



CCWAA 2009 Site Organizer's Guide

Are You Interested In Becoming A Site Organizer?

Has Chiari affected you or someone you love? Are you interested in becoming a Site Organizer for the 2nd Annual Conquer Chiari Walk Across America? Our first year's walk was a huge success (20 cities, \$170,000 raised for research) thanks to the Site Organizers who unselfishly gave their time to support our cause.

On September 26th of this year, thousands of people across this great country will gather to show their support in raising awareness and funds for medical research on Chiari Malformation. Site Organizers are critical to making this a successful event. They are the key to every step of planning, from picking out a site, to promoting the event, to signing up corporate sponsors, the local Site Organizers are completely responsible for each local walk.

This is not to say, however, that the Organizers must do this by themselves. Conquer Chiari provides materials and support, such as this Guide, to help Organizer's create the best event possible.

If you would like to organize a walk in your area, please carefully review this guide to understand what is expected of each organizer. It is a significant commitment of time and energy, and should not be taken lightly. If you think you are up to the challenge and want to fight back against Chiari, then simply fill out and submit the Site Organizer Application posted on the Conquer Chiari website. Please note the deadline for applications is May 1st. Also, please keep in mind that in large cities there may be more than one person interested in being the Site Organizer. If you are not chosen to be an Organizer remember that there are plenty of other ways you can help with your local walk.

Training & Questions:

Once you are approved as a Site Organizer, you will be required to review key responsibilities and guidelines (via the phone or web) with Conquer Chiari. This is to ensure that everyone understand their duties and what is expected of them. It will also provide a forum for you to ask questions and get clarification where necessary.

Questions regarding being a Site Organizer should be emailed to director@conquerchiari.org

Dates To Remember:

March 1st - Walk information posted on website

May 1st – Last day to apply to be a site organizer

June 1st – Last day to finalize site location

July 17th – Last day to submit a corporate sponsor for inclusion on T-shirts

August 7th – Last day for walkers to pre-register (guaranteed T-shirt)

September 26th – Day of the Walk!!

Site Organizer Responsibilities:

Organizer responsibilities and expectations include, but are not limited to:

- Finding and securing a suitable site for the walk
- Solicit and sign up corporate sponsors
- Promoting the event via flyers, newspapers, radio, and TV
- Organizing additional volunteers
- Ensure the safe handling of all monies associated with the walk and sending all cash and checks to Conquer Chiari in a timely manner
- Entering all required information on the CCWAA on-line system in a timely manner
- Register walkers the day of the event, distribute T-shirts to those who pre-registered, recognize sponsors at the event and in general ensure a safe and fun time for everyone
- Organizer additional activities at the walk site to create a fun atmosphere
- Abide by all local, state, and federal regulations
- Abide by the policies which Conquer Chiari has set forth
- Act in an ethical manner at all times
- Participate in Organizer training through Conquer Chiari
- Treat all participants and volunteers with respect
- Do not act in a manner which results in personal gain
- If able, pay for incidental expenses out of pocket (not required)

Conquer Chiari Will Supply:

As stated before, Conquer Chiari will provide materials and support to help ensure a successful walk, including:

- A Site Organizer's Guide
- Site Organizer Training
- An On-Line Walk System for walker registration and fundraising, and for site organizers to enter and track data associated with their site
- PDF files for Walk Flyer and Press Kit
- T-shirts for pre-registered walkers

- Reasonable expenses (see Expenses section, must be pre-approved)
- Help in finding volunteers
- Register Conquer Chiari as a charity in your state

Finding A Location For The Walk:

Once you have been approved as a Site Organizer, the first task you need to complete is to find a suitable site for the walk. Scout around your area for a park or facility that has held walks (or 5ks) before. Contact each potential location and check the availability for Sept. 26th. Also find out what the rules are for using the venue. Some parks will have many restrictions (for example about signage or other activities at the park), some will have virtually none. When picking a location consider whether there is suitable parking, toilet facilities, and whether any after walk events can be held there.

