The Information You Need
A guide to raising money and awareness for Angioma Alliance

Dear Angioma Alliance family, friend and supporter:

On behalf of everyone at Angioma Alliance, I would like to extend our sincere thanks for your interest in helping us boost our awareness and fundraising efforts. Whether you have already hosted your own fundraiser or are new to the Angioma Alliance community, your active participation means the world to us.

We’ve compiled this guide because it’s critical for all of us to work together within a well-defined set of guidelines. We ask that you carefully review this information (and keep it handy!) as it contains important legal procedures that are necessary to follow when raising money on behalf of Angioma Alliance. While we value the wonderful creativity and initiative of our volunteers, our growing organization also needs to ensure that we effectively follow the stringent tax codes established by the IRS with regard to nonprofit fundraising activities.

So once again, thank you. Your participation and your leadership are invaluable to us. Leaders are ordinary people with extraordinary determination. It is because of leaders like you – people who donate their time and money to our cause – that we are able to support and inform those affected by cavernous angioma, support research, and educate health professionals and the public.

Together, we can continue to make a difference.

Together, we can raise awareness higher than ever before.

Together, we can raise money, which funds our work to find better treatments and a cure.

Connie Lee, President

We wish to extend our deepest thanks to the Parent Project Muscular Dystrophy for providing the template for this very useful guide.
Angioma Alliance Fundraising Events Guide

This guide is designed to help you navigate your way as you are planning, executing and wrapping up your fundraiser. Angioma Alliance has streamlined this process as much as possible to ensure you receive proper support from us and have a smooth, successful event from beginning to end.

Angioma Alliance is a tax-exempt 501(c)3 organization. This nonprofit status is crucial to our ability to work toward our mission; it must be held in the highest regard. You can help by following Angioma Alliance’s event guidelines below.

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The Basics

Let Us Know About Your Event
Inform Angioma Alliance about any event you plan to carry out in its name or under its logo.

Why this is necessary:

Angioma Alliance has an obligation to assure both its Board of Directors and the Federal Government that its activities are compliant with those required of all 501(c)3 nonprofit organizations. Even as a volunteer, the work you do on our behalf “counts.” Each state has its own regulations regarding allowable fundraising activities and its own required registrations. We need to be in compliance in order to maintain our privilege of fundraising across the country.

By providing Angioma Alliance with this information in advance, we will be able to assist you as you begin planning your event. If have trouble deciding what type of event to host, give us a call. We will do our best to offer suggestions. Choose the type of event that best reflects your personality, is rewarding for you and one that you have the time and the resources to manage.

Please contact Connie Lee at info@AngiomaAlliance.org or at 757-623-0615 to discuss the fundraising event you have in mind.

Some basic information you should have ready for Angioma Alliance:

- Name of your event
- What kind of event it is (auction, dinner, golf tournament, etc.)
- Location (City, State)
- Contact name and phone number

Q: What should the name of my event be?

A: Angioma Alliance suggests choosing a name that reflects two things: the kind of event you are having, and Angioma Alliance or cavernous angioma. Some examples are “The Lee Family Golf Tournament for Angioma Alliance”, “Race for Cavernous Angioma Research” or “Brainy Bowling for Angioma Alliance.” (Names like “Michael’s Challenge” or “Race for Tim” are not as specific and may be confusing to first-time event attendees in regards to what it’s about.)
Event Committee

If you are doing more than a home party, Angioma Alliance strongly encourages you, the event leader, to organize an event committee.

Why this is necessary:

Events can be overwhelming. Form a committee, or team, to help you plan, coordinate and execute your event. We suggest gathering a group of family and friends that you can trust and depend on (for deadlines, assistance, honesty, etc.). Sharing responsibilities also makes everyone more invested in the success — and fun — of the event!

Once you have determined who will be on your event committee, organize a kickoff meeting to review the timeline and delegate tasks. By making these decisions early, you help give everyone involved an idea of what you expect from their participation. It will also give you a great guide as you move forward with your event.

Q: Who should I ask to join my event committee?

A: Ideally, you should try to organize your committee with real “go getters.” It takes a certain type of fearless person who is committed to the cause to solicit auction items, sponsorships and donations. It is also wonderful, if possible, to include individuals who have connections with the local business community, the media, local celebrities or local charitable foundations, or anyone who has organized a fundraiser in the past. This is also a great opportunity to involve those family members and friends who always ask, “What can I do to help?” By inviting them to be on your event committee and by assigning them tasks, you empower them to create change in the cavernous angioma community.

