

# DO IT YOURSELF FUNDRAISING



Guidelines and ideas for organizing  
a successful fundraiser to benefit NF Midwest



Neurofibromatosis Midwest is a registered 501(c)3  
473 Dunham Rd, Suite 3, St. Charles, IL 60174  
630-945-3562    [info@nfmidwest.org](mailto:info@nfmidwest.org)    [www.nfmidwest.org](http://www.nfmidwest.org)

# DIY Planning

Thank you for considering Neurofibromatosis Midwest as a beneficiary of your fundraising activities. NF Midwest appreciates your efforts and looks forward to working with you as a partner in raising funds to fight Neurofibromatosis (NF).

Unlike our signature event, Great Steps 4NF, a Third Party Do It Yourself (DIY) Fundraising event or promotion is one that is conceived and created completely by volunteers—an individual, organization, or business—and can range from a bake sale to a local golf tournament. The event organizer is responsible for all details of the event or promotion, including recruiting volunteers to help at the event, creating flyers to publicize the event, underwriting all the related costs (except in special pre-approved circumstances), and working at the actual event.



*An Italian restaurant in Illinois held a dinner and ravioli eating contest for many years. an event that regularly produced \$3,500!*

Do something you love and know! Some past events and promotions have included:

- Dinner Parties
- School Fundraisers
- Wine Tasting
- Office Parties
- 1K Color Fun Runs
- Golf Outings/Tournaments
- Bake Sales
- Jewelry Sales
- Jeans Days at Work
- Yard Sales
- Whiffle Ball Tournaments
- Ravioli Eating Contest

This packet contains the following information:

1. An overview of NF Midwest including a brief history, its purpose and an overall summary of how funds are raised and spent.
2. A copy of the NF Midwest's Policies and Procedures for fundraising activities. Please review these carefully.
3. An event proposal form. This form should be completed and returned to the NF Midwest office as soon as possible.

## Remember...

## Whether \$50 or \$5,000—YOU can make a difference!



Please remember that the NF Midwest office has a very small staff. Although we are not able to manage your event or promotion for you, we can provide you with support throughout the process and greatly appreciate your efforts.

As a final note, although NF Midwest actively encourages DIY Fundraising events, all events and promotions must be approved in advance by our office. This is an important safeguard in preserving the integrity of the NF Midwest name and brand, and in protecting our members and donors whose generous contributions are based upon our pledge to keep overhead costs low and raise as much money as possible.

For more information about our DIY Event Fundraising program, please contact:

NF Midwest Event Coordinator  
(630) 945-3562  
events@nfmidwest.org  
Thank you for your support!



*Hoosier Crane, an Indiana company, held an employee event and raised over \$4,000!*

# What is Neurofibromatosis?

Neurofibromatosis (NF) is a complex, often devastating set of genetic disorders (including NF1, NF2 and schwannomatosis) affecting approximately 1 in 2500 people that can cause tumors to grow on nerves in or on the body. These tumors can cause loss of limb, hearing, or eyesight; pain; paralysis; disfigurement; and more.

Depending on the type of NF, people with NF are also at a higher risk of variety of other complications. For instance, learning disabilities are very common in NF1. There is also a higher risk of cancer, bone deformities, seizures, autism spectrum disorder, ADD, high blood pressure, scoliosis, speech problems, poor fine or gross motor skills and much more. NF is highly variable in that some people can be mildly affected and others severely. It is also a chronic, lifetime disorder that will progress, though it may be fast in some and slower in others.

NF affects all races, ethnicities, and genders equally and while it is a genetic disorder that can be passed on through inheritance, over half the babies born with NF did not inherit it but rather have what is called a “spontaneous mutation”. So, anyone can suddenly find that they have a loved one with NF.

# About NF Midwest

NF Midwest is committed to improving the lives of the increasing number of men, women and children challenged by neurofibromatosis. Our continued focus and foundation is on Clinics, Awareness, Research, Education and Support.

## NF Midwest C.A.R.E.S.!

Established as a nonprofit 501(c)3 since 1982, we are staffed by people with a personal interest in NF, with real experience and a determination and motivation to use precious funds in an efficient manner.

