Angioma Alliance Programs

Our Vision
A cure for cavernous angioma

Our Mission
The mission of Angioma Alliance is to inform, support, and mobilize those affected by cerebral cavernous angioma (cavernous malformation, cavernoma) and drive research for better treatments and a cure.

Our Programs

Research and Treatments
- **Study and trial enrollment**, industry consultation on clinical trial design and partnerships
- Annual **International Scientific Meeting** – attendees from 5 continents, only meeting entirely focused on cavernous angioma
- **Patient Registry**, now directly accessible by researchers
- DNA and Tissue Bank used by labs around the world
- **Patient education** regarding non-pharmaceutical interventions being researched to reduce risk.

Clinical
- **Free genetic testing** for anyone with multiple lesions that can’t be explained by a DVA or history of brain radiation and who can’t obtain insurance coverage for testing
- **Patient educational materials**: booklet, website, webinars, and video presentations
- **Center of Excellence Program** with Centers of Excellence at U of Chicago, U of New Mexico, Boston Children’s Hospital, Mayo Clinic Rochester, Cincinnati Children’s Hospital, UCSF, and the Barrow Neurological Institute, and a Clinical Center at University of Virginia
- **Clinical Care Consensus Guidelines** published in *Neurosurgery* in 2017
- **Outreach to special populations**: including the Baca Family Historical Project that includes public presentations and genetic testing in New Mexico, the CCM Common Deletion project that traces genealogy among a related group of families in Appalachia, the Deep South, and Oklahoma, and those of Eastern European Ashkenazi descent.

Patient Support and Empowerment
- **Supportive community**: on Facebook, our website’s Community Forum, virtual peer support meetings, and regional organized Angioma Community Alliances
- **Patient conferences and events**: regional and national
- Opportunities to engage in **legislative advocacy and awareness-raising**

Angioma Alliance is a 501(c)3 non-profit organization. All donations are tax deductible.