THE MPS MAGAZINE

Society for Mucopolysaccharide Diseases	Support Research Awareness	Spring 2015
		www.mpssociety.org.uk

Rare Disease Day 2015

28th February was International Rare Disease Day, a day when the rare disease community all around the world came together to raise awareness and show solidarity.

Read all about this important day on pages 22 - 23

#Fight4Treatment

The fight for the funding for Vimizim, on both a permanent and interim basis, rages on. Our Communications Officer Charlotte, along with Katy Brown and Angela Paton write about their campaign experiences and the current situation.

Read these reports on pages 26 - 28

Wear It Blue 2015

MPS Awareness is fast approaching, and we are inviting all our members and supporters to help raise awareness on this day. Our article on pages 38- 39 will give you inspiration for the day, whether you Wear It Blue or Confess For MPS!

Front cover photo: Kamal and mum, Suzanne Mallah, outside Parliament.

Society for Mucopolysaccharide Diseases

Registered Address:

MPS House, Repton Place, White Lion Road,
Amersham, Bucks, HP7 9LP, UK

www.mpssociety.org.uk

T: 0345 389 9901
Out of Hours: 07712 653258
F: 0345 389 9902
E: mps@mpssociety.org.uk

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To submit content email;
magazine@mpssociety.org.uk

The articles in this magazine do not necessarily reflect the opinions of the MPS Society or its Management Committee.

Staff

Christine Lavery
Chief Executive
c.lavery@mpssociety.org.uk

Rebecca Brandon
Advocacy Support Officer
r.brandon@mpssociety.org.uk

Debbie Cavell
Advocacy Support Officer
d.cavell@mpssociety.org.uk

Steve Cotterell
Social Work Student
steve.cotterell@mpssociety.org.uk

Sue Cotterell
Trust & Grant Fundraising Officer
s.cotterell@mpssociety.org.uk

Toni Ellerton
PA to CEO
t.ellerton@mpssociety.org.uk

Joanne Goodman
Lead Clinical Trial & Patient Access Officer
j.goodman@mpssociety.org.uk

Liz Hardy
Trust & Grant Fundraising Officer
e.hardy@mpssociety.org.uk

Mak Khan
Business Developer Manager
m.khan@mpssociety.org.uk

Benedicta Marshall-Andrew
Clinical Trial & Patient Access Officer
b.marshall-andrew@mpssociety.org.uk

Elkie Riches
Fundraising and Communications Officer
e.riches@mpssociety.org.uk

Charlotte Roberts
Communications Officer
c.roberts@mpssociety.org.uk

Gina Smith
Finance Officer
g.smith@mpssociety.org.uk

Sophie Thomas
Senior Advocacy Support Officer
s.thomas@mpssociety.org.uk

Martine Tilley
Office Administrator
m.tilley@mpssociety.org.uk

Alison Wilson
Advocacy Support Officer
a.wilson@mpssociety.org.uk

MPS Conference 26-28 June 2015

For those of you who have not yet booked to attend our Conference in June, there is still time to secure your place. Just fill in a booking form, which if you haven't already received one, you can download from our website or call the office to get a copy sent to you.

Entitled 'Conference on Paediatric and Adult Perspectives in Management and Treatment of Mucopolysaccharide, Fabry and Related Diseases', this conference is dedicated to the sharing of information for families and professionals.

Last chance to book your place is Friday 15th May 2015.

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.

Our Aims:

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

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 can result in death in childhood.

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

PLEASE NOTE

Our office telephone number has now been changed to 0345 389 9901.

This change will make it more economical for our members and supporters to contact us.

Thank you.

Contents

facebook.com/mpssociety

twitter.com/MPSSocietyUK

Welcome

Following on from our Winter 2014 magazine, we have included articles on the fight to get funding for Vimizim. You can find this update on pages 26 - 28. Getting funding for this crucial drug is important not only to those affected by MPSIVA, but also to anyone who will at some point need a drug to treat a rare disease. Please follow and like us on Twitter and Facebook for up to date news on this issue.

Thank you to everyone who contributed to the 'Your Stories' section (page 13 - 19). We have an incredible story of positivity from Samantha, and also some heartfelt accounts of the loved ones lost. If you would like to share your story please email magazine@mpssociety.org.uk.

Lastly, with MPS Awareness Day fast approaching please take a look at our article on pages 38 and 39 for some inspiration. With your help we can make this day bigger than ever!

Best wishes

The MPS Team

Visit our online shop

www.mpssociety.org.uk.

Purchase our information resources and MPS merchandise including our T-shirt!

Chief Executive's Report

Christine Lavery

With three months to go until the **MPS National Weekend Conference in Coventry, 26 – 28 June 2015,** we are delighted to see the bookings from our MPS individuals and families flooding in along with those of clinicians and scientists. The Weekend Conference has something for everyone: On Saturday three conferences running in parallel will address a wide range of talks and discussions on clinical management, treatment, support and care for those affected by MPS, Fabry and the related lysosomal storage diseases; on Sunday the half day conference turns its attention to such topics as the impact of being a carer, antibodies and carrier testing and educational options.

Of course the care of our children and vulnerable adults is paramount. The advocacy team and volunteers are planning a wonderful weekend of fun and surprises. On Saturday we propose to take the children to Drayton Manor Theme Park, zoo and ThomasLand with an experienced team of volunteers and on Sunday there will be a half day outing to Birmingham SeaLife Centre. For those too unwell or aged two years old and under, there will be a dedicated crèche and activity area at the hotel. Whilst childcare is on hand for Saturday night, the adult delegates will enjoy a gala dinner and entertainment. So if you haven't booked for this 'weekend not to miss' please send in your paper booking form as soon as possible.

On Thursday 25 – Friday 26 June a group of leading clinicians, scientists, representatives of the pharmaceutical industry and regulators will meet at the Hilton Hotel for an Expert Workshop on MPSIII, Sanfilippo Disease. Whilst this meeting is closed to families we are offering an **MPSIII Workshop feedback and discussion session, led by Dr Simon Jones and Dr Brian Bigger, between 4.30pm and 5.30pm on Friday 26 June** prior to dinner.

Also on Friday 26 June we are hosting an **Expert MPSIIIB Parents' Focus Group involving 16 MPSIIIB parents**. This Focus Group will start with a finger buffet lunch and finish by 4pm. If you are interested in knowing more and participating please do contact Toni Ellerton at t.ellerton@mpssociety.org.uk as soon as possible. We will be looking to provide care for children and vulnerable adults for this focus group.

Finally we are inviting individuals over the age of 18 years diagnosed with Fabry disease to participate in a Packaging Consultation Workshop over lunch at the end of the MPS Conference Weekend on Sunday 28 June. If you are interested in taking part or would like to know more please contact Toni Ellerton - t.ellerton@mpssociety.org.uk

So many of you are following and supporting the Vimizin Campaign and I would like to thank every one of you. We have been so touched at the spirit of not just those MPSIVA children and adults and their families closest to the Campaign but also to the young people and families with experience of the other MPS diseases who have used Facebook and Twitter to spread the word to friends and acquaintances. The fight goes on and will go on until the four National Health Services of the United Kingdom recognise that children and young adults with the ultra-rare diseases have the same right to treatment to arrest their diseases and give them as much improved quality of life and life expectancy as people with common conditions. Anything less is paramount to discrimination by rarity of disease.

Further on in this Magazine you will be brought up to date with events the MPS Society has lined up for you and I hope we will see as many of you as possible over the coming months.

Christine Lavery
Chief Executive

Best Wishes to Faith Parrott

After 6 years serving as a Trustee, for personal reasons, Faith Parrott has resigned from the MPS Society Board of Trustees. When Faith was elected she was the youngest Trustee ever to serve the MPS Society in this way.

On behalf of the MPS Society and the Board of Trustees we wish Faith every success for the future and trust that in years to come she will have the time to consider returning to serve again as a Trustee.

Christine Lavery

MPS onlne survey using Survey Monkey

We want to thank all those members who took part in the online survey using Survey Monkey. Although the response rate was small, the feedback we received has been invaluable and we hope that when we seek feedback in the future even more of you will give us your thoughts. We are pleased to share some of the feedback below:

More help for day-to-day living challenges. Also suggest a Northern office based at Manchester Children's Hospital

The MPS Society has experience of a Northern office and has found it more cost-effective to operate out of one office for England, Wales & Scotland. In Northern Ireland we do have a separate 'office', a room in Belfast City Hospital that is economical and meets the needs of families in the whole of Ireland

Helped tremendously with forms/education. Support invaluable

Particularly helpful with adaptions and equipment

When the team get involved, people listen to them and take note

Comforting to know someone is there to help

Support was exemplary and of the highest standard

Disappointed not to find information on current clinical trials. More up to date research needed

The suggestion of more information on current clinical trials is welcome and we are committed to giving this a high priority. New information can be found in every MPS Magazine

Appreciated the ability to meet with other parents

News From the Board of Trustees

The Society's Trustees meet regularly. Here is a summary of the main matters discussed and agreed at the Trustee Board Meeting on the 29th November 2014 at MPS House, Amersham.

Governance

The MPS Society's Operating Agreement with MPS Commercial agreed by the Board of Trustees at its meeting on 5 September was duly signed by the Chair, Sue Peach. Sue Peach talked to the Trustee Self-appraisal Form and invited all Trustees to complete and bring to the next meeting. A discussion was had on Board representation for the 2015 International MPS Network Meeting in Austria in July 2015. It was agreed that Sue Peach will participate with the MPS CEO, Christine Lavery.

Personnel

The CEO presented her personnel report and a discussion on Key Performance Indicators for all staff took place. The Board welcomed the Society providing support for children and adults with Lysosomal Acid Lipase (LaL). The CEO confirmed a grant has been agreed towards advocacy support for LaL individuals and parents.

Treasurer's Report

Treasurer, Judith Evans presented her report. The £25,000 of consolidated stock was discussed. Subject to external financial advice it was agreed the consolidated stock be cashed in. The draft budgets for 2015 which had been circulated for comment prior to this meeting were discussed and approved unanimously

Clinical Management

The CEO spoke of the unwelcome news of a second wrong diagnosis at Bristol Children's Hospital. The CEO confirmed that the family are being supported by members of the advocacy team and a rebuttal to Bristol Children's Hospital CEO, Robert Woolley's letter in response to our letter of complaint has been sent..

Access to New Therapies

The CEO confirmed the MPS Society submission to NICE in respect of Vimizim has been submitted and have nominated three MPSIVA stakeholders to participate at the NICE hearing on 17 March 2015. Trustees spoke in positive terms on the sustained campaign to get NHS England to provide interim funding for Vimizim.