The area we serve includes Illinois, Wisconsin, Indiana, Iowa, Kentucky, and the eastern half of Missouri.

We are dependent on funds raised by special events, foundations and individual donations and appreciate your efforts to make a difference in the lives of those with neurofibromatosis.



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## Have Fun Organizing Your Own Event!

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**Raise money for NF Midwest and qualify for valuable recognition gifts. The more you raise the greater the gift... shirts, jackets, bag chairs, blankets, and more!**

# DIY Event Policies/Procedures

The DIY Event organizer(s) is solely responsible for the development and execution of the event or promotion.

In general, there are several things NF Midwest can do, and additional things NF Midwest cannot do.

## NF Midwest can:

- Offer advice and event planning expertise
- Provide promotional materials
- Provide and approve NF Midwest logo use
- Help promote your event through our website, email blasts and our social media sites
- Provide a letter of authorization and validation to assist in fundraising
- Provide tax acknowledgement letters for gifts of \$100 or more made payable directly to NF Midwest

## NF Midwest cannot:

- Provide funding or reimbursement for expenses, except in special pre-approved circumstances
- Provide donor or vendor mailing lists
- Solicit businesses or vendors for financial or in-kind support
- Guarantee event attendance by NF Midwest staff or volunteers



*Marissa's Mob, a Wisconsin family, raised \$2,500 with a party and raffle in their home*

## *It's Your Show!*

Plan your event,  
publicize to draw a crowd,  
and celebrate your results.

- The DIY event organizer may not use the NF Midwest name or logo or otherwise indicate to the public that an event or promotion is being held to benefit NF Midwest without the prior consent of the NF Midwest office. The NF Midwest official logo should not be altered in type face, color, or configuration.
- An approved DIY event or promotion shall not promote NF Midwest as the organizer of the event, but rather the beneficiary. As an example, the naming of the event should not read: "The NF Midwest Golf Tournament" but instead "The Woodlands Charitable Golf Tournament to benefit/support NF Midwest."



- A DIY event or promotion shall be administered in a manner that reflects positively on the image of NF Midwest. No conduct which is unlawful or deemed offensive by NF Midwest shall be associated with any event benefiting NF Midwest. NF Midwest reserves the right to withdraw its endorsement of any DIY event or promotion it deems offensive. NF Midwest also reserves the right to refuse any fundraising proceeds from a DIY event or promotion deemed offensive.

## Finances

- The DIY event organizer should write one check (or money order) for the net revenue (revenue less expenses) from the DIY event or promotion. Please make the check out to NF Midwest and mail to NF Midwest, Attn: DIY Events, 473 Dunham, Suite 3, St. Charles, IL 60174. Please include details of the event or promotion when mailing the check.
- NF Midwest will not pay for or reimburse any individual for expenses incurred as a result of an event, except in special pre-approved circumstances. This means that if you intend to pay for certain expenses prior to remitting the net proceeds to NF Midwest, consider having donations made in cash or payable to the DIY event organizer so that you have sufficient funds to pay these expenses.
- DIY event organizer is responsible for acknowledging all donations made payable to them. NFMidwest will issue a tax acknowledgement letter for donations over \$100 to donors only if the gift is made payable directly to NF Midwest. Donations and/or fees made out to the DIY Organizer are not tax deductible.
- The DIY event organizer may not set up a temporary bank account in NF Midwest's name. If a bank account is needed for the event, the organizer should open a bank account with the event or promotion name. The organizer may not use NF Midwest's taxpayer identification number or assert exemption from state sales and use taxes under NF Midwest's name.
- NF Midwest can provide the DIY organizer with a letter of authorization to assist in fundraising. This letter can be used to validate the authenticity of your event or promotion.
- DIY Organizer may want to discuss accepting online donations under an online account established through NF Midwest, if desired for the event.



