ALLIANCE TO CURE CAVERNOUS MALFORMATION NEWSLETTER

Research Explosion Drives the Need to Identify and Communicate Patient Priorities

The year is flying by; it has been full of activity and excitement in research and the development of treatments, with much more to come. In this issue, you'll read about new medicines moving into clinical trials for CCM and receive an update on the REC-994 trial which is successfully completing enrollment (thanks to you!). The 19th Annual International CCM Scientific Meeting is on our doorstep. We've had a glimpse into the research being presented, and anticipate paradigm-shifting work. Also in this issue, you'll find important new research on oral contraceptive use and hormone replacement therapy for women with cavernous malformations (CCM). We have introduced federal CCM legislation to increase research funding for our scientists, and we are directly funding four research grants with talks underway for additional work. Research efforts are moving ahead full steam; one of our roles is ensuring we understand and communicate to researchers what's important to you and your doctors.

To accomplish this, the Alliance to Cure Cavernous Malformation is developing a long-term roadmap reflecting patient priorities to guide research efforts and funding for the next five to ten years. As the first step in development, we launched two patient surveys. The first survey, comprised of open-ended questions, was distributed to members who had completed our patient-expert course. Their responses allowed us to create a closed-ended anonymous survey that was translated into 7 languages and distributed to the international patient community.

What We Learned

We had a large global response, with 464 patients and caregivers from 33 countries (43% were non-US) completing the Patient-Driven Research Roadmap Survey.

Overall, we were struck by how consistent the responses were across all the subgroups we analyzed, with just a few exceptions. In our analysis, we looked for differences between genders, race/ethnicity identification, surgery/no surgery, with a lesion/no lesion, caregiver/patient, US/outside of US, and level of disability.

A majority of our patients and caregivers (53%) feel that preventing lesion hemorrhage, proliferation, and growth should be the primary focus of research. The remaining respondents were divided among three other options. Safer removal of lesions was endorsed as the most important by 23% of our sample. This could include safer traditional surgery or non-invasive removal methods. Finding ways to reduce CCM symptoms was endorsed as the most important by 15%. Finally, addressing deficits caused by CCM hemorrhage or surgery was endorsed as most important by approximately 9% of respondents. Men were more likely to endorse addressing deficits as more important than symptoms.

As we drilled down, we asked patients to rank which research to prevent problems from lesions should be prioritized. Patients ranked non-invasive removal of lesions (31%) as a priority over developing medications to prevent hemorrhage (20%) or lesion growth (20%). While this may seem non-intuitive, safely and non-invasively removing a lesion would ideally be a permanent, one-time solution rather than require ongoing treatment.

We also asked patients which symptoms were most in need of research. By a wide margin, patients and caregivers in all groups indicated seizure (48%) was most in need of additional research. This was followed by headache (16%), pain (12%), and fatigue (9%). See the complete chart on page 2.

Next, we asked patients' opinions on their willingness to experience a range of treatment side effects relative to the benefit of treatment. Side effects were generally of two types: those that impact quality of life like fatigue, mouth sores, headache, and brain fog versus those that impact long-term health, like increased blood pressure and diabetes. For this question, there were group differences. (Cont.)

Women, non-white, and disabled members were generally less willing to experience those side effects that impair quality of life, even if there was significant benefit from treatment. We also found that those with moderate to severe disability were more likely to accept long-term health impacts from a medication.

We asked patients and caregivers about treatments that might not be as simple as taking a pill, including subcutaneous injections, IV infusions, and focused ultrasound treatments at various frequencies, from weekly to annually. All modes of administration at any frequency were widely accepted by patients (at least >80%, and most modes/frequencies were >95%).

For those with familial disease, we asked about gene therapy. Most people answering this question would be willing to undergo or consider gene therapy if the risk were relatively low (2% chance of death), but they were less willing to allow their children to undergo it. As the risk went up (5% chance of death), only those who are moderate to seriously disabled remained willing to try it, but they would not want this for their child. In other sections of the survey, gene therapy was not endorsed as a high priority for respondents.

Finally, we asked patients to rank other potential research areas to tell us what mattered to them. The highest priority for respondents was pediatric CCM (29% endorsed this as the most important). Behind this, patients and caregivers wanted more research on ongoing disease management (19%), a better understanding of long-term outcomes of the disease (13%), spinal CCM research (10%), and an understanding of why there is such variability in disease severity, even in the same family (9%).

