

MPS magazine

Society for Mucopolysaccharide Diseases

Autumn 2018 • www.mpsociety.org.uk

A focus on new beginnings

IN THE WORLD OF
MPS, FABRY AND
RELATED DISEASES

'Ask the experts'
holiday tips
inside

Expert meeting

our latest get together for MPS I and
MPS II families and professionals

BACK TO SCHOOL

Photos and advice
from the team

MPS COMMERCIAL

Who they are and
what they do

MPS and related diseases

Mucopolysaccharide (MPS) and related diseases affect 1:25,000 live births in the United Kingdom. One baby born every eight days in the UK is diagnosed with an MPS or related disease.

These multi-organ storage diseases cause progressive physical disability, and in many cases neurological deterioration, and can result in death in childhood.

At present there is no cure for these devastating diseases, only treatment for the symptoms as they arise.

The MPS Society

Founded in 1982, the Society for Mucopolysaccharide Diseases (the MPS Society) is the only national charity specialising in MPS and Related Diseases in the UK, representing and supporting affected children and adults, their families, carers and professionals. We aim to:

- act as a support network for those affected by MPS and related diseases
- promote and support research into MPS and Related Diseases
- bring about more public awareness of MPS and related diseases.

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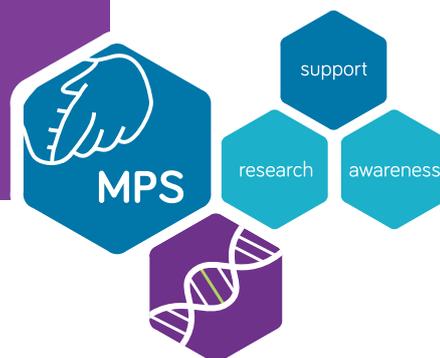
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BACK TO SCHOOL

All your back to school pictures from the autumn term and a guide to what to look for when choosing a new school



EXPERT MEETING
MPS I and MPS II
expert meetings



CHALLENGE YOURSELF
Our sporty fundraisers
continue to amaze

As we look ahead, what matters most? Your views.

A large number of Members and friends of the Society have recently completed an online survey to help guide how we shape the future. We are very grateful to all of you who took the time to give us thoughts. We will be sharing the results, and our plans, at our 2019 Conference in June. Ultimately, we are only successful if we are doing what members want us to do.

Christine's skills, experience and connections are irreplaceable. But working together and drawing more closely on the talents and energy of our members and families, we are sure that we can continue to make a profound difference to our families and all those with MPS and related conditions.

WELCOME

Welcome to this winter edition, the theme of which is "new beginnings". With all that is going on within the charity and in the world of rare diseases, it couldn't be more appropriate.

2018 is a year of transition for the Society. We are using the shock of the loss of Christine Lavery, our CEO, to review all that we do, to learn, and to decide how to shape the charity for the future.

Christine left us with a powerful legacy to build on: an extraordinary reputation and influence within the rare disease community; a business that can help generate income for us at a time when fund raising is increasingly difficult; and a very capable staff team. These give us significant opportunities. In this issue are photos from the new school term, a guide to visiting schools and an article about a new-look international MPS network.

From the Group Chief Executive



Bob Stevens
Group Chief Executive

This is my first report as Group CEO and as I write this I am filled with mixed emotions. The initial shock of losing Christine back in December 2017 has passed and has been replaced by a determination and optimism within Team MPS to carry on her legacy. Yes we are still sad but also immensely proud of what we all achieved under Christine over the last 36 years. The vision going forward will remain the same but the journey will be different and to that end the MPS Society is changing.

Paul Moody has stepped down both as Chair and as a Trustee of the MPS Society. Paul joined as a Trustee alongside me back in 2006 and has been a vital part of the Trustee team for the last 12 years. We all wish Paul and his family all the best in the future. Replacing Paul as Chair is James Garthwaite. James has been involved with the MPS Society since 1996 and after a short absence has returned to the Board of Trustees. The rest of the Board and the staff team believe James is the right person to guide us through this new chapter at the MPS Society.

The world of Fabry, MPS and related diseases is also working more collaboratively. I have recently become co-Chair of the worldwide umbrella organisation for MPS, the International MPS Network (IMPSN). I have also become Vice Chair of the UK LSD Collaborative. It is clear that organisations must work more closely to obtain the best outcomes for the patient communities we all serve.

“ We are still sad but also immensely proud of what we all achieved under Christine over the last 36 years.

Whilst outwardly very little may appear to be changing within Team MPS there is a significant modernisation program underway. In order to ensure the future sustainability of the MPS Society we must invest in new systems and communication methods. Work has begun on a new website and this will go live at our conference next year. The magazine will move to two issues a year, a spring and autumn issue, together with regular email newsletters.

The biggest changes however will be led by you, our key stakeholders. We are undertaking a consultation with everyone who interacts with us to ask for your opinions and hopefully you have all seen and had a chance to fill in the survey. We are hoping to communicate with clinicians, nurses, physios, the pharma industry and with patients and their families in order to develop a new, inclusive plan for the charity that puts our members at the very heart of what we do. Keep your eyes on the magazine for the findings.

Finally I would like to mention next year and the two conferences we are planning. The big difference to previous years is that we're holding a separate Fabry event. You can save the date for the MPS conference on 28–30 June at The Hilton Coventry and will soon be able to book your place. We hope you can join us for workshops, presentations and to share your experiences as MPS families and individuals at a conference with a more intimate feel in 2019.

Although at the moment the MPS Society and MPS commercial are going through a period of change they are all necessary to ensure our future sustainability. On behalf of the team I ask that during this time you not only bear with us but actively assist by being involved in the consultation process. If we all work collaboratively then we will have a modern and stakeholder led charity that reflects the wishes and needs of the community we serve.

Only together can we be the difference between coping and not coping for all individuals, families and support networks dealing with MPS, Fabry and related diseases.

Bob

News from the Board of Trustees

Since the last update from Trustees, there have been a number of developments as the Board has negotiated the inevitable changes that followed the loss of Christine Lavery, Group Chief Executive, last December.

Management

In an emergency meeting in December, the Board appointed Bob Stevens as Group Chief Executive, successor to Christine. Bob was previously Head of Operations.

Board of Trustees

Also in December, the Board appointed David Patton as a Trustee. David is a chartered accountant and his wife and two children have Fabry. He brings valuable skills and insights to the Board and helps ensure that it has representation from across the conditions that the charity is involved with.

In recognition of the particular need for a broad range of skills and experience on the Board following the loss of Christine, two ex-Trustees, Judith Evans and James Garthwaite, were both reappointed to the Board in April.

James has since been appointed Acting-Chair to succeed Paul Moody who will be stepping down from the Board in the Autumn.

Financial management

In June, John Illankovan, the charity's newly appointed Head of Group finance, presented his assessment of the charity's finances. Trustees were impressed with his grasp of the charity and the clarity of his reporting, something that gave considerable confidence at a time of change.

In June, the Trustees approved the charity's financial accounts and decided to pay-off the remaining mortgage on MPS House, the charity's permanent office.

MPS Commercial

Also in June, Gordon Harvey, a business consultant with extensive experience in rare diseases, presented a review of MPS Commercial, the MPS Society's patient access and research business. It highlighted a growing appetite in the rare disease world for the services that MPS Commercial provides and clear opportunities for the business to develop, for the benefit of the charity.

Strategic review

The Board has initiated a strategic review and is drawing upon the views and insights of members, staff, and the wide range of stakeholders that the charity has contact with in order to help shape its future.

GDPR

An extensive programme of work within the charity was approved by Trustees in June. The unusual nature of the charity and its close relationship with its members meant that specialist assistance was required to ensure that the charity is compliant with the new legislation.

Memorial

Trustees were closely involved in the organisation of the memorial service held in April to commemorate Christine Lavery's life and her enormous contribution to the lives of those with MPS diseases. A memorial fund has been launched that is well on the way to reaching its target.

Thank you

The Board wants to record its thanks to the staff team led by Bob Stevens, which has continued to do a remarkable job of supporting families, organising events, raising funds, generating awareness doing all the other things that they do to support the charity's members and help it fulfil its objectives.

WHAT'S ON?

Regional Clinics

Great Ormond Street Hospital

MPS I –
27 November 2018

MPS III –
11 December 2018

Birmingham Children's Hospital

MPSIII –
19 October 2018

MPSVI –
16 November 2018

Mixed clinic –
21 December 2018

Queen Elizabeth Hospital Birmingham

Adult Fabry –
13 November 2018,
11 December 2018

Regional events

Lapland UK

4 December 2018

Northern Ireland Glenarm's family day

8 December 2018

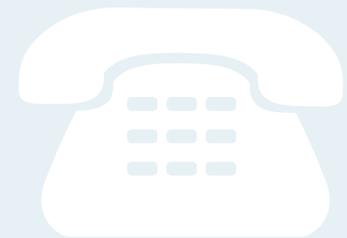
Conferences and expert meetings

15th Annual WORLDSymposium

4-8 February 2019

MPS Society National Conference

28–30 June 2019



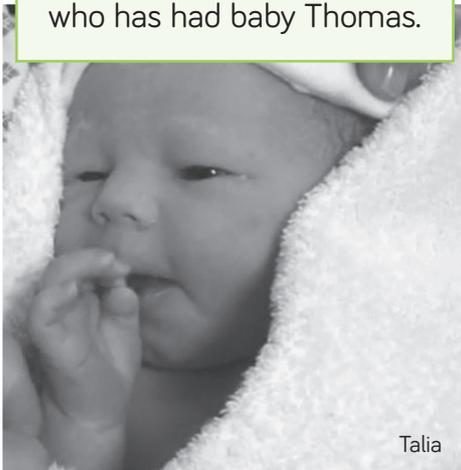
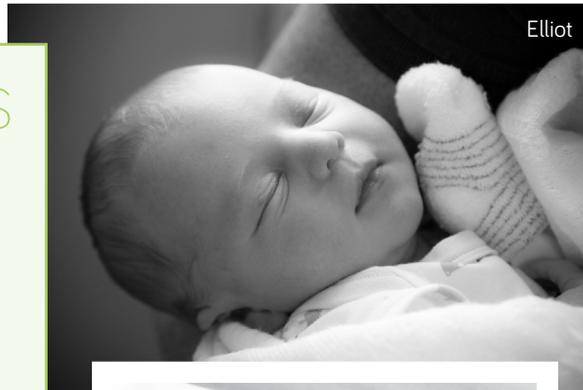
Please let us know if your contact details have changed.

We want to make sure we have your correct phone number, email and postal address so if you've moved house please tell us at:
magazine@mpsociety.org.uk

Announcements

NEW ARRIVALS

We're delighted to announce the arrival of three beautiful babies to the MPS Society team. Congratulations to two of our Trustees who are celebrating recent arrivals, Jessica welcomes Elliot and Daniella welcomes Talia, and in the office we say congratulations to Sam who has had baby Thomas.



Happy birthday to Josh who celebrated his 21st birthday this year. Looks like you had a fantastic time at Gino's Josh.

BEREAVEMENTS

We wish to extend our deepest sympathies to the family and friends of:

Ben Lloyd who had MPS III Sanfilippo and passed away on 1 January 2018 at the age of 20.

Parvash Hasan who had MPS III Sanfilippo and passed away on 21 January 2018 at the age of 16.

