

CCM Connect: Achieving Our Vision

CCM patients often face delayed diagnosis and inadequate treatment. They may live far from expert care or may face barriers to follow-up. To improve the quality of life for our families, we’re launching **CCM Connect**, a comprehensive program to achieve our vision to make quality CCM care available, accessible, and affordable to all. Here’s how we’re starting:

Free, updated CCM Clinical Consensus Diagnostic and Care Guidelines to improve care. The Alliance to Cure Cavernous Malformation managed a two-year project with CCM experts to update our 2017 clinical care consensus guidelines. The completed update reflects advances in CCM treatment and care, and it adds diagnostic, pediatric, and spinal cavernous malformation guidelines. The guidelines have been peer-reviewed and will be published in the scholarly journal *Neurosurgery* and on our website in the coming weeks. To ensure they are accessible to all, we are paying for the guidelines to be available without a paywall. To learn more about the guideline development process and updates, watch our recent webinar with Dr. Issam Awad, Chair Emeritus of our

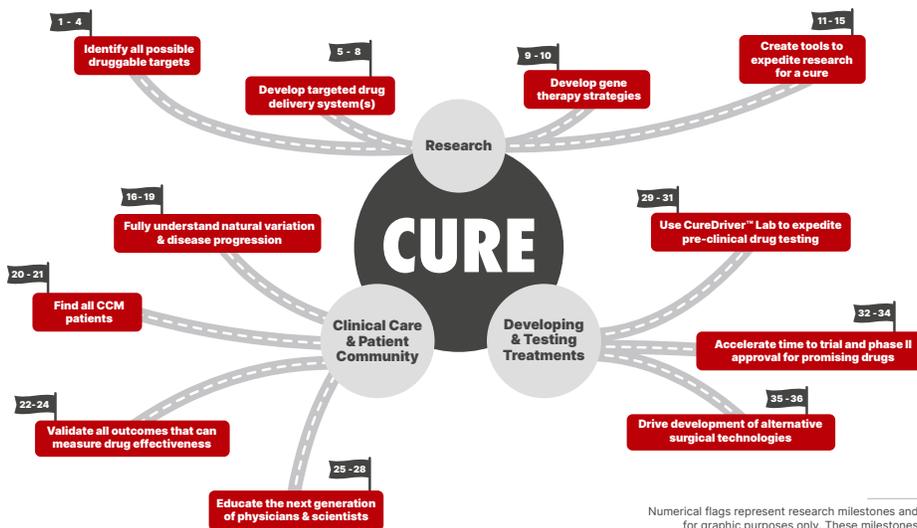
Scientific Advisory Board, available on our YouTube channel: youtube.com/@AngiomaAlliance.

Vast outreach to CCM providers in the U.S. For the first time, we have contact information for every US-based PCP, neurologist, and neurosurgeon who saw one or more CCM patients in the last 2 years. This information will allow us to connect with thousands of providers and boost their access to ongoing CCM medical education. Our near-term plans include sending providers the updated Care Guidelines and creating opportunities to confer with clinicians at our CCM Centers.

Oversight and expansion of our CCM Center of Excellence and Clinical Center network. Since 2016, we have accredited 12 hospitals as CCM Centers of Excellence and eight hospitals as CCM Clinical Centers. Both designations mean that patients are cared for by a multi-disciplinary team of CCM experts. Centers of Excellence also conduct research, often as clinical trial sites. Our newly hired Clinical Programs Director Katie Garbarini is engaging in an intensive review of existing Centers to ensure they

ROADMAP TO A CURE

FOR CAVERNOUS MALFORMATION (CCM)



Numerical flags represent research milestones and are for graphic purposes only. These milestones are non-competing and may be completed concurrently.

continue to meet our criteria. We are also receiving applications for new Centers and reaching out to higher volume institutions that are not yet in our network.