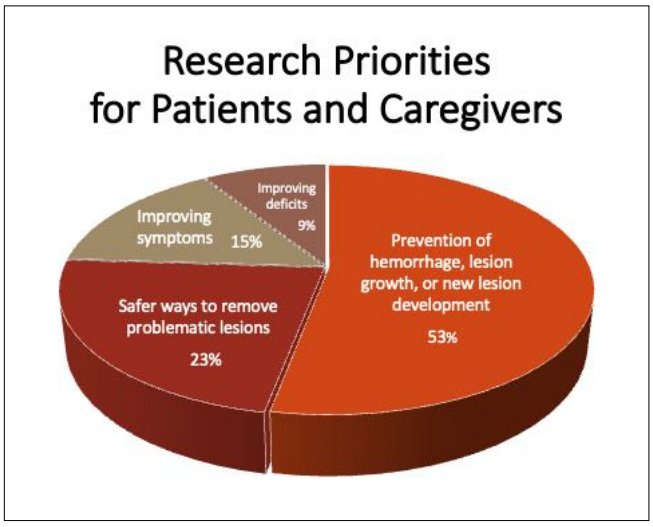
What's Next

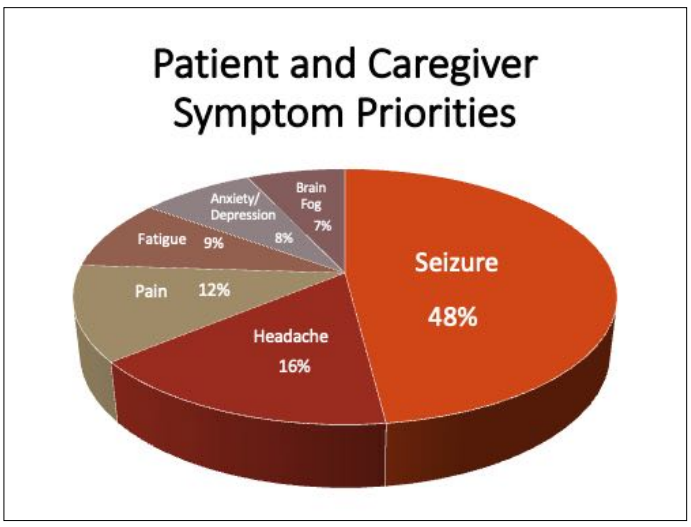
In this article, we have presented top-line results. Later, we'll release an extended report with the full underlying data. We have already used this information to create a CCM Clinician Research Priorities Survey that was distributed to our Clinical Centers, Centers of Excellence, and international expert physicians.

Once the clinician results are analyzed, we'll assemble groups of researchers to discuss the findings and create a roadmap to address the highest priorities, identifying hurdles that must be surmounted. We will also use this information to invite new researchers and industry partners into the field and to make grant funding decisions.

We're very grateful to the patients and caregivers who participated in this effort. We have learned more about our community than we could have imagined, and this information will guide our work for years to come.

Our Cavernous Malformation Registry remains our main tool for distributing surveys and informing members of new research opportunities. Please join the registry at ccmregistry.org to find out how you can participate.



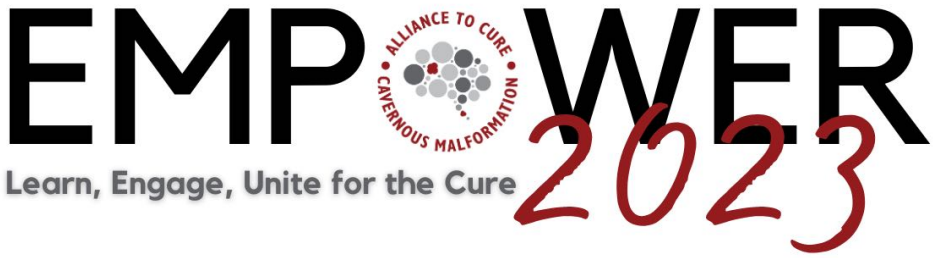


Join Us for Empower 2023 on July 29

Empower 2023 is our internationally broadcast event to empower individuals to take action toward finding a cure for cavernous malformations. The event will provide a unique opportunity for participants to learn about the latest research, engage with the CCM community, and unite with others who share the same passion for finding a cure.

