



# National Niemann-Pick Disease Foundation, Inc. Fundraising Packet

Rev. 4/11

**This packet has been prepared to help you get started fundraising in support of the National Niemann-Pick Disease Foundation's programs of research and family services. Please read through this packet, and contact the NNPDF's Central Office (tele: 920-563-0930; email: [nnpdf@nnpdf.org](mailto:nnpdf@nnpdf.org)) if you have additional questions or need assistance with your fundraising efforts. Detailed NNPDF contact information is on the last page of this document.**

## **We can help you get started...**

### **The NNPDF can provide:**

- NNPDF brochures, newsletters, posters, banners, letterhead, envelopes, logo graphics, etc.
- Ideas, guidelines and tips for successful fundraising projects and events
- Publicity via the NNPDF's Web site, Facebook page, blog, listservs, etc.
- Media support, assistance with press releases, etc.
- Charitable donation information – tax-deduction receipts, matching funds requests, protecting the NNPDF's 501(c)(3) status, etc.
- Sample letters/flyers and support in developing one for your event; "Family & Friends" letters
- NPD Awareness Month proclamations – guidance for making requests to government officials
- Certificate of insurance for larger events such as walk-a-thons, etc.
- Wristbands and other promotional items

### **NNPDF Informational Videos – Each VHS tape or DVD contains all three video segments:**

**Video # 1** "Ryan's Story" - Profile of two-year-old Ryan Richardson (NPC) to be shown at fundraising events for Niemann-Pick Disease.

**Video #2** "Learning About Niemann-Pick Disease" - 7-8 minute video with basic information on Niemann-Pick Disease, services provided by the NNPDF, and information on how viewers can help. To be used as a tool for fundraising and awareness events.

**Video # 3** "Living with Niemann-Pick Disease" - An orientation video for families, health care professionals, educational staff, and support services. More details on the symptoms and progression of the various types of NPD and information on day-to-day management of NPD so those affected may enjoy the best quality of life and comfort possible through the various changes in their health care needs.

## **What is the National Niemann-Pick Disease Foundation?**

The National Niemann-Pick Disease Foundation, Inc. is an international, voluntary, nonprofit organization made up of parents, medical and educational professionals, friends, relatives and others who are committed to finding a cure for all forms of Niemann-Pick Disease.

The foundation was established in February of 1992 by parents of children suffering from Niemann-Pick Disease (NPD). Concerned with cutbacks in funds for medical research, knowing without research there was little hope for their children, these parents united to form an organization which became the National Niemann-Pick Disease Foundation, Inc. (NNPDF).

### **The NNPDF's primary goals are to:**

- Promote medical research into the cause of NPD in order to find a cure
- Provide medical and educational information to assist in the correct diagnosis and referral of children with NPD
- Provide support to families of NPD patients
- Encourage the sharing of research information among scientists
- Support legislation that positively affects those with NPD and their families

### **The NNPDF:**

- Has funded nearly \$5 million in research from 1993 to 2011
- Assisted in funding the research that led to the discovery of the NPC1 gene
- Provides services and support to families affected by Niemann-Pick Disease
- Promotes awareness by providing medical and educational materials to assist in accurate diagnoses and referrals
- Collaborates internationally with other NPD organizations to facilitate research and maximize resources

In spite of the daily challenges of caring for a family member with a serious illness, the families of the NNPDF support and advance these goals with their time, talents, and financial donations.

Living with the certainty of a child's gradual decline and death creates an emotional burden too difficult to bear alone. There is little that can make the situation easier. However, contact with other parents can reduce the feelings of isolation that can contribute to despair.

