



# ANGIOMA ALLIANCE NEWSLETTER

because brains shouldn't bleed

## Join Us: Celebrate Together for a Cure

On August 29, we'll be celebrating together around the country. We celebrate being together again. We celebrate the launch of the first clinical trial of a medicine specific to CCM (see page 3). And we celebrate the opportunity to accelerate the cure. We are organizing an unprecedented event with more than 50 host sites. Each party will be different, but each will share live streamed video content allowing us to celebrate from the East coast to the West coast simultaneously. Our event will include updates from researchers, patient stories, and an important update on why this is a key moment in our search for the cure.

Please join us as a host or attendee! There are numerous fun events in the works – a tequila tasting/pool party, a fishing contest/Texas BBQ, a lakeside wine-tasting, and more. Something is happening near you, or we can help you create your own party. Events can be as large or small as you like and require only an internet connection and a screen. We'll assist you with planning and will find other members in your area if you would like to open your party. If you aren't comfortable with a large event, please use the opportunity to celebrate with your loved ones at home, but be sure to let us know. More information is on our website: [www.angioma.org/ways-to-give/celebrate-together-for-a-cure-2021/](http://www.angioma.org/ways-to-give/celebrate-together-for-a-cure-2021/)

**What does the cure look like?** The cure means that the parent with a brainstem cavernous angioma will know that they'll always be there for their kids. The child with CCM will not face the trauma of brain surgery or endure lifelong disability. Families with hereditary CCM will not pass the illness to their children. Cavernous angioma lesions will no longer hemorrhage or cause seizures. They will disappear and not come back.

We've come a long way on the path to a cure. We have researchers who have identified numerous treatment candidates, many of which have already been tested in animals. We have thousands of members joined in a community, united and motivated.

CCM is a solvable problem, and we know exactly what is needed for better treatments and a cure. In addition to continuing to grow our communities, we will identify the most promising of the many treatment candidates that exist. We'll find good companies and advocate for them to choose CCM as the disease for their drug in development. Currently, in addition to supporting the companies with trials already planned, we are in talks with other companies that are working to solve the PIK3CA inhibition problem, that are working out how to remove hemosiderin from brain tissue, and that are exploring gene therapy for CCM. We are supporting focused ultrasound research and looking for ways to move microRNA-based treatment to CCM. There is much promise and hope during this exciting time.

**How are we doing this?** To start, we have hired an Industry Relations Director Dr. Jianbo Hu, a PhD scientist with a background in moving treatments from academic labs to industry (see page 6). He has already been reaching out to researchers and companies to form relationships. He has also been identifying the places where one or more pieces are still needed to bridge a gap and where we may need to fund the last experiment or animal model that will help a company feel comfortable taking us on. Soon, we will have a roadmap that will move us forward at breakneck speed. This work is cutting-edge and revolutionary. And it is how we will get our cure.

Today, we're at a tipping point, we have momentum, and together, we can reach our goal. Our goal is to raise an additional \$500,000 over 3 years so children and adults can remain productive and independent and able to raise families, living full, long, and happy lives. On August 29, we will celebrate being together and we will also celebrate the opportunity to accelerate the cure for CCM. Even if you've already given this year, we ask that you consider giving again—and giving generously—for this very special effort.

We are the only ones who can do this.

*Connie Lee*



**ANGIOMA ALLIANCE**  
because brains shouldn't bleed  
Angioma.org

**Celebrate Together for  
a Cure**

**August 29th, 2021**

**Are you ready to be part of  
something bigger?**

Imagine! On August 29, 2021, more than 50 parties taking place simultaneously around the country, all celebrating the promise of a cure.

Why now? We have missed each other! And we're on the cusp of something big. Our treatment pipeline is full, and we're ready to accelerate a cure. You can make this happen.

Perhaps you'd like to celebrate in a small way with family and friends; that's great! Maybe you are up for something bigger that includes other Angioma Alliance members near you; even better! We will have streamed video with words from doctors, patients, and Angioma Alliance for you to share during your event. We will even have a chance for your party to hop onscreen to say hi to all the other parties!