This live stream event is designed to be easy to watch from the comfort of your home or vacation spot, making it accessible to anyone, anywhere.

If you or someone you know is affected by cavernous malformations, don't miss out on this opportunity. Join us on July 29th for Empower 2023 and become part of the movement towards finding a cure. The live stream will begin at 3:00 pm ET (noon PT, 20:00 BST), and new sessions will start every hour on the hour, with the final opportunity beginning at 8:00 pm ET. The link will be shared on our social media outlets, website, and email mailing list closer to the event. Come and be empowered!



United States: Take Action to Support the CCM-CARE Act

On Rare Disease Day, Senator Ben Ray Lujan introduced federal legislation called the CCM-CARE Act of 2023. It is known as Senate Bill 543 or S.543. This legislation will be under consideration through the end of the session in December 2024.

The CCM-CARE Act Calls For The Following:

Support for the creation of additional Centers of Excellence that can coordinate drug trials as well as secondary clinical centers that can provide outstanding care;

Increased funding for research at all levels – basic, translational, and clinical;

Prioritization of CCM medications at the FDA since, unlike other illnesses, we do not yet have a single approved pharmacological treatment; and

Collection and analysis of data on CCM by the Center for Disease Control so that we better understand how many people are affected by the illness and how they are affected.

How You Can Help

We need you to call or visit your legislators to tell them this legislation is important to you. During the summer, legislators and their staffs are in their home districts more often, including a long stretch from August 8 through Labor Day – this is the perfect time to catch them.

We particularly need those of you represented by members of the Senate HELP Committee, the House Energy and Commerce Committee, and those living in states where we have active research programs or CCM Clinical Centers to call your legislator's office and ask them to co-sponsor the bill. It's very likely that your initial contact will be with a summer intern – calling their office is not as scary as you may think. There are scripts on our website that you can modify to fit your family's story.

If you are able to schedule an appointment with a health policy staff member or a legislator, we're happy to join. More information can be found on our website: www.alliancetocure.org/legislative-advocacy/national-legislation/.

Join us in Miami at our Family Conference!

Are you or a loved one affected by cavernous malformation? Do you want to learn more about the latest advances in research and treatment options? If so, you won't want to miss the Alliance to Cure Cavernous Malformation family conference in Miami, Florida, on July 7 and 8.

This conference is a unique opportunity for patients and their families to connect with top scientists and doctors in cavernous malformation research.

You'll have the chance to hear from Dr. Kelly Flemming and Dr. Gary Steinberg, two renowned experts actively working to cure this disease, who will answer your questions. You'll also hear from Recursion CEO Dr. Chris Gibson, and Dr. Jacques Morcos, University of Miami neurosurgery Chair and incoming President of the American Association of Neurological Surgeons. You'll have breaks and lunch with our scientists, who are happy to share their work with you.

In addition to hearing from these experts, you'll connect with other patients and family members affected by cavernous malformation. This can be an incredibly valuable experience as you share your stories, ask questions, and find support from others who understand what you're going through. There will be activities for children to meet and connect with each other and a teen and young adult program.

The Alliance to Cure Cavernous Malformation patient conference is a must-attend event for anyone affected by this disease. More information is on our website at www.alliancetocure.org/care-community/ccm-family-conference-2023/. Some financial support is available – there is a link on the registration form with details. We hope to see you there!

Thank You to our Sponsors!

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Research News

Ovid Therapeutics and Graviton Announce Collaboration on New Drug for CCM

Two pharmaceutical companies, Ovid Therapeutics and Graviton Bioscience Corporation, have entered an agreement to develop and test a novel ROCK2 inhibitor for the treatment of CCM. The drug, known as GV-101, has entered Phase 1 safety trials in healthy subjects. From their press release,

"Initial clinical development is anticipated to address cavernous malformations in the brain, for which there is strong mechanistic evidence for inhibiting ROCK2. The collaborators intend to harness the expertise held by the team at Graviton, who previously pioneered the development of Rezurock,® the first approved ROCK2 inhibitor for graft vs. host disease, and Ovid's development capabilities in rare brain conditions."

