

# ANGIOMA ALLIANCE NEWSLETTER

because brains shouldn't bleed

## From Pandemic to Promise

Each year, Angioma Alliance members choose a theme word. At the beginning of 2021, they chose the word *Resilient*. Then, they showed us every day exactly what a resilient community looks like.

Our Accelerate the Cure Celebration provided an opportunity to see your resilience. We originally planned this late August celebration as a hybrid event with large gatherings all over the country. As the Delta wave crashed our parties, you made the shift to smaller, more intimate formats. We celebrated the opportunity to accelerate the cure together from coast to coast, with some of you even Zooming in to our live broadcast. Your participation was exceptional, raising \$200,000 and inspiring us to keep laser-focused on our goal of a cure by 2030. It is not an overstatement to say that we were brought to tears by your commitment to this community and by your generosity, which will change the future for our families. Look for upcoming news of another national celebration in 2022.

For the Angioma Alliance scientific community, the pandemic affected the year in multiple challenging ways. Our November International CCM Scientific Meeting was forced to transition from an in-person event to a hybrid event, and eventually to a fully virtual event, because the international travel ban was not lifted soon enough for our attendees. While we lost the intense discussions, networking, and community-building that an in-person event brings, we were relieved to find that important research has progressed and that the work presented in our 2021 virtual meeting offered critical new understandings. We look forward to sharing their insights as they are published over the next year, and our scientists look forward to coming together again in 2022.

This year also saw the publication of data from the University of Chicago/Mayo Clinic/Angioma Alliance CCM COVID-19 registry. This registry exists because you stepped up, even after serious illness, to share your experiences in order to help others. A peer-reviewed paper published in the *Journal of Stroke and*

*Cerebrovascular Diseases* indicated that, unfortunately, there is greater risk from COVID infection to those with CCM, particularly those with the sporadic form of the illness. As a result, a new Scientific Advisory Board statement was issued, describing this risk, and offering advice regarding vaccination (see page 10). While the news about CCM and COVID was not good, it helped many of us make decisions to improve our health outcomes.

Your participation will continue to have an impact. We have been working for several years on the CCM Health-Index, a survey specifically designed to measure the burden of disease each adult patient experiences. We are excited to announce that the final phase of development, a longitudinal study, has launched. Once finished, we should have an instrument that can be approved for use in clinical drug trials and other research (page 3). The CCM Health-Index longitudinal study is a year-long critical effort that needs 400 of you!

As we are now seeing the light at the end of the pandemic tunnel, we also are marching forward toward a cure for CCM. This year saw significant advances in clinical trials. There are now four medicines that are either in trials or on the cusp. Propranolol will finish a Phase I/II trial in Italy by the end of this year and should have results shortly after. Atorvastatin should complete enrollment of a Phase I/II trial at the University of Chicago by the end of the year. Recursion Pharmaceutical's REC-994 Phase II trial will open shortly (see page 4), and many of you will be eligible to participate. Finally, BA-1049 was licensed by Neurelis over the summer, and the company will be submitting an investigational new drug application to FDA in 2022, allowing the medicine to enter Phase I trials. Many other drugs are in the pipeline just waiting to move forward. The newly announced Chan Zuckerberg Initiative award (page 2) will offer huge support and hope to this process. The promise of 2022, our 20th anniversary year, is writ large.

Connie Lee

## Angioma Alliance Awarded \$600,000 Grant from the Chan Zuckerberg Initiative to Advance Rare Disease Research

### New Grants Support Organizations Prioritizing Diversity and Diagnosis in their Disease Areas

We are thrilled to share that Angioma Alliance has been announced as one of several patient-driven rare disease organizations that will join the Chan Zuckerberg Initiative (CZI) Rare As One Network and receive a \$200,000 award each year for the next three years. Funding from these grants will support Angioma Alliance's mission to inform, support, and mobilize those affected by cavernous angioma, and drive research for better treatments and a cure. Funding will also be used to advance the development of an international, patient-led collaborative research network surrounding cavernous angioma, strengthen organizational capacity, convene our community, and align patients and researchers towards shared priorities. Specific projects will be announced in the coming months.

Angioma Alliance seeks to reduce barriers to cavernous angioma (CCM) diagnosis and improve care in all settings, for all people. This generous grant award and the tools offered by CZI will allow us to create the infrastructure needed to advance research and accelerate the cure for CCM.

