



IMAGING CAVERNOUS MALFORMATIONS

An Expert Panel Update

Presenter Q&A Summary

August 20, 2026 — 7:00 pm ET via Zoom, hosted by Alliance

CCM stands for cerebral cavernous malformation. It's a cluster of blood vessels in the brain or spine that can sometimes leak or bleed. Before this webinar, people who signed up were asked: "Do you have a question about CCM imaging, MRI scans, or monitoring you'd like our panel to answer?" This document lists those questions by topic. Each question is followed by the answer the panel gave live during the webinar.

Panelists: Issam Awad, MD (Neurosurgeon, University of Chicago) · Richard Beegle, MD (Neuroradiologist, Mayo Clinic Florida), Lindsay Williams, MD (Vascular Neurologist, Mayo Clinic Florida). **Moderator:** Rabih Tawk, MD (Neurosurgeon, Mayo Clinic Florida).

Getting the Right Scan Ordered

Q: How can I get my doctor to order the right imaging, or learn more about CCM?

A: [Dr. Williams / Dr. Awad / Dr. Tawk] The panel's advice: use the Alliance to Cure's resources. Print out the CCM Care Guidelines, or the "Imaging and Monitoring" page from the Learning Hub. That page lists the exact scan types you need. Dr. Awad said these guides work well both to teach patients and to hand to doctors. It also helps to get your scans done at the same place, using the same machine, each time. Comparing scans from different machines can make it look like you have new or bigger lesions, when really the newer scan is just better at showing small details.

Resources:

- CCM Care Guidelines: <https://www.alliancetocure.org/home/for-patients/newly-diagnosed/ccm-care-guidelines/>
- Imaging and Monitoring (recommended scan types): <https://www.alliancetocure.org/home/cavernous-angioma-in-depth/diagnosis-imaging/>

Q: What should be included in the imaging order?

A: [Dr. Williams] For your first scan, ask for one with contrast dye. It should include these scan types: T1, T2, SWI, FLAIR, and DWI. A 3T machine is best. Some patients need a 1.5T machine instead — for example, if they have certain implanted medical devices. Pregnant patients should not get contrast dye.

How Often You Need MRI Scans

There's no single rule for everyone. The CCM Care Guidelines (linked above) explain the basic approach.

Q: Does the location of a CCM — brainstem or spine — change how often I need imaging?

A: [Dr. Tawk / Dr. Williams / Dr. Awad] Not by a strict rule. If a CCM in the brainstem bleeds, patients usually notice right away, because it causes symptoms quickly. So, Dr. Tawk treats brainstem CCMs the same way as CCMs anywhere else. For CCMs in the spine, Dr. Williams looks at symptoms and a physical exam to decide when to scan. Spine and brain CCMs often happen together — about 20 to 30 out of 100 people with a spinal CCM also have one in the brain — so if you have a spinal CCM, your doctor will likely order a brain scan too.

Q: How often should imaging happen for a patient with no symptoms and no recent bleed?

A: [Dr. Tawk / Dr. Awad / Dr. Williams] The panel's general plan: start with scans close together, then space them out once things look stable. For a new CCM with no symptoms, get a scan again in 3 to 6 months. If it looks the same, repeat at about the same interval. After about a year of no change, it's often okay to wait 6 to 12 months between scans, and the gap can grow even more after that, depending on your case. A recent bleed changes this plan — so does a new bright spot on a certain scan called T1, which can mean recent bleeding. Either one usually means a new scan within a couple of months. Even when scans are far apart, the panel said regular doctor visits still matter. A detailed checkup can catch new risks, like starting a blood thinner or hormone medicine, or new symptoms that would change the plan.

Q: How should doctors handle new or changing spots in the inherited (genetic) form of CCM? Does the word "stable" even make sense for this form?

