

ALLIANCE TO CURE NEWSLETTER

CAVERNOUS MALFORMATION

Red Carpet Premiere for "Eloquent," First Film Documenting the Lives of Patients with Cavernous Malformation

Tickets Available Now for Philadelphia area Premiere, September 25, 2022

We are thrilled to share that *Eloquent*, the first-ever film documenting the lives of our patients and families, will premiere at the Ambler Theater in Ambler, PA, the morning of Sunday, September 25, 2022. *Eloquent* is the story of how families and individuals, through a devastating diagnosis and heartbreak, find hope and community. Tickets are free and can be reserved at bit.ly/EloquentPremiere. Seating is limited.

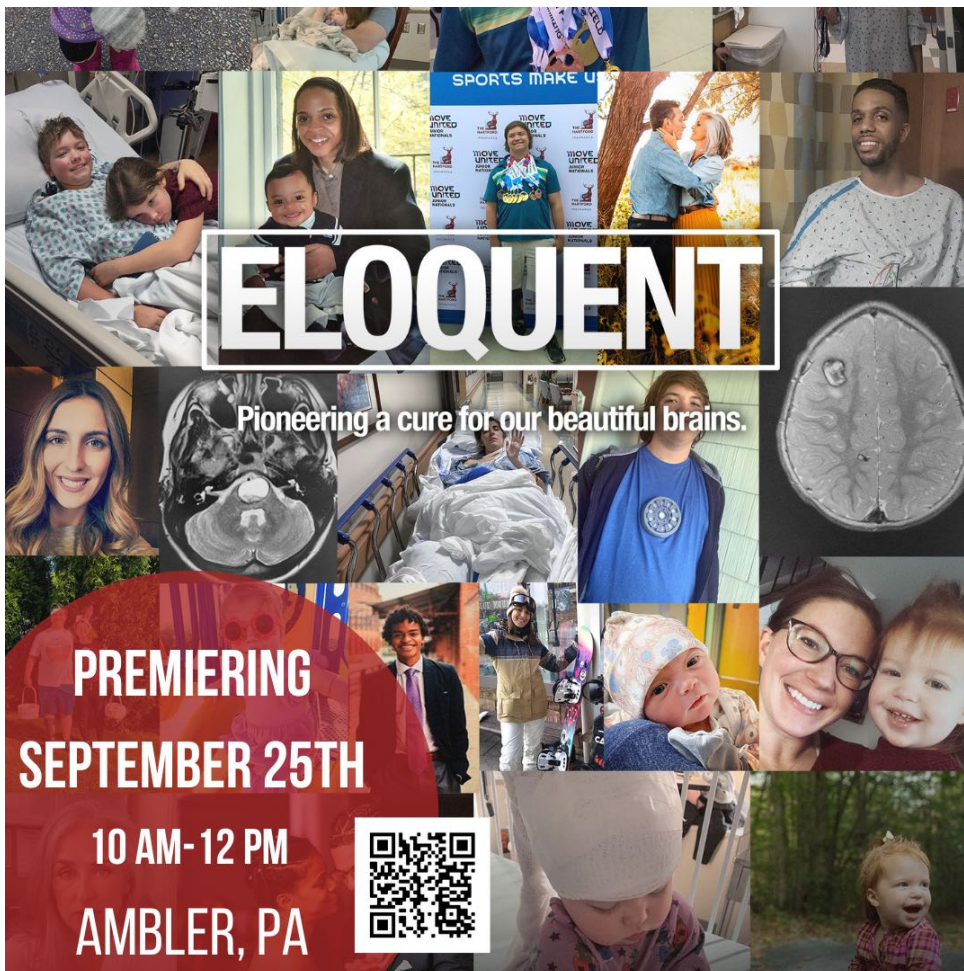
The film tells the compelling stories of five patients and their families, from New Jersey to New Mexico, illustrating the diversity of patients, breadth of disease outcomes, and importance of finding a

cure. The first documentary produced by Alliance to Cure Cavernous Malformation, together with Matthew Burnell and ClickBid, *Eloquent* is the most complete portrayal yet of life with cavernous malformation, and it describes cutting-edge progress toward treatments and a cure.

Our team has submitted *Eloquent* to film festivals and will share festival updates online at bit.ly/EloquentFilm, where the trailer is available now. In advance of the online world premiere, which will take place later this year, the documentary is available for private showings. If you are interested in hosting a private screening in your home or other venue, contact Lindsay@AllianceToCure.org to make arrangements.