Be sure to inquire about insurance requirements and if there are any fees. Conquer Chiari will take care of the insurance requirements (\$1,000,000 or less), and if necessary pay for a minor usage fee.

Walk the route that will be used to make sure it is suitable for a large group. The route length should be no longer than 5k. Also, if possible, have an option for people to walk a shorter distance. Remember, people with Chiari may not be able to walk far.

Once the site is booked and confirmed, enter the site information into the on-line system, including: Site name, address, length of walk, start time for walk, and insurance requirements.

Promoting The Event:

The Walk Across America is a great opportunity to raise awareness about Chiari. To help you promote the walk, and Chiari in general, Conquer Chiari will supply you with an electronic template for a Walk Flyer and a Press Kit. You can modify the Flyer to add additional details but we would like to keep the general look and feel the same. Organizers should not modify the Press Kit except to add their contact information. Organizers are expected to print copies of the flyers and press kits themselves. Often you can find a print shop to do it for a discount. Don't be afraid to ask.

Based on our experience last year, it is suggested that organizers

Make a lot of copies of the flyers and spend time posting them in local supermarkets, community centers, and on other neighborhood bulletin boards.

Contact any city or township television stations, these stations usually are the easiest to get coverage on. Because they normally only focus on local events. Tell them what you are doing and why it is important for people to know about this event. Leave a copy of the Press Kit so they have the details of the walk.

Contact local network television stations, or send them the Press Kit on your event. Ask them to please advertise the event. If you are mailing them material you should call first and ask for the person who would be best suited to make a decision on the airing of this event, then send the pamphlet and flyer to that person directly. After you have mailed the material, call the person directly a week later and see if they have reached a decision or if there is any other information that you can send to them.

Check your local newspaper website and see who would be the best person to contact about the event. Send them a quick email and attach the Flyer and Press Kit and perhaps even a link to the Conquer Chiari website so they can learn more!

Many times the reporters for the newspaper, television channels and radio stations will ask you to give them an interview so that they can get more information on Chiari Malformations. Also they may want to talk to someone at Conquer Chiari to get information from them as well. Please refer these interview requests to Rick Labuda at Conquer Chiari (724-940-0116, director@conquerchiari.org).

It is your job to create as much buzz about the event as you can. Tell everyone you know about the walk and ask them to spread the word. Persistence pays off!

Finally encourage people who are going to participate to pre-register for the walk through the Conquer Chiari website

Corporate Sponsorships:

One of the main tasks of Site Organizers is to line up Corporate Sponsors for the walk. While others in your walk area are allowed to approach corporate sponsors, the burden really falls on the organizer to maximize corporate support. Before approaching local businesses, review the available sponsor levels in the CCWAA Corporate Sponsor Opportunities document. Print out copies of this document to take to businesses. Contact local grocery stores, salons, restaurants, attorney's offices, and other small business owners. Tell them of the event and advise them that for a minimal donation they will get their company name on the T-shirts and be recognized as a corporate sponsor. Advise them that there are multiple levels of sponsorships, and they can choose which level they are most comfortable with. Don't forget to remind them that their donation is tax deductible.

IMPORTANT: Focus on the three local levels of support. Do not approach any large, national companies about a national sponsorship without first communicating with Conquer Chiari. Unless you have a very good connection in such a company there is virtually no chance of getting a national sponsorship by cold calling. It is much more effective to sign up smaller businesses, or local affiliates of large companies for the local sponsorship levels.

Corporate sponsors can sign up and pay in three ways. First they can fill out the form and provide a check to you, the organizer. In this case, it is your responsibility to input

their information into your site page using the on-line system and to send the check to Conquer Chiari.

Second, they can fill out the form and send a check to Conquer Chiari.

Third, they can sign up on-line using a credit card.

The deadline for corporate sponsors to be included on the walk T-shirts will be strictly enforced. Corporate donations after that date can be recognized at the walk, but inclusion on the shirt is not guaranteed.

