



Thank you for your interest in organizing a Great Steps 4NF™ Walk. It may seem like a lot at first, but you will quickly realize that it includes information that covers walks of all sizes. Not all of the information enclosed may be applicable for your location, but we certainly didn't want to leave anything out.

It is never too early to start the planning phase of a walk. Some potential walk locations even require a reservation (and maybe even a deposit) a year in advance. Getting started early also gives you plenty of time for finding volunteers, sponsors and donations.

In addition to your friends, family and other NF families that may help you, the NF Midwest office is here to help. We take care of the t-shirts, registration, brochures and keeping in contact with registered participants through email (such as letting them know the best ways to fundraise and info for the day of the walk). We also are the main starting point for contacting NF families in your area about the walk.

When it comes to Great Steps 4NF walks, there are a few things that we like to see in order to keep continuity in the walks:

- When promoting the walk in newspapers, Facebook, posters, etc. please use the Great Steps 4 NF logo or use the wording "Great Steps 4NF" or "Great Steps 4NF Walk" (Rather than "NF walk"). NF Midwest holds the trademark for Great Steps 4NF and it is important to keep it consistent. We can email the Great Steps 4NF logo to you.
- Include some sort of
 - Entertainment- music, kids' games or other
 - Food/drinks- continental breakfast, lunch or both (Water is a must)
 - Raffle- this brings in additional donations as well as entertainment
 - Goodies for the walk- this has become one of the hallmarks of the walk. Get "goodies" donated such as candy, pens, powdered drink mixes, product samples, etc. and hand them out to walkers at 4 or more stations along the walk. This is especially fun for the kids-like trick or treating 4 NF

Hosting a Great Steps 4NF walk does take organization, help from friends and family and a drive to get it done, but it is so worth it! Every dollar that is raised helps in the fight against NF. It helps make living with NF easier by improving care, while bringing us closer to a cure. Please be sure to let us know if you have ANY questions. We are here to help!



Guidelines and ideas for holding a successful Great Steps 4NF Walk



Neurofibromatosis Midwest is a registered 501(c)3

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Thank you for considering holding a Great Steps 4NF Walk in your community!

Great Steps 4NF, which benefits NF Midwest, is a great way to raise awareness of NF and raise funds for support and research. It's also a great way to socialize and meet other NF families.

Great Steps 4NF Philosophy

The *Great Steps Walks for Neurofibromatosis* are different from a lot of other walks in that while the ultimate goal is to raise funds for the cause, the emphasis is on **fun**. A party atmosphere adds to the enjoyment. We encourage all walks to include food at the beginning (breakfast) and at the end (lunch). A trademark of a Great Steps 4NF is volunteers passing out candy or other goodies at various stations throughout the walk route.

Goal of Great Steps 4NF

Your ultimate goal is to build awareness and raise funds for Neurofibromatosis. Many businesses like to donate items or provide items at a reduced cost to support local events. Remember that how much is raised is offset by how much is spent.

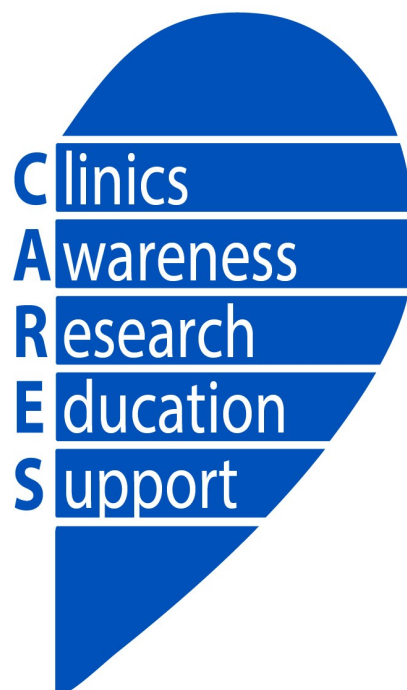
Where Does the Money go?

Neurofibromatosis Midwest is dedicated to the increasing number of men, women and children challenged by neurofibromatosis. We've been a nonprofit 501(c)3 since 1982 and we are determined to continue our work to educate, comfort, improve clinical care and fund research for treatments and a cure. We are staffed by people with a personal connection to NF, with real experience and a determination and motivation to use precious funds in an efficient manner.

