

ALLIANCE TO CURE

CAVERNOUS MALFORMATION



FUNDRAISING WALK GUIDE

UPDATED FEBRUARY 2023

WELCOME

Dear Friend in the Fight Against Cavernous Malformation,

Thank you for your interest in holding a walk in your community to sustain our mission to inform, support, and empower individuals affected by cavernous malformations and drive research for a cure. It is only with friends like you that we can continue to expand our mission!

Alliance to Cure Cavernous Malformations Walks are community-organized walks to raise awareness and funds for The Alliance. You have taken the first and most difficult step: deciding to do it! A walk in your community will allow you to honor a special someone affected by cavernous malformations, and allow their friends and family an opportunity to show support on their journey. This packet is a resource and can be used to ensure that your walk will be a success in its first year and grow every year after that!

This guide will serve as a toolkit to successfully plan your event, raise funds and awareness, and have fun! And remember, we are here to ensure you are successful, so please reach out when you are ready to start planning. We suggest allowing 4-5 months of planning time. We can also help you recruit additional committee members and promote the event.

Whether your first walk is a home-run or humble and grassroots, it will grow, and so will your supporters!

Collectively, our efforts result in a nationwide community bound together by Cavernous Malformations, but we do not let our diagnosis define us - it only empowers us.

Warm Regards,

Lindsay Ramirez
Alliance to Cure Cavernous Malformation
Community Development Director
lindsay@alliancetocure.org



SCHEDULING

The first step in planning your walk is to secure a date and venue. Walks can be held anywhere and anytime of the year! Venues may include parks, malls, schools, YMCA camps or private property. Use your connections and be creative to ensure an attractive and cost-efficient venue. There are local and state requirements that may apply to your event. Please read this section carefully.



PRO TIPS

- If the venue costs more than \$500. Look at other options
- Ask if a security deposit is required.
- Make sure there are adequate restrooms, parking, and shelter if needed.
- Ask if the venue allows amplified sound.
- Make sure the venue is easy to find with Google maps.
- Is the venue ADA compliant.
- Ask if the venue allows food (catered, pre-packaged, BBQ...)
- Check community calendars to make sure no other conflicting events occur on the same day.

Once you have negotiated the contract, requirements, and fees, and are ready to have the contract signed, please send to lindsay@alliancetocure.org. All contracts must be in the name of Alliance to Cure and be signed by Alliance to Cure CEO, Connie Lee. This is to ensure you are not liable for any damage or incidents that occur.

The Appendix of this guide includes a template letter for soliciting venues. Once your venue and date are confirmed, email lindsay@alliancetocure.org to help with the promotion of the event



STATE CHARITY REGISTRATION

Thirty-nine states require a non-profit to register before engaging in fundraising activities. The Alliance is registered in states where we have had previous events, but may not be registered in your state. Please give us at least 6 weeks' notice before your event so we can file the appropriate registration application.

INSURANCE

All venues will require liability insurance in case of damage or injury during your event. Angioma Alliance's general liability policy will cover any insurance needs, but we will need to ask our insurance company for a new declaration page listing the venue as "co-insured". Once you have the venue insurance requirements, please send them to lindsay@alliancetocure.org. We will need the name and address of the event, the date of the event, and the expected number of attendees.

BUDGET

It is critical to establish a conservative budget for your event. It would not make sense to put a great deal of effort into an event only to have it lose money. Donors just like you look at our "cost to raise a dollar" to ensure that the most amount of money is spent on the mission of The Alliance. A general rule to follow is that 20% of your fundraising goal can be spent on expenses.