Hannah Shannon who had MPS III Sanfilippo and passed away on 13 April 2018 at the age of 16.

Oliver Illingworth who had MPS III Sanfilippo and passed away on 7 May 2018 at the age of 15.

Yusha Ahmed who had MPS I Hurler Scheie and passed away on 11 May 2018 at the age of 3.

Brooke Harvey who had Fucosidosis and passed away on 25 July 2018 at the age of 19.

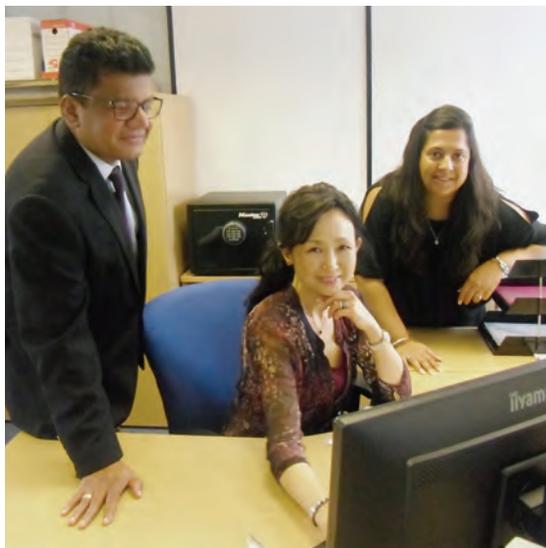
Rajiv Levy who had MPS III Sanfilippo and passed away on 31 July 2018 at the age of 20.

Sophie Clarke who had MPS III Sanfilippo and passed away on 13 August 2018 at the age of 22.

Raymond Wright who had Fabry and passed away on 9 October 2018.

Chair stepping down

Paul Moody is stepping down as Chair of the MPS Society Board of Trustees after nearly two years in the role. Paul has been a Trustee for many years and first became involved with the MPS Society when his son, Ollie, was diagnosed with MPS VI. Paul has been a brilliant Chair and a friendly, approachable face to staff. We want to say thank you very much to Paul for his time and commitment and wish him all the best in the future.



New-look finance department

Our new-look finance team is complete and have been working all together for the last six months. As well as streamlining our financial operations they are also implementing new systems that will allow for better reporting across the charity and for the Board of Trustees.



Welcome to new staff

Jocelyn comes from a background in education where she was a secondary school drama teacher. Her love of theatre remains as she still volunteers at a local theatre. Jocelyn has joined the MPS team as a fundraising administrator so will be answering your fundraising queries and sending your packs and merchandise. Jocelyn is keen to make sure MPS and related diseases get wider awareness with the public as she gets to grips with the various diseases and achieve a clearer understanding of the diseases. When not at the MPS Society Jocelyn will be at home curled up with her cat, Cleo.

NEW MEMBERS

Lynne has recently been in contact with the Society. She and her son, Ashton, and daughter, Corralynn, have Fabry Disease. Ashton, age ten, has recently started ERT. The family live in Ayrshire, Scotland.

Angie and Michael have recently been in contact with the Society. Their son, Lennie, has a diagnosis of MPS I Hurler Disease. Lennie is one year old. The family live in Essex.

Sarah has recently been in contact with the Society. Her son, Rory, has a diagnosis of Hunter Disease. The family live in the Lancashire area.

Rachel has recently been in contact with the Society. Her daughter has diagnosis of the infantile form of Gangliosidosis Disease. The family live in the Essex area.

Mrs Ikhlef has recently been in contact with the MPS Society. Her daughter Nur has a diagnosis of Fucosidosis. Nur is 16 years old. The family live in the London area.

Mrs Sultani has recently been in contact with the MPS Society. Her daughter has a diagnosis of MPS IV Disease. Narges is five years old. The family live in London.

Jackie has recently been in contact with the Society. She has a diagnosis of Fabry Disease. The family live in the South West of England.

Rachel has recently been in contact with the Society. Her daughter has a diagnosis of MPS I Hurler Disease. Evie is three years old. The family live in Wales.

Save the date for the

MPS SOCIETY CONFERENCE

28-30 JUNE 2019

We hope to bring you a something new and different at the next conference. Whatever is organised we know it will be a fun and relaxing time for families, professionals and anyone affected by MPS, Fabry or related diseases.

Advocacy

This issue of the MPS Magazine has a focus on new beginnings and our advocacy team are here to help with anything new or different you are facing. With specialist knowledge in the many diseases under the MPS and Fabry umbrella we can support you through a new diagnosis and what this might mean to you and your family. We can help you with housing adaptations as a new phase of your disease means you have to change the way you live, and we will be there for any transition you go through – from starting school, moving to university or starting a job.

Whatever you need we're here providing a service that's as unique as you are.

Fabry Patient Group Summit Amsterdam 15/16 February 2018

I attended the Fabry Patient Group summit with seventeen other Patient support members in Almere, Amsterdam covering over twelve different countries in Europe. Together with the support of six clinicians from Switzerland, France, Italy and Denmark we explored a range of topics from patient management and monitoring to family testing and disease monitoring.

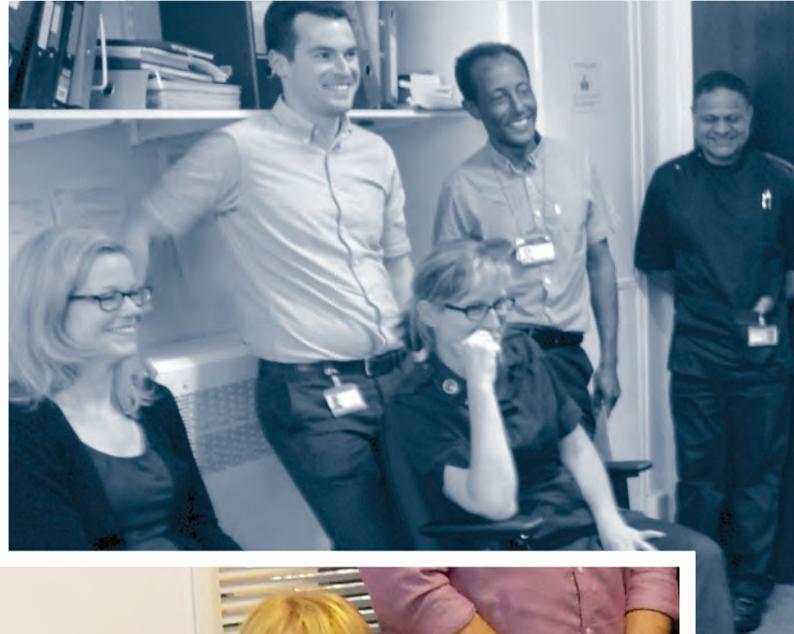
The first afternoon covered topics such as Therapeutic goals in Fabry Disease and FASTEX (Fabry Stabilization Index) which is a mathematical scoring system, which is a way of monitoring the disease to establish the patients stability levels with the disease progression. FASTEX showed a statistical correlation with clinical judgement in about 92% of patients.

The following day we covered subjects such as Evolution of women's diagnosis, care and monitoring in Fabry Disease, How do I talk to my family about Fabry Disease and Disease monitoring in children.

There were a number of breakout groups to establish what support is provided in each country and although some of the European countries have services that are not in the UK, we come out very high up the score for the services that are provided by our specialist centres, and the MPS Society.

A good conference and some interesting ideas to think about improving the support services in the UK.

Rebecca Brandon, Advocacy Support Officer





Nurses from the Queen Elizabeth Hospital Birmingham

The MPS Society is likely viewed differently by every member and every specialist centre that they work with, depending on the nature of the input they have received. Although, I imagine one element stays the same for all centres, and that is that the MPS Society team are viewed as a part of the multidisciplinary team; both within the hospital setting and in the community. As a result the relationship we have is reciprocal. We work together for individual patients and families, and the wider patient community but we also draw upon each other's knowledge bases for advice and support.

It is important to us that the MPS society is visible in our clinics and to our patients so that they know they can access this support independently of us and their care, knowing that we will also link up as and when needed. The Society is mentioned early on in our patients' journeys to encourage this additional input and support through receiving a new diagnosis and helping to support families as a whole.

Within our clinics here in Birmingham, we are fortunate that Rebecca from the MPS society comes to join us. They are busy clinics, as I'm sure is universal, with multiple doctors to see and tests to do, but also present we have a physiotherapist, a welfare advisor, and a psychologist. We aim to have a relaxed waiting area that promotes Rebecca being able to catch up with people and also that our patients can meet each other if they wish.

Here to help

Our advocacy support service is at the core of everything we do at the MPS Society. We know how isolating and challenging it can be living with MPS or a related disease so we want you to know that you are not alone and we are here to help. We are always striving to improve the support we offer and to sure we respond to each individual need as best we can. For help at anytime contact us below or get in touch with someone from the team directly.

For more information on any of the above or if there is anything else that you would like to chat with the advocacy team about please contact us:

 advocacy@mpssociety.org.uk

 0345 389 9901

 [facebook.com/mpssociety](https://www.facebook.com/mpssociety)

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A guide to visiting schools

As the new school year begins so does the open evenings to view potential schools. Your child may be beginning school, moving onto the next stage of education or you might be looking for a more suitable option to meet your child's needs.

Here are a few tips and advice to consider when visiting and choosing a school for your child.

If your child has complex needs or has an EHCP (education, health and care plan) in place you may consider visiting schools within the school day. Open evenings can give an insight, but can be busy and you may not have the opportunity to discuss your child in detail with staff.

Allow plenty of time for a visit and think about whether you would like your child to attend with you. Choose a time when lessons are happening so that you get a true picture of the school, the atmosphere and teaching styles. Also ask if you can meet the staff who would be involved in your child's school day such as class teacher, assistant or SENCO (Special Educational Needs Co-ordinator). Schools are happy to have visitors and will welcome your questions

Looking for a school within the EHC plan process.

If you receive a proposed or draft EHC plan for your child you will be asked which is your preferred school for your child. In order to make an informed decision you may like to visit a few schools before you make this preference.

Before visiting read through the proposed plan and think about what the school will need to do to meet your child's needs and what needs to be put in place. Ask the school how they will meet these points.

Visiting the school

- You may like to go with a friend or relative so that you can discuss the school after the visit.
- Think about how your child would travel to the school. How far is the school? Could transport be provided? Would the transport be free? Does your child require an escort? What arrangements would you need to make to get your child to school?
- Ask to meet the staff who could be involved with your child's education and care.
- If you would like to meet with a specific member of staff, such as the Headteacher, ask for an appointment in advance.