Eloquent highlights issues important to our community, including the potential for drugs to be developed to treat cavernous malformation, the value of Centers of Excellence in providing superior patient care, and the need for a diverse patient base in clinical trials. In interviews, the world's leading experts and visionaries explain the disease, convey the urgency in finding a cure for this difficult-to-solve problem and show just how close we are to achieving it.


Eloquent will inform and inspire patients, families, and our community with a powerful story of our beautiful brains and the promise of a cure. We hope to see you at the premiere!



ELOQUENT

Pioneering a cure for our beautiful brains.

**PREMIERING
SEPTEMBER 25TH
10 AM-12 PM
AMBLER, PA**



2022 National Patient Conference: Together Again

Please join us on Friday and Saturday, November 18-19, at the Washington Duke Hotel and Golf Club in Durham, North Carolina for our 2022 National Patient Conference.

This conference is held concurrently with the International Scientific Meeting, so patients and researchers can share sessions and meals. Patients can attend the keynote lecture by Dr. Douglas Marchuk of Duke University, and have breakfast, lunch, and breaks with researchers on Friday. The remainder of the day will be filled with patient-targeted expert presentations. On Saturday, there will be additional talks, conversation groups, a tour of the Duke lab and campus, and opportunities to participate in research studies.

Past conference participants have described our meetings as life-changing because of the insights and hope they gained and the lifelong friendships they made.

Registration is now open. Please note the early and late registration dates. Visit our registration page at bit.ly/2022CCMPatientMeeting for more information.

- Early registration through September 30 is \$60.
- Registration from October 1 – October 31 is \$80
- Late registration (after October 31) is \$100

Hotel reservation information is available on the registration page and our website. Rooms at the Washington Duke Inn are \$199/night for single or double occupancy.

COVID precautions: attendees must have proof of vaccination and be willing to mask and undergo a COVID antigen test.

We would love to see you. Come and be inspired!

Recursion REC-994 Sycamore Trial Update Webinar

Please join us on Thursday, September 29, at 7 pm ET, 4 pm PT, for an update by Dr. Glenn Morrison, Recursion Pharmaceutical's Vice President for Clinical Development, Neuroscience, and Rare Disease as he shares the latest information on the REC-994 Phase 2 Sycamore Trial.

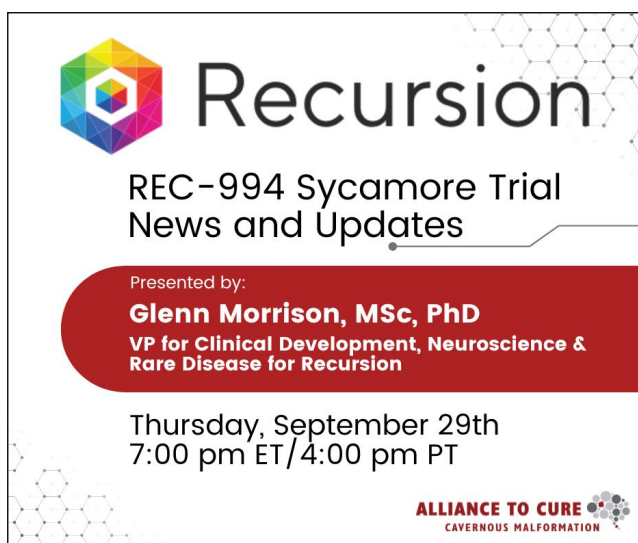
This is the first medicine to go to trials that has been developed specifically for CCM. Currently, clinical trial sites are open around the United States, including in:

Phoenix, AZ	Palo Alto, CA
Los Angeles, CA	Jacksonville, FL
Ridgewood, NJ	Pittsburgh, PA
Philadelphia, PA	Dallas, TX
Charlottesville, VA	

More sites will be opening over the coming months.

To register for the webinar, please visit bit.ly/RecursionWebinar

To learn more about the trial, please visit our website: www.alliancetocure.org/research-clinical-trials/participate-in-trials/rec-994/



The poster features the Recursion logo (a colorful hexagon) on the left. To its right, the word "Recursion" is written in a large, black, sans-serif font. Below this, "REC-994 Sycamore Trial News and Updates" is written in a smaller, black, sans-serif font. A red banner with white text follows, stating "Presented by: Glenn Morrison, MSc, PhD" and "VP for Clinical Development, Neuroscience & Rare Disease for Recursion". Below the banner, the date and time "Thursday, September 29th 7:00 pm ET/4:00 pm PT" are listed. At the bottom right, the "ALLIANCE TO CURE" logo is displayed, with "CAVERNOUS MALFORMATION" written underneath it. The background of the poster is white with a faint, light blue molecular structure pattern.

