ALLIANCE TO CURE CAVERNOUS MALFORMATION MAGAZINE | FALL 2026

CCM CURE



One patient's search for answers and how finding community in the Alliance to Cure has changed her life and drives her today.

Patient Profile | PAGE 10

ALLIANCE TO CURE
CAVERNOUS MALFORMATION

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Letter from our CEO

I'm excited to share with you the Fall 2026 edition of our CCM Cure magazine. In the months since our last publication, we've been hard at work driving the research and building the kinds of partnerships that get us closer to a cure.

In this issue, you'll read about new progress in our CureDriver™ Lab, a growing interest from drug companies in partnering with us, and the next step for REC-994 that you helped make possible. You'll also see our network of CCM centers expand, relive Family Weekend, and meet community members who are raising awareness and funds for a cure. We finish the issue with our donor recognition roll for our fiscal year ending September 30.

As an Alliance supporter, you are helping us advance CCM treatments at every phase of the clinical trial pipeline, guide patients to experienced, multidisciplinary CCM medical care, and ensure that no one with CCM feels alone.

We want to be clear: all of this is only possible because of donors and fundraisers like you. Your support has enabled us to remove and overcome roadblocks and get closer to the world we envision. One where CCM patients have the answers, the resources, the care, and the treatments they need to not just survive, but thrive.

Thank you, and let's continue to drive a cure — together.

Connie Lee, CEO
Alliance to Cure Cavernous Malformation



RESEARCH ROUND-UP

CCM cell-lines now part of our CureDriver™ Lab

This fall we have exciting news coming out of our CureDriver™ Lab — **we're developing our own CCM cell-lines** to test possible CCM treatments. We have contracted with a biotech company to lead gene-editing, validation, and new growth of edited CCM cells, and we are currently screening six drugs and drug combinations. Having our own lines gives us more control over our research timelines and will enable us to conduct more cost-efficient tests of potential CCM drugs. The results of those experiments will help us determine the best drug candidates to advance.

A new partner brings a possible CCM drug to our lab

Our CureDriver™ Lab is attracting the interest of drug companies with potential CCM drugs. In August, we announced a **new collaboration with Atlas Discovery**. This Y Combinator-backed biotech startup uses a system of AI research agents to find existing drugs with the potential to be repurposed for other illnesses. Atlas' program identified an FDA-approved medication with properties that could help CCM patients and approached the Alliance with the opportunity to test this drug in our cell-lines. We enthusiastically accepted! For the last two years, we've worked hard to build our CureDriver™ Lab with the resources and expertise to explore the pre-clinical treatments that aren't prioritized and funded by academic or pharmaceutical institutions.