In the classroom

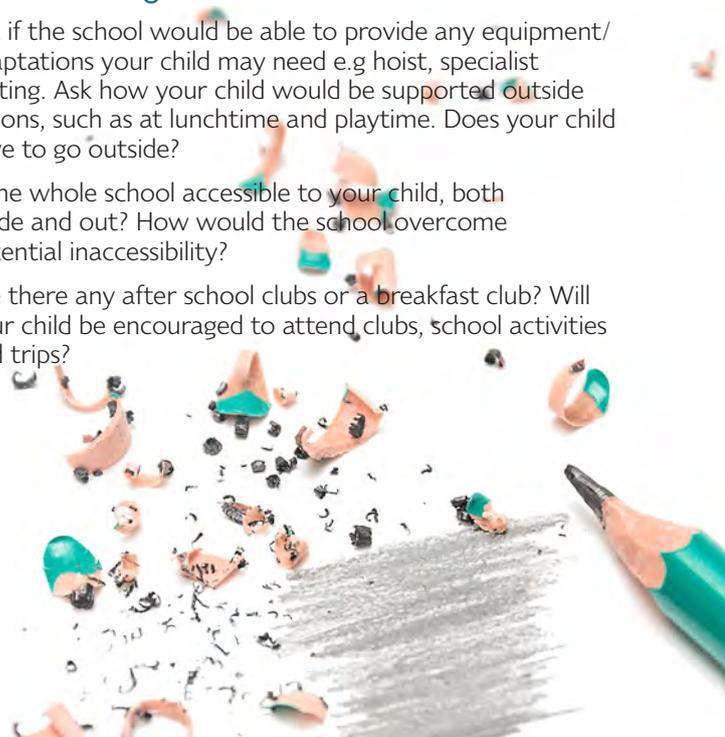
- Ask how the individual needs of each child is met within the classroom.
- How many children are in a class?
- What is the structure of the day? How flexible is this?
- Which adults will work with your child?
- Are there any children in the school with similar needs? Has the school any past experience or knowledge of MPS/ related conditions?
- How would the school maintain your child's independence?
- Does the school offer support for children who struggle to complete homework?
- How is progress measured and how is this shared with parents/carers? How does the school communicate with parents/carers?

Therapy

- Ask which services are placed or visit the school relevant to your child such as
 - Speech and language therapist
 - Occupational therapist
 - Physiotherapist
 - Sensory needs
 - Play therapy
 - Counselling and mentoring
 - Do specialist teachers visit?
- Would the school be happy for the child to receive ERT whilst at school?
- What provision would the school put in place to ensure learning is not missed through accessing therapy and medical appointments?

The school in general

- Ask if the school would be able to provide any equipment/ adaptations your child may need e.g hoist, specialist seating. Ask how your child would be supported outside lessons, such as at lunchtime and playtime. Does your child have to go outside?
- Is the whole school accessible to your child, both inside and out? How would the school overcome potential inaccessibility?
- Are there any after school clubs or a breakfast club? Will your child be encouraged to attend clubs, school activities and trips?





My name is Samantha Downey. I have MPS I Hurler Scheie. The end of the summer is an exciting one as my son started school today. We have spent the last few weeks planning and shopping in preparation for his school arrivals. Huge achievement as a person with MPS I to be able to do all these things with her son.



Here is a picture of Emily on her first day back at school. She is now in year 5 and loves her new class. Emily is learning all about WW2 in history and her current choice of book to read is *The Lion, The Witch and the Wardrobe*. She still very much loves Harry Potter and has read the first three books. She is putting the fourth book on her Christmas list. Emily had also signed up to do netball after school too. She is a very busy girl now.



- What will you need to provide for your child? E.g uniform, stationery, books.
- Look at the range and condition of equipment and furniture.
- What ICT facilities are there?
- Does the school have links with any other schools or units? Is there the opportunity for dual registration or outreach support at a special school?
- Does the school have a school nurse?
- Ask for copies of any policies that interest you such as behaviour, SEN or disability/inclusion (these may be available on the school website).
- Are there opportunities for parents to become involved in the school?

School expectations

- Ask to see the school discipline and anti-bullying policies.
- How does the school manage challenging behaviour? Does this suit your own expectations of your child?
- Do the children look happy and well-behaved?
- Does the school seem welcoming?

You may want to consider your child's individual needs as there might be important points or questions not included here.

You may find it helpful to write the questions down before your visit so that you don't forget to ask. Also, ask for a copy of the school's prospectus as this may include further information and contact details. The school website can provide useful information too.

Additional Support and Information is also available

These organisations can be a useful source of further information:

GOV.UK

www.gov.uk/browse/education

For general education information such as admissions, attendance, special educational needs and transport.

To find local schools in your area:

www.gov.uk/find-school-in-england (this page also gives links to schools in Scotland, Wales and Northern Ireland)

Ofsted

School reports can be downloaded from:

www.ofsted.gov.uk/ofsted-home/inspection-reports

SENDIASS

Local Authorities provide a support service for children with educational needs and disabilities. This is known as SENDIASS (Special Educational Needs and Disabilities Information Advice and Support Service).

They can provide information about processes, rights and services and also support with EHC plan applications and reviews.

If you would like support and advice regarding visiting a school or the education process the MPS Society advocacy support team are happy to help with any queries you may have. The team can be contacted on 0345 389 9901.

Clinics

**GREAT ORMOND STREET
HOSPITAL
MPS III CLINIC
12 DECEMBER 2017**

(1)



**BIRMINGHAM CHILDREN'S
HOSPITAL
MPS II CLINIC
16 MARCH 2018**

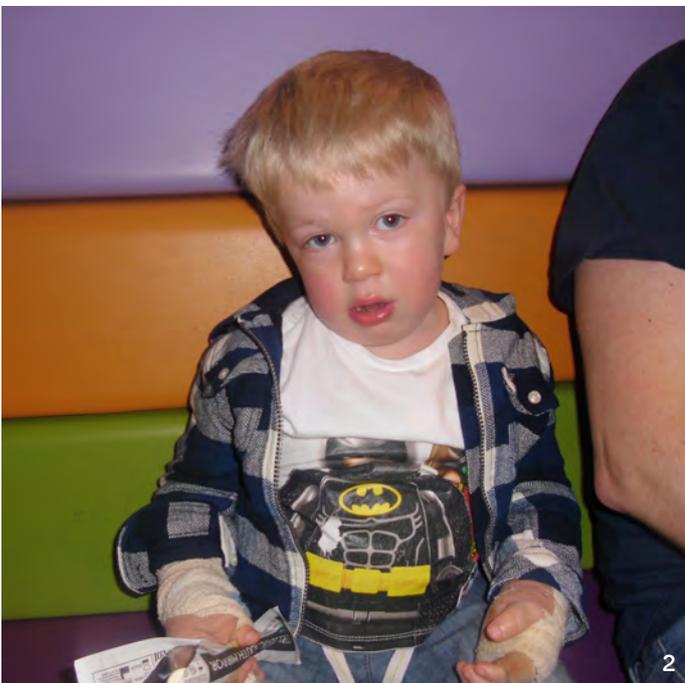
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It was a cold but bright day for the trip to Birmingham. I didn't arrive quite early enough for one family who must have been at clinic at the crack of dawn as I caught them going home at 9am! After that we had a steady flow of the regulars then it was a now you see me, moment with them all, going from one team member to the next, for the dentist, physio, etc

It was lovely to see the families again and some were going to the MPS II expert and patient meeting in April so I would see them there as well.

Thank you to the team for looking after me and I will see you all again soon.

Rebecca

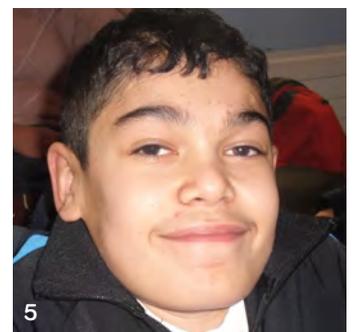


**GREAT ORMOND STREET
HOSPITAL
MPS IV CLINIC
27 MARCH 2018**

(5)

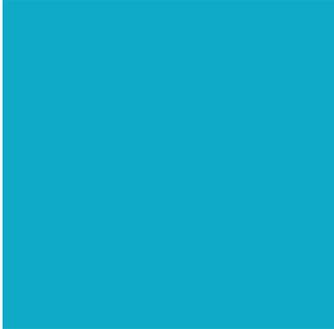
It was good to be introduced to Matilda, the new metabolic nurse at GOSH, and meet with Doctor Davison and Michelle the physiotherapist alongside our wonderful three MPS children.

Debbie

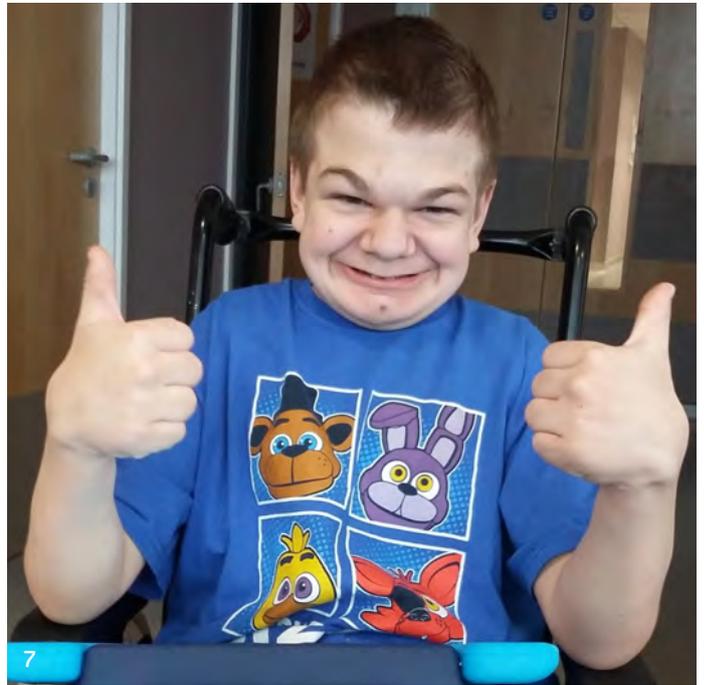


**ROYAL MANCHESTER
CHILDREN'S HOSPITAL
MPS I CLINIC
20 APRIL 2018**

(6)



6



7



8



9

**ROYAL MANCHESTER
CHILDREN'S HOSPITAL
MPS I CLINIC
27 APRIL 2018**

(7-11)



10



11

The boys are always up for a nice picture to be taken for the MPS Magazine and this time was no exception! It's good to hear they are all doing well.

This young lady is usually very shy but at clinic she was persuaded to have a picture taken and share with the MPS community...Hurrah!! As you can see, she has the most beautiful hair and she had lovely plaits in curtesy of her mum!

**GREAT
ORMOND
STREET
HOSPITAL
MPS I
CLINIC
26 JUNE
2018**

(12-13)

The children were in good spirits at the clinic. This lovely girl enjoyed meeting with the other children attending and getting stuck into some colouring! Her mum said she is always cheerful – she certainly has a beautiful smile! This young man attended clinic on his lovely bike! He was well and very chatty as he told me all about his new bike and of course his smart safety hat.



12



13

ROYAL MANCHESTER CHILDREN'S HOSPITAL

13 JULY 2018

POST-HSCT CLINIC

(14-17)

We had photos of all girls at today's clinic – I think they were the ones happy to strike a pose for the autumn issue of the MPS magazine. Everyone was very chatty, on good form and happy to see the other children at the clinic.

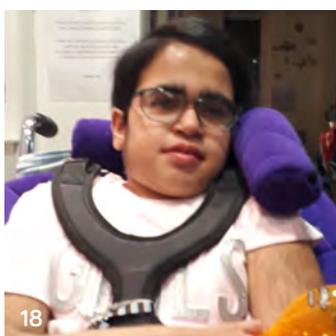


BIRMINGHAM CHILDREN'S HOSPITAL

MPS III CLINIC

20 JULY 2018

(18-20)



It was lovely to see everyone at this clinic. It was great to see families that had older children offering advice and support to families that have just started attending this clinic.