A: [Dr. Tawk / Dr. Awad] For the inherited form of CCM, which usually causes multiple CCMs, the panel's plan is to keep the same scan schedule unless something important changes — they don't automatically scan more often just because one new tiny spot shows up. Dr. Awad explained the difference between two kinds of change:

- First, tiny new spots that only show up on a special scan called SWI are called “punctate” lesions. These mostly show that the disease is active in general, and are worth checking for causes like ADHD medicine, hormone use, or low vitamin D — but they don't usually change the monitoring plan.
- Second, a truly new or bigger spot, larger than 4 millimeters on a T2 scan, is treated like a silent bleed. This is a real change: it resets the clock and usually leads to a follow-up scan within a few months.

So “stable” may not be the perfect word for the inherited form, since there's often small activity happening — but in practice, the panel only changes the plan for meaningful new or bigger spots, not tiny punctate ones.

Yearly Scans vs. Scans Only When You Have Symptoms

Q: Is a yearly MRI the standard? Or can scans instead be based on symptoms? Does this depend on which doctor you see?

A: [Dr. Tawk / Dr. Awad] How often you get scanned should depend on how your own CCM has been behaving. In real life, it does vary somewhat from doctor to doctor. Part of this is because the science is still developing: for example, doctors only recently learned how important a bright T1 spot is, and started using a newer scan called QSM. Once a CCM has been stable for a long time, say, 10 years, yearly scans usually aren't needed anymore. But any new symptom should lead to a scan right away, no matter how long it's been.

MRI Machines, Scans, and Contrast Dye

Q: Can hardware from an old surgery affect MRI safety or picture quality?

A: [Dr. Tawk] It depends on the type of hardware and where it is. Something like a metal clip used for an aneurysm will blur the picture right around the clip. Small titanium plates and screws from skull surgery usually cause only a small blurry spot on the skull's surface — this doesn't affect the picture of the brain underneath. It's best to ask your imaging center or radiologist directly about hardware you may have and how it could impact imaging.

Q: Why might the number or size of my lesions look different between scans? Does the MRI's power level (1.5T, 3T, or 7T) matter?

A: [Dr. Beegle] Often, this isn't a real change between scans. It's usually caused by differences in how the scan was done. This can include the MRI's power level (1.5T, 3T, or 7T), the type of scan used (an older type called GRE versus a newer, more sensitive type called SWI), how thick each image slice is, or even the angle of the scan. All of these can make lesions look bigger, smaller, or different in number between two scans.

When you have a choice, 3T usually gives a clearer picture than 1.5T, so 3T is usually best. Doctors use 1.5T instead for patients with certain implanted devices. But the panel said something even more important: using the same machine and settings every time matters more than always getting the strongest machine. The best way to tell if something has truly changed is to compare scans from the same place, using the same machine and scan types. If you do switch machines or locations, let whoever reads your new scan know.

Q: What new technology is coming? This includes AI, QSM, 7T machines, and faster scans.

A: [Dr. Beegle / Dr. Awad] There's progress on several fronts:

- Faster scans: new software is already making scans quicker at many hospitals. It can be used to make the picture clearer or to make the scan shorter.
- AI, or computer help: Dr. Beegle said AI is not yet making the actual diagnosis. It can't yet look at a scan and tell a true CCM apart from something that looks similar, like a developmental venous anomaly, which is a normal but unusual-looking vein pattern (this was also asked about in the live chat). What AI is starting to help with, though it's not standard yet, is counting lesions automatically. AI is also very consistent — it applies the same rules every time, which people can't always do — but AI can still make mistakes.
- Separately, Dr. Awad's research combines QSM, a scan that measures iron in the brain, with the bright T1 spot mentioned earlier. Together, these two things predict a coming bleed better than blood tests or other methods. The FDA now also accepts QSM as a way to measure whether a drug is working in research studies, because it can show results with fewer patients.
- Both the AI and QSM work are still being studied and need further testing across multiple hospitals before they become standard care.
- 7T machines are available and becoming a little more common. Right now, they're mostly used to solve tricky cases, for example, to help confirm whether something really is a CCM, and they aren't used for routine checkups yet. As the technology improves and gets cheaper, 7T machines should become more common.

