

Our New Name: Alliance to Cure Cavernous Malformation

We have a new name! After 20 years, Angioma Alliance has become the **Alliance to Cure Cavernous Malformation**. Why are we making this change? There are three primary reasons.

First, we finally have our own code in the International Classification of Diseases, the ICD-11, which is used globally to identify the illness. In the ICD-11 the illness is called cerebral cavernous malformation in both English and Spanish. We want to embrace this consistency to reduce confusion and make it easier to find each other. This also helps our organization's visibility and reputation in the greater medical community.

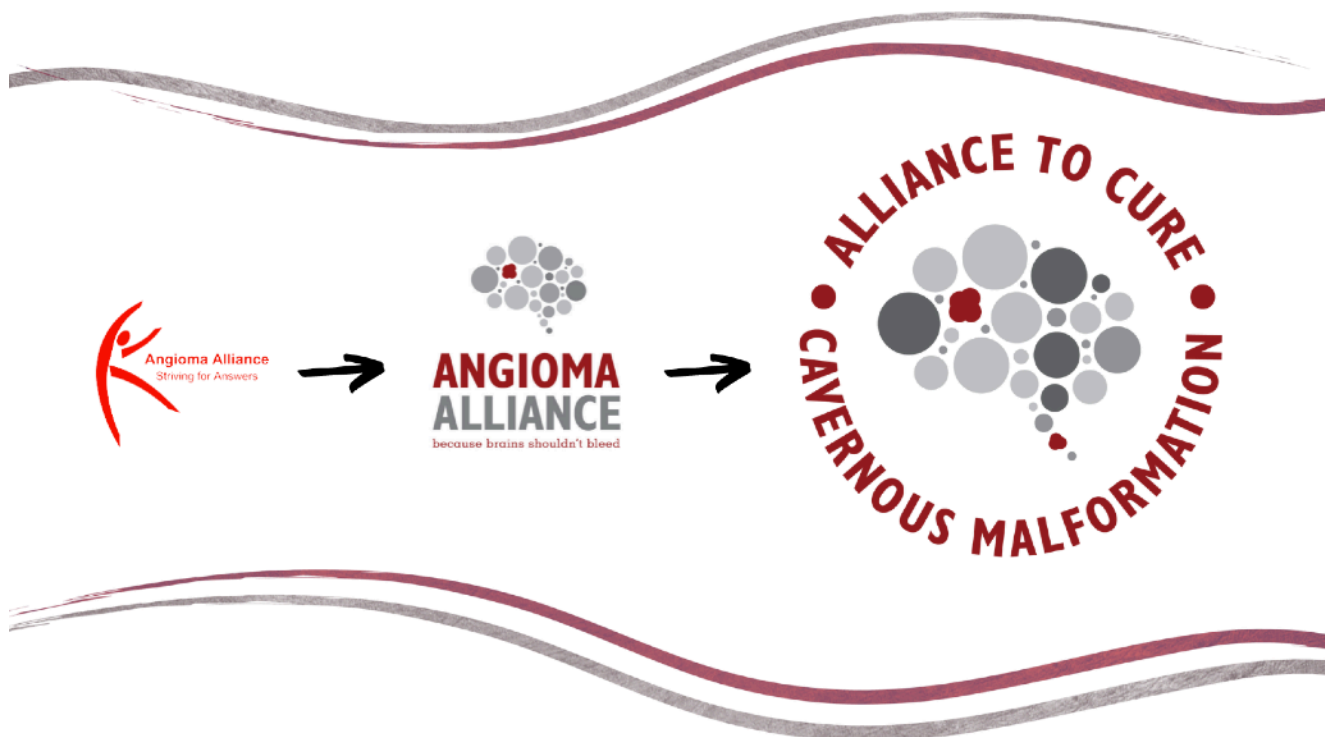
In this issue you'll read about the surge in CCM Clinical Centers and Centers of Excellence that are being recognized. These CCM Centers will soon be using the ICD-11 and unifying around "cavernous malformation." We are keeping a step ahead.

Second, we are an Alliance to Cure. Our mission is to find the cure to this disease, and it involves everyone who takes part: patients, families, friends, researchers, healthcare providers, government, and industry. All stakeholders who are interested in a cure are welcome to be part of our alliance, unified around this mission.

In this issue you'll learn about ways that we continue to push toward the cure. There are stories on medicines under consideration or in trials, new technology that may offer hope, and our work to support science by providing critical resources. In every effort, our Alliance to Cure includes you, our researchers, our care providers, and more.