Coordinating researchers and clinicians to improve CCM clinical care. This year we will hold our first CCM Clinical Directors Committee Conference so that CCM Center leaders can identify and address gaps in CCM care across the 20-hospital network. Topics will likely include pediatric CCM care, CCM epilepsy, and post-surgical care and rehab. We will hold these meetings twice a year so that clinicians can meet frequently and advance CCM clinical care together. We will also offer opportunities for Center staff to participate in case reviews and journal clubs.

Patient Navigation and Resources. Patients have many needs that fall outside of simple neurological care. In our 2024 patient and caregiver needs assessment survey, members identified multiple areas where the Alliance to Cure could make a difference. We hope to smooth the journey for those patients who are struggling with finding information, support, or resource connections after diagnosis.

To address this, we will be offering navigation services to any US-based CCM patient or caregiver. On our website, you'll soon find a form to request a one-to-one needs assessment. Our intent is to help you find the resources you need – information, agency connections, or peer support – in areas such as insurance, school, and employment advocacy or other areas where outside resources would be helpful. Our program is just beginning; it will expand and improve as we work with families and better understand their needs.

Our program will also improve ongoing services for everyone. We will continue to offer virtual support groups both on Zoom and Facebook. We are exploring other platforms to augment our Facebook groups, and we'd like to add opt-in text message check-ins. To improve the ease and speed of finding information on our site, we have introduced a Chatbot that distills information to answer questions in natural language. Finally, we plan to simplify our website navigation and language without losing the depth of content.

CCM Connect is a big-vision program with the potential to dramatically improve lives. We are excited to begin moving this effort forward and welcome your feedback as we grow.

Meet our CCM Connect Team Leaders

Katie Garbarini, Clinical Programs Director

katie@alliancetocure.org

Darla Clayton, Patient Affairs Director

darla@alliancetocure.org

Katie and Darla head our CCM Connect programs. Katie is a licensed genetic counselor who joined us in January. She is responsible for our CCM Clinical Center and Centers of Excellence program. Darla is a licensed clinical psychologist who has been leading our patient support and education programs since 2019. She will supervise our new patient navigation service and improvements to our website. Our patient navigation team also includes Jessica Biggs and Linda Fuchser.

We are grateful to the following individuals and foundations for their generous financial support of these programs: Ann Hatch, Julian Grace Foundation, Dan Engle, and Kohl's Cares.

CureDriver™ Lab

The Alliance to Cure Cavernous Malformation has launched its CureDriver Lab to screen potential drug treatments for CCM in a variety of pre-clinical models. We are excited to be moving this effort forward. We have completed the first cell-line screening and have nearly completed proof-of-concept studies in our murine model to make sure they develop cavernous malformation lesions as expected. The next step will be moving promising drug candidates into the animal model for testing.

We are also in discussions with pharmaceutical companies that may be looking for a place to test their potential treatments. Our service would expedite their preclinical work and get them to trials more quickly.

Your financial investment in this cutting-edge program is making a critical difference in the search for better treatments and the cure.

An NIH-Funded Research Success Story: The CCM Program Project Grant

The National Institutes of Health (NIH) occasionally provides Program Project Grants (PPGs), for a team of researchers, often from different institutions, to work together to perform research that could not be accomplished in one laboratory. The goal is to create a team that can make progress towards understanding disease, with each laboratory bringing their unique expertise to the project.

Some years ago, Drs. Douglas Marchuk (Duke University), Issam Awad (University of Chicago), Mark Ginsberg (University of California at San Diego), and Mark Kahn (University of Pennsylvania) wrote an NIH PPG proposal that was funded for 5 years, and which was competitively renewed for another 5 years.

Over the years, our research team has made seminal discoveries on CCM pathogenesis, some of which are leading to new approaches to treatment. Recently, our team's NIH Program Officer Dr. James Koenig, who recently retired from NIH, told us that our PPG was one of the most successful grants he had seen in his decades-long career as an NIH official.