Atorvastatin Trial Has Completed Enrollment

The atorvastatin experimental proof of concept trial to treat cavernous malformations with symptomatic hemorrhage, hosted at the University of Chicago, has completed enrollment.

From Dr. Issam Awad, "We thank the patient community for their engagement in this project and urge all enrolled subjects to maintain compliance and complete the required follow-ups to allow us to test the hypotheses which are critical to further progress in treating CCM patients."

The atorvastatin experimental proof-of-concept CASH trial aims to evaluate the effectiveness of a currently approved and widely used drug, atorvastatin, in stabilizing cerebral cavernous malformations that have caused a symptomatic bleed. Atorvastatin is a statin cholesterol-lowering drug also used to prevent stroke and heart attack.

Statins have wide-ranging effects in the body and are known to alter many different chemical signaling systems. CCM researchers have shown that the Rho Kinase (ROCK) inhibiting activity of statins may have potential therapeutic effects in human CCM patients. In mice, statin treatment can reduce lesion size, number, and bleeding.

It is unclear if statins in general, and atorvastatin at the prescribed dose, are safe to treat cavernous malformations. It is possible that statins might not prevent bleeding in cavernous malformations in humans as they did in mice. It is even possible that the drug might worsen bleeding or cause other complications in this disease. A clinical trial is the only way to determine whether the drug might be helpful and prevent a drug from being widely used without benefit or even with an added risk. The trial is designed to answer the question of whether atorvastatin decreases (or worsens) bleeding in a cavernous malformation after a recent symptomatic bleed.

Because the trial requires participants to take the medicine for two years, we may not have final results until 2024. However, interim results may be released earlier. As soon as we have information, we will invite Dr. Issam Awad to share the results in a webinar.

Blood clot formation in cerebral cavernous malformations

In a new study from Uppsala University, researchers show that blood coagulation and blood clot formation are very relevant for CCM disease and that antithrombotic therapy may be beneficial for cavernoma patients. For a long time, antithrombotic therapy was not prescribed for CCM patients because of the risk of hemorrhage, but more recent studies show that such therapy does not promote hemorrhage and could even be beneficial.

To determine the role of blood coagulation and the formation of blood clots (thrombosis) in CCM, the researchers in the present study have examined mice with a mutation that results in blood vessel lesions similar to the ones in humans with CCM. They have also examined brain tissues from CCM patients.

"Our experiments have provided several indications that coagulation is an important factor in CCM. In both mice and humans, we discovered blood clots in the vessel lesions. Several genes that are involved in coagulation were also more active in mice with CCM lesions than in control mice," says Peetra Magnusson, researcher at the Department of Immunology, Genetics and Pathology, who has led the study.

The researchers were able to identify a number of proteins that contribute to coagulation but also some anticoagulant proteins. These proteins were localized in different areas of the lesions, which suggests that some regions are prone to thrombi while others are prone to hemorrhage.

The study also showed that the tissues surrounding the lesions with thrombosis were hypoxic.

"Prolonged exposure to hypoxia may lead to neural cell loss and cell death. We think that this might cause the neuropathological conditions such as stroke," says Magnusson.

The results from the study, published in *Blood*, support the concept that antithrombotic therapy may be beneficial for patients with CCM. An increased understanding of the molecular mechanisms behind the coagulation could give insights regarding suitable antithrombotic pharmaceuticals for CCM patients.

Maria Ascencion Globisch et al, Immunothrombosis and vascular heterogeneity in cerebral cavernous malformation, *Blood* (2022).

Consortium Wins Grant to Plan International Trial

A consortium led by Professor Rustam Al-Shahi Salman at the University of Edinburgh and joined by Dr. Issam Awad, Dr. Roberto Latini, Dr. Helen Kim, and a group of patient advocacy organization leaders, has won a grant award to begin planning an international trial that would test multiple medications at a time. The Patient Advisory Board, consists of Connie Lee, David White of Cavernoma Alliance UK, Jana Bergholtz of the European Cavernoma Association, Carlos Casaus from the Alliance to Cure, and João Prosperó of the Portuguese CCM patient organization.