### **The NNPDF strives to:**

- Give and receive emotional support
- Provide assistance through a crisis
- Share resources and ideas about such issues as doctors, clinics, insurance companies and other health and human service programs
- Provide members with practical suggestions about day-to-day care for NPD-affected children and adults
- Establish enduring relationships with others who, on a personal level, understand both the anguish and the recovery of being a parent of a dying child

### **Family Services Programs:**

The NNPDF's Family Services Programs link families affected by Niemann-Pick Disease with other families experiencing similar circumstances. Resources provided by the NNPDF include:

- **NNPDF Newsletter** - The NNPDF newsletter is sent to all families and contributors on the mailing list.
- **Family Directory** – A Family Directory including contact information is provided for NNPDF member families.
- **Informational Packets** - Information and support is provided for families recently diagnosed with NPD.
- **NNPDF Family Conference** - The NNPDF Family Support and Medical Conference is held annually. The purpose is to bring together families, researchers, and medical professionals to share information and support.
- **NNPDF Web Site** - [www.nnpdf.org](http://www.nnpdf.org) - The NNPDF Web site contains current information on the foundation, research, medical information, fundraising and awareness events, and links to additional resources for NPD families. It is updated several times each week and is reviewed frequently for accuracy.
- **NNPDF Electronic Mailing Lists/Discussion Groups (listservs)** –The email list groups (listservs) offer discussions about concerns, problems, and solutions. There are specific listservs for NPD Types A, B, & C families, as well as a siblings listserv, and a listserv for those who have lost a family member.
- **NNPDF Blog, RSS Feed & Face Book Pages ~ Niemann-Pick Disease Awareness Site and Updates**

### **Present Status & Future Goals:**

The National Niemann-Pick Disease Foundation currently has a membership of approximately 400 families directly affected by Niemann-Pick Disease. The membership also includes thousands of medical, corporate, professional, friends and family sponsors in support of our goals.

The NNPDF Board of Directors is comprised mostly of families with children afflicted with NPD, and all board members carry out the work of the foundation on a volunteer basis. Most of the money raised to support the work of the NNPDF is a result of families fundraising in their local communities. Over 90% of NNPDF's expenditures are program services, such as medical research grants, educational materials, and family support services.

The foundation will continue to work toward the goals as set forth in the bylaws, mission and vision. As families of those suffering from NPD, we are committed to finding a treatment or cure to save our children and future generations from this disease.

**Please visit the NNPDF Web site at [www.nnpdf.org](http://www.nnpdf.org) for more information about the work of the foundation.**

## **Fundraising Guidelines**

### **Charitable Contributions**

The NNPDF is a tax-exempt 501(c)(3) nonprofit organization; therefore, donations to the NNPDF are tax-deductible (*see Charitable Contributions Guidelines later in this document*). **All checks should be made payable NNPDF and submitted to the NNPDF Central Office for cashing and deposit. Funds raised in the name of the NNPDF may not benefit the fundraiser/organizer personally, at the risk of jeopardizing the foundation's non-profit status.**

### **Official Receipts for Tax Deduction Purposes**

The NNPDF acknowledges each and every donation. The foundation office sends an *official receipt* for tax purposes. To facilitate provision of official receipts, fundraisers should keep a record of the names and addresses of donors and forward the list to the foundation, together with the fundraising proceeds. This record should also include the value of any item(s) or services received by the donor, as only the amount of the donation beyond the value of goods or services received is tax-deductible.

**A worksheet to help fundraisers track donations is available upon request from the NNPDF. You may wish to send a personal thank you note to contributors; however, all official charitable donation receipts must come from the foundation office, based on documentation provided by the fundraiser's organizer.**

### **Bank Accounts**

**Please do NOT open any bank account in the foundation's name!** Ask all donors to make their checks payable to the National Niemann-Pick Disease Foundation (or abbreviate to "NNPDF"). Cash should not be sent through the mail; rather, it should be deposited in a bank account with a check or money order sent to the foundation. All proceeds submitted should include a list of the donors and their addresses (*see Official Receipts section above*). All proceeds must be sent to the NNPDF for deposit into the foundation's account. All monies are the *personal responsibility* of the fundraiser until received by the foundation office. Please let the foundation office know when you are mailing fundraising proceeds, so we can watch for them and confirm their receipt.

