

Science Highlights: 2023, A Year of Promise

2023 has been a year of great promise for CCM treatment development. Our treatment pipeline is growing and progressing, as you'll read below and see in the graphic on Page 2.

The CCM Treatment Pipeline graphic illustrates the most promising treatment opportunities and where they are in development. Treatments are grouped by their class. For example, the three treatments that inhibit a protein called Rho Kinase (ROCK) – atorvastatin, NRL-1049, and OV-888 – are grouped together. The colored bars represent the progress of each treatment.

2023 Highlights

Drugs in Development Specifically for CCM

We filled our first industry-sponsored clinical trial in June, ahead of schedule, with the completed enrollment of Recursion's REC-994 Phase 2 Sycamore trial. This trial will finish in June, 2024, and, after data analysis, we'll find out whether the REC-994 can move to an expanded trial. Our members stepped up to participate, and we are so proud of them.

Neurelis's ROCK inhibitor NRL-1049 entered Phase 1 trials this spring. This means the medicine is being tested in healthy volunteers to understand better how it is processed by the body and to establish its safety. Neurelis anticipates opening a Phase 2 trial for our patients in the second half of 2024.

Ovid Therapeutics has entered the CCM field with a ROCK2-specific inhibitor, OV-888, which is also in Phase 1 clinical trials. We are working closely with them to help move this trial forward.

The Patient Preferences survey conducted by the Alliance to Cure last spring is informing clinical trial design, including meaningful endpoints, and the formulations of treatments. We are grateful to our community for participating in such a large way to the success of trials.

Repurposed Treatments

Repurposed drugs are medicines that have been developed and approved for other diseases, and, based on animal studies, we think may be effective for treating CCM. There are several repurposed drugs that have been identified.

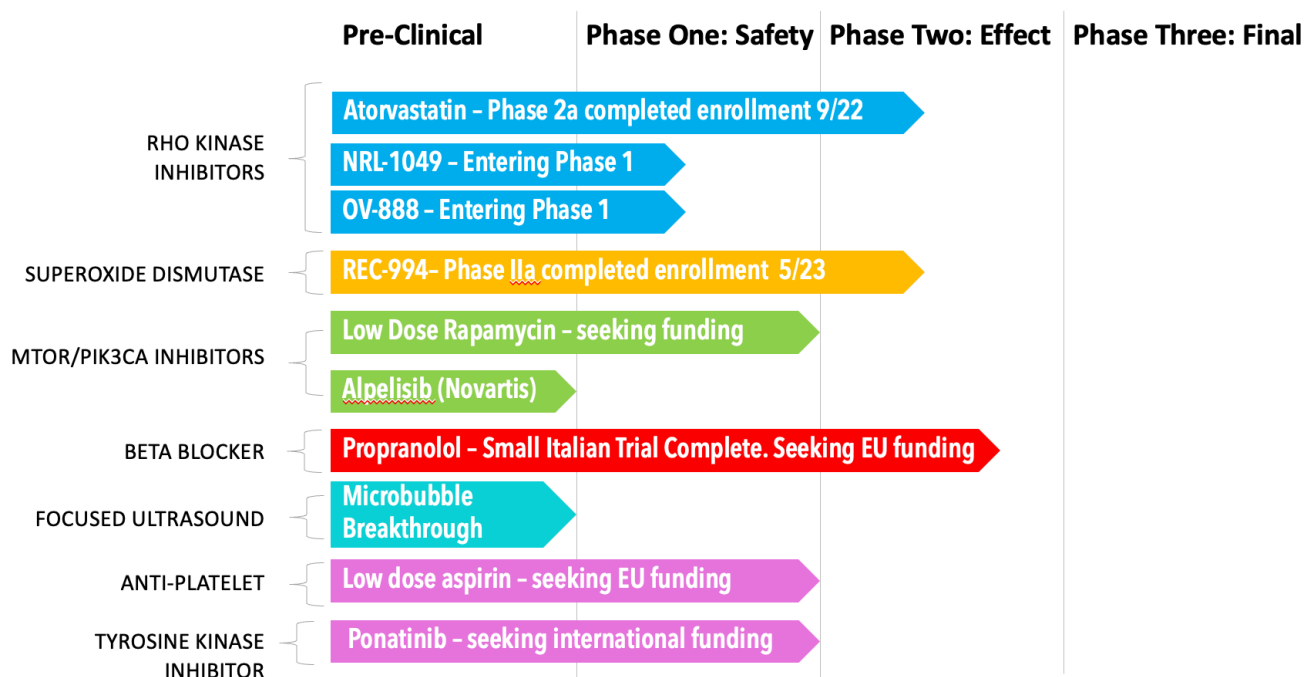
The atorvastatin experimental proof of concept trial at the University of Chicago is a year away from completion. In late 2024, we will find out whether atorvastatin is safe for CCM patients and whether it may have an effect in preventing a second hemorrhage. We'll also have a sense of whether MRI with qualitative susceptibility measurement (QSM), a software setting that allows for precise measurements of iron, is a way to measure meaningful change in CCM lesions. If so, QSM may be taken to the US Food and Drug Administration (FDA) to gain their approval to use in other clinical trials as a measure of a treatment's effect.

