

# **ANGIOMA ALLIANCE COMMUNITY ALLIANCE PROGRAM**

## **WHAT IS AN ANGIOMA COMMUNITY ALLIANCE?**

An Angioma Community Alliance is an informal, structured group of volunteers in a specific geographical area that may be multi-state, statewide, or metropolitan, who work closely with Angioma Alliance to find and engage those affected by cavernous angioma, improve care through interactions with medical professionals, raise public awareness, and raise funds for a cure. Angioma Community Alliance fosters stronger links between Angioma Alliance and families around the country.

## **MISSION STATEMENT**

Each Angioma Community Alliance is dedicated to informing, supporting and empowering those affected by cavernous angioma and driving efforts toward better treatments and a cure.

## **PURPOSE STATEMENT**

Each Angioma Community Alliance is dedicated to:

- Raising revenue to drive research in the diagnosis, cause, management and care of cerebral cavernous angioma via national Angioma Alliance programs;
- Delivering support and education programs including finding patients, organizing informal adult or family meetups, disseminating patient education and resource information, and engaging local health care providers and the general public.
- Where appropriate, Angioma Community Alliances may organize conferences, serve as ambassadors to nearby Angioma Alliance Centers of Excellence and Clinical Centers, engage in legislative advocacy, or participate in other mutually agreed upon activities.

## ANGIOMA ALLIANCE COMMUNITY ALLIANCE AGREEMENT

### I. Grant of Community Status

- a. **Affiliation.** The Community Alliance, although self-governing, operates under the Certificate of Incorporation and Bylaws of Angioma Alliance and by Angioma Alliance’s policies and procedures. A Community Alliance is not separately incorporated.
- b. **License.** Angioma Alliance grants the Community Alliance a revocable license to use the Angioma Alliance name and logo in its title and to use such designation in connection with the Alliance’s activities described in this Agreement for so long as it is a recognized Community Alliance.
- c. **Name.** The name of the Community Alliance is the “Angioma Alliance \_\_\_\_\_ Community” (Examples: Angioma Alliance Florida Community, Angioma Alliance Greater Washington, DC Community, Angioma Alliance Intermountain Community). Following the effective date of this Agreement, the Community Alliance can only change its name with written approval from Angioma Alliance. All name changes must be approved by the Angioma Alliance Board of Directors.
- d. **Location.** The primary mailing address and contact information for Angioma Alliance correspondence to the Community Alliance is:

#### Community Alliance

Community Name: \_\_\_\_\_  
Street: \_\_\_\_\_  
City, State & Zip: \_\_\_\_\_  
Phone Number: \_\_\_\_\_  
Email Address: \_\_\_\_\_

#### Community Alliance Contact(s)

Name: \_\_\_\_\_  
Street: \_\_\_\_\_  
City, State & Zip: \_\_\_\_\_  
Phone Number: \_\_\_\_\_  
Email Address: \_\_\_\_\_

Name: \_\_\_\_\_  
Street: \_\_\_\_\_  
City, State & Zip: \_\_\_\_\_  
Phone Number: \_\_\_\_\_  
Email Address: \_\_\_\_\_

The Community Alliance will notify Angioma Alliance in writing thirty (30) days prior to any change in contact information.

- e. **Term.** This Agreement will supersede any prior understandings and agreements between Angioma Alliance and the Community Alliance, whether in writing or verbally.

The Community Alliance may terminate this Agreement for any or no reason with one hundred eighty (180) days prior written notice to Angioma Alliance. This lead time

should serve to prevent lost revenue due to aborted contracts with event venues and will allow Angioma Alliance an opportunity to provide alternatives for those Community Alliance members who wish to remain engaged. Angioma Alliance may terminate this Agreement immediately in its good faith determination that “Cause” has occurred or exists. For purposes of this Agreement, Cause shall include without limitation (i) any material breach of the terms of this Agreement, (ii) any misappropriation of Angioma Alliance funds or resources, (iii) disparagement of Angioma Alliance, (iv) material deviations from budgeted programs or (v) misuse of Angioma Alliance intellectual property.