### **Expenses**

The foundation does not generally cover fundraising expenses. Fundraisers should strive to get items, services and supplies donated, if possible, thereby maximizing their fundraising proceeds. Expenses, if not donated, should come out of the fundraising proceeds. ***The foundation will not be responsible if expenses exceed the proceeds from a fundraiser.***

Tracking the costs associated with a fundraising event helps determine the success of the effort, and gives a basis on which to make future fundraising plans. Before organizing a fundraiser, it is very important to make sure it is financially worthy of your time and effort. **A worksheet to facilitate recording fundraising expenses is available upon request from the NNPDF.**

### **Donated Expenses**

Expenses which are donated for fundraising events can be claimed as an "in-kind" charitable contribution on a personal tax return. Please send expenditure receipts to the foundation office to receive a written acknowledgement of your "in-kind" donation.

### **Non-Profit Verification - 501(c)(3) Tax-Exempt Number**

Many businesses require a copy of the foundation's verification of tax-exempt status prior to making a donation. Please contact the NNPDF Central Office for a copy of the verification letter.

## Raffles

Licensing and regulations vary from state to state. Be sure to contact your State Office of Charitable Gaming for guidelines. If a raffle is conducted, the name “National Niemann-Pick Disease Foundation” and/or the Web site address “www.nnpdf.org” should be printed on each ticket (if possible) to promote awareness.

## Bulk Mailing

If you plan to do numerous mailings and each one is over 200 pieces, you may want to work with a local non-profit to utilize their nonprofit permit. There are a number of requirements for each mailing to qualify for either a non-profit or for-profit bulk rate and the U.S. Postal Service has become very strict about the rules.

**We ask that you contact the NNPDF office before and after your fundraiser with details of your event. Please forward a picture or two, news clippings, details of the event, etc., for acknowledgement on the NNPDF Web site and newsletter, and to help give other families ideas for future fundraising strategies.**

## Charitable Contributions

### What is a Tax-Deductible Donation?

Contributions to charitable causes are not taxed because they improve the general public good and do not benefit the taxpayer personally. Gifts that are given to a qualified nonprofit organization, for which the donor receives no premiums (goods or services) in return, are considered tax-deductible. If the donor receives something in return for the donation, only the difference between the amount of the donation and the value of the item/service received in return is deductible.

### There are two general rules for Charitable Contributions:

- A donor is responsible for obtaining a **written acknowledgment** from a charity for any single contribution of \$250 or more before the donor can claim a charitable contribution on his/her federal income tax return
- A charitable organization is required to provide a **written disclosure** to a donor who receives goods or services in exchange for a single payment in excess of \$75

### How does the NNPDF Acknowledge Charitable Contributions?

The NNPDF sends an official receipt for tax purposes for all charitable contributions received, including the following information:

1. Name of organization (NNPDF)
2. Amount of contribution/donation (not including any amount for which goods or services were received)
3. Description (but not the value) of non-cash contribution(s) (also known as “in-kind” donations)
4. Statement that no goods or services were provided by the organization in return for the contribution, if that was the case
5. Description and good faith estimate of the value of goods or services, if any, which were provided in return for a contribution

### Special Substantiation Rules

Special Substantiation Rules apply when donors receive something in return for a contribution that is greater than \$75. Charities are required to disclose **in writing** that the deductible amount of a contribution is limited to the value of the contribution less the value of the goods or services received in return. The charity must also disclose what the value of the benefit is that the donor receives. This should be done in a manner which will come to the attention of the donor. (*See example below.*)

**Example** – A ticket for a concert is donated to a fundraiser event. The fair market value of the ticket is \$40. The ticket is sold for a \$100 donation with proceeds forwarded to the NNPDF. The donor should be informed that the \$60 (the amount over the fair market value of the concert ticket) is tax-deductible. The fair market value of the item (\$40, in this example) should be stated on advertising materials, event programs, event tickets, etc. If this information is not disclosed the organization risks being penalized for each failure to do so.

### Donated Expenses

Expenses and costs which are donated for fundraising events can be claimed as an “in-kind” charitable contribution on a personal tax return. Please send receipts to the foundation office to receive a written acknowledgement of your “in-kind” donation.