Some of the important discoveries made by our team that are leading to new avenues for CCM therapy include:

- the role of somatic mutations in CCM disease, in particular in the gene for the signaling protein PI3 kinase, which is currently leading to novel approaches for CCM therapy including the use of rapamycin and alpelisib,
- the importance of Rho kinase signaling in CCM disease, which has led to the current clinical trials of statins and ROCK inhibitors like NRL-1049 and OV-888 for CCM disease,
- the role of the gut microbiome in promoting CCM growth, leading to further studies on gut health in CCM disease,
- the role of another signaling protein, beta-adrenergic receptors, in CCM disease, leading to clinical trials of propranolol and other beta-adrenergic receptor antagonists for CCM therapy,
- the role of hypoxia (low oxygen levels) in the development of CCM lesions, leading to studies to determine if sleep apnea plays a role in CCM disease.



Another important metric of success of an NIH PPG is to train the next generation of scientists, with the hope that they will continue research on the disease under study. In this endeavor, our PPG was also very successful, with dozens of graduate students and postdoctoral fellows across all four institutions who worked on these collaborative studies and who have gone on to the next stages in their careers. In particular, through this award, Dr. Miguel Lopez Ramirez (UC San Diego) furthered his training and was recently awarded his own NIH grant on CCM pathobiology, with an emphasis on the role of hypoxia (low oxygen levels) and neuroinflammation in CCM pathology.

We are grateful to the NIH for the funding to carry out this work, and especially to the Alliance to Cure Cavernous Malformations for their continued support of our research team. Unfortunately, our NIH PPG award ends on May 31, 2025. NIH PPG awards are only renewable once, so our collaborative team that has worked together so successfully for the past decade cannot reapply again for funding. Individually, each of us has written NIH grant proposals on CCM that we hope will be funded in the future. However, there is some concern about the future of NIH-funded research.

Although for many decades the NIH has enjoyed bipartisan support of their mission to improve the health of our nation, the NIH is now under onslaught. We encourage all of you to contact your congressional representatives and ask them to continue to support the mission of NIH, especially with continued support for research on CCM.

Douglas Marchuk, Chair, Alliance to Cure Cavernous Malformation Scientific Advisory Board

The CCM CARE Act of 2025 has been drafted by Senator Ben Ray Lujan's office and is seeking co-sponsors in the Senate. The legislation calls for increased funding for CCM research at the National Institutes of Health, accelerated pathways to treatment approval at the Food and Drug Administration, and better tracking of disease incidence at the Centers for Disease Control. Look for more information soon on social media and our website.

Honoring Karen Asbury Buck for her 17 years of service

In 2007, Karen Asbury Buck invited Connie Lee to lunch as a welcome to the greater Norfolk, Virginia area. Karen had a husband and daughter affected by CCM and shared her interest in helping the Alliance find solutions. By the time lunch was finished, Karen had agreed to become the organization's Treasurer.

Karen, with the help she solicited from her family, has offered so much to our cause. For example, in the early days, Karen's family stuffed our quarterly newsletters into envelopes and stored our materials in their garage. In addition to Treasurer, Karen has served as bookkeeper, human resources department, and chief financial officer all in one package. In the meantime, she lost her husband to a CCM-related condition and gained a CCM-affected grandson. We are forever grateful to Karen for her commitment to our organization and all we serve.

Karen stepped down on March 1 after 17 years of service. She has always had a soft spot for our children who face the challenges of living with this disease, and we hope to honor her by giving her a metaphorical opportunity to hug each child affected by CCM. In honor of Karen, our new program Karen's Kuddles provides a free teddy bear to children affected by CCM who are struggling with their diagnosis. These special bears are a small but meaningful way to remind children that they are not alone.

If your child could use a little extra comfort, request a bear by sending your child's name and mailing address to Linda Fuchser at linda@alliancetocure.org.

Thank you, Karen!



Recursion Announces Promising Clinical Data on Lead AI-Based Drug Candidate for Brain Disease

Cerebral cavernous malformation (CCM) patients treated with oral drug, REC-994, showed reduction in total cerebral and brainstem lesion volume.

On February 5, Recursion announced favorable efficacy data in the Phase II trial for REC-994, the company's lead AI-derived candidate to treat the potentially fatal brain disease, cerebral cavernous malformation (CCM), in a late-breaking presentation at the International Stroke Conference (ISC) held in Los Angeles.

