



# Fundraising Guide

Registered Charity Number: 1144406  
Company Limited by Guarantee  
Registered in England and Wales No:07775835,  
Registered as a Charity in Scotland No: SCO45407



# Making a Difference to the Lives of those Affected by Niemann-Pick

We are a charitable organisation dedicated to making a positive difference to the lives of those affected by Niemann-Pick disease (NPD)

We work tirelessly to raise much needed awareness, whilst also providing practical and emotional support, advice, and information to those affected by this rare condition and their families. Through our unique care and support services, we aim to improve quality of life and to relieve feelings of anxiety and isolation that can so often accompany a diagnosis of Niemann-Pick disease. Due to the impact of our work, people often forget that we are in fact a small charity with less than five hundred members! As a result, much of the work we do is funded entirely through fundraising activities and successful grant applications - therefore our strength comes from the dedication of our much valued families, members, benefactors and volunteers who work with tremendous effort and loyalty in support of the charity.

Thank you for considering fundraising for NPUK. We hope that this guide will be helpful to you when planning your event - remember that we are always here to support you through every step of the way!

# Where Your Money Goes...

**£5**

will help us provide newsletters and research updates to families



**£10**

will help us continue to provide a free helpline service to our community



**£25**

will enable our clinical nurse specialist to provide support during clinics



**£50**

will help us provide a home visit from our families officer



**£100**

will help us support vital research projects



# YOU Can Make a Huge Difference!

We rely entirely on voluntary donations, charitable grants and fundraising to support our work with those affected by Niemann-Pick diseases, their families and the health professionals caring for them.

We've only been able to achieve what we have thanks to the voluntary donations and fundraising efforts of people like you. However, we know that we can achieve much more so please continue to support us in any way you can – your kindness and donations will help change lives and help us to fulfil our three core aims which are to...

Raise much needed awareness about Niemann-Pick disease

Facilitate research into potential therapies for Niemann-Pick disease

Provide practical and emotional support to those affected by Niemann-Pick disease

# The History of

# npuk

We are incredibly proud of our history here at NPUK; from humble beginnings to becoming a recognised and trusted voice on Niemann-Pick disease (NPD), we have certainly come a long way.

Throughout our journey, one thing has always remained consistent, our dedication to making a positive difference to the lives of those affected by Niemann-Pick disease. Follow the timeline below to see some of the landmarks we are most proud of!

1991

10 families affected by Niemann-Pick disease attended a satellite seminar at the University of Keele - resulting in the formation of what would become NPUK

1995

The Clinical Centre for Niemann-Pick Disease at the Willink Biochemical Genetics Unit of The Royal Manchester Children's Hospital was established to support the needs of affected families and health professionals

1997

The Niemann-Pick Disease Group (UK) was granted charitable status as an independent charity and formed a dedicated Board of Trustees to support and guide the future direction of the charity

1999

A generous grant from BBC Children In Need enabled us to employ a dedicated Niemann-Pick Support Nurse, who could offer expert information and advice regarding any aspect of NPD

2006

We underlined our commitment to research with the introduction of the first Peter Carlton Jones Memorial Award, which was presented to a young researcher working in the NPD field

2009

Together with the NNPDF (USA patient group) we hosted a global meeting of NPD patient support groups, resulting in the formation of The International Niemann-Pick Disease Alliance (INPDA)

2010

We strengthened our support service with the addition of a Families Officer, who can provide expert non-clinical advice, information and support to families affected by NPD

2016

On our 25th birthday NPUK welcomed a huge rebrand; this included a new-look logo, website and an extensive social media strategy - helping us to better reach and support our community

# A Few Fundraising Ideas...

One thing that our amazing fundraisers have shown us over the years is that the only limit to how you can fundraise is creativity!

From Morris dancing to sky diving... or sponsored football matches to cake sales - the list is truly endless. But sometimes we know you need a little inspiration before you get started, so how about one of the options to the right or those listed on pages 11 & 12?

No matter which one works best for you NPUK will *always* be with you throughout your fundraiser, and will do all that we can to spread the word about your efforts!