Finally, note that there will be a limit to the total number of sponsors which can be recognized on the walk T-shirt. Last year, only one site came close to this limit, so if you are fortunate and hard working enough to get close, we will coordinate.

Donated Items:

Some companies may ask if they can donate items instead of cash. Of course all (almost all) donations are welcome; however unless the donated items are of a significant value (above \$100), then the companies will not be listed on the walk T-shirts. Coupons do not count as they have no intrinsic value.

There are several things you can do with donated items. Many grocery stores or health stores will be willing to supply water and/or energy bars for the event. It is important to have water available for the participants. Other places may want to give coupons. Use these to build a goodie bag for each participant (see later section). Significant gifts, such as apparel, or gift cards, can be used as door prizes at the event.

If a company donates items such as water, snacks etc, please make sure you capture the same information as you would with a cash donation, plus a detailed description of the items donated, and enter it into the online system. This information is necessary so that the companies receive a formal thank you letter which they can use for tax purposes.

IMPORTANT – There should be NO alcohol at the walk or related activities. Therefore do not accept donated alcohol.

Handling Checks & Money:

The proper handling of cash and checks is an important duty of Site Organizers. In general, donations associated with the walk will come in one of several ways:

1. On-line. The majority of donations will come in through our on-line system. This is the easiest and most secure method, so please encourage everyone to use it. Donors will immediately get receipts and walkers and teams will automatically get credit for the donations.

2. Checks before the walk. Checks **MUST** be made payable to the organization (Conquer Chiari or C&S Patient Education Foundation, or something close). Receipts will **not** be issued for checks made out to individuals who then write a check to the organization. However, a receipt will be sent for all proper checks which Conquer Chiari receives. This year, each walker will be able to enter donor information for checks they receive through their walker web page. This will be **required** for walkers to receive credit for these donations. Checks may be sent to Conquer Chiari at any time before the walk.
3. Checks turned in at the walk. Should be treated similarly to checks before the walk. Checks must be entered into the on-line system for walkers and teams to receive credit. Organizers need to keep the checks with the associated donation form (so that Conquer Chiari can verify the checks that have been entered). This is very important. If checks come in not attached to a form, there is no way to associate them with a walker.
4. Cash. Conquer Chiari will **NOT** issue receipts for cash donations. Small cash donations received before the walk can be sent through the mail. Cash received the day of the walk should be handled by the Site Organizer. The Organizer should count the cash and turn it into a money order or check to be sent to Conquer Chiari (see below).

One of the most important things to keep in mind the day of the walk is to maintain safeguards of the cash and checks being donated. Registration for the event tends to get very hectic right before the walk and it is important to have safeguards in place beforehand. Site Organizers should have a container to hold all cash and checks received at the walk. Bankers boxes or small fire safe boxes work great for this because they come with a key that you can have in your pocket during the walk. Although we do recommend having several volunteers working your registration line it is also recommended to only have one or two people actually taking in the cash/checks. The other remaining volunteers will be able to assist you in having the walkers fill out their waivers and distributing the T-Shirts. When it is time for everyone to begin the walk please make sure you have secured your container somewhere safe where it is not in the view of the public. When the walk is finished please count all the cash and issue one check or money order made payable to C&S Patient Education Foundation. On the check/money order please write public cash donations.

Please remember to keep the checks attached (paper clips) to their associated donation forms.

Mail all the donations to Conquer Chiari within 7 days of the walk..

Registration:

Remember to register yourself as a walker!!

There is no registration fee to walk, however a \$25 donation is suggested. Walkers are encouraged to register on-line before the walk. Those who do will get their own web

page which they can use to raise funds, set a target, see who sponsored them, etc. Walkers who register on-line will accept a waiver as part of the process.

This year, we are providing a way for Teams to be formed through the on-line system. Each team will have a captain who will be able to see how much their team has raised.

Walkers who register at the walk **MUST** sign a waiver. No exceptions. All waivers should be sent to Conquer Chiari after the walk.

