



NATIONAL NIEMANN-PICK DISEASE FOUNDATION, INC.

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Fundraising Packet

We can help you get started...

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

- 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, Envelops, informational brochures
- Media Press Kit, A James Brown "Public Service Announcement" Video
- Charitable donation information
- Sample Letters, flyers, & posters
- Wrist-bands, 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 & DVD's

Three fundraising or informational videos on Niemann-Pick Disease are also available

Video # 1 "Ryan's Story" - A heart-wrenching day-in-the-life 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 you can help. To be used as a marketing tool for fundraising and awareness events.

Video # 3 "Living with Niemann-Pick Disease"

An orientation video for families, health care professional, 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 would eventually become the National Niemann-Pick Disease Foundation, Inc.

Our primary goals are to:

- Promote medical research into the cause of NPD in order to eventually 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 patients and families with NPD.

The National Niemann-Pick Disease Foundation:

- Raised over \$1.6 million and has funded 31 research labs 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 people with NPD
- Collaborates Internationally with other NPD Organizations to facilitate research and maximize resources.
- Provides funding for a National Coordinator for NPC at Columbia University in New York

These accomplishments are significant in the fact that families affected by Niemann-Pick Disease volunteer their time, energy and expenses to accomplish these goals while at the same time dealing with the neurological decline and ultimate death of their child(ren) affected by NPD.

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 hopes 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 each other with practical suggestions about day-to-day care for our children;
- 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 programs of support services link terminally children and adults, their parents, siblings and extended family members with 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 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 for all NPD families 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 our mailing list three times a year.
- **NNPF 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 your child, as well as, personal interest stories, newspaper articles, research updates, medical information, family support information, fundraising news, memorials, and any information families wish to share.
- **Family Directory** – A family Directory including contact information is provided for NNPDF Member families.
- **Support 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 Website - 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/Chat room** –The Electronic mailing list and scheduled chat rooms offer email discussions of concerns, problems, and solutions with other Niemann-Pick families. Currently we have specific list-servs for our NPD Type A, B, & C families, as well as, a siblings list and a family list-serv for those whose family member has died.

Present Status & Future Goals:

The National Niemann-Pick Disease Foundation currently has a membership of approximately 300 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

The Foundation will continue to work toward the goals as set forth in our by-laws missions and Purpose. 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 website 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 fund raiser 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 be deposited in your personal bank account with a personal check 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 fund raising 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

Before making a donation many businesses may require a copy of the foundation’s verification of tax-exempt status. Please contact the NNPDF Central Office for a copy of the verification letter.

Raffles

Licensing and regulations vary from state to state. Make sure and contact your State’s Office of Charitable Gaming for guidelines. Include the name Niemann-Pick Disease on each tickets 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 Post Office 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 Website 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, 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 Receipts for tax Purposes containing the following information:

1. Name of organization
2. Amount of cash contribution
3. Description (but not the value) of non-cash contribution
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 \$100 donations with proceeds forwarded to the foundation. The donor

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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 occasions

Walk-a-thons, bike-a-thons, swim-a-thons, etc. Create competition among local businesses 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 want to get involved.

Garage and rummage sales This may also be done through schools, churches and other organizations on a large 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. Make sure and contact your states Office of Charitable Gaming for guidelines. Include the name Niemann-Pick Disease on each tickets to promote awareness

Pancake Breakfasts, spaghetti dinners, chili suppers, barbecue etc. Many businesses are willing to donate supplies for these events. These events frequently turn into annual events everyone looks forward to.

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 sit down dinner or other special event.

Home demonstration parties for a percentage of sales.

Grocery tapes from local cooperating grocery stores: A percentage of value of total purchases goes to the foundation.

Bake sales, candy, hot dogs, soda sales, etc. Many Special events such as; Ice Capades, Ringling Brothers Circus, local sports events, musical events etc. allow charitable organizations to conduct fund raisers around their scheduled programs.

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 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 so much 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 a NPD Awareness Campaign

Ask your local State Representative to present a proclamation to the Governor of your state (or mayor of your city) to proclaim a day/week/month for those affected by Niemann-Pick Disease. (A proclamation and procedures are available at the NNPDF Central Office)

During Niemann-Pick Awareness day/week/month:

- Contact your local news media for a personal interest story or Public Service announcement. 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 corresponding events, updating them on how your child is doing. Encourage Family and friends to also write letters or send emails.
- Include local businesses and service organizations in your mailings. Your local Chamber of Commerce should have all addresses and a contact person. Make sure and ask about matching funds.
- Include information in school newsletters, church bulletins, local Public Service stations and cable networks.
- Ask local fast food restaurant 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 marques and 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 s during this week.

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.
- Publicity and human-interest stories – print and broadcast media in local publications. (See the NNPDF website for Press Release.
- Involve a local or national celebrity to endorse and participate in your event.
- Approach a local service club, church, youth group, etc. and ask them to co-sponsor the event with you to provide manpower, their contacts, a facility, etc.

Helpful Tips (continued...)

- 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 one 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 or have done in your community. Help them coordinate and promote the event even from afar, and attend the event with your family.
- Find out from family, friends, co-workers, etc. people they know who have family foundations. Quite often personal recommendations from family members, who serve on the board of their family foundation, are how The funds are divided each year among “favorite” charities.
- 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 (spend) even more during the event.
- Gather annual reports, newsletter, 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.

Tips in Garnering Other Funds for Niemann-Pick Support

Memorials/In Honor

- Have available or request preprinted memorial remit envelopes from the NNPDF 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 NP research and family support.
- Provide the address(es) to person write obituary of NNPDF so people can send gifts without needing a remit 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 the NP cause.

Charitable Giving

Approach investment brokers, accountants, lawyers, etc. in your community and educate them on the NPD cause and your family. Have brochures from the Foundation available to give to these local professionals to have on file to promote the NP cause to wealthy clients. 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. You may never know the amounts of funds that might be given to the NNPDF as a result of this.

United Way Donations

Contact your local United Way Chapters 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:
501c(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 fund raising 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 single guide to designate their donations.

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

The NNPDF CFC number is 1005 located under National Agencies 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 you with help in locating and writing a successful grant.

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 what money is needed for and how much we need.
- Background information on the NNPDF needed for writing Grants.
- Grant writing ideas and tips on what to include in your proposal.

Fundraising Worksheet

Event: _____

Location: _____

Date: _____

Sponsor: _____

In Honor/Memory of : _____

Event Income:

Admission/ticket sales, etc. _____

Raffle _____

Silent/Live Auction _____

Other

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

Donations:

Please Submit record of all in-kind donations and monetary

Donations to the NNPDF Office for IRS Record of Receipt

(See Donation Form)

Total Receipts: \$ _____

Minus Total Expenses: \$ _____
(Total Expenses from back)

Net Income From Event : \$ _____
(Remitted to NNPDF)