Policies

A draft Reimbursement policy was tabled for Trustees to consider. There was considerable discussion and the Trustees agreed this policy would be considered in greater depth at the next Board meeting. The finalised Business Continuity Plan was tabled and the CEO confirmed packs would be made available for next meeting. The Strategic Plan was tabled and the CEO explained that these are designed to tell a story to our funders and the 2015 Strategic Plan was approved.

MPS Commercial

Bob Stevens, Chair of MPS Commercial reported to the Board on the activities of MPS Commercial and new business. He confirmed the year end for the company is the 31 Decembers and confirmed any profits will be gifted to the MPS Society.

What's On

MPS Regional Clinics 2015

MPSI - GOSH:
14th July
22nd September • 22nd December

MPSIII - GOSH:
26th May
8th September • 8th December

MPSIV - GOSH:
9th June
13th October

Fabry clinic - BCH:
22nd May • 23rd October

Adult Fabry clinic - QE Birmingham
21st April

MPS clinic - BCH:
15th May
12th June • 27th November

MPSI Post HSCT (over 6 years) - RMCH:
17th April
17th July • 16th October

MPSI Post HSCT (under 6 years) - RMCH
24th April
24th July • 23rd October

N. Ireland MPS clinic - Royal Belfast Hospital for Sick Children
15th May

Conferences and Regional Events

Scottish Family Weekend, Ayr
10th April - 13th April 2015

Northern Ireland 20th Anniversary Meeting and Dinner *
14th May

UK MPS Conference Hilton, Coventry
26th – 28th June 2015

Irish MPS Society: All Ireland Conference - Clarion Hotel, Dublin
11th-12th September 2015

Childhood Wood planting
25th October 2015

* *see page 20 for more details*

Announcements

Welcome Back!

We were delighted to welcome our Senior Advocacy Officer Sophie back from her maternity leave on 1st January 2015.

As you can see, Sophie's daughters Imogen and baby Freya were on hand to help out!

New Face at the MPS Office

Hello, my name is Benedicta Marshall-Andrew and I live in Amersham. I joined the MPS Society in the middle of February and I'm working as a member of the Clinical Trials Patient Access team.

I studied Ancient History for my Masters at University College London and then went on to do something completely unrelated to my degree: I worked in the insurance industry as a claims handler. So I'm really looking forward to working for a charity which does so much to help people suffering with the MPS conditions.

It's been a steep learning curve so far but everyone has been so friendly and really helped me to learn about the various conditions. They've also helped me to better understand and appreciate just how much the MPS Society does to support sufferers and raise awareness of MPS.

In my spare time I enjoy reading and playing golf. I've only really started playing golf so there's much improvement needed!

I'm really looking forward to experience more of my role and doing my part to help MPS sufferers and their families.

New Members:

Mrs Brook has recently been in contact with the Society. Her son Dylan has a diagnosis of Sanfilippo Disease. Dylan is 2 years old. The family live in the East of England.

Amritpal has recently been in contact with the Society. He has a diagnosis of Fabry Disease. The family live in the West Midlands area

Lexi has recently been in contact with the Society. She and her son have a diagnosis of Fabry Disease. The family live in the Somerset area..

Maggie has recently been in contact with the Society. She has a diagnosis of Fabry Disease. The family live in the East Midlands area.

Louisa has recently been in contact with the Society. Her daughter has a diagnosis of MPSVI. Jessica is 2 years old. The family live in the South of England.

Amanda has recently been in contact with the Society. She has a diagnosis of Fabry Disease. The family live in the Suffolk area.

Fay has recently been in contact with the Society. She has a diagnosis of Fabry Disease. The family live in Teeside, North-East England. Fay would like to thank the MPS Society for their support.

Advocacy

The MPS Advocacy Support Service has been established since the Society was founded in 1982. At this time there were only 40 known families throughout the UK. The support provided was on a voluntary basis and depended heavily on individuals and parents to provide support to individuals diagnosed within their immediate and surrounding areas.

However in 1991, the Society opened its first office and with this the advocacy service we know today was born.

The MPS Society provides, through a team of skilled staff, an individual advocacy support service to its members. The service is flexible and a wide range of support is offered on a needs led basis.

The rarity of these conditions means that in many cases, accurate assessments, support and advice are not given due to the vast majority of social care and health professionals knowing very little if anything about the diseases.

Support provided by the team

• Telephone Helpline

0345 389 9901– the Society provides an active listening service, information and support. This includes an out of hours service

• Disability Benefits –

In understanding the complexities and difficulties individuals and families have in completing claim forms for Personal Independent Payment, the Society continues to provide help and support in completing these forms and, where needed, will take a representative role in appeals and tribunals

• Housing and equipment

– The Society continues

To take a major role in supporting and advocating appropriate housing and home adaptations to enable the needs of an individual with an MPS or related disease to be met. Where requested, we can provide comprehensive and detailed housing reports based on individual need

• Education –

The Society helps members to access appropriate education and adequate provision for its implementation. This is achieved through providing educational reports used to help inform and educate professionals, and in many instances, to inform Statements of Special Educational Need. Where requested, we also provide information days/ talks to schools and relevant professionals

• Respite Care –

The Society continues to work closely with a number of respite providers and, where appropriate can make individual referrals

• Independent Living/ transition –

The Society provides advice, information and support through the transition from child to adult services. This could include access to independent living, learning to drive, further education and employment

• MPS Careplans –

The Society undertakes a comprehensive assessment of the issues which need to be addressed when caring and providing support to a specific individual diagnosed with an MPS or related disease, as well as other family members through the writing of a careplan

• Befriender Service –

The Society links individuals and families affected by MPS and related diseases for mutual benefit and support

• Bereavement support.

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:

Email: advocacy@mpssociety.org.uk
Telephone: 0345 389 9901

Advocacy Resources

The Advocacy Team have also developed a range of information resources focussing on particular issues which are available to download free of charge from the MPS website, www.mpssociety.org.uk

- Life Insurance
- Travel Insurance
- Hospital Travel Costs
- Disabled Access Holidays • Carers Legal Rights
- Carers Allowance
- Wheelchairs and Flights • Guide to Housing and Disabilities Facilities Grant
- Benefits including, Personal Independent Payment, Benefit Cap, Council Tax Benefit and Universal Credit

Each of our England based Advocacy Officers works with specific disease groups as listed. However, every member of the Advocacy Team has knowledge of all the diseases and may at times provide support in other areas dependant on need and individual assessment.

Team Members

SOPHIE

Manages the MPS Advocacy Team

STEVE

MPSIII Sanfilippo type A,B, C and D, MLD AGU, Winchester
Geleo Physic Dysplasia Sly, Gangliosidosis, Sialic Acid Disease

ALISON

Supports members living in Ireland

DEBBIE

MPSIVA Morquio, MPSI Hurler BMT, Hurler Scheie, Scheie, MPSVI Maroteaux-Lamy, MSD, MLII

REBECCA

Fabry
MPSII Hunter
MLIII / MLIV
Mannosidosis, Fucosidosis

Can you help?

MPS CONDITIONS – ARE YOU ABLE TO HELP COMPILE INFORMATION LEAFLETS FOR FAMILIES

Nathan Grant lives in America and has contacted the UK MPS Society asking for the help of MPS families.

Nathan has a brother, Nik, who has MPSII. When Nik was diagnosed in 2002 there was very little help on how to deal with the progression of the disease and the impact. He has also found in the USA that there is not much information for siblings and families.

He wants to tell his story and compile information, advice and hints on how to deal with living with MPS diseases, but also to include other perspectives. This will be posted on various websites.

He would like to collect stories from parents and siblings on their experiences. If you would like to help Nathan with this please contact him on grantn@countryday.net

Bereavements:

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

Jack Stuart who suffered from MPSII Hunter disease and passed away on 29th December 2014 aged 20 years.

Jessica Hambly who suffered from MPSI Hurler Scheie and passed away on 1st February 2015 aged 16 years.

Jonathan Oyemade who suffered from MPSIII Sanfilippo and passed away on 22nd November 2014 aged 24 years.

Max Cawkwell who suffered from MPSI Hurler and passed away on 6th January 2015 aged 1 year.

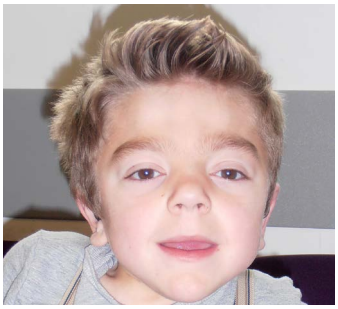
Manchester MPSI BMT Clinics - January

16th & 23rd January 2015

Demi

Morgan

Rubina



Sonny

GOSH MPSIVA Clinic

10th March 2015

Kamal

Sara & Suhila

I attended the two Royal Manchester Children's Hospital post HSCT clinics in January and it was lovely to meet with all the families. The clinic was so busy on 16th January that the team did not have time for a break, so the following week I came with hot cross buns for the team – which were appreciated.

I also attended the GOSH MPSIV clinic in March and I had the pleasure of meeting with Dr Footitt, who is taking on the care of some families following Dr Vellodi's retirement. The verbal feedback from families seems to be very positive regarding the Multi-Disciplinary Clinics they are holding.

Debbie Cavell
Advocacy Support Officer

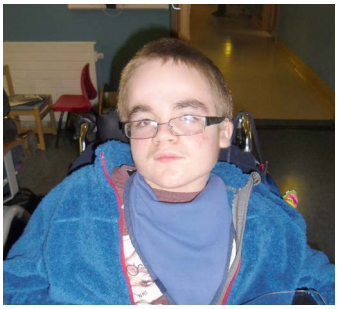
GOSH MPSIII Clinic

The Metabolic Team at Great Ormond Street Hospital hosted an MPSIII clinic on the 24th February. This was the transition clinic to introduce children and their parents to new consultant specialist in light of Dr Vellodi's retirement. As ever the clinic was bustling with people and there was an opportunity for me to catch up with everyone and for families to also chat and gather themselves following the commute to London. Bobby was on particularly good form, chatting away down the corridors and Luke, Ana and Ollie seemed content to take in their surroundings.

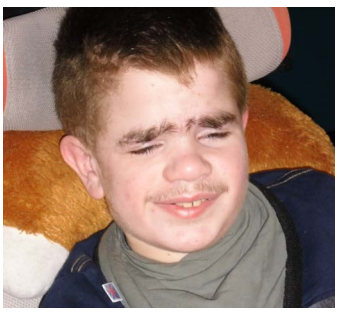
I know that the families wanted to pass on their thanks to Dr Vellodi for all his support over the years. They anxiously awaited their first consultation with their new doctors, but they were soon reassured and seemed very happy when they returned to the waiting area. We would like to thank the team at Great Ormond Street for their continued support with these clinics and we look forward to the next one on 26th May.