T-Shirts:

In 2008, the walk T-shirts were very popular, but they also caused a lot of problems. Based on our experience last year, following is the T-shirt policy for 2009:

- In general, remember we are not **SELLING** shirts. They are awareness items people receive as a thank you for participating. Conquer Chiari will consider selling walk shirts on-line after the event, but this is not guaranteed.
- Each site will have a walk T-shirt. The front of the shirt will be the same for each site, but the back will be different and list the local sponsors for each walk
- T-shirts will be given to those who pre-register and donate at least \$25 before the deadline (August 7th)
- T-shirts will also be given to those who pre-register and have at least \$25 in *processed* donations by the deadline. This means on-line donations or checks received by Conquer Chiari.
- People registering after the deadline or bringing their donations the day of the walk will **NOT** get a shirt.
- Walkers can select their T-shirt size when they register on-line. Sizes beyond the options at that time are **NOT** available.
- Someone who donates more than \$25 is not entitled to more shirts. In other words, if someone donates \$100 when they register, they do not get 4 shirts. For families walking, each person needs to register and donate \$25.
- Walkers must pick up their T-shirts. No Exceptions. Conquer Chiari will not mail any shirts to individuals. If someone does not show up at the walk, the organizer should temporarily keep the shirt. We will try to contact the walker to see if they can pick up the shirt. If they can not, extra shirts are to be sent back to Conquer Chiari. If you, as an organizer, want to send a shirt to someone who could not make the walk, it will be at your own expense. Organizers should use their judgment in giving a shirt to a friend/relative of a walker who may be reasonably expected to give them the shirt.
- Extra shirts will **NOT** be available at the walk. It is impossible to judge how many shirts to have available, especially with the addition of teams which means that some people will likely create their own shirts. Conquer Chiari is considering a small awareness item to make available to all attendees.
- No T-shirts are to be given away for free. No Exceptions. Organizers are not entitled to free shirts.

- Conquer Chiari will supply a shirt for each corp sponsor in recognition of their donation. Organizers are expected to distribute these shirts.
- Organizers will be able to use the on-line system to print a list of which walkers receive a shirt at check-in and their size(s).

Awareness Month:

Several states have passed resolutions recognizing Chiari Awareness Month. In addition to the walk, it is our goal to get every state to recognize September as Chiari Awareness Month. Therefore, if you live in a state which does not have a resolution, we ask that the site organizers contact their state representative to try to make this happen. Conquer Chiari will support this effort in any way it can (sometimes states require an organization to be involved).

Volunteers & Day of Duties:

Organizing a walk is a huge task. Just when you think you have possibly thought of everything that needs to be done, something else will pop up. Fortunately, there are likely to be many people willing and eager to help. Organizers are strongly encouraged to engage as many people as possible as volunteers. This will not only help ensure a successful event, but it can serve as the foundation for new Chiari focused groups.

Once the sites are posted on the Conquer Chiari website, we will ask for volunteers for each site. Organizers will be notified of those in their area who want to help. Try to be inclusive in your approach.

In general, the greatest need for additional volunteers will be at the actual walk event, especially if there are hundreds of walkers. Make sure to arrive very early to set up for the event. Make sure you are aware of who to contact in case of emergency and it is a good idea to have a first aid kit handy. One of the best ways to ensure a smooth event is to have enough volunteers to help. Some ideas for how to use volunteers at the event, include:

A set up crew of about 4 to 6 volunteers will help you get your event set up without having too many people tripping over each other. These volunteers will be responsible for posting signs to your event, marking the walk, setting up the registration table, organizing the T-shirts by size, setting up water stations, getting any entertainment ready and set up, and fixing any snack and refreshment tables at the walk.

When the time arrives for the walkers to start arriving, have your registration staff in place. Set up two stations, one for pre-registered walkers and another for walkers who have not pre-registered. Make sure you have someone welcoming the walkers as they arrive and getting them in the appropriate line to make the transitions happen smoothly. For those walkers who have not preregistered make sure you have a couple of people ready to supply them with the walk waivers. Everyone participating in the walk **MUST** sign a waiver.