Q: What are the major tasks I should expect?

A: For any public event, you should expect to:
   1. Create a timeline
   2. Create a budget
   3. Find a location
   4. Advertise the event
   5. Gather the materials and personnel needed for the event
   6. Follow-up with thank you’s and accounting for donations and expenses

   You will find templates for a number of these activities in the Appendix.
MATERIALS
Angioma Alliance offers Angioma Alliance-produced materials to support your event.

Why this is necessary:

After you’ve called us to discuss your event idea and have an organized plan, please contact us to discuss what Angioma Alliance materials might help you promote, publicize, or support your fundraising efforts. Our materials range from brochures and fact sheets to lapel pins, lip balm, pens, wristbands, magnets, shirts, and briefcases. We are very happy to discuss the materials we have available and which may be the best fit for your event.

Q: Is there a charge for using Angioma Alliance’s materials at my event?

A: We offer brochures and lapel pins free of charge to help you promote the Angioma Alliance’s mission. Our only request is that you return any unused items to Angioma Alliance. This helps us maintain a healthy supply of materials and reduce the cost to produce them. For other more expensive logo items, please contact us so that we can talk about how many you will need and how they will be used.

PRINTING (AND PUBLICIZING)
Always use the entire name of our organization: “Angioma Alliance” and please use “cavernous angioma” as the name of the illness.

There are many names for our disorder: “cavernous angioma”, “cavernous malformation” and “cavernoma” are the most common. Our best understanding at the time of this writing is that “cavernous angioma” most accurately reflects the nature of the disorder. It also makes the connection with our organization’s name clear.

Before sending out any correspondence – including event invitations or letters – please let us review them for terminology and spelling.

If you plan on creating your own printed materials to use in conjunction with existing Angioma Alliance materials, please follow Angioma Alliance’s branding guidelines and message points included in the appendix. By following these guidelines and using consistent message points, you effectively raise awareness for cavernous angioma.

Angioma Alliance Logo
We will email you a digital version of the Angioma Alliance logo or of the Brainy Bowling logo if you email your request to info@AngiomaAlliance.org. Any event materials you create, which include our logo, must be approved by Angioma Alliance. Please ensure the Angioma Alliance logo on your document looks exactly like the ones online. For instance, it cannot be squished,
Important:

Before you print your own materials, please send a draft copy of invitations, tickets, programs, press releases etc., to Connie Lee either via email or regular mail. We need to review these materials to ensure that they are in compliance with IRS regulations and that they contain accurate information about our organization and the disorder. For example, invitations to a benefit dinner must list the amount of the registration fee that is tax deductible (this figure is the full registration fee minus the value of the dinner the attendees receive). There are many other examples of required elements that may not be immediately obvious.

Angioma Alliance also offers templates for some printed event materials such as pledge collection envelopes, invitations, and registration forms. We’re happy to share these templates that other Angioma Alliance fundraisers have used successfully in the past.

Q: Can I use Angioma Alliance letterhead for our solicitation letters?

A: No. Angioma Alliance’s policy is to provide each fundraiser with an official letter of support from our organization. We can also work with you to produce a special event letterhead for your fundraiser.
MANAGING FUNDS

Accumulate

All fundraising events carried out under the Angioma Alliance name and logo must adhere to generally accepted accounting procedures (GAAP) for nonprofits.

Why this is necessary:

As we mentioned earlier, Angioma Alliance has a legal responsibility to report its income using generally accepted accounting practices (GAAP) for nonprofits. Please follow the guidelines listed below to help us keep track of proceeds from your event.

How to accept donations by check

Please ensure that all checks and donations are made out to: “Angioma Alliance”. Please make sure the check includes the address of the donor or please write the address on the face of the check.

Make photocopies of all checks and event-related correspondence. When you collect donations and in-kind items for your event, please make photocopies of checks and correspondence for your records and ours. Keeping copies will provide a cross-reference if there are any problems, and will also provide you with a list from which to write personal thank-you notes.

Please bundle your donations together and mail them to Angioma Alliance. (See the “submit” section below for more information on how to send us the donations you’ve collected.)