Propranolol and low-dose aspirin trials are seeking funding in the European Union and the United Kingdom. A small Italian propranolol trial reported its findings in late 2022 and there was some sign that propranolol may be helpful in stabilizing CCM. Low-dose aspirin has not been tried in CCM patients, but retrospective studies of clinical databases seem to indicate anti-thrombotics may offer some protection against hemorrhage.

Low-dose rapamycin and alpelisib are used widely in other disorders that include vascular malformations as a symptom. CCM mouse testing of rapamycin has been underway, and several studies have been promising. A small rapamycin clinical trial is seeking funding in the United States. CCM animal testing of alpelisib is required before a decision is made about advancing to CCM trials.

Ponatinib is a medicine already in use for leukemia, and in lower doses was effective in CCM mouse models. A clinical trial is being explored outside of the US.

CCM Treatment Pipeline Autumn 2023



Pre-clinical treatments haven't been tested in humans; they are still in research in animal models.

Phase 1 treatments are being tested in healthy humans to understand how the medicine is metabolized and whether it seems safe. Some medicines are already approved for use in other illnesses and can skip this step.

Phase 2 treatments are being tested in a small number of CCM patients, with the initial trial focusing on safety, determining

the right dose, and seeing whether there is any measurable effect on the disease. Our Phase 2 trials are also designed to test a variety of methods of measuring improvement, like changes in imaging, blood, and patients' report of how they feel.

Phase 3 trials are larger, and are intended to prove the efficacy of a treatment. None of our treatments have reached Phase 3 yet.

Other Treatment Modalities and Tools

Focused ultrasound is being explored as a non-invasive treatment for CCM lesions. At our scientific meeting, a talented graduate student from the University of Virginia shared exciting and unexpected results indicating that focused ultrasound can stop lesion growth and prevent new lesion development in mice simply by opening the blood brain barrier for a short period. Additional experiments are needed to discover why this happens and whether this effect is permanent.

Duke University received a major grant to develop methods of delivering CCM3 gene therapy to brain blood vessel cells. Targeting only blood vessels in the brain rather than the entire body may help to prevent unwanted side effects associated with gene therapy.

With the participation of hundreds of our members, the University of Rochester completed development of the CCM Health Index earlier this year. This is the only patient-reported symptom and experiences survey specific to CCM. The tool will then be presented to FDA with the intent of qualifying it as a clinical trial tool.

Because we are understanding that some of the best treatments for CCM may come from oncology where drugs have more side effects, we are funding research for alternate, targeted delivery methods. The most promising and widely used targeted delivery method uses nanoparticles to encapsulate a medicine and carry it to a target. The Alliance to Cure is funding research at the University of Pennsylvania to develop a nanoparticle delivery system that is as specific to CCM lesions as possible.

