

Resource Summary Report

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Angioma Alliance

RRID:SCR_008729

Type: Tool

Proper Citation

Angioma Alliance (RRID:SCR_008729)

Resource Information

URL: <http://angioma.org/>

Proper Citation: Angioma Alliance (RRID:SCR_008729)

Description: Established in 2002, Angioma Alliance is a patient-driven, non-profit patient advocacy organization. Our mission is to inform and support individuals affected by cerebral cavernous malformations while facilitating improved diagnosis and management of the illness through education and research. We are dedicated to improving the lives of those affected by cavernous angioma. There are many needs that we have been addressing together. First and foremost, people diagnosed with cavernous angiomas have needed more information and a way to talk to others who have the illness. Physicians are frequently unfamiliar with the disease. Internet information has been scarce and technical, and until Angioma Alliance there had been no active internet forums. Many of us have never known anyone else with the illness. Angioma Alliance's website, peer support program, patient literature, family conferences, and medical convention exhibits have been providing vital information and opportunities for support to those of us affected by cavernous angioma and to the physicians who care for us. Second, we have needed to increase if the public awareness of cavernous angioma. Third, we have needed a way to connect with the research community. Angioma Alliance can be as active and effective as those who choose to volunteer. If you or a family member or friend is affected by cavernous angioma, please consider joining us in our effort.

Abbreviations: Angioma Alliance

Resource Type: nonprofit organization

Keywords: cerebral cavernous malformation, cavernous angioma, rare disorder, rare disease, cavernous malformation

Resource Name: Angioma Alliance

Resource ID: SCR_008729

Alternate IDs: nlx_143720, grid.476860.b

Alternate URLs: <https://ror.org/05980d896>

Record Creation Time: 20220129T080249+0000

Record Last Update: 20260815T182349+0000

Ratings and Alerts

No rating or validation information has been found for Angioma Alliance.

No alerts have been found for Angioma Alliance.

Data and Source Information

Source: [SciCrunch Registry](#)

Usage and Citation Metrics

We found 4 mentions in open access literature.

Listed below are recent publications. The full list is available at [dkNET](#) .

Padarti A, et al. (2022) In-silico analysis of nonsynonymous genomic variants within CCM2 gene reaffirm the existence of dual cores within typical PTB domain. Biochemistry and biophysics reports, 29, 101218.

Shkoukani A, et al. (2021) COVID-19 in a Hemorrhagic Neurovascular Disease, Cerebral Cavernous Malformation. Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association, 30(11), 106101.

Han G, et al. (2020) A Novel CCM2 Missense Variant Caused Cerebral Cavernous Malformations in a Chinese Family. Frontiers in neuroscience, 14, 604350.

Akers A, et al. (2017) Synopsis of Guidelines for the Clinical Management of Cerebral Cavernous Malformations: Consensus Recommendations Based on Systematic Literature Review by the Angioma Alliance Scientific Advisory Board Clinical Experts Panel. Neurosurgery, 80(5), 665.