Steve Cotterell
Social Work Student

Bobby



Luke



Oliver

All Ireland Advocacy Support Update


Grace and Cezy meet Elsa!

Since I last updated you it has been a busy time in Ireland. I've spent some time over the last few months improving my own knowledge and awareness through attendance at conferences and courses; and I look forward to applying my new knowledge to further support those living with MPS and Fabry Disease in Ireland. Conferences and events are a really important part of the life of the MPS Society, knowledge is power and we all know that with power comes the ability to stand up and fight the battles that MPS brings. I do hope that our members in Ireland will consider attending the National MPS Conference in Coventry in June, it would be great to spend time learning more about MPS together. If you have any questions or are worried about attending a conference for the first time please give me a call and I would be more than happy to talk it through with you. We have a team heading to the conference from Northern Ireland so I can assure you that you will not be alone!

Please remember, if you have any unmet support needs and live in Ireland (North or South) you are more than welcome to contact me on 0044 77862 58336 or a.wilson@mpssociety.org.uk

Northern Ireland Clinics

We have had the second of our new format multidisciplinary MPS clinics and four Cardiac and Genetics Fabry clinics in last few months – it's been a very busy time! I of course want to extend a huge thank you to all those professionals involved in making these clinics happen – many work outside of their usual work areas and go very much above and beyond on these exceptionally busy and productive days. However, it's the families that put in the biggest effort on the day. Many travel quite some distance to attend (and we all know how difficult that can be with all your 'kit' in tow) and spend a long day in the hospital having a series of investigations.

We know that clinic days can be tough, but we hope that you get as much out of them as the clinic team do. If there's anything we can do to improve your experiences at clinic please do not hesitate to let me know.

Southern Ireland Clinic

On the 6th March the team in Dublin held a one day clinic for some of the Irish MPS families. These clinics are very important to families as it gives them a chance to see a number of professionals in one day as well as bring up any Advocacy and Support needs they might have (I've come away with quite a few items on my to-do list!). Again, both families and professionals put a lot of work into making these clinics happen and I want to extend a huge thank you to you all for inviting the MPS Society to be a part of the day.

On the day there were a team of doctors, nurses and play therapists (and even a very friendly therapy dog!) on hand to look after everyone who attended. I think that everyone would agree that the day was really beneficial for all those who attended. If you are from a family who didn't get a chance to come along to this clinic, don't worry, there will be more clinics in the future.

Although most of the children were a little camera shy on the day I did manage to get snap a couple of lovely photos of Grace Cogan (6) and Cezy Fosca (8 years) who were absolutely delighted when Elsa arrived to tell us all about what's been going on with her and Anna in Arendelle.

Some things to look forward to

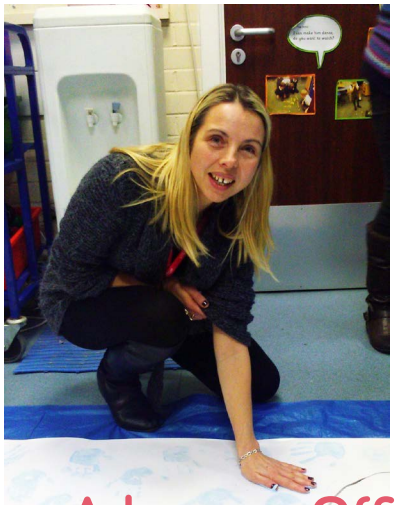
In the coming months we have a lot to look forward to in Ireland.

On the 14th on May we are looking forward to an event for families and professionals to celebrate the 20th Anniversary of the MPS clinic in Northern Ireland. This is such a huge achievement and I know I am looking forward to a night of looking back at where we've come from as well as looking to the future and how our clinic and services will continue to develop. The event will involve a professionals' meeting followed by a celebration dinner and will be held in the Hilton Hotel in Templepatrick. There will be a few surprises on the night and we look forward to welcoming as many of you as possible.

In my last update I let you know that the consultation period for the Northern Ireland Rare Disease plan ended on the 19th February. We are now patiently awaiting publication of the final plan. I hope that by the time you read this we will be celebrating it's publication and considering how it will impact the provision of services from Rare Diseases. In my next magazine update I will take you on a guided tour through the plan and explain what it all means for families in Northern Ireland.

In Southern Ireland the National Plan is in place and we are awaiting news in relation to the opening of a National office for Rare Disease. I will keep you up-to-date with progress and hope that in the coming months we will continue to see positive improvements in relation to the management of Rare Diseases in Ireland.

Alison Wilson
Advocacy Support Officer



A Week in the Life of an Advocacy Officer: Debbie

Our Advocacy Support team covers the whole of the UK, each officer specialising in specific conditions. They work tirelessly to offer both telephone and face-to-face support to affected families, and impart up to date information which covers a wealth of topics, from home adaptations to all aspects of social care.

Debbie works with families affected by MPSI, MPSIV and MPSVI, amongst other rarer conditions, and here she gives her account of a typical week in the life of an Advocacy Officer

Wednesday – I travelled up to Yorkshire to meet with a new MPSVI member Lewis and his Mum Sarah. I visited the family home and it was lovely to meet them and to have a chat. Sarah requested help with a housing application and I suggested composing a letter of support and information for the housing team about the condition and how to meet Lewis' needs. I had also arranged to go to the school and meet with the staff and I provided a staff training session to give an overview of MPSVI and what measures the school can put in place to support Lewis.

Thursday – I spent the day in the office and sent out information to the Yorkshire school that they had requested. I wrote up the draft housing support letter and sent it to Sarah for approval. I had a meeting with Charlotte, our Communications Officer, who is working very hard with the Vimizim campaign to devise a presentation for a school assembly the following week.

Friday – I was up very early to be in Manchester for 9am to attend the MPSI post HSCT clinic at Manchester Children's Hospital. Even though the journey is long, I enjoy the clinic as it is a great opportunity to meet up with families and see how they are getting on and if they need any support. It is also good to catch up with the wonderful team at the Willink Unit and share news.

Monday – I was back in the office and spent my time preparing for a school training session on Wednesday. I made a powerpoint presentation and gathered written information to give to the school. I like to have a chat with the family beforehand to check if there are any specific issues or points they want me to make. I also like to include some photos of the child in the presentation too and I have seen some lovely ones!

Tuesday – I was in the office again and had another meeting with Charlotte to go through our assembly presentation and to finalise the details. I made my travel plans as I would be out of the office for the rest of the week. I also contacted families that I had been working closely with to inform them I would be out of the office for a few days.

Wednesday – I drove up to Barnsley and the snow was blizzard-like on the way after Nottingham. Luckily it wasn't settling on the roads and the journey was stress-free. I went to a school to give a training session for Lyla who has MPSI. Mum, Sarah, attended and gave lots of input too and the school found the session helpful. Lyla is due to have surgery and we had discussions around how this will impact her education. After the session I drove to Leeds where I was meeting with Charlotte and staying overnight in preparation for our school assembly the following day.

Thursday – Charlotte and I woke early and after a hearty breakfast set off to Sam's school. Sam has MPSIV and has been on the clinical trial for Vimizim. Sam's family have been campaigning tirelessly to challenge NHS England. The assembly was attended by the local MP and the local press and television stations. Charlotte and I were given microphones and were quite nervous to have such an audience. The children at the school made a banner and letters and pictures for the family to take to 10 Downing Street.

After the assembly I gave an informal staff training session which was a question and answer meeting and discussion about how MPSIV impacts on Sam's education. Luckily the snow had begun to thaw on my way back home.

Friday – And it was back on the early train to another MPSI post HSCT clinic at Manchester Children's hospital....

Debbie Cavell

If you would like support from the MPS advocacy team please phone 0345 389 9901 or email advocacy@mpssociety.org.uk

Your Stories

Enola's TV Interview

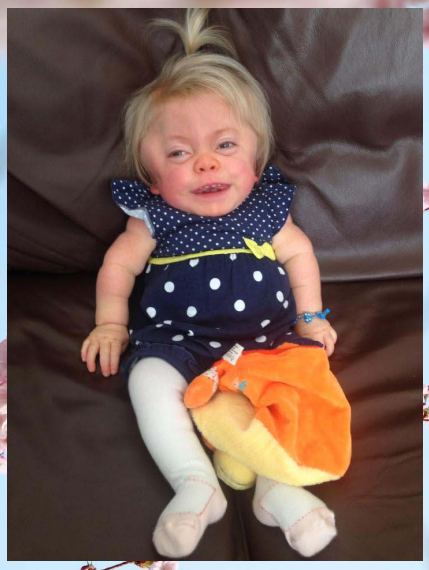
Enola Halleron-Clarke (MPSIV) was approached by radio and television to speak about what Vimizim means to her, and she has written in to tell us about her experience of being a media star!

Being on the radio and news was an amazing experience. On the day, my mummy picked me up from school early so we could get home for the reporter, David Guest. I didn't know anything about it till then. I was a little scared at first, but mummy said, "it will be okay, I'll be there all the time". I knew it was important because of my special medicine. Mummy had told me that it might stop in the future because the NHS can't make a decision. I need it because it makes me stronger and better at getting through the day.

David, the reporter, was really nice, he made me feel calm. He asked me to play with something, so I used my Lego. I think mummy was a little worried too. I answered some questions, which was a bit weird, but I managed.

Actually, being on the news was really fun and I had the best time ever. I felt like a movie star with all of the lights and cameras; it was amazing, I only wish I could do it again.

Enola Halleron-Clarke



Gracie's Story

On 3rd December 2012 our beautiful daughter Gracie Bella Sims was born. She was tiny at just 5lb, but so perfect in every way. We loved her so much from the minute we saw her and somehow that love managed to grow every day. On 6th February 2013, at 2 months old, she was diagnosed with Mucolipidosis Type II (I-Cell Disease). We were devastated; we were told that our daughter would probably not live to see her first birthday, that she would fail to thrive, be in and out of hospital and need assistance feeding. No new parent is ever prepared to listen to such heart-breaking diagnosis. So we went away and let Gracie have as much of a normal life as possible. She had some appointments up in London and she had local physiotherapy and speech and language appointments, but other than that she did amazing. Gracie managed to take her bottles well and then went on to solid food at 6 months old like any other child. She always stayed quite small, but she was our little Gracie and that's the way she was meant to be.