Organoids are cavernous malformation lesions that have been grown in a lab. Some even originate from surgically removed cavernous malformation tissue, rather than stem cells, and are the closest thing to the human condition that we can have for screening and testing treatments. CCM organoids will allow us to screen more efficiently. We have seen many drugs pass initial screenings but fail later after a significant investment of time and funds. If a drug will not be effective, we want to know that early. Our summer scientific meeting featured a session on organoids and included the announcement that CCM organoids have been successfully grown as a proof of concept. We are not ready for large-scale screening, but we are one step closer.

Future Focus of the Alliance

In addition to funding nanoparticle delivery development, supporting clinical trials, and growing our biobanking and patient registry, the Alliance to Cure is researching ways to increase the number of medicines that are tested in mouse models of the disease. Through large screenings, academic researchers have identified many promising treatments, but they don't have the resources or the incentive to test more than a few. Additionally, pharmaceutical companies are struggling to find academic CCM labs that are available to test their compounds, which can lead to their choosing a different first indication for their medicine. Our goal is to create a sustainable mouse testing program that can be accessed by industry, and where we can execute extensive trials of existing medicines that could be repurposed for CCM.

At the same time, we have not forgotten current care. We're coordinating an update of the CCM Clinical Care Consensus Guidelines, initially published in 2017. In addition to incorporating the latest research, the update will include diagnostic guidelines and have an increased focus on spinal cavernous malformations and pediatrics.

We look forward to an equally exciting 2024 as we learn the results of two clinical trials and prepare for

additional trials to come. You are a critical member of the cure team. Your participation in our Cavernous Malformation Patient Registry and clinical trials, your assistance raising funds for research, and your support of the other affected families in our ever-growing community are irreplaceable!

Lurie Children's Hospital Recognized as CCM Clinical Center

We are pleased to announce that the Ann & Robert H. Lurie Children's Hospital of Chicago has been recognized as the newest addition to our growing care network of CCM Clinical Centers.

Dr. Sandi Lam, Pediatric Neurosurgeon, will be the Director of the new CCM Clinical Center at Lurie Children's. Dr. Lam's background includes staff and faculty appointments at the University of Chicago, Texas Children's, Baylor, and Northwestern University. She is a strong supporter of the collaborative, multi-specialty approach to patient and family care. Her team will include a nurse coordinator, Daisy Vasquez, and multiple specialists in neurology, genetics, and radiology.

Our CCM Clinical Centers are recognized by Alliance to Cure Cavernous Malformation as providing high-quality interdisciplinary care for both sporadic and familial cerebral cavernous malformation patients. The standards of care at the Centers are expected to meet or exceed the consensus guidelines recognized by the Alliance to Cure Cavernous Malformation Medical Advisory Board.



Family Weekend!

In 2024, thanks to the support of a generous donor, the Alliance to Cure will host its first Family Weekend. Unlike our patient conferences, which focus on education, our Family Weekend will focus on fun, laughter, and community. The details:

When: June 28-July 1, 2024 (3 nights, 4 days)

Where: Silver Bay YMCA Conference and Retreat Center on Lake George in the Adirondack Mountains of upstate New York. The camp offers hotel-like lodging with individual family rooms and a 700-acre waterfront campus. All meals and activities are provided.

Activities: You can look forward to boating, swimming, nature walks, rock wall climbing, crafts, music, games, campfires, archery, pickleball, and more. We'll have planned group activities and time for you to relax.

Cost: The cost to attend is being heavily subsidized to encourage as many families as possible to attend. The cost per adult is \$150 for the entire 3-day event, children aged 5-18 will be \$100, children aged 2-5 will be \$50, and children under 2 are free. This price includes all meals, activities, and three nights' lodging. Please reach out to us if your family requires financial assistance to attend.

How to Register: Registration is available at rebrand.ly/CCMFAMILYWeekend or using the QR code provided here.

Who: Family Weekend is for everyone! While we want our children to meet and make special memories together, we encourage anyone interested in joining our community to attend. Most activities will have an adaptive option, and all activities are optional to accommodate the need for rest.

Extras: Alliance to Cure staff will attend and host discussion groups and information sessions. Let us know which topics interest you, and we'll try to make them happen. We also plan an adult self-care evening while the kids enjoy a movie night.

