



## NATIONAL NIEMANN-PICK DISEASE FOUNDATION, INC.

# Fundraising Packet

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### **NNPDF**

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## 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
- Informational NPD Brochures ~ ASMD & NPC & Newsletters
- Charitable donation information
- Sample Letters & Flyers
- NNPDF Logo, Letterhead, & Envelopes
- Wristbands & Posters

### **NNPDF Informational Videos & DVD's**

Accessible on our website at [www.nnpdf.org](http://www.nnpdf.org)

#### **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 ~ "And This, My Child"**

A letter written to Breann Chavez (2/1/03 – 6/8/06) by her mother Lisa Chavez.

# What is the National Niemann-Pick Disease Foundation?

The National Niemann-Pick Disease Foundation, Inc. (NNPDF) 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 (NPD).

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 anyone 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:**

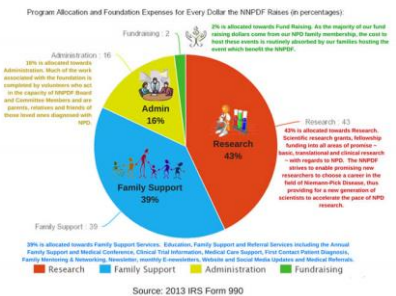
- Directed over \$5.6 million and has funded 31 research labs since 1992
- Provides services and support to families affected by Niemann-Pick Disease
- Assisted in funding the research that led to the discovery of the NPC1 Gene
- Promotes awareness by providing medical and educational materials to assist in the correct diagnosis and referral of people with NPD
- Collaborates internationally with other NPD Organizations to facilitate research and maximize resources.

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) or young adults 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 and young 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 or young adult.



# Ongoing Family Support Services

The NNPDF programs of support services link those diagnosed with NPD, their parents, siblings and extended family members with families experiencing similar circumstances:

- **NNPDF Newsletter** - The NNPDF Newsletter is sent to all families and contributors on our mailing list once a year. This is a year in review summary of the Foundation.
- **NNPF E-Newsletter** – A monthly e-newsletter is emailed to all on the third Tuesday of the month in the United States and two weeks later in Canada. The e-newsletter includes medical trail updates, information on the annual Family Conference and other pertinent information to help keep families up to date.
- **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](http://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 Facebook Awareness Page & E-mail Listserv** – The NNPDF hosts and monitors the Niemann-Pick Disease Awareness Page on Facebook. The E-mail Listserv is a resource for all NPD families and for those who have an interest in NPD. 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 over 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 and young adults afflicted with NPD. They represent all disease types and a variety of family dynamics. They all donate their time on a volunteer basis, devoting many hours to help the NNPDF to reach its goals.

82% 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. As parents, extended family members and patients, we are committed to finding a treatment or cure to save all those affected by NPD as well as future generations from this disease.

Please visit our website at [www.nnpdf.org](http://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.** 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 ticket to promote awareness.

## **Certificate of Insurance**

The NNPDF office can obtain a certificate of insurance for your event if it is necessary. There is a form to fill out and there are some stipulations as suggested by our carrier. Please request a few months ahead of your event for processing.

**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 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 the packet to record 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.

# 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, and dynamic speakers etc. as drawing cards.

**Recipes for Success** – The NNPDF office has a set of “recipe cards” to assist in planning a fundraiser. These cards will assist you so that your event is fun and easy!

# **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 NNPDP 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 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 NNPDP 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.
- Develop a sponsorship benefits package to approach local, state or national companies for event underwriting sponsorships – try to get all expenses underwritten.



## Helpful Tips (continued...)

- 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 dinner, 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 NNPDP 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 NNPDP 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 NNPDP 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 NNPDP 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 NNPDP has qualified for the Combined Federal Campaign. Federal Employees and Military personnel may choose the NNPDP as your Charity of Choice.

***The NNPDP CFC number is 1005 located under National Agencies in the guide.***

## **Grants**

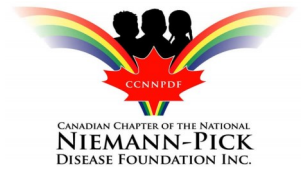
Millions of dollars in philanthropic grants are awarded annually to those who apply. Look into community or state grants that might be given for medical research, family support, or causes affecting children. The NNPDP Central Office can provide you with help in locating and writing a successful grant.

Please contact the NNPDP Office for:

- Various resources to help locate local and state grants
- Information to determine if the NNPDP 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 NNPDP needed for writing Grants.
- Grant writing ideas and tips on what to include in your proposal.



**National Niemann-Pick Disease Foundation  
(NNPDF) & Canadian Chapter of the NNPDF  
Fundraising and NPD Awareness Tiered  
Services Plan**



<b>NNPDF &amp; CCNNPDF Fundraising and NPD Awareness Services</b>	<b>Proceeds from the event &amp; donations are payable to NNPDF/CCNNPDF</b>	<b>Awareness of NPD &amp; NNPDF/ CCNNPDF and there are no monies raised</b>	<b>Awareness of NPD but proceeds from event go to another agency</b>
NNPDF Central Office Staff assist in identifying the fundraising event/NPD Awareness Campaign that best matches your ability	☑	☑	☑
NNPDF/CCNNPDF Brochures & Newsletters (Disease Specific)	☑	☑	☑
Provide access to NPD related advertising items (NPD Persevere posters & wristbands) *	☑	☑	☑
Post fundraising event information when first notified on NNPDF & CCNNPDF "Upcoming Events" Web Page	☑	☑	☑
Post fundraising information one week before event on all NNPDF Social Media platforms **	☑	☑	☑
Post fundraiser information in E-Newsletter if time and space allow	☑	☑	
Central Office Staff assistance with Publicity and Press Releases	☑	☑	
Provide NNPDF Federal Non-Profit 501(c)(3) status & W-9's as well as Canadian Charitable Status. Available upon request.	☑	☑	
Certificate of Insurance/Liability ***	☑	☑	
Central Office Staff can assist with creating an online event registration page	☑		
Central Office Staff processes and mails all event thank you letters & receipts to contributors for donor tax purposes	☑		
In-Kind receipts for donor tax purposes are available	☑		
Access to reports associated with the fundraiser including contribution tallies & donor list for personal notes	☑		
Knowledge that the funds raised for NNPDF/CCNNPDF will be allocated to research that has been reviewed by NPD experts and the NNPDF Scientific Advisory Board	☑		

\* Minimal Cost

\*\*As Time and Staff Availability Permit

\*\*\*Rules & Restrictions Apply (U.S. residents only)

# 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)



