

40 years



Transforming lives

Celebrating 40 years of the MPS Society

In 2022 we celebrated 40 years of the MPS Society. From its humble beginnings round a kitchen table to an international patient organisation transforming the lives of those with rare diseases, we've achieved so much. In 2022 we took the time to celebrate these achievements and look back over the past. These are the highlights of our celebratory year.



2022



Launch of our 40th Anniversary challenge

As soon as Big Ben chimed, we welcomed in the year jumping into January, by celebrating a remarkable milestone, our 40th year as a rare disease charity. In 1982 Christine Lavery started a journey of hope, founding the Society of Mucopolysaccharide Diseases (MPS Society), to bring people with MPS and related diseases together when there was no other support. To celebrate the extraordinary achievement, we planned a year of celebratory events as well as focusing on something close to our hearts each month. We also chose to celebrate the extraordinary achievements of exceptional individuals by having a fundraiser of the month.

We started our celebratory year by inviting you to take part in the 40th Anniversary Challenge by thinking of a fundraising challenge based on the number 40. We had people challenging themselves by doing 40 sit-ups, walking around their garden 40 times and baking 40 blue cookies. Thank you so much for everyone who got involved and helped to raise £5731.52.

Fundraiser of the month

Kicking off the year for fundraiser of the month was a very remarkable lady, Marina Foster. Marina set up a charity shop 'Marina and Friends' in Bristol in 2003, eight years after her twin granddaughters were diagnosed with MPS IIIA Sanfilippo. She has raised a staggering £250,000 for the MPS Society over the last 20 years in her shop.

[Read Marina's inspirational story](#)



February



Rare Voices

The focus in February was on rare voices, our group for young people aged between 15 and 30 who have regular get togethers and share experiences and knowledge. This month they organised a quiz as part of the 40th celebrations.

[Find out about the Rare Voices](#)

Fundraiser of the month

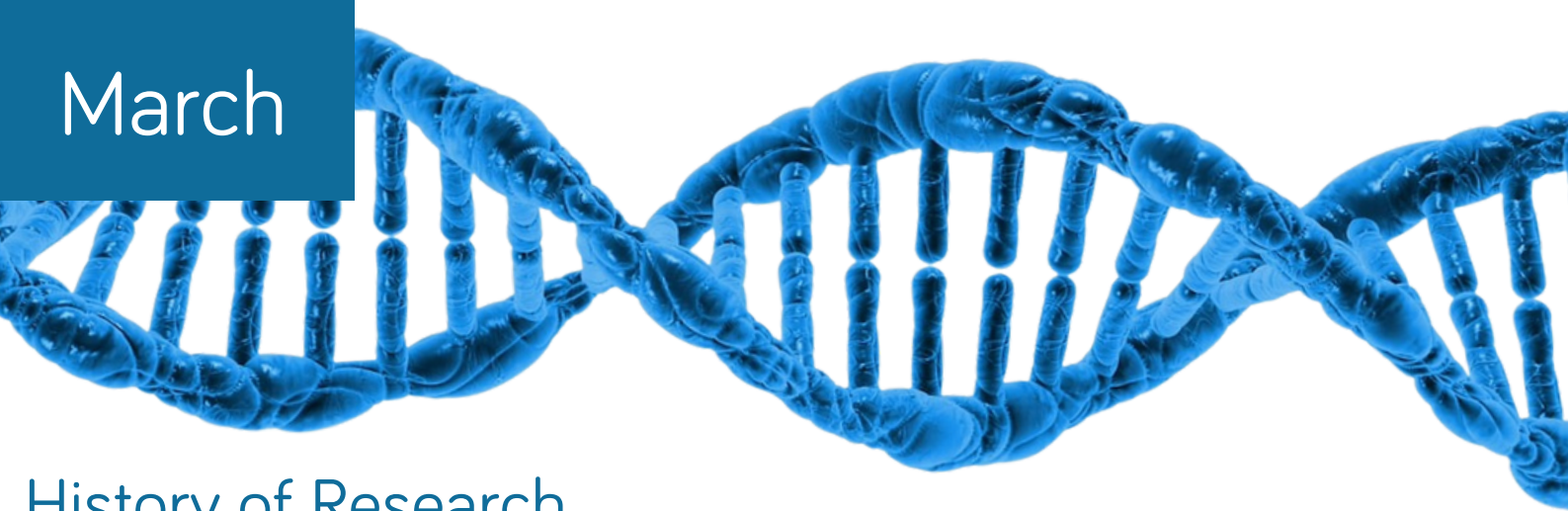
Rolling into February, we celebrated the remarkable achievements of our second fundraiser of the month, Andy. Andy is a dancer with the Towersey Morris men (photo at top of page). The side started to raise money for research into MPS when Andy's son Matthew, who had MPS II Hunter, was a boy - even making him an honorary member, with his own waistcoat and bell pads



Matthew sadly died in 1994 and after this, Andy became a member of the Haddenham Mummers too. Through Andy, the Towersey Morris men and Haddenham Mummers (photo to the left) have raised thousands of pounds for the MPS Society over the past 35 years.