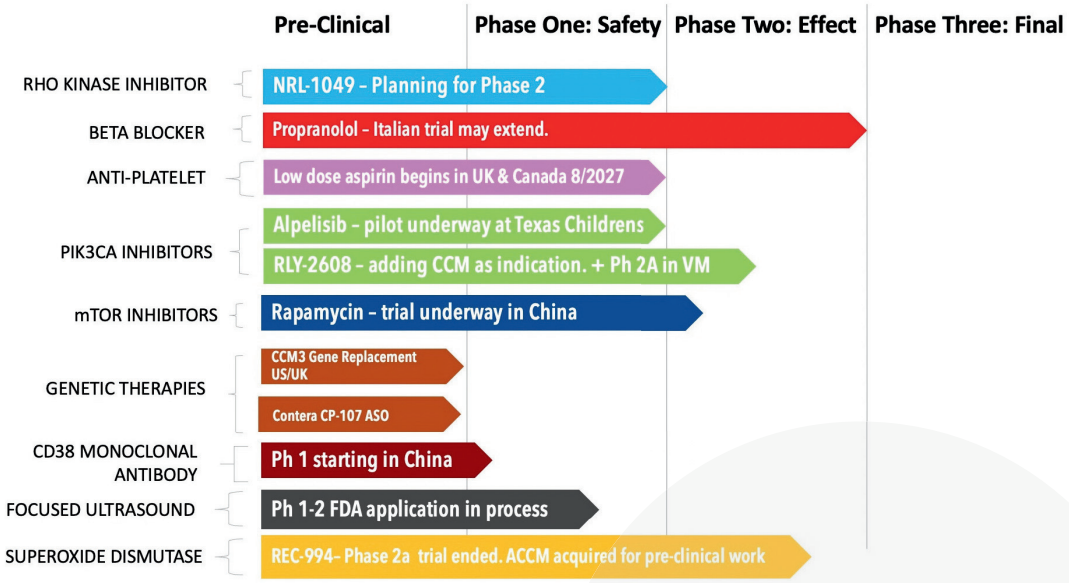
Meeting potential industry partners

In October, we had an exciting opportunity to meet potential industry partners to accelerate CCM treatment development. In partnership with Cavernous Malformation Canada, CAUK, and Cavernoma Aliança Brasil, the Alliance was invited by **Aspire Biosciences** to participate in an incubator event in London. The conference brought together patient organizations and life-sciences companies to pitch our respective offerings during this *Shark Tank*-like event with the goal of forging new partnerships. CEO Connie Lee and Chief Scientific Officer Angela Glading (see photo, with UK Trustee Alex Ford) shared the Alliance's cutting-edge work, including the potential of REC-994 and the resources and expertise we can provide through our CureDriver™ Lab. Industry representatives were impressed by our research capabilities, and several are discussing partnerships to test their drugs for CCM.



REC-994 Update: Together, we unlocked The Singer Fund's generous gift match, raising the $50,000 needed to bring REC-994's data, biosamples, and imaging to the Alliance. Our 18-month analysis can now begin, and if the data show REC-994 helped a specific group of patients, we believe drug companies will want to sponsor a new clinical trial.

CCM Treatment Pipeline, October 2026



While brain and spinal surgery remain the only available CCM treatments, CCM lends itself to a variety of treatment approaches and targets. The current CCM treatment development landscape reflects this.

In 2027, we expect at least three clinical trials to begin enrolling CCM patients worldwide.

Our Capabilities: Models, Infrastructure, Training, and Recruitment

Pre-clinical compound screening/testing: We have the expertise and resources to run the full range of pre-clinical work. This includes but is not limited to designing and conducting cell-line and mouse model screening and interpreting pre-clinical data.

Partnering on clinical trial infrastructure: We have built and fostered extensive researcher, clinician, and patient networks. We can facilitate introductions with researchers, potential Clinical Advisory Board members, and international patient advocacy organization leaders; provide consultation on the range of possible clinical endpoints, efficacy measures, and site selections; organize patient focus groups, and distribute patient surveys.

Driving clinical trial enrollment: As an organization founded and staffed primarily by families of patients and patients themselves, we lead with sensitivity and strategy. We can train drug company staff and the research firms that run their trials on patient experiences and needs, circulate trial enrollment information across our communication platforms, and serve as patient navigators and advisors.

CCM FAMILY WEEKEND

From July 17-20, CCM patients, caregivers, and loved ones from across the U.S. joined the Alliance outside of Rochester, Minnesota for our second-ever Family Weekend. Families came from as far as Washington, Florida, and New Mexico to be among a CCM community that understands and embraces one another.

For some, this retreat offered a chance to deepen existing relationships built over years in the Alliance's support groups. For others, this was their first time being around someone else with CCM or even coming to grips with their new diagnosis. Wherever someone is on their journey, Family Weekend offered a safe space to reflect, learn, and understand.

"We truly started to accept my disease and disabilities this summer... and I truly feel like I have a support system."

The weekend featured fun and accessible activities, including zip lining, horseback riding, archery, water games, and more, along with connection-focused moments around the campfire, in small groups for coffee chats, and in conversation circles. Families also had the opportunity to have their top-of-mind CCM questions answered in a Q&A with Mayo Clinic's Dr. Kelly Flemming and Dr. Guiseppe Lanzino.

"It truly was a life changing experience."

We're thankful to everyone who was able to make it, and to those who couldn't but supported from afar. We also want to extend our gratitude to the generous donors and sponsors for the contributions that made Family Weekend possible! To view our video from Family Weekend, check out our YouTube.

