

# FAST FACTS: CAVERNOUS MALFORMATION

1. A cavernous malformation is a cluster of abnormal, small blood vessels resembling caverns with slow moving blood. Resembling a raspberry, they have thin leaky walls.
2. A cavernous malformation is most often found in the brain. In this location , it is referred to as a Cerebral Cavernous Malformation (CCM).
3. A cavernous malformation may also be known as a cavernous angioma, or a cavernoma.
4. Cavernous malformation is classified as rare by the National Organization for Rare Disorders.
5. Approximately 1 in 500 people have at lease one cavernous malformation in their brain.
6. There is equal prevalence across gender.
7. Most people with a cavernous malformation have no symptoms.
8. For those with symptoms, the most common presenting symptom is seizure (50%), followed by hemorrhage (25%), and focal neurological deficits (25%) such as blurred or double vision and weakness in limbs.
9. In symptomatic patients, there is no typical way that symptoms present themselves. Symptoms may be varied and of different degrees of severity.

10. A cavernous malformation is non-cancerous.
11. A cavernous malformation can form at any age, including in young children.
12. Cavernous malformation is hereditary in about 20% of people who have it.
13. Those with the familial (hereditary) form will have more than one cavernous malformation and will develop more lesions over time.
14. The familial form of cavernous malformation does not skip generations. Each child of an affected person has a 50/50 chance of inheriting the disease.
15. The familial form can be caused by a mutation on any one of three genes: CCM1, CCM2, or CCM3.
16. There is no cure for cavernous malformation.
17. Currently, surgery is the only treatment for cavernous malformation, though a number of medications and proposed treatment options are currently under investigation.
18. A cavernous malformation is most often diagnosed via imaging. Magnetic Resonance Imaging (MRI) with susceptibility-weighted (SWI) sequencing is the gold standard in cavernous malformation diagnostic imaging.

19. In an acute setting such as a hospital emergency room, Computed Tomography (CT) may be the primary imaging used, to quickly rule out a cavernoma hemorrhage.

20. Patients diagnosed with a cavernous malformation may see specialists such as a neurologist, vascular neurosurgeon, dermatologist, geneticist, neuro-ophthalmologist and epileptologist. For symptomatic patients, additional regulation health professionals can be involved in care, such as a psychologist, social worker, occupational therapist, physiotherapist, physiatrist, nurse practitioner, and nutritionist.