We made the most of every day – she was our bridesmaid at our wedding, had her own Christening day, went to Disneyland Paris, Cornwall on holiday, Lapland UK; she enjoyed swimming, music classes, she went to a McFly concert, the pantomime, made friends with Mister Maker, and even tried out horse riding. Gracie was our little miracle and she did so much that we were told she would never do. She had a big Minnie Mouse first birthday party with lots of friends and family. Gracie loved being the centre of attention

and was always smiling and giggling. She was always playing her favourite game 'Peekaboo'. She made our lives complete.

In April 2014 we found out that Gracie was going to be a big sister, something we always wanted for her. She is so happy and good with other children that we knew she would be the best big sister in the world. We couldn't wait to see them playing together and learning from each other.

"Gracie was our little miracle and she did so much that we were told she would never do."

On 27th May, we took Gracie to get her checked at the hospital after we thought she seemed not quite right; the hospital said that she appeared to be well but did a chest x-ray to be sure. The results showed that Gracie did have a chest infection so they planned to keep her in for a couple of days on antibiotics and then we would be allowed home. After only 2 days in hospital, Gracie took a turn for the worst. At 12:27am on Thursday 29th May, sadly Gracie passed away due to pneumonia and sepsis. The infection was more than anyone had realised and she was showing signs of doing so well. Our sweet little girl couldn't fight it anymore and had to go and be with the angels.

Every day without her gets harder and we miss her so much. Her little sister is due to be born in November (2014) and we know that Gracie will be watching over her. We are simply devastated and still in shock; we have no regrets, just many happy memories that we shared together. Gracie gave us the best 18 months of our lives and she will always be our precious baby. She taught us how to live life to the full and for the moment. We learnt never to take anything for granted and every day is a blessing. Mummy and Daddy love her more than anything in the world.

Lauren and Mat Sims

As featured in our Winter 2014 magazine, Lauren and Mat welcomed Gracie's little sister, Nancy Gracie Sims, into the world on 13th November 2014.

Samantha's Story

Proud mother, Samantha, might suffer with MPSI Hurler Scheie, but she has not let her condition stop her achieving her dream of having a happy family of her own.

As a girl I remember thinking how I longed to get married and have a family, knowing that with my condition it was probably never going to happen.

When I was 9 years old I was given the chance to take part in the trial for enzyme replacement therapy and it was the best choice anyone could of made as it has given me the life I have today which would have been completely different I am sure if I did not take it. I am always thankful for this treatment it has been truly lifesaving for me.

I am now nearly 24 years old and got married in 2013 and live in my own house that in itself is something I thought would never happen to me!

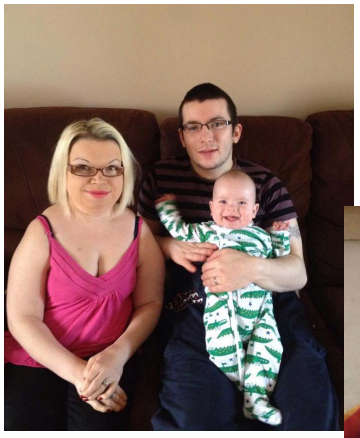
But, last year I had a baby, a little boy Leo John, weighing 5 lb 11 oz, born via cesarean section at 37 weeks.

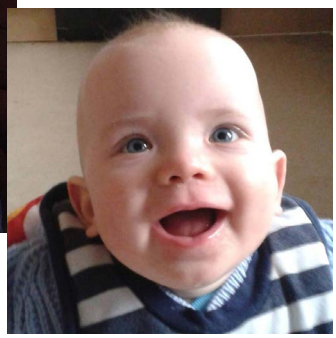
The pregnancy went better than I thought it would but still had its hard moments, I thought I would end up staying in hospital for a long time and was constantly worried that the baby would come early, but that never happened.

The problems I had in pregnancy were I got SPD, which is hip and lower back pains and could not move too much, just round the house towards the end. I also had pneumonia at 36 weeks; I never suffered with that before then but I think it was caused by me not moving with the pain in my hips and back. I luckily got sent home two days before my c–section! It was a chaotic week indeed.

Myself and the doctors decided that the safest way to have him was through c–section as if there was any hiccups the right anesthetists etc. would be there just in case of complications. There were many back up plans if certain things did not go right because of my condition. The doctors took each week as it came and watched my progress and weighed the choice of leaving the baby as long as possible for his health and making sure my body was ok to keep going but they did not want to push me too much, which is why they decided on the c-section at 37 weeks. We were sent home 5 days later.

It did go well I did not know whether It would be a boy or girl and got given my little boy who was born healthy





and bigger than I thought he would be as I am not that tall myself, 4ft 11.

My life has been complete though since he has arrived and he is a very happy, smiley baby. He is now 10 months old and is moving around and into everything. He is very cheeky and adventurous but I am lucky as he has slept through the night since he was 3 months old.

Even though I have my condition it does not stop me trying to reach my goals it just makes me more determined and it makes me grateful for things like my beautiful boy, my husband Ashley and my supportive family who are always by my side and have helped me a lot especially with appointments as I had a baby scan nearly every two weeks. I had back pain after having Leo too but it is slowly getting better with physiotherapy and time.

I thought I would send this story in as a positive as although we may have a condition you can still fight for things you want to achieve, it may take us longer and have more complications in the journey of getting that dream but it is all worth it. I am loving motherhood and am truly blessed. I am now just looking forward to having my own little family unit and raising our son.

Samantha Downey

Exploring the needs and experiences of women with an MPS or related condition during conception, pregnancy, birth and the postnatal period.

Are you a mum with MPS? Would you be interested in helping the MPS Society to learn more about the experiences of pregnancy in women with MPS?

If so, please get in touch with the advocacy team to find out more about our upcoming research project.
advocacy@mpssociety.org.uk

Jack Stuart

4th September 1994 - 29th December 2014

Jack lived the life he chose, not the one chosen for him! This was how a friend's mum described him when he passed away on 29th December 2014. And what a life it was, so much packed in to 20 years. This was driven by Jack's determination, resilience and spirit. I guess we, his family played some part in this as we never held him back and helped him to find ways to overcome his limitations. Jack had Hunter's, this is true - but it never had him. He was Jack - funny, friendly, sociable, bright, strong and at times grumpy! He was also quite a proficient complainer but this was mostly to do with "what was for dinner", our choice of TV (no Jeremy Kyle allowed in the lounge), our cheek at using his en suite and frequently his sisters, Emma and Millie. He however, never complained about his MPS, and was proud to belong to a unique brotherhood, along with Tom, Louis, Joshua, Jackson, Jake and Antimo, (to name but a few).

Health wise Jack stayed well until he reached 18 when it became apparent that his airway was not playing ball. In March, 2013 he was admitted to Royal Manchester Children's Hospital and under the care of the Dream Team; Rob Walker, Iain Bruce and Mike Rothera - he had a tracheostomy. This was a tough time for Jack, particularly when he lost his voice for nearly a month. He still had plenty to say and we got through half a dozen notebooks as he hastily scribbled down his opinions and requests. Again, most of his complaints were directed at the food, which was clearly not as good as "Mum's". (This did score me some brownie points). With the support of an incredible team of nurses, doctors and of course the legendary Willink Crew - Jack fought the fight and after 9 weeks he finally went home. He mastered the art of 'suctioning', carrying his pump with him in a backpack that was nearly as big as him! It drew some funny looks at times but he just shrugged them off in his usual way.

Apart from several return trips to Manchester for more surgeries and changes of T tube, Jack continued to live his life. He was learning to drive, had a part time job in a local pub, was enjoying the use of his mobility scooter and had the most fantastic group of friends. He also spent 4 hours a week with Liz, his PA, which included shopping trips, pub meals and much laughter. Jack also looked forward to his infusions on a Tuesday, as he was lucky enough to have a great team of very lovely nurses. In March 2014 he reached his goal and went on a fabulous holiday with his Dad, Greig and Uncle Ross to visit his cousins in Barbados. Jack definitely took to island life and became quite a rum connoisseur and lover of reggae. He planned to go back for his 21st birthday. Sadly this was not to be as Jack lost his battle with the deterioration to his airway.

"Jack lived the life he chose, not the one chosen for him"

Since his passing, the people of Calne, (our little market town), have supported our family and us. Jack didn't have a church and so instead the King's Arms, his local pub has been the focus of love and support. It was here that we raised a glass to him with his many friends on the evening he passed away. It was also here that we had his two wakes and a fabulous music night in memory of him and to raise funds for the MPS Society. He would have loved them all. He would also be delighted to know that the pub is naming one of the bars after him. His friends tell us he was an inspiration and a legend and many are struggling to adjust to life without him, as are we. We will continue to support each other in Jack's bar. But we are blessed with the most amazing memories of an incredible son and brother who was the centre of our world. We will love and miss him forever but will always be proud of his legacy, his spirited determination to overcome the obstacles in his path.

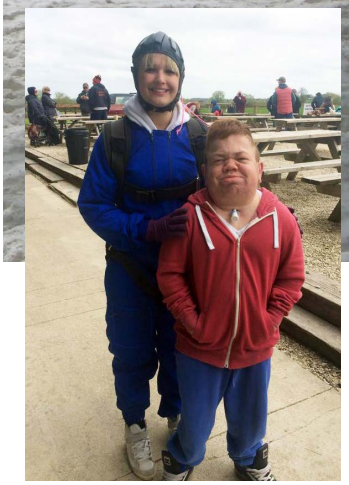
Manda Stuart (Jack's Mum)

We have received an overwhelming display of support in memory of Jack, from both family and friends, and we thank everyone who has donated or raised money in any way.

Last year Jack sister, Emma, bravely did a sponsored skydive for the MPS Society. Below she writes about this experience, her reasons for doing it and her plans for the future

On April 19th last year I jumped out of an aeroplane strapped to a stranger from 10,000 ft raising just under €1000 for the MPS society. Having a brother with MPSII Hunters syndrome was often difficult growing up and I am forever thankful to the MPS Society for the opportunity they gave me to attend the sibling weekends. It allowed me to meet with people that understood the difficult times and the worries that you face as a sibling. The conference weekends also allowed us as a family to know that we are not alone and the MPS Society has given us friends for life. I decided that I would raise as much money as I could for this amazing charity to say thank you. I also did it because I wanted to show my appreciation for all the help and support the MPS Society gave Jack and my family over the years. Sadly, Jack passed away at the end of last year and I am so thankful that he was there to watch me jump out of the plane. I am extremely grateful that I got to see his proud, smiley face after I had landed. I am going to do another jump but this time on my own. I am going to try and beat the money raised last time and it will be in memory of my amazing, hilarious, legend of a brother, Jack.