How to take credit card donations

Angioma Alliance can also provide you with Credit Card Information forms that will allow you to take credit card donations at your event. We do not send actual credit card processing machines. We send a simple, short, fill-in-the-blanks form. The information you collect is necessary for Angioma Alliance to receipt the donor.

What to do with cash donations

If you receive cash donations, please go to your local bank and get a bank check (issued to Angioma Alliance), or a money order for the total cash amount. Then, mail it to Angioma Alliance.
Q: Can I open a bank account, deposit all the donation checks there, and then cut a big check to Angioma Alliance?

A: No, this does not adhere to generally accepted accounting practices (GAAP) for nonprofits. If you deposit a check made out to Angioma Alliance into your bank account, this is considered “co-mingling” funds. Secondly, if your donors make a check payable to you, then they haven’t made a “donation” to Angioma Alliance; therefore we can not provide them with a receipt acknowledging their gift and giving them the opportunity to deduct it from their taxes. Lastly, to open a bank account under the organization’s name is illegal.

How to record non-monetary items that have been donated, including auction items, food/beverages, etc.

Angioma Alliance must have a record of non-cash donations for tax purposes and to acknowledge the donor. For items that are auctioned, we need to know the name and address of the donor and the “fair market value” of the item – how much it would cost to buy retail. We realize that for some items, particularly used items, this will be an approximation. We also need to know for how much the item sold and who purchased it. Typically, purchasers do not receive a tax deduction for items purchased at charity auctions unless their winning bid is over the fair market value of the item. They may then deduct the difference between fair market value and the actual purchase price. We send them a tax receipt for this amount. We have posted a form online that you may use to record these donations.

For non-monetary donations of food or other items that were used at the event, we will need to know the name and address of the donor, the items, and the fair market value of the items. You may use the same form as the one used for auction donations to record this information.

For both auctioned items and donated goods to support an event, we will not list the fair market value of the item on the tax receipt that we send the donor. This figure is for our records only.

We do not need to know about services that are donated as part of the event. For example, if your event includes live music, we do not need to know what the volunteer musicians would charge if they were playing at a for-profit event. Any service that an individual puts into an event is considered volunteer activity and is not tax deductible even if it is in the individual’s line of work.
Submit

Please mail donations, donor information and any additional event correspondence to Angioma Alliance within 30 days after your event. Our address is 142 W York St, Norfolk, VA 23510-2015.

Only send donations in the form of checks, credit card information, bank check or money order.

If someone gives you cash, please send us the person’s name, address, and donation amount if this is available.

If you ask your donors to mail their contribution directly to the Angioma Alliance office, please ask them to write your family’s name somewhere on the check so that we can notify you when their donation has been received.

Why this is necessary:

The donor’s information is entered into Angioma Alliance’s database with a note that they made a contribution via your fundraiser. Doing this helps us appropriately categorize donations in our database. In turn, we’re able to generate accurate fundraising reports and donor receipts in a timely manner.

The donor’s information is not shared with any other individuals, organizations, or corporations. Some individuals in our database may receive information directly from Angioma Alliance in the future, most often our quarterly newsletter.

Your friends may be placed on our newsletter mailing list unless we are told otherwise by you. We believe that donors like to know how their donations are being used, and our quarterly newsletters are full of this information. Our newsletters also include a donation envelope that your friends can use, if they choose, to send in additional donations, but they are not obligated to do so. If we have not received an additional donation from an individual for two years or more, Angioma Alliance will remove them from the mailing list. If you believe your donor(s) would not like to receive the newsletter, please let us know and we will not add their names. The donors also have the opportunity to remove their names by emailing or calling us.

Expense Reimbursement Forms

Angioma Alliance recognizes that hosting an event often incurs associated costs. It is our policy to reimburse you for event-related expenses after the event has occurred. All expenses must be submitted with corresponding receipts and the expense reimbursement form you will find online.
All events must keep fundraising costs under 30% of the gross proceeds, as outlined by Angioma Alliance’s fundraising policies. By adhering to these strict fundraising percentages, Angioma Alliance maintains excellent percentages in our reporting, which helps us secure government, foundation and corporate giving.

Send Thank You Notes
Angioma Alliance believes in the importance of donor integrity and is committed to acknowledging the generosity of all Angioma Alliance donors.