The Chan Zuckerberg Initiative announced \$12 million in funding to the 20 patient-led, rare disease advocacy organizations that are newly joining the Rare as One Network. These grants are part of CZI's Rare As One (RAO) Project, aimed at supporting and lifting up the work that patient communities are doing to drive progress in the fight against rare diseases. The Rare As One Project is committed to uniting rare disease patient advocates in their quest for cures.

## Chan Zuckerberg Initiative

### About the Chan Zuckerberg Initiative

The Chan Zuckerberg Initiative was founded in 2015 to help solve some of society's toughest challenges — from eradicating disease and improving education to addressing the needs of our local communities. Their mission is to build a more inclusive, just, and healthy future for everyone. For more information, please visit [www.chanzuckerberg.com](http://www.chanzuckerberg.com).



## News

### Volunteers Needed for CCM Health-Index Survey

We need 400 Angioma Alliance members with CCM to assist in the next phase of developing the CCM Health-Index by completing a 20-minute survey three times: now, in 6 months, and then again, in 12 months. The CCM Health-Index is the first CCM-specific tool to measure the impact of the illness on patients. Once completed, it may become one way that we measure whether a treatment is having an effect. Your participation is critical.

#### Longitudinal Evaluation of the Cerebral Cavernous Malformation Health-Index (CCM-HI) for Use in Future CCM Clinical Trials

**What:** The purpose of this study is to assess the ability of the Cerebral Cavernous Malformation Health-Index (CCM-HI) survey to measure patient-relevant changes in disease burden over time. This study is being conducted by Dr. Heatwole from the University of Rochester Department of Neurology. This study will take place over the course of one year. If you decide to participate, you will complete 3-4 surveys at baseline, 6 months, and 12 months. You will be asked to complete demographic information about yourself as well as answer questions about your symptomatic burden of CCM, your overall changes in health over time, and your preferences with using the surveys administered throughout this study.

**Who can participate:** Individuals with CCM, aged 18 and older.

**How to participate:** Interested participants may sign up at [redcap.link/ccm.health.index](https://redcap.link/ccm.health.index). This link will direct you to a web page with more information about this study. If you have any questions or comments, get in touch with the study coordinator, Jamison Seabury at [jamison.seabury@chert.rochester.edu](mailto:jamison.seabury@chert.rochester.edu) / 585-867-1461.

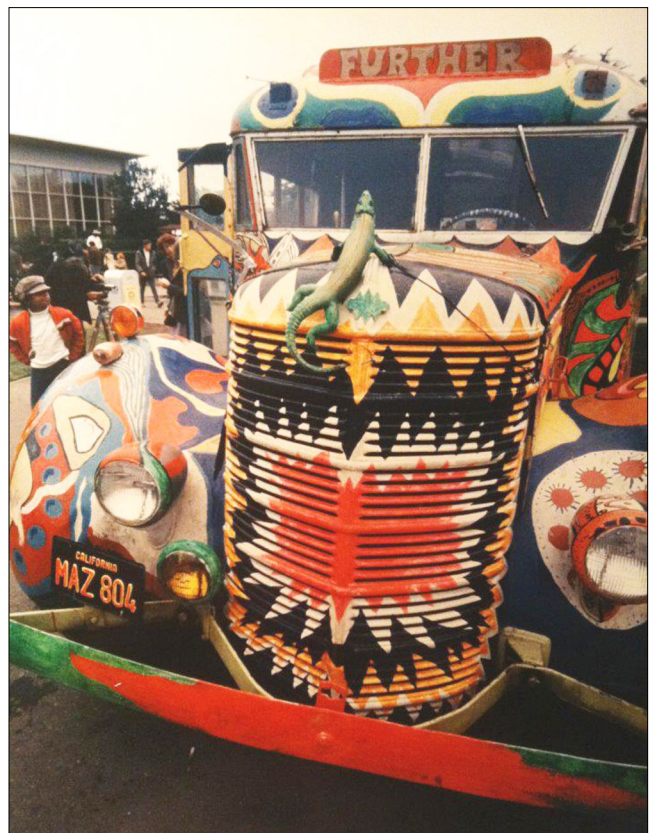
### 60s Party and Book Reading in San Francisco, February 5

Angioma Alliance Board member Isaac Babbs is throwing a San Francisco Bay area 60s Counter-Cultural Party/Literary Event. The event will feature Isaac's father, Ken Babbs, reading from his soon-to-be-published book "Cronies" on his escapades with Ken Kesey, Neal Cassady, and the Merry Pranksters. Stay tuned for ticket and location details on our social media and website.