[Read Andy's story](#)

March



History of Research

Our focus in March was research. The MPS Society has funded research into treatments, to one day find a cure, for MPS and related diseases since 1983. Research makes up one of our three pillars, alongside Support and Awareness, stating our most important aims as a charity and commitment to those we work with. This document has been updated for our 40th anniversary to look back at those many and varied research projects that have been funded thanks to the support of our individual fundraisers and donors as well as grants from philanthropic organisations.

[Read our History of Research publication](#)

Fundraiser of the month

In March we celebrated our fundraiser of the month, who were The Hampden Arms. Louise Lucas, owner of the pub in Great Hampden, Bucks has a close connection with the MPS Society and has been fundraising and raising awareness for us for a number of years.



Louise says, "In 2005 I fell pregnant with my first child and gave birth to a healthy daughter Evie. At the same time, the daughter of a couple who lived in Great Hampden had a son who sadly was diagnosed with a disease that comes under the MPS umbrella."

[Read Louise's story](#)

April



Fabry Awareness

We had an action packed April, as our focus of the month was Fabry Awareness Month. Our main aim was to highlight what life is like living with Fabry disease and delve into a world that can often be hidden from society. We had lots in store over the month. We heard from a plethora of guest bloggers, who talked candidly about what it was like to live with Fabry, as well as exploring what the treatment options are. We also highlighted something extremely important for parents/carers to understand, the link between heat intolerance and Fabry disease, giving you tips on how to manage this symptom.

[Find out more about Fabry disease](#)

Fundraiser of the month

Our April fundraiser of the month was Steven Gill. Steven's father, Andrew Gill was diagnosed with Fabry disease later in his adult life, a week before Steven's wedding in 2013, aged 48. Throughout Andrew's life, he experienced many symptoms of the disease, but owing to the varying and sporadic nature of the symptoms it was hard to diagnose him. Steven says, "It is always easier to join up the dots once the equation has been solved, but I suspect Dad, deep down, knew something was wrong."



Steven wanted to do something in honour of his father to raise awareness of Fabry disease, as well as other very rare diseases, so he set himself a challenge to raise vital funds by doing #59events, with a team of amazing people over the course of two years,

[Read Steven's inspirational story](#)

May

MPS Awareness

We marched into May, with a very important week in our calendar, MPS Awareness Week, from 9-15 May. The week started off with us celebrating at the UK House of Commons, with a handful of our members and all the people and companies that make the work we do at MPS Society possible. to celebrate our 40th year!



[Check out our photos here](#)

We also achieved a milestone for our Wear it Blue fundraising campaign which was launched 10 years ago by Katrina Fanneran-Mullins – a clear contender for fundraiser of the month in May.



Fundraiser of the month

We're springing into May with our fundraiser of the month, Katrina, Kevin and their three children - Ethan, who has MPS VI, and his younger siblings Kaitlyn and Cohen.

Ethan and his family have had a huge impact on the MPS Society as ten years ago this May 15th when Ethan's mum Katrina started the Wear Blue Day event, she and Ethan faced their first MPS Awareness Day after Ethan was diagnosed.

This first Wear Blue Day for Ethan event inspired the MPS Society's annual 'Wear It Blue' campaign and has seen the family inspire thousands of people around the world to join them by wearing blue and posting photos to their Facebook event page in honour of Ethan and all those with MPS.



Through their annual Wear Blue Day campaign, and along with numerous physical challenges that both Ethan and his stepdad Kevin have completed, the family have raised an incredible amount of money for us, all told, approximately £40,000.

[Read their amazing story](#)

June



Our members

We jumped into June by focusing on our members who are at the heart of everything we do. We have the privilege of knowing some extraordinary people who don't let their disease define them and throughout June we heard from some of our lovely members.

[Read some inspiring stories from our members here](#)

Fundraiser of the month

In June Anthony Wright was our fundraiser of the month. Anthony's sister-in-law, Katie, was diagnosed with Fabry disease at the age of seven and having seen Katie go through many challenges with her diagnosis, Anthony decided to embark on an epic challenge to fundraise for the MPS Society and to raise awareness of Fabry disease. Read about Katie's remarkable journey and find out about Anthony's fundraising challenge.