Why this is necessary:

One phrase commonly used in the nonprofit sector is “thank before you bank.” This phrase simply underscores the importance of sending tax receipts and thank-you letters in a timely fashion after an event.

All tax receipts must be issued from the Angioma Alliance corporate office in order to comply with Federal Law. However, we also encourage you, the fundraising host, to send a personal “thank you.” In your note, you may want to include a sentence that states, “Keep an eye out for your official tax receipt in the mail from Angioma Alliance.”

Q: How soon will donors receive their “thank you” letter and tax receipt from Angioma Alliance?

A: Once donations are received in the Angioma Alliance’s development office, we input each check and issue “thank you” letters and tax receipts. This process usually takes anywhere from 1-4 weeks, depending on the time of year and volume of donors.
Media Relations Roadmap

Hosting an Angioma Alliance fundraising event in your community, is a terrific opportunity to garner media attention. The effective use of free media opportunities gives you the chance to raise awareness about cavernous angioma among your community and to call attention to the importance of raising funds for research.

You don’t have to be a seasoned public relations professional or publicist to capture the attention of editors and reporters. However, you have a better chance of getting your event covered by many with some proven methods of generating media interest. It often takes lots of friendly follow up and persistence to break through the clutter in a newsroom. Your biggest strength is your passion and enthusiasm for — and accurate knowledge of — the importance of raising cavernous angioma awareness and research dollars.

Tools to help you get press:

To make it easier for you, Angioma Alliance has put together some tips on how best to catch an editor’s ear and communicate messages about Angioma Alliance and cavernous angioma. On the following pages, you’ll find:
• Tips for pitching the media
• Key talking points on Angioma Alliance and cavernous angioma
• A “swiss cheese” pitch letter and press release (you fill in the blanks!)
• General interview tips

Confidentiality and Sensitivity Issues

Angioma Alliance is sensitive to the fact that discussing cavernous angioma can bring up sensitive issues for you and your family. We understand if there are parts of these press materials that you would like to edit in order to keep you and your family comfortable. Talking about cavernous angioma can be difficult, but we also encourage you to ‘go for it’ because of how hugely important it is to bring this disorder to the forefront.

Research: know your local reporters and their beats

As with any form of communications, know your audience. Before you send a pitch letter, press release or pick up the phone, compile an accurate media list. Find the names of editors and reporters who report on related topics, such as community-, health- or science-related topics. In other words, find out their beat. And you can often find their contact information (phone, fax, email) and instructions for submitting a story idea online or in a hard copy of the publication.
Here are some reporters most likely to cover your story:

**Daily newspapers** – Features Editor, Calendar Editor, Health Reporter, Metro Desk

**Weekly newspapers** – Features Editor, Calendar Editor, Health Reporter, Metro Desk

**Television stations** – Assignment Desk, News Desk or Health Reporter

**Radio news stations** – News Desk

**Pitch: tell your story**

A “pitch” is used to make an editor or a reporter sit up and take interest in your story. It can take the form of a one-page letter (see appendix) or a phone call. The two most important things to remember: keep it brief (it’s a teaser) and give them a compelling reason why they should cover your story. For instance, why would your event or your personal story be of interest to their readers? Why are you hosting a fundraising event? At the end of the letter or conversation, offer to send them more information in the form of a press release (see appendix).

**Tips for talking about cavernous angioma**

With its complex nature and extensive scientific terminology, cavernous angioma can be difficult to understand fully. We’ve compiled our recommendations below to help you better communicate about cavernous angioma with reporters, event attendees and other parents.

<table>
<thead>
<tr>
<th>Negative adjectives and phrases to avoid</th>
<th>Positive adjectives and phrases to use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffers from</td>
<td>Diagnosed with</td>
</tr>
<tr>
<td>Terrible, debilitating disease</td>
<td>Abnormal blood vessels in the brain or spine</td>
</tr>
<tr>
<td>Afflicted with / Suffers from</td>
<td>Affected by</td>
</tr>
<tr>
<td>Disease (viral)</td>
<td>Disorder/ Illness</td>
</tr>
<tr>
<td>Fatal, terminal</td>
<td>Can disable, and occasionally, lead to death</td>
</tr>
<tr>
<td>Crippling or crippled</td>
<td>Disabled</td>
</tr>
</tbody>
</table>

Words like ‘normal’, ‘fulfilled’ and ‘productive’ should be used carefully so the sentence does not imply that those affected by cavernous angioma aren’t ‘normal’, ‘fulfilled’ or ‘productive’.