In addition to the reading and the question/answer session, highlights include:

- Optional 60s attire
- Yummy food
- Silent Auction
- Groovy Photo Opportunities

Isaac's youngest son, Lukas, 23, has a cavernous angioma. Lukas had a stroke and is, fortunately, fully recovered but still lives with the disease.





## Recursion's REC-994 Phase 2 Trial Announced

We are excited to announce that it's time for Recursion Pharmaceutical's REC-994 to be tested in a limited number of CCM patients in a one-year Phase 2 trial. Recursion Pharmaceuticals is developing REC-994 specifically for the treatment of cerebral cavernous malformations. The medicine has successfully completed a Phase 1 trial in healthy adults. A Phase 2 trial is designed to test the safety of a medicine in our patients and to refine measurement tools that might be used in a larger trial.

As of this writing, the initial trial sites have not been announced, but we know there will be multiple sites in various regions of the US. As soon as the site list becomes available, we will be posting it on our website.

Inclusion and exclusion criteria for participation in the trial are posted on the [clinicaltrials.gov](https://clinicaltrials.gov) website (NCT05085561) and summarized below. There are only 60 participants allowed into the trial, so, if you fit the criteria and are as excited as we are, it would be good to jump in early. The sooner we fill the trial, the faster we can move this potential treatment forward.

We recently hosted Dr. Lisa Boyette, Senior Medical Affairs Director at Recursion, in a webinar about REC-994. You can watch a recording of the webinar on our YouTube channel at [youtu.be/DTri7rCIqjo](https://youtu.be/DTri7rCIqjo).

### Summary of the Trial

This Phase 2 study is expected to start on December 1 and complete by June 1, 2024. We hope it will end sooner. These dates are dependent on how quickly the trial is enrolled.

Individuals in the trial will be randomly assigned to one of three treatment groups. They will be taking either REC-994 200 mg daily, REC-994 400 mg daily, or

a placebo. The study team and patients will not know who is on lower or higher dose REC-994 or on placebo until the trial ends.

You may be eligible for the trial if you are age 18+ and have one or more symptomatic CCM brain lesions.

You would not be eligible for the trial if:

- Your symptoms are deemed by the study investigator to be caused exclusively by irreversible neuronal damage from prior stroke or neurosurgery
- You have a history of cranial irradiation or surgical/radiosurgical treatment of the primary symptomatic CCM lesion
- You are pregnant or breast feeding
- You are unable or unwilling to participate in MRI assessments (e.g., claustrophobia, metal implant, implanted cardiac pacemaker, allergy to gadolinium)
- You have liver dysfunction or active liver disease as defined by baseline serum transaminases  $>2\times$  upper limit of normal (ULN)
- You have severely impaired renal function (eGFR  $<60\text{ml/min}$ ) or active renal disease
- You have had a previous diagnosis of skeletal muscle disorders (myopathy) of any cause or have a baseline creatine kinase level  $>5\times$  ULN
- You have a history of alcohol or substance abuse within one year prior to screening
- You have a clinically significant laboratory abnormality
- You have had an intracerebral hemorrhage within three months of screening or any brain surgery within six months of screening



Recursion

### Join our email list

This newsletter is wonderful for sharing what has happened in the last months, but our email list keeps you up to date on upcoming events and breaking news. If you aren't on our email list, you may have missed monthly webinar announcements, real-time research announcements, and our Scientific Advisory Board's latest COVID-19 statement. It's easy to sign up. Just visit [www.angioma.org/sign-up-for-updates/](https://www.angioma.org/sign-up-for-updates/) and enter your email address. You'll hear from us weekly with the latest information.

## VMLY&Rx Foundation Day Supports Angioma Alliance

On September 30, the London-based staff of VMLY&Rx, a healthcare communications company, dedicated their annual Foundation Day to supporting the work of Angioma Alliance. Understanding that our primary mission is to accelerate the cure, they set about creating materials that we can use as we approach industry to interest them in CCM. We now have an attractive, informative slide deck that presents the excellent partnership opportunities we offer, a map of the disease's significant biological pathways with the medicines already known to affect these, and the outline for a white paper. Dr. Ankita Batla, Dr. Rick Morton, and Caitlin Rich spearheaded the day. Dr. Batla's words below about the importance of patient advocacy organizations in treatment development are worth reading.

