



np uk

Fundraising Guide



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 families affected by this fatal group of diseases. Through our work we hope to improve the quality of life for those affected by NPD, whilst also decreasing the isolation that can often be felt in the wake of a diagnosis.

Due to the impact that we have, 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.

We thank you for considering becoming a part of NPUK by being one of our fantastic fundraisers. We hope that this fundraising guide is helpful to you when planning out your event - remember that we are always here to help every step of the way - together we can both succeed!

By the way...

Where Your Money Goes...



£5

a month will help us provide newsletters and research updates to families



£10

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



£25

a month will enable our clinical nurse specialist to provide support during clinics



£50

a month will help us provide a home visit from our families officer



£100

a month will help us support vital research projects



What You Raise Will...

Make a huge difference to us here at NPUK, in fact we rely entirely on voluntary donations and fundraising to enable us to continue our work in supporting the children, adults, and families that are affected by Niemann-Pick disease.

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...

Allow us to raise much needed awareness about Niemann-Pick disease

Help 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, we have certainly come a long way. Follow the timeline below to see some of the landmarks we are most proud of!

We use the success of our past to drive us forward into a positive future, together: we will strive always to make a difference to the lives of those affected by Niemann-Pick disease.



1991

10 families affected by Niemann-Pick disease attended a satellite seminar together at the University of Keele - and later set up a NPD parent support group which would become NPUK



1997

Granted charitable status as an independent charity: The Niemann-Pick Disease Group (UK), registered as a charity and appointed six patrons in the process



2003

The first Central Office was established in order to better facilitate the charity's rapid development and expansion



2009

Together with the NNPDF we hosted a meeting of NPD patient support groups, resulting in the formation of The INPDA – a global collaboration to help those affected by NPD



2011

Jim Green stepped down after 20 years as chairman, during which time he guided the group from humble beginnings to an internationally recognised family support and healthcare charity



2016

On our 25th birthday NPUK welcomed a huge rebrand; this included a new website, a new logo, 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 kind efforts!

For more info email: 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 owe our success to the wonderful people who have helped support us over the years; donors, fundraisers, volunteers, and everything else in between. They are the reason that NPUK is such a strong positive force in the fight against Niemann-Pick disease. As NPUK steps into a new chapter, under our new re-brand, one thing that will never change is the importance of our supporters - the amazing people who give their time, their money and their voice to improve the lives of those affected by Niemann-Pick disease.



Our Fantastic Researchers...

Where appropriate we facilitate research into Niemann-Pick disease, as we hope that through research we may someday realise a cure to the devastating group of disorders that are Niemann-Pick disease. That's why researchers, such as the amazing research team from The University of Oxford (*pictured left*) are so important to us! Many of the researchers are both active members of our community as regular attendees of our Annual Family Conference, and also tireless fundraisers...it's not hard to see why they have a special place in our hearts!



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 are what keeps 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 puts in their 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 (both cardboard and plastic) 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 a cheque 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



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 help to the Charity – they generate much needed income, they raise awareness of NPD and the work of NPUK.

Online Fundraising Platforms...

What you need to know!

40% of the world's population now have an internet connection (it was less than 1% in 1995), which means that it has never been easier for people to either give or raise money. Online fundraising platforms such as *Just Giving* and *Virgin Money Giving* (two platforms which NPUK has accounts with) offer a fantastic service, which takes a bit of the pressure off you as a fundraiser - let's look at them both in a bit more detail:

Just Giving is currently considered to be the market leader, with a whopping £700,000,000 raised for charity on the site to date, and a further £100,000,000 claimed back in gift aid, it's not difficult to see why! If you decide to go with *Just Giving* you know that you have a well-known and reliable brand, as well as access to great resources containing must-have advice for each and every fundraiser. Creating your own dedicated fundraising event page is also quick and easy - allowing you to share the link on social media and engage your friends and followers directly!

Virgin Money Giving is a secure online way to collect sponsorship, and although less well known, is considered to be the main competitor to *Just Giving*. They offer a similar service, but also offer a more practical helping hand with fundraising efforts by also providing access to free interactive training six times a week on reporting, coding, and fundraising campaigns - which for a first time fundraiser, could prove to be invaluable!

For further information on online fundraising platforms you can email us at info@npuk.org



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 and Community Amateur Sports Clubs (CASC). 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 in any way that we possibly can.



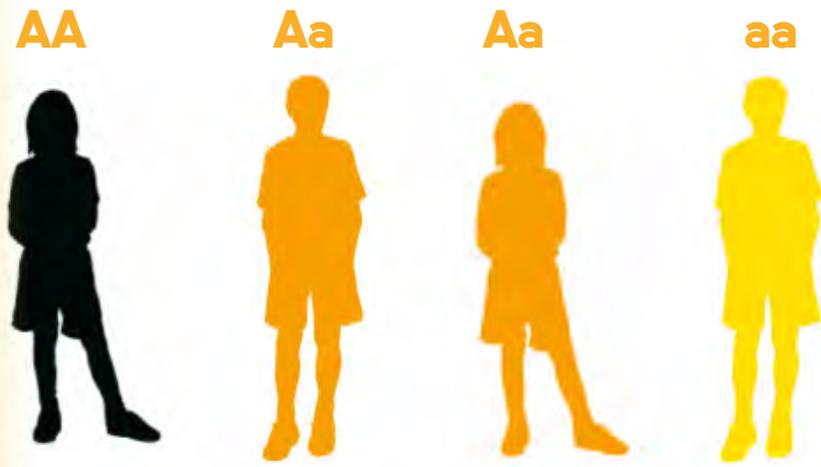
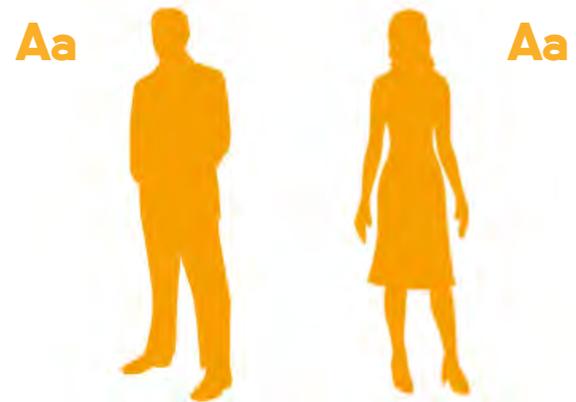
Niemann-Pick diseases are acquired through autosomal recessive inheritance, which means that the affected individual inherits two faulty (mutated) genes, one from each parent. If an individual has a single copy of the mutated gene, they are known as a carrier, and it will have no noticeable effect on their everyday lives and health.

The child may inherit identical mutations from each parent (referred to as homozygous), which can sometimes arise through intermarriage, although this may not be obvious over many generations. In other instances the parental mutations may be different and is referred to as heterozygous. In every pregnancy of a couple who each carry a copy of the faulty Niemann-Pick gene:

- There is a 25% probability that their child will inherit NPD
- There is a 25% probability that their child will be unaffected
- There is a 50% probability that their child will be a carrier of NPD

Specialist care centres can provide comprehensive, integrated, multi-disciplinary care for patients, as well as information and support for family members. They aim to incorporate networks of all relevant medical disciplines within the core team. They have effective links with national networks of testing laboratories and other care centres at a national and international level.

For further information please give us a call on 0191 415 0693, or email us at info@npuk.org.



Normal Carrier Carrier Affected

We Can Help Your Campaign!

If you are planning a fundraising event in support of NPUK then there are a number of ways in which we can help people get behind your event:

To the right we have a few of our personalised NPUK promotional graphics, which we shared with our community and supporters in the run up to each event. We feel this is a great example of how we can help you promote your fundraiser!

We are always happy to do the same for any NPUK campaign, and can offer: promotional graphics, posters, videos, and much, much more, to help boost the overall awareness and understanding of your event...remember that if more people are aware of your event, more people will likely donate towards your cause.

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



Prudential RideLondon-Surrey, one of the world's greatest festivals of cycling will take place on the 30th July, and you could be involved as a fundraiser for NPUK!

Don't miss your chance, email us as soon as possible at: info@npuk.org or phone us at: 0191 415 0893



Shona Mannion is jumping for Roman:

In four weeks time Shona will take part in a daring tandem sky dive. In order to raise funds for NPUK! She is motivated to take part on behalf of Team Roman, who are dear friends as well as people whose strength she truly admires.

Let's all get behind this fantastic fundraiser!



Masquerade Black Tie Ball
Woodland Suite at Ribby Hall Village, Wrea Green
14th October 2017

For Further Details Call: 07966309865



Charity Bingo Night for Annie Pyne & NPUK
Where: America Hall De La Rue Way, Pitkoo, EX4 8PQ
When: Friday 25th November, 19:00 arrival for 19:30 start

Bingo will be £10 for 10 Games
Come Join the Fun!

Pre-booking tickets is required. Please email info@npuk.org or call 07966309865 / 0191 415 0893 for further details.



The "Masquerade Black Tie Ball" which is held in memory of Calum (pictured), who sadly lost his fight with Niemann-Pick in 2011, will once again be hosted by his loving parents Carl and Emma Burdon. Don't miss this fantastic event!

I care about someone rare! #RDD2017

- Rare Disease Day is held on the last day of February every year to raise awareness of rare diseases, such as Niemann-Pick disease

- This year the theme is "Research". Research is key. It brings hope to the millions of people living with a rare disease across the world and their families. With research, possibilities are limitless.

To view a cartoon with updates



We want to wish a safe flight to Jen, Mike, and Susie Elliott...

They are setting off on an adventure of a lifetime and raising money for NPUK in the process!



Great North Run 2017

Challenge yourself this year by running alongside four time olympic gold medalist and three time GNR winner



np uk

Show you care about someone rare!



WHO?
Some of the best rock bands in the UK

WHAT?
A rock festival that really makes a difference

WHERE?
Trillians Rock Bar Newcastle Upon Tyne

WHEN?
7/8th July 2017

WHY?
All money raised goes to Niemann-Pick UK, a charity which supports those affected by the rare and fatal disease Niemann-Pick

FEATURING MORE FANTASTIC BANDS THAN EVER



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 put controls in place to make sure any money raised goes directly towards meeting NPUK's aims, therefore:

- 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



Get in Touch!

Our Central Office, based in Washington Tyne and Wear, provides us a perfect base in which to operate!

You can get in touch with us with 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

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



@NiemannPickUK



@NiemannPickUK

} Follow Us!



Supporting those living with Niemann-Pick

If you live in the UK you can donate to NPUK easily from your mobile phone – simply text: NPUK02 followed by the amount you'd like to donate to 70070. For example e.g. "NPUK02 £5" to 70070 (UK ONLY)

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