Louise





BIRMINGHAM CHILDREN'S HOSPITAL WATERFALL AUGUST 2018

(21-27)



Well it was an exciting day at clinic as the new rare disease centre at Waterfall House is up and running. It is a lovely airy space with lots of great interactive games for the children and one of the great things is there are windows...strange I should be excited by that but the research centre was like being in a box. There is a lovely sensory room, changing room and lots of toilets and a few chill out rooms away from the main reception area. All the children at the clinic liked the new space and were excited to start using it. The added bonus is the outside space which is confined, unless you are one of the clever ones to find the button to let you out into the main entrance area! Due to the holidays, there were staff shortages and Katherine came back from her annual leave a day early to attend the clinic, what a star... She was joined by Dr Vijay and the rest of the team, and Rosie and Emma were happy, with persuasion, to have a photo in one of the clinic rooms. The children have all had a good summer holidays and the parents especially, are looking forward to them going back to school. Good luck to the team in your new home. *Rebecca*

This was the first LAL D clinic that we have been to in Birmingham in the new centre for rare diseases. It was great to meet some of the LAL D families that I have spoken to by email or by phone. As always it was lovely to catch up with the LAL D families that I have already met. *Louise*



BIRMINGHAM CHILDREN'S HOSPITAL LAL D 10 AUGUST 2018

(28-29)



Your stories



Shirley Jamil explained that she finds it therapeutic to be able to talk about her family and Mucopolipidosis to an audience that understands the isolation of living with a rare disease. “I think I got fed up with just ‘glossing over and hiding away’ the diagnosis and now think it’s important to talk about it and get its name out there and ‘stumbling off’ lips. We won’t find a cure if no one knows about it.”. Here Shirley has once again shared her adventures in the world of Mucopolipidosis and where it has taken her and her family this time.

May 19th 2018, whilst the world watched the Royal Wedding, myself, my youngest son Edward, my sister, brother-in-law and friend all decided to walk up Mount Snowdon in Wales. Packed for all weathers, suncream and sowers and plenty of snacks, we set off early morning. The sun shining; it was a beautiful day for a walk up a mountain. After nearly three gruelling hours walking up 3,560ft, we reached the top of Mount Snowdon to beautiful clear 360 degree views in the sunshine. We did it!! We even had some Royal guest walkers with us!

Meanwhile, back at base camp, Sam, his dad – Shamim, aunt and two pesky younger cousins entertained themselves. Shamim pushed Sam in his wheelchair to and from the beach, carried him in and out of the swimming pools, and carried Sam up and down two flights of stairs twice! The TV in our groundfloor chalet didn’t work. Aunties did, but she was up two flights of stairs. Once to watch the Royal wedding, and more importantly, to watch the Cup final – but they don’t mention that game now!

“ I think I got fed up with just ‘glossing over and hiding away’ the diagnosis and now think it’s important to talk about it and get its name out there and ‘stumbling off’ lips. We won’t find a cure if no one knows about it.

At the end of the day, Sam laid his head on dad’s shoulder and said ‘I like you’. Coming from a 15 year old teenage boy to his dad – I think at that moment, Shamim felt he was on top of the world – never mind Snowdon!

Our aim was to raise awareness for Mucopolipidosis for my eldest son Sam. We were also raising funds to try and help our family of four to be able to attend the ISMRD conference in Atlanta USA in July 2019.

We set up [Gofundme.com/5eoko1s](https://www.gofundme.com/5eoko1s) in hope of doing various events over the next year to help raise funds and Mucopolipidosis awareness.

We chose to wear MPS and ISMRD t shirts on our walk as both charities help our family greatly.

MPS help us with our day to day requirements including advice and help on education and advocacy queries which can be a mine field if you don’t know where to turn. Plus the fun days out and pantomimes. Rebecca is always at the end of a phone or email when we need her.

www.ISMRD.org help us join together with people all over the world who suffer from Mucopolipidosis, Alpha/ Beta Mannosidosis, Sialidosis, Fucosidosis, Galactosialidosis, Aspartylglucosaminuria and Schindler Disease. In England, those affected with the conditions mentioned are very few and it’s hard for us to connect with families with Mucopolipidosis. www.ISMRD.org connect worldwide with these rare diseases and provide a platform where we can all discuss our experiences, hopes, fears and news of medical research and advancement in other countries.

We have been to previous ISMRD conferences in St Louis and Rome. Just being able to talk to their friends without having to explain ‘what is wrong’ with them. For parents, to be able to share experiences and not have other adults stare pitifully at you and your child. We’re all on a level playing field from the start.

Sam quietly takes a lot in from listening to his friends and their families discuss their condition and what they do to ease the symptoms. At the end of the day, he’ll ask us questions. Questions no child his age should be asking, but he’s growing up and wants to understand what is happening to his body and why.

So, as well as fulfilling a lifelong desire to climb a mountain, we raised lots of money to try and enable us to attend the ISMRD conference in Atlanta 2019, plus money for research in to a cure for Mucopolipidosis. We’ll keep you informed of our adventures. ‘Onwards and upwards’!



Mum

Christine's son, Andrew, shares his words and thoughts about his mum and all she worked to achieve in her life.

What an honour it is for me to be able to share with you some of my thoughts and feelings of my mother within a publication she first began publishing over 35 years ago when MPS was little known by healthcare professionals almost anywhere.

I am Andrew, Christine Lavery's eldest son and brother of Simon Lavery, my older brother, who passed away in 1982 at the age of seven from Hunters Disease, when I was just four years old. I have lived through a life of MPS and I have absolute respect for the wonderful community that has been built by families coming together through hardship and tragedy spanning three decades, but emerging from the other side of their experience, stronger and most certainly 'supported' and not forgotten.

Many of you will know Christine Lavery as your friend or colleague, or indeed both. I know for sure that my mum would certainly categorise many that crossed her path as 'friends' and I know full well that every individual's contact with mum, especially on a professional basis, was highly personal and in confidence.

Thank you to all who were able to attend the most finely organised and wonderful memorial service in memory of Christine Lavery on 13th April 2018 to say your own goodbyes to your friend Christine.

We all have our own way of remembering our lost loved ones when they pass and this for all of us is a personal journey that takes time, love, support and positive reflection. That day was a day of positive reflection and with so many iconic speakers, the day affirmed that Christine has, without a doubt, left a legacy of medical growth that will continue to save many many lives and protect and inform many many families for ever more.

Not least, thank you so so much to all at Kings Church who graciously gave their wonderful new church as a fitting venue for the memorial service.

Early days background

I want to just touch on some of mum's early years in the world of rare diseases and the founding of the MPS Society.

Now, some of you that remember me as a toddler or remember my brother Simon before he passed in 1982 will also remember the society being based out of the front first floor bedroom of 30 Westwood Drive in Little Chalfont... coffee mornings, family data being recorded on simple index cards and a map of the UK with coloured pins to denote sufferers locations and their condition, as well as the regular MPS camping holidays...as my mum and dad LOVED a tent!

But...

Before that, before the founding of MPS Society, like many parents around the world, mum and dad were struggling with their first son, my brother, Simon. (Simon, whose clawed hands – a symptom of Hunters Disease remains the logo of the Society to this day.)

Now, mum was sure that Simon did not have the same cognitive skills as other babies and toddlers, and at the time, even with her limited medical nursing knowledge questioned Simon's health to doctors, hell bent on getting to the bottom of why Simon looked and acted differently from most. Simon was diagnosed with Hunters Disease, one of the disorders within the Mucopolysaccharide umbrella and from there on Christine sought to gain more information on MPS but also to connect with other families (if there were any).

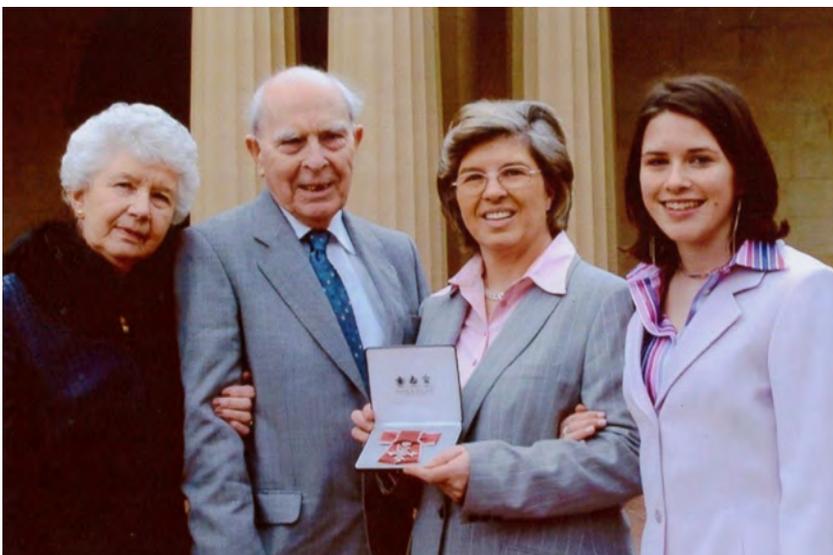
Of course there were! MPS had been around for at least 80 years before the founding of the Society. So...there mum went! On the off...with her coffee mornings, fundraising, her maps and her pins, finding new families and new diseases, conferences, making newsletters, etc.

But crucially; with several large doses of "NO, is not an acceptable answer", especially when dealing with the bureaucracy of the

NHS and indeed ANY Secretary of State for Health. Christine did not have a filter on how high to take a complaint, especially in the interests of MPS and many of you drawn to reading this article will have been on the sidelines for one or more of her battles for medical fairness and justice, for a patient, family member or child of your own, and without a doubt this unwavering persistence of Christine to seek and achieve the best outcome remained her life blood until the very end.

Publication

In 1988 Christine worked full time at Contact a Family (CaF) in Victoria Street London, alongside building the MPS Society. My dad Robin also worked around the corner at the Department of Trade and Industry and I can only imagine their shared trips home together on the London Underground more than likely, regularly and dominantly involved plenty of chat on Christine's pursuit of further medical knowledge for the benefit of MPS. Christine's time at CaF was intrinsic to her broad medical knowledge as time went on. The Contact A Family Directory of Specific Conditions and Rare Syndromes was published in 1991 and endorsed by HRH the Princess Royal, Princess Anne. The directory filled a much needed gap by putting together in one publication, full descriptions of over 200 conditions. Parents looking after children with special needs or disabilities often feel isolated and have an urgent need to talk to others in a similar situation. The directory gave both the carer and the medical professional regularly updated,



“ I can not say with any more passion how highly she used to speak of her own colleagues in the MPS office, her advisors and her trustees.

thorough but concise information on each condition. Each entry contains a short medical description of the condition together with details of inheritance patterns and pre-natal diagnosis, followed by details of the related support networks; their activities, publications; and what they offer to families. The remarkable late Dr Ed Wraith and Dr Michael Patton were close medical advisers to the directory, and amongst other consultants and scientists support worldwide, with such support from Ed at the Manchester Children's Hospital – which is a regular home for many MPS children and Michael, a former consultant clinical geneticist at St Georges Hospital Medical School, Christine had undoubtedly the finest network and support of rare disease consultants in the world.