Finally, we want our members with spinal cavernous malformations to know they belong here. Our new name intentionally doesn't include "cerebral" because lesions aren't just in the brain. You will notice in our new logo that there is a second lesion in the spinal cord. Eventually, we also intend to replace our "because brains shouldn't bleed" tagline with something more inclusive (ideas are welcome).

In summary, our tent is broad, and is growing. And together, in the Alliance to Cure Cavernous Malformation, the cure is promised. To mark this, please join us on July 10 as we celebrate Promise 2022. This is a national hybrid event with live gatherings, program watch parties, and an opportunity to contribute by bidding on auction items and more. We hope to see you there.



Alliance to Cure Cavernous Malformation To Fund Focused Ultrasound Research

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. Alternately, it can be used in combination with a substance that becomes caustic when it's exposed to focused ultrasound. This is called sonodynamic therapy and requires a minimal increase in temperature. Instead of heating and destroying tissue, the sensitizer combined with focused ultrasound causes the death of abnormal cells over the course of days, allowing healthy cells to reproduce and take their place.

As of this writing, focused ultrasound has been used to treat approximately 2,000 patients with brain disorders, primarily for brain tumors and tremors. It is not yet in human trials for cavernous malformation, but it is under investigation in mouse models at the University of Virginia. We do not yet know whether the technique can be used safely and effectively.

The Alliance to Cure Cavernous Malformation is providing funding to the lab of University of Virginia Assistant Professor of Neurosurgery Dr. Petr Tvrđík. His lab has developed mouse models suitable for testing focused ultrasound, and they are now ready to use these mice to determine whether FUS may hold

promise for our patients. Through your donations, the Alliance to Cure Cavernous Malformations will provide one year of salary support for a post-doctoral scientist who will be performing the experiments, and we will be co-funding mouse breeding/housing, reagents, and FUS machine access.

This is a high-risk project that is not yet eligible for funding through the National Institutes of Health. It is entirely possible that we may find out that FUS is not helpful. However, this is an experiment we must fund because the reward for a positive answer—a non-invasive method for removing lesions—could be immense.

CCM Biobank is Expanding

The Alliance to Cure Cavernous Malformation has had a DNA/Tissue Bank since 2006, providing cavernous malformation tissue and patient DNA samples to laboratories around the world. This has been an invaluable resource for research, contributing to many new findings.

We have recently signed a contract with Texas Heart Institute in Houston to relocate our existing Biobank from our facility in Wisconsin. The move to Texas Heart will allow us to expand the type of samples we are able to collect to serve researchers' current needs. In addition to tissue and DNA, we anticipate storing and distributing plasma and urine samples, which are being used for biomarker development. Biomarkers may one day be able to help us diagnose and predict hemorrhage. We'll also be

able to increase the number and types of tissue samples we can collect. We'll be sharing details about how you can participate when the new facility opens in the fall.



PROMISE 2022: A Hybrid Celebration

Join together Sunday July 10, for our largest event of the year with gatherings and watch parties across the country. Get a behind-the-scenes look at the impact of our cavernous malformation community, how your contributions have helped, and why a cure is within our reach. Some of the highlights include:

- A look into the future of Alliance to Cure Cavernous Malformation.
- A day in the life of some of our patients and families.
- The founder's story.

After you've heard the stories, become part of the cure by bidding on excellent auction items – a Berkshires ski package, a Napa Valley golf outing, and lots more.

Visit the link below or scan the QR code for details:

bit.ly/Promise2022



Join one of these in person events:

Boston: bit.ly/Promise2022-Boston

Minneapolis: bit.ly/Promise2022-Minneapolis

Ladera Ranch, CA: bit.ly/Promise2022-SoCal

Host a watch party with friends and family
OR

Watch from the comfort of your own home on a phone, tablet, computer, or smart TV using this link:
cureccm.cbo.io

Questions or interested in hosting? Email Lindsay at lindsay@alliancetocure.org.