For more info email: [info@npuk.org](mailto:info@npuk.org)



# The A-Z of Fundraising:

**A**

Abseiling  
Antiques Fair  
Art Exhibition  
Athletic Races

**B**

Ball  
Ballet Show  
Book Sale  
Bring and Buy

**C**

Car Washing  
Concert  
Cycle Ride  
Children's Party

**D**

Dance-a-thon  
Darts Evening  
Dog Show  
Disco

**E**

Eighties Night  
Egg and Spoon  
Exhibition  
Eyebrow Shaving

**F**

Face Painting  
Fancy Dress  
Fashion Show  
Film Evening

**G**

Games Night  
Garden Party  
Go-Karting  
Golf Challenge

**H**

Halloween Party  
Horse Show  
Hook a Duck  
Hula Hooping

**I**

Ice Cream Eating  
Ice Skating  
It's a Knockout

**J**

Jam Making  
Jewellery Making  
Juggling  
Jumble Sale

**K**

Karaoke  
Kite Flying  
Knitting Competition

**L**

Line Dancing  
Litter Picking  
Log Throwing  
Luncheon

**M**

Magic Show  
Marathon  
Murder Mystery Evening  
Music Festival

**N**

Night Walk  
Name the Teddy  
Netball Tournament  
Non-Uniform Day

**O**

Obstacle Course  
Office Olympics  
Opera Night

**P**

Paintballing  
Pantomime  
Pet Show  
Pub Crawl

**Q**

Quiz Night  
Quit Something  
Queen for a Day

**R**

Raffle  
Rag Week  
Rowing Comp

**S**

Swimming Gala  
Swim-a-thon  
Swear Box  
School Play

**T**

Talent Competition  
Tombola  
Triathlon  
Treasure Hunt

**U**

Unwanted Gift Sale  
University Challenge  
- Style Competition

**V**

Valentines Event  
Vintage Car Day  
Vintage Fair  
Volley Ball Competition

**W**

Waxing Event  
Window Cleaning  
Wine Tasting

**X**

X Factor Concert  
Xmas Disco  
Xmas Party

**Y**

Yoga Day  
Youth Club Disco  
Yo-Yo Contest

**Z**

Zumba Event  
Zzz...Pyjama Party



## Our Amazing Supporters...

We are very grateful for the amazing support of our families, friends, corporate supporters, donors, volunteers and grant providers. The efforts of these wonderful people have greatly contributed to the success of our Charity and helped us to become a recognised and respected voice for those affected by Niemann-Pick diseases.

Our supporters are hugely important to us and we gratefully recognise the time, energy, determination and courage given to fundraising on our behalf, all of which helps to improve the lives of those affected by Niemann-Pick disease.

To keep up to date on the latest fundraisers and events, and to find out how you could get involved as an NPUK volunteer, please visit our website: [npuk.org](http://npuk.org).



## Supporting Research...

Facilitating research into Niemann-Pick disease is central to all we do. For over 25 years, we have actively supported and where appropriate funded scientific research, thanks to the generosity of our fundraisers.

Our Board of Trustees, the majority of whom have family members or friends directly affected by NPD, understand the urgency to find effective therapies and the fact that progress never seems fast enough. By working together to support further research, we believe progress will be even faster.

We are currently supporting studies at the University of Oxford, Cardiff University, University of Sheffield and the University College London. To find out more about these projects and how you can support further research, visit our website: [npuk.org](http://npuk.org).

# How to Plan your Fundraiser

So you want to be one of our fundraising heroes here at NPUK? *Great!* Well before you get caught up in the excitement of putting on a sure to be fantastic fundraiser – you should first draw up a plan of action. By using these five steps, you will be well on your way...

1

## Choose something fun

If it's your first event, you may want to keep it simple and start with something comfortable yet fun! If you love a game of footy, why not a sponsored football match? If you love channeling your inner *British Bake Off*, why not a cake sale? However, if you're an old-hand at putting on events, you could try something a little more adventurous - the choice is yours!