If the Phase 1 trial is successful, Ovid Therapeutics will move the medicine into clinical trials with our patients. As yet, there is no published research on GV-101.

The ROCK pathway has long been studied as a possible target for CCM treatment. Atorvastatin is being tested as a drug that may prevent hemorrhage because of its impact on the ROCK pathway.

Neurelis also has a ROCK2 inhibitor in development, with promising mouse data. NRL-1049 received investigational new drug approval from FDA, allowing it to enter Phase 1 safety trials. On March 24th, the company announced it had dosed the first healthy subjects. From their press release:

"NRL-1049 will be evaluated in a randomized, dose-escalation, double-blind, placebo-controlled single ascending dose study to establish safety, tolerability, and pharmacokinetic parameters in healthy volunteers. The primary objectives of the study are to determine the maximum tolerated dose (MTD) of a single oral dose of NRL-1049 and collect data on clinical safety and tolerability."

"The NRL-1049 Phase 1 study was built on strong preclinical data, both providing greater insight into its potential, which helped inform our decision to initiate this clinical program," said Chief Scientific Officer Stuart Madden, Ph.D., CCHEM, FRSC. "We are excited about what NRL-1049 could mean for patients and appreciate the contributions of the trial volunteers and investigators."

We look forward to supporting the Neurelis and Ovid/Graviton programs as they move forward.

Recursion REC-994 Phase 2 Trial Update

On May 8th, Recursion Pharmaceuticals released the following statement regarding the Phase 2 trial of REC-994:

As of March 31st, Recursion has "advanced… an exploratory Phase 2 study of REC-994 in Cerebral Cavernous Malformation where more than 80% of planned participants have enrolled."

"Our Phase 2 SYCAMORE clinical trial is a double-blind, placebo-controlled safety, tolerability, and exploratory efficacy study of this drug candidate in 60 participants with CCM. We have enrolled the majority of participants associated with this study, and most participants who have finished their first year of treatment have now enrolled in the long-term extension study. We expect to share top-line data in [the second half of] 2024."

Our role in recruiting for this study has been tremendously successful. We are grateful to our community for stepping up to be part of this first-ever industry-sponsored CCM trial. If this phase is successful, the plan is to expand the trial to gather enough data to determine definitively whether REC-994 reduces symptoms associated with active CCM. An expanded trial will be another opportunity for members interested in trial participation to enroll.

The REC-994 trial is being conducted at 15 sites around the United States, allowing many patients to access the trial without air travel. For those who must travel, all expenses are compensated. Additionally, the trial provides a stipend for each visit to offset the cost of missed work or childcare.

Oral Contraceptive Use Raises Risk of Intracranial Hemorrhage in Young Females with Cerebral Cavernous Malformation

Patients with cerebral cavernous malformations (CCM) had a higher risk of intracranial hemorrhage after taking female hormone therapy, according to a study published online Feb. 8 in Neurology.

Oral contraceptives (estrogen and/or progesterone) for girls and women of reproductive age and menopausal hormone therapy for postmenopausal women are known to increase the risk of stroke and venous thrombosis, researchers noted. But less is known about the risk of intracranial hemorrhage in patients with CCM, which can result in seizures or stroke.

The Class III evidence raises concern about using oral contraceptives and other hormone therapies in females aged 10 to 44, wrote lead author Susanna M. Zuurbier, MD, PhD, of Amsterdam UMC in the Netherlands, and colleagues.

"Physicians should inform female patients diagnosed with CCM about the potential increased risk of intracranial hemorrhage due to oral contraceptive use, and alternative methods of contraception that are not associated with thrombosis might be offered," they said. "The possibility that female hormone therapy increases the risk of intracranial hemorrhage from CCM, perhaps due to thrombus formation that may trigger these events, raises a hypothesis that calls for additional prospective studies, as well as other prospective cohort studies."

The investigators gathered the data from a systematic review of two large, prospective, multicenter, observational cohort studies, in which they looked for an association between the hormone therapy and hemorrhages from CCM. The patients were at least 10 years old; had been diagnosed with CCM; and were consecutively admitted to University Hospital Essen, Germany, between Jan. 1, 2003, and Nov. 1, 2020, and the Mayo Clinic in Rochester, MN, between Jan. 1, 2015, and Oct. 1, 2021.

The researchers compared patients' use of female hormone therapy and intracranial hemorrhage resulting from CCM over a five-year follow-up period.

