Cracking the code on cavernous malformations

Introduction:

Cavernous malformation: Although most have never heard the term, as many as 1 in 500 people may have this condition, which can cause bleeding, seizures, muscle weakness, and motor and memory problems.

"Cavernous malformations are rare – even to a neurologist or neurosurgeon," says Dr. Kelly Flemming, a Mayo Clinic neurologist. "Having coordinated care by providers familiar with the disease is very important to patients."

In 2017, the Angioma Alliance named Mayo Clinic a Center of Excellence for treatment and research into cerebral cavernous angiomas, which go by many names, including cerebral cavernous malformations, cavernous hemangiomas and cavernomas.

Dr. Flemming serves as medical director of the effort, and Mayo patients like Kandie Nelson of Sioux Falls, South Dakota, are helping too.

	AUDIO
Graphic bug: Re-enactment Kandie Nelson	“I was working at the front desk at a hotel. And I went to answer the phone, and it came out, ‘Blah, blah, blah.’ I just – I couldn’t talk.”
Title: **Kandie Nelson** **Patient**	“And my hands and my feet started going numb. And, then, I fell to the ground.”
	Kandie Nelson was rushed to the hospital …
Kandie Nelson	“They did every test imaginable.”
	… and was eventually diagnosed with a cavernous malformation.
Title: **Kelly Flemming, M.D.** **Neurology** **Mayo Clinic**	“They look like this little raspberry or cluster of grapes in the brain.”
	Neurologist Dr. Kelly Flemming says a cavernous malformation happens when tiny capillaries divide abnormally and create a small tangle of blood vessels.

Graphic: **Cavernous malformations** • **1 in 500 people** • **Symptoms are rare**	As many as 1 in 500 people have this condition and don't know it, since symptoms are rare.
Kelly Flemming, M.D.	"We find these accidentally. Somebody had a head trauma, and they are being scanned, looking for trauma, but we incidentally find one of these. Or they may have migraines, and they undergo an MRI."
Kandie Nelson	"They can just kind of blow out, and that can cause a hemorrhage in your brain."
Title: **Giuseppe Lanzino, M.D.** **Neurologic Surgery** **Mayo Clinic**	"Quite often there is displacement rather than destruction of the surrounding tissues, and that's the reason why many patients can have even a significant, fairly large bleed without having major symptoms. This is also the reason why many patients, after a symptomatic bleed, can have some degree of improvement."
	Neurosurgeon Dr. Giuseppe Lanzino says surgery to remove one of these malformations is considered only when it's causing problems – as was the case for Kandie.
Kandie Nelson	"It's very close to the surface of the brain, so it would be very easy to get to. So we opted for that."
Kelly Flemming, M.D.	"If it's in a difficult place, like deep inside the brain or in the brain stem, then, typically, we would wait and watch and only do surgery if there was a second bleed or increasing symptoms."
	It's still unclear why a vast majority of people develop these malformations. But in about 20 percent of cases, there's a family connection. And that's true for Kandie Nelson.
Kandie Nelson	"So my children had 50 percent chance of having it."
	… and two of them do, including her son, Bryan.
Kandie Nelson	"They're usually in the brain or the, the brain stem. But he had one in the spinal cord."

	Bryan had that cavernoma removed just weeks before his high school graduation. Kandie says a second malformation on Bryan's brain stem later affected his ability to walk and talk.
Giuseppe Lanzino, M.D.	"In his case, we were able to remove the cavernous malformation from the brain stem, along with the fresh blood that was there from the recent bleed, and he was able to make quite a remarkable recovery."
	"My scar starts right here, and it just kind of goes along back behind my ear."
	In Bryan's sister, Kayla, cavernous malformation struck in a different way.
Graphic bug: Re-enactment Kayla Nelson	"I was going up the stairs. I remember kind of going into a seizure.'
Title: **Kayla Nelson** **Patient** **Mayo Clinic**	"So I had texted my mom and told her what had happened, and she was, like, 'All right – yep, you're going to the Mayo Clinic. I'm making an appointment now.'"
Kelly Flemming, M.D.	"It was in a particular location in the brain called the temporal lobe, which is common for any type of abnormality to provoke seizures. And even though she went on seizure medications, …"
Kelly Flemming, M.D.	"… she was still having them. And, so, if people are having recurrent seizures, despite trials of medications, then surgery would be recommended there, as well."
	Kayla became the third member of her family to undergo surgery and find relief from cavernous malformation.
Kayla Nelson	"My seizures are gone."
Kelly Flemming, M.D.	"I think a lot of patients I talk to – this disease is rare even for neurology and neurosurgeons – and, so, they struggle with finding people with the correct expertise to answer a lot of their questions."
Giuseppe Lanzino, M.D.	"The center here at the Mayo Clinic, we have expertise in all different areas, including the diagnosis – both clinical and imaging – the surgical

	treatment and the nonsurgical treatment of cavernous malformations.”
	And, thanks to families like the Nelsons, that expertise continues to deepen.
Kandie Nelson	“All three of us have donated our malformations to science, so that, hopefully, they can try to figure out how they grow and what they can do to stop them from growing.”
Kandie Nelson	“God puts you here for a reason. I believe one of my reasons is to help find a cure for this.”
	For the Mayo Clinic News Network, I’m Jeff Olsen.