The Angioma Alliance Board of Directors may terminate this Agreement at any time with thirty (30) days’ notice, with or without Cause, in its sole and exclusive judgment.

## II. **Constituency**

- a. **Definition.** The Community Alliance will not discriminate based on any class protected by Federal law. Angioma Alliance actively seeks to include anyone who has demonstrated an active interest in the Community Alliance without regard to gender identification, race, age, ethnicity, sexual orientation, religion, creed, or socioeconomic status. A relationship with the Regional Community carries with it an automatic association with Angioma Alliance.
- b. **Recordkeeping.** The Community Alliance will maintain a current list of Committee members, individuals, donors, supporters, sponsors, volunteers, events and all groups who have demonstrated an interest in the Community Alliance using an Excel or Google spreadsheet and will share with Angioma Alliance as needed. The Community Alliance will report at least monthly and not later than the tenth day of the month to the Angioma Alliance Development Director any changes to volunteer leadership, event dates, or significant sponsor activity. To maintain our non-profit status, the Community Alliance will maintain financial records as instructed by the Angioma Alliance Treasurer.

## III. **Angioma Alliance Obligations**

Angioma Alliance is committed to the success of the Community Alliance. To further this, Angioma Alliance will:

- a. Provide contact information for the Angioma Alliance Director of Development, and/or her designated alternate, who will serve as the Community Alliance’s primary liaison to Angioma Alliance. It is anticipated that, as the Community Alliance program grows, regional leaders will be designated to serve as primary Community Alliance liaison.
- b. Distribute written policies, standards, procedures and guidelines for key aspects of Community Alliance operations.
- c. Provide training, materials, and other resources.
- d. Establish and use communication systems that promote frequent and meaningful interaction.
- e. Respond promptly, professionally, and effectively to Community Alliance needs.

- f. Annually review and communicate organization-wide progress toward strategic goals.
- g. Recognize Community Alliance contributions towards achieving Angioma Alliance goals.
- h. Develop and make available high-quality, medically-sound and useful educational and public awareness materials.
- i. Maintain registered charity status in the Community Alliance's locale.
- j. Provide fundraising event consultation and materials.
- k. Identify and implement potential opportunities for collaborative revenue generation efforts including nationwide campaigns and corporate relationships.
- l. Establish and maintain a section of the Angioma Alliance website devoted to the Community Alliance.

#### **IV. Community Alliance Obligations**

- a. **General.** To support the mission of Angioma Alliance, the Community Alliance will:
  - i. Indicate its affiliation with Angioma Alliance in all official and public communications.
  - ii. Train Community members, officers, and volunteers for performance of their roles.
  - iii. Educate volunteers about national activities.
  - iv. Comply with all Angioma Alliance policies, standards, and procedures.
- b. **Governance.** Strong governance is critical to the success of a Community Alliance. To that end:
  - i. The Community Alliance will be governed by a Committee of no less than 5 members elected to one-year renewable terms.
  - ii. The leadership of a Community Alliance includes a chair, vice-chair, treasurer, peer support co-chair and event co-chair. The leadership follows the policies and procedures of Angioma Alliance.
  - iii. Community Alliances must create and implement an action plan annually to carry out local mission-related activities.
  - iv. Community Alliance Chairs are not compensated and cannot be employees of Angioma Alliance.
  - v. Community Alliance Committee members serve at the pleasure of the Angioma Alliance Board of Directors.
  - vi. Community Alliance Committees must meet at least three times annually; one meeting must be in person. To qualify as a meeting, a simple majority quorum must be present.
  - vii. Community Alliances must maintain open and accessible records of the Community Alliance Committee meeting agendas and minutes.
  - viii. Community Alliance Committee members must disclose any conflicts of interest in advance of serving on the committee.
  - ix. Community Alliances are encouraged to form standing and ad hoc subcommittees such as Fundraising, Education, and Outreach.
  - x. The Community Alliance must create and submit an annual operating plan.