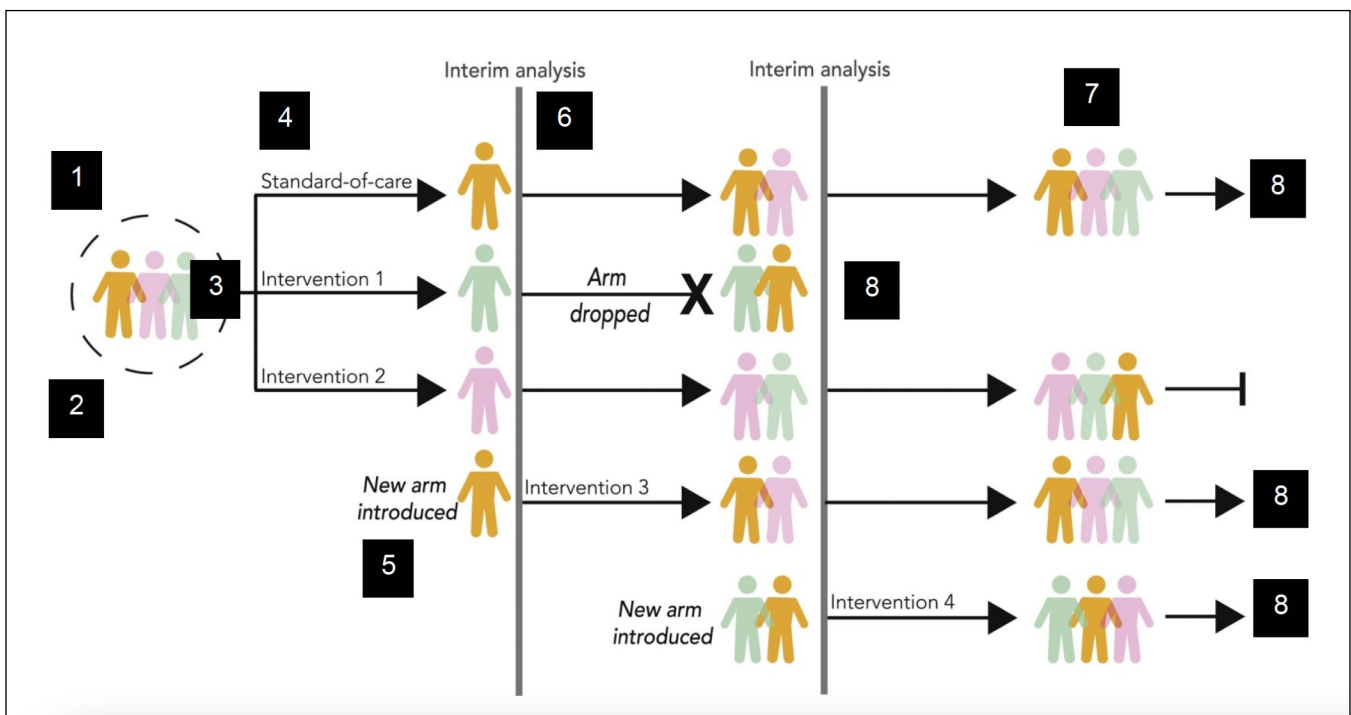
The aim of the project is to design a clinical trial using a “platform” clinical trial design. In this design, there are multiple treatment arms that share a placebo arm. Pre-planned interim evaluations allow ineffective treatments to be dropped early and new treatments to be added as replacements. This design speeds trials and requires smaller enrollment overall because of the shared placebo arm. That said, testing multiple medicines simultaneously will still require

funding and a level of participation that likely will need to reach beyond any one country’s borders.

The current grant period is short, and the planning work is expected to be completed by May 2023. Subsequently, the group can begin applying for funding for the planned trials. The medicines to be tested have not been selected; such decisions will be made during the planning process. Likely, these will be medicines that have already shown themselves to be safe for our patients.

Platform trials are cutting edge and have not yet been used for many diseases. This is primarily because of the amount of cooperation required between international research groups and the amount of funding required. We are fortunate to have a scientific community that works cooperatively to further treatments. We hope that CCM will become a model disease for this more efficient method of testing potential treatments.

Diagram reprinted from Jay J.H. Park et. al. An overview of platform trials with a checklist for clinical readers. Journal of Clinical Epidemiology. Vol. 125. Sept 2020. pp 1-8.