MPS grew worldwide and with this growth an influx of greater knowledge, funding for research and more informed families, carers and more punctual diagnoses for sufferers.

Abortion Bill

Christine wanted more children after Simon but did not want to see abortion as a typical option and so as science was progressing so were tests for early detection - the Amniocentesis. In 1978 mum through her clinicians had the amniotic fluid of me sent off to Maryland in the US in order to trial the groundbreaking 'Amniocentesis'. From there forward it became a regular medical process for pregnant women in the UK. I can't have imagined mums delight to find me to be a healthy baby, and then Ben too.....but it didn't stop there.... Many diseases have an

inheritance pattern and it was not genetically relevant to male donor genes within MPS II, however when my sister, the third healthy baby, Lucy, now was born and with my mums now substantial knowledge of MPS, as the founder and director she would have been very anxious that Lucy was a carrier but indeed in due course through mums diligence, the relief must have been overwhelming when it was confirmed that Lucy was not a carrier of MPS. Christine took her fight to Parliament iconically to lobby for changes to the abortion legislation with a Pro-Life view but to assist in options for child termination for mothers carrying a genetically impaired phetous. Christine's lobbying continued and her influence became pivotal to driving relevant legislation around rare diseases medical research and pharmaceuticals, not just in the

UK, but overseas. Christine's passion for information growth and change was evident from an early point.

Christine's confidence to take on 'everything' nurtured a wonderful rare diseases medical family and continuous pharmaceutical and research business all over the world. I cannot say with any more passion how highly she used to speak of her own colleagues in the MPS office, her advisors and her trustees.



We all know how much of a planner she was and she has left the charity and the business worldwide finely tuned for continued growth into the future and beyond. Christine had

so much passion and time for Fabry, her worldwide network and certainly the Japanese colleagues from where her young motherhood began.

Mum was so enthralled with the progress of the awareness of Lysosomal Storage Disease alongside Biomarin, Genzyme and many other groups. Close to her heart was the venture of MPS Commercial which runs alongside the charity but helps support the charity that she helped found, but fantastically they both support each other, to ensure financially both will be, and are successful. Mum's planning knew no bounds. Wouldn't the world be a very organised and a very kind place if we all had the vision and planning of Christine Lavery?

Awards

Christine was awarded the Member of the British Empire for her services to Metabolic diseases by the Queen in the New Year's Honours List for 2002 and this was to accompany my father's OBE presented in 1997 by the Queen at Buckingham Palace.

Notably, mum and dad were so pleased as they had both achieved their Gold Duke of Edinburgh's Awards which were also presented at the palace, and this for both of them demonstrated their own immense love for each other and the family, compatible like minds and their unwavering devotion to their causes and each other. For the gongs were not a statement of self admiration; in fact, I remember them both feeling very uneasy, not to have the suffix be shown on letterheads or the front of envelopes as humbly they both omitted these suffixes as often as they possibly could...on the other hand...Christine was strategic in owning her award as a sure fire way of getting desired results for the greater good and I think this award did go some way to assisting further growth of medical science, 'from tiny acorns, great oak trees grow'.

At the 2006 International Symposium on Mucopolysaccharide and Related Diseases Christine received 'A Life Time Award' from the International MPS Community.

Our family are so very proud of her achievements but we also recognise that these have been accomplished through mum's connection with every soul she crossed. Thank you.

Home life

I have had the luxury of living with my mum Christine for the last two years, in fact, the first week I arrived at mum's door I escorted her to the Chiltern Hospital in Great Missenden,

to go through the process of what eventually was her Myeloma Cancer diagnosis. Mum did so well through her therapy and I was so proud of her as I know we all were. Does it surprise you that she would routinely be going through chemotherapy, in a hospital bed in central London, and on two mobile phones and laptop...business as usual?! How remarkable hey! The people requiring her input and attention were never not in her thoughts.

Mum's life with dad was a good one. In fact, not just good, but I would blueprint it as an example to what many of us miss in life. They worked hard and they played very hard. They did both enjoy life and they travelled well. After dad's passing mum had 10 years where she simply continued to work and she enjoyed her travels and meeting all of you, still, despite her grief. Mum missed dad so much and her house was adorned with pictures of robin red breast birds, symbolic of Dad; but without Dad or any other, life at home took her into other hobbies, such as the family tree where she would nightly meticulously research people and names and apply for great numbers of birth, death and marriage certificates to corroborate her findings. When she had time or if she found herself local to a site connected to the family tree, she may ponder on the grave of a long lost relative from 1700s and before. Mum thrived on taking her wonderful parents out on walks with her brother Terry, often in the Alps on low level walks as well as closer to home, in the Lake District. Mum was also very content in her own company although she was never too far from a phone...and she loved meeting any of you, being with you, helping you, planning with you...travelling with you!

Mum enjoyed being a grandmother to my boys, Keegan and Jacob, but I do know how enthralled and proud she was at the birth of my brother Ben's and his wonderful wife Hannah's new baby Arthur. Mum was a great sister to my uncle, her brother Terry and I can't imagine how proud her parents, my grandparents Kenneth and Pamela are of all she has achieved, although I do know how very proud of them she was.

Closure

Christine has selflessly left a legacy and a love that will remain ongoing in the interests of society. Christine had a way of protecting and understanding families through the good and through the tough times. I want to pay tribute to her kindness and forethought. Mum was just the spark for the future of understanding and progressing cures for rare diseases and there will now be no end to the fire that progresses the science and medical research in our lifetimes. Sadly mum's spark has run out but she left a respectably tight ship and a mentored group of professionals to lead her vision without her guidance and she would be wishing you all the best of success.

Christine would want us all to remember all the good times we shared with her.

You will live in our hearts and our memory forever.

Andrew Lavery

Information & resources

Encouraging Independence in LSD ERT Homecare

In England and Wales ERT is provided for Lysosomal Storage Disorder (LSD) patients in a way that isn't available in other countries – even America. We encourage all our patients to have their infusions at home, supported by well trained nurses from a Homecare Provider (Healthcare at Home, Lloyds Pharmacy Clinical Homecare or Pharmaxo). There are now almost a thousand patients with an LSD getting treatment safely at home and there are 20-30 new patients every year.

While this is an amazing achievement you will all be aware that the NHS has struggled to get new treatments for LSDs into routine use. The simple reason for this is that there isn't enough money to support all the new drugs that the NHS wants to use, and LSDs are now considered for funding alongside treatments for muscular dystrophy, renal transplants and cancer. With very small numbers of patients, it can sometimes be very difficult to make the case for funding, especially when we offer home infusions (which also have a cost) at the same time.

A group of patient representatives through the LSD collaborative and healthcare professionals (including nurses, pharmacists and doctors) have been working together for the last five years to make sure that home treatment of LSD ERT continues to be high quality and value for money. In 2013, 160 different homecare services were whittled down into one overall package (the "framework"). This continues to offer excellent care for you and you continue to tell us how much you value the freedom and convenience this framework offers you. While prices have gone up, it has enabled the NHS to reduce homecare spending from £10m per year, to only £7m. It's also helped the NHS to encourage another homecare provider into the market which means that you have more choice, and the NHS is less likely to see events like the failure of Medco happen in the future

About 70% of patients still have a regular nurse visit every week for their infusion. While this is important to many of you, we regularly get requests for weekend or evening infusions in our clinics because you all want your illness to disrupt your lives as little as possible. We have difficulty helping with these requests because there are fewer nurses available in the evenings and at weekends. However, there is a way that we can facilitate infusions,

at a time to suit you and this is through what we call "reduced support infusions."

With reduced support infusions, you can opt to have a nurse help you access your "port" or help you get a needle into a vein, or help you make up the infusion or even both. The nurse will then make sure that everything's okay and leave you to infuse your ERT yourself. Over time, some patients and carers become happy to cannulate and prepare the ERT themselves, and they don't need a nurse visit at all.

We want to start encouraging ERT patients to think about this, because it's important that we encourage patients with chronic diseases to become more independent. LSDs are now much more common than we previously thought and as a group may not be considered "rare" diseases for very much longer. People with other complicated treatments – parenteral nutrition or immunoglobulin infusions – have no choice but to learn to infuse themselves after a short period of training in order to help them normalise their conditions. We don't want to ever be in that position, but it's important to learn from these services, and support patients to become more independent.

To support this, we're proposing to introduce a new initiative to LSD centres. We're going to train all LSD nurses (in LSD centres and in homecare companies) in motivational coaching techniques to help patients old and new to think about reduced support infusions. We'll ask patients to complete a "Patient Activation" questionnaire every three months which will help us and you see when you're ready to try reduced support infusions. We have also developed a training programme that will take interested patients from full nursing support to reduced support infusions over a twelve-month period.

All newly diagnosed patients will go onto this initiative from the start of homecare, and nurses and doctors will discuss the options with all existing patients at their next annual review appointment. Please don't worry – the very first steps of the initiative are to identify those patients who want to do it. There is no intention to remove funding from patients on homecare. The NHS will continue to pay for homecare for all patients for the time being. Where patients become unwell or individual

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Ask the experts

circumstances change our Homecare partners will be ready to provide full nursing support again when you need it.

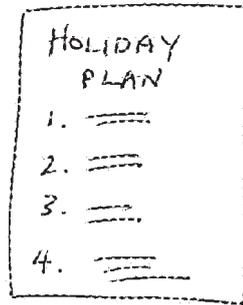
Your homecare nurses and Clinical Nurse Specialists will start talking to you about this initiative in the next few months, and we'll be providing information to help you make informed choices. No one will be forced to do something that they don't want to do. In the coming months you'll also start seeing stories from ERT patients about their experience of reduced support infusions

This initiative has been developed to help NHS LSD ERT services be more resilient to issues in the homecare market, to help homecare services develop more capacity for more new patients, and to help you make sure that your disease doesn't affect your life any more than it needs to do. With reduced infusion support you can have infusions on your terms, at a time that suits you with the right amount of help that you need.



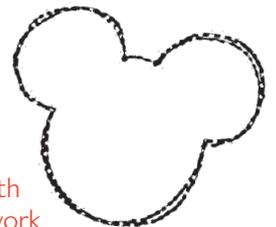
What holidays would you recommend for individuals or families who are disabled? What's worked for you?

The best holiday advice I can offer is always plan in advance. Ensure travel insurance companies cover you and make them aware in every detail the nature of how MPS affects you. This removes the possibility of the insurer turning down your claim if you need to make one. If using powered medical equipment including wheelchairs make sure they can be charged in the country you are visiting. Like the UK, places around the world have varying levels of disability access, be it transportation, accommodation and attractions. Travel arrangement companies should be able to link customers to a tourist office who will be able to advise on what's available in the destination you want to go. The country tourist board will have info regarding accessible networks and organisation who may be able to offer support.



Disneyland Paris. We stayed at the Sequoia Lodge in a golden forest room for disabled. They were so kind and couldn't do enough to help. The only thing I would say is the park does need proper changing rooms for disabled. But they are so helpful in the park with the rides and if you go to city hall they give you a card so you can go on rides without the queues.

Personally the best place I have been is Orlando Florida. The theme parks and other visitor attractions have really good access and help for people with disabilities. The public transport network is also really good.