Getting Around: There are a limited number of accessible rooms available. Please indicate on your registration if you need an accessible room. Silver Bay YMCA Conference and Retreat Center is set up in such a way that everyone should be able to get around easily. The dining room and meeting room are wheelchair accessible. Most areas have paved roads and sidewalks, and the camp offers golf cart assistance to farther out spots like the beach and boathouse.

We look forward to a fantastic extended weekend with our Alliance to Cure family!

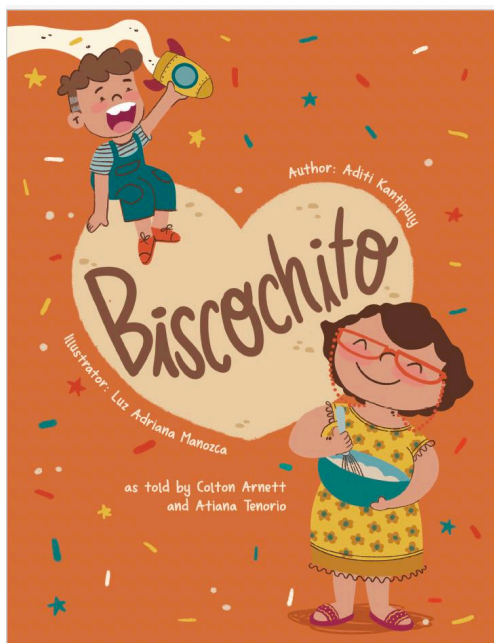


Silver Bay YMCA - Silver Bay, NY

June 28th-July 1st, 2024



Children's Book "Biscochito" Released



In January, Dr. Aditi Kantipuly, a recently graduated physician specializing in public health and rare diseases, joined the Alliance to Cure for a 6-month fellowship. Dr. Kantipuly focused her activities on our New Mexico families affected by the Common Hispanic Mutation. She had one special project in mind – creating a book to help explain familial CCM to younger children. Dr. Kantipuly had prior experience, having written and published *"The Rare Alphabet"* as a medical student.

The project started with a Zoom conversation with two of our New Mexico children. Dr. Kantipuly learned from Colton Arnett and Atiana Tenorio that kids with CCM mostly want reassurance they will be okay. The kids talked about their medical involvement and how the illness runs in their family.

Dr. Kantipuly also researched New Mexico and its Hispanic heritage to find an authentic and empathetic way to present medical information. She discovered that New Mexico is the only state that has a state cookie, the biscochito – a sugar cookie with many variations. The cookie served as inspiration. *Biscochito* tells the story of Nana and her

grandson Mateo baking cookies and sharing information about Nana's health condition through cookie shapes. Nana's wisdom goes beyond the kitchen walls, through lessons of love and strength that arise from supporting each other, one biscochito at a time.

On October 14th, the New Mexico chapter held a book launch event in Albuquerque that included a biscochito bake-off, won by our newest member of the Board of Directors, Christina Campos, and a book signing featuring authors Colton Arnett, Atiana Tenorio, and Dr. Kantipuly.

The book has been beautifully illustrated by Luz Adriana Manozca and designed by our member Sarah Baron. You can obtain a hardcover copy with a \$20 or more donation at rebrand.ly/biscochito. The book is most appropriate for those with the hereditary form of CCM.

Family Conference 2023: Watch the Highlights

Our family conference in Miami brought together adults and children from around the world to spend time learning from the experts and each other. In case you couldn't be there, the following conference presentations are featured on our YouTube channel: rebrand.ly/FamilyConf2023Video.

- Dr. Chris Gibson, Recursion Pharmaceuticals, Keynote address: *Revolutionizing Drug Development – Insights from the Past and Visions for the Future*
- Dr. Kelly Flemming and Dr. Gary Steinberg Answer Your Questions
- Dr. Ed Smith, Boston Children's Hospital, *What Good Care Looks Like*
- Delaney Fisher, UVA, *Progress in Focused Ultrasound Research*
- Dr. Connie Lee, Alliance to Cure, *Patient Priorities*
- Dr. Miguel Lopez Ramirez, UCSD, *Molecular, Genetic, and Cellular Mechanisms that Regulate the Vasculature*
- Dr. Darla Clayton, Alliance to Cure, *Coping and Cognitive Rehabilitation*
- Dr. Jacques Morcos, University of Miami, *CCM Clinical Decision-Making*
- Alliance to Cure Science Team, *Getting to a Cure*