When you talk about cavernous angioma to a reporter, here are few things to keep in mind:
Be prepared.

• Know the five “Ws” of your event: who, what, when, where, why (and how).
• Be familiar with a publication and its audience.
• Have Angioma Alliance’s mission statement and key messages with you for reference.

Be truthful and direct.

• Make your key points as simply and as often as possible.
• Have engaging examples or anecdotes to back up your key points. Tell your personal story.
• If you don’t know the answer to a reporter’s question, admit it and offer to get the information for the reporter as soon as possible. (Be sure to follow up!)

Be confident and relaxed.

• You are the expert.
• A successful interview is often a conversation, not an inquisition.

Be sure you understand the question before you answer.

• If you’re not sure what the reporter is asking, say so.
• It’s OK to ask a reporter to back up or rephrase a question.

Be aware of saying things “off the record”

• It doesn’t exist; what you say can be quoted.
• Never say “no comment.”
• Give a reason for why you can’t discuss certain topics or issues.
• There are many ways to give a “non-answer” answer. You can redirect the conversation by saying, “I can’t discuss that, but what I can tell you is that our program is successful because…”

Don’t be afraid to show emotion.

• This is a very emotional topic for you and your family…and for many other families out there who may really connect with your message and be inspired by your story. Silences, or long pauses, are OK.
• When you’ve made your point, stop speaking. Don’t feel like you have to keep talking. People often speak nervously to fill the silence, which may dilute their original, well-articulated point.
Remember, you have control over what you say in an interview.

The editor has ultimate control over what finally appears in print or on the air.

Press Release:

Angioma Alliance has written a “swiss cheese” Event Press Release (see appendix). It contains key points and messages and leaves “holes” for you to fill in and distribute to the media. It’s suitable for all types and sizes of events - from letter writing campaigns, to change drives, to bake sales, to dinner dances. Any and every event counts and we want as many people as possible to know about it.

After you’ve personalized your press release, you’re ready to send it via fax or email to the contacts on your media list. Be mindful of publications’ deadlines. In some instances, they need to be notified six weeks before the event in order to be included in the calendar listing.

Follow up: be friendly, yet persistent

After you distribute your press release to your media list, be sure follow up. Editors and reporters are typically under deadline and have a lot going on, so give them a few days to get to it. Then pursue your first-round of follow up with a call or email. We suggest that you ask if they received the release OK, gauge their interest in covering your story and stress that you’re available to help.

Don’t be discouraged if it takes you several attempts to reach an editor or reporter. Follow up, whether it’s the first-round or third-round, is a great opportunity to stay in the reporter’s mind and build a relationship. Sometimes just a string friendly, informative 30-second conversation can go a long way.

Press Placement

Angioma Alliance would appreciate receiving a copy of all press placements you receive, so we can keep our media records as accurate and up-to-date as possible.

Final Outcome

Please do not to be discouraged if your press releases and story ideas do not get placed. For whatever reason, many press releases slip by the wayside and never make it to print. Your efforts are still worth it, and we appreciate all the time you’ve spent.
Appendices

Appendix A  Angioma Alliance Key Messages
Appendix B  Pitch Letter to the Editor
Appendix C  Press Release
Appendix D  Auction Item Solicitation
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Appendix F  Sample Benefit Auction Timeline for Live/Silent Auction
Appendix G  Gift in Kind Tracking Form
Appendix A
Angioma Alliance Key Messages

About Cavernous Angioma:

- Cavernous angiomas are abnormal blood vessels in the brain and spine that can hemorrhage and cause seizure, disability, and occasionally, death. They can become symptomatic at any time from infancy to old age.

- 1 in 200 people have a cavernous angioma. It is estimated that 1 in 3 people with a cavernous angioma will have symptoms at some point in their lives.

- Cavernous angiomas can hemorrhage and cause seizure, a wide variety of neurological deficits depending upon what area of the brain or spine is affected, and chronic severe headache.

- The only current treatment for cavernous angioma is brain or spinal surgery.