According to the results of the 62-person Phase II study, 50% of patients with cerebral lesions on the highest dose of REC-994 (400 mg) showed reduction in total lesion volume compared to 28% of patients on the placebo after 12 months of treatment. Patients on the lower dose of REC-994 (200 mg) had similar changes in lesion volume compared to placebo. Similar trends were seen in patients with brainstem lesions, a population with high unmet need as cavernomas located in the brainstem are not amenable to surgical intervention.

Additionally, the modified Rankin Scale, which is widely recognized and approved by the U.S. Food and Drug Administration (FDA) to assess functional outcomes in acute stroke trials, indicated positive trends in patients on the 400 mg arm.

"My co-investigators and I are encouraged by these initial findings and we look forward to continued work with Recursion on the REC-994 program," said Jan-Karl Burkhardt, MD, division head, cerebrovascular surgery at University of Pennsylvania and principal investigator of the study.

CCM is caused by gene mutations that impact redox homeostasis. Specifically, loss-of-function mutations activate pathways associated with downstream elevation in reactive oxygen species (ROS). REC-994 is a redox-cycling nitroxide compound and free-radical scavenger that is hypothesized to treat CCMs through a reduction in ROS.

Najat Khan, PhD, chief R&D officer and chief commercial officer at Recursion, emphasized that these data are particularly relevant as CCM lesion volume and CCM brainstem location are among the top predictors of re-hemorrhage risk.

"These preliminary results show promising MRI-based and functional outcome signals, and we look forward to continued discussions with the FDA, and

the CCM scientific and patient communities on next steps," Khan told GEN.

CCM impacts approximately 360,000 symptomatic individuals in the U.S. and EU. Connie Lee, PsyD, CEO of the patient advocacy group, the Alliance to Cure Cavernous Malformation, and Amy Akers, PhD, the organization's CSO, concurred that Recursion's phase II data show "tremendous progress in the research space and provide hope for our community."

"With no approved therapy and brain surgery as an option for only a subset of the population, CCM patients frequently face stepwise decline from the oozing and growth of cavernous malformation lesions. We look forward to working with Recursion and regulatory agencies to continue this momentum on our path to better treatments," Lee told GEN.

First-in-disease challenge

Recursion CEO Chris Gibson, PhD, said REC-994 originated from his graduate school work at the University of Utah in the lab of Dean Li, MD, PhD. (Li is now executive vice president and president, Merck Research Labs.) Leveraging open-source software developed by Anne Carpenter, PhD, who is now senior director of the Imaging Platform at the Broad Institute, Gibson used AI-based imaging screens of healthy and diseased cells to identify REC-994.

"After that work, I said, 'Well, let's go start a company and try and do this for many other diseases.' And after a couple of years of building the platform, we went back to the university and licensed the know-how around REC-994 as one of our first candidates," Gibson told GEN Edge last September.

"The challenge of being first in disease is, it's an exciting opportunity to make an impact for patients. It also means that there's an increased burden to not only prove out the molecule, but the path itself towards the treatment."

Fay Lin, PhD. Excerpted from Genetic Engineering and Biotechnology News, February 5, 2025.

The Alliance to Cure Cavernous Malformation hosted Recursion CEO Chris Gibson in a webinar in which he presented detailed results of the Phase 2 trial. A recording is now available on our YouTube channel.



Recursion

Patient Profile: My Cavernous Malformation Story

In June 2020, I woke up and could not walk straight. I bumped into the wall, had numbness in my face, my senses of taste and smell were off, and my peripheral vision was affected. I bit my tongue and lip chewing because my natural reflex to avoid doing so did not work. An MRI revealed I had cavernous malformations throughout my brain, including one on my brainstem that had bled and caused my symptoms.

There was no treatment for my bleed, so I weathered several months of constantly veering left when walking, having pronounced headaches, and being unable to walk downstairs to my office without spilling my cup of tea. During the subsequent six months most of the symptoms resolved.

I found out my uncle had this disease decades ago. In his 70s, when he couldn't take the headaches any longer, he elected to have a high-risk surgery to remove the problematic malformation on his brainstem. He survived the surgery, but he never regained the ability to swallow and, for the remainder of his life, fed himself through a feeding tube.

Oddly, in our family only three men have been diagnosed with CCM, all in our 60s. I was diagnosed at

62. At roughly the same time my brother was diagnosed at age 67. Luckily, he has not had serious symptoms. Even though our CCM is clearly familial, we test negative for CCM 1, CCM2, and CCM 3 mutations.

Finding the Alliance to Cure Cavernous Malformation was a blessing. The group gave me perspective on the widely varying symptoms and their severity, and provided sources of information to help me understand this disease.

My condition was stable for 4 years. At the end of 2023, we spent the holidays in California. On Saturday, December 30, 2023, I boarded a plane on the first leg of our trip home to Boston. During the first flight, I started to feel something was wrong with my legs. When we arrived at our layover, I had difficulty getting off the plane and had to use a roll-board suitcase for support. Getting to the next gate was a difficult, long walk. With things progressing so quickly, I was concerned that I might not be permitted to board the second flight. During the second flight my condition progressively worsened. In Boston, I managed to get off the plane, again using the roll-board as a crutch, but needed a wheelchair to get to the car. We went straight to Massachusetts General Hospital (MGH), where I was helped into a wheelchair. That is the last time I stood up.

At MGH, my diagnosis of a cavernous malformation bleed on my spinal cord was confirmed. By Monday, 2 days after getting on the first plane, I was completely paralyzed from the waist down. I spent all of January and February at MGH and Spaulding Rehabilitation Hospital, returning home on March 6, 2024.

My wife and I are adjusting to our new life with me in a wheelchair. I still have CCM lesions throughout my brain, and we live with the prospect that additional bleeds could cause further symptoms.

I am choosing to fight back. Last fall I was honored to be asked to join the Board of the Alliance, and I have embraced raising awareness and funds for our mission. I am eager to see our research initiatives flourish.

John Andres



Board of Directors Updates

We are pleased to announce three new members of our Board of Directors:

John Andres is an attorney with over thirty years of experience in the medical device industry. He is a private consultant, specializing in patent/business strategy development and execution. He also is a partner of Hawk Healthcare, LLC, which provides strategic transaction management to private individuals and companies. John is a member of the Board of Directors of Longevity Neuro Solutions, LLC, which develops and sells implant products for cranial reconstruction. In the non-profit sector, John was a member of the Executive Board of the Connecticut Yankee Council of the Boy Scouts of America from 2000 until 2012 and of The Spirit of Adventure Council from 2021-2024.

John shares his connection to CCM in this newsletter edition's Patient Profile.



Ken Brevoort is an economist with 25 years of experience working on financial issues. He is a Principal Economist at the Federal Reserve Board in Washington, DC., where his work focuses on credit access, credit risk, and related banking

issues. Previously, he held positions at the Consumer Financial Protection Bureau and the Office of Homeownership Preservation in the U.S. Treasury Department. Ken has maintained an active research agenda throughout his career, authoring over 30 research papers and peer-reviewed journal articles. He received his Ph.D. in Economics from The Ohio State University. Ken's involvement with the Alliance to Cure Cavernous Malformation began in 2020 when a family member was diagnosed with CCM1. He is deeply committed to helping find treatments and, ultimately, a cure for cavernous malformations.

We are delighted that Ken has joined our board as Treasurer.



Joseph Zabramski, MD, is an emeritus neurosurgeon and research investigator in the Barrow Aneurysm and AVM Research Center at Barrow Neurological Institute. He is also co-director of the Barrow's CCM

Center of Excellence. As an Alliance to Cure Board member, Dr. Zabramski serves as a medical advisor.

In 1994, Dr. Zabramski created a grading system for cavernous malformations which has come to be called the Zabramski classification. The system characterizes lesions as Types I through IV based on MRI characteristics. Zabramski criteria are widely used in research and have also been validated clinically as a useful tool for surgical decision-making (see reference below.)