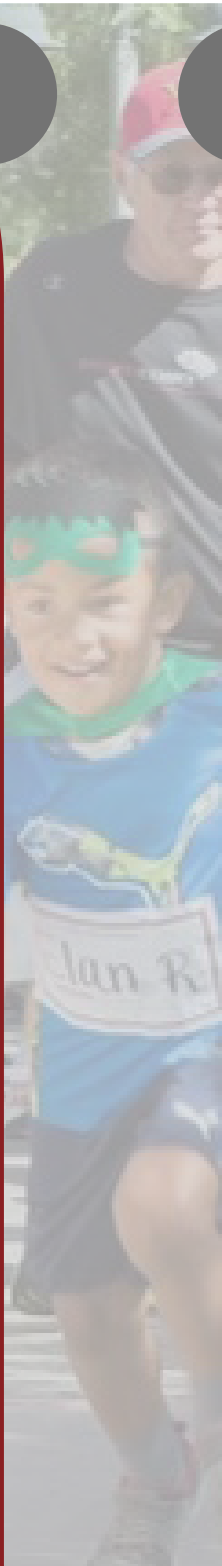
Fundraising should be your committee's top priority! The main goal of the Walk is to raise funds first, and in doing so, you will raise awareness. Income can be generated in many ways, but most funds are raised before the event takes place! Your entire committee will each devote some time to fundraising. Whether it is recruiting family and friends, soliciting their work for a corporate sponsorship, or securing in-kind donations for the silent auction, everyone on the committee should raise funds in some way.

PRE-EVENT

- **SPONSORSHIPS:** This can be the largest source of income for your event. Sponsors can have their names on t-shirts, banners, and awards.
- **PEER -TO-PEER:** Alliance to Cure Cavernous Malformation uses Network for Good for registration and peer-to-peer fundraising. Your event will have its own event webpage.
- **REGISTRATION FEES:** You can have a registration fee if you like. Some suggest that not having a registration fee encourages participants to fundraise beyond the amount of a registration fee.
- **GRANTS:** Some of our organizers have obtained \$1000- \$5000 in local grants at the time of their walks. If there is a local corporation with an associated foundation, call them to find out the application requirements for small grants.
- **T-SHIRT SALES:** It is your decision to include a t-shirt in your registration fee, or people can purchase them at a separate cost.

DURING EVENT

- **RAFFLES:** Most walks offer raffle items as an additional income source.
- **SILENT AUCTION:** Common items include beauty gift baskets, gift cards, restaurant gift certificates, experiences, hotel stays, golf foursomes, etc. If you have one or more big-ticket items like a vacation condo or airline tickets, you will want to silent auction or live auction it to create even more excitement!
- **FOOD SALES:** Water should be provided for free, but other pre-packaged items can be sold – soft drinks, bags of chips, granola bars, and yogurt are popular options.
- **CHARGE FOR DAY OFF ACTIVITIES:** for example, face-painting, cake walk, and a bounce house for kids. It is possible to offer simple activities or competitions (with prizes) during your event and charge for participation.
- **T-SHIRT SALES:** It is your decision whether or not you'd like to sell t-shirts the day of or not. Some will have t-shirts available for those who register day of.



MARKETING

APPROVED LOGOS

Do not change or modify the Alliance to Cure Cavernous Malformation logos in any way.



ONLINE

- **Social Media**
 - Create a Facebook event page
 - Post on Facebook, Instagram, Twitter, LinkedIn
 - Post in local community Facebook groups
- **Community Groups**
 - Nextdoor
 - Community pages for radio, newspaper, tv station



NEWSPAPER

- Submit to a Community Calendar. Many towns have more than one paper – a large city paper and smaller town, special interest, or advertising papers – and you can submit to all of them.
- Create a press release, making sure to include the personal connection to the event, and submit it to the Health editor and Local editor. (Please allow us to read your press release before you send it out to check for accuracy and so we can help you refine it.)

TELEVISION/RADIO

Go directly to the anchors who cover health, wellness, or community events.

Set meetings with all the major news stations to pitch our story to them.

Make sure everyone who talks with media has a similar message. Each person should be able to tell:

1. The highlights of the affected person's illness
2. How their symptoms and experiences compare to others with the illness
3. What the future possibilities are
4. How money raised will be used
5. Use the sample talking points in the Appendix as a guide.