- About 25% of people with the illness have a hereditary form. Each child of someone with the hereditary form has a 50/50 chance of having the illness. With the hereditary form, people usually have more than one cavernous angioma and can develop more over time.

The greatest challenges that our fundraiser will help Angioma Alliance to address:

- Scientists do not know why cavernous angiomas hemorrhage. Gaining this knowledge could help them to develop less invasive treatments. Angioma Alliance puts more than half of its financial resources into supporting research.

- People with cavernous angiomas often feel isolated because they do not know anyone else with the illness. Angioma Alliance provides many opportunities for individuals and families to have contact with others who are in a similar situation. They also distribute information about the illness so that patients can make informed decisions about their care. Angioma Alliance puts more than a quarter of its financial resources into patient support and information.

- Physicians, including neurologists, are not familiar with the illness. Angioma Alliance has been working to create physician education materials and to encourage neurology residents to learn about cavernous angiomas. Angioma Alliance puts most of its remaining funds into physician education.
About Angioma Alliance

Angioma Alliance is a patient-directed non-profit organization founded in 2002. The mission of Angioma Alliance is to inform and support individuals affected by cavernous angiomas of the brain and spine while facilitating improved diagnosis and management of the illness through education and research. Our work is overseen by a group of leading cerebrovascular surgeons, neurologists, and neurogeneticists.

Angioma Alliance’s specific activities include the following:

Patient Education: Angioma Alliance provides a website in English, Spanish and Portuguese that serves 5000+ visitors per month. The site provides information about the symptoms and course of cavernous angioma, available treatments, the genetic basis of the illness, and related issues. We produce printed educational materials in English, Spanish and Portuguese which are made available through our site and through physicians.

Patient Support: We host a community forum on our website, offer a peer-to-peer support program for those who are newly diagnosed, sponsor an annual national family conference, and provide a toll-free support and information line.

Research: Our largest program is a DNA/tissue bank and Patient Registry in which we work with patients who would like to donate their surgically removed cavernous angiomas for use in research. We also host annual international scientific workshops, and work closely with the National Institute of Health and various researchers to promote increased funding of cavernous angioma research. Most recently, we worked with Representative Tom Udall of New Mexico to introduce legislation into the House calling for increased awareness, education and research for cavernous angiomas (HR 1193).

Physician Education: We sponsor an annual Neurology Resident's Award to encourage these residents to learn about cavernous angioma treatment. We are working with the state of New Mexico, where this illness is more prevalent than in any other place, to produce physician literature to be distributed to primary care and specialty doctors throughout the state.

International: We have an active organization in the United Kingdom - Cavernoma Alliance UK - that mirrors our services for those in the UK and Europe, and in Brazil - Associação Brasileira de Angioma Cavernoso.
Appendix B
Pitch Letter to the Editor

Editor or Reporter’s Name
Newspaper or other publication
Address (City, State, Zip)

[Date]

Dear [Editor or Reporter’s Name]:

I am writing to suggest a story idea to raise awareness about a devastating, little known disorder that 1 in 200 people in the United States – including our [son/daughter/friend, etc – we’ll use son in this example].

Despite its prevalence, not much is known about cavernous angiomas in our own neighborhoods and communities. Cavernous angiomas are abnormal blood vessels in the brain and spinal cord that can hemorrhage and cause seizure, disability, and occasionally, death. They can become symptomatic at any time from infancy to old age. To date, the only treatment is brain or spinal surgery. Our [son], [your son’s name], was diagnosed with cavernous angiomas in [year], and we’ve become active members of a nonprofit organization called Angioma Alliance.

On [date of event], we are hosting a [type of event] to raise awareness of cavernous angiomas and raise funds for Angioma Alliance. The organization’s mission is to inform and support individuals affected by cavernous angiomas of the brain and spine while facilitating improved diagnosis and management of the illness through education and research.

We ask that you consider covering our event. You could help your readers gain invaluable information about cavernous angiomas, which can affect any family in our community. You’d also be giving your readers a great way to support our efforts on behalf of Angioma Alliance.

Please help us in our fight against cavernous angiomas.