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07.10.22



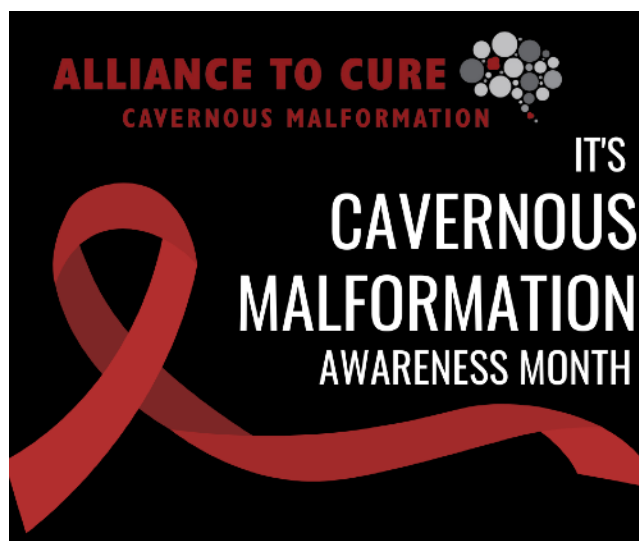
June Cavernous Malformation Awareness Month

June is Cavernous Malformation Awareness Month! This year, we've bookended our month with the Strides to Cure CCM and the Promise 2022 events.

In June or anytime, here are some easy ways to help us raise awareness.

- Follow us on social and share our posts with the #CavernousMalformationAwareness hashtag
- Share your story and tag @AllianceToCure
- Wear your Alliance to Cure Cavernous Malformation gear, post a picture, and tag us.

Watch our social media pages for other fun activities and challenges throughout the month.



Recursion Pharmaceuticals offers best wishes for a successful event!



The Symptomatic Cerebral Cavernous Malformation Trial of REC-994 (SYCAMORE)



Please visit [ClinicalTrials.gov](https://clinicaltrials.gov) and search for SYCAMORE for more information on the study and participating sites

Congratulations to our New CCM Centers

As the Alliance to Cure Cavernous Malformation continues in its mission to develop, recognize, and grow our network of Clinical Centers and Centers of Excellence, we are thrilled to announce the addition of two new Clinical Centers and one Center of Excellence. Our Centers are held to rigorous standards and provide high-quality interdisciplinary care for patients with sporadic or familial cavernous malformation. They are expected to meet or exceed the clinical care consensus guidelines that are recognized by the Alliance to Cure Cavernous Malformation Scientific Advisory Board.

We congratulate and recognize **Ascension St. John Medical Center in Tulsa, Oklahoma** for achieving the status of CCM Clinical Center, led by Dr. Yashar Kalani and Dr. Errol Gordon. Ascension St. John Medical Center received the Get With The Guidelines-Stroke Gold Plus Quality Achievement Award and is the only Joint Commission-certified comprehensive stroke center in eastern Oklahoma. They draw patients from several surrounding states and provide care and follow up services to underserved communities in their catchment area. In 2018, Dr. Kalani led the effort at the University of Virginia Health System to achieve recognition as a CCM Clinical Center, which then led to their elevation to Center of Excellence status in 2021. Dr. Kalani's move to Tulsa allowed him to share his expertise while working with his team at St. John Medical Center to pursue and achieve Clinical Center recognition.

We congratulate and recognize **UCLA Health and Mattel Children's Hospital** in Los Angeles, California for achieving the status of CCM Clinical Center, led by Dr. Anthony Wang and Dr. Jeremiah Johnson. UCLA Health hospitals are highly ranked, both locally and nationally, and have retained their spot on the U. S. News & World Report's 2020-2021 Best Hospitals Honor Roll, which names the 20 hospitals that provide the highest-quality care across a wide range of procedures and conditions nationwide. We look forward to collaborating with them on initiatives that will advance our working relationship.

We congratulate and recognize **Stanford Health Care** in Palo Alto, California for achieving the status of

CCM Center of Excellence, led by Dr. Gary Steinberg and Dr. Neil Schwartz. Stanford Hospital has also been named to the U.S News & World Report's 2020-2021 Best Hospitals Honor Roll as well as holding the distinction of being one of the nation's best teaching hospitals by The Leapfrog Group, a top healthcare advocate organization that evaluates providers based on rigorous quality and patient safety standards. Stanford Health Care is now an active site for the REC-994 clinical trial and is participating in a data collection study to better understand risks associated with familial CCMs.

The Alliance to Cure Cavernous Malformation extends deep appreciation to these new Centers and their interdisciplinary care teams for their hard work and dedication to our patients and families. For additional information, please refer to the Care and Community page on our website. We are actively meeting with and evaluating several additional institutions for our Clinical Centers and Centers of Excellence program, so please stay tuned for more exciting news.