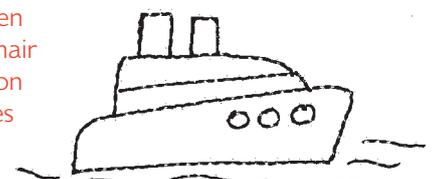
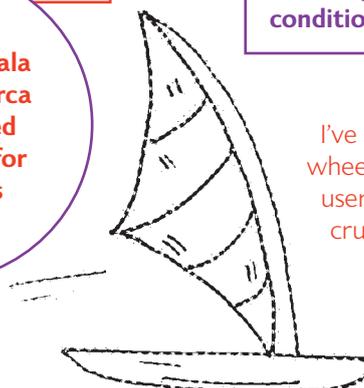


Neilson holidays are perfect for active Fabry sufferers who miss out on warm European destinations. Lots of water-cooled fun...sailing, kayaking, paddle boarding, windsurfing, etc. Lovely air conditioned hotels. Fab.

Majorca! Less than 2.5 hours on a plane and a beautiful Island! Win win! TUI family life holidays are great for the whole family. The TUI team are amazing we have been on 3 different family life hols now and never been disappointed!

We went to Cala Millor in Majorca - lots of paved areas - great for wheelchairs

I've seen wheelchair users on cruises



International

New beginnings for the international MPS network

Meeting in San Diego at the 15th International Symposium on MPS and related diseases, over 20 of the 40 patient organisations that form the International MPS Network (IMPSN) came together to breathe new life into the group. The aim of the meeting was to put a plan in place to reinvigorate the international offering for all patient organisations supporting MPS and related diseases. A collaborative and bold decision was made, for the first time, to have a Board that speaks for all continents. While this has not yet been fully achieved there is a renewed sense of optimism that all countries will be equally represented in the future. The newly formed Board, now affectionately known as the magnificent eight, is represented by USA, Brazil, Canada, New Zealand, Australia, Malaysia, Europe and the UK and was formalised with Terri Klein (US) and Bob Stevens (UK) taking on roles of joint Chair and Jenny Noble (New Zealand) voted in as vice chair.

On his return to the UK, Bob Stevens, Group Chief Executive of MPS Society said:

“I have been given the privilege of being elected joint Chair of the International MPS Network. Together with the new Board we have a chance to bring the world together in the name of MPS and related diseases.”

He added:

“The newly established Board is committed to bringing the world of MPS, a world of many voices, into the IMPSN with one joint vision. Only by doing this can we truly combat the ever increasing hurdles and access to new treatments and therapies.”



Photo (from left to right): Terri Klein (USA), Amira Awada (Brazil), Kim Angel (Canada), Jenny Noble (New Zealand), Maria Jolditz (MPS Europe), Bob Stevens (UK), Lee Sing (Malaysia), Vanessa Ede-Scott (Australia)

“ The newly established Board is committed to bringing the world of MPS, a world of many voices, into the IMPSN with one joint vision.

International MPS III (Sanfilippo) survey

We would like to thank everyone who took part in our MPS III survey. We have been working hard to bring together the results from the 13 countries that took part and the 149 families that completed the survey.

Plans are underway to publish the information we gathered and we will keep you updated on our progress with this.

Events

MPS I and MPS II Expert Meeting

The MPS I and MPS II Expert Meetings were held in Northampton on 28th and 29th April 2018. With a range of speakers, professionals and patients, the weekend was a unique opportunity to understand more about these diseases and a chance for families and professionals to meet together to share their experiences and knowledge.

“Very informative, great opportunity to meet other families, up to date and relevant.”

“ Less focus on a sad future, and more focus of positive outcomes, treatments, adult transition and thinking and feeling positive.”

“A fantastic opportunity to meet other families.”



“ Very informative,
great opportunity to
meet other families, up
to date and relevant



MPS Commercial – Have you ever heard of us?

In a recent survey we learned that three-quarters of you had never heard of MPS Commercial. Here we give you a bit of an insight into who we are and what we do. We will also tell you a bit about the services we offer and how you, as a member of the MPS Society, can benefit from the work that we do.

Let's get started

Our official blurb is 'MPS Commercial is a wholly owned, not for profit subsidiary of the Society for Mucopolysaccharide Diseases (MPS Society, UK) whose social objectives are to reinvest any profits for the purposes of education, enhancing needs-led advocacy support, quality of life (QoL) research and scientific research to the MPS community'.

In simpler terms, we are the business arm of the MPS Society. We are paid to provide a range of services (see **What we do**), but unlike other commercial organisations, the profits that we make do not go to any shareholders, but instead are given back to the MPS Society.

So, how does MPS Commercial support the work of the MPS Society?

- MPS Commercial is a business
- The services we provide help those affected by MPS, Fabry and related diseases
- We provide income for the MPS Society

Support for those on clinical trials

- Booking travel and accommodation
- Helping with relocation
- Paying expenses

Patient focussed research

- Reporting the effects of disease on individuals and their families
- Communicating the challenges of diagnosis

Access to treatment

- Supporting those on the MPS IVA Managed Access Agreement
- Collecting data to support the final decision on access to treatment

Any profit goes to support the work of the MPS Society

What we do

There are four arms to MPS Commercial:

Clinical Trial Logistics

If you have ever taken part in a clinical trial you may have been looked after by our Clinical Trial Logistics team. They organise travel and accommodation for trial visits and arrange payment for any out of pocket expenses that you may incur to attend a study visit.

Managed Access Agreement

We help individuals to stay on elosulfase alfa (Vimizim) treatment by collecting information on pain, mental health and day-to-day activities.

Research

You may have heard from us inviting you to take part in one of our surveys but did you know how important this type of research is?

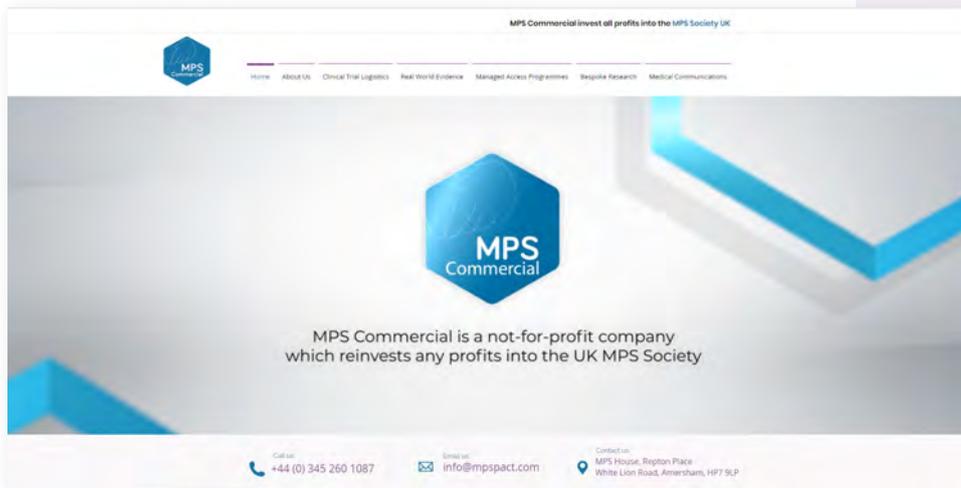
The information they generate can help doctors recognise the early signs of MPS, and understand how the diseases affect children and adults over time. It can also help with the design of clinical trials and support decisions to make new treatments available on the NHS.

Communications

We publish the results of our research studies at scientific/ medical meetings and in journals. This means that the work we do is seen by the wider MPS and related diseases community, their doctors and patient organisations around the world.

We also work with Pharmaceutical companies to help them develop information for people receiving their treatments.

MPS Commercial are pleased to announce their new website



We would really love it if you visited our new website to learn about all the services we offer at www.mpscommercial.com. If you have any questions, feel free to contact us, either through the website or on: Email: info@mpsact.com | Telephone: + 44 (0) 345 260 1087



My name is Tom Kenny, I started working at MPS commercial in September 2018.

I am a public health doctor and after working for a short time in general practice I have spent the largest part of my career working for the NHS design, planning, funding and monitoring services

for rare and very rare disease. I am delighted to be working for MPS commercial and helping them to streamline and simplify their ways of working. MPS commercial is part of the MPS Society that provides services especially logistics for complex clinical trials, patient focused research, support for Managed Access programmes and medical communication so there is a huge potential to benefit large numbers of patients in ways that bring together charitable aim and the needs of commercial organisations such as pharmaceutical companies.

I am a dad of two boys one of whom uses a wheelchair, because of my experiences I have a tendency to get passionate when I see health services failing to understand the needs of individuals. I love being active and can often be spotted cycling my Brompton bicycle between meetings in central London.



My name is Sarah and I joined MPS Commercial in August 2018 as a Clinical Trials & Patient Access Officer. My background includes working within the healthcare sector, more recently working directly with patients through the NHS, providing them with support, information & guidance on a range of concerns. I am truly inspired by my current

team, who I see go above and beyond every day to make sure all of our patients across the globe have the smoothest possible journey attending each of their clinical trial visits. Ensuring our patients have the best possible access to their trials is pivotal. I am eager to fully get to grips with my role and to understand what it means for our patients & families to live with MPS and Lysosomal storage diseases, as well as learning about the different types of MPS and the impact they each have. Outside of work my interests include music, playing the piano and kicking some ass in martial arts!

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Board of Directors

Chair: Bob Stevens

Board: Derek Beards, David Patterson

MPS Commercial is a Private Limited Company Registered No. 08621283.

MPS Commercial trades as Patient Access to Clinical Trials (MPS PACT), and is a wholly owned, not for profit subsidiary of the Society for Mucopolysaccharide Diseases (the MPS Society), Registered Charity in England and Wales No. 1143472.

MPS Commercial's social objectives are to reinvest any profits for the purposes of education, enhancing needs-led advocacy support, quality of life research and scientific research to the MPS community.

**You can now reach MPS Commercial on their own dedicated number:
0345 260 1087**

Supporting the MPS Society

As the non-profit subsidiary of the MPS Society, we are proud of the contribution we are able to make to the work of the charity.



The evolution of MPS Commercial

Reimbursement

The MPS Society's Advocacy team originally provided support for patients/families taking part in clinical trials. This service came about as families were struggling to receive payment for the out of pocket expenses they had paid to attend clinical trial appointments.

Christine Lavery worked closely with Sponsors to develop 'reimbursement policies' to ensure that patients/families were paid for the amount they were due.

PACT - 2012

The existing trial in the UK extended to include patients from Europe.

Managed Access Agreement - 2015

We were given the responsibility of collecting quality of life information* from individuals on the elosulfase alfa (Vimizim) managed access agreement.

* Pain, mental health, mobility, and activities of daily living (eating, personal care etc.)

Communications - 2016

We received 'Best Poster' award for our publication on the elosulfase alfa (Vimizim) MAA, at the 2016 International MPS Symposium, Bonn, Germany

Managed Access Agreement - 2018

We currently collect quality of life data, from 61 individuals on treatment

Two years and 9 months into the 5-year programme
779 individual appointments
1285 questionnaires completed
Only 2 missed*
99.8% completion rate

Completed 2-year review meeting (March 2018);
next review meeting (November 2018)

Collect additional patient reported outcomes data

*Respondent repeatedly failed to answer calls/respond to messages at one time point

Patient Access to Clinical Trials (PACT) - 2011

The first dedicated member of staff to oversee reimbursement and clinical trial logistics (travel and accommodation) joined in 2011.