Emma Stuart



Celebrating Jack's Life

There are so many ways to individualise the funeral of a loved one and celebrate the uniqueness of the life lived to the full but cut so short. At the MPS Society we never ceased to be amazed by the forethought, dignity and courage of MPS and Fabry families who have lost a son, daughter, mother, father, brother or sister from one of these devastating diseases.

I was privileged to meet with Jack's parents, Grieg and Amanda and his two sisters Millie and Emma a few weeks after Jack died from Hunter disease, just months before his 21 birthday. Those who had the pleasure to know Jack will remember a larger than life, independent young man who lived life to the full and loved nothing better that being surrounded by his friends and family with a pint in hand!

In death as in life Jack made a big statement with the exterior design of his coffin. Although this is a difficult subject for so many of our members we are grateful to Jack's family for letting us show a picture of Jack's coffin as it is the first time we have seen wrap round family photos be used to such great effect in this way.

Christine Lavery

Colin Arrowsmith

Lessons to be Learnt

It was with great sadness to Colin's parents, John and Barbara, his sister, Claire and all Colin's extended family that Colin lost his life following a mitral and aortic valve replacement and 130 days in cardiac intensive care at the Freeman Hospital, Newcastle upon Tyne on 8th February 2012.

Prior to his planned admission to hospital Colin had enjoyed a wonderful family holiday in Sidari, Corfu, where the family had visited on many occasions and always had a fantastic time. Colin frequented the stands of his beloved 'Newcastle United' as he had been a season ticket holder since the age of 8. Colin passed his driving test first time at the age of 16, and drove himself to hospital for that fateful procedure. Colin loved life, adored his family and in equal measures he was adored in return by his family, friends and members of the MPS Society who knew Colin and his beautiful smile and infectious chuckle.

The Pathway to the Inquest

It took 2 years and 11 months to come to a full inquest hearing for Colin. It has been a painful and at times desperate time for the family who endured three pre-inquest reviews and at times wondered what if anything might be achieved. After all was said and done nothing was going to bring back a devoted son, brother, uncle, nephew, cousin or friend. In an effort to get answers the MPS Society supported the family to submit a complaint to the Freeman Hospital. This was met with a derisory response not worthy of the paper Sir Leonard Fenwick sent it on. Access to Colin's substantial medical notes was an unimaginable experience where the family were expected to view them in a smelly dirty staff room until Claire and I stepped in. In a little over four hours the family were expected to read the contents of 8 hospital files!

When requested by a bereaved family the MPS Society will support them through the inquest process especially when there is the possibility of a whitewash and injustice as was the case with Colin. The difficulty is that the Hospital Trust is always represented and there is no public funding for families to be represented at an inquest. At the risk of alienating the Coroner I and Trustee, Jessica Reid, supported the Arrowsmith family at the first pre-inquest hearing and whilst we persuaded the Coroner to provide the family with a complete set of Colin's Hospital notes for the period, we knew we needed to find a barrister if we were to get justice for Colin. Jessica's networking as a solicitor led us to Paul Clarke who generously agreed to represent the Arrowsmith family pro bono resulting in a just inquest for Colin with a narrative verdict.

Lessons to be learnt

Following Colin's death there were many unanswered questions for Barbara, John, Claire and extended family members. The Coroner's narrative verdict and letter under Rule 28 at least recognised the less than optimum care and communication endured by Colin and his family. The Rule 28 letter (printed in its entirety on the following page) alerts the Secretary of State for Health and NHS England to new measures needed and enables the MPS Society to work with expert clinicians and NHS England to bring about robust National Standard Operating Practices (SOPs) in respect of transitioning and adult MPS patients due to undergo a surgical procedure. We have no doubt that this will save lives and it would be what Colin wanted even though his life could not be saved.

In other words Colin's Protocol

However whist a formal protocol is drafted and agreed, parents of transitioning young adults and adults with MPS and related lysosomal storage diseases can take important steps to achieve the best surgical outcome possible. Sadly due to the nature and complexity of these diseases this may not be the outcome desired but at least the right

communication pathway, surgical team, anaesthetic and ENT team as well as the LSD Expert Physician should be working together.

Act Now
Ensure you discuss any proposed surgery in detail with your LSD Expert Clinician as well as the team proposing to carry out the surgery.

Ensure your LSD Expert Clinician is included in the Multi-Disciplinary Team (MDT) meetings in relation to your surgery

Be prepared to have the surgery in a hospital supported and recommended by your LSD Expert team even if other try to persuade you otherwise.

Ensure there is the level of anaesthetic and airway expertise to support the complex needs of your condition. If you are not comfortable with this level of expertise or don't know speak to your LSD clinical Expert.

Be sure you understand the communication strategies between your LSD clinical Expert and the surgical team. If you are not comfortable with the level of communication speak to your LSD clinical Expert and the surgical team about this.

Be sure you understand the nature of the surgical procedure you are going to undergo, the risks taking into account your underlying disease and make sure YOU and YOUR PARENTS / CARERS READ THE CONSENT FORM and understand it BEFORE SIGNING IT. IF YOU HAVE ANY QUESTIONS ASK BEFORE SIGNING!

Christine Lavery

Regulation 28 - Report to Prevent Future Deaths

Following the inquest of Colin Arrowsmith, Senior Coroner for the City of Newcastle Upon Tyne, Karen Dilks, wrote to the Secretary of State for Health, Jeremy Hunt under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 setting out matters of concern and making recommendations that could prevent future deaths in MPSII and of absolute relevance to all our adults with MPS, Fabry and other related Lysosomal Storage Diseases.

The conclusion of the inquest on Colin was a narrative conclusion stating that Colin died due to a combination of complications of surgical procedures and his underlying MPSII, Hunter disease. His death followed a long and complicated post-operative course.

The Coroner's Concerns are that during the course of the inquest the evidence revealed matters giving rise to concern. In the Coroner's opinion there is a risk that future deaths will occur unless action is taken. In the circumstances it is the Coroner's statutory duty to report these concerns to the Secretary of State.

The matters of concern are as follows:-

1. There are no national guidelines or protocols for the management of Adult MPSII patients (this is the case for all MPS and related diseases)

2. There are no national guidelines or protocols for pre-operative assessment of Adult MPSII patients (this is the case for all MPS and related diseases)

3. There are no national guidelines or protocols requiring mandatory input / advice from a specialist centre to assist in the management of Adult MPSII patients (this is the case for all MPS and related diseases)

4. Absence of 'ideal' national expert centres with requisite equipment, facilities and staff to manage and undertake complex procedures for Adult MPSII patients leads to a resulting risk that is preventable such patients will occur in future. (this is the case for all MPS and related diseases)

5. The provision of such facilities could prevent future deaths

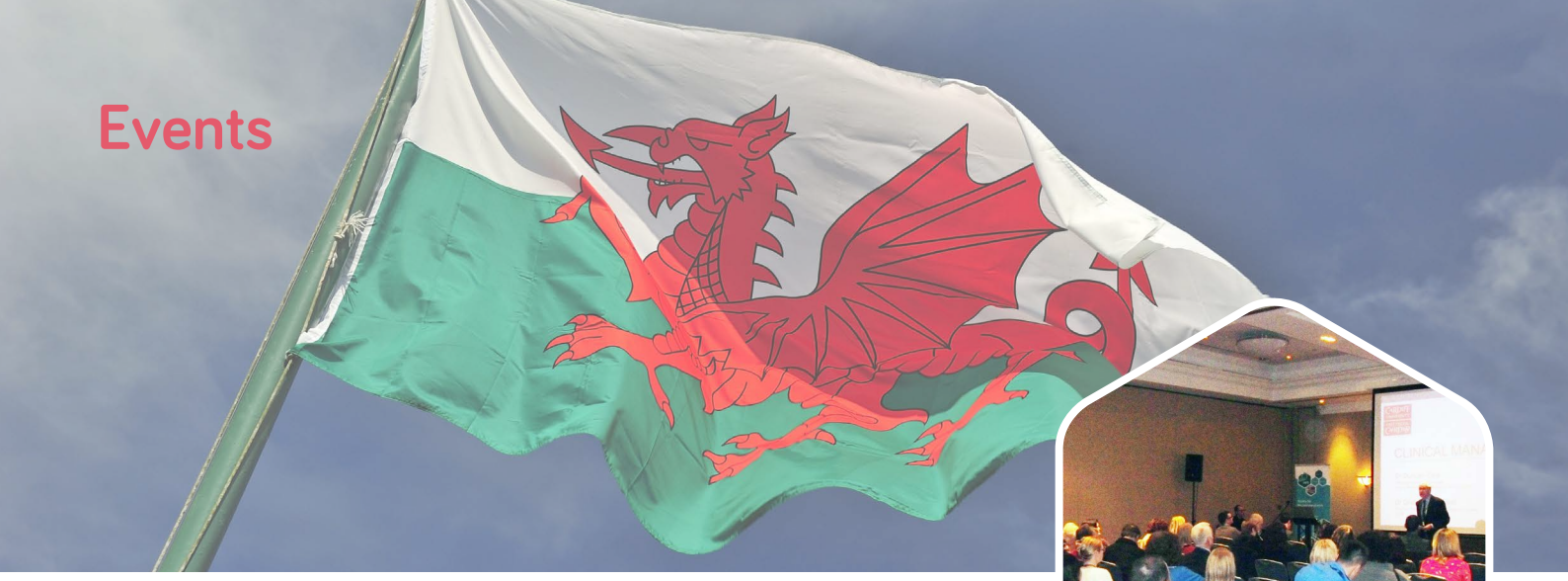
It is the opinion of the Coroner that action should be taken to prevent future deaths and she believes the Secretary of State has the powers to take such action.

The Secretary of State is duty bound to respond to this report within 56 days of receiving the Coroner's Report namely 2 April 2015. The Secretary of State must set out details of actions taken or proposed to be taken, setting out a timetable for action. Otherwise the Secretary of State must explain why no action is proposed.

The MPS Society has written to the Secretary of State to remind him of his duties and urge him to use his powers to implement national guidelines and make it mandatory for the patients' expert clinician to provide meaningful advice and input into their patients' overall clinical management when being treated in another department or hospital to ensure the complex needs of these patients are managed safely on a daily basis.

If anyone has concerns for themselves or a family member when hospitalised please talk / contact your MPS, Fabry or LSD specialist or contact the MPS Society Advocacy Team on 0345 389 9901.