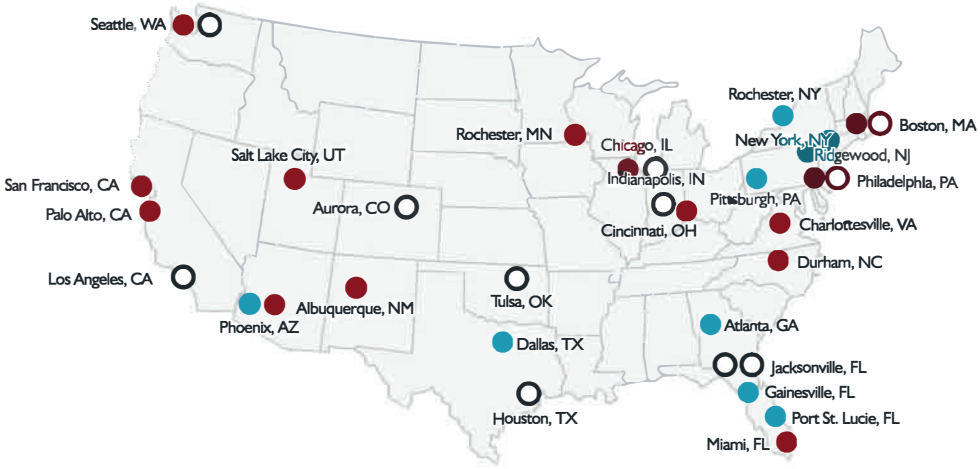






PATIENT SUPPORT

We are thrilled to see our list of **CCM Clinical Centers and Centers of Excellence** growing — this means more specialized care and expertise for patients and families across the country! In just the last several months, we've welcomed Children's Hospital in Aurora, Colorado and Riley Children's Health in Indianapolis, Indiana as CCM Clinical Centers and the University of Utah as a CCM Center of Excellence. By the end of the year, we expect at least one more center to receive a designation. This brings our current total to **25** centers in **17** states, serving roughly **3,000** patients nationwide.



14 Centers of Excellence
Full multidisciplinary CCM programs meeting the Alliance's highest standards of care and research.

11 Clinical Centers
Hospitals with demonstrated experience treating cavernous malformation patients.

9 Additional Trial-Ready Sites
Additional US trial-ready sites that are not Centers, but where CCM clinical trials have been hosted.

Patient Testimonies from CCM Center Survey July 2026

"I am SO VERY appreciative that these meetings are offered in a virtual platform. I live 20+ miles from any major city and without this option it would be highly unlikely that I would be able to meet with these specialists."

"My son remains seizure free because the cavernous malformation was successfully removed. Forever grateful…"

"The doctor saved my daughter's life. After 3 strokes and a craniotomy that removed a ping pong ball sized CCM from my daughter's thalamus, she is almost completely back to normal."

"Excellent help from Alliance to Cure staff and website helping me understand info. Still recovering almost 2 months after the brain surgery but I am so much better."

"Care at a CCM center vs other centers is better and more understanding. The providers listen, are not rushed during the appointment, seem to care, and are knowledgeable on CCMs."

"Everyone was A++. There are no resources available for me where I live, as I am out of state of any CCM Center. It was fabulous."

Clearer Answers Lead to Better Care

SPONSORED GUEST ARTICLE | **MAYO CLINIC**

When you're diagnosed with a complex neurovascular condition, it's natural to wonder what the best treatment might be. But before treatment, the most important step is getting the right diagnosis and a clear understanding of your condition.

Today's biggest advances in neurovascular care aren't just new procedures or more powerful technology. They're helping specialists answer critical questions with greater confidence: *Is this really the right diagnosis? Does this condition need treatment now? Which treatment offers the most benefit with the least risk?*

That is where expertise and experience are the biggest difference makers.

Take cavernous malformations, for example. Advanced imaging like 7-tesla (7T) MRI is giving specialists an unprecedented view of these vascular lesions. But the technology itself isn't the breakthrough. It's what experienced clinicians can learn from the clearer images it provides.

As Mayo Clinic neurosurgeon Giuseppe Lanzino, M.D., explains, "The 7-tesla magnet gives us significantly greater definition of a cavernous malformation. We are able to better understand the anomalous venous structures often associated with a malformation — which are probably, in many cases, the malformation's cause."

For patients, that added clarity can lead to more informed decisions and treatment plans tailored to their unique situation. Whether the condition is a cavernous malformation, stroke or another complex neurovascular disorder, the goal is the same: giving specialists the information they need to make the best recommendation. Just as importantly, expertise often means recognizing when *not* to intervene.

"Cavernous malformations are challenging because there may be substantial risk of bleeding, but also risks associated with surgical removal, especially when malformations are located in highly eloquent areas of the brain," says Mayo Clinic neurologist Kelly D. Flemming, M.D. "We have a multidisciplinary team with experience in the natural history and outcomes of cavernous malformations that works together to evaluate the risks and determine the best management strategy."