At this time, PACT was supporting 48 UK patients and their families travel to a single clinical trial based in the UK. Other trials, including elosulfase alfa (Vimizim), soon followed.

PACT - 2013

PACT started to support the first clinical trial based in Europe. PACT relocated their first patient to enable them to take part a clinical trial.

PACT - 2016

Since 2016, PACT has gone on to support clinical trials outside of Europe, from the west coast of America to Australia!

Research - 2017

Our research team carried out two of their largest research studies, to date on MPS III and Fabry in families

Communications - 2018

We presented 2-year data on patient reported outcomes information from individuals on the elosulfase alfa (Vimizim) MAA, at the 2018 International MPS Symposium, San Diego, USA.

Our colleague, Tabea Friedel, from the German MPS Society presented MPS Commercial's award-winning MPS VII study poster at The German Society of Paediatrics and Adolescent Medicine Conference.

PACT - 2018

Our PACT team currently organises logistics for 170 patients, to participate in 15 clinical trial, across 13 countries, involving 34 sites (hospitals).

To date, the team have relocated 20 families across the USA and Europe to enable them to take part in clinical trials.

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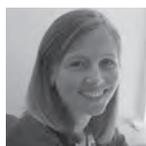
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Fundraising

The Kili Girls 2018 Challenge – WE DID IT!



After a year of planning, four intrepid local friends, Cathie, Chris, Franny (all from Cottenham) and Lenja (from Cambridge) made it to the top of Mount Kilimanjaro in Tanzania. Walking up the tallest freestanding mountain in the world and highest peak in Africa presented us with a few challenges and an unforgettable experience that we would like to share a little with you.

The journey took us through the different climatic zones of the region; including lush, wet rainforest jungle, heath and moorland zones, alpine desert and the steep, exposed arctic summit region. Even though we had chosen the 8 day Lemosho route that allowed for acclimatization, altitude was a major challenge and something that we all had to overcome as we approached the higher stages of the trek.

Camp life was an experience; bed tea at 6 am, a bowl of washing water (washy, washy), all meals provided, taking down and packing up the 2 man tents and a portable loo - our amazing porters would rush on past us to the next destination, carrying vast amounts on their heads and backs. Always cheerful and greeting us with Jambo (hello) or Pole Pole (slowly slowly), as they passed. The guides walked with us and we had a ratio of 1 guide per 2 trekkers.

Our party of 16 was cared for by a team of 64 amazing porters and guides and it was humbling to reach one of the earth's most iconic mountains supported by such kindness from those who in our terms have so little. We had our own mess tent. Food was plentiful and nutritious for walking; porridge, eggs, bacon, toast and fruit for breakfast, excellent packed lunches and 3 course dinners, including the local dish, plantain stew on our last evening. Always lots of soup. We had to drink at least 3 litres of fluid a day to avoid dehydration and we became accustomed to spotting good rocks and shrubs to hide behind on our rest breaks! We started walking most days at around 8.30 am and finished mid afternoon. Sleep was sometimes scarce because of altitude but our tents were cozy.

On summit night, we set off at midnight, it was really tough due to the altitude but our guides pulled us through and we sat at dawn to watch the sun rise over the curvature of the earth. We made it to Stella Point and after sweet tea, set off on the final push from there, along the crater rim to the highest point, Uhuru Peak, 5,895 metres. The temperature was around - 10 degrees C but there was only 50% oxygen so it was difficult to breath.

Photos were taken, hugs and tears shared and we made our rapid descent down the scree - it was more of a scree jog and quite exhilarating. After lunch and a rest at base camp, we descended further to our final camp and after breakfast, were treated to a brilliant singing celebration by our porters and guides. This was also our chance to say thank you and we could donate kit and give tips. More hugs and tears.

Our last day took us quickly down towards the warmth of the rainforest and we were treated to lots of animal hoots and bird song, something that we hadn't heard for a while. As we signed out from Kilimanjaro National Park for the final time, we were able to reflect on our journey of a lifetime and of those days spent amongst companions with whom we will share everlasting memories.

We self funded our adventure and raised money for our chosen charities. Cathie - Cambs College RDA Group (Riding for the Disabled), Chris - Alzheimer's Society, Franny - MPS Society (Mucopolysaccharidosis), Lenja - Pinpoint Cambridge. Thanks to the support and encouragement of so many of our friends and families we were able to raise significant donations, so would like to thank you all so much for such generosity. We are very touched that your donations are still coming in.

Climbing Kili was an experience that isn't easy; at times it was uncomfortable and rather breathless but also rewarding in more ways than we could have imagined possible.

<https://uk.virginmoneygiving.com/Team/Kiligirls2018>





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1 Three marathons for MPS

“It’s a pleasure to be supporting MPS Society, I know my wife’s family have had a lot of support from the charity in years gone by. I have completed the Liversedge and Sheffield half marathons, unfortunately the Wigan half was cancelled due to snow so I have entered the Leeds half to replace it. This is on 13th May so hopefully that will give me the opportunity to raise a bit more over the next few weeks.”
Alex Mayor

2 Isle of Wight ultra challenge

Kevin Mullins, Davy O’Neill and Adam Fairbrass took on the Isle of Wight ultra challenge. Before the challenge Kevin explained why it is known as an ultra challenge: “Staying awake for 24 hours will be a huge challenge for me, add to that the fact that I’ll be required to be physically active for that entire time and it highlights the effort this weekend will bring.”

He sent in some photos and let us know that although it was incredibly hot all three managed to get round and complete the challenge.

3 10K winter run

“The winter run went very well. Everyone finished and had a great time! So far, we have raised £1242 for the MPS Society!!”

4 Marsden to Edale and back in the day

I thought you might like to hear about an MPS fundraiser that my family held last week...

It’s nearly 6 months since my 4 year-old niece Isla was diagnosed with MPS III changing our lives forever. In that time the MPS Society has been a source of support and advocacy to Isla’s parents and they are grateful to the Society for a number of fun family days out which have helped to lift their spirits a small way.

So to commence what will probably be a lifetime of fundraising for our family, Isla’s uncle, Ryan Townrow, ran the 24-mile ‘Trigger’ fell race from Marsden to Edale on Sunday the 14th January. This gruelling race has over 4,500 feet of ascent and some challenging navigation over the wildest parts of the Dark Peak. Not content with this level of punishment, Ryan committed to running all the way back again (after a very short rest) raising more than £4,000 in sponsorship!

Local businesses from Marsden donated prizes for a raffle held at the local Cricket Club where there was quite a party to welcome Ryan home! The raffle raised a further £500 and Isla’s parents Nic and Darren have been overwhelmed by the love and generosity from their local community.

Sarah Kay (Isla’s aunty)

Read Ryan’s account of this epic run here: <https://bit.ly/2R7xTOo>

5 Newport Marathon

The Newport Marathon was our first ever marathon and was a very tiring experience! Over two years ago I (James) donated bone marrow to an unknown recipient. Last year we, and our family, were able to meet the recipient and his family. It was an amazing day! The recipient was Jack and he has Hurler syndrome. We decided we would like to raise some money for the MPS Society to help the amazing work they do supporting people like Jack and his family. It’s been a tough few months of training, culminating in the hardest challenge we have ever done. However, we know that this is nothing compared to the challenges Jack and his family face daily. We have always wanted to complete a marathon and have now done so, crossing the finish line hand in hand. It’s been a team effort and we couldn’t have done it without each other. We are grateful for the generosity of family and friends who have helped us raise money and who have supported us over the past months. It makes us incredibly happy to know that whilst completing a “bucket-list” challenge, we’ve been able to help the amazing work the MPS Society does.
James Evans

6 Prudential Ride London

Thank you to our team of three – Tuan, Ed and Matt – who cycled the 100 miles across London and raised a staggering £11,449.72 for the MPS Society.



7 London Marathon

Our amazing marathon runners raised a total of £27,498.70 – a record amount for the MPS Society. We are so grateful for all the hard work our supporters put in, not just training for the event but also all the sponsorship they collected and fundraising they did. Here's what they said.

“Apparently there were a few people cheering me on in the last few miles but I was in a tough spot mentally and was in my own wee dark bubble! I didn't even notice the grandstands at the end. Ha! But for 75% of the race it was a very enjoyable experience and the crowds were amazing. And we had a flood of donations in the last few days which is great news. Thank you for giving me the opportunity to run my first marathon for a great cause.”
Andy Weston and Amanda Scott

Katy and Lindsay earned one of our precious marathon places and were joined by Simon (who won a place via the ballot and chose to raise for the MPS Society) and Ian who didn't get a space with the Society but was able to run the marathon for another charity. Katy told us: “We had a fab day. It was an amazing experience - albeit very hard because of the heat!!”

“It was, without question, the hardest thing I have ever done. The heat on the day (the hottest London Marathon on record!) and my lack on training in the weeks leading up to the event, due to injury, made for an extremely difficult day. The demons in my head were ever present, constantly playing games and telling me I couldn't finish. My time was extremely slow but at times I really didn't think I'd finish at all so making it up The Mall was such a relief and a feeling I will never forget.”
Rebecca Caplan

Safe haven raised £626.00 on a charity day which included a raffle, wearing blue and even having a big blue bear visit.

Each year residents of Grace Lodge (Churchill Retirement Apartment) nominate a charity to support. This year the MPS Society was their choice, kindly donating £170.00 earlier on in the year and ending the year with a further £405.00.

Adam Brimacombe and Classic Builders (South West) Ltd have raised £150.00 through a Christmas Jumper Day at work.

Louise Lucas from the Hampden Arms raised £227.00 through their annual Boxing Day charity pub quiz.

Daisy Mitcham – Harding and her Grandma – Pam Mitcham, raised £85.00 through a Christmas pom-pom sale with the help of Blossom Street Gallery, York.

Sylvia Holyhead raised £150.00 raffling off a Christmas hamper of goodies, with a further £50.00 being raised by the girls in the Nurses Recruitment Office.

Dorothy and Colin Robinson raised £100.00 from card making and woodworking.

Teresa Ferguson and The Terry School of Dance raised £300.00 through a dance show held at the Johnstone Town Hall Theatre in Scotland.

Andy Hardy and The Haddenham Mummers raised £650.00 through a costume drama performance at various pubs, restaurants and Hostelrys in the area.

Vikki Brown on behalf of Terry Clarke who raised £250.00 through the auction of a pair of antique boxing gloves.

Jacqui McMillan and other members of staff from the Novotel Blackfriars Hotel raised £533.00 through a raffle event raising awareness for one of their nephews who has MPS.

Sofia Hazel raised £100.00 by standing outside the main reception area of her university to raise awareness for the MPS Society.

Hannah Watts raised £25.00 through selling glass Christmas decorations.

Sean Pearson raised £300.00 with his colleague Alex Mellor doing dry January on behalf of his nephew Archie Pearson who has MPS VI. Contributions were made from very generous friends and staff at TIC.

Tracy Milby's brother James raised £1158.60 inspired by his niece Katie who has Morquio, through proceeds from a Halloween party where friends and family dressed up for a disco and donated very generously to a raffle.

Julie Scott and Sunny Dermott from Eden Bridge House raised £404.23 through a series of office Christmas Charity events including; a Christmas Jumper day, raffle and Senior Managers doing a hot chocolate trolley.

Carol Westland and her friend Joan Phippard raised £205.00 by selling handmade crafts and Christmas decorations.