Get more information about parties near you and about hosting your own party on our website at [www.angioma.org/ways-to-give/celebrate-together-for-a-cure-2021/](http://www.angioma.org/ways-to-give/celebrate-together-for-a-cure-2021/)

Our heartfelt thanks to the many generous sponsors of this event who are featured in this newsletter.

**Please join us for one day, one celebration, to accelerate the cure.  
Because brains shouldn't bleed.**

## Breaking News: Launch of Recursion's REC-994 Phase 2 Trial for CCM

### First Trial of a Medicine Specifically for CCM patients



On September 30, please join us for an exciting webinar with Dr. Lisa Boyette, Recursion's Senior Director of Medical Affairs, who will be sharing details of the new REC-994 trial for cavernous angioma (CCM) which is poised to begin this fall.

REC-994 is the first industry-sponsored medicine to reach trials for our families, and we are thrilled to share news of the Phase 2 launch with our community. Dr. Boyette will provide an overview of clinical trials in general and will offer specifics of the REC-994 trial, including the nature of the medicine, where the first sites will be, and who and how many will be eligible to participate.

REC-994 has completed Phase 1 trials in which healthy individuals tried various doses of the medicine to insure it is safe. The Phase 2 trial will be the first trial that includes cavernous angioma (CCM) patients.

Recursion is also using this trial to continue validating the CCM Health Index, a survey that measures changes in a patient's quality of life as reported by the patient. Once validated and qualified by FDA, this tool can be used in other CCM research to measure efficacy of treatments.

To register for the REC-994 Phase 2 Launch webinar, please visit [bit.ly/REC994Webinar](https://bit.ly/REC994Webinar).



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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 an Angioma Alliance-designated Clinical Center of Excellence. Find out how UChicago Medicine's neurology and neurosurgery teams are fighting for patients at [UChicagoMedicine.org/ccm](https://UChicagoMedicine.org/ccm).



AT THE FOREFRONT

**UChicago Medicine**

## Upcoming Events

Our Celebrate Together for a Cure event is just the start!

### Torrington Wine Tasting

On September 17, please join us for the 7th annual Wine Tasting for Angioma Alliance at the Torrington County Club in West Goshen, Connecticut. The wine tasting will feature more than a dozen vendors with tastings of wine, craft beer, and specialty chocolates. Tickets are \$35 and can be purchased at the door. Tickets to the VIP room where you can sample fine liquors are \$50. The DeMichiel and Ponte families are hoping you'll be there!

### Orange County Walk/Run

On September 19, please join us at the 5th Annual Orange County 5K Walk/Run being held at Florence Joyner Olympiad Park in Mission Viejo, California. This year's theme is "Say I Won't," and the morning will feature the company of friends and family, food, raffle, silent auction, and good old family fun! Registration is free, but if you raise or donate \$30 or more, you'll receive a 2021 Angioma Alliance Resilient t-shirt. Register at [give.classy.org/ocangioma](http://give.classy.org/ocangioma).

## Call for research participants: Texas Tech El Paso

Texas Tech University Health Sciences Center El Paso has begun a project to identify the genetic factors that cause cerebral cavernous malformations (CCMs) and validate new potential blood biomarkers for early detection. They are seeking to recruit Hispanic CCM patients to donate a blood sample and clinical data. Blood biomarkers will allow us to predict whether a patient is at risk for hemorrhage soon, making it easier to decide who is most in need of treatments.

More information about how you can participate can be found on the Texas Tech website at: [elpaso.ttuhs.c.edu/research/ccm-survey.aspx](http://elpaso.ttuhs.c.edu/research/ccm-survey.aspx).

## Watch our Webinars

Angioma Alliance hosts educational webinars monthly, usually on the last Thursday of the month. Each webinar offers the opportunity to ask questions of leading CCM research and clinical experts. Recent events included:

- Dr. Jan-Karl Burkhardt, University of Pennsylvania: CCM Clinical Decision-making
- Dr. Issam Awad, University of Chicago: Rapamycin, Atorvastatin, Biomarkers and more
- Dr. Mark Kahn, University of Pennsylvania, and Dr. Doug Marchuk: PIK3CA Mutation and CCM
- Dr. Anuska Andjelkovic-Zochowski, University of Michigan: Solving the Problem of a Leaky Lesion
- Dr. Connie Lee, Angioma Alliance: CCM Genetics and You

These and previous webinars are available, with closed captioning, on our YouTube channel at [youtube.com/AngiomaAlliance](http://youtube.com/AngiomaAlliance).