We are committed to improving the lives of children, adults, and families impacted by neurofibromatosis. Our continued focus and foundation is on **Clinics, Awareness, Research, Education and Support** in the states of Illinois, Indiana, Iowa, Kentucky, Wisconsin, and the eastern half of Missouri.

You make the walk what you want!

You don't have to do everything in this packet. Make this walk as big or as simple as you want! Once you decide you want to do a walk for NF, we will help you and give you more information.



First Steps to Planning a Great Step 4NF Walk

Below is a general outline. If it seems overwhelming, don't worry, we are here to help! Smaller and inaugural walks often don't need some of what is outlined here.

Step 1 – Secure Volunteers

Get the commitment of at least 2 or 3 reliable volunteers to begin working on the walk.

Step 2 – Book a Location and Date

Secure a location for the walk and set a date – once the date and location are confirmed, you are on your way!

- Find out what the site requires.
- Is there a cost to rent the location?
- Is there a contract and/or deposit required?
- What are the insurance requirements?
- Does the site allow for easy walking with a path that is approximately 3 miles?
- Is there a pre-approved route that needs to be used?
- Do the City and/or Park District require permits for raffle, amplification, tent, etc.?
- Do they require security or traffic control personnel?

Step 3 – Hold your first planning meeting

Hold the initial planning meeting (try to round up more volunteers to invite to this meeting). At this meeting start doling out responsibilities either to individuals or committees. Be specific in what their jobs are (NF Midwest can provide you with job descriptions). People may select more than one job. Use the Event Committee Suggestions sheet to help delegate responsibilities.

Step 4 – Prepare to solicit walkers and sponsors

NF Midwest will provide the Chairperson material needed to solicit walkers and sponsors, such as:

- A sponsor letter with a sponsor level sheet will be provided to solicit sponsorships and material or in-kind donations
- Posters to promote the event
- A press release to give to the media
- A webpage and Facebook event page where people can find information on the walk
- Brochures to mail out and leave at local businesses

Your committee's responsibilities include:

- Distributing posters in the area
- Sending out press releases and contacting the media
- Soliciting sponsors and in-kind donations (such as food, water or raffle items)
- Sending out emails and mailing brochures to those you know

NF Midwest's responsibilities include:

- Maintaining contact with your walkers
- Sending out a Fundraising Packet/Walker Information Packet – this will include but may not be limited to:
 - Sponsor letter with sponsor level sheet
 - Donor forms and envelopes
 - Sample donation request letter
 - Walker information sheet
 - Brochure about NF
- Maintaining registration information
- Tracking sponsorships and donations
- Emailing walkers with helpful hints for fundraising
- Sending the team captains donation reports

Step 5 – Prepare for the day

In the months before the walk you and your committee will need to:

- Create a list of all volunteers and their job duties – see attached spreadsheet
- Get prizes for raffle & awards donated (top team(s), most spirit)
- Get food, goodies and give-a-ways donated
- Find entertainment: music, kids' games, face painters, bounce houses, etc.
- Find corporate sponsors
- Work on site layout – where will you put registration, food etc. Is there electricity?

NF Midwest will provide:

- Banner(s)
- Walk directional signs, if needed
- Walk – up registration forms
- T-shirts will be mailed the week of the walk
- Final team totals
- Team incentive prizes
- NF Awareness Merchandise to sell

Committee Suggestions

Below are suggestions for committees along with checklists to help you set up an event. For large events you may want to try and get one volunteer for each area, though it is reasonable to share and mix-up responsibilities. Some of these suggestions and checklist items may not apply to your event. **These are just suggestions.**

Chairperson: Coordinate planning meetings

- Work with NF Midwest to develop the walker information sheet
- Keep committees and volunteers on track
- Fill in any areas that aren't covered
- Take minutes of planning meetings and handle all correspondence related to the event
- Ensure committee appreciation
- Conduct post-event evaluation meeting

Facilities Coordinator: Handle all details related to the venue.

- Work on venue set-up – tents, tables, signage
- Develop signage for day- i.e. sponsor signs
- Order portable toilets (if there are not bathrooms on-site)
- Order a dumpster (if required)
- Check the site for safety and traffic management issues
- Contact law enforcement agencies about local ordinances, road closures, security issues etc. if this is necessary for your venue

Food/Beverage Coordinator: Arrange for all food and drinks at the walk. Try to get in-kind donations or great discounts.