Meet Our New Board Members



Christina Campos has served as the administrator of Guadalupe County Hospital, a 10-bed PPS hospital in rural Santa Rosa, New Mexico, for over 19 years. Under her leadership, her hospital was recognized as a Top 20 Community Hospital by the National Rural Health Association in 2019, 2020, and 2021. She is married to Jose Campos, and together they have three adult children and two grandchildren. Joe and two of Christina's daughters are affected by the Common Hispanic Mutation.



Kristen Lewis became involved with our organization shortly after she was diagnosed with CCM1 in 2011. This is Kristen's second time serving on the board. Kristen received her law degree from UCLA and currently works as a public interest attorney, with a focus on juvenile law. Kristen lives in Portland, Oregon with her husband, two teenagers, and Doodles. Having personally undergone both brain and spinal cord surgery, Kristen is not only passionate about finding a cure, but also helping to support and improve the patient experience.



Dorothy Robinson is an attorney who has spent her legal career in the higher education and nonprofit world, including serving as Yale University general counsel for some 30 years. Dorothy has served on numerous boards in higher education, research, K-12, and in other types of nonprofits and is currently a board member of Swarthmore College and of Oak Spring Garden Foundation in Virginia. Dorothy's daughter, a San Francisco artist, was diagnosed with cavernous malformation as a young adult, which led to Dorothy's enthusiastic involvement with the Alliance to Cure Cavernous Malformation.

Our Values

The Alliance to Cure Cavernous Malformation has adopted a Values Statement to guide us in our mission to inform, support, and empower those affected by cavernous malformations and drive research for better treatments and a cure. We embrace these values internally as an organization and as the public representatives of the patient community.

Think big and act big. We are in urgent pursuit of finding a permanent cure for CCM. We will persevere until no one ever suffers from CCM again. We innovate, collaborate, and aim high to achieve our goal.

Earn trust, always. We strive to be a trusted partner who can always be counted on to do the necessary work, and to act with transparency, discretion, and integrity in everything we do. We believe that a culture of trust makes us more productive and better collaborators.

Empower and engage everyone. We know that solutions don't look the same for everyone, so we meet each community and individual where they are. Our diverse community is stronger and our research is more powerful when there is equity, access to information, and everyone is included and feels a sense of belonging.

Champion each other. Patients and their families are our North Star. Every day we aim to support each other as we face the many challenges from CCM in all its forms. Whether it is with resources, support, or our vision for a cure and better treatments, we hold our community close.

Seize opportunities. We believe that developing a cure requires science and so much more. So, we listen for ideas from endless sources—from global experts to individual families—to synthesize viewpoints from this broad base and understand the big picture. This is our superpower: we identify and create sweet spots where science, patients, and partners converge to move us forward to the cure.

Patient Registry and Biobank Need You!

The Alliance to Cure has a new Cavernous Malformation Registry and Biobank, and we need your help to fill them!

Our Patient Registry

The Alliance to Cure has hosted a patient registry since 2011, but it has had some limitations. This year, we've been busy moving to a new platform, adding IRB oversight, and updating our surveys so they are asking the most relevant questions. We have built the Cavernous Malformation Registry, and now we need our members to come.

Even if you are in our original registry, we ask that you re-register at ccmregistry.org. It takes only 20 minutes and is the most important thing you can do to advance research toward a cure. The Cavernous Malformation Registry is also where you would let us know you're interested in our free genetic testing program.

With a robust Cavernous Malformation Registry, we can tell researchers and industry partners about the lived experiences of our members. We get their attention when we mention to treatment developers that our original registry has over 3,500 participants. This level of participation is unusual for a rare disease, making it easier for those launching clinical trials to create good study designs. They need information like how often patients hemorrhage or have seizures, the brain location of lesions, or the geographic distribution of patients. With this information, they can determine how many people are needed in their trial and where to locate the sites.