Events



Welsh Information Day

On the 16th January the MPS Society hosted a one day conference at the Marriott Hotel Cardiff. There was a full programme with a variety of speakers giving information about MPS conditions, relevant services available in Wales and varying perspectives in relation to access to treatments, including those from commissioners in Wales. We heard particularly moving accounts from our members, their battle to achieve treatment for their children, hopes for the future and the sacrifices that they have had to make to access treatment.

The day was certainly a great success with many families and professionals in attendance and with ample opportunity to have far reaching discussions and to ask questions to those that have answers, I know that many of our members came away with more questions for the Welsh Assembly and intended to pursue these following the meeting.

The MPS Society would like to thank all speakers and delegates for their contribution to making the day such a success.

Steve Cotterell
Social Work Student

UPCOMING EVENT

Northern Ireland 20th Anniversary Meeting and Dinner

The Identification and Management of MPS in Northern Ireland
A Twenty Year History
14th May 2015

With talks from professionals on subjects ranging from the diagnoses of MPS disorders and current treatment, to the history of the Northern Ireland clinic and the role of the MPS Advocacy and Support Service, this meeting will prove especially informative to professionals, and also anyone affected by an MPS disease.

The meeting, finishing at 5:30pm, will be followed by a drinks reception and buffet dinner to celebrate the 20th anniversary of the Northern Ireland clinic. In recognition of MPS Awareness Day on the 15th May, the dinner will have a Wear It Blue theme!

The meeting and celebratory dinner is free of charge for MPS sufferers and their immediate family. Professionals are also welcome to attend for free and will be able to claim CPD points for the meeting.

If you are interested in attending or would like some more information, please email Alison at a.wilson@mpssociety.org.uk

London Transition Focus Group

Sophie and I arrived at the O2, in South-East London, on the morning of the 22nd February for a transition focus group event. This event was part of our work to support young people through transition, as funded by the City Bridge Trust, the city of London Corporation's Charity,

It was bright and chilly so perfect for the Emirates Airline Cable Car. We were joined by our invited group of young adults and we were soon suspended high above London with far reaching views across the city to Canary Wharf, the Gherkin and Shard. At the other side of the Thames we found a café and introduced the purpose of the day. Discussions began and soon we were staring to understand the challenges, positives aspects and support areas for those entering and going through the various transitions in life such as becoming an adult, moving to adult health and social care, the journey through education. Ideas for projects came thick and fast with discussions about forums, social events, publications and further focus groups at conferences. Soon enough it was time for lunch and we headed to a restaurant and our discussions continued. We talked of the support that the MPS Society currently provide and ways in which we can offer more and improve our services to young people in transition. The feedback provided will be invaluable in the development of our service and we hope that such developments will be positive for the young people we support. We also took the opportunity to discuss the health transition passport that has been devised. if anyone has any further comments about this document or indeed about the support we offer, please do get in touch.

After lunch there was an opportunity for our young people to relax, get to know each other better and to enjoy some of the entertainment available at the O2: car simulators, racing wheelchairs and sky studios - all good fun. All in all the day was a great opportunity for the MPS Society to gather feedback and to devise future projects, and also for young people to get together and make friends. We would like to thank the City Bridge Trust for supporting our work in this area.

Steve Cotterell
Social Work Student

If you have any comments about the Health Transition Passport or the support the MPS Society offers, please get in touch by calling 0345 389 9901 or emailing advocacy@mpssociety.org.uk

Photos left to right: Carl, Simran, Louis & Tom in the cable car; the group playing the Game of Thrones!; Tom & Louis at the Sky Sports newsdesk

International

Rare Disease Day 2015

"Living with a Rare Disease: Day-by-day, hand-in-hand"

On 28th February 2015, hundreds of rare disease patient organisations around the world came together to raise awareness for rare diseases, and the MPS Society was no exception.

Together on this day, these organisations sent out an international message of solidarity, showing support for those affected by a rare disease and to advocate for the treatments, care, resources and services that are needed by pushing for an advance in rare disease policies.

This important day was initially launched by Eurodis, a non-governmental patient-driven alliance of patient organisations, which represent over 600 rare disease patient organisations in more than 50 countries. Since its launch the campaign has grown from year to year, becoming truly worldwide. 2015 saw first-time participants from Bolivia and Estonia, who joined organisations from such diverse places as the Philippines, Russia and Hong Kong.

If you follow the MPS Society on Facebook (www.facebook.com/mpssociety) you will have seen our post highlighting Rare Disease Day which contained a link to the official video, which brings to the fore the day's theme of 'Living with a Rare Disease: Day-by-day, Hand-in-hand' – essentially the importance of the friends, families and carers whose daily lives are affected by rare diseases. This video, along with numerous other communications and the thousands of awareness-raising events, which took place across the globe, helped to pull rare diseases into the spotlight.

You can still take a look at the official Rare Disease Day video by searching 'Rare Disease Day 2015' on YouTube.

Rare Disease Day at Genzyme

On 27th February I was invited to come along to Oxford to help mark Rare Disease Day with pharmaceutical company, Genzyme Therapeutics. Representatives from other rare disease groups, such as Toni Matheson from Niemann-Pick UK and Helen Whitehead from Gaucher's Association, were also present.

After an opening from Brendan Martin, General Manager UK&I for Genzyme, myself and each of the representatives there took turns to give an overview of our charity did and how we support our members, as well as speaking about our fight to raise awareness of our respective conditions.

Genzyme had invited members of staff and visitors from other offices around the estate to hear the presentations. The afternoon was rounded off by some very good cakes especially made for Rare disease day.

Thank you to Genzyme for helping to raise the profile of rare diseases on this special day.

Rebecca Brandon
Advocacy Support Officer

Top photo: Helen Whitehead (Niemann-Pick UK); Toni Matheson (Gauchers Association); Brendan Martin (Genzyme); Rebecca (MPS Society); Viv Beckett (Genzyme)

Research

Abeona Therapeutics and Nationwide Children's Hospital - Columbus, Ohio

Abeona Therapeutics was founded in 2013 and has a mandate to develop therapies for patients with lysosomal storage diseases, including MPSIII. Abeona has exclusive rights to to develop its two lead products: ABX-A and ABX-B, for MPSIII. These therapies have been developed by Dr Doug McCarty and Dr Haiyan Fu at Nationwide Chgildren's Hospital (NCH). Abeona is currently working with these doctors and scientists at NCH to get ABX-A ans ABX-B through the regulatory asnd manufacturing processes necessary before clinical trials in humans can begin. Progress to date:

Natural History Study at NCH
This study has nearly completed recruiting the 15 MPSIIIA and 10 MPSIIIB patients to the study. A data review is underway and this will provide data to justify the clinical efficacy endpoints for the clinical trials.

Clinical Trials for MPSIIIB
It is expected that the IND (Investigational New Drug) application for MPSIIIB trial in the USA will be submitted very soon and within 30 days the FDA will issue an IND allowance. This will allow the NCH Internal Review Board to give its approval shortly afterwards. The clinical programme plans to recruit six to nine MPSIIIB patients in the USA. It also plans to run a similar clinical trial in Spain recruiting another six to nine patients. It is anticipated that recruitment will start in the USA and Spain later in 2015.

Clinical Trials for MPSIIIA
The MPSIIIA clinical trial programme is still in its pre-IND stage and a few months behind the MPSIIIB clinical trial programme.

MPSII Evidera Research Study

Are you diagnosed with Mucopolysaccharidosis Type II (MPSII), otherwise known as Hunter syndrome?

Or do you have a child at least 3 years old who has MPSII, Hunter syndrome?

If so, you and/or your child may be eligible to participate in 1 or more non-treatment research studies.

The goal of this research is to learn more about the natural progression of the disease, as well as the daily life and impact of living with and providing care for children with the disease.

For more information about this research, please call us at the MPS Society on 0345 389 9901 and leave your name and contact information.

Once you have consented to participate we will either pass on your email address or mobile number to Evidera who are conducting this research

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If you or your child qualify to participate in one or more of these studies, you may be asked to do the following:

• Either take part in a 1-on-1 parent/caregiver phone Interview Study
• You will be asked to take part in a 1-time phone interview that will last about 60-90 minutes and complete several brief questionnaires.
• You will receive £65 in the form of a select voucher of your choice (such as Tesco, John Lewis, M&S, Boots).

OR

• Take part in a Questionnaire Study
• You and/or your child will be asked to fill out several questionnaires at 2 time points about 2-4 weeks apart.
• The first set of questionnaires should take about 45 minutes to complete, and the second set of questionnaires should take about 15-30 minutes to complete.
• You will receive £50 in the form of a select voucher of your choice (such as Tesco, John Lewis, M&S, Boots) if both you and your child participate. Or, you will receive £30 in the form of a select voucher of your choice (such as Tesco, John Lewis, M&S, Boots) if only one of you participates.

LYSOGENE

Mucopolysaccharidosis IIIA (MPS IIIA) or Sanfilippo syndrome type A – clinical research study

Lysogene plans its phase II/III clinical study, to assess the efficacy and safety of its AAVrh10-SGSH gene therapy, in MPS IIIA patients.

Key Study Facts:

• Inclusion and exclusion criteria are being defined for participation in the phase II/III study. Inclusion criteria are characteristics that the prospective subjects must have if they are to be included in the study, while exclusion criteria are those characteristics that disqualify prospective subjects from inclusion in the study. Inclusion and exclusion criteria may include factors such as age of the patient and stage of the disease.

• Clinical trial sites will be selected in Europe and the US.

• Patients will be eligible to participate from a variety of geographical locations.

• We currently envisage that patients recruited to the trial will need to relocate to one of the clinical trial sites for an initial period of a few weeks. Additional visits to the clinical site, for a day or two, will be planned every 6 months. Patients can be seen by their normal treating physician for non-trial consultations.

• Two to three face-to-face meetings between families and the investigator at the clinical trial site, will take place before formal inclusion. Translation will be provided when necessary.

• An information letter and informed consent document, in the parents' own language, will be provided before inclusion into the study

• Arrangements for travel to clinical trial sites will be made through our partner. They will provide a safe and independent logistical resource to families of children recruited to the trial. This resource will continue to support families throughout the time their children are on the clinical trial.

• We will set up a patient/family logistics and reimbursement policy to be implemented for patients recruited to the study

• We are currently working towards a start-date of the trial for the beginning of 2016

About Lysogene

Lysogene is leading in the basic research and clinical development of gene therapy for neurodegenerative disorders. Our mission is to radically improve the health of patients suffering from incurable life threatening conditions. We do this by developing AAV vectors that have demonstrated their effectiveness in safely delivering genetic material to the central nervous system.