Sincerely,

[Your name]
[Your phone number] [Your email]

P.S. A press release is available upon request.
Appendix C

Press Release

For Immediate Release: [Date]
Contact: [Your name, Phone, Email]

LOCAL FAMILY FIGHTS FOR A CAUSE CLOSE TO THEIR HEART AND HOME
[Your hometown] Family Hosts a [Type of event] to Raise Awareness and Funds for Cavernous Angioma Research and Support

(HOMETOWN, STATE) – [Your affected person’s full name] is a fighter. (For instance, five-year-old Brandon Smith is a fighter.) And the name of his toughest opponent is cavernous angioma. When [affected person] was [your affected person’s age of diagnosis], he was diagnosed with cavernous angioma in his [brain/spine]. Cavernous angiomas are abnormal blood vessels that can hemorrhage and cause seizure, disabilities, and, occasionally, even death. However, with the spirit of any good fighter, [he] lives life to the fullest, surrounded by the love and support of [his] family and community.

On [event date], [your affected person’s name] family and friends will host a [type of event] at [event location] to raise awareness of cavernous angiomas, a little known and often misunderstood disorder, and to raise funds on behalf of Angioma Alliance. Angioma Alliance is a national nonprofit organization started in 2002 by the mother of a toddler who had had several brain surgeries as a result of cavernous angioma hemorrhages. The [your family’s name] family is actively involved with Angioma Alliance and hopes to inspire the [your city/town’s name] community to come out, have fun and make a generous contribution in support of [your affected person’s name] and Angioma Alliance.

(Use this or draft a similar quote) “We want everyone to know more about cavernous angiomas and how they affect people in our own neighborhoods and communities,” said [your full name]. “Our [type of event] is a fun way to raise awareness; however, the purpose of the event is very serious because much more research is needed to fight this disorder.”

Many people do not recognize early signs of a cavernous angioma hemorrhage because the symptoms can be subtle – headaches that can be misdiagnosed as migraine, numbness or tingling in arms or legs, or vision problems. These symptoms can occur in people at any age from infancy to old age. Over time or quite suddenly, people with one or more cavernous angiomas can become more and more affected. The illness is very common – about 1 in 200 people have a
cavernous angioma and as many as one third will become symptomatic at some time in their lives. About 25% of people with the illness have a hereditary form in which they typically have more than one cavernous angioma. Each other their children has a 50/50 chance of having the illness as well.

**About Angioma Alliance**

Angioma Alliance is a patient-directed non-profit organization founded in 2002. The mission of Angioma Alliance is to inform and support individuals affected by cavernous angiomas of the brain and spine while facilitating improved diagnosis and management of the illness through education and research. Angioma Alliance is the only organization in the US focused entirely on support and research for cavernous angiomas. The organization works closely with patients, families, researchers, physicians, and legislators and is internationally recognized as the leader in advocating for cavernous angioma research. For more information, visit [www.AngiomaAlliance.org](http://www.AngiomaAlliance.org)

**Interviews Available**

The [Your family’s name] family, Angioma Alliance executive staff, and experts on cavernous angiomas are available for interviews.

**Event listing details:**

**Who:** (your family name & any other community partners)

**What:** (name of event)

**Where:** (address, intersection, location and directions, if needed)

**When:** (day, month, date, year, time frame)

**Why:** To raise awareness and money for cavernous angioma research on behalf of Angioma Alliance

**Additional Info** (ticket cost, entertainment, etc.)
Appendix D
Auction Item Solicitation

Contact’s Name
Company Name
Address (City, State, Zip)

[Date]

Dear [Contact’s Name]:

The [your family’s name] family, in collaboration with Angioma Alliance, will hold a benefit dinner and auction to support cavernous angioma research and education.

In [year of diagnosis] our son, [son’s name], was diagnosed with a cavernous angioma in [his] [brain/spine]. Cavernous angiomas are abnormal blood vessels in the brain and spine that can hemorrhage and cause seizures, disability, and even death, at any age. About 1 in 200 people have a cavernous angioma and up to one third of these people will have symptoms. To date, there is no cure and there is no treatment other than brain or spinal surgery.