Michelle Crook, RN, Clinical Programs Director

Recursion's REC-994 Phase 2 Trial Enrolling

Recursion Pharmaceuticals' Phase 2 trial of REC-994, the first industry-sponsored medicine for cavernous malformation, known as the SYCAMORE trial, is open for general enrollment. At the time of this writing, there are 4 sites actively enrolling (Stanford, University of Virginia, Baptist Health in Jacksonville, and 21st Century Neurology in Phoenix). Additional sites will be opening shortly in the mid-Atlantic with more to follow around the United States.

This trial is seeking a total of 60 adult patients with symptomatic cerebral cavernous malformations. Symptoms must be caused by an active brain lesion and can include seizure, headache, neurological deficits, or other issues that are not solely from a prior hemorrhage or surgery.

More information, including contact details, can be found on our website at www.alliancetocure.org/research-clinical-trials/participate-in-trials/rec-994/.

The University of Chicago Medicine is at the forefront of using science to advance healthcare and bring the latest treatments to patients.

We are proud to be the first Angioma Alliance-designated Clinical Center of Excellence in the world. Find out how UChicago Medicine's Dr. Issam Awad and his team are fighting for CCM patients at UChicagoMedicine.org/CCM.



AT THE FOREFRONT

UChicagoMedicine

DR. ISSAM AWAD Director of Neurovascular Surgery and
Director of Safadi Program of Excellence in Clinical and Translational Neuroscience



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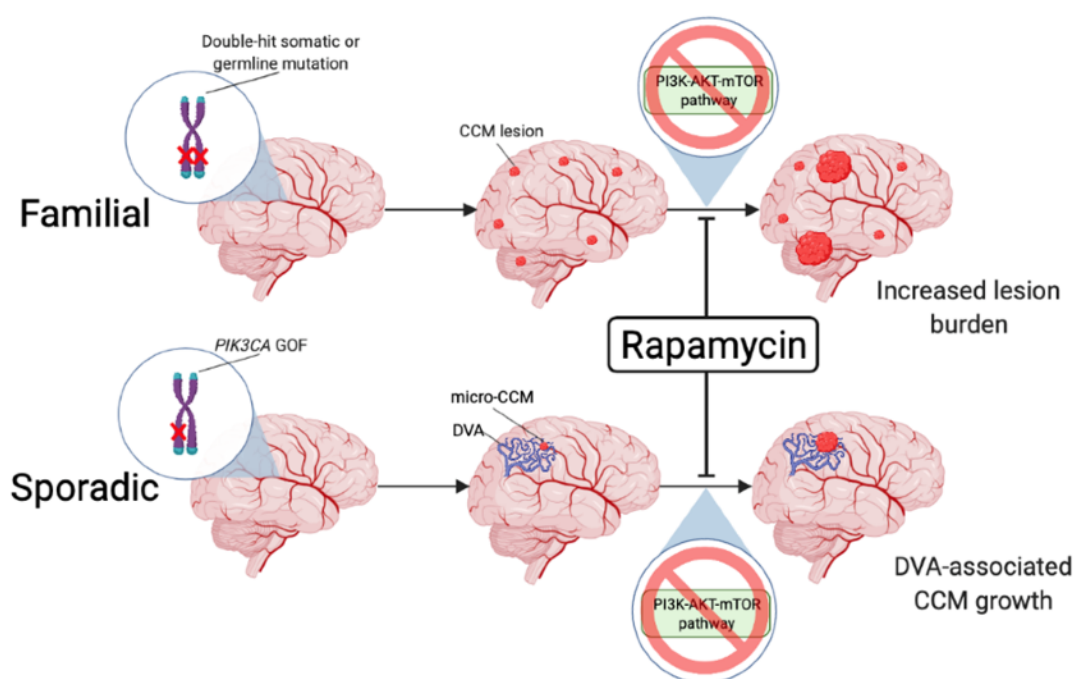
Low-Dose Rapamycin as a Potential CCM Treatment

Collaboration between researchers and physicians in the CCM field has advanced our understanding of how cavernous malformations (CCM) form and grow. We now know that disruption of many different molecular signaling pathways can cause CCM. Recent evidence suggests that most of the familial and sporadic CCM pathways cross at one point: the activation of the mTOR gene. Activation of mTOR has been shown to be a key to CCM lesion formation and growth.

transplant rejection, are obviously not appropriate for our patients. Several of our laboratories are now exploring the use of low-dose rapamycin and alternate dosing and delivery strategies as options to treat CCM. At lower doses, rapamycin is well-tolerated with few side effects; the goal is to find out whether low-dose rapamycin is also effective at treating CCM.