Upcoming Events

September is here, and our event season is, too! We have walks in the Western US and a benefit concert and documentary premiere (see page 1) in the East. If you are nearby, please be sure to take part.

These events matter. For 20 years, the Alliance to Cure has been the only patient-driven organization that supports those affected by cavernous malformations. When we congregate as family and friends to walk and fundraise, whether in Orange County, Malibu, Phoenix, or Philadelphia, we build hope and community. One more dollar, one more step, and one more story shared bring us closer to the cure.

Philadelphia Benefit Concert, September 24, 2022, from 4-6:30pm. The Sergent family is hosting a concert and art auction at Sutcliffe Park Pavilion in Conshohocken, PA. Music by Allusive Green. Entry is free. Please RSVP at bit.ly/BellasConcert

Eloquent Documentary Red Carpet Premiere, September 25, 2022. Ambler Theater, Ambler PA. 10am-12pm. Seating is limited. Tickets are free and can be reserved at bit.ly/EloquentPremiere.

Orange County 6th Annual Walk, September 25, 2022. Registration starts at 8 am. Florence Joyner Park, Mission Viejo, CA. The leaders of this walk are Lindsay Ramirez and Linda Fuchser. Learn more at bit.ly/OrangeCwalk

Malibu 8th Annual Walk, October 2, 2022. Registration starts at 8 am. Zuma Beach, 30000 Pacific Coast Hwy, Malibu, CA. The leaders of this walk are Judy Kogan and Linda Fuchser. Learn more at bit.ly/malibubeachwalk.



MALIBU 5K
BENEFITTING THE
ALLIANCE TO CURE CAVERNOUS MALFORMATION

ZUMA BEACH 30000 PCH, MALIBU

OCTOBER 2, 2022 EVENT INFO:

8:00 AM REGISTRATION	WALK/RUN, GAMES,
9:00 AM START	RAFFLE, & FOOD
FREE REGISTRATION	RAISE/DONATE \$35
	FOR A T-SHIRT

Questions
JUDITHAMANDA@GMAIL.COM

SCAN ME



Arizona 2nd Annual Walk, November 5, 2022. Foothills Park, 5708 W Union Hills Dr., Glendale, AZ. The leaders of this walk are Megan Loden and Chris Coates.



6TH ANNUAL ORANGE COUNTY 5K WALK/RUN

SUNDAY SEPTEMBER 25, 2022

8 AM REGISTRATION 9 AM START
FLORENCE JOYNER OLYMPIAD PARK
22760 OLYMPIAD RD MISSION VIEJO

EVENT INFO

WALK/RUN, 1 MILE SCAVENGER HUNT, GAMES,
RAFFLE ITEMS, AND BIG E'S FAMOUS BREAKFAST
WITH NOTHING HEALTHY ON THE SIDE

SCAN ME



ARIZONA COMMUNITY
Alliance to Cure Cavernous Malformation
Walk @ Foothills Park



Join us: Saturday, November 5, 2022
5708 W Union Hills Dr. Glendale, AZ 85308
Registration begins @ 8 AM; Event will include a walk through the park, a silent auction, and games for the kids.

SCAN ME



Alliance to Cure Establishes a Medical Advisory Board

The Alliance to Cure Cavernous Malformation has established a Medical Advisory Board (MAB), separate from its existing Scientific Advisory Board. Dr. Edward Smith, Director, Pediatric Cerebrovascular Neurosurgery and Medical Director of the Alliance to Cure's Center of Excellence at Boston Children's Hospital will be the inaugural chair of the Medical Advisory Board and Dr. Kelly Flemming, neurologist and Medical Director of the Alliance to Cure's Center of Excellence at the Mayo Clinic will serve as Vice-Chair.

The MAB provides direction to the Alliance's Board of Directors and staff in the areas of advocacy, program development, and overall service needs. Advisors serve as a resource on scientific and medical issues, including:

- Offer general opinions on methods of managing and treating the condition.
- Review Alliance to Cure literature to ensure information is medically accurate.
- Collaborate on revisions to the CCM Clinical Care Consensus Guidelines and other clinical guideline documents as they are developed.
- Offer opinions, guidance, and referrals for CCM Clinical Center standards and sites.
- Stay up to date on newly published CCM research.

Some MAB members may take part in the following:

- Advance research.
- Offer opinions on clinical trial prioritization, clinical trial design, and industry relations.
- Identify and advise on promising areas of clinical research.
- Promote the Alliance's Patient Registry to patients and peers.
- Share information and raise awareness.
- Speak with the media as a subject matter expert and offer quotes for press releases.
- Actively educate professional and lay audiences about the condition.
- Educate patients including in webinars and at patient conferences.