The team found 722 patients with CCM, of whom 137 used female hormone therapy during the follow- up period and 585 did not. Forty-six of the 137 patients who had hormone therapy then had an intracranial hemorrhage, compared with 91 of the 585 patients who did not undergo such therapy.

"Female hormone therapy use (adjusted for age, mode of presentation, and CCM location) was associated with an increased risk of subsequent intracranial haemorrhage [sic]. … Use of oral contraceptives in female patients aged 10 to 44 years adjusted for the same factors was associated with a higher risk of subsequent intracranial hemorrhage (adjusted hazard ratio 2·00, 95 percent CI 1·26-3·17; p=0·003)," researchers said.

They added that the association between menopausal hormone therapy and risk of intracranial hemorrhage initially was not significant. But when they excluded 22 patients who used transdermal hormones, they found that hormone therapy, oral contraceptives taken by females aged 10 to 44, and menopausal hormone therapy in women 45 and older were significantly associated with a higher risk of subsequent intracranial hemorrhage.

Their findings align with those of previous studies that reported females who use oral contraceptives and menopausal hormone therapy have a greater risk of developing arterial and venous thrombosis, researchers said.

"The association between female hormone therapy and a higher risk of intracranial hemorrhage from CCM is consistent with the hypothesis that the occurrence of intracranial hemorrhage may be triggered by thrombus formation in the dilated caverns of CCM in which blood flow is slow or in an associated developmental venous anomaly," they said. "A comparable pathophysiological mechanism underlies hemorrhagic infarcts in patients diagnosed with cerebral venous thrombosis."

In an accompanying editorial, Tracy E. Madsen, MD, PhD, of the Departments of Emergency medicine and Epidemiology at Brown University in Providence, RI, and Kathryn Rexrode, MD, MPH, of the Division of Women's Health in the Department of Medicine at Brigham and Women's Hospital in Boston, said the study's clinical implications "are important to highlight." Still, they noted, "additional prospective, observational studies are needed to further understand the possible role of exogenous female hormone therapy in hemorrhagic stroke risk among female patients with CCM."

"As prior data on female hormone use and stroke in this specific population are lacking," Drs. Madsen and Rexrode wrote, "This study adds to our knowledge of the role of hormone therapy and risk of hemorrhagic stroke in a select group of female patients with CCM and should be further investigated in other cohorts, considering key factors like hormone type, formulation, dose, and route of administration."

Caitlin West, Reprinted from Neurology Today

Congratulations to Our New CCM Clinical Centers

We are pleased to announce that two new Clinical Centers have been recognized for providing expert, integrated, multi-disciplinary care to CCM patients and families. Congratulations to **Thomas Jefferson University Hospitals** and **Beth Israel Deaconess Medical Center**!

Thomas Jefferson University Hospitals is a comprehensive healthcare facility in Philadelphia, Pennsylvania, that provides specialized care for a broad spectrum of patients. Their facility offers a multidisciplinary team of vascular neurosurgeons, seizure neurologists, neuroradiologists, geneticists, and a dedicated nurse to help each patient navigate the system. Led by Dr. Pascal Jabbour, they offer diagnostic and state-of-the-art treatment options for patients with CCMs throughout the processes of evaluation, treatment, and follow-up.

Under the leadership of Dr. Christopher Ogilvy, Beth Israel Deaconess Medical Center in Boston, Massachusetts, provides leading-edge endovascular/surgical treatment for patients with brain aneurysms, cavernous malformations, and other brain and spine vascular problems. Their multidisciplinary team of specialists works closely together to create a customized care plan for every patient, giving patients a broad range of treatment alternatives, including less invasive options when appropriate.

Our program for Clinical Center and Center of Excellence recognition begins with the submittal of a comprehensive application and the CVs of faculty members. If the institution qualifies, an in-depth interview is conducted. Recommendations are summarized and discussed with the Medical Director(s). Our recognized Centers are expected to maintain the clinical criteria that form the basis of our program. We welcome applications and are available to assist with any questions or concerns. Additional information can be found in our website's Care and Community section.

