



NATIONAL NIEMANN-PICK DISEASE FOUNDATION, INC.

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Fundraising Packet

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We can help you get started...

Please contact the National Niemann-Pick Disease Foundation's Central Office for:

- Ideas/guidelines on various successful fundraising projects and events
- Governor's NPD Awareness Week Proclamation and guidelines for contacting your local representative
- NNPDF logo, letterhead, envelopes, informational brochures
- Media Press Kit; A James Brown "Public Service Announcement" Video
- Charitable donation information
- Sample letters, flyers, and posters
- Wristbands, t-shirts and order forms for personalizing other promotional items
- Ideas on how to get reduced cost banners and signs
- Note cards, NNPDF magnets, cookbooks and other awareness materials

NNPDF Informational Videos & DVDs

Three fundraising and informational videos on Niemann-Pick Disease are available

Video # 1 "Ryan's Story" - A heart-wrenching profile of two-year-old Ryan Richardson 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 to provide information in the 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. 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.

The foundation'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 National Niemann-Pick Disease Foundation:

- Has funded \$3.5 million in research since 1993;
- Provides services and support to families affected by Niemann-Pick Disease;
- Assisted in funding the research that led to the discovery of the NPC1 gene;
- Promotes awareness by providing medical and educational materials to assist in the correct diagnosis and referral of patients with NPD;
- Collaborates internationally with other NPD organizations to facilitate research and maximize resources;
- Provides funding for a Coordinator of Education, Referral and Advocacy (CERA)/Registered Genetic Counselor.

Families affected by Niemann-Pick Disease volunteer their time, energy and financial support to accomplish these goals while at the same time dealing with the neurological decline and ultimate death of their child(ren).

What Services are Available to NPD Families?

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 National NPD Foundation 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.

Ongoing Family Support Services

The NNPDF's support services programs link terminally children and adults, their parents, siblings and extended family members with other families experiencing similar circumstances:

- **NNPDF National Coordinator for Education, Referral and Advocacy** - The NNPDF provides families access to a Coordinator for Education, Referral and Advocacy (CERA) through the services of Cate Walsh Vockley, a senior genetic counselor at Children's Hospital of Pittsburgh, PA. Ms. Walsh Vockley is able to provide assistance identifying and obtaining genetic, medical and social services, and serves as an educational resource for families or other interested parties with questions related to NPD.
- **NNPDF Newsletter** - The NNPDF newsletter is sent to all families and contributors on the mailing list twice a year.
- **NNPDF Family Support Newsletter** – A special Family Support Newsletter supplement is included for all NPD families. The Family Support Supplement includes helpful information on caring for a child with NPD, as well as personal interest stories, newspaper articles, research updates, medical information, family support information, fundraising news, memorials, and other information families wish to share.
- **Family Directory** – A Family Directory including contact information is provided for NNPDF member families.
- **Informational Packets** - Information and support is provided for families with a new diagnosis of 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** - The NNPDF contains current information on the foundation, research, medical information and events, as well as links to resources for NPD families.
- **NNPDF Electronic Mailing List/Discussion Group** –The electronic mailing list and listservs offer email discussions of concerns, problems, and solutions with other Niemann-Pick families. There are specific listservs for NPD Type A, B, & C families, as well as a siblings list and a family listserv for those whose family member has died.

Present Status & Future Goals:

The National Niemann-Pick Disease Foundation currently has a membership of approximately 350 Niemann-Pick families. The membership also includes thousands of medical, corporate, professional, friends and family sponsors in support of our goals.

Board members consist of families with children afflicted with NPD who continue to work on a volunteer basis while donating many of the operating costs. Most of the money raised is a result of NPD families fundraising in their local communities.

Over 90% of 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 parents of children suffering from NPD, we are committed to finding a treatment or cure to save our children and future generations from this disease.