### Powerhouse Partners: Why Patients Are the Foundation of Everything in Health

Doctors are starting to recognize something that I learned as a physician many years ago: a person's health is much more than a set of clinical symptoms; there's a deeper human context that needs to be understood. Today, progressive physicians are deferring to patients to uncover that context. They're abandoning paternalism in healthcare and giving patients the leading voice in decisions about their care. These are momentous steps forward. We can't allow COVID to set the movement back.

So how do we keep progressing? Pharma can play a significant role. Companies are increasingly discovering that if they properly partner with patient groups—and work with them to understand how a given condition impacts all aspects of patients' and carers' lives—the opportunity to transform their health experiences is huge.

After decades of developing solutions in isolation, companies are starting to see the value of co-creation. The smartest are bringing patients into the mix early in the development cycle and working with them throughout it, as true partners, to design treatments and services that match their everyday needs.

It's a wonderful development. Because, as the rise of patient advocacy groups (PAGs) over the last three decades has shown us, the power to drive change sits firmly with patients. All they need is the tools to engage, a seat at the table, and the knowledge that their voice will be heard and valued.

The influence of patient groups is growing. Everywhere you look, and in almost every disease category, there are amazing examples of patient advocacy driving incredible change. Today, PAGs are no longer just support groups: they're powerhouses and catalysts, driving research, guiding policy, and influencing the way regulators make decisions. Their achievements are fired by a passion that only comes from being personally affected. When it's your child, your loved one, or your life, determination is elevated to a whole new level. Pharma companies invest heavily in R&D because they want to make a



difference. But patient groups invest their hearts and their souls to make change happen, because to them it matters more.

It's no surprise that today's pharma companies want to work with patient groups every step of the way. How can we be distant from them? We have to get closer. If it works for patients, it works for us all.

In pharma, patient advocacy strategy has traditionally had a very narrow focus. In the past, and arguably still today in some parts of the industry, working with patient groups was often little more than asking patients how a drug made them feel. This "insight" would inform the value proposition and shape reimbursement strategy, but we were looking at the patient contribution through a very limited lens. We now know it's nowhere near enough.

If we're going to maximize the real power of patient advocacy, we need to go deeper than simply understanding the clinical implications of disease. We need to understand its impact in its full human context. What is it like to live with a condition? How does it affect all aspects of life? Rather than just focusing on symptoms and treatments, we need to find out how a condition impacts relationships, routines, livelihoods, everything. That means building deep, trusted partnerships with patients so we can see the bigger picture and co-create connected health experiences that make a meaningful difference.

The patient voice is getting louder and stronger and the role of PAGs in amplifying it is becoming ever more powerful. But, together, there's much more we can do.

Patient groups are driven by a raw, human passion that, like it or not, can never be matched by commercial organizations. However, many PAGs are small operations that don't have the resources, technical expertise, or marketing capability to make their voices heard at scale. The opportunity for pharma to help them, and to harness the power of patients to create better health experience, is immense. It's why VMLY&Rx hosts the world's largest patient outreach project, Foundation Day, giving PAGs access to the tools and expertise that can help carry their voice worldwide.

Initiatives like this are vitally important as we push for true collaboration. Because yes, there's a power shift in healthcare, with patients increasingly calling the tune. But if we want to make the most of it, we need to give them the tools, platform, and freedom to co-create, and pave the way for proper patient partnerships.

*Dr. Ankita Batla, VMLY&Rx, Chief Medical Office Lead – Health Insights and Patient Partnerships*



**ANGIOMA ALLIANCE**  
because brains shouldn't bleed®

# Partnership Opportunities in Cavernous Angioma (CCM)





## Angioma Alliance Recognizes Penn Medicine/The Hospital of the University of Pennsylvania and the University of Miami/Jackson Health System

Angioma Alliance is excited to announce new additions to our growing network of Centers of Excellence. We have recognized Penn Medicine, The Hospital of the University of Pennsylvania, and the University of Miami/Jackson Health System as CCM Centers of Excellence for their outstanding medical care and cutting-edge research.