We are grateful to Dr. Smith and Dr. Flemming for their willingness to spearhead this important addition to the Alliance to Cure Cavernous Malformation's program to improve patient care. We will be announcing additional members of the MAB as they are added.



Duke University Hospital Recognized as a CCM Center of Excellence

Duke University Hospital has been recognized by the Alliance to Cure Cavernous Malformation as a CCM Center of Excellence. Duke has long had a leading CCM research lab, led by Dr. Doug Marchuk. Now, Duke has added a multi-disciplinary integrated clinical program to offer expert care to our patients.

Led by neurosurgeon Dr. David Hasan, who trained under Dr. Issam Awad, and neurologist Dr. Wayne Feng, the CCM Center of Excellence sees more than 80 CCM patients each year. The Center's faculty includes cerebrovascular neurosurgeons, a pediatric neurosurgeon, stroke and epilepsy neurologists, a geneticist, ophthalmologist, and a high-risk obstetrician.

We congratulate Drs. Hasan and Feng for their commitment to our families and for excellence in patient care. Attendees of this year's National Patient Conference will have the opportunity to meet the Duke Center staff. A plaque presentation ceremony will be part of the conference.

To schedule an appointment at the Duke CCM Center of Excellence, please call 919-604-3964.

Spines Shouldn't Bleed: Lizzie's Story

"When she was four, Lizzie became paralyzed from the belly button down overnight. She woke up in the middle of the night crying but couldn't really explain what she was feeling, what was bothering her," shares Christy Schulz, Lizzie's mother and her fiercest advocate. Christy and Lizzie's father Ryan rushed Lizzie to urgent care in their Evansville, Indiana hometown, but because Lizzie threw up while they were being seen, the doctor sent them home, saying, "Oh, she has a stomach bug."

A visit to the pediatrician a few days later led to a more specific, but still wildly incorrect diagnosis. According to Christy, the doctor told them Lizzie "probably had viral synovitis, meaning some kind of virus she had was causing her not to want to walk." As a safeguard, the pediatrician sent her for a hip x-ray to rule out any hip issues that might be causing the paralysis. While the result was normal, something unusual happened during the x-ray procedure. "When she was on the table, getting an x ray of her hips, she wet herself," said Christy. This happened again when she got home. Lizzie had been potty-trained for years.

A few days later, at the urging of a friend who was in the medical field, Christy and Ryan took Lizzie to their local emergency room. "It didn't take them very long to say, 'We don't know for sure what's going on, but this is bigger than what we can deal with,'" said Christy. The emergency room staff sent the family to a larger children's hospital in Indiana.

At the children's hospital, Lizzie had a brain and spinal MRI and a lumbar puncture. Christy notes, "it was such a whirlwind. There were just so many things that happened, that I don't think I remember them all." The radiologists saw blood in Lizzie's spinal cord but couldn't explain why it was there. They felt the likeliest explanation was transverse myelitis, an inflammation of the spinal cord. To treat the transverse myelitis, "she had several rounds of IV Ig. She had a strong steroid. She did physical therapy and occupational therapy. We were there for three weeks."

After three weeks, they were transferred to Cincinnati Children's Hospital for inpatient rehabilitation where they met with the transverse myelitis team. "And they were immediately like, that's not what's going on here. We're not sure what it is, but that's not it," said Christy. Lizzie had more imaging. At Cincinnati Children's, more than a month after she became paralyzed, Lizzie received a diagnosis of cavernous malformation in the spinal cord.

While cavernous malformations are often thought of as a brain disease, that sometimes isn't the case. About 10% of patients have a lesion in their spinal cord. The spine is divided into three sections: the cervical spine which ends below the neck, the thoracic spine which ends above the small of the back, and the lumbar spine. Cavernous malformations form primarily in the cervical and thoracic spine. These lesions can cause motor weakness or paralysis, neuropathy (tingling, pain), and loss of bowel and bladder function. The part of the body that is affected and which symptoms are present depend on the lesion's level in the spine and the size and its activity.