The idea of bringing together specialists with different perspectives is another key characteristic of expert neurovascular care. Rather than relying on a single opinion, neurologists, neurosurgeons, neuroradiologists and other experts work together to determine the approach that's right for each patient.

Research is also changing what's possible. New clinical trials are exploring better treatments for stroke, improving recovery, and finding ways to address conditions that have long had limited options.

William D. Freeman, M.D., a vascular neurologist at Mayo Clinic, puts it this way: "Our three shields of patient care, research, and education flow around the needs of the patient. All three shields work together to offer patients hope."

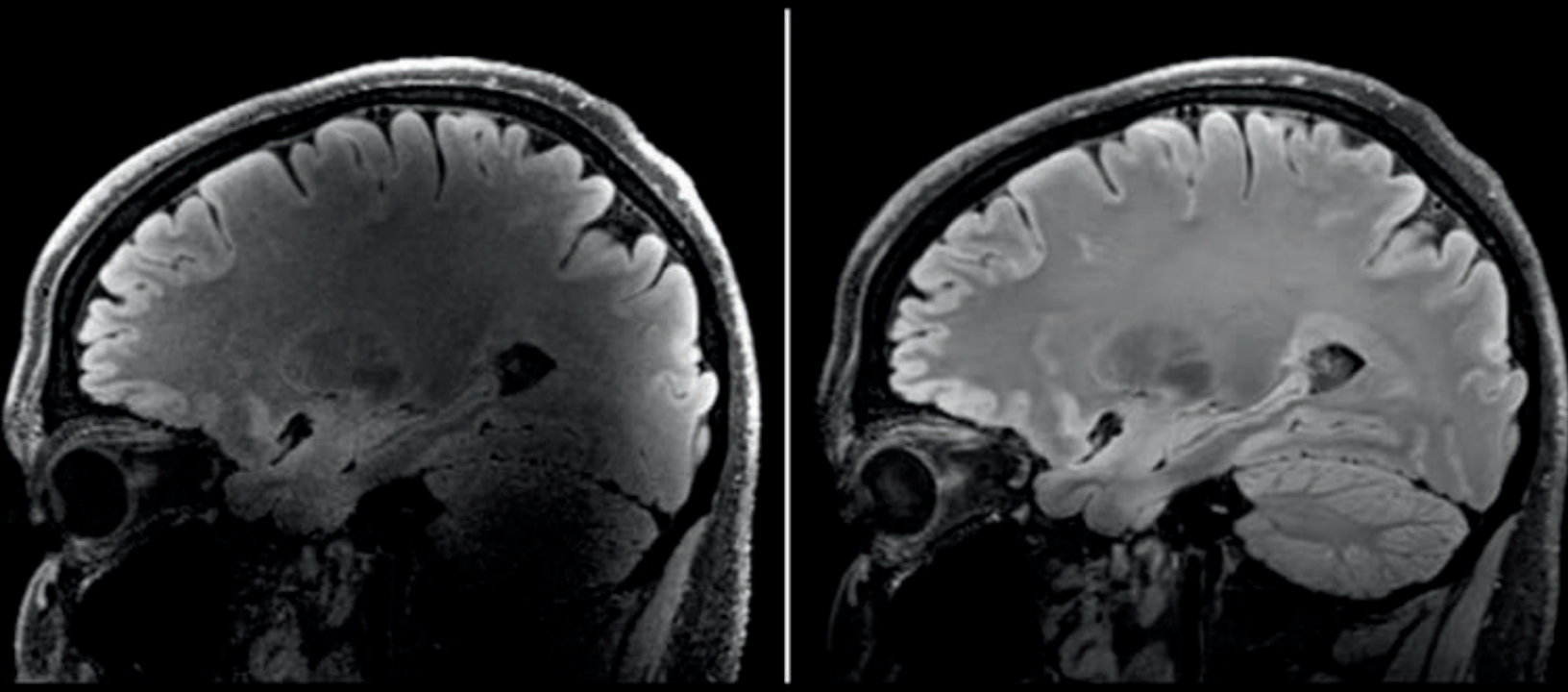
Perhaps that's the most encouraging message for anyone living with a neurovascular condition.

Expert care isn't simply about having access to the latest scanner or the newest treatment. It's about having a team with the experience to interpret what they see, weigh every option carefully, and recommend the path that's right for you.