The Penn Medicine Center of Excellence is led by neurosurgeon and Medical Director Dr. Jan-Karl Burkhardt. The full faculty list as well as a summary of Penn's research program can be found here [www.angioma.org/penn-medicine/](http://www.angioma.org/penn-medicine/). More information about Penn Medicine's cerebral cavernous malformation (CCM) program can be found on their website: [www.pennmedicine.org/for-patients-and-visitors/find-a-program-or-service/neurosurgery/neurovascular-surgery/cavernous-malformation-center](http://www.pennmedicine.org/for-patients-and-visitors/find-a-program-or-service/neurosurgery/neurovascular-surgery/cavernous-malformation-center).

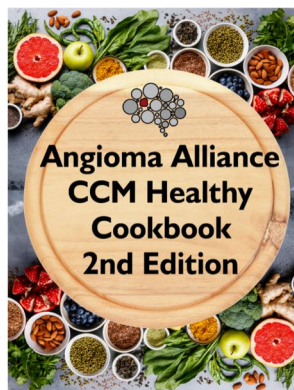
We are excited to recognize Penn Medicine as the first CCM Center of Excellence in the Mid-Atlantic, providing our patients with this rare disease an option for expert care closer to home. We applaud Dr. Burkhardt for his work in raising visibility of the condition within his institution and for his passion to serve patients.



Additionally, Angioma Alliance has elevated our recognition of the University of Miami/Jackson Health System, led by neurosurgeon Dr. Robert Starke, from CCM Clinical Center to CCM Center of Excellence. The full faculty list can be found here: [www.angioma.org/care-community/care/centers-of-excellence/university-of-miami-jackson-health-system/](http://www.angioma.org/care-community/care/centers-of-excellence/university-of-miami-jackson-health-system/).

Angioma Alliance Clinical Centers and Centers of Excellence are recognized by Angioma Alliance as providing expert, integrated, interdisciplinary care for both sporadic and familial cerebral cavernous malformation patients. The standard of care at the Centers is expected to meet or exceed the consensus guidelines recognized by the Angioma Alliance Scientific Advisory Board.

## Share a Recipe for the CCM Healthy Cookbook



There is still time to help the Angioma Alliance community by sharing a recipe for the 3rd Edition of the CCM Healthy Cookbook!

Research indicates that diet, specifically emulsifier and artificial preservative use, has a negative effect on the gut lining and cavernous angioma (CCM) health. We are soliciting recipe submissions for a cookbook to help our families make angioma-friendly food choices. It's easy to submit a recipe and you'll get rewarded with a FREE copy of the cookbook before it's available in our store! Here's the link to share a recipe: [www.angioma.org/recipes2021/](http://www.angioma.org/recipes2021/).

Want to share an emulsifier free grocery item, dining out suggestion, or another tip? You can do that here: [www.angioma.org/tips/](http://www.angioma.org/tips/).

If you want to learn about why it's recommended to avoid emulsifiers, this is a great place to start: [www.angioma.org/cavernous-angioma-in-depth/lifestyle-maintenance/microbiome-gut-health/](http://www.angioma.org/cavernous-angioma-in-depth/lifestyle-maintenance/microbiome-gut-health/).

## CCM Crisis in the Time of COVID

CCM emergencies can happen at any time, including during peak pandemic. Michelle Stanley shared the story of her daughter Kyleigh's CCM emergency in April and May 2020 when the United States was in the height of lockdown. Advocacy, from family and from care providers, made all the difference.

"On Wednesday, April 29, 2020, our 22-year-old daughter Kyleigh woke up at 1 am with what seemed to be a migraine," said Michelle. Through the night, Michelle tried to ease Kyleigh's pain with acetaminophen, ibuprofen, and migraine medication, but nothing touched it. Kyleigh reported that her pain continued to rage at a level 9 of 10.

Michelle said, "I reached out to our family doctor who said he could call something in for her and see her in a couple of days. But my mother's instinct kept telling me she needed to be seen. I pushed and he agreed. I had her at his office within the hour."

At the doctor's office, Kyleigh got a shot for nausea and a shot of Toradol for pain. "She kept asking me how long it would take to start working. I tried to stay calm for her. I told her, 'soon.'" Michelle wanted to believe this, too.

Upon returning home, Kyleigh went to bed in a darkened room, but shortly after, Michelle heard Kyleigh call out for her. Michelle ran to her room and saw Kyleigh's level of distress. Her pain had gotten even worse. "I immediately sent a text to our doctor, and he said he wanted me to take her in for a STAT CT or MRI."

Michelle was ready to go, but Kyleigh was not. When Michelle went to her room, Kyleigh kept saying, "M o m , I ' m s o dizzy." Michelle helped her daughter to the bathroom,

hoping that a cold washcloth would help.

