WHAT IS A CAVERNOUS MALFORMATION?
A cavernous malformation is a cluster of tiny, abnormal blood vessels that are enlarged and irregular in structure. They can be located anywhere in the body, but become more serious when they are found in the brain or spinal cord. It can also be referred to as cavernous angiomas, cavernous hemangiomas or cavernomas.

WHAT CAUSES THIS?
There are two types of cavernous malformations: familial (which run in multiple family members) and sporadic (which only occur in one person in a family). In familial cavernous malformations, there are three genes that are known to cause them: KRIT1, CCM2 and PDCD10. Familial cavernous malformations are more likely found in people with Hispanic heritage and have multiple cavernous malformations. People with sporadic cavernous malformations usually only have one lesion. We do not understand what causes sporadic cavernous malformations.

WHAT TREATMENTS ARE AVAILABLE?
For people with asymptomatic cavernous malformations, we watch and wait. For people with symptomatic cavernous malformations, we help treat the symptoms. There are medications and other treatments to help with things like headaches and seizures. Surgery may be considered for lesions that are accessible, for those who have progressive neurological deficits, seizures, or recurrent bleeding, on a case-by-case basis.
Cavernous Malformation

WHAT SHOULD WE EXPECT FOR THE FUTURE?

About 25% of people with cerebral cavernous malformations never experience any symptoms. Other symptoms that can be associated are seizures, headaches and other neurological deficits like weakness of one side, speech changes or vision problems. If any of those symptoms suddenly occur, the person should be taken to the emergency room as soon as possible. There is a risk of bleeding from these malformations at a rate of about 1% per year.

WHAT OTHER TESTS MAY BE NEEDED?

Cavernous malformations are usually diagnosed with an MRI of the brain with an MR angiogram. Your doctor may recommend follow up MRI of the brain after the initial one to follow for any progression or appearance of new lesions.

WHAT RESOURCES ARE AVAILABLE?

Hemophilia & Thrombosis Center at CU Anschutz Medical Campus
Our clinic specializes in care for pediatric stroke and other related conditions including cavernous malformation. We work with Children’s Hospital Colorado and have comprehensive, multi-disciplinary services for our patients. Contact us at the details below or see our website here: medschool.ucdenver.edu/htc

Angioma Alliance
http://www.angiomaalliance.org/

National Organization for Rare Disorders
https://rarediseases.org/rare-diseases/cavernous-malformation

We are located in the CU Medicine Building at the Hemophilia and Thrombosis Center
13199 E. Montview Blvd., Suite 100
Aurora, CO 80045
Office Hours: M-F 8 am-4:30 pm

Scheduler: 303-724-6158
Questions for doctors or nurses: 720-777-6895
Website: medschool.ucdenver.edu/htc