Q: Does MRI or CT involve radiation risk, and should patients ask for an MRI instead of a CT in the ER?

A: [Dr. Beegle / Dr. Tawak] MRI does not use radiation, so getting regular MRIs to watch a known CCM is not a radiation risk. CT scans do use a small amount of radiation. The risk from just one CT scan is small, but it adds up if you get many over time. That's why the panel recommends MRI, not CT, for regular CCM checkups.

In the emergency room, though, CT scans still make sense for sudden new symptoms: CT is fast and good at spotting a fresh bleed. Also, many freestanding emergency rooms — ones not attached to a hospital — only have CT machines, not MRI, so you may not have a choice in an emergency.

Understanding Your Scan Results

Q: If I have more than one CCM, how do doctors know which one is more likely to bleed?

A: [Dr. Awad / Dr. Beegle] The best sign is whether that specific spot has bled before — a CCM that has already bled is more likely to bleed again. Beyond that, a new bright spot on a T1 scan is a strong warning sign, even without new symptoms: it makes a bleed about 2 to 3 times more likely, and it's one of the main signs the panel watches for. A new spot, or one that grows bigger than about 4 millimeters on a T2 scan, is treated like a silent bleed — a concerning change that leads to closer watching. Two other tests are being studied as possible warning signs: permeability imaging, which checks if contrast dye leaks out of the CCM, and QSM, which measures iron buildup. Both are still research tools, and aren't standard practice yet.

Q: Can an MRI show roughly when a bleed happened?

A: [Dr. Awad] Yes, to some degree. A bright spot on a T1 scan usually means blood from the past few weeks — in other words, a recent bleed. On a CT scan, that bright blood signal fades within 2 to 3 days, but on an MRI it can last for several weeks. That's why doctors look for a bright T1 spot when trying to find out if a bleed happened recently.

Using Contrast Dye

Q: Is contrast dye needed for every MRI, or just the first scan?

A: [Dr. Beegle / Dr. Awad / Dr. Williams] For regular follow-up scans of a CCM you already know about, contrast dye is often not needed. Dr. Beegle said a scan without contrast is usually enough once the diagnosis is confirmed and the goal is just to check for changes. Contrast matters most for your very first scan — it helps confirm the diagnosis, rule out other problems like tumors, and show any developmental venous anomaly nearby. There are some exceptions where doctors keep using contrast: Dr. Awad uses it at every visit, partly because about 20 to 30 out of 100 people with the inherited form of CCM also have small brain tumors that can't be seen or measured over time without contrast dye, and a change in how a spot lights up with dye can also be an important clue. Contrast dye is not used during pregnancy.

Q: What's the real difference between a scan with contrast and one without? Is the contrast dye safe?

A: [Dr. Beegle / Dr. Awad] Contrast dye, called gadolinium, helps tell a true CCM apart from other things, like tumors. It also helps show developmental venous anomalies, and it can reveal patterns that catch a doctor's attention. There is growing awareness that this dye can build up in brain tissue after many scans — so far, no harm from this has been proven. Doctors are extra careful with patients who have serious kidney disease, though newer versions of the dye are safer for the kidneys. Dr. Awad also warned that skipping contrast dye completely has, in his experience, caused doctors to miss other problems, like a hidden skin cancer called melanoma. So this decision should be made with your own doctor, based on your situation, rather than following one strict rule for everyone.

Cost & Access

Q: How can I lower imaging costs, get better equipment through an HMO insurance plan, or deal with providers who won't accept scans from another hospital?

A: If you have problems with cost, insurance, or getting scans accepted from another hospital, reach out to Alliance to Cure (help@alliancetocure.org) — they may be able to point you toward resources or support.

Alliance to Cure Cavernous Malformation

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