Because when the diagnosis is clearer and the decisions are more informed, patients can move forward with clarity after a life-changing diagnosis.

Mayo Clinic in Rochester, Minnesota, is an Alliance-designated CCM Center of Excellence. This article was provided by Mayo Clinic as sponsored content.

Upgraded 7T MRI
The image on the right uses new technology to create a clearer, more detailed brain scan than the image on the left. Sharper images can help doctors see the brain more clearly and make more informed decisions about care.



ALLISON'S STRIDE TO A CURE



PATIENT PROFILE
Allison Mintz

Allison's CCM story began in Mongolia in 2009, when she was a Peace Corps volunteer. She began having numbness and tingling down her arms to her wrists and hands, followed by pain. Peace Corps medical staff told her not to worry. Through the remainder of her time in the Peace Corps and even once she left and began attending law school, Allison raised her concerns to doctors. Her discomfort was dismissed, and she was eventually misdiagnosed with carpal tunnel syndrome.

Nearly a decade later, while studying for the bar exam in California, Allison was struck by a debilitating pain in her hand and wrist. A hand surgeon suggested she had thoracic outlet syndrome, but a physical therapist rejected this. Answers still felt out of reach. Finally, a sports medicine doctor ordered an MRI and sent Allison to a junior neurosurgeon at Stanford. He escalated her case to Dr. Gary Steinberg (see cover photo)— the head of neurosurgery who was able to diagnose her cavernous malformations. They were in her spine and her brain, and she'd had several hemorrhages. She was told she needed spinal surgery quickly, or she risked adverse health effects like paralysis.

Within weeks, Allison was in surgery. Unfortunately, she experienced a seizure on the operating table and spent days post-op in the hospital in overwhelming pain. She was then sent to an inpatient rehab center. Thankfully, she had the support of her family, friends, a team of nurses and physical and occupational therapists. Eventually, she was released to outpatient rehabilitation to continue learning how to walk again. Not long after, she discovered the Alliance to Cure.

"It wasn't until I found the Alliance and attended one of its support group meetings that I truly understood that my family and I were not alone."

A year later, Allison realized her dream of becoming a lawyer when she moved to Washington, DC, and passed the bar exam. She hopes to work on rare disease law and/or advocacy, and she supports the Alliance's mission through awareness-raising and fundraising. She leads the DC-area Alliance patient group and was a top fundraiser for our 2026 Strides to Cure, along with her twin sister Elizabeth.

We deeply appreciate Allison, her family, and her friends for their commitment to driving a cure. If you'd like to volunteer or fundraise for the Alliance, email volunteer@alliancetocure.org.

VOLUNTEER SHOUTOUT

We are grateful to our volunteer fundraisers who commit their time and energy to organizing fun, family activities that raise awareness and vital resources that help us get closer to a cure.

This edition, we want to shout out Genise and Jeff Oldenburg for hosting the first "Drive! a Cure Golf Scramble" in Midland, Michigan on September 26. The event was a huge first-year success, raising $15,000 with the help of generous sponsors, 22 volunteers, and 72 golfers.

> *"Having been on this CCM1 journey for 11 years, it has just been since July 2026 that we have come to truly understand that there's no 'I' in TEAM. We have grown away from not talking about it to recognizing that the time is now for us to step up and do what we can to help fund research and find a cure. It was a wonderful event, and we had SO MANY people asking, "So what is CCM?' And that makes our hearts happy:* ***spreading awareness one hit at a time.***" – Genise Oldenburg, organizer of Michigan's "Drive! a Cure Golf Scramble" (with husband Jeff in photo to the right)

Save the Date for next year's Michigan Drive! A Cure Golf Scramble on September 25, 2027. Follow @CCM Drive a Cure Golf Scramble on Facebook for more details.

We also want to shout out and celebrate Brian and Julie Heine (pictured to the right) for organizing the 7th annual "Heine Strong" Benefit Golf Tournament on September 28 in Eureka, Missouri. Each year, this event raises funds to advance the Alliance's research efforts and support other organizations for people with disabilities. Thank you, Heine Family, for your ongoing dedication and care for our community!









OUR MISSION is to drive a cure and improve lives for all affected by cavernous malformation.

OUR VISION is a permanent cure for cavernous malformation - available, accessible, and affordable for all.

WAYS YOU CAN GIVE



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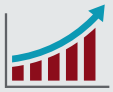

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