Contact:
samantha.parker@lysogene.com

It is very difficult to give you a synopsis of where we are up to as the situation is changing at such a fast pace the moment we go to print this article will be out dated. So instead, with the input of some of our families, we will update you with what we have been doing and the impact it has been having.

Angela Paton and Katy Brown have kindly written about their experiences campaigning for Vimizim which gives you an overview of our actions on this battle over the next few pages.

The pharmaceutical industry have been pushing to engage with NHS England but unfortunately to no avail. BioMarin, following this lack of communication from the NHS, have been left with no choice but to make plans to withdraw free drug currently being offered compassionately to those who were on the clinical trial. Whilst this is hugely disappointing we need to maintain pressure and expose the failings of NHS England. While these failings are directly affecting Vimizim for MPSIVA now, the outcome will also have implications for future treatment developments for ultra-rare diseases.

We have been hugely supported by Greg Mulholland MP. On top of him trying to coordinate MPs across the parties and asking questions no less than 3 Prime Minister's questions and Health Questions, he has also tabled an Early Day Motion. We are hugely grateful for all his support in demanding answers and demonstrating the current failings.

We know we have made an impact politically: David Cameron has been asked a direct question on television about Vimizim and although he wasn't entirely accurate in his response he knew what the question related to and responded.

On occasions people have asked 'is it about money?' but we have been told by NHS England that it isn't about the money it's about governance. However poor governance shouldn't impact on the lives of children and young adults.

David Suchet has supported the campaign highlighting NHS England's failings with a YouTube made with the Tuberous Sclerosis Association featuring Sam Brown. You can find the video by looking up '#Fight4Treatment with David Suchet' on YouTube.

If access to treatment is important to you there are a number of ways you can help

Actions

- Contact your MP
- Share our David Suchet video calling for action
- Do you have any media contacts or famous friends?
- Please follow us on Facebook and Twitter
- If you use twitter please tweet with #Fight4Treatment or #fundourdrugsNOW

If you do have any correspondence with your MP please share it with us. Through tracking the different responses received from all the correspondences to date we have been able to highlight the lack of clarity to the Health Select Committee to demonstrate the need for them to intervene. Thank you so much to everybody who has been in touch and is doing everything they can to raise awareness of the campaign. We look forward to hearing from you with any updates soon.

Charlotte Roberts
Communications Officer

Picture (above) shows Sam Brown delivering his petition to No 10 Downing Street as featured in BBC News in Pictures

The Fight for Vimizim

Katy Brown

Mum to Sam Brown (MPSIV) and passionate campaigner in the fight for treatment

Well, it has certainly been a busy few months on the Vimizim campaign trail. After a frustrating meeting in Westminster with George Freeman, Minister for Life Sciences, in November, we had a quiet family Christmas and then started the year with an open letter to the press, expressing how we feel about the debate and delay surrounding the NHS funding of Vimizim. We were hoping for some national press coverage, and despite some interest unfortunately we didn't manage to make it happen.

Then in January Sam's school held an assembly to talk about Morquio, and then the whole school made a banner and wrote letters and drew pictures for us to take to Downing Street to hand in to the Prime Minister. It was an amazing day, and we got some fantastic local TV, radio and newspaper coverage. A week or so later, traveling with ITV and BBC local news we headed down to Downing Street with Sam to hand over our petition. We didn't get to meet the Prime Minister unfortunately, nevertheless we certainly got our message across. We were astounded to discover that the picture of Sam at Downing Street made it into the BBC's Week in Pictures - which showcases the best global news photos of the week!!

Then proving how beneficial good local journalists and press contacts can be, two things happened in one day. Sam and I appeared on national BBC Breakfast News - which was a fab experience - and then in the evening our local ITV news programme took the opportunity to directly ask David Cameron about Vimizim whilst he was visiting the region - meaning that the issue was firmly put to the Prime Minister's attention.

The support of our MP Greg Mulholland has been superb throughout. He has gone above and beyond the call of duty, really taking Sam's case and the cause to heart. He has raised the issue twice directly to David Cameron during Prime Minister's Questions, and once during Health Questions. He has organised a letter to David Cameron signed by a number of MPs, and in the last few days raised an Early Day Motion - which we are hoping to get as many MPs to sign as possible.

In the past few months I've learnt a lot about politics. Unfortunately we are still in the middle of a lot of smoke and mirrors, with no one prepared to give a straight answer to a simple question. The buck, it would appear, stops with no one.

If the Vimizim campaign is to be successful, it needs continued action from every single one of us. We have to appear to be bigger than we actually are. Letters and emails to every MP, re-tweet every tweet, share and share on Facebook - and if you feel able to, get in touch with local media. Our experience has been overwhelmingly positive. They are journalists, but they generally have local interest at heart, and will fight your corner for you. Keep Sam Smiling has now almost 3,000 followers. Some of the posts have reached over 40,000 people. The power of social media is immense and if we all continue to join together as we have done in the past few months ... who knows where this could lead!! We need the government to know that the current situation is unacceptable and that we will not be fobbed off. They need to know that we will not stop. My sense is that behind the scenes they know this already. Continuing to increase the pressure and the profile of Vimizim through as many voices as possible is the only way that we are going to get the solution that every single Morquio sufferer deserves. All of us have incredibly powerful stories to tell.

Hope unfortunately is not a strategy. Believe you can and you are already half way there.

Katy Brown
@KeepSamSmiling

The Fight for Vimizim

Angela Paton

When I started the clinical trial for Vimizim I had many different worries, hopes and thoughts about what the trial would bring. I never imagined, however, that three years later I would find myself in the situation I am now in, fighting what often feels like a losing battle to gain access to this treatment on the NHS.

Vimizim has had a massive impact on my strength, stamina and overall quality of life, allowing me the opportunity to do so much more than I previously could. Instead of using this new found stamina and well being to spend more time with my friends and family, enjoying life, for the past few months, the majority has been spent trying to fight for continued access to Vimizim.

It has been a constant process of writing articles to highlight the situation to send to anyone and everyone who may listen, emailing MPs, the prime minister, journalists and anyone else who might have the power to intervene in this situation or at least bring it the attention it deserves. Pushing petitions and highlighting the situation in general on social media in the hope that the people seeing these updates will feel even a small amount of the rage and injustice that I currently feel about this situation. This process has been exhausting and the worry and stress sometimes quite overwhelming.

Yesterday's letter from BioMarin to NHS England was devastating. It is now an absolute reality that unless someone with the power to do so intervenes imminently, I will lose my treatment in ten weeks..

Today is infusion day for me and I have spent my morning filming for ITV Calendar news. I am usually a very private person and until very recently I would never have willingly chosen to appear on TV but I now feel so desperate and so helpless at the situation I find myself in that I feel I have no choice. If in ten weeks time I lose access to Vimizim I have to know I did anything in my power to keep it. I will continue to fight up to and beyond the point of losing Vimizim. NHS England and the people in power must realise that we will not go away and we will not shut up. There may not be many of us with Morquio but we still deserve the same chances in life as everyone else and I will not stop fighting until every person in the UK with Morquio is given that chance, until everyone who wants it gets Vimizim.

Angela Paton

PEDIGREE ANALYSIS: A CALL TO ACTION TO RAISE AWARENESS OF FABRY DISEASE AND THE IMPORTANCE OF FAMILY HISTORY EVALUATION

Nesrin Karabul[1]; Aoife Bradley[2]; Juan de Dios García Díaz[3]; Luis Figuera[4]; Roberto Giugliani[5]; Ozlem Goker-Alpan[6]; Christine Lavery[7]; Atul Mehta[8]; Lorraine Thompson[9]; Norio Sakai[10]; David G. Warnock[11]

[1]**Department of Paediatrics, University Medical Centre, Johannes Gutenberg University, Mainz, Germany**; [2]Belfast City Hospital, Belfast, Northern Ireland; [3]Hospital Universitario Príncipe de Asturias, Madrid, Spain; [4]CIBO-IMSS, Guadalajara, Mexico; [5]Med Genet Serv/HCPA, Dep Genetics/UFRGS and INAGEMP, Porto Alegre, Brazil; [6]Lysosomal Disorders Research and Treatment Unit, CFCT, Fairfax, VA, USA; [7]MPS Society, Amersham, UK; [8]Royal Free Hospital, London, UK; [9]Salford Royal NHS Foundation Trust, Salford, UK; [10]Osaka University Graduate School of Medicine, Osaka, Japan; [11]University of Alabama at Birmingham, Birmingham, AL, USA

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BACKGROUND

- Fabry disease is a rare, genetic disorder that is highly under-recognized and under-diagnosed[1,2]
- Early diagnosis is critical to prevent the life-threatening organ damage associated with the disease
- However, it can take over 10 years to achieve a correct diagnosis[3]
- It is known that for each index Fabry disease patient, there can be five additional cases in the same family on average[4]
- Family history evaluation can therefore be crucial in helping physicians identify at-risk relatives and offer these individuals testing and appropriate diagnosis and management

METHODS

- The *Pedigree Analysis* initiative was established in 2013 in close collaboration with an international, multi-disciplinary Steering Committee of 13 genetics and Fabry disease experts
- The Steering Committee comprised pediatricians, geneticists, a hematologist, a specialist nurse, and a genetic counsellor, in addition to the head of the patient organization Fabry International Network
- The objective was to form a "Call to Action" to raise awareness of Fabry disease and the relevance of pedigree analysis to its diagnosis

RESULTS

- The Steering Committee developed a range of educational materials and activities to raise disease awareness among physicians and highlight the importance of pedigree analysis and appropriate genetic counselling
- The materials included:
  - an information leaflet for patients and their families [Figure 1]
  - a "Call to Action" booklet for healthcare professionals [Figure 2]
  - a best practice slide deck for presentation to healthcare professionals [Figure 3]
  - a multi-platform digital tool allowing physicians to generate family trees for their patients [Figure 4]

Figure 1: Patient information leaflet, to inform patients about the genetics of Fabry disease and support their communication with family members

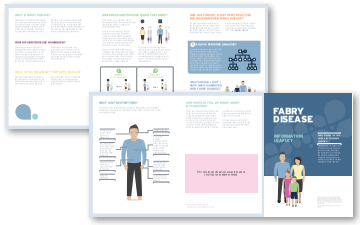


Figure 2: "Call to Action" booklet for healthcare professionals, to raise awareness of Fabry disease and the importance of pedigree analysis

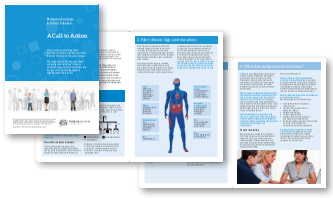


Figure 3: Best practice slide deck to be adapted and used at local meetings for healthcare professionals to raise awareness of Fabry disease and pedigree analysis