Alternative dosing strategies are possible:

1. Dosing can be individualized and kept as low as possible. Hagan et. al. wrote an excellent review paper on rapamycin dosage to treat CCM. They



Reprinted from Hagan MJ et. al. with permission from the American Chemical Society.

Rapamycin, already approved for use in other diseases, inhibits the mTOR pathway and seems to impact CCM. In infant mice engineered to have a CCM mutation, an intra-belly injection of one high dose of rapamycin inhibits CCM growth by about 75%. In adult mice engineered to develop a cavernous malformation somewhat later in development, an under-the-skin injection of rapamycin almost eliminated CCM formation. This suggests that rapamycin holds great promise for treating human CCM.

The extremely high doses of rapamycin that are used in treating other diseases, such as kidney

concluded that low doses between 2 and 4 mg/kg/day should be tested for CCM in mice. Additionally, much lower doses could be tailored to the individual. Different people metabolize rapamycin differently after taking an oral pill. Therefore, when therapy is started, doctors could test a patient's blood level of rapamycin right before they take the next low-dose rapamycin pill. This will ensure they are taking the lowest recommended dose that is giving a therapeutic benefit.

2. The pill might not need to be taken every day. Blood rapamycin levels stay high for several days

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after taking only one pill. Some patients take rapamycin once every several days as an effective treatment for their diseases. In fact, once per week dosing is the most common schedule. The combination of an optimal dose plus an alternate dosing schedule can be tested in animal models.

3. There may be alternatives to pills. To reach a constant effective blood level using a pill, it takes a higher oral dose of rapamycin than if the medicine, or one like it, is given using a single IV injection. A low-dose IV injection once a week or once every other week, although inconvenient, could be another option to test in mouse models.

4. There are FDA-approved medicines with similar mechanisms of action that may be tested as alternatives. These medicines, as you would imagine, have their own strengths and weaknesses. Among these medicines, everolimus is used most often in other diseases and may have a lower side effect profile than rapamycin. However, it's not clear that everolimus is a better choice, because it is absorbed and eliminated faster than rapamycin. Therefore, a

patient may need to take more everolimus to get the same therapeutic effect.

In summary, low-dose rapamycin is an already-approved medicine that potentially holds great promise for the treatment of both sporadic and familial CCM. There is great enthusiasm in the research community for bringing this medicine to human trials. The current research focus is determining the optimal dose, schedule, and delivery method of low-dose rapamycin to keep side effects at bay while still reducing CCM lesion growth and activity. Stay tuned for much more news to come.

Jianbo Hu, Ph.D., Industry Relations Director

Hagan MJ et. al. Rapamycin in Cerebral Cavernous Malformations: What Doses to Test in Mice and Humans. ACS Pharmacol. Transl. Sci. 2022, 5, 266–277. doi.org/10.1021/acspsci.2c00006

Ren AA et. al. PIK3CA and CCM mutations fuel cavernomas through a cancer-like mechanism. Nature. 2021 Jun;594(7862):271-276. doi.org/10.1038/s41586-021-03562-8.

Patient Conferences - SAVE THE DATES!

November 18-19, 2022: National Patient Conference

We are gathering in person in November! Happening concurrently with our International CCM Scientific Meeting, our patients will have the opportunity to hear from scientists both in lectures and informally over meals. We'll also have a chance to meet each other, share stories, and form friendships. This year's meeting will be November 18-19 in Durham, North Carolina, at the Washington Duke Inn. You can make hotel reservations now (\$199/night) at bit.ly/CCMMeetingHotel. Conference registration will open shortly.

July 7-8, 2023: Family Conference with Adult & Children's Program

We haven't had a family conference with children's programming since 2015, and we are thrilled to be able to do this again. Please save July 7-8, 2023, for our conference at the Intercontinental Hotel, Miami, Florida. We have reserved a block of rooms with availability starting on July 4-9. Plan your summer vacation around our meeting. You will be giving your child the gift of a lifetime. Kids who attended the 2015 family conference created bonds that continue to this day; they know that they are not alone.



What a way to celebrate 20 years! A HUGE thank you to all who participated in our first ever Strides to Cure CCM national walk, run, and roll! There were over 400 participants across the country sharing their stories, and over \$22,000 was donated through the event!

