

Key Talking Points

About Cavernous Angioma

Cavernous angiomas are abnormal mulberry-shaped leaky blood vessels in the brain and spinal cord. They are also known as cavernous malformations or cavernomas and the condition is referred to as CCM. Cavernous angiomas can hemorrhage and grow, potentially causing severe neurological deficits, epilepsy, and death. Cavernous angiomas can become active at any age, even in children.

Cavernous angiomas can occur either sporadically, or they may run in families and be inherited due to a genetic mutation. The mutation does not skip generations, and every child of an affected parent has a 50/50 chance of inheriting the illness. Individuals with the hereditary form of the illness can develop over 100 lesions in their brain.

1 in 500 people have at least one cavernous angioma and many of these patients have multiple lesions. The only known treatment for cavernous angiomas is brain or spinal cord surgery, but this isn't an option for everyone.

About Angioma Alliance

Angioma Alliance is a national 501c3 nonprofit patient advocacy and research organization whose mission is to inform, support and empower individuals affected by cavernous angioma and drive research for better treatments and a cure.

How we help:

- Host an annual International Cavernous Angioma Scientific Meeting, the only meeting of its kind, to discuss cutting-edge research to find a treatment and cure.
- Facilitate a DNA and Tissue Bank used by research labs throughout the world.
- Manage a Patient Registry for clinical drug trials and other research.
- Offer free genetic testing for families.
- Provide a supportive community for patients and their families to connect 24/7 through online forums, one-on-one peer support, and family conferences.
- Establish Clinical Centers of Excellence where families can receive expert, coordinated care.
- Publish national clinical care guideline for medical professionals and a comprehensive Patients Care Guide for those affected by CCM and their families.
- Introduce and advocate the CCM-CARE Act to speed the development of treatment options, save lives, and save countless dollars in health spending.

For more information about Angioma Alliance and cavernous angiomas, visit <http://www.Angioma.org>.

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