2

## Set a date, a time, and a target

Setting a date and time is the first step towards making your fundraising goals really happen - and having this organised allows you to focus on the fundraising target you may have in mind. By setting up a fundraising page on JustGiving or Virgin Money (see pages 19 and 20) you can make it easy for people to donate.

3

## Get in touch with us at NPUK

Let us know what you have planned as soon as possible, as that way we can do everything we can to support you! We can promote you and your event on our social media pages, we can write a blog post on our website, and we can be sure to send you all of our NPUK goodies to help you along the way, including badges, shirts, collection boxes (see pages 17-18), to name but a few!

4

## Spread the word

People need to know about your amazing event, or they won't turn up and you won't raise funds...so make sure you shout it from the roof tops! You could utilise your email, Facebook, and a whole host of various social media platforms to let people know about what you are planning. You could also get in touch with local newspapers, radio, and TV stations in your area.

5

## Recognise that you're a hero

Your dedicated efforts keep NPUK going, so never doubt yourself - you are making a true difference!

## REMEMBER!

Big or small, large or a little...we appreciate each and every person who gives up their time and effort to help fundraise in support of NPUK.

# NPUK Collection Boxes: Practical Advice and Guidance

We hope that the following guidelines will assist you in ensuring the safety of your collection box:

1. NPUK collection boxes/buckets are only to be used for their intended purpose - to raise funds for NPUK.
2. It is illegal to collect money in a public highway or street, or on a house-to-house basis, without a valid licence from your local authority. NPUK does not hold a national collection licence and therefore it is not authorised to allow individuals to conduct street collections on its behalf.
3. Plastic collection boxes/buckets are numbered and traceable, if you place a box with a local business or another venue other than your home, please do let us know the name of the business, the location and who to contact.
4. Boxes should be emptied frequently, the contents checked by two people, the amount raised recorded (forms are available to assist you with this process), and all funds forwarded to NPUK as soon as possible.
5. We advise that collection boxes/buckets are locked safely away at night, to reduce the risk of theft.

If you have any questions about collection boxes, would like a supply of collection forms, stickers or leaflets, or if you would like to inform us of any changes, please contact the Central Office on 0191 415 0693 or email [info@npuk.org](mailto:info@npuk.org)

6. The boxes are issued on a trust basis and remain the property of NPUK at all times, we reserve the right to recall a box if we feel it is not being used appropriately.

7. Finally, collection boxes are a great way to support NPUK – as they generate much needed income, and raise awareness of NPD and the work we do.

# Online Fundraising Platforms...

## What you need to know!

**On-line fundraising platforms help ordinary people raise extraordinary amounts for charities such as ours - so why not get involved and create a unique page for your event?**

We would love it if you would help us to do great things by creating your own personalised fundraising page. You can choose from the following three platforms; *JustGiving*, *BT MyDonate* and *VirginMoneyGiving*. They are all great at what they do and have a range of tools and resources designed to support and maximise your efforts! Creating a page is simple, fun to do, and also helps to alert us to your event so that we can better support you! Here are a few tips to get you started:

- Choose which online fundraising platform you wish to use, and then create your page! Make sure to include information about why you are supporting NPUK, and why it is important to you. Sponsors love to see as much information as possible, so don't forget to add photos, videos, and links to our website ([npuk.org](http://npuk.org)).

- Let everyone on your social media know about your fundraiser! Copy the link to your fundraising page, and share on your Facebook, Twitter, and Instagram accounts (as well as anywhere else you think may be suitable!) The more people that know about your event the better - so be sure to tag us in any of your posts. We are proud of each and every fundraiser, and always pleased to share their efforts with our community!

- On average, 20% of donations are raised after the fundraising event date, so make sure to re-share your page again after the event - perhaps with photos of the day as proof of all your hard work!

- Last but not least, make sure that you engage with your supporters throughout the entire process so that they feel more involved. This will make them more likely to share, and re-share your page...which will in turn attract more people to your fundraiser!