The Cavernous Malformation Registry is also how we communicate research opportunities to you. By keeping your contact information current, you will receive an email whenever a study opens for which you might qualify. Often, the studies are surveys. Sometimes, they involve interviews or blood samples. In all cases, the only way we can move treatments forward is with your participation.

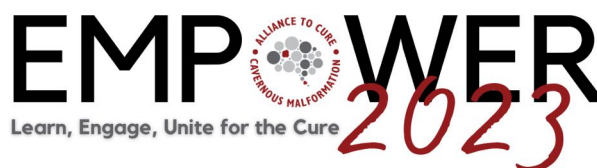
Our Biobank

The Alliance to Cure has hosted a DNA/Tissue Bank since 2006 and has been the major source of cavernous malformation tissue to academic research labs globally, particularly from 2008 to 2017. After 2017, research shifted, and tissue was not as in demand. In the last two years, there has been a resurgent need for tissue and other types of biological samples, like plasma. To address this, we have opened a new Biobank at Texas Heart Institute, where we hope to build a robust resource for research. Our current advantage is that we have a network of CCM Clinical Centers. We are asking the neurosurgeons at institutions where tissue is not already used for research to work with us to preserve this precious resource. If you have surgery scheduled at one of our Centers, please let us know. The most useful tissue for researchers is tissue from individuals for whom we know the history of the disease, e.g., does the donor have a long history with CCM, or is this a new diagnosis? When you enroll in the Biobank, we ask that you also enroll in the Cavernous Malformation Registry and provide this kind of information. Your surgeon is not allowed to share it with us. Your identity is never released to a researcher without your permission. The details of your experience and the tissue you donate will remain anonymous.

We sincerely thank you for taking the time to create this resource. For questions, please email coordinator@allliancetocure.org.

Empower 2023

Thank you to all who attended our summer special event, Empower 2023. The event provided a unique opportunity for viewers to learn about the latest research, meet our families, and engage with others who share a passion for a CCM cure. If you missed it, a recording is available on our YouTube channel at rebrand.ly/Empower2023.



Tracy's Spinal CCM Story

"All my life of being a nurse, I've battled so hard for my patients, going up against physicians and surgeons by being their advocate; I was like, 'It's my turn now.'"

In January 2020, Tracy Sacre was on the mountain, snowboarding with her family, when she first noticed symptoms. She'd bum-dropped from the chairlift when she began to feel off; a couple of days later, she developed bilateral weakness in both legs.

In the following days, Tracy developed further symptoms, though, as a nurse of 32 years in the Canadian health system, she was hesitant to suspect that they were anything more than age and work-related. "I just chalked it up to getting older. I'm a nurse, so still working 12-hour shifts; it's hard on the legs."

She held on to this belief for some time, but when she began to develop significant weaknesses and involuntary muscle twitching, she realized her situation was more serious than she'd thought.

As a healthcare professional, Tracy understood the importance of diagnosing an illness in its early stages. She'd done some personal research on the internet, but she knew she needed a professional opinion.

"I actually worked with a neurologist, so I called him up. I'd Googled myself mad – I thought that it was all ALS symptoms. I went into his office, and he started testing reflexes. I had hyper-reflexes on the

right and hypo-reflexes on the left. Then it switched between my arms and legs. He was like, 'It's not ALS. It's something higher up in your spinal cord,' but he couldn't quite figure it out."

Tracy had an MRI, but not at the hospital where she worked because she wanted to get in sooner. When she got her results back, she was upset to find out she'd been diagnosed with an astrocytoma.

Realizing the implications of such a condition, Tracy asked for a second MRI at her home institution to confirm the diagnosis.

"I begged and pleaded with a few of the techs I worked with, and eventually, they gave me a second MRI."

Tracy wasn't able to have her reports read by a specialized neuroradiologist. Instead, her reports were read at her local hospital, and just as in the first report, the diagnosis was an astrocytoma.

Despite a second diagnosis of the same condition, Tracy remained undeterred; she was an example of the power of self-advocacy. "So many times, with patients, we would find something different if we pushed a little harder, so that was the drive within me."