## **Fundraising Ideas and Events**

visit [www.nnpdf.org](http://www.nnpdf.org) to see many examples of past and future fundraising events by NNPfD families

**Family and Friends Letters** - Get started by sending letters to friends and family with information about Niemann-Pick Disease, updating them on how your child is doing. Contact the NNPfD for brochures or newsletters to enclose with your letter, or for sample letters and assistance writing yours. This may answer a lot of questions friends and family may have while providing them with a way to help. People are often just waiting to be asked to help – a Friends and Family letter makes a personal request to those most invested in our cause.

**Special Occasions** - Ask that a donation be made to the NNPfD in lieu of a gift to honor a birthday, anniversary, graduation, retirement, or other special occasion.

**Walk-a-thons, Bike-a-thons, Marathons, etc.** - Create a friendly competition among local businesses/schools/churches for participation. The NNPfD can provide a certificate of insurance for larger events which may require liability coverage.

**Services** - car washes, housecleaning, yard work, attic cleaning, window washing, dogwashing, etc. This is a great type of project for a high school group or a church youth group that wants to get involved.

**Garage and Rummage Sales** – Sales may also be done on a larger scale through schools, churches and other organizations with a percentage of sales donated.

**Raffles** - Quilts, sports items, money, shopping spree, vacations, dolls, etc. Licensing and regulations vary from state to state. Be sure to contact your State Office of Charitable Gaming for guidelines. Include the name “National Niemann-Pick Disease Foundation” on each ticket if possible to help raise awareness.

**Pancake Breakfasts, Spaghetti Dinners, Chili Suppers, Barbecues, Quilt Shows, etc.** - Many businesses are willing to donate supplies for these events. These events frequently turn into popular annual community events.

**Card Parties, BINGO, Chess or Checker Tournaments, etc.** - Charge a fee to enter. Ask local businesses to donate prizes.

**Sporting Events** - Golf outings, volleyball, basketball, softball tournaments, fishing tournaments, celebrity sports events etc. These may take a little more work to set up but can be a lot of fun and can raise significant amounts to support research and family services!

**Silent/Live Auctions** - sports memorabilia, white elephant items, services, etc. Collect items of interest and auction to the highest bidder. Businesses and friends often donate many of the items. Hold the auction in conjunction with a dinner, golf tournament, or other special event.

**Home demonstration parties** – Items are sold (or orders are taken for such items) and a percentage of the sales profits are donated.

**Grocery tapes from local cooperating grocery stores** – Some grocery stores offer a donation to nonprofit groups, with a percentage of sales donated to the specified organization.

**Bake Sales, Candy, Hot Dogs, Concession Sales, etc.** Many special events or retailers such as; Ice Capades, Ringling Brothers Circus, local sports events, musical events, Walmart, etc. allow charitable organizations to conduct fundraisers around their scheduled programs or in front of their businesses.

**Block of Tickets** - Buy a block of tickets for a football game, a musical event, or a play at a reduced rate and sell for a profit. Better yet -- see if the sponsor of the event will donate the tickets for a good cause.

**Recycle Newspapers, Aluminum Cans, etc. on a seasonal basis** --fall cleanup and recycling or spring cleanup and recycling. Send out flyers ahead of time and arrange for a certain day to pick up items.

**Cookbooks** - Ask members of your church, school, support group or any other organization to furnish their favorite recipes for a special cookbook. Various publishers provide a step-by-step instruction kit, and then will compile, print and bind your cookbook for a percentage of sales. The cookbook may be dedicated in memory of or in honor of a local family affected by NPD.

**Sit-Down Dinner** - This may take a little more work and planning but can be an excellent way to inform people about Niemann-Pick Disease and the work of the foundation. Charge per plate or charge per table. Contact local businesses to sponsor a table. Include celebrities, entertainment, motivational speakers, etc.