Lizzie was diagnosed with two lesions in the thoracic spine, one at the 9th thoracic vertebra (T9) and one that spanned an area between the 11th and 12th thoracic vertebrae (T11-T12). Lesions at this level of the spine can cause issues with the legs – paralysis,



weakness, tingling, pain – and bladder and bowel difficulties. Four-year-old Lizzie had no reflexes, no muscle tone, no bowel and bladder control, and, from the Schulz's perspective, there no indication from the care team that these deficits could be anything but permanent.

Now that the family had a diagnosis, they were faced with making treatment decisions. Ryan Schulz found the Alliance to Cure Cavernous Malformation through a friend of a friend who happened to have a young daughter with a brainstem lesion. The family was connected to Tony Mayer, Alliance to Cure Board Chair, and Connie Lee who offered support and



referrals to experts.

Even experts disagreed on the best course. Two suggested immediate surgery, but the family wanted to be sure before committing to such a potentially dangerous and permanent procedure. When the family contacted Dr. Ed Smith at Boston Children's Hospital as a third expert, they received a different opinion.

"He said that he would wait on surgery and do imaging a little further down the road once things in her spinal cord calmed down to see what it looked like. We could go from there. And so, then, we're faced with this huge decision. We've got some these experts saying, 'Do surgery and get rid of it.' And then Dr. Smith saying, 'No, I would wait'. It was scary. We had never heard of cavernous malformation before. We had no idea what we were in for. We decided to go with what Dr. Smith said and take a more conservative approach and just wait and see. And the thing that got us was when he said, 'You know if we do surgery now, and she doesn't walk again, you'll never know if it was because of the surgery or if she just wouldn't have regained the ability to walk. But if we wait, and she does regain the ability to walk, then that's pretty big.'"

After three more weeks at Cincinnati Children's, the family returned home for two days a week of home therapy. Lizzie had regained some movement in the right leg, but none in her left. She still had no bowel or bladder control. A subsequent urinary tract infection led to the decision that Lizzie would need catheterization to urinate. This was expected to be lifelong, and she would eventually need to learn to do this herself.

Two months after discharge, Lizzie had repeat imaging. The happy surprise was that only one cavernous malformation, the one at T9, was visible. The other lower lesion had likely been just a pool of blood. The family had been worried that Lizzie's condition was genetic since she was diagnosed with multiple lesions. Christy and Ryan have two other children – Lizzie might not have been their only child with the illness. With this imaging news and negative genetic tests, they were confident Lizzie's case was sporadic.

Lizzie's original spinal cavernous malformation hemorrhage was 6 years ago. She is now 10 years old and in 5th grade. In the meantime, she has been through outpatient rehabilitation in Louisville Kentucky five times a week with a 4-hour roundtrip each day, followed by ongoing therapy closer to home at least twice a week since. She has learned to catheterize herself and has figured out how to work this into her regular life, including her school life. Her bowel issues are equally self-managed. Her cavernous

malformation has reduced from 15 millimeters to 7 millimeters.

Best of all, she is walking. In fact, "her left leg is only 10-15% weaker than her right leg," says Christy. "She's still making a lot of improvements. She is really involved in school. She does cheerleading, gymnastics, and horseback riding. She learned how to ride her bike without training wheels a couple summers ago and rides her bike all over the neighborhood. Of course, there's a lot of behind-the-scenes work that makes this possible, and it's always still in the back of our minds that her cav could act up again. But she's doing really well."

When asked how the Alliance to Cure Cavernous Malformation has been helpful, Christy teared up, "There's this group of people that understands it, that knows about it, that lives with it daily. I know people empathize with what she's experienced, but this group actually understands on a bigger level."

Christy recently joined the Alliance to Cure's Board of Directors. When asked how she hoped to make a difference, she replied, "I think the biggest thing for me personally, is to be able to help other people that might experience this be able to find their place here as well. To be able to spread awareness, to share knowledge, to share life experiences, and help others who might be new to it and that are scared and wondering what it's gonna look like down the road and what to expect moving forward. It's such a vast group because everyone's experiences are so different, and their symptoms are so different. But I think that's something that's great about it too, because I've learned so much from other people in the group and want to be able to be a part of that and share with others moving forward."

The Alliance to Cure Cavernous Malformation's work for faster diagnosis, better treatments, and a cure includes spinal cavernous malformations, because spines shouldn't bleed either.

For more information about spinal cavernous malformations, please visit our website at www.alliancetocure.org/cavernous-angioma-in-depth/symptoms/spinal-lesions/

Scary Mommy Blog on Medical Gaslighting Features Board Member

Alliance to Cure Cavernous Malformation Board Member Dr. Kimberly Foley was featured in an article on the blog *Scary Mommy* discussing medical gaslighting. Medical gaslighting is a term coined to describe medical professionals dismissing concerns of patients. In the article, she shared her own experience.