"I sat her down on the toilet, put her hand on the counter as we have a small bathroom. I said, 'hold on'. In the less than 5 seconds it took me to grab a washcloth, I came back into the bathroom to find her unconscious. She had fallen over, half in the bathtub with her back arched. Before moving her, I moved her hair away from her face to make sure there were no obvious injuries from falling over, and she immediately regained consciousness." Michelle got her out of the tub and sat her on the floor. "With me sitting right next to her, I called 911. Calling 911 for our baby was probably one of the hardest things I've had to do."

The paramedics arrived quickly, assessed her, and got her out to the ambulance and to the hospital. "I met them at the hospital but, due to COVID, I wasn't allowed to be with her. I sat in the waiting room scared, not knowing what was happening."

"The next thing I remember getting was a phone call from Kyleigh crying, saying, 'Mom, the doctor said I have a mass and bleeding in my brain.'"

Michelle shared, "The ER doctor came out and brought me into a room just inside the ER exam area.

The words that I will never forget are, 'this is a life-or-death situation.'"

The neurosurgeon at the Stanley's local hospital in Illinois scheduled an MRI for the next morning. From there, Kyleigh went to surgery. The neurosurgeon said his plan was to place a drain and biopsy the mass.

"After surgery, which seemed to last forever, he came out and took me to the doctor's lounge where he showed me her MRI," said Michelle. "He said there was so much blood, he only felt comfortable placing the drain, and he wanted to transfer her





to the University of Illinois Chicago to his colleague Dr. Fady Charbel.”

Kyleigh arrived at UIC at 11:45 pm that evening and was immediately admitted to neuro ICU. Michelle spoke with the admitting neurosurgeon who shared that Kyleigh would have another MRI in the morning and would then go to surgery.

“Again, because of COVID, we weren’t allowed to even be at the hospital. Dr. Charbel called me and my husband and explained that he would be performing a craniotomy. He would have us updated during surgery, and he would call us once surgery was complete.”

“I paced a hole in my living room waiting for those phone calls. When the call came from Dr. Charbel, he said the words, ‘It’s what I thought it was, a cavernoma. She’s waking up and moving all of her extremities.’ I burst out in tears and couldn’t thank him enough for saving our baby girl.”

Kyleigh spent three days in neuro ICU at UIC. She was transferred back to a hospital closer to home because Dr. Charbel said she was doing well and, sadly, due to COVID, they needed the ICU beds. She arrived back at the Stanley’s local hospital and was readmitted to ICU. Due to still having a drain in her head, they wanted to take all precautions to prevent infection.

“After nine days in ICU, we received a call that Kyleigh could come home. She is our only child, and I was so scared and depressed that I spent those 9 days in bed. The only time I got up was when we were able to video chat with her. My husband tried so hard to get me to eat, but I just couldn’t. Everything made me nauseous.”

“Driving to pick her up I had so many mixed emotions. I was worried that she would still be in a lot of pain, and I wouldn’t know what to do for her. At the hospital, I had to wait at the front door for her to be brought down. As soon as I saw her in the wheelchair, the tears started falling. I tried so hard not to cry but there was no way of stopping it. The nurse who brought her down gave me the biggest hug even though, because of COVID, she wasn’t supposed to. It meant the world to me.”

Although Kyleigh had many wonderful nurses who took great care of her, she has kept in touch with one whose name is Heidi. Heidi was there with her when Michelle couldn’t be. She advocated for Kyleigh when she knew Kyleigh’s anxiety was out of control or when her pain wasn’t being controlled well enough.

“We will forever be grateful for everyone that helped take care of Kyleigh. This is a ‘family’ we never thought we would be a part of, but this is definitely a family of strong people.”

## 5th Annual Orange County 5K Walk/Run Brings Families Together

On September 19, in Mission Viejo at Florence Joyner Olympiad Park, the Southern California Angioma Alliance Community hosted a 5K benefit walk/run. This was a long-awaited opportunity for many families to see each other again and for our new families to meet.

Some had never met another affected patient, even though they had been diagnosed for years. In fact, in attendance was Olympic-level para-athlete Erica Davis, whose spinal cord cavernous malformation hemorrhage caused paraplegia. In 2010, she was the first woman with paraplegia on Mount Kilimanjaro’s summit, and she is now a competitive para-canoeist. Erica and her family found Angioma Alliance just this year.