Please visit our Web site at www.nnpdf.org for more information

Important Information Before You Get Started

Charitable Contributions

Any donations to the NNPDF are tax-deductible—(See *Charitable Contributions Guidelines – page 7*). In order to qualify as a tax-deductible donation under the National Niemann-Pick Disease Foundation all proceeds from the fundraiser must be forwarded to the NNPDF. Proceeds should not benefit the fundraiser personally at the risk of jeopardizing the foundation’s non-profit status.

Written Acknowledgement

The NNPDF acknowledges each and every donation. The foundation office sends an *official receipt* for tax purposes. We ask you to please keep a record of the names and addresses of donors and forward the list to the foundation office. A worksheet to keep track of donors needing receipts is provided in this packet. You may wish to send a personal thank you to contributors, however, all charitable donation receipts must come from the foundation office.

Bank Account

Please *Do Not* open any bank account in the foundation’s name. Make checks payable to the National Niemann-Pick Disease Foundation (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 monies are the *personal responsibility* of the fundraiser until received by the foundation office.

Expenses

The foundation does not usually pay for fundraising expenses. 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. Before organizing a fundraiser, it is very important to make sure it is financially worthy of your time and effort.

Donated Expenses

Expenses which are donated for fundraising events can be used as a charitable contribution on your personal tax return. Please send 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. Include the name Niemann-Pick Disease on each ticket to promote awareness.

Bulk Mailing

Learn about how bulk mail for non-profits works – if you plan to do a lot of mailings (and each one is over 200 pieces), you may want to work with a local non-profit to utilize their nonprofit permit (be aware there are a number of requirements for each mailing to be qualified for a non-profit or even for-profit bulk rate and the U.S. Postal Service has become very strict about the rules)

We ask you to please contact the NNPDF office before and after your fundraising event with details of your event. Please forward any pictures, news clippings, details of events, etc. for acknowledgement on the Web site and newsletter, and for future fundraising ideas and strategies. Please let us know of any special considerations or acknowledgements.

Guidelines for 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 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 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?

For **all** charitable Contributions, the NNPDF sends an official receipt for tax purposes, including the following information:

1. Name of organization
2. Amount of cash contribution
3. Description (but not the value) of non-cash contribution(s)
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, that an organization provided in return for the 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.

Example - Tickets are donated for a concert. The fair market value of the ticket is \$40. The ticket is sold for a \$100 donation with proceeds forwarded to the foundation. The donor should be informed that the \$60 is deductible. This information can be placed on solicitation materials, event programs, event tickets, etc. If this information is not disclosed we risk being penalized for each failure to do so.

Proceeds

In order to qualify as a tax-deductible donation under the National Niemann-Pick Disease Foundation proceeds must be forwarded to the NNPDF.

Expenses

It is very important to track the costs associated with a fundraising event. An elaborate accounting isn't necessary - just the basic information. A simple worksheet is included in this packet to facilitate recording expenses. The foundation does not pay for fundraising expenses. 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. Before organizing a fundraiser, it is very important to make sure it is financially worthy of your time and effort.

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

Fundraising Ideas and Events

Friends and Family Letters - Get started by sending letters to friends and family with information about Niemann-Pick Disease and updating them on how your child is doing. This may answer a lot of questions friends and family may have while providing them with a way to help.

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

Walk-a-thons, Bike-a-thons, Swim-a-thons, etc. - Create a friendly competition among local businesses/schools/churches for participation.

Services - car washes, housecleaning, yard work, attic cleaning, window washing etc. This is a wonderful project for a high school group or a church youth group who wants to get involved.

Garage and Rummage Sales - This may also be done through schools, churches and other organizations on a larger scale 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 Niemann-Pick Disease on each ticket to promote 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!

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

Home demonstration parties - for a percentage of sales.

Grocery tapes from local cooperating grocery stores - A percentage of total purchases with tapes submitted goes to the foundation.