[Read Anthony's story](#)



July



Events and get togethers

In July we encouraged you to embrace the return to face-to-face events by organising your own celebration event. From picnics to pamper days and not forgetting our Big Blue Bake Off we loved seeing your ideas. We were also ecstatic to be able to take some members to Legoland in Windsor.

Fundraiser of the month

We kick-started the glorious summer with another fundraiser of the month with the Cooling family. Richard, whose brother Jonathan has MPS III, explained why they fundraise to say thank you.

Five years ago in 2017, Jonathan was diagnosed with the genetic disorder MPS III Sanfilippo. Jonathan, says, “We have become aware of the MPS Society and the amazing work they do during that time.”



“As a thank you for the support they offer, we try to do some form of yearly fundraising event. In 2019 we completed a 100km walk, in 2020 we completed a 100k bike ride and last year we ran a 12-hour football match.”

[Read their inspirational story](#)

August

Support and advocacy

The Support and Advocacy Team are the beating heart of our organisation and have been instilling hope across our special community since 1986. Back then they supported approximately 70 families, giving advice and information and visiting newly diagnosed families.

All these years later, it is Steve who has been handed the baton, to head up the Support and Advocacy Team. We now have six amazing people helping 1,600 people, to overcome the challenges of living with MPS or a related disease.

[Find out about the team](#)



Here for you since
1986 and **always**



Support and Advocacy team





Fundraiser of the month

Elliot Moody is an exceptional individual, who has been an outstanding fundraiser for the MPS Society over the years. Elliot has a strong connection to the MPS Society as his brother Ollie has MPS VI Maroteaux-Lamy.

Elliot says, “To me, I’m not a sibling of an MPS patient – I’m just a sibling, like anyone else, Ollie’s nature commands that, and would never allow me to feel that way.”

[Read Elliot's story](#)



September



Wood of Remembrance and Hope

In September we relaunched the Childhood Wood as the Wood of Remembrance and Hope. This special oak wood commemorates the lives of loved ones lost to MPS, Fabry and related lysosomal diseases. It was first established in 1993 after families chose to mark the tenth anniversary of the MPS Society with the creation of this woodland.

The wood allows others the space and time to come together to reflect, thinking about their loved ones, exploring the vast expanse of the woods, in a peaceful and tranquil setting. Just like our community, the trees that have been planted have grown and blossomed, with hope being at the very roots.

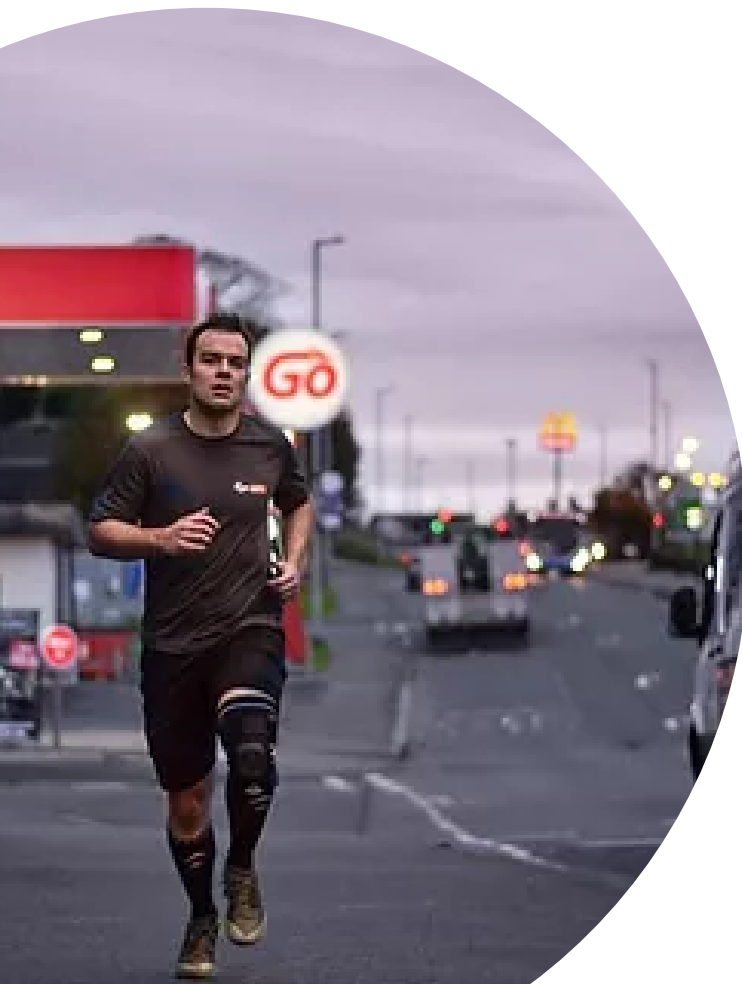
We hope the month was a chance for our lovely community to come together to support each other. Find out more about our grief and bereavements services.