*SamJam, an annual Illinois music festival, has raised more than \$67,000 in its first six years!*

**What's your passion? What do you like to do?**  
**What can you use to create a fundraising event?**

## Promotion

- Advertising and promotion of the event is the sole responsibility of the DIY organizer. All promotional materials must clearly state that a percentage of net proceeds and/or portion of ticket price that will benefit NF Midwest.
- When appropriate and given sufficient time, NF Midwest may help promote the event or promotion to its database via our website, [nfmidwest.org](http://nfmidwest.org), our social media sites and possibly (given space availability) in an upcoming issue of our newsletter.
- The NF Midwest office can provide brochures, pamphlets, and other information promoting and explaining NF Midwest and its goals and accomplishments. Please provide as much advance notice as possible and let the office know the quantity needed.

## Legal

- DIY organizers who offer NF Midwest a percent of sales or revenue should provide a projection of dollars to be donated to NF Midwest. Additionally, disclaimer language should appear on all materials noting that: "NF Midwest does not endorse any product or service."
- If a DIY event involves a raffle or other type of gambling activity, or if you plan to sell or serve alcohol at your event, you must obtain a license from the state. You will be solely responsible for obtaining the license.
- The DIY organizer is responsible for obtaining any permits and a certificate of insurance for the event as required by local, state and federal laws. Please note that NF Midwest's insurance policy does not cover DIY events or promotions.



# Fundraiser Proposal Form

Name of Person/Group Sponsoring Event or Promotion: \_\_\_\_\_

Contact Person (if different): \_\_\_\_\_

Company: \_\_\_\_\_

Address \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone (cell): \_\_\_\_\_ Phone (home): \_\_\_\_\_

Email: \_\_\_\_\_

Connection to neurofibromatosis: \_\_\_\_\_

Please provide a brief description of the event or promotion:

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Date and time of event: \_\_\_\_\_

Location of event: \_\_\_\_\_

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Will there be any publicity before the event? If so, please describe:

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Estimated Number Attendees/Participants: \_\_\_\_\_

How will the money be raised (pledges/contributions, donations, etc.)?:

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# Fundraiser Proposal Form

Please describe what assistance, if any, you are requesting from NF Midwest staff: \_\_\_\_\_

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How much of your estimated net proceeds will be contributed to NF Midwest?: \_\_\_\_\_

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If possible, please include a proposed budget for your event or promotion (see attached form) and specify which costs or expenses, if any, you expect to be underwritten or donated as gifts in kind.

A budget is recommended, but not required. It is especially recommended for larger events and is required if NF Midwest is going to underwrite, or pay for any part of the event.

*I/we acknowledge receipt of the NF Midwest Policies and Procedures for Do It Yourself (DIY) Fundraisers and agree to comply with all provisions in organizing and holding our fundraising event.*

\_\_\_\_\_  
*Date*

\_\_\_\_\_  
*Signature of Responsible Party*

\_\_\_\_\_  
*Date*

\_\_\_\_\_  
*Signature of Responsible Party*

**Please return completed proposal form and proposed budget to:**

NF Midwest  
Attention: Event Coordinator  
473 N Dunham Road, Suite 3  
St. Charles, IL 60174

(630) 945-3562 • FAX (630) 689-1213 • [Events@nfmidwest.org](mailto:Events@nfmidwest.org)

# DIY Event Proposed Budget

A budget is recommended, but not required. It is especially recommended for larger events and is required if NF Midwest is going to underwrite or pay for any part of the event.

Submitted by: \_\_\_\_\_

Date: \_\_\_\_\_

## INCOME

Donations: \_\_\_\_\_

Sponsors: \_\_\_\_\_

Tickets/Registration Fees, etc.: \_\_\_\_\_

Other: \_\_\_\_\_

TOTAL: = \_\_\_\_\_

## EXPENSES

Decorations: \_\_\_\_\_

Entertainment: \_\_\_\_\_

Fees, etc.: \_\_\_\_\_

Food: \_\_\_\_\_

Postage: \_\_\_\_\_

Printing: \_\_\_\_\_

Supplies: \_\_\_\_\_

Other: \_\_\_\_\_

TOTAL= \_\_\_\_\_

GROSS INCOME = \_\_\_\_\_

EXPENSES = \_\_\_\_\_

NET INCOME = \_\_\_\_\_