Eventually, she got an MRI at Vancouver General, where a neuroradiologist read it. This time, finally, she was diagnosed with a cavernous malformation in the spine. Tracy was told that this was her best-case scenario and that she should go back to living life as



normal; they advised that she only have surgery if she became unable to walk.

Though this diagnosis partly came as a relief to Tracy, who, up until this point, was preparing for the worst, something didn't sit right with her. The uncertainty and "wait and see" attitude wouldn't do.

Through the end of 2022, her symptoms worsened. Slowly, she began to lose more strength in her legs, and new deficits like balance issues emerged. Around this time, Tracy began to research cavernous malformations. She eventually found The Alliance to Cure and joined the Facebook group where she read patient stories, both good and bad.

One day, Tracy was scrolling through the Facebook group when she encountered a comment on a post. The comment was from a mother who shared her son's story of successful surgery for a spinal cavernous malformation in the exact location as Tracy's. Dr. Gary Steinberg had performed the surgery at Stanford Health Care, an Alliance to Cure CCM Center of Excellence. Recognizing her condition's worsening state and limited treatment options, Tracy knew she had to get in contact.

"I phoned the international health team at Stanford in late February of 2023 and said, 'This is who I am. I'm in Canada; can I somehow get an appointment with Dr. Steinberg?' The team was amazing."

The team at Stanford told Tracy to send in her scans for review. Less than three days later, Tracy received a message through the team from Dr. Steinberg saying he believed he could operate safely.

"He said that my scans had shown that my cav had bled multiple times."

Two weeks later, Tracy was down at Stanford for the removal of her cavernous malformation, which was located between her T5 and T6 vertebrae.

"I think it was the biggest spinal cavernous malformation he'd ever removed. It was like an inch and a half thick, compressing 60% of my spinal cord. That was March 28, 2023."

Before her surgery, Tracy was told she would have to spend a few nights in the neuro ICU, then move to a neuro floor and eventually to neuro rehab.

"I got out of surgery at midnight and spent that day and night in the hospital. I was discharged the next day, walking, not all that fabulous, but walking." Six days post-surgery, Tracy and her husband flew back to Vancouver.

"I was using a walker for long distances. In the house, I was stumbling around but walking on my own. I started intensive rehab two weeks later. I've been doing rehab for two to three days a week. I'm no longer walking with a walker; I'm back driving and fighting to get back to work."

Tracy explained the support she's received from her colleagues throughout her journey. "As they found out that I was heading down to Stanford for surgery, they said, 'If anybody's going to come out of this and be ok, it's you because you have so much nursing karma behind you.'"

She's still an active member of the Facebook group, also signing up for all the Alliance's studies and surveys. She maintains a friendship with the mother whose comment first informed her of Dr. Steinberg and the Stanford team.

"I sent her a message after I had surgery and said, 'You saved my life the day you posted.' Without the Alliance, I wouldn't be where I am."

Tracy explained that, above all else in her journey, she's learned to be patient with herself and to allow herself time to recover.

"You know, patience with yourself for sure, and allowing yourself to take the time to heal. I'm trying to get back to work, and they're not letting me; I want to, but I need to be patient with myself."

She reflected on the importance of maintaining a positive mindset and having faith in the hands of others, even when faced with great uncertainty.

"It's so weird because I wasn't nervous on the day of my surgery. I knew I just needed to hand it over to them now. There was nothing I could do. There was nothing left to do; that was weird for me because I'm a control freak. I always have plans B, C, D, and E. It was just this feeling of knowing, and you won't ever know what that feeling is like until you're in that situation. It felt right, for lack of any better way to explain it. It's almost unexplainable."

Robert Neithart

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Where the world comes for answers



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 (also known as cavernous angiomas or CCM). Our mission is to inform, support, and empower individuals affected by cavernous malformation and drive research for treatments and a cure. We are monitored closely in our educational efforts by a Scientific Advisory Board comprised of leading cerebrovascular neurosurgeons, neurogeneticists, and neurologists.

Alliance to Cure Cavernous Malformation

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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.

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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.
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- 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.
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- 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.