## Find our Support Groups

We are now hosting five regular Zoom meetings to offer support and information to our members. Time and registration information for our groups can be found on our online calendar at [www.angioma.org/calendar/](http://www.angioma.org/calendar/).

**Support Group:** Every Thursday, our general discussion support group is open to all members.

**CCM-101:** The first Thursday of every month, we host a session for newly diagnosed members in which we review CCM basics and answer questions.

**Parents group:** The third Thursday of each month, we host a breakout group for parents of children affected by CCM.

**Black CCM Patients:** Every second Wednesday, our Black CCM patients meet for conversation and support. These groups will often feature special guest speakers.

**Teens/Young Adults:** The first Tuesday of every month, we host a social group for teens and young adults that includes games and lots of laughs. Young people age 13+ affected by CCM and their siblings are welcome.

You can also find support in one of our many Facebook groups. Our largest group is at [www.facebook.com/groups/AngiomaAlliance](http://www.facebook.com/groups/AngiomaAlliance).

**Angioma Alliance Thanks our  
Celebrate Together for a Cure Sponsors!**



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## Angioma Alliance Hires Industry Relations Director



We are thrilled to announce that Dr. Jianbo Hu has joined Angioma Alliance as our full-time Industry Relations Director. In this brand-new position, he will be dedicated to moving promising treatments to clinical trials.

Specifically, he will be consolidating the information we have about CCM, our patients' journeys, our treatment pipeline, and clinical trial structure into a single document that will provide a roadmap for researchers and potential industry partners. He will be reaching out to industry, including companies that are not yet familiar with CCM, to educate and advocate for our condition as a treatment target. Dr. Hu will be working closely with Dr. Amy Akers, our Chief Scientific Officer, Dr. Connie Lee, and our Scientific Advisory Board to accelerate the cure.

Dr. Hu has over twelve years of experience in technology development, translation, and commercialization. Prior to joining Angioma Alliance as Industry Relations Director, he served as Thomas Jefferson University's Associate Director of Technology Licensing. He was a senior technology licensing officer at Penn State University where he independently managed all aspects of the College of Medicine's technology transfer needs. Prior to his Penn State position, Dr. Hu was an intellectual property and commercialization specialist and a co-manager for Oregon State University's venture development fund. He obtained his Ph.D. in Physiology from Washington State University.

You can reach Dr. Hu at [jianbo.hu@angioma.org](mailto:jianbo.hu@angioma.org).



## Breaking Barriers for Black Health Empowerment



This year, Angioma Alliance launched a new initiative to find and engage Black CCM patients. Our Health Equity Program and Outreach Specialist Jessica Biggs has been busy developing the program. Funded by Julian Grace Foundation and Global Genes, Breaking Barriers for Black Health Empowerment is off to a great start. So far, we have a dedicated Facebook group and bi-weekly Zoom support group. We have been interviewing members, one-on-one as part of a study to understand challenges in diagnosis and care for Black patients. We are in the beginning stages of creating a "Second Look" program with the intent of bringing Black neurologists and neurosurgeons into the CCM fold. Additionally, Jessica has participated as a panelist or moderator in several awareness-raising events, and she serves on work groups organized by larger health organizations. Shortly, we should begin seeing national coverage of CCM because of our public relations outreach.

We are learning some surprising things. For example, because of a conversation in support group that was followed by a question to an expert dermatologist, Dr. Barrett Zlotoff who saw many of our patients in New Mexico, we learned that there are no pictures of the skin vascular lesions that are common to familial CCM on Black skin. In other words, if a doctor sees a Black patient with familial CCM who has a skin lesion, there is nowhere the doctor can look to find a comparison picture to identify the lesion; they do not exist in the medical literature. We will be working with Dr. Zlotoff to correct this.

We are excited to see the program get off the ground and are looking forward to the work ahead.