**Whatever type of fundraising event you choose to do, remember that it is personal stories of families directly impacted by Niemann-Pick Disease that motivate donors to support our vital Quest for a Cure. Don't hesitate to contact the NNPfD Central Offices for more ideas and support. We are here to help!**

## **October NPD Awareness Month Campaigns**

October is designated annually as Niemann-Pick Disease Awareness Month. Please ask your local government representatives to proclaim October as NPD Awareness Month. Submit photos of the proclamation-signing event to your local media. August is a good time to approach your mayor/senator/representative with the request for an October proclamation. (A sample proclamation is available from the NNPfD Central Office.)

### **Other Activities for October Niemann-Pick Awareness Month:**

- Contact your local news media to do a personal interest story or Public Service Announcement (PSA). Tell them about Niemann-Pick Disease Awareness month. Include a press release on NPD and how it affects your family. (Contact the NNPfD if you need assistance writing a press release.) If you are holding a fundraising event, ask the media if they will send a reporter or photographer to cover the event. Make sure to include details about how donors or volunteers can contact you or the NNPfD.
- Send out a letter or email to friends and family with information on Niemann-Pick Disease, news of upcoming events, updating them on how your child is doing, etc. Encourage family and friends to also write letters or send emails to connections of their own. Use your Facebook page or other social media to promote October Awareness Month.
- Include local businesses and service organizations in your mailings. Your local Chamber of Commerce should have addresses and a contact person. Make sure to ask about matching funds, as many employers offer this type of contribution.
- Submit information about upcoming events, NPD Awareness Month, etc., to school newsletters, church bulletins, local public access stations and cable networks.
- Ask local fast food restaurants to feature an item such as Blizzards, Big Macs, tacos etc. for a day/ week with all or a certain percentage of proceeds being donated.
- Request local businesses to put October Awareness announcements on their marquee or billboards.
- Ask local churches to include all those affected by NPD in their weekly/daily prayer concerns.
- Ask friends and family to help plan various fundraising/awareness events for October.

## **Tips for a Successful Fundraising Event**

- Set your date carefully – check other competing events/happenings to make sure they aren't on the same date – other charitable events in your community, graduations, big local sporting events, 3-day weekends where people leave town, etc. Once you have set your date, get the word out to other charities and groups in town so they don't set their date on yours.
- Approach a local service club, church, youth group, etc., and ask them to co-sponsor your event to provide manpower, their contacts, a facility, etc. Find a women's sorority, a men's service club, a high school service group, etc., which is looking for a charity to adopt and ask them to adopt the NPD cause.
- Piggyback onto an existing local charitable event. Supply volunteers to staff the event in exchange for a portion of the fundraising proceeds and the opportunity to distribute brochures, etc.
- Solicit publicity and human-interest story coverage from local print and broadcast media. (See the NNPfD Web site or contact the NNPfD Central Office for press release assistance.)
- Enlist a local or national celebrity to endorse and participate in your event.
- Develop a sponsorship benefits package to approach local, state or national companies for event underwriting sponsorships – try to get all expenses underwritten in order to maximize fundraising proceeds.

- Research what other similar events charge and maximize your net proceeds -- you may be able to charge more for admission/purchase than you realize, as attendees like to support a good cause.
- Minimize expenses – try to use only volunteers, get donations, do trade-outs where you can't secure a donation (give tickets in exchange for donated beverages, for example).
- Print a bright and informative “Save the Date” postcard and send to as many potential attendees as possible.
- Try to set the event up so that it can continue and grow each year as an anticipated annual event.
- Encourage family and friends in other communities to replicate the project you are doing in their community. Help them coordinate and promote the event even from afar, and attend the event with your family.
- Ask family, friends, co-workers, etc. who they might know that has a family foundation. Quite often personal recommendations from family members who serve on the board of their family foundation, are how funds are allocated.
- Maximize your revenue potential by “layering” a variety of opportunities for attendees to contribute more during an event. For example, host a golf tournament and add the option to purchase “Mulligans;” follow a gala dinner with a silent auction and raffles; sell hotdogs, sodas and wristbands at a walk-a-thon, etc.
- Gather annual reports, newsletters, event programs, etc. from other local charities, agencies and private schools to identify philanthropic individuals and companies. Look for repeat donors or sponsors who specifically give to charities that involve children and/or health care issues. Get these people involved in your event or project.
- If you have held an event in the past, identify those who gave generously and who might be in a position to give more. Approach them on a personal basis and ask them to continue supporting your event. Your family’s personal story is powerful and people will want to help; sometimes all it takes is a personal “ask” to bring in a significant donation.