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 to 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 - Have your church, school, support group or any other organization you may belong to furnish their favorite recipes. These could be favorite recipes in memory of or in honor of, etc. There are various publishers who will provide a step-by-step instruction kit plus compile, print and bind your cookbook for a percentage of sales.

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, dynamic speakers etc. as drawing cards.

Fundraising Ideas and Events (*continued.....*)

Take fundraising and awareness to the Legislative Level with a **Niemann-Pick Awareness Campaign**.

Planning an NPD Awareness Campaign

Ask your State Representative to present a proclamation to the Governor (or mayor of your city) to proclaim a day/week/month for those affected by Niemann-Pick Disease. (A sample proclamation is available from the NNPDF Central Office). October is designated as Niemann-Pick Disease Awareness Month – August would be a good time to approach your representative with this idea.

During Niemann-Pick Awareness day/week/month:

- Contact your local news media to do a personal interest story or Public Service Announcement (PSA). Tell them about Niemann-Pick Disease Awareness week/day/month. Include a press release on NPD and how it affects your family. If you are holding a fundraising event ask if they will send a reporter or photographer to cover the event. Make sure to include donation information.
- 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.
- Include local businesses and service organizations in your mailings. Your local Chamber of Commerce should have addresses and a contact person. Make sure and ask about matching funds.
- Include information in 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 information on their marquee or billboards.
- Put donation cans and posters in retail stores and businesses.
- 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 events for Awareness day/week/month.

Helpful Tips for Conducting a Successful Fundraising Event

- Piggyback onto an existing local charitable event.
- Try to become the beneficiary (or co-beneficiary) of an existing charitable event and add your component onto it to maximize proceeds – provide the manpower needed through your volunteers.
- Solicit publicity and human-interest story coverage from local print and broadcast media. (See the NNPDF Web site for press release assistance.)
- Involve a local or national celebrity to endorse and participate in your event.

Helpful Tips (continued...)

- Approach a local service club, church, youth group, etc., and ask them to co-sponsor the event to provide manpower, their contacts, a facility, etc.
- Develop a sponsorship benefits package to approach local, state or national companies for event underwriting sponsorships – try to get all expenses underwritten.
- You can probably charge more than you would think...research what other similar events charge in your area and maximize your net.
- 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).
- 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.
- 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 annual event to which people and companies look forward.
- Find a women's sorority, a men's service club, a high school service group (like Key Club), etc., which is looking for a charity to adopt and have them, adopt the NP cause.
- 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.
- If you plan a project, do it big. It takes a lot of work, but you maximize your revenue potential...host a golf tournament at which you sell mulligans, produce an event program with paid advertising, follow with a gala diner, add a silent auction, etc. Plan the dinner program well so it has an emotional response about your family and the cause followed by a raffle, silent auction, or some way that the attendees can contribute even more during the event.
- Gather annual reports, newsletters, event programs, etc. from other local charities, agencies and private schools to see which individuals and companies are philanthropic. Look for repeat donors or sponsors who give to charities that involve children and/or health care issues. Get these people involved in your event or project.
- If you have had a project(s) in the past, study those who gave generously and are in the position to give more. Approach them on a personal level and ask them to continue giving to your annual event.

Matching Funds

Many local businesses or organizations may offer “matching funds.” They will match any 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 for Niemann-Pick Disease Support

Memorials/In Honor

- Have available or request from the NNPDF 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(es) 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 whether or not 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 CFC number is "10121" in the 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 locating and 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

Fundraising Worksheet

Event: _____

Location: _____

Date: _____

Sponsor: _____

In Honor/Memory of : _____

Event Income:

Admissions/Ticket Sales, etc. _____

Raffle Income _____

Silent Auction/Live Auction _____

Other:

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Donations: Please submit record of all in-kind donations and cash donations to the NNPDF Office for official IRS Record of Receipt

Total Receipts: \$ _____

Minus Total Expenses: \$ _____
(see Expenses worksheet, next page)

Net Income from Event: \$ _____
(Amount remitted to NNPDF)