## Rho Kinase Inhibitor BA-1049 Moving Forward for CCM

The medicine being developed by BioAxone to treat CCM has been licensed to the San Diego-based biotech company Neurelis to move forward to trials. Neurelis intends to file an investigational new drug application with FDA in 2022. We will have another trial and another potential treatment!

Dr. Connie Lee, President and CEO of the Angioma Alliance, stated, "We are so pleased to learn that BioAxone Biosciences has partnered with Neurelis to advance BA-1049 development forward to provide hope for patients with CCM. BA-1049 has shown great promise in preclinical experiments completed in collaboration with our research community. It has been our dream to see BA-1049 and other pre-clinical stage assets advance to clinical trials, an important milestone in the path for potential regulatory approvals and the marketplace for patients who are waiting for life altering therapies."

BA-1049 is a Rho kinase inhibitor like fasudil and is more targeted than atorvastatin, the statin drug

currently in a clinical trial for cavernous angioma with symptomatic hemorrhage (CASH) at the University of Chicago.

Angioma Alliance played a large role in the development of this drug by bringing CCM to the attention of BioAxone, connecting the company with our academic labs, and supporting their efforts to license the medicine to a larger company. Since BA-1049 has shown an effect in mice bred with CCM mutations, the next step for the medicine will be filing an investigational new drug application with FDA and moving to Phase I trials, in which healthy individuals take the medicine to make sure it is safe. Neurelis has the capacity to move the drug forward in this way. If Phase 1 trials are successful, a Phase 2 trial can test safety of the medicine in our patients. We look forward to seeing BA-1049 advance and potentially to offer a non-surgical option to our patients.

Read the BioAxone/Angioma Alliance statement here: [bit.ly/BioAxoneCCM](https://bit.ly/BioAxoneCCM)

Read the Neurelis statement here: [bit.ly/NeurelisCCM](https://bit.ly/NeurelisCCM).



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## **UVA Recognized as CCM Center of Excellence**

Angioma Alliance is pleased to announce that we are recognizing the University of Virginia Health System as a CCM Center of Excellence. UVA was first recognized as a CCM Clinical Center in 2018, a designation that indicates they provide integrated, expert multi-disciplinary care for CCM patients.



Under the leadership of Medical Director Dr. Min Park, UVA Health System now meets the additional criteria required for CCM Center of Excellence status.

Specifically:

- UVA is now seeing 100+ CCM patients each year.
- They have an active research program that is working on several projects, including testing focused ultrasound as a potential treatment, developing new ways of using mice to measure the efficacy of treatments, and analyzing their clinical database to understand better the factors that lead to better or worse patient outcomes.

- They have added two additional faculty to the CCM program, Dr. Erika Axeen, a pediatric neurologist, and Dr. Nancy Vilar, a neuro-ophthalmologist.

The UVA Center of Excellence page on our website ([bit.ly/UVA-CCM-COE](https://bit.ly/UVA-CCM-COE)) has a complete list of their faculty as well as contact and local lodging information.

Congratulations to UVA!

***Recursion Pharmaceuticals offers best wishes for a successful event!***



**RECURSION**  
p h a r m a c e u t i c a l s

## **New Research: Cancer-linked mutation accelerates growth of CCM lesions**

CCM lesions develop when blood vessel cells (endothelial cells) lose the function for one of the CCM genes. New research shows us that, for lesions that are actively growing and causing symptoms, the endothelial cells also have acquired mutations in a common cancer-causing gene called PIK3CA. This discovery adds to the body of knowledge related to CCM biology and identifies a new target for treatment and a possible class of medicine.

PIK3CA is a gene commonly mutated in cancers. Gain-of-function mutations turn on the gene, sending it into overdrive to stimulate cell proliferation and growth.

The PIK3CA mutation found in aggressive CCM lesions is a somatic mutation. These mutations develop by chance in cells of the body (not sperm or eggs). They are not inherited, nor can they be passed on to the next generation.

In the new study, *Pik3Ca And Ccm Mutations Fuel Cavemomas Through a Cancer-Like Mechanism*, published in the prestigious journal *Nature*, we learn that somatic mutations in genes other than the CCM genes play an essential role in CCM lesion growth. This is true in both sporadic and familial forms of CCM disease.