After Waivers are signed have an additional two people ready to take the donations that the walkers have in hand. Because of the Cash handling in this station please make sure that this is someone you have trust in and who is aware of the safeguards that need to be put in place with accepting cash/checks.

Then the last table should be the T-shirt table.. Before any walkers arrive please make sure you notify the volunteers of the entire T-Shirt policy and answer any questions they may have.

Because these walks do tend to vary in length, it is extremely important that you have enough water on hand for this event. An average of about 3 bottles per walker would be a safe assumption for water. Water should be an item that you have tried to get donated by a business or organization. Some walks will be able to set up water stations half way through the walk for the walkers. These stations should be handled with two volunteers. Other walks may just have a water station at the registration site.

If your walk route is a route that you can have drivers, have at least 2 drivers driving the route, so that can stop and pick up any walkers that may not be able to make the entire route.

You will need 2 volunteers to help distribute the goodie bags (if you have them) to the walkers.

Finally a clean up crew to help take down any signs and dispose of any trash that was created throughout the walk.

Every walk is going to have a different setup and different amounts of people however you can use this section as a guide to help you out in your own particular walk. As stated in the beginning of this section your volunteers are the key to making your walk run smooth. We ask that you please remember that these people are giving up their free time to help in the fight for research and awareness. Please stress to everyone the importance of Teamwork especially on the day of the event. It's going to be a very busy day and there are a lot of things that need to get done to make your walk a success. Remember to Have Fun and thank everyone for coming.

IMPORANT – There should be no alcohol at the walk or any of the related activities. This is a family event.

Recognizing Corporate Sponsors:

Remember to acknowledge and thank corporate sponsors (especially large ones) verbally at the event.

Conquer Chiari is evaluating providing signage to each walk which would include the local corporate sponsors. If we can not do this, organizers should find some other way to visually acknowledge the corporate sponsors.

Additional Walk Activities:

In addition to raising awareness and money for research, there is another great thing that this walk does. Namely, it brings together Chiari sufferers and their families with others. At the walk when you look around you will be able to see a bit of healing happening. People will begin to seek others out to hear their stories and to share experiences. Here they will talk about doctors, hospitals, and families. The power of this gathering will be something that you may never have seen before. To encourage this, think about adding a activities after the walk. These activities can be at the walk site or at a nearby location.

Expecting a lot of kids at the event? Perhaps you can find someone to donate their time as a clown.

Want something to keep people entertained before the event? Maybe you could find a DJ or band that may be able to donate time.

Have a restaurant that wants to donate some goods? Maybe they can donate food to be distributed after the walk, so that the walker can sit down and meet others. Also consider having a guest speaker, such as a local politician, celebrity, Chiari doctor, or child with Chiari, give a short speech before the event.

Walks that begin to attract attention may also attract vendors that want to sell items at the event. In general we discourage this. If you believe there should be an exception, discuss it with Conquer Chiari before agreeing to allow a vendor at the event.

While we encourage extra activities please familiarize yourself with your local restrictions and the rules of the venue where your walk is being held.

IMPORTANT: Raffles are a highly regulated activity. Conquer Chiari prohibits raffles at the walk and associated events.

If you do receive donated items from local businesses please give them away at the walk, either in goodie bags, or as part of a prize drawing (everyone must be eligible to receive a prize whether they donated money or not).

After the Event –

Please mail the donations, sponsor forms, and waivers to:

Conquer Chiari
Attn: Rick Labuda
320 Osprey Court
Wexford, PA 15090

Include a copy of each walker's sponsor form and keep the checks with the associated donation forms (this is very important!). Although Conquer Chiari will send out receipts and thank you letters, if you know (or see) any of the businesses to sponsored the walk, be sure to thank them again and let them know the walk will be held again next year.

Please return any extra shirts or other Conquer Chiari supplied items.

Everything should be mailed within 7 days of the walk.

Checklist:

Use the Site Organizer Checklist (separate document) to keep track of what needs to be done.