*For further information and tips on online fundraising platforms you can email us at: [info@npuk.org](mailto:info@npuk.org), or give us a call at the Central Office on: 0191 415 0693*

The logo for MyDonate, featuring the word "mydonate" in a white, lowercase, sans-serif font inside a white circle, which is set against a dark blue background.The logo for Virgin Money, featuring the word "Virgin" in a white, cursive font inside a red circle with a white outline, followed by the word "money" in a white, lowercase, sans-serif font.

# JustText Giving™

by  **vodafone**

## Are you based in the UK and planning a fundraiser in support of NPUK?

Whatever network you're on, JustTextGiving lets anyone donate to you by text. It's really easy to set up and every penny of your donation will go directly to Niemann-Pick

UK. It also doesn't matter which mobile network your supporters are on either, as they can simply text your unique code (for example, NPUK02) and an amount of £1, £2, £3, £4, £5 or £10 to 70070. You'll be able to see these donations on your page – and they'll be included in

your fundraising total. Don't forget to remind your supporters they can still add Gift Aid to their donation to boost your overall fundraising target (see pages 23 & 24).

If you need any assistance or information, you can email us at [info@npuk.org](mailto:info@npuk.org).

## CHEQUE IN WITH NPUK!

Online fundraising platforms, and the opportunity to text a donation are of course fantastic... but sometimes the old tried and tested methods are just as good!

Whether you have just completed an NPUK fundraiser and want to offload the funds raised, or perhaps you wish to make a personal donation/donation on behalf of someone else, sending a cheque directly to the **NPUK Central Office** is an easy way to do this. Simply make the cheque payable to 'Niemann-Pick UK', pop it in an envelope, and post to '**Niemann-Pick UK, Suite 2 Vermont House, Concord, Washington, NE37 2SQ**'.

Another way to make a donation is by bank transfer. Contact us for details and further advice on how to easily set up a payment.

**For further information please don't hesitate to get in touch, by email at: [info@npuk.org](mailto:info@npuk.org), or phone on: 0191 415 0693**

# The Benefit of Gift Aid:

**£100  
DONATION**

**+ 25%**



**£125 TO  
NPUK!**

**Gift Aid gives you an extra 25p for every £1 you donate**

Gift Aid is an income tax relief designed to benefit charities. If you're a UK taxpayer, Gift Aid increases the value of your charity donations by 25% as we are able to reclaim the basic rate of tax on your gift at no extra cost to you!

The process is really simple; all you need to do is fill out a Gift Aid Declaration form. This is a statement from you to us (NPUK) confirming that you want to donate through Gift Aid and receive tax back on your donation. As a charity, we do not pay tax on most types of income, which is why the tax paid on financial gifts can be claimed back.

**Please Note:** Your donations won't qualify for Gift Aid if they are more than four times what you've paid in tax that tax year. If you stop paying enough tax at any point, you must let us know.

# About Niemann-Pick Disease:

Niemann-Pick diseases are a group of rare inherited lysosomal storage disorders that can affect both children and adults.

Acid Sphingomyelinase Deficiency (ASMD) includes Niemann-Pick Disease Type A (NP-A) and Type B (NP-B), which are caused by a lack of the enzyme acid sphingomyelinase leading to a build-up of toxic materials in the body.

Niemann-Pick Disease Type C (NP-C) is a devastating neurodegenerative disease caused by an accumulation of lipids (fats) in the liver, brain and spleen.

At NPUK our primary goal is to make a positive difference to the lives of those affected by Niemann-Pick disease.



# MEET OUR TEAM:

In order to make a positive difference to the lives of those affected by Niemann-Pick disease, we need a team of people who are passionate about making that change - thankfully we do!

*You can meet them all here:*

## Toni Mathieson: Chief Executive

I became involved with NPUK in 2003, when our daughter was diagnosed with NP-C. Since 2005, I have been involved in all aspects of the Charity's work, including strategic and operational management, patient support and research. My personal experiences have provided me with empathy, compassion and the resolve to realise a brighter future for all affected by Niemann-Pick diseases.