The consortium research team from the University of Pennsylvania, Duke, and the University of Chicago carefully studied the genetics of individual endothelial cells from lesions. In both sporadic and familial cases, they discovered a proportion of the samples where some of the blood vessel cells had as many as three somatic mutations. The mutations included loss-of-function mutations in both copies of the CCM gene and a gain-of-function mutation in PIK3CA.

The activation of PIK3CA is biologically relevant because it stimulates growth through a signaling network (a network of molecules that interact with each other). That network includes another molecule, called mTor, which is a key component of cell metabolism and growth. When the network is disturbed by PIK3CA activation, mTor becomes misregulated, too. The resulting change in signaling contributes to cancer, overgrowth syndromes, and metabolic and autoimmune disorders.

mTor is overactive in CCM lesions and contributes to the rapid clonal expansion and cancer-like growth of these lesions. Although the growth of an individual lesion is cancer-like, CCM lesions do not metastasize and spread the way malignant cancers do.

Interestingly, mTor is also overactive in other vascular and lymphatic malformations that already have treatments. Specifically, the FDA-approved drug rapamycin (sirolimus) targets mTor and blocks its activity.

Using mouse models, the study team showed that rapamycin treatment decreases lesion numbers in the acute neonatal model and inhibits lesion growth in mature CCMs. These findings suggest that rapamycin or another drug in its class may become a treatment for fast-growing lesions, those that are known to most commonly cause stroke, seizure and are associated with hemorrhage.

According to Mark Kahn, MD, senior author of this study: “By discovering that most aggressive, surgical CCMs harbor gain of function PIK3CA mutations and that we can prevent CCM growth by blocking that pathway, we think we have identified a mechanism that is truly druggable. Rapamycin and similar drugs that block mTORC1 are already FDA approved and this pathway is already a big target for cancer drugs that can be potentially also applied to CCM disease. In comparison with some of our other recent findings, e.g., the microbiome, I think this has more direct and more rapid translation to the clinic.”

New technologies and technique refinement are helping to accelerate the field of somatic cell genetic research, particularly at the single-cell level. In a related study, a Chinese research team found somatic mutations in CCM1, CCM3, PIK3CA, and in MAP3K3. MAP3K3 is a known player in CCM signaling, and the authors suggest the additional somatic mutation may contribute to the clinical variability between individuals affected by CCM. It remains to be seen how many other genes may harbor somatic mutations and contribute to CCM lesion development, growth, and/or activity.

### **References**

<https://pubmed.ncbi.nlm.nih.gov/33910229/>  
<https://pubmed.ncbi.nlm.nih.gov/33891857/>

## A Father's Story

In 2006, we held a conference in Santa Fe, New Mexico, in the ballroom of the historic Spanish Colonial Hilton hotel. We had been listening to expert speakers for a very full morning. This was our largest conference ever and the ballroom was packed and standing-room only.

I was the emcee, about to adjourn the meeting for lunch. Tim Gallegos, a small man in his 30s, stepped out of the audience and interrupted me, whispering that he wanted to say a few words. I knew Tim, but this was unexpected.

Tim took the microphone and turned to the crowd. He said, "We lost our 9-year-old daughter Jenae to cavernous angioma last year." The crowd hushed. "Jenae came home from the last day of school with symptoms of a stomach flu. By the time we and the local emergency room realized the cause was

brain hemorrhage, it was too late." I looked out and saw emotion flood the crowd.

But Tim hadn't stood up simply to tell his daughter's story. He turned to me, saying, "For the last few months, my family has been holding fundraisers for Angioma Alliance. We sold Frito pies. We had a bike-a-thon. We went door-to-door asking for donations." He handed me an envelope. "Here is the \$26,000 we raised. Please use it for research, to help all of our families." He gestured at crowd in the very full room.

Tim's faith in our work, his generosity, courage, and compassion for others in the audience who all faced the same possibility, overwhelmed me. This quiet father had taken it on himself to channel his grief into powerful action. He ended with, "If I, an average Joe, can fundraise, then anyone else can do it. I challenge every one of you to do something, anything at all. Together we can help make a difference."