Wang, J., Yu, Q., Huo, R., Sun, Y., Jiao, Y., Xu, H., Zhang, J., Zhao, S., He, Q., Wang, S., Zhao, J., & Cao, Y. (2024). Zabramski classification in predicting the occurrence of symptomatic intracerebral hemorrhage in sporadic cerebral cavernous malformations. *Journal of Neurosurgery*, 140(3), 792-799. doi.org/10.3171/2023.7.JNS231069.

In case you missed it...

Check out the latest webinar recordings on our YouTube channel, [youtube.com/@AngiomaAlliance](https://www.youtube.com/@AngiomaAlliance).

- REC-994 Trial Results with Recursion CEO Chris Gibson
- Updates to the CCM Clinical Care Consensus Guidelines and Atorvastatin Trial Results with Dr. Issam Awad
- Healing from CCM Medical Trauma with Sasha McBain
- Our CCM Cure Roadmap with Amy Akers and Connie Lee

To receive regular email updates about research, webinars, and events, go to:

www.alliancetocure.org/sign-up-for-updates/

Events



JUNE 2025
CAVERNOUS MALFORMATION
AWARENESS MONTH

Strides to cure CCM
June 1st - June 30th

www.alliancetocure.org



HOLY SMOKIN' BAR-B-QUE BASH
2025

Be a spark for a brighter future!

Que up the *band*, fire up the *bar-b-que*, load the *auction*, stock the *bar*, and pour the *bourbon* - Then settle in for a magical night under the stars.

Please join us in supporting ground breaking research that aims to ease the burden of brain diseases, disorders and injuries...including the rare condition that our sweet Elle bravely faces each day.

May 1, 2025
4th Annual
Holy Smokin' Bar-B-Que Bash
The Cathedral of St. Philip, Atlanta, GA
7:00pm

Celebrate, Support, Cure!
Benefiting
Alliance to Cure Cavernous Malformation & Emory Brain Health Center

Info & Tickets




2025 CCM PATIENT, FAMILY & PROVIDER CONFERENCE

OPEN TO ANYONE WHO WOULD LIKE TO LEARN MORE ABOUT CAVERNOUS MALFORMATION

JUNE 14, 2025 / 10AM-3PM
UNM DOMENICI CENTER
1001 Stanford Dr. NE Second Floor
Albuquerque, NM 87106

Save your spot by scanning the QR code to register.
<https://forms.office.com/r/fntaep1F53>
Need assistance, email CCMIinfo@salud.unm.edu



First Annual
STANFORD CAVERNOUS MALFORMATION PATIENT PICNIC

The Stanford Center of Excellence for Cavernous Malformation invites all individuals and families affected by CCM to a picnic lunch

SATURDAY, MAY 3, 2025
1-4 p.m.
SHORELINE LAKESIDE CAFE
MOUNTAIN VIEW, CA

RSVP by April 15 by scanning the QR code or email linda@alliancetocure.org

Stanford **ALLIANCE TO CURE**
CENTRE OF EXCELLENCE CAVERNOUS MALFORMATION



SWINGING FOR A CURE CHARITY GOLF TOURNAMENT
15 MAY 2025
TWIN OAKS GOLF COURSE
SAN MARCOS, CA
1 pm Shotgun start
11 am Check-in

MONDAY, JUNE 9, 2025
CHIP-IN FOR A CURE GOLF SCRAMBLE
PB DYE GOLF CLUB
9526 DR PERRY RD
IJAMSVILLE, MD 21754
Check-in: 8:00am
Shotgun start 9:30am

Register Here
Questions: Linda@alliancetocure.org

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 in the enclosed envelope 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 angioma 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, the media, 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 Alliances, our upcoming Patient-Expert Certification, legislative advocacy, and public events.

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. Our mission is to drive a cure and improve lives for all affected by cavernous malformation. We envision a world with a permanent cure for cavernous malformation – available, accessible, and affordable for all. 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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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@angioma.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.