

Angioma Alliance Strategic Plan Mission, Goals, Objectives for 2020-2022

Our Vision: A Cure for Cavernous Angioma

Our Mission: To inform, support, and mobilize those affected by cavernous angioma and drive research for better treatments and a cure by developing and executing strategic, creative, high-return interventions as a model for rare disease.

Our Goals and Objectives:

- 1) Facilitate and participate in cavernous angioma research to achieve a complete understanding of the disease and facilitate clinical drug trials and other treatment improvements.
 - Initiate and deepen relationships with biotech/pharmaceutical companies and developers of other potential treatments to introduce cavernous angioma as a potential target.
 - Introduce academic and industry partners to each other and encourage collaboration.
 - Remain conversant and share information regarding the progress of non-pharmaceutical, non-invasive treatment development, such as microbiome, focused ultrasound, and hypoxia treatment. Create educational campaigns.
 - Fully enroll clinical drug trials
 - Upgrade, promote and expand our International Cavernous Angioma Patient Registry.
 - Work closely with FDA, NIH, academic researchers, and the pharmaceutical industry to develop realistic clinical outcomes and trial design, including assisting in the creation of guidelines for the conduct of clinical trials which can be used as an introduction and map for sponsors, serving on Clinical Advisory Boards, and organizing and/or attending FDA meetings as possible.
 - Partner as the participant recruiter in the development of a patient-reported burden of disease measure.
 - Identify, communicate, and address (where possible) barriers to clinical drug trial participation and retention.
 - Create a multimedia educational campaign.
 - Address logistical barriers, possibly including small travel stipends for trials, etc.
 - Develop collaborative relationships among researchers and institutions by connecting them through projects and conferences.
 - Expand our patient identification and support program for special populations and their providers, including Hispanic patients, Black patients, those with founder mutations and CCM3 mutations.
 - Establish a network of clinical research centers in preparation for clinical drug trials and to facilitate consistent treatment.

- Support dissemination of clinical treatment guidelines. Plan to update guidelines as needed.
 - Extend invitations to potential clinical centers and assess interest and readiness
 - Assist in correcting disease knowledge deficits at centers
 - Expand the clinical component of the annual Scientific Meeting, led by Center of Excellence key personnel.
 - Develop and implement a genotyping campaign to increase the number of patients eligible for clinical drug trial participation
 - Continue to fund and create a genotyping subsidy program for those unable to afford testing
 - Target those believed to be at risk for founder mutations on the basis of genealogy, offering genealogy services, community-building, and testing in order to expand our patient base and increase awareness of the illness in specific geographies and groups.
 - Participate in consortia and as an IRB-approved enrollment site for translational and clinical research, leveraging our unique position with the patient community.
- 2) Provide disease and resource information to educate and improve the lives of people affected by cavernous angioma, caregivers, health professionals, researchers, policy makers, the media and the general public.
- Maintain a website and printed materials that provide up-to-date information.
 - Organize and host regional educational events.
 - Place specific focus on increasing health professionals' knowledge of the condition.
 - Create a webinar series to provide information and progress updates.
 - Create a Patient-Expert Certification Program to develop and recognize mentors.
- 3) Foster and promote a caring community to provide support.
- Provide multiple avenues of online community support internationally, nationally, and regionally.
 - Develop programs to support members which may include local face-to-face support, teleconferencing, and other avenues of outreach.
 - Develop programming for those who are living with CCM-related chronic deficits.
 - Foster international sister organizations who can assist in locating and organizing patients and researchers, including assisting with the formation of international consortia.
- 4) Get people involved in advocacy and active participation toward a cure.
- Develop a Community Alliance program to establish and nurture local affiliate groups to promote grassroots growth that includes mutual support, public awareness, Center of Excellence identification and development, and fundraising.
 - Inform and encourage every individual to actively participate to their full potential.
 - Encourage people to share their experiences and provide a public social media platform to raise awareness.
 - Encourage and facilitate research participation.
 - Provide tools for more successful fundraising events.

- Encourage and train people to contact their legislators on both the federal and state level to promote increased funding of cavernous angioma-related research and services, particularly leveraging information gained from founder mutation outreach.
 - Encourage people to educate and engage with their medical providers to expand the Angioma Alliance umbrella.
 - Mentor a new generation of volunteer leadership to sustain and develop the Board of Directors and Board activities.
- 5) Build and sustain a broad base of funding sources to support our mission and goals.
- Develop and execute an efficient, effective, long-term fundraising strategy that includes peer-to-peer events, major and individual donors, and corporate and foundation support.
 - Leverage local affiliate groups as potential fundraising event organizers.
 - Schedule and integrate major donor development into executive level organizational activities.
 - Offer training to Board members to facilitate their role as community stewards.
 - Explore mechanisms for planned giving.
 - Use fundraising activities to increase awareness and understanding of cavernous angioma and the work of Angioma Alliance.