Michelle M. Crook, Clinical Programs Specialist

Alliance to Cure Receives Global Genes Grant

The Alliance to Cure is pleased to announce that we have received an $8600 grant from Global Genes to facilitate our efforts in creating a public face that reflects our values. The grant will underwrite the following activities:

1) Train our website and social media staff in digital accessibility, and remediate our website to achieve WCAG2.1 accessibility compliance. This will ensure our site is usable by members with low vision, limited hand use, or cognitive issues secondary to their cavernous malformation hemorrhage. We will also review our website for content sensitivity to such issues as socio-economic status and access to care.

2) Offer speaker and story-crafting training to at least seven patients representing diverse communities we have found more challenging to engage, including men, disabled, Black, and Hispanic members. This training will allow these individuals to represent our organization on video, with media, and in person.

This ambitious project will result in an improved experience for all community members. If you are interested in participating as a website reviewer or speaker, please contact Jessica Biggs at Jessica.biggs@alliancetocure.org.

Thank you!

We want to take a moment to express our heartfelt gratitude to **Evan Compton**, **Melinda Wilson**, **Lori Merrick**, and **Ryan Westmoreland** for recently hosting fundraisers in support of Alliance to Cure Cavernous Malformation. Your generosity and hard work are truly inspiring, and we are in awe of the incredible impact that you have made on our cause. Thanks to your efforts, we are one step closer to finding a cure. We cannot thank you enough for your unwavering commitment to our mission.

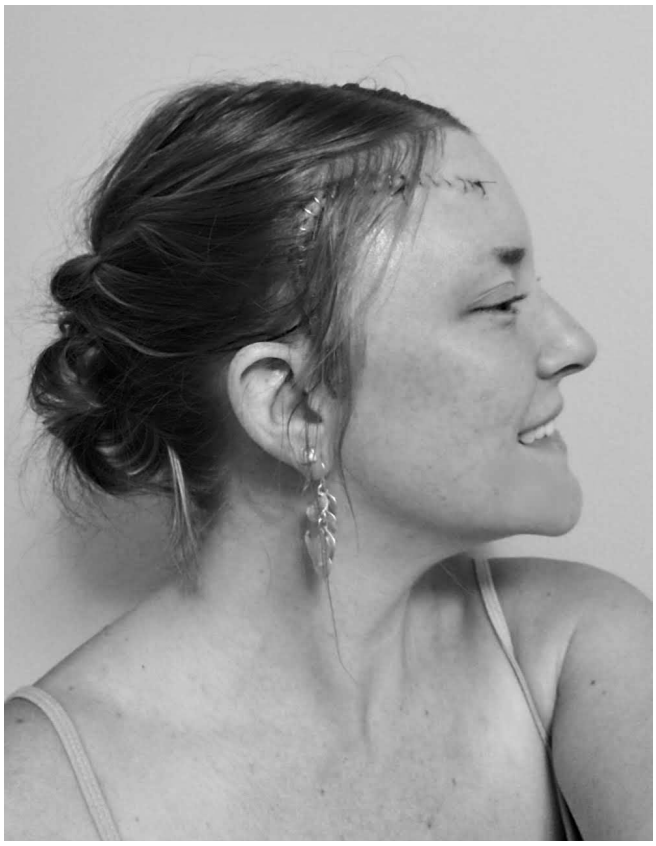
Keep an eye on our social media accounts and email mailing list for news of upcoming events, including a patient conference and Reds game in August, the return of Saber Seminar: The Science of Baseball benefitting the Alliance to Cure, a golf tournament in Colorado, and our annual wine tasting in Torrington, Connecticut.

You Don't Know How Strong You Are

In 2016, Audrey Rozell was a recent college graduate, working full-time at a physical therapy clinic, leading a normal life. Without warning, she developed a migraine that continued for two full weeks.

Eventually, the migraine subsided, but other symptoms appeared. She began to experience instances of ringing in the ears, left-sided weakness, and a left-sided facial droop. When she awoke in the middle of the night with muscle spasms, she knew it was time to head to the emergency room. As many of our members have experienced, especially younger patients, doctors look for obvious explanations, leading to a misdiagnosis. Audrey shared, "They ended up just telling me I had low potassium."

Not satisfied with this answer, Audrey followed up with a neurologist who initially diagnosed her with a complex migraine, another strange diagnosis in her opinion, as she had never suffered from headaches, let alone migraines. Eventually, the neurologist ordered an MRI to put her mind at ease.