- c. Program.** The Community Alliance will seek to create a community of affected families in their geographic area and facilitate better care. To this end,
- i. The Community Alliance will use only Angioma Alliance approved materials.
  - ii. The Community Alliance will accept patient and family referrals from Angioma Alliance and provide outreach that includes peer support and resource information.
  - iii. The Community Alliance will promote its activities in the Angioma Alliance Facebook groups, on its webpage, and in other forums as appropriate. It will attempt to develop an ongoing relationship with local media outlets to raise public awareness of the Community's existence and of cerebral cavernous angioma.
  - iv. The Community Alliance will provide opportunities for Community members to interact. Examples include a designated Facebook group, scheduled Google Hangout, or a Community picnic. A budget for outreach and support events can be negotiated with Angioma Alliance.
  - v. The Community Alliance will encourage their members to distribute Angioma Alliance materials to area medical professionals.
  - vi. The Community Alliance will encourage medical professionals to refer patients and families to Angioma Alliance and the Community Alliance.
- d. Enhanced Program Activity.** Some Community Alliances will find they are in a position to add specific additional programming. Budgets for programming can be negotiated with Angioma Alliance as part of the annual budgeting process. Enhanced program activities may be decided upon by the Community Alliance and must be approved by Angioma Alliance. Activities could include:
- i. Patient conferences in partnership with local medical and research professionals/facilities.
  - ii. Ambassador program in which Community Alliance members take an active role in meeting patient families and working with medical professionals at Angioma Alliance designated Centers of Excellence or Clinical Centers, if any exist in the Community Alliance's geographic area.
  - iii. Legislative advocacy at the local, state, or national level as allowed and defined under Section 501(c)3 of the Internal Revenue Code.
  - iv. Other activities as mutually agreed upon.
- e. Revenue Generation.** The Community Alliance will conduct enthusiastic fundraising campaigns and commit to generating annual net revenue goal of at least five thousand dollars (\$5,000). Angioma Alliance encourages conducting year-round fundraising, carrying out signature events, and establishing relationships with local corporations, foundations, and individuals for gifts, sponsorships and other support. To fulfill its financial obligation, the Community Alliance will:
- i. Abide by Angioma Alliance fundraising policies and procedures, as well as federal, state, and local laws.
  - ii. Work with the Angioma Alliance Development Director to create a fundraising plan and materials.
  - iii. Ensure that 75% of every dollar raised is spent on mission activities.

- iv. Maintain records of funds collected and fundraising expenditures as directed by the Angioma Alliance Treasurer.
  - v. Utilize Angioma Alliance online donation, peer-to-peer, and credit card processing platforms.
- f. **Financial Management.** The Community Alliance will manage its financial responsibilities coordinated with the Angioma Alliance Treasurer in accordance with generally accepted accounting principles. It will:
- i. Maintain accurate financial records in accordance with Angioma Alliance policies and procedures and in accordance with all IRS and other required regulations and standards for non-profits.
  - ii. Deposit funds collected into an Angioma Alliance designated bank account or send funds to the Angioma Alliance office within two weeks after collection.
  - iii. Promptly inform Angioma Alliance Treasurer of any fundraising expenses to be paid by Angioma Alliance and provide invoices.
  - iv. Provide donor information, including gift-in-kind donations, for acknowledgement purposes to Angioma Alliance within two weeks.
  - v. Not co-mingle Community Alliance funds or donations with any other business or personal assets.
  - vi. Present an annual budget as a starting point for negotiations with Angioma Alliance regarding desired program expenditures. Budgets should be submitted by September 1 for consideration for the Angioma Alliance fiscal year, October 1 – September 30.

**V. Limitations.**

- a. Neither Angioma Alliance nor the Community Alliance will:
- i. Advertise or imply that Angioma Alliance is a medical or professional counseling organization.
  - ii. Endorse any one treatment plan or medical professional for cavernous angioma.
  - iii. Provide information on treatments that are not generally accepted by the established medical community and/or reviewed and approved by Angioma Alliance's medical and scientific advisors.
  - iv. Publicly espouse any religious or political ideology.
  - v. Share or allow to be shared any personal medical information ("Protected Health Information") of Angioma Alliance constituents without written authorization approved by Angioma Alliance. Community Alliance Committee members will sign the Angioma Alliance Volunteer Confidentiality Agreement.