Tim's fundraising supported the Angioma Alliance tissue and DNA bank. In fact, the first DNA samples were collected at that conference and included his wife and many of her affected family members. The DNA and tissue bank has supported the research of a dozen or more labs through the years, led to significant breakthroughs, and continues to do so today.

Through Tim, I was able to feel the weight of the mission of Angioma Alliance. The need to accelerate a cure is front and center for Tim, who now serves on our Board of Directors, and for me. We are at a place where we can see a cure in the not-too-distant future. If we work together, children and adults can be relieved of brain hemorrhage and seizure. They will no longer live with the fear of death or disability. They will remain productive and independent and able to raise families, living full, long, and happy lives.

Without our action, there is no end in sight. More parents will lose children. More children will lose parents. One in every 500 people will remain at risk for the devastation of brain hemorrhage. To me, it feels like we have no choice but to try as hard as we can.

*Connie Lee*



## Meet the Authors: Daniel Shapiro and Heather Rendulic

### Daniel Shapiro – The Thin Ledge



Please join us on August 3rd at 7 pm ET, 4 pm PT for a book chat with Daniel Shapiro, the author of *The Thin Ledge*. In his profoundly honest memoir, Daniel shares the reality of living through his wife's battle with

cavernous angioma. Dan's is a caregiver story and can offer insight to anyone whose life has been turned upside down by profound illness of a partner.

From his website: "Shapiro was a successful attorney in his early forties when his wife, Susan, suffered a brain bleed and a diagnosis that her future was uncertain. Stunned, and with three young children, the couple made the most of the few years that followed, before a massive second hemorrhage changed everything... Shapiro addresses the questions that people living through unspeakable tragedy may never mention, but almost always ask."

Register in advance: [bit.ly/Shapiro-ThinLedge](https://bit.ly/Shapiro-ThinLedge)

### Heather Rendulic - Headstrong



On August 13th at 7 pm ET, 4 pm PT, Heather Rendulic, author of *Headstrong* will share her story of overcoming 5 brain bleeds from a thalamic lesion and brain surgery at the age of 23. Heather firmly believes

we can overcome anything, and she hopes to inspire and motivate.

From her website: "Heather Rendulic wants to live in a world where everyone feels empowered when they face life's challenges. She knows how hard life can get. As a young stroke and brain surgery survivor, she learned the tools needed to become an overcomer. When she's not working as a Human Resources Professional, Heather is sharing her message of hope as a motivational speaker/mentor and sharing the art of finding beauty in the chaos."

Register for this meeting: [bit.ly/Heather-Headstrong](https://bit.ly/Heather-Headstrong)

Learning your child has a cavernous malformation can spark a million questions...

At Boston Children's Cerebrovascular Surgery and Interventions Center, we've got answers.

617-919-1379

[bostonchildrens.org/cvd](https://bostonchildrens.org/cvd)



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## 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.angioma.org/care-community/community/volunteer/](http://www.angioma.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.angioma.org](http://www.angioma.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@angioma.org](mailto:info@angioma.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 angioma 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 angioma, 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 Angioma Alliance



**ANGIOMA  
ALLIANCE**

Angioma Alliance is a non-profit, international, patient-directed health organization created by people affected by cerebral cavernous angiomas (also known as cavernous malformations or CCM). Our mission is to inform, support, and empower individuals affected by cavernous angioma and drive research for treatments and a cure. We are monitored closely in our educational efforts by a Scientific Advisory Board comprised of leading cerebrovascular neurosurgeons, neurogeneticists, and neurologists.

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A copy of the latest financial report, registration filed by this organization and a description of our programs and activities may be obtained by contacting us at: Angioma Alliance, 520 W 21st St STE G2-411, Norfolk, VA 23517, [info@angioma.org](mailto:info@angioma.org). If you are a resident of one of the following states, you may obtain financial information directly from the state agency.

- Florida – A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE, WITHIN THE STATES, 800-435-7352 (800-HELP-FLA) OR BY VISITING [www.800helpfla.com](http://www.800helpfla.com). REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL OR RECOMMENDATION BY THE STATE. Florida Registration CH20096
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- 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.