Fundraiser of the month

We're stepping into September with Stephen McCawille, who ran his way into being fundraiser of the month. Stephen's motivation is his brother Shaun.

Stephen says, "My brother Shaun was diagnosed with MPS II Hunter in 1992 and to raise funds in his honour I decided to run the Belfast Marathon in 2011. Then four years later I ran the Dublin Marathon and when Shaun sadly passed away in 2016, I decided to do an annual marathon to help fundraise for the MPS Society."

[Read Stephen's story](#)



October

AGSD US
Association for Gaucher Storage Disease

BDF
Bioscience Development Foundation

CATS
CURE & ACTION FOR SANFILIPPO FOUNDATION

POMPE
SUPPORT NETWORK

mid
SUPPORT ASSOCIATION UK

Gauchers
ASSOCIATION

Krabbe
uk

np
uk

Our special friends

LSD
Collaborative

Our special friends

In October we focused on our special friends. Over the last forty years the MPS Society has been fortunate enough to develop long lasting friendships with people, as well as an array of organisations we collaborate with. Without our special friends we wouldn't be the charity we are now and we are eternally grateful for each and every organisation.

The special friends we highlighted in October included the specialist centres, patient organisations that make up the LSD Collaborative and our international friends, MPS Europe and the International MPS Network.

[Find out about our special friends](#)

Fundraiser of the month



This October we passed the fundraiser of the month trophy to an inspirational individual, Duncan Clarke. When Duncan Clark's niece, Lilia, was diagnosed with MPS III Sanfilippo last June, he set himself a "crazy challenge" of completing 12 marathons in 12 months, to raise funds for the MPS Society. His dedication to helping us carry out our work has made him our 'Fundraiser of the Month' this month!

[Read about his family's reaction to the diagnosis and the support they received.](#)

November

Christine Lavery

As her birthday month we couldn't let November pass without celebrating Christine Lavery MBE, our founder. Christine led a remarkable life and in May 1982 established the MPS Society after her son passed away following a diagnosis of MPS II Hunter disease. Christine started to link up with other MPS families in the UK to offer mutual support and share much needed information. From these very small beginnings, around a kitchen table, the charity was born.



It was an instant success. As Christine said in her very first secretary's report in 1982, "The initial response from families with affected children and the various members of the medical profession has been most enthusiastic, and my postbag grows daily."

Fundraiser of the month

With the clocks turned back it was time to celebrate another exceptional fundraiser and this time we have a family, the Scott family who were fundraisers of the month in November. The Scott family have raised a staggering £50,000 for charity since their daughter Sophia was diagnosed with MPS IIIA (Sanfilippo Syndrome), seven years ago.

[Read the Scott family's story](#)





The Big Give Christmas Challenge

We dived into December focusing on one of our biggest fundraising campaigns, the Big Give Christmas Challenge, to potentially raise a whopping £28k...the most ever raised from this challenge!

Throughout the week we heard some inspirational stories from our community, as well as Victoria, our newest Advocacy and Support officer. We gained an insight into what life is like living with a very rare disease as we understand what barriers some of our members face and the hurdles they have to go over.

[Read their stories](#)

Thank you for your kind generosity



You smashed it

Over £29,000

Thank you



Fundraiser of the month

We finished this year, feeling very merry celebrating our last but not least fundraisers of the month, who are the Brown family. Harvey was diagnosed with MPS IVA Morquio in 2013 and missed the Vimizim trial for treatment, explains his mum Vikki.

They joined the MPS Society campaign for NICE to fund the Enzyme Replacement Therapy (ERT) treatment once the trial had finished, including starting a petition to give Harvey the treatment he needed and were able to collect the 10,000 signatures needed to get the go-ahead for treatment.



Since Harvey's diagnosis the Browns, along with their family and friends have raised over £3,000 for the MPS Society. We'd like to say a huge thank you to this entire family for their ongoing support!

[Read their story](#)



Thank you for being
on our journey with us



Celebrating 40 years of
the MPS Society