

## Family Assistance & Support Program

The NNPDF Family Assistance & Support Program offers help to eligible NNPDF U.S. member families facing a financial obstacle. Funding includes but is not limited to, specialized medical equipment, durable medical goods, utility bills (heating and cooling, electricity, phone, water, and sewer), adaptive home repairs, home and car repairs, car payments, rent and mortgage payments, and bereavement expenses.

The Family Assistance & Support Program (FASP) provides relief to members facing a situation that requires financial funding that otherwise is not available or that causes hardship. It is intended to provide short-term financial assistance and is not intended to address long-term financial challenges.

The NNPDF FASP does not assist with expenses associated with medical procedures, medical travel, insurance co-pay, deductibles, or premiums, NNPDF Family Support and Medical Conference, or wish granting type experiences.

To be eligible for funding, NPD individuals and families must reside in the U.S. and must be enrolled as a member of the NNPDF for a minimum of 6 months prior to request\*. Funding is available for up to \$1000 per 12-month period per eligible member. Families with multiple children diagnosed with Niemann-Pick Disease are eligible to apply for each affected individual. Families that have lost their loved one due to Niemann-Pick Disease are eligible to apply. *\*6-month enrollment does not apply to newly diagnosed families.*

The NNPDF Board of Directors and Family Support Committee members work to keep the Family Support & Assistance fund fiscally sound by being the last resort to be used, by limiting regular, recurring use by any one recipient, and encouraging donations.

Please review the *NNPDF Family Assistance & Support Program Guidelines* on the following page before completing the application.

If you have a question regarding the eligibility of your request or if you need assistance completing the application, feel free to contact us at 920-563-0930 or [familyservices@nnpdf.org](mailto:familyservices@nnpdf.org).

# NNPDF Family Assistance & Support Program Guidelines

## PROCESS:

- 1) Only parents/guardians of an affected individual or an affected adult who reside in the United States and are enrolled as members with NNPDF for a minimum of 6 months prior to request\* are eligible to apply.  
*\*Those with new diagnoses are eligible to apply if the diagnosis was no more than 6 months prior to the request.*
- 2) Strictest confidentiality regarding application, names and funding will be maintained by NNPDF.
- 3) Funding is to provide short-term financial assistance and is not intended to address long-term financial challenges.
- 4) Funding includes but is not limited to, specialized medical equipment, durable medical goods, utility bills (heating and cooling, electricity, phone, water, and sewer), adaptive home repairs, home and car repairs, car payments, rent and mortgage payments, and bereavement expenses.
- 5) Multiple requests may be submitted in a 12-month period, not to exceed \$1000 per affected individual.
- 6) All supporting documentation must accompany the application form prior to application being reviewed. Applications will be reviewed by the Family Assistance and Support Team upon receipt of all documentation, and the Family Services Manager will notify the applicant of the funding decision.
- 8) Funding will be paid directly to the vendor/supplier upon NNPDF receiving an original or photocopy of the invoice/quote/estimate from the applicant. In unusual situations, the individual may be reimbursed for approved costs upon submission of payment proof.

## APPLICATION REVIEW:

- 1) Application will be reviewed once all the required documentation is received.
- 2) The Family Assistance and Support Team will review a summarized and de-identified version of the application and determine funding status. Applicants will be notified of this determination by NNPDF's Family Services Manager.
- 3) The Family Assistance and Support Team interpretation of the regulations outlining the Family Assistance & Support Program and any decisions made by the Committee are binding. Appeals can be made to the Board of Directors in writing within 60 days of denial. The appeal will be reviewed at the next regularly scheduled Board meeting.
- 4) In the event that funds budgeted for the current year are depleted, the application will not be reviewed that calendar year. Applications will be accepted and reviewed after January 1 of the following year.

## SECTION I: Family/Applicant Information

Name:				Date:	
Address:					
City:					
State:		Zip Code:			
Phone:					
Email:					
Name of NPD Affected Individual:					
Date of Birth:		NPD Type:			

## SECTION II: Household Information

Annual household income:	\$	Annual out of pocket medical expenses:	\$
Number of people in household:	Number of Adults:	Number of Children:	Number of adults currently employed:
Employer(s):			
If the adults are not currently employed, please explain:			
Have you previously received funding through NNPDP?			<input type="checkbox"/> Yes <input type="checkbox"/> No
If yes when was funding received?		Amount Funded:	\$
Reason for funding (i.e., emergency hardship, conference travel, etc.):			

## SECTION III: Non-NNPDF Funding Sources

Have you applied for funding assistance through any other available resources? (Local civic groups, city and state programs, family foundations, etc.)			<input type="checkbox"/> Yes <input type="checkbox"/> No	
Please list contact information for all resources you have investigated below. Use additional paper if necessary. <i>Please note: NNPDF may verify information with the groups/agencies listed by the applicant.</i>				
Name of Organization/Group:				Date of contact:
Name of contact:		Phone Number:		
Please describe attempts and the results:				
Name of Organization/Group:				Date of contact:
Name of contact:		Phone Number:		
Please describe attempts and the results:				
Will the other groups/agencies be willing to provide a matching grant if partially funded by NNPDF funds?			<input type="checkbox"/> Yes <input type="checkbox"/> No	

## SECTION IV: NNPDF Funding Request

Amount Requested:	\$	If applicable, amount currently owed:	\$
<i>Funding will be paid directly to the vendor or supplier, except in unusual situations.</i>			
Detailed description of how money will be used. Please provide copies of quotes, statements/invoices, detailed bills, or receipts showing balances owed:			
Please provide additional details such as current balance owed, anticipated out of pocket expenses to be incurred:			

If cost of item is more than funds available, what additional funding is in place?

If payment is for an item or service not yet purchased, please include/attach an estimate or quote from the vendor/supplier including all costs and vendor name and contact information:

## Additional Information for Durable Medical Goods Assistance

Are you applying for assistance with purchasing durable medical goods?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I have submitted this request through insurance. <i>(Please include insurance EOB or denial)</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I have a letter of medical necessity or prescription for this item.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Are you willing to donate this item to NNPDF's Families Helping Families program when no longer needed?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<input type="checkbox"/> Please attach a letter of medical necessity from medical professional.		
<input type="checkbox"/> Please attach any additional insurance paperwork such as plan exclusions, denial, or EOB.		

Please include a written statement which includes why receiving this grant is important to your family.

Please include the expected benefit to your family and how it will affect and improve the immediate health and safety of your family. Please feel free to use additional paper if necessary.

Signature  
of Applicant

Date: