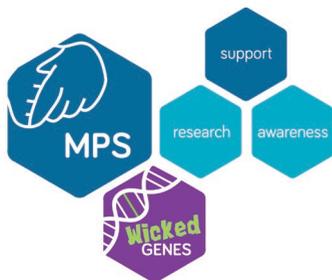


Your Guide to Fundraising

Inspiration & Information





The Society for Mucopolysaccharide Diseases (the MPS Society) is the only UK charity supporting individuals and families affected by 25 MPS and related Lysosomal Storage Disorders. The Society also funds and promotes ground-breaking research into treatments for these devastating genetic diseases.

Your Guide to Fundraising



Thank you for choosing to fundraise in aid of the MPS Society.

The Society for Mucopolysaccharide Diseases (the MPS Society) is the only UK charity supporting individuals and families affected by 25 different MPS and related diseases. These are progressive, life limiting genetic conditions.

Since the MPS Society was first established over 30 years ago it has been involved in funding vital research and supporting developments into new treatments, as well as providing professional support to those affected by these diseases and actively trying to raise awareness.

One of the biggest issues the MPS Society faces is lack of knowledge and understanding of MPS and related diseases, and as Mucopolysaccharide isn't the easiest thing to explain raising awareness through fundraising is vital.

Your money helps us to support children and adults with MPS and related diseases, their families and the professionals that work with them through our unique, individual Advocacy Service. You are also helping to fund vital research and raise awareness of this rare group of devastating diseases.

You'll find sections within the guide for fundraising at work, school, uni and in your community and we have filled it with ideas and top tips to help you beat your fundraising target. Please don't hesitate to contact us about how we can support you and don't forget we have plenty of useful information, guidance and resources at www.mpssociety.org.uk

Your help is vital to the continuation of our work – **Support, Research and Awareness.**

Many thanks and good luck!

Christine Lavery MBE
Chief Executive





“We were blown away by the generosity of friends, family and people we hadn't even met”

- Suzy Elliott, Great South Run 2015

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Why fundraise for the MPS Society?

MPS diseases are rare, genetic conditions that are life limiting and cause progressive physical disability and in many cases severe degenerative mental deterioration.

There is currently no cure for MPS and related diseases and many sufferers will not reach their teenage years.

Thanks to research supported by the MPS Society there are now treatments for some of the diseases which, although not a cure, can help delay the progression of the disease.

As the UK's only charity supporting those affected with MPS and related diseases, your fundraising changes lives by:

giving emotional and practical support through our professionally trained Advocacy Team.

support

research

continuing to invest in and develop pioneering research into MPS and related diseases.

awareness

bringing to the attention of the public these rare conditions and to campaign for change – to improve the lives of children, adults and their families for the future.

Christian has MPSIV Morquio. When he could no longer climb the stairs, Christian needed his bedroom on the ground floor, but we knew we simply couldn't afford to adapt our home. We knew that we needed help finding this money, so we contacted the MPS Society. Their Advocacy Team were so helpful. They managed to get grants from seven different organisations so Christian could have his new bedroom."

- Christian's Mum



How does fundraising help?

£5

buys 10 small flasks to grow cells for testing effectiveness of therapies for neurological genetic diseases.

£16

buys 200 storage containers for blood samples so that patient samples can be stored and used to test effectiveness of therapies and to develop new biomarkers of the disease.

£25

supports a tree planting and inscription in memory for one bereaved family at the MPS Childhood Wood.



£100

is the average cost of a home visit from a member of the Advocacy Team for a newly diagnosed family providing practical and emotional support.

£200

enables a child, who lives with a brother or sister with MPS, to attend a sibling activity weekend encouraging peer support and an opportunity to share stories and fun!



"I was diagnosed with MPSVI, Maroteaux Lamy in 1999 when I was just four years old. At this time there was no cure or treatment to help slow down the progression of the disease but with the research largely funded by the MPS Society, eventually a treatment was developed called enzyme replacement therapy (ERT).

At the age of 11 I had my first infusion at Manchester Children's Hospital. Within months I started noticing improvements in my health which included: increased energy levels, the straightening of my joints and most importantly after my height had halted to less than 4ft tall . . . I began to grow once again!"

- Oliver



Miya has MPS I, Hurler

“My husband and I are trying to stay strong. Now we know what Hurler is, we understand that we will need courage for the future. I know that in the difficult times to come, the MPS Society will be there for us as parents, and for Miya, offering us the support we will all need.”

- Miya's Mum

Fundraising ideas for you, your club or community!

There are lots of ways that you can raise funds for the MPS Society to help support those affected.

On the following pages we have given you a few suggestions, whether you want to do something big or small, as an individual or as a group, but the sky is the limit. It is your event, your choice; so if you think it will work, go for it!



Jason Smith ran 7 marathons in 7 days, inspired by the positive attitude of his young neighbour Archie, who suffers from MPSVI.

Although you may not be ready to try something as challenging as this, have a think about if you have any personal goals and then try to build your event around that, whether that is running an ultra-marathon or going without alcohol for a month.



I fundraised by:

- ▶ “Running the Brighton half marathon because of my great nephew William”
- ▶ “Growing a ridiculous moustache because of my son Bobby”
- ▶ “Organising a fashion show at university because of my neighbour Tillie-Mae”
- ▶ “Persuading 6 of my school mates to join me for a 70 mile bike ride because I’ve got Hunter ”
- ▶ “Encouraging people to Wear It Blue because of my son Ethan”
- ▶ “Leaping out of a plane because of my nephew Daniel!”
- ▶ “Cycling across South Africa because of my kids Sophie and Tom”
- ▶ “Choosing the MPS Society as our work Charity of the Year”



support

research

awareness



For more information about the MPS Society and our work, please visit www.mpsociety.org.uk



THESE BOOTS ARE MADE FOR FUNDRAISING

Wicked Walkabout

Have fun and get fit with friends, family and colleagues by holding a Wicked Walkabout!

Sponsored walks are a great way to raise funds and awareness for MPS and related diseases, and the best bit is that you can make it what you want, whether you fancy a midnight stroll around your local town, a forest hike or a coastal walk. You can even decide how you would like to fundraise - you could ask each person for an entrance fee or request a minimum sponsorship amount.

Get in touch for more info and a fundraising pack. You can also download a how-to guide and Wicked Walkabout poster from www.mpsociety.org.uk.

Fundraising at Work

Whatever the size of your company or the level of commitment you can give, we can work together and make a real, tangible difference to the lives of those with genetic diseases.

Whether you are a company looking for a charity partner for a year-long **Charity of the Year** partnership, or just wanting to do something as a one-off event we have some great ideas to help you have fun at work and raise some money.

Employee Fundraising:

- ▶ **Office It's a Knock Out** – department against department?
- ▶ A **Tug of War** is great for team building
- ▶ **Teetotal Challenge** - get your colleagues to forego that pub visit and instead put the money they have saved in a fundraising pot. Result: a healthier officer, and support for a great cause.
- ▶ **Dress-Down Day** – pay £1 to dress down or up for the day
- ▶ **Charity Eco-Challenge** - get your colleagues to be healthy and kind to the environment by walking or cycling to work. Collect all your unused petrol money and donate to the MPS Society.

Top Tips

- ▶ Find out if your company has a **Charity of the Year** and nominate the MPS Society!
- ▶ Ask whether your company offers **Give As You Earn** – a tax efficient way for you to donate to us
- ▶ Find out if your company can take part in a **Matched Giving** scheme to double your total raised



"It was really hard in the last year when he stopped talking. Our greatest fear is having to watch the Tommy we know and love gradually disappearing from us. I would just love to be able to listen to him say mummy and daddy again."

- Mother of Tommy, MPSIII, Sanfilippo

Fundraising at School

Fundraising at school is a great way of engaging pupils and staff across the whole school. Giving children a free reign to be creative in developing fundraising ideas can really motivate them. By getting involved your school will also help by raising awareness in the community.



Why not try a...

- ▶ **Wicked Wellie Waddle** – get the children booted up for a Wicked Walkabout for little legs!
- ▶ **Charity mufti day** – pay £1 and dress up or down for the day
- ▶ **Sponsored Silence** - peace and quiet at school

Fundraising at Uni

Raising and Giving on Campus

Does your University hold a RAG (Raise and Give) Week? If so we would love to be your Charity Partner! Many universities have RAG committees dedicated to supporting local and national causes. Sign up today – and if there is no committee, then why not create one!



Let us know how we can support your application.

You could...

- ▶ Organise a **Ball** or **Club Night**
- ▶ **Wax, dye, shave, or paint yourself** in the name of charity!
- ▶ **Escape & Evade** - get sponsorship to get as far away from your university and back in a set amount of time, without spending any money.

Visit www.mpsociety.org.uk or email us at fundraising@mpsociety.org.uk for stickers, posters, sponsor forms and other exciting fundraising materials!

Stay safe and legal!

We want you to have lots of fun during your fundraising, but we also want you to stay safe (and legal). Here are a few things you need to consider, they may sound daunting but don't forget we are always on the end of the phone to advise you.

▶ **Budgeting** – Ensure you keep any outgoing costs to a minimum and keep a record of your expenditure

▶ **Charity logo and registered charity numbers** – Please contact us first for prior permission to use our charity logos. In all cases, our logos should always appear with our registered charity numbers (Charity no. 1143472 and Scotland SCO41012)



▶ **First Aid** – Please ensure you have adequate cover available for the scale of your event. For more information please visit www.hse.gov.uk

▶ **Food** – For information about food hygiene regulations at events visit www.food.gov.uk

▶ **Health and safety** - The MPS Society cannot accept liability for any loss, damage or injury suffered by you or anyone else as a result of taking part in a fundraising event. Please ensure you get adequate cover and ensure that third party suppliers have likewise. Identify

hazards and evaluate risks at your event. Further information can be found at www.hse.gov.uk

▶ **Licences** – Check with your local authority whether or not you need to obtain any special licenses, e.g. alcohol, collections, public entertainment licenses

▶ **Raffles and lotteries** – Check the latest information and advice at www.gamblingcommission.gov.uk

▶ **Responsibility** – The MPS Society accepts no responsibility or liability for fundraising events that are held in aid of the MPS Society

▶ **Sporting events** – Ensure you are adequately fit and have done all the necessary training. If in doubt seek advice from a professional

Please Note

- ▶ Please make it clear you are raising funds in aid of the MPS Society and that you are not an actual representative of the charity.
- ▶ You cannot use our logos or charity details if you are fundraising for an individual.

An A - Z of fundraising ideas

We have already mentioned a whole load of fundraising ideas which will hopefully inspire you to raise money and awareness for the MPS Society. Just in case you need a bit more inspiration, here is an A-Z of fundraising ideas:

A

Arts & Crafts stall
Aerobic-a-thon
Abseil

B

Bake sale
Barbeque
Beard shave

C

Coffee morning
Charity cycle
Car washing



D

Dress up/down day
Disco/dance
Dog show

E

Easter egg hunt
Ebay old clothes

F

Fun run

Fete

Film night

G

Garden party
Golf tournament
Guess the weight

H

Halloween party
Head shave

I

Ironing service
Italian evening

J

Jumble sale
Jewellery making

K

Karaoke
Knitting
Knobbly-knees competition

L

Limbo competition
Litter picking
Line-dancing party

M

Marathon running
Magic show
Murder mystery night

N

Night walk
Name the teddy
No chocolate week

O

Open garden
Online auction
Office swear box

P

Pub quiz
Plant sale
Picnic

Q

Quiz night
Quit smoking

R

Race night
Raffle
Riding competition





S

Skydive
School play
Swim

T

Tombola
Talent show
Tug-of-war

U

Unwanted gift sale
University Challenge
Unicorn hunt (!)

V

Vintage fashion show
Valentine's Day event
Variety show



W

Waxing
Wine tasting
Wig wearing

X

X-Factor evening
Xmas cards sale

Y

Yoga marathon
Youth Club event

Z

Zip wire challenge
Zany tie/clothes day



Make the most of your fundraising

► Getting sponsorship

You can create your own online fundraising page to collect donations - take a look at JustGiving, BT MyDonate or Virgin Money Giving.

You can also download paper sponsorship forms at www.mpssociety.org.uk.

► Spread the word

After you've set up your online sponsorship page, share the link on social networking sites and email the link to everyone you know.

► Getting publicity

The easiest way of spreading the word about your fundraising is to write a press release and send it to your local press. Download a sample press release from www.mpssociety.org.uk to send to your local press and follow it up with a phone call to the editor. Always refer to the MPS Society for factual information where necessary.

► Gift Aid

Ensure your sponsors sign up for Gift Aid to make their donations go further. For more information visit www.mpssociety.org.uk.

If you need help, advice or inspiration, we are always here to help. Please get in touch with us at fundraising@mpssociety.org.uk or by phone on **0345 389 9901**

► Most importantly - enjoy it!

If you organise an event that you and all the participants will enjoy people are more likely to get involved and support you, and want to do it again!

Sending in your money

When you have completed your fundraising event, there are a number of ways you can pay the money to the MPS Society, all our contact details are given below. The quicker you send in your money, the sooner we can use it to fund our work and the sooner we can send you a thank you for your fundraising!

By credit/debit card

Donate online at www.mpssociety.org.uk or phone us on 0345 389 9901. Please ensure you make it clear how the money was raised.

At a bank

You can pay money directly into our bank account at Barclays Bank, Sort Code: 20-02-06 Account No. 33986306. Please use your name as a reference and let us know that you have paid the money in so that we know to thank you!

By post

Please make cheques payable to the MPS Society. Please don't send cash in the post.

When we receive your money

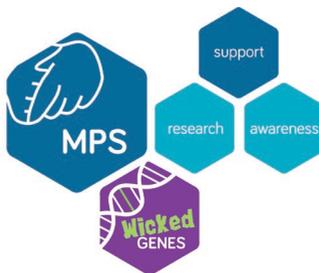
Once we receive your money we will write to say thank you! If you would like a certificate to put up on display please let us know!



Other ways to support the MPS Society

If taking part in a sponsored event or a fundraising activity is not for you, there are plenty of other ways you can help support our work . . .

- ▶ Make a donation – This can be either a one off or regular donation. Setting up a direct debit reduces the amount of administration and allows us to plan for the future.
- ▶ Consider leaving a legacy to the MPS Society in your Will. By remembering us in your Will you can make a real difference, and help us to continue our vital work.
- ▶ Visit our website to purchase from a range of merchandise.
- ▶ Volunteering – We are always looking for volunteers to support our regional events.
- ▶ Tell everyone you know about us and our work to help raise awareness and get more people involved in fundraising.



Society for Mucopolysaccharide Diseases

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Tel: 0345 389 9901 Email: fundraising@mpssociety.org.uk Web: www.mpssociety.org.uk

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Registered as a Charity in Scotland No. SCO41012



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