**Consensus Statement by the Angioma Alliance Scientific Advisory Board Regarding COVID-19 and Cavernous Angiomas, and the COVID-19 Vaccine**

The Angioma Alliance Scientific Advisory Board continues to monitor any specific reports or emerging concerns about COVID-19 and cavernous angiomas. Results from a registry of cavernous angioma patients and COVID-19 has been published (J Stroke Cerebrovasc Disease, 2021). While numbers were small, this study suggested a potential increased incidence of new symptomatic bleeding in solitary cavernous angiomas that are associated with a developmental venous anomaly among those with a recent COVID-19 diagnosis. Beyond this report, we are aware of other CCM bleeds documented in familial cases in association with COVID-19 as well.

We are aware of reports of stroke in young patients, excessive clotting, and other neurologic manifestations of COVID-19 in the general population, but it remains unclear how these may impact cavernous angioma patients specifically. It is possible that a thrombosis in an associated venous anomaly branch may trigger a bleed in an associated cavernoma.

The registry data revealed no evidence that cavernous angioma patients are more likely to be infected, hospitalized, or die from COVID-19 than other patients of similar age, medical co-morbidities, and levels of disability. Persistent symptoms are common after recovery from COVID-19, and these may be difficult to distinguish from cavernous angioma symptoms. It is hence prudent to repeat magnetic resonance imaging (MRI) on patients with known cavernous angioma who report new headache, seizure, or other neurologic symptoms after known diagnosis of COVID-19.

Until further evidence arises, patients with cavernous angiomas with recent bleeds in the past year and associated new neurologic symptoms, surgery on the brain or spine in the past 6 months, persistent neurologic disability from prior bleeds, or active seizures may be a group considered as having a comorbidity and are potentially at higher risk with COVID-19. This is in addition to other cases designated high risk by the Center for Disease Control (CDC) because of age 65 years or older, heart disease, chronic lung conditions, immunocompromise, pregnancy, diabetes, severe obesity (BMI > 40),

chronic kidney disease undergoing dialysis, and liver disease.

COVID-19 vaccines are now widely available in the United States. Based on exceptional effectiveness data (greater than 90% protection from COVID-19 serious illness), the durability of benefit after a recommended second dose, and minimal reported side effects, we strongly recommend that the CCM patient community seek vaccination through any one of the approved vaccines, including any recommended follow-up doses. There is no reason to believe that CCM patients react any differently to these vaccines than the general population, and no scientific basis to fear the vaccine more than COVID-19, which has taken or interfered with so many lives.

For high-risk individuals, regardless of vaccination status, it is important to adhere to social distancing, wear facial masks in indoor spaces, and practicing hygiene per CDC guidelines. It is also important to avoid contact with individuals (including family and caretakers) exposed to COVID-19, or exhibiting fever or other flu-like symptoms, until those persons prove negative testing for COVID-19, or until 14 or more days after their exposure, travel, or last symptoms. Caregivers and those individuals who are sharing a home with high-risk cavernous angioma patients should follow the same precautions.

We encourage patients to not delay medical care or imaging for cavernous angioma if recommended by your physician, including necessary travel for medical care and timely evaluation if new neurologic symptoms arise. Patients should continue their seizure medications, and other medications for medical conditions, and notify their cavernous angioma doctors about any positive test for COVID-19. It is recommended that patients in clinical trials continue to adhere to ongoing trial procedures and notify their trial investigators about positive testing for COVID-19.

*Dr. Issam Awad, Chair, Angioma Alliance Scientific Advisory Board, University of Chicago Neurosurgery*

*Dr. Kelly Flemming, Mayo Clinic Rochester Neurology*

*Dr. Kevin Whitehead, University of Utah Cardiology*

## 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 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
- Georgia – A full and fair description of our programs and our financial statement summary is available upon request at our office and email indicated above.
- Colorado – Colorado residents may obtain copies of registration and financial documents from the office of the Secretary of State, 303-894-2860, [www.sos.state.co.us/](http://www.sos.state.co.us/) Reg. No. 20063003635.
- Maryland – For the cost of copies and postage, from the Office of the Secretary of State, State House, Annapolis, MD 21401.
- Michigan – MICS # 35000
- New Jersey – INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FOR THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING 973-504-6215 AND IS AVAILABLE ON THE INTERNET AT: [www.state.nj.us/lps/ca/charfrm.htm](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.