This year Marina & Friends secondhand shop in Bristol has raised a further £5939.15 bringing their grand total to £190,607 for research into the Sanfillippo MPS condition.

Sarah O'Mahony; Jesus Segovia; Anne Dupraz; David Hall; Mahesh Kudari; Agathe Guillot; Nicolas Koebel; Darren Walsh; Joe Datt; Adrien Lemoine; John Lavarino; Charles Skinner; Laetitia Schwab raised an amazing £1242.39 doing the Winter Run.

Daryll Brook and the LV Ipswich Office raised an amazing £406.79 through a Christmas raffle .

Kerry Siddall and colleagues at Bluestone Credit Management raised a fantastic £359.84 by holding a Wear it Blue day playing 'play your cards right', held a raffle and did a bun sale.

Liz Mee raised £160.00 by putting on a coffee morning for her local village which was a great success.

Teresa Jeffery, along with friends and family, has once again raised an impressive £1120.00 from a quiz night and MPS fun day.

Wayne Bond and colleagues at Clark and Partners raised £244.56 on MPS day by wearing it blue and holding a collection, one of the colleagues decided to dress up as smurf!

Sandra and Rash Singh each year hold Daniel's fete on the 13th May and this year they raised a massive £1653.33. The day was full of sunshine, live music, stalls and fairground entertainment with hundreds of people having fun.



Wayne Bond and family designed these fab car stickers and sales blew up when it was shared on the MPS Society Facebook page. Not only did Wayne buy more stickers to sell he also organised all the sales and postage raising an impressive £225 and selling 160 stickers.

Sylvia Holyhead organised a tombola on MPS Day at work to raise awareness and also managed to raise £115.86.

Charlotte Wright nominated MPS Society to be sponsored at Diss Young Farmers Club's 75th Anniversary Ball at the Royal Norfolk Showground on Saturday 16th June 2018 raising £643.20 before the event and even more after. (Look out for more about the event in the next magazine.)

Michelle Brooker held a collection at the school on MPS Day as well as having donations from friends and family and raised £95.00.

Maureen Collings and her fellow villagers organised a fun horse racing evening which they named 'The Charles Pennock Memorial Race Night'. Charles was on the team that organised this annual event so they decided to donate the £2000.00 they raised in his honour.

Mr A D Selwood and Mrs P A Selwood sent in £20.00 for MPS day



Mark Hughes has once again dressed up and raised money at the Cambridge Arbury Carnival. He told us: "It was a very hot day and fun was had by all attending with lots of floats. I was dressed as batman to draw the kids in, and had some photos taken by some of the parents. We didn't get many photos of the stall as Zack took control of my camera and said that it was grandpa's and no one was allowed to use it except him! Then along came a chap in a red cape and he very nicely said we could have our photo taken with him and use it in the MPS Magazine." Mark and his team raised £253 on the day - holy fundraising Batman!

Tracy Cunningham raised £437.46 at the school on MPS Day and Aimee Cunningham raised £148.00 on her Facebook fundraising page.

Sidrah Zanib and her family collected £165 during Ramadan and chose to donate it to the MPS Society.

F B Jenney and Newton Ferrers and Noss Mayo Bridge Club raised £100.00

Helen Barber and Teresa Jeffery organised a fun day at Preston Baptist Church raising a fantastic £500.00 through sales of a tombola, cakes, bric-a-brac, toy and plant stalls, bouncy castle, tea and coffees Louise Penny raised £232.85 at her school on MPS Awareness Day this year holding a cake sale. She also along with other teachers at the school competed in the Manchester Run and raised an amazing £872.00!

Carol Westland and Joan Phippard raised an amazing £415.00 selling crafts and upcycled items.

A big thanks to Bridge and Patribourne CE Primary School for raising an incredible £945.00 through wearing blue and having a blue cake sale.

Maurice Patton and Ards Allotment Open Day raised £283.00.

Linda Whybrow and colleagues at The Red House (Chartered Financial Planners) decided to donate £1,000.00 to the MPS Society by sharing a proportion of their profits. Linda put the charity forward in memory of her Brother, David Fryer.

Mystique Offer raised a fantastic £1080.00 taking part in the Jurassic Coast Challenge 2018.

Our very own Steve Cotterell has raised an amazing £260.00 taking part in the Chilterns 100 Cycling Festival.

Congratulations to Dennis Brogden who completed a Skydive and raised an incredible £265.00.

Liz Green raised a fantastic £570.68 to date taking part in the National Three Peaks Challenge.



Ann Todd had a 40th birthday party on 16th June and asked for donations in lieu of presents. She received £860 on the night which she chose to donate to the MPS Society as her brother, William, had MPS I Hurler Scheie and passed away on 17th December 2016 aged 37 years.

Vikki Brown sent in a donation for £2220.00 that was raised by friends and colleagues. Her friend Leah Larkin did a 5km run for the MPS Society and her Son Harvey's friend Burac made lemonade and sold it at their after show performance raising £77.00 - we are told he has many other ideas for Fundraising for us!



Caitlan Leaming has organised many events including a raffle, a skydive, a fun run and making and selling these hoodies. She's raised £240 for the MPS Society in memory of Jessi and Terri Hambly.

Tia Copsy

It was fantastic to see Tia at clinic recently especially after a lengthy operation from which she is recovering from (hence neck collar). It was great to hear that Tia had a very short hospital stay and was home with her family before they knew it! And back at school within a couple of weeks. Tia didn't stop there though, she then proceeded to organise a "bake off" where she and some friends baked and sold cakes to their school friends, raising a grand total of £50.00! Well done Tia it was a massive effort at the best of times but even more so after surgery!!



The MPS Society wants to say a HUGE thank you to Tia as all money raised goes directly back into supporting our members and families in so many different ways – and it all makes a difference.

Sally, Advocacy Support Officer



Towersey Morris

We were once again invited to the final dance of the season with Towersey Morris side this August. The Towersey Morris men jointly support the MPS Society and Multiple Sclerosis Trust in their fundraising and collecting throughout the year and we are so grateful for their donation of £720. Thank you to The Three Horseshoes in Towersey for hosting us and big thanks to all the morris dancers and music makers who joined Towersey Morris on the day.

Halloween party

My daughter Katie Milby aged 16 has Morquio. Her uncle James wanted to do something for her to raise money for the MPS society and they chose to put on a Halloween party. We had a buffet and disco we also had lots of raffles donated by family friends and local shop owners we had some games and a prize for the best costume. Everyone that came made a great effort with their costumes and a great sum of £1158.60 was raised for the MPS society.



Donations

Andy Hardy, Julie Bond, Kayleigh Carter, James Cooper, Caroline Macpake, David Tonge, Margaret Thornley, Sue and Vic Howry, Karen Crayton, Mrs A Baker, Mrs A. J Gunary, Mr B Wood, Mrs D E Peterson, Elizabeth Carnie, Asher Rickayzen, Leah Cooper, Ann Baker, Chris Spillman (Bowen Lodge), Miss J A Scott, John Michael Brown, Diane O' Beirne, Anne Cotton, Liz Rodda, Paul Black, Vivienne and Andrew Culley's neighbour, Britannia Village Primary School, Robert Oulsnam and Company Limited, Gordon and Mary Mellor, Keith and Susan Macdonald, Sylvia Holyhead, Neil Coney, Mr and Mrs Tony Eaton, Kate Picton and the Misbourne Matins Rotary Club, Caitlan Celik, Waitrose High Wycombe, Polly Rebecca Rigg, Mick Yates, Thea's Trust, Frances Gee, Frances Dvovchik, bptw partnerships, Roy Brown (on behalf of Cookie – Eleanor Brown), Mrs M Cowles, Susan Swayne and E Bates, Stephen McCallum, S Zanib, Elizabeth Daubney, Wayne Bond, Anita Roberts-Engel, The Gosling Foundation, Barbara Cooke, C M Dowie, Ruth Baker, Myai Lynam, Sophie Zemenides, Lorraine Bolton, Fiona Hamilton, Stephanie Nuttall,

Nettleworth Infant and Nursery School, Anne Lincoln, Mubarak Omar, Mr & Mrs Allen, Heather Woods, Ann Baker, Joan Crespin, Peter Merchant, Jean Davy, Burstled Wood Primary School, West View Primary School, Select Care Services, Joan Hitter, Amara Copsy, Wayne Bond, Janet Handley

Used Stamps and foreign money

Amanda Iles, Karen and Andrew Weedall, Hannnah and Ben Brock and Aunty Delia, Brenda Walker, Ellen Nicholson, Elizabeth Rodda, Mr and Mrs Croft, Marilyn Eggleton, A G Office Supplies, Ellen Nicholson,

Old mobile phones/ Ink Cartridges/ Paypal Giving/ EBAY for Charities

Rachel Todd

In memory of

Alan Cooper, Kathleen Mary Chambers, Pamela Margery Booty, Maureen Fullalove, Mrs Margaret Williams, Jennifer Norsworthy, John Musker, Robert Henry, Daniel Allen, Shujah Altaf, Jack Heath, Mrs Joan Coral Sheppard, Graham Lionel Boroughs, Joan Doyle, Janet Gremo, James Bernard Edwards, Jan Gremo, Stephen

Maurice Podmore, Catherine Kershaw, Ollie Illingworth, Lisa Nurse, Joan Coral Sheppard, Oliver Illingworth, Ian Darke's Grandpa, Janet Gremo, John Butler, Susan Grace Clarke,

In memory of Christine Lavery

A D Walker, Alan Dickerson, Ema Brock, Fer Pidden, Brian Fisher, Anne and Chris Stanley, Glen McKee. David Brooks-Daw, Carol Westland, Douglas and Alison Gunary, F G Robinson, P A Skidmore, Brian Bigger, Jibreel Arshad, Cheralea Rogan, Anna Eaton, Mr and Mrs Shannon, Francis Pang, Christian Hill, Lucinda Quin, Sailesh Tailor, Dean Brown, Marina Foster, Susanne Birks, Marylin Eggleton, Linda Rowland, Kathryn Wallis,

Collection Box

Karen Crayton, Barbara Penny

Thank you also to all those who donated anonymously – we don't know who you are, but we think you're great!

2018 MPS SOCIETY Christmas card collection

Order your MPS Society Christmas cards via our online shop by visiting www.mpsociety.org.uk

Please order early and allow 14 days for delivery. All orders are date stamped on receipt and are dealt with in rotation.

Last date for orders is Friday 7th December 2018



This year join our Christmas fundraising campaign and bake cookies for MPS.

Get your Christmas tree cookie cutters for **£3.00** from the online shop and get baking!



Knitted penguins £3.25



Have a lovely Christmas £3.35



Santa's gallery £3.50



Six trees £3.25

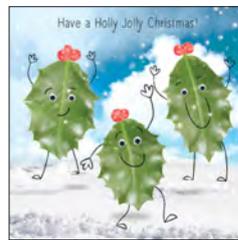
We also sell notelets
Perfect as thank you cards, choose from tulips and lilies or snowdrops



Talking robins £3.25



Robin and snowdrops £3.30



Holly jolly Christmas £3.25



The gifts £3.00



Tower bridge £3.40



Robin's boot £3.25



Snowman cake £3.25



Snowman family £3.25



Christmas hearts £3.50



Post box £3.35