Thank you to Elle's Angels Atlanta for hosting an incredible event! Melinda Wilson and her family and friends raised over \$80,000 towards accelerating a cure for cavernous malformation in honor of Elle Wilson! We are truly grateful!



#Strides2CureCCM

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Other Trials in the US and Around the World

Along with the exciting research stories in this issue, we want to share with you, or remind you about, some of the other ongoing work toward better treatments and a cure happening here and around the world.

CARE Trial

In the UK, Cavernoma: A Randomized Effectiveness (CARE) Pilot Study is being conducted as a first step to help understand, in a scientific way, what approach – conservative treatment versus traditional surgery versus stereotactic radiation (gamma knife) – is best for treating symptomatic cavernous malformations. As of this writing, the CARE Trial has randomized 17 patients of the 60 patients that they hope to enroll. The purpose of the pilot study is to create a trial network and establish the feasibility of a larger study that may serve to answer the larger research question. To learn more, visit the University of Edinburgh website at www.ed.ac.uk/usher/edinburgh-clinical-trials/our-studies/all-current-studies/care/care-study/about-study.

CASH Trial

The University of Chicago is host to a Phase 1/2 experimental-proof-of-concept trial of atorvastatin, enrolling patients with cavernous malformations that have recently hemorrhaged. The trial is in its final push toward full enrollment of 80 patients and, with the help of our families, hopes to complete enrollment by the end of the year. The trial is determining whether atorvastatin is safe for our patients, whether specialized imaging can be used to detect a medicine's effect, and whether there may be an indication that atorvastatin influences disease course. To find out more, visit our site at www.alliancetocure.org/research-clinical-trials/participate-in-trials/atorvastatin-trial/. Along with the atorvastatin trial, there is a parallel effort to standardize clinical trial procedures across five institutions so that these hospitals are poised to run a coordinated multi-center trial.

TREAT CCM

In Italy, a Phase 2 safety trial of propranolol is nearly complete. We anticipate a report of results by the end of the year. In this trial, 79 patients with familial CCM were enrolled to test the tolerability and safety of propranolol use in CCM patients and to look for indications that the medicine may influence the disease course. If the study results are positive, the hope is that a larger international trial can be funded to determine whether the drug is indeed helpful. In Europe, only familial CCM is considered a rare disease, and currently, government funding for this trial is available only from rare disease agencies. Therefore, only familial patients are being enrolled. However, there is no reason to think that results from this and subsequent studies would not carry over to sporadic patients.

Help Research Without Leaving Your Home

You can help research toward the cure from your computer. Joining the Cavernous Malformation Patient Registry hosted by the Alliance to Cure Cavernous Malformation is the first and easiest step to being part of the solution. Twenty minutes of your time makes an enormous difference. The registry serves many purposes:

1. It allows us to share information about research studies for which you may qualify, as well as information about recent research as it's published.
2. It gives us a snapshot of the experience of living with cavernous malformation. We never share identified, individual data, but we can tell researchers about trends so that they can design new and better studies. You can also see trends after you enroll in graphs available only to registrants.
3. You can use the patient registry to request free genetic testing through the Alliance to Cure Cavernous Malformation. US and Canadian patients with multiple lesions that can't be explained by a DVA, or history of radiation may qualify.

To join, visit www.angiomaregistry.org. If you are already a member, please be sure to watch for email messages with links new surveys. It's important that we follow you over time, so we'll give you an opportunity every 3 months to tell us about changes.

Deania George: “The Key is the Aftercare”

Deania George is a Masters-level registered nurse in Newport News, Virginia. She shared her cavernous malformation experiences with Jessica Biggs, our Health Equity Specialist, as part of a Breaking Barriers research study. We are reprinting parts of her interview with her permission.

Tell us about how your family managed sickness when you were young.

I grew up in St. Thomas Virgin Islands with a single mom who was very traditional and believed in home remedies. As a child, if we had a cold or the flu, my mom would administer home remedies, like tea for example, prior to taking us to a doctor to get antibiotics. The only time that we went to the doctor was if we were really sick or if we needed to register for school.

What led to your diagnosis?

In 2011, the Friday after Thanksgiving, I experienced the worst headache I ever had! I remembered taking Tylenol and Advil but the headache did not go away. I went to sleep and woke up the next morning feeling very dizzy, nauseous, and unsteady while walking. I was throwing up everywhere and was unable to get my balance. By Saturday after my symptoms did not get any better, I finally went to the closest ER.