## Christine Jopling: Finance & Administration Officer

I have witnessed firsthand the direct impact that our charity has had on people's lives. From fund-raising events to research grants, we are always striving to do as much as we possibly can!

## Laura Bell: Clinical Nurse Specialist

As Clinical Nurse Specialist for Niemann-Pick diseases, I am always available to offer support and advice to you and your family regarding any aspect of Niemann-Pick disease, plus home visits whenever necessary.

## John Lee Taggart: Social Media & Communications Officer

I joined the team to help NPUK communicate more effectively, so that our message of hope and positivity for those affected by Niemann-Pick disease can be heard by more people than ever before! By harnessing social media, online platforms, and other forms of media I believe we can achieve these goals.

## Elizabeth Davenport: Senior Families Officer

As Senior Families Officer, I offer non-clinical advice, information, and support to suit each and every person's individual needs. I understand the struggles of families who are dealing with Niemann-Pick disease and am here to support you and your family.

## Steve Neal: Project Families Officer

My family and I have a proud history with NPUK; we have been part of the NPUK family for a number of years as my mother (Gloria) is affected by NP-C. This has given me a great passion to help and support all of those families associated with the charity.

## Louise Metcalfe: Project Team Leader

As Team Leader for the Big Lottery funded project 'Shaping our Future Together', I am working to enhance the support already provided by NPUK. By successfully delivering the project aims, we hope to ensure that our community is better equipped to cope, both emotionally and practically, with the challenges of Niemann-Pick disease.



# We Can Support your Campaign!

As you can see from the smiling faces to the right, we are blessed with an abundance of dedicated volunteers and fundraisers...they support us, so we always strive to support them too!

If you are planning a fundraising event in support of NPUK then there are a number of ways in which we can help! Through our extensive reach on social media, including Facebook, Twitter, and Instagram we can let our community know about your efforts and how they can support you. We are always thrilled to share the story of each and every fundraiser and to help bring positive attention to your event. Remember the more people are aware of your event, the more people will likely donate towards your cause!

We also have a stock of NPUK posters, leaflets, wristbands, balloons, badges, t-shirts and so much more, for each and every budding NPUK fundraiser.

*Please don't hesitate to get in touch with John, our Social Media & Communications Officer, at [john@npuk.org](mailto:john@npuk.org), for more information about your potential fundraising strategy and campaign.*



# IMPORTANT INFO

There are a number of legal points it is important to take into consideration when taking part in a fundraising activity:

## - Insurance / Third Party Liability:

This is an important one, particularly if you are one of our more adventurous fundraisers! NPUK cannot accept liability for any loss, damage, or injury as a result of your fundraiser: so we urge you to look into getting insurance where necessary to protect yourself.

## - Collecting in Public Spaces:

If you want to collect money or sell items in a public area you might need a street collection licence, depending on your local council. You could be fined £200 if you collect money for charity without a licence, so make sure you contact your local council to find out if you need one.



**It is important to ensure people are aware of the purpose of your fundraiser, and where the funds will go!**

- Make sure that all collection boxes are regularly opened and the contents counted by at least two people

- After the fundraising event get all funds raised to us as soon as possible at: Suite 2 Vermont House, Washington, NE37 2SQ

**PLEASE NOTE: Niemann-Pick UK cannot accept liability for any loss, damage, or injury as a result of fundraising on behalf of NPUK.**



# Get in Touch!

Our Central Office is based in Washington Tyne and Wear, however we provide a service which spans the whole of the UK, including home visits where necessary.

You can get in touch with us if you have any questions or queries about fundraising *(or anything else!)* in a number of ways... we will always be happy to help.

**Our address is:** Niemann-Pick UK Central Office, Suite 2, Vermont House, Concord, Washington, Tyne and Wear, NE37 2SQ

**You can get in touch by email at:** [info@npuk.org](mailto:info@npuk.org)

**Or give us a call on our 24 hour helpline at:** 0191 415 0693

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With thanks  
to our grant  
providers:

