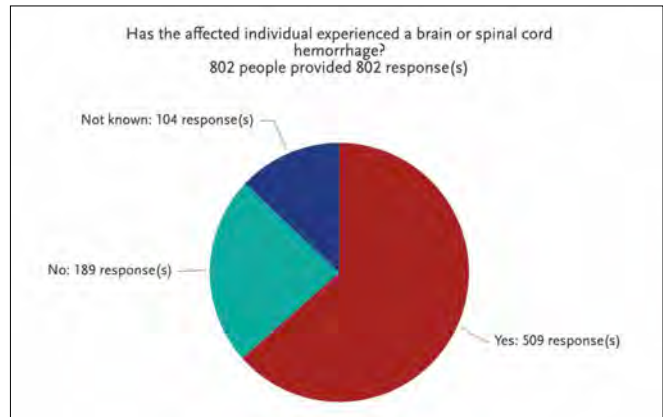
The Patient Registry is Growing!

Since our upgrade early this year, we've had more than 800 people update their registry surveys or sign up as new registrants. Scientists are already accessing the anonymous data to help with their research. We've been using the registry to reach out to registrants to let them know about research studies for which they might qualify. The registry is making a difference.

Here are some reasons to join:

- You'll be the first to learn about new research. We'll send you an email whenever new CCM research is published that may affect your decision-making about care.
- You can view compiled data to see how your experience compares with others, like the data you see on this page. In addition to these graphs and charts, you'll find data about symptoms, treatment choices, and about other illnesses our members with cavernous angioma have.
- You'll be contacted whenever there is a research study for which you might qualify. Our lead story describes the development of the CCM-Health Index, a large undertaking that will need everyone's participation. We are also recruiting for research through the Brain Vascular Malformations Consortium and for the atorvastatin clinical trial. Several other clinical studies are in the planning stages. This is exciting work that you'll want to hear about.
- You'll help researchers understand what our patient population faces so they can design better studies and trials. For example, natural history data, like that collected in our registry, helped us understand that a second hemorrhage is most likely to occur within 3-5 years of a first hemorrhage. Researchers will also see, for example, that our members include more people with brainstem lesions than in the general population, so they can design their trials to take this into account.

Registering takes just 10 minutes. Visit www.AngiomaRegistry.org to set up your account and answer surveys. Our goal is 1,000 registrants by the end of June. This is the most important thing you can do to speed us to a cure!



I Didn't Know My Brain Could Bleed: Coping With a Cavernous Angioma Diagnosis

At 27, I thought I was at the pinnacle of health. I went to the gym every morning before work, climbed the stairs whenever possible, and played outside with my 5-year-old son every evening. Then, one day, I felt sick and started to experience tingling in my face and arms. I started losing my balance and throwing up. A nurse told me over the phone that it sounded like I was having a stroke, which I told her was impossible, given my age and healthy lifestyle. As a precaution, I drove myself to the hospital (and parked far from the entrance, my typical strategy to get in some extra steps). But I was stumbling and had to grasp the walls to make it into the ER.

This is how I discovered cavernous angioma. I am now 53, and have survived two brain surgeries, a seizure during childbirth, a stroke, and partial paralysis. My purpose in writing today is not to throw myself a pity party or give you a play-by-play of my ordeal. Instead, I want to share how my faith and great support from family, friends and co-workers, as well as my involvement in research through the Cavernous Angioma Registry, has pushed me to overcome a grim diagnosis and make the most of my situation.

But first, you may be wondering what the heck cavernous angioma is. It's a relatively unknown condition that causes mulberry-shaped abnormal blood vessels with thin, leaky walls to bleed within the brain or spinal cord, causing seizures, neurological deficits, and more. Approximately one out of every 500 people has at least one cavernous angioma, but only some are actually affected by the disease. For at least 20 percent of those with the illness, including me, cavernous angioma is caused by a hereditary genetic mutation.

Being told that you may not wake up from a risky brain surgery, or that you're never going to walk again without a cane can be seriously detrimental to a person's mental health. As someone who ran four

miles a day, I couldn't imagine not being able to walk on my own. But I have learned through this tumultuous journey that a person's strength, determination, and support system can make a world of difference.

Faith has played a vital role in my ability to stay positive. I was very blessed that the first day I ended up at the hospital, there happened to be a neurosurgeon on call who was studying the genetic mutation of cavernous angioma, at a time when very little was known in the medical community. So, I was diagnosed quickly, which is usually not the case for this disease. Before my surgery, my doctor told me the angioma was in a very dangerous place and I might not survive. I told him I believed in God. When the surgery was over, he said, "I think you were right about God. You came out with almost no deficits." Within six months, after lots of hard work in physical therapy, I was working, driving, and even running again.

My strong support system was absolutely crucial. I work for the University of New Mexico Foundation and have had several brain bleeds while on the job — one time right before a major event that I was overseeing for 250 people. My coworker saw that my face was white, and I was holding onto the wall, and



immediately said, "Give me your notebook, and get to the hospital. We can handle this." That was 16 years after my first brain surgery, and this time I was in the hospital and rehab for 49 days. My co-workers, friends, and family came to see me regularly to raise my spirits.

This recovery was extremely difficult. I had been intubated and my vocal cords were paralyzed. I had to relearn how to walk, talk, and eat. I went to live with my sister, who showered me with tough love. She had me do laps in her yard with my walker, with her French poodle nudging me to keep walking. She had me practice my vowels to get my speech back and use a typewriter to get mobility back in my hands.

I wouldn't be where I am today without my love for exercise. We always read about the benefits of fitness, and my story proves it. After my first brain surgery, a friend took me to water aerobics to help build my strength and get me back to walking and running. After my second surgery, my physical therapist wanted me to use a walker. I refused and used a cane, and then one day showed up without the cane. She said I wasn't strong enough, but I was determined to walk on my own. Now I am back in the gym every day, using the treadmill, although I still have to hold on to the sides. I also went back to college to help exercise my brain. My foundation of exercise and hard work has given my body and mind

the strength I've needed to endure the seemingly impossible.

And finally, my participation in research has helped me become part of something that's bigger than myself and has given me a sense of community. Through my involvement with the Angioma Alliance, I joined the Cavernous Angioma Registry (www.AngiomaRegistry.org), an online registry to help connect patients to research, support clinical trial recruitment, and expedite the fight for a cure. The registry also offers subsidized genetic testing for families, which was very helpful for my sons, who thankfully did not inherit the mutation. Becoming part of the Angioma Alliance community, connecting with others who share my experiences, and contributing to research to try to find a treatment or cure has been deeply meaningful and has given me a renewed sense of hope for the future.

For others who have debilitating illnesses, I leave you with this: You are stronger than you think. But you can't do it alone. Let the powers of faith and community propel you to be the best possible version of yourself.

Long-time Angioma Alliance member Candelaria Romero's story was published on the national health website The Mighty (themighty.com) in recognition of Brain Awareness Week. Reproduced with permission from The Mighty.

Genealogy Project: CCM2 Exon 2-10 Deletion

At Angioma Alliance, we know a number of US families with the CCM2 Exon 2-10 Deletion (CCM2 Common Deletion), and we suspect that all these families are distantly related. We are working on a project to find common ancestors of those who are affected in the hope of identifying the original founding couple and understanding the geographic distribution of the CCM2 Common Deletion.

Understanding the family tree is important for several reasons. It will help us:

- find and connect more at-risk families;
- identify geographic areas where we should put more resources into medical provider outreach to improve care; and
- tie the illness to the story of a state or region, which can raise visibility among the public and among legislators who have influence on research funding.

We would love to introduce patients affected by the CCM2 Exon 2-10 Deletion to our growing community of families via Facebook and invite you to join this exciting project which now includes a professional genealogist. You don't need to have extensive genealogical information to participate: that's our role. However, you must be known to have a deletion of exon 2-10 of the CCM2 gene through genetic testing of you or an affected family member. This is a unique change to the gene different from other CCM2 mutations. To let us know you are interested, please email Connie Lee at clee@angioma.org.

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 Connie Lee at clee@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
520 W 21st Street, Suite G2-411
Norfolk, Virginia 23517
Fax: 757-623-0616
www.angioma.org
www.facebook.com/AngiomaAlliance
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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.