Following the MRI, Audrey got a call from the doctor's office telling her to stay away from aspirin and blood thinners. At a follow-up appointment, she learned she had a cavernous malformation on her brainstem.

"It's weird. I was relieved, because for whatever reason, I'd convinced myself that I had a different brain disease, so I was actually relieved that it wasn't that. But it was still something in my brain that's basically there, and there's nothing they could do. So, it definitely gave me some anxiety."

Knowing little about her condition, Audrey turned to the internet, researching CCM and the symptoms of the disease. Through this search, she found the Alliance to Cure, a critical resource in the early months of her diagnosis and greater journey.

"Just having more information and a community of people who have gone through or are also living with the diagnosis was the biggest thing that [the Alliance] did. Initially, you definitely feel very alone when you don't know anyone who has had this … so it was really reassuring to see other people living with the condition."

Audrey met with a neurosurgeon who explained that, due to the size and location of her brainstem cavernous malformation, it would be best to watch and wait rather than have surgery. Surgery could result in permanent deficits. Many of her symptoms subsided, though she was encouraged to follow up with MRI every six months.

One year later, she had a routine MRI, expecting to hear that her condition remained status quo. Instead, they discovered a second cavernous malformation in her temporal lobe on the left side of her brain. It had developed and hemorrhaged in the short time since her previous checkup.

Audrey was referred to Dr. Issam Awad at the University of Chicago Department of Neurosurgery. She learned that the temporal lobe cavernous malformation hemorrhaged a second time since the initial bleed in January. Two hemorrhages in two months indicated it was an active lesion. Dr. Awad recommended they remove the lesion due to the relative ease of access and low risk associated with the surgery. She underwent the operation in late April 2018.

"It was stressful, but they made the process smooth. They took really good care of me. It was overall a good experience, the best you could have after having brain surgery."

Developing two cavernous malformations raised the possibility that Audrey had a familial form of the illness. She took advantage of the Alliance to Cure's free genetic testing program and discovered that she had a CCM1 mutation, but not one she inherited. Audrey had mosaicism, which meant the mutation occurred sometime during embryonic development. She was the first in her family with the illness.

Audrey isn't one to sit on the sidelines when faced with a new challenge. She participated in research at the University of Chicago with Dr. Awad's team, providing blood samples and participating in specialized MRIs aimed at assessing the permeability of one's blood vessels.

"He had lots of experience, and I knew he had done a lot of the research, so I trusted him. He clearly cares about this disease and is actively learning about it; that was a huge thing for me, too."

Following her operation, Audrey remained in the ICU for two days before being discharged. She returned to business as usual after taking four weeks off work.

"Thankfully for me, I can live my normal daily life. I don't have any significant deficits or anything really that limits me and my ability to live independently. I feel super fortunate for that."

As far as future treatment options are concerned, Audrey is most excited about the development of preventative measures like focused ultrasound, saying that an alternative to surgery would be ideal. "That would be a huge step forward, but even more would be a cure. My concern is the cost. Just maintenance-wise when you're diagnosed with this, you have to have MRIs and checkups, so it gets expensive."

In 2019, Audrey joined a group of five patients at a meeting with the Food and Drug Administration in Washington, DC, to testify about her experiences and help the agency understand the disease. In front of a standing-room-only crowd of federal officials, she bravely shared her ongoing symptoms and the impacts on her life. As the field moves toward drug approvals, this testimony is an enormous service to the Alliance to Cure community. Audrey has also served as an officer of our Michigan Community Alliance.

In 2022, Audrey married her long-time partner, Jesse, and she currently works for a property development company. Explaining what she's learned from her experiences with CCM, Audrey remembered a Bob Marley quote she encountered at the start of her journey. "It was 'you don't know how strong you are until being strong is the only choice you have.' I definitely learned my strength. I've learned to stay positive and focus on the things I have and what I'm able to do. It's been quite a journey. Just try to stay focused in the present moment and don't let the worries about the future overwhelm you."

Robert Neithart

Duke HBCU Neuroscience Career Day

Alliance to Cure Board Officer and General Counsel Kandance Weems Norris addressed North Carolina Central University students who attended Duke University's HBCU Neuroscience Career Day. Kandance shared her CCM story, discussed the importance of representation in medicine, and answered questions.

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.

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