#### **Matching Funds**

Many local businesses or organizations offer “matching funds.” They will match money raised through local fundraisers, or employers may match donations made by their employees up to a certain limit. Find out their limit and make that your goal.

## **Other Sources of Support**

### **Memorials/In Honor**

- The NNPDF can supply preprinted remittance envelopes so funeral homes, relatives, friends, individuals can give gifts in memory of someone you know.
- Suggest to family and friends, if appropriate, that memorial gifts for a loved one or friend be given to support NPD research and family support.
- Provide the address of NNPDF so people can send memorial donations without needing a remittance envelope.
- If you are close to a family whose relative is soon to pass away and you feel it’s appropriate, ask them to consider suggesting that in lieu of flowers, memorial gifts be made for NPD research and family support services.

### **Charitable Giving**

Approach investment brokers, accountants, lawyers, etc. in your community and educate them about NPD and your family’s experience with NPD. Have brochures from the foundation available to give to these professionals. They may have clients who are looking to give to a worthy charity for tax and philanthropic purposes, or who wish to establish a trust or bequest naming a worthy charity as a beneficiary.

### **United Way Donations**

Contact your local United Way office to find out if they accept “donor choice” designations. If they do, visit companies, teacher associations, unions, manufacturing plants, etc. in your community and encourage them to designate their United Way pledges to the NNPDF through “donor choice” designations. Because the funds are not used locally, many chapters may take an administrative fee (usually 8-15%) from the donation.

***Designate The National Niemann-Pick Disease Foundation, Inc. as your charity of choice:  
501(c)(3) organization - IRS # 35-1844264.***

## **Combined Federal Campaign**

Contact Federal employees to make them aware of the Combined Federal Campaign (CFC). The CFC is the annual fundraising drive conducted by Federal employees in their workplace. Each fall, Federal employees and military personnel raise millions of dollars through CFC for thousands of non-profit charities. Employees can select from a guide to designate their donations.

The NNPDF has qualified for the Combined Federal Campaign. Federal Employees and Military personnel may choose the NNPDF as their Charity of Choice.

*The NNPDF's Combined Federal Campaign number is "10121" in the CFC guide.*

## **Grants**

Millions of dollars in philanthropic grants are awarded annually to those who apply. Look into community or state grants that might be given for medical research, family support, or causes affecting children. The NNPDF Central Office can provide help in writing a successful grant application.

Please contact the NNPDF Office for:

- Various resources to help locate local and state grants
- Information to determine if the NNPDF meets the criteria for any local and state grants
- Information on which projects need funding and the amount needed.
- Background information on the NNPDF (for grant proposals)
- Grant writing ideas and tips on what to include in your proposal

**Please contact the NNPDF for sample income and expense worksheets, or if you have any questions or concerns. We are here to help!**

**Please submit donor lists and fundraising proceeds to:**

**NNPDF  
P.O. Box 310  
Fort Atkinson, WI 53538**

**Questions? Contact the NNPDF Central Office at:**

**NNPDF  
P.O. Box 49  
401 Madison Ave., Suite B  
Fort Atkinson, WI 53538**

**Telephone: 920-563-0930  
Toll Free: 877-287-3672  
Fax: 920-563-0931  
Email: [nnpdf@nnpdf.org](mailto:nnpdf@nnpdf.org)  
Web Site: [www.nnpdf.org](http://www.nnpdf.org)**

**Thank you for your support of the NNPDF's mission to support and promote research to find a cure or treatments for all types of Niemann-Pick Disease, and to provide support services to individuals and families affected by NPD.**