"I know what it feels like to be in the patient's seat, wanting to be understood and listened to. At age 36 years old, I was diagnosed with cavernous cerebral angioma. I had just returned from a trip overseas and experienced an extreme left-sided electric headache while still at the airport... As the frequency and intensity of the pain increased, I wondered if this was the 'worst headache of your life' described in textbooks — a subarachnoid hemorrhage and life-threatening — or if it's just an earache. Even with slight numbness and tingling in my left hand and foot, I attributed my symptoms to being tired and stressed. This was not your normal headache, but I'm not a hypochondriac," explains Foley.

When her symptoms persisted for over 24 hours, Dr. Foley's husband made her go to urgent care. "The urgent care doctor looked in my ear and said it looked OK, had no infection, and sent me home. Symptoms persisted over the weekend until the start of my shift, and I knew something wasn't right," shares Foley. "I asked a colleague, who happened to be a neurologist, to examine me, and to both our surprise, I showed signs of transverse myelitis or multiple sclerosis. An MRI was ordered, showing numerous lesions in my brain and an acute brainstem lesion that had just bled."

She continues, "How could I miss this? Had I gaslighted myself? To downplay my symptoms and ignore them, for as a Black female, I have implicit biases and fear of being a hypochondriac and slacking... something to think about."

Read the full article with Dr. Foley's tips for avoiding medical gaslighting here: www.scarymommy.com/lifestyle/medical-gaslighting-signs

ALLIANCE TO CURE

CAVERNOUS MALFORMATION



Thank you to our Promise 2022 sponsors!



Recursion



AT THE FOREFRONT
UChicago
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How You Can Help

Volunteer: Share your talent and time in any number of ways including Community Alliances, peer support, events, legislative advocacy, and much more: www.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 mobilize individuals affected by cavernous malformation and drive research for better treatments and a cure. We are monitored closely in our educational efforts by a Scientific Advisory Board comprised of leading cerebrovascular neurosurgeons, neurologists, and researchers.

Alliance to Cure Cavernous Malformation

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A copy of the latest financial report, registration filed by this organization and a description of our programs and activities may be obtained by contacting us at: Alliance to Cure Cavernous Malformation, 520 W 21st St STE G2-411, Norfolk, VA 23517, info@angioma.org. If you are a resident of one of the following states, you may obtain financial information directly from the state agency. Angioma Alliance d/b/a Alliance to Cure Cavernous Malformation, EIN 02-0600697, complies with state charitable registration requirements.

- Florida – A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE, WITHIN THE STATES, 800-435-7352 (800-HELP-FLA) OR BY VISITING www.800helpfla.com. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL OR RECOMMENDATION BY THE STATE. Florida Registration CH20096
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- Colorado – Colorado residents may obtain copies of registration and financial documents from the office of the Secretary of State, 303-894-2860, www.sos.state.co.us/ Reg. No. 20063003635.
- Maryland – For the cost of copies and postage, from the Office of the Secretary of State, State House, Annapolis, MD 21401.
- Michigan – MICS # 35000
- New Jersey – INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FOR THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING 973-504-6215 AND IS AVAILABLE ON THE INTERNET AT: <http://www.state.nj.us/lps/ca/charfrm.htm>. REGISTRATION WITH THE ATTORNEY GENERAL DOES NOT IMPLY ENDORSEMENT.
- New York – Upon Request, Attorney General Charities Bureau, 102 Broadway, New York, NY 10271
- North Carolina – Financial information about this organization and a copy of its license are available for the State Solicitation Licensing Branch at 919-807-2214. This is not an endorsement by the state.
- Pennsylvania – The official registration and financial information of Angioma Alliance may be obtained from the Pennsylvania Department of State by calling toll-free within Pennsylvania 800-732-0999. Registration does not imply endorsement.
- Virginia – State Division of Consumer Affairs, Department of Agriculture and Consumer Services, PO Box 1163, Richmond, VA 23218.
- Washington – Secretary of State at 800-332-4483 or <http://www.sos.wa.gov/charities/>. REGISTRATION WITH A STATE AGENCY DOES NOT CONSTITUTE OR IMPLY ENDORSEMENT, APPROVAL OR RECOMMENDATION BY THAT STATE.