- Check with your municipality to see if a food permit is required
- Food for the morning (suggested items: donuts, bagels, fruit, and coffee. Bagel / donut shops are usually very willing to donate)
- Food for lunch (suggested items: pizza, hot dogs, sub sandwiches, ice cream or cookies)
- Beverages – water, soda, sports drinks
- Plates, napkins, cups
- Volunteers to serve and work in the food tent

Activities Coordinator: Plan activities for the walk.

Some ideas include:

- DJ, vocal or band performers, iPod with speakers
- Fun stuff for the kids – clown, face painter, games
- Get a celebrity or someone special to kick off the event
- Volunteers to run games for the kids

Sponsorships Coordinator: Secure business sponsorships. Everyone involved should attempt to get sponsorships

- Develop a personal letter to distribute to local businesses (we have templates)
- Arrange to visit companies personally
- Post sponsorships on event facebook page with link to sponsors website/facebook page

Publicity Coordinator: Handle publicity for the walk.

- Contact newspapers, radio and other media outlets
- Put walk info on social media sites including event facebook page
- Get volunteers to distribute posters to local businesses
- Photograph the event for future publicity

Walkway Coordinator: Handle where people will actually be walking and all arrangements regarding it.

- Create a 3 mile map of the walk – make note of how many walkway signs are need (turns and straight)
- If possible, create a 1 mile walk for those who are unable to do a 3 mile walk
- With help from friends, family, find at least 4 different goodies to hand out. Donations are best! See if a company would like us to hand out their promotional items- pens, stress balls, chip clips, etc.
- Have volunteers to pass out goodies along with walk
- Have 2 -4 volunteers put out the directional signs the day of the walk at least an hour before the walk starts.

Raffle/Awards Coordinator: Everyone involved should attempt to get donations but the raffle coordinator might:

- Determine what kinds of awards and prizes will be given, which could include top team fundraisers & best accessories/most spirit
- Send out letters and contact companies for donations
- Organize all raffle prizes, making baskets/lists of contents or silent auction
- Organize and set up the raffle/auction the day of the event
- Coordinate volunteers to sell raffle tickets the day of the walk

Registration/Accounting:

- Register walk-ups the day of the walk
- Collect registration fees/additional donations
- Sort and pass out t-shirts
- Calculate team totals after registration ends

Volunteer Recruitment and Coordination: Find Volunteers to help with the day of the walk (see spreadsheet)

Areas you may need volunteers may include:

- Set-up
- Registration
- Food
- Walkway
- Merchandise Sales
- Raffle ticket sellers
- Clean-up

Other Helpful Information

Walking as a Team

Creating and fundraising as a team encourages fun competition among everyone! Whether they are on a team or not, each participant needs to register.

Each team is given a team number by NF Midwest and may choose to create a team name. They also need to designate a team captain. Only the team captain will receive donation totals and event information from NF Midwest. It is up to the team captain to keep the participants on their team up-to-date.

Doing a Run

We generally don't recommend adding a run to a walk, unless it is a simple untimed "Fun Run". Otherwise, it creates a lot more work and very little return. Please call us if you would like to do a run.

Getting Donations

Once people have registered to walk through NF Midwest, they will be encouraged to begin collecting donations for the event as soon as possible.

Participants may raise funds any way they like – i.e. mail, email, personal fundraising pages, small fundraisers, garage sales, home parties, etc. Any money that is raised should be turned in immediately along with a completed donor form that designates what team it is for.

The proven way to get donations is to contact friends, family, neighbors, co-workers, etc. and simply to ask and ask again. What we have found really works is to send out personal letters (a sample will be included in the participant's fundraising packet) along with a donor form that can be prefilled with the team's information and an envelope already addressed to NF Midwest. This eliminates any awkwardness in asking. The recipient of the letter can choose whether or not to send a donation with no pressure.

Team Captains should create a personal fundraising website on www.firstgiving.com/nf. Personal Fundraising websites are a good way to tell your story and explain why you are walking. Your team members may also create their own personal fundraising page or they can direct people to yours.

Teams may also choose to have their own Third Party fundraising events to raise money for their team. By doing this, they not only raise money for the cause, but they also raise NF awareness. Contact the NF Midwest Office for more information on Third Party Events.

The Walk Chairperson should consider getting prizes donated for the teams that raise the most money and those who show the most spirit. These may be tickets to sporting events, gift certificates for overnight stays at hotels, restaurant gift certificates, or whatever you can get donated.