Figure 4: Digital genealogy tool, to enable healthcare professionals to conduct pedigree analysis for Fabry disease on a range of devices

- Exemplary case studies were included in the "Call to Action" booklet for healthcare professionals and included Pedigree diagrams to illustrate a patient's family history [Figures 5–7]

CASE STUDIES

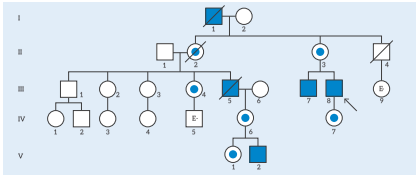
Key

Proband; Deceased; Not tested; Hemizygous male; Heterozygous female; E: Tested; family-specific mutation excluded

Case study 1 [Figure 5]

- The proband (male, 25) was diagnosed with Fabry disease after renal failure. His mother (II-3) was identified as heterozygous for the family-specific Fabry disease mutation
- Analysis of the family medical history revealed that individuals I-1 and II-4 had died of stroke, suggesting that they might have been carrying the mutation. Individual III-5 had also been suffering from strokes, and further investigations revealed that individual III-2 had been diagnosed with fibromyalgia/multiple sclerosis
- Following pedigree analysis and targeted testing, patient IV-6 was found to carry the family-specific Fabry disease mutation, as were her two children (V-1 and 2), who had been experiencing multiple pain crises but were without a diagnosis. Cases I-1, II-2 and III-5 were then identified by pedigree analysis, patient III-4 by targeted testing, and patient III-7 by clinical analysis. Individuals III-9 and IV-5 were tested and found free from the Fabry disease mutation
- Targeted testing is recommended for the other at-risk individuals in this family (III-1,2,3) and, should they be diagnosed with Fabry disease, their progeny (IV-1,3,4). (Adapted from materials courtesy of Dr O. Goker-Alpan, LSD Research and Treatment Unit, CFCT, O&O Alpan LLC, Fairfax, US)

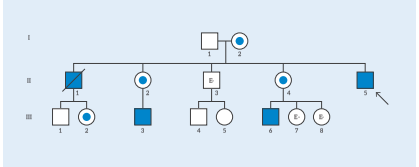
Figure 5: Pedigree diagram for case study 1



Case study 2 [Figure 6]

- The proband (male, 23) presented with angiokeratomas, and was referred to the geneticist by a dermatologist who raised the possibility of Fabry disease. The geneticist then noticed that the patient also complained of pain in the hands and feet during winter time that was sometimes of high intensity and not relieved by usual pain killers
- The patient was not aware of family members presenting with similar symptoms, but reported that his older brother (II-1) had died after being treated with hemodialysis for some years, and that one of his sisters (II-2) had a hospital admission due to cardiac arrhythmia. The son of this sister (III-3) had a stroke at the age of 37 years, and the son of his other sister (III-6) was being evaluated following findings of proteinuria
- Following mutational analysis, the proband was diagnosed with Fabry disease. Further investigations of the family conducted by interviewing relatives and reviewing their medical records, as well as biomedical and genetic tests allowed the identification of the affected individuals in the family (I-2, II-2,4 and III-2,3,6), as depicted in the pedigree diagram below. (Adapted from materials courtesy of Prof R. Giugliani, Clinic Hospital of Porto Alegre, Rio Grande do Sul, Brazil)

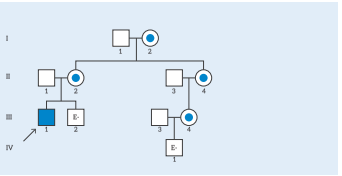
Figure 6: Pedigree diagram for case study 2



Case study 3 [Figure 7]

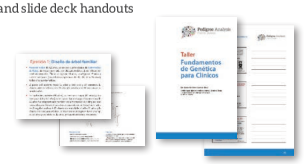
- The proband (male, 16) presented with thriving difficulties and was diagnosed with Fabry disease. The patient's mother (II-2) had been previously diagnosed with chronic fatigue, the aunt (II-4) with multiple sclerosis and the grandmother (I-2) had severe pain and suffered from depression
- After having been misdiagnosed for several years, they were all found to be affected by Fabry disease following pedigree analysis and testing. Targeted testing also identified the proband's cousin (III-4) as heterozygous for the Fabry disease mutation, whereas his brother (III-2) and second degree cousin (IV-1) were unaffected. (Adapted from materials courtesy of Dr N. Karabul, Children's Hospital of Johannes Gutenberg Universitätsmedizin, Mainz, Germany)

Figure 7: Pedigree diagram for case study 3



- The Pedigree materials have been translated, adapted and distributed to audiences around the world; each local modification addresses the specific needs of that particular country and takes into account differing privacy laws on the disclosure of patients' family medical history
  - Local adaptations have taken place in Spain, Turkey and Germany and the initiative is now being rolled out globally
- Spotlight on the local adaptation of the *Pedigree Analysis* initiative in Spain
  - To date, five meetings have taken place: in Alcazar, Barcelona, San Sebastián and Madrid
  - A range of supplementary materials were developed for these meetings including a workshop manual and slide deck handouts [Figure 8]
  - All attending physicians had some experience in managing Fabry disease patients but a limited understanding of genetics
  - Feedback from local meetings was extremely positive: 100% of attendees would recommend the meetings to peers, 100% would attend a second workshop session, and 98% considered the speaker as the most influential clinical geneticist in Spain
  - There are future plans for nine more Spanish meetings with 5–8 attendees each

Figure 8: Locally developed Spanish meeting materials; a workshop manual and slide deck handouts



- Regular genetics meetings are also ongoing where the Steering Committee and other experts educate small groups of physicians on pedigree analysis and genetic counselling using educational content generated by the initiative
  - To date, four meetings have taken place in European locations with plans for quarterly meetings and expansion to other regions moving forward

CONCLUSION

- The initiative has generated a range of educational, expert-led, and local-specific content
- Positive feedback from healthcare professionals and patient organizations affirmed the *Pedigree Analysis* initiative's objective of increasing awareness of Fabry disease and providing information on both the condition and family history evaluation

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The authors thank Andreas Gal and Dominique P Germain for their contribution to this project

Fabry Disease

Information & Resources

The Charlie Cookson Foundation

The Charlie Cookson Foundation (CCF) provides financial support to parents of seriously ill children with life limiting conditions that require 24 hour nursing care or specialist nursing facilities.

Parents can apply for support with mortgages, utility bills, food, petrol or any other costs which may be difficult to keep up with when caring for a seriously ill child. Financial support is provided over a three month period within our one payment budget.

If you would like to learn more please take a look at their website: http://www.charliecookson.co.uk/

AskSARA

Ask Sara is a great resource where individuals can complete self assessments for a range of needs and equipment and they can provide advice and signposts for daily living. They also can loan equipment for trial for up to two weeks.

Take a look at their website for more information: http://asksara.dlf.org.uk/

Over the Wall camp

Over the Wall children's charity, founded by the late Paul Newman, is unique in the UK and a member of The SeriousFun Children's Network.

Their free therapeutic recreational activity camps boost the confidence and self-belief of seriously ill children aged from 8 - 17, helping build their resilience and allowing them to see themselves as someone other than just a child with an illness.

They also run free camps for siblings and family weekends.

http://www.otw.org.uk/

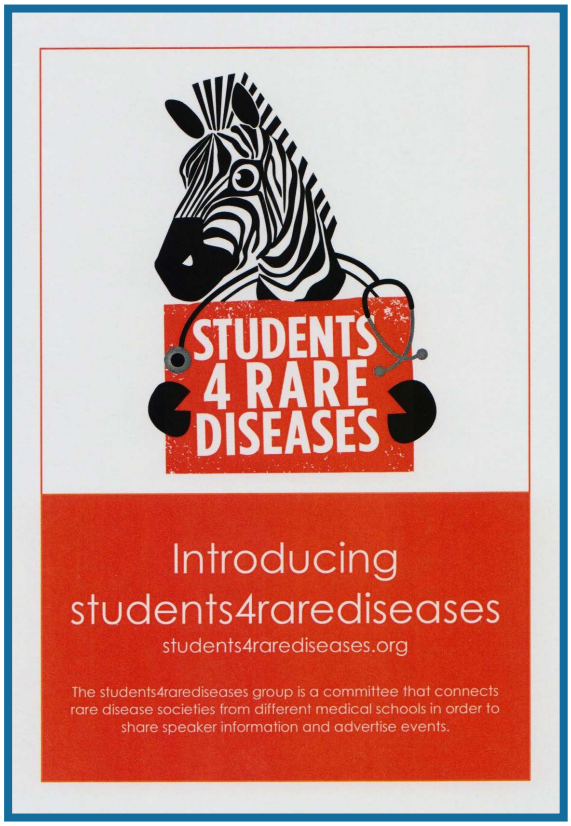
FODMAP Diet for Fabry Disease

If you have Fabry Disease and suffer with gastrointestinal problems, it has been suggested by professionals working with Fabry patients, that the FODMAP diet has proved to help alleviate some of these digestive symptoms.

Usually used to treat Irritable Bowel Syndrome, FODMAP is an acronym for Fermentable Oligo-, Di-, and Mono-saccharides And Polyols, and the diet focuses on lowering the amount of these nutrients consumed.

Although there is a long list of foods that are high in these FODMAPs, there are luckily just as many that are low in them, and these are the foods to stick to.

You can find a full list of high and low FODMAP foods by visiting http://www.ibsdiets.org/fodmap-diet/fodmap-food-list/



Previous page: information poster on the pedigree analysis of Fabry Disease.by Christine Lavery et el.

Matt Carter did a great job of supporting his son, Jacob, who recently underwent a Bone Marrow Transplant. Matt raised a spectacular £3,211.02 for the MPS Society at the same time!

You can read more on page 33.

Fundraising

Welcome to the fundraising section of the Spring 2015 MPS Magazine.

In our last edition we were hard pushed to fit all of your fundraising stories in (which is a fantastic problem for us to have!), and you have shown no sign of letting up. So many of you have been in contact to report your fundraising plans - many of which are active events: runs, marathons, cycles and walks. Thank you to everyone who has registered for such an event, and to anyone that is considering undertaking a physical challenge to fundraise, you can read more about the charity places we have left on page 41.

As you will all be aware, MPS Awareness Day is fast approaching, and this is the day when we need to pull together to really make a noise about MPS, Fabry and all the related diseases. We have included an article on page 