After the CT scan results came back, I was transported to another local trauma hospital that night. I was diagnosed the next morning after completion of the MRI with a hemorrhage from a cavernous malformation in my left middle peduncle.

Did you have any symptoms beforehand, that in retrospect, might have been associated with a cavernous malformation?

As a teenager and young adult, I've always suffered from migraine headaches and motion sickness. The first time that I found out about cavernous malformations was when I was diagnosed in 2011.

After you were diagnosed, what was the suggested treatment?

After my first bleed (2nd and 3rd) I was treated with medications such as steroids, pain and nausea



medicine. We did discuss surgery but my neurosurgeon decided that it was best if we did the watch and wait. He basically told me to go home and rest and wait for the bleeding and swelling to go down.

At that time, I was very nervous because it's brain surgery! It's very nerve wracking and I was a new mom with a 1-year-old daughter.

But I recovered, each time. I did inpatient and at-home physical therapy which helped a lot. I also got several second opinions.

What has happened since then?

I've had a total of three major bleeds since 2011. My second and third bleed was in 2013 and 2017. After each bleed I went home and rested for about two to three months while doing physical therapy. I've had several second opinions from doctors in New York, at Weill Cornell and Columbia. I also went to UVA and VCU.

Also, I had repeat MRI's just to track the growth of the cavernoma in my brainstem. Because of the location of the cavernoma, we've decided not to pursue surgery at this time due to the high risk of debilitating symptoms. The symptoms I've experienced during a bleed are very devastating. At times I can't walk, talk, or eat until I rest and recover.



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Do you worry about your daughter?

I do. Sometimes when she complains of a very bad headache I wonder if it's a cavernoma. But I've had genetic testing done after my second bleed and it's not genetic.

Can you think of a time when that you ever felt disappointed or frustrated by the care that you received? What could have helped?

It's very frustrating after recovering from a bleed and everyone sees the aftereffect and they think that everything is fine. They don't know the days/weeks of physical therapy that you have to undergo to get back to normal. They see me and they think "Oh, she's fine" but I'm not fine every day.

Even now, I'm not fine. I still have days when I feel very fatigued and deal with balance issues. I can't do anything with my eyes closed, with the fear of falling over. So, it's kind of hard when they see me walking and talking and then they think, 'oh, you're fine,' but really and truly I'm not fine.

I had to advocate for physical therapy for myself every time I've had a bleed. I don't think that there are too many people with my diagnosis living in my area so resources are not readily available. I wish there were better rehab facilities in my area geared towards my needs that were readily available, especially after my last bleed.

I think a good social worker would have helped a lot, or a case manager. Not just any type of social worker but someone with experience with patients who've had brain injuries. Someone that would know what the patient needs upon discharge such as physical, occupational, and speech therapy automatically. Not just discharging them home with their family and wishing for the best. And most importantly, mental health and cognitive support also. Because dealing with this type of diagnosis is very devastating for the patient and their family.

I think ongoing support for a longer period of time after discharge would have been helpful for me, when I had my bleed. Something as simple as talking on the phone was very taxing. I couldn't talk on the phone without throwing up. So, when the case managers started calling at first to check to see how I was feeling, it was very difficult to talk without even

throwing up. Even if you call to check on a patient right away, the patient might not be feeling well. I feel like they just gave up and never called back, not even two or three weeks later, to check on my progress. They checked initially, but they didn't follow through.

Who has been supportive?

My primary care providers were very supportive in my care. I had two female providers previously but they've relocated. They were really great at showing concern and having patience, also for filling out my family medical leave paperwork for my job. My neurosurgeon is also a good support. I've been seeing him for over 10 years. He's a good surgeon but his focus is on surgery, not support.

My family and friends have been through this experience with me, and it's kind of devastating when it happens. They are amazing! Every single one of them. When I have a bleed everything stops, like, I can't work, I can't talk. I can't walk. I can't do anything for myself. It's kind of like taking care of a baby again, or something.

So, my support team would be my family and my close friends. And the cavernoma people, like Connie [Lee] for getting information and stuff.

Have there been ways the Alliance has been helpful?