Once you have determined the date, time, and venue of your walk, we can set up your event page on Network for Good. Network for Good is our fundraising platform. Individuals can go to this link, register for the event, donate, and create their own fundraising webpage. Please reach out to lindsay@alliancetocure.org to receive an event link. You can charge a registration fee or the preferred method is to not charge a registration fee with the expectation that individuals will fundraise on their page. If you wish to charge a registration fee the event registration, we can discuss this with you to come up with a plan for your event. You will be notified every time someone registers and you can get a complete list of registrants in Excel format from us.

INCOME

ONLINE FUNDRAISING

We use Network for Good to collect online donations and will set up a personalized event page for you with an event link to share.

CHECKS AND CASH DONATIONS

If you collect cash, you will want to record the name and address of the donor and send it to us within two weeks. Checks should be written out to "Alliance to Cure."

SQUARE TRANSACTIONS

A square credit card reader is available for you to use with your tablet or phone before the event and on the day-of. Please note, the square reader does not capture donor information, only credit card information and the amount. You will need to capture the donor's name, address, email and the last four digits of the card. Reach out to lindsay@alliancetocure.org to have the Square sent to you.

EXPENSES

We require that you submit expenses with receipts and invoices. Expenses can be paid at the time they are incurred or at the end of the event. There are several ways to pay for event expenses:

1. You can pay for the expense upfront and submit a receipt for reimbursement. We will send a check to you within a week of receiving your receipt.
2. For larger expenses, we can call in a credit card number to the vendor. lindsay@alliancetocure.org can help with this.
3. You or a donor can pay for the expense and use it as a gift-in-kind donation to be claimed as a charitable tax deduction. We will need the name and address of the donor, the item donated, and the fair market value of the item (what it would cost to purchase).
4. If you have collected cash before the event and carefully tracked its source and the amount, you can draw on this cash to pay small expenses. Receipts must be submitted for cash expenditures at the end of your event.

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| <input type="checkbox"/> | Alliance table | <input type="checkbox"/> | |
| <input type="checkbox"/> | Silent Auction Tables | <input type="checkbox"/> | |
| <input type="checkbox"/> | Walk route set | <input type="checkbox"/> | |
| <input type="checkbox"/> | Food Set Up | <input type="checkbox"/> | |
| <input type="checkbox"/> | Water stations | <input type="checkbox"/> | |
| <input type="checkbox"/> | Kids Activities | <input type="checkbox"/> | |
| <input type="checkbox"/> | Signs/Banners | <input type="checkbox"/> | |
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Have fun!

ACCOUNT FOR AND SUBMIT FUNDS

All checks should be made out to Alliance to Cure and you should include the donor's address if it's not on the check. All expenses should be accompanied by a receipt. Please turn cash collected into a cashier's check and let us know the amount of each source of cash – raffle ticket sales, on-site registrations, etc. Expenses and income should be sent to Alliance to Cure Cavernous Malformation within two weeks of the event.

THANK YOUR VOLUNTEERS, SPONSORS, DONORS,, AND PARTICIPANTS

For large events, you may not be able to thank every donor individually, but you can post to your social media outlets. Personal notes for large donors and sponsors will be appreciated.

Alliance to Cure Cavernous Malformation will provide tax receipts for all donations and sponsorships. We can also send a special note to donors that need some special attention.

Reach out to lindsay@alliancnetocure.org.

FOLLOW UP WITH BUSINESSES OR INDIVIDUALS WHO OFFERED FUTURE HELP

Many times, events will spur ideas or offers, like Alliance to Cure Cavernous Malformation Day at a retail business or other opportunities for fundraising. While you don't need to pick up on these offers immediately, don't forget about them. Set up a time a few weeks from your event to meet and discuss options.

WRITE DOWN WHAT DID AND DIDN'T WORK

At Alliance to Cure Cavernous Malformation, we can use your experience to inform others who are planning events. You'll also want a record for reference for future events you plan.



TAKE A BREAK

Your event likely has been exhilarating but tiring. It has taken some of your family and personal time. Give yourself as much time as you need to rest and reconnect before beginning your next effort.

Thank you for all of the energy and time you and your team put into working toward a cure. Alliance to Cure Cavernous Malformation runs on volunteers like you. Together, we can shorten the time to real treatments dramatically. Your work has given hope to patients and their families everywhere.