Angioma Alliance is a patient-directed non-profit organization founded in 2002 by the mother of a toddler who had had several brain surgeries as a result of cavernous angioma hemorrhages. The mission of Angioma Alliance is to inform and support individuals affected by cavernous angiomas of the brain and spine while facilitating improved diagnosis and management of the illness through education and research. Angioma Alliance is the only organization in the US focused entirely on support and research for cavernous angiomas. The organization works closely with patients, families, researchers, physicians, and legislators and is internationally recognized as the leader in advocating for cavernous angioma research. For more information, visit www.AngiomaAlliance.org

Our benefit dinner and auction will be held at [location of event with address] on [date]. We expect over [estimated number] people to attend and bid on auction items. Will you support our fight against cavernous angiomas? We invite you to participate in one or more of the following ways:

- Donate auction items (goods or services).
- Make a cash donation (to be used towards the purchase of needed items for the dinner or auction).
- Attend the dinner auction.
If you are interested, please send your cash donation or auction items to [name and address]. We would like to receive all gifts by [date]. We are also happy to arrange pick-up of any item. Please keep in mind: your gift is tax deductible. You will receive a letter and receipt from Angioma Alliance to be used for tax purposes.

Thank you for considering our request. Feel free to call me at [###-###-####] with any questions. Together we can both benefit. You/your company will receive recognition at the auction and Angioma Alliance will come closer to finding a cure.

Sincerely,

[Your name]
## Appendix E
### Sample Auction Budget Form

**Income**
- Ticket Sales-- ____ @ $____ $ ________
- Silent Auction $ ________
- Live Auction $ ________
- Total Income $ ________

**Expenses**
- Food $ ________
- Beverages $ ________
- Invitations $ ________
- Postage $ ________
- Venue $ ________
- Auctioneer $ ________
- Programs $ ________
- Decorations $ ________
- Advertising/Promotions $ ________
- Insurance $ ________
- Liquor License (if needed) $ ________
- Miscellaneous $ ________
- Total Expenses $ ________

**Net Revenue** $ ________
Appendix F
Sample Auction Timeline

12-14 weeks before the auction

- Assemble committee and co-chairs
- Find and confirm location for event (or earlier if possible)
- Assign subcommittee responsibilities in the following areas:
  - Securing auction items
  - Auction operations
  - Food and refreshments
  - Invitations and promotion

10-12 weeks before the auction

- Send letters soliciting auction items

8-10 weeks before the auction

- Write and design auction invitation
- Do follow-up calls for auction items
- Secure services of auctioneer
- Solicit donated food and refreshments or meet with caterer
- Begin compiling invitation list

6-8 week before the auction

- Begin writing auction program (Assign smaller auction items for silent auction; bigger items for the live auction, usually no more than 10 or 12 items for the live auction.)
- Send invitation to printer
- Recruit volunteers for following jobs:
  - To check-in guests on the night of auction
  - To set up auction tables, decorate, and arrange auction item
  - To act as bid spotters for the live auction
  - To prepare food if not catered
  - To take payments after the auction
  - To cleanup after event

4-5 weeks before the auction

- Recruit volunteers to address and mail invitations
- Finalize auction program to include with invitation
• Mail media releases to local news outlets

3-4 weeks before the auction

• Address and mail invitations with program
• Make follow-up calls to potential donors of food and wine if you’re seeking them
• Tour auction location and note any special requirements or potential problems

1-2 weeks before the auction

• Prepare bidder’s cards (assign each guest a number for use to record bids)
• Prepare silent auction bid sheets (assign a minimum bid for each item)
• Confirm auctioneer
• Confirm volunteers to work on day of event

1 week before auction

• Visit venue to make final arrangements for decorating
• Purchase decorations
• Create attendance lists for check-in table
• Arrange for drop off of auction items

Day of event

• Decorate venue
• Set up auction tables with silent auction items and bid sheets
• Set up refreshment/drink tables
• Set up check-in tables
• Be sure volunteers are in place and understand the tasks assigned

Final checklist and tips

• Ask auctioneer or MC to encourage bidding on silent auction items
• Set a firm time for closing silent auction bids and announce the time remaining at five minute intervals
• Be prepared at end of auction for buyers who will want to pay and receive their items all at the same time.
Appendix G  
Gift In Kind Tracking Form  

Event Coordinator Name: ____________________________________________________________

Type of Event: _____________________________________________________________________

Date of Event: ___________________ Location of Event: _______________________________

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<th>Donor Name</th>
<th>Donor Street Address</th>
<th>Donor City/ST/Zip</th>
<th>Item Donated</th>
<th>Fair Market Value</th>
<th>Purchaser (if applicable)</th>
<th>Purchase Price</th>
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