Yes, in getting information, definitely. I went to one of the conferences in 2018 prior to COVID. The conference was amazing. I was able to meet with doctors, researchers, and get plenty of information. I also was able to speak with physical and rehabilitation therapists. I thought that was good, because even though you have a good surgeon, the key is the aftercare. Even as a nurse, I think that is the most important thing. Because your surgeon can do a really good job, but you know, it's the aftercare providers who are going to take care of you, who are going to help you exercise and live a better life. That's what I think is most important, Not just having a really good surgeon, but the aftercare and nursing care, too.

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Catherine Lopes

Hope Love

Maxine & Bob Lowy *in honor of Eric Lowy's birthday and recovery*

Kathryn Lyday

Derick Machado

Emanuel Machado

Lawrence Marino

Susan McGonigle

Terry McLaughlin

Marcos Merced

Carmen Merced

Lindsey Michaux

Meredith Middleton

Wade Miller

Amy Mininberg

Molly Moore

Mehrdad Nedjat-Haiem

Tamara Olsen

Maria Oxley

Katie Parish

Claire Parker

Allison Payne

Lauren Penter

Margaret Peterson Pinkham

Angela Plummer

Chris Porter

Kathleen Rakowski *in honor of Nicki Milin*

Alyce Ritchie

Paul Rizzo *in honor of Cara Lee Martin*

Heather Rodbell

Mike Ryder

Maria Schneider

Taylor Schwieger

Charles Sergeant

Karen & Scott Snavelly

Sandi Souza *in honor of Liz Neuman*

Ellie Sullivan

Ann Terrell *in honor of Wayne Jackson*

Carol & David This *in honor of Kristen Fowler*

Kristin Thomas

Julie Thomas

Torrington 4 Wheel & Off Road U-Haul

Michael Upwall

Greg Upwall

Lindsay Veillette

Stephanie Vettese

Landria Voigt

Kathleen Waldrop

Suzanne Wallace

Matt Walsh

Arthur Wasser *in honor of Brian Fairbank*

Kristine Whigham

Sharon Winsmith

Lyndsie Yamus

Cindy Yrigollen

Dianna Zengel

Jennifer Zink

How You Can Help

Volunteer: Share your talent and time in any number of ways including Community Alliances, peer support, events, legislative advocacy, and much more: www.alliancetocure.org/care-community/community/volunteer/.

Donate: Your contributions help fund our research initiatives toward a cure and our patient support programs. To donate, please send a check or money order to the address below or visit our website at www.alliancetocure.org to donate with a credit card.

Sponsor: 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. Contact us at info@alliancetocure.org to learn more about these opportunities and valuable benefits for your company.

Our Mission and Goals

It is our mission to inform, support, and mobilize those affected by cavernous malformation and drive research for better treatments and a cure. We do this by developing and executing strategic, creative, high-return interventions as a model for rare diseases:

1) **Facilitate and participate in cavernous malformation research to achieve a complete understanding of the disease** and facilitate clinical drug trials and other treatment improvements. We do this through our Accelerating Cures program, Scientific Meetings, patient registry and biobank, genetic testing program, research collaborations, and outreach to special populations.

2) **Provide disease and resource information** to educate and improve the lives of people affected by cavernous malformation, caregivers, health professionals, researchers, policymakers, and the general public. We achieve this through our website, publications, webinars, conferences, and media appearances.

3) **Foster and promote a caring community to provide support.** We offer live and online support opportunities and broad international outreach.

4) **Get people involved in advocacy and active participation toward a cure.** Involvement can include activities like research participation, community events, Patient-Expert Certification, and legislative advocacy.

5) **Build and sustain a broad base of funding sources to support our mission and goals.** We count on you!

About Alliance to Cure Cavernous Malformation



Alliance to Cure Cavernous Malformation is a non-profit, international, patient-directed health organization created by people affected by cerebral cavernous malformations (also known as cavernous angiomas or CCM). Our mission is to inform, support, and empower individuals affected by cavernous malformation 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.

Alliance to Cure Cavernous Malformation

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Follow Us on Social Media

www.alliancetocure.org
www.facebook.com/AllianceToCure
info@alliancetocure.org
Twitter: @AllianceToCure
Instagram: @AllianceToCure

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: Alliance to Cure Cavernous Malformation, 520 W 21st St STE G2-411, Norfolk, VA 23517, info@alliancetocure.org. If you are a resident of one of the following states, you may obtain financial information directly from the state agency: Angioma Alliance d/b/a Alliance to Cure Cavernous Malformation, EIN 02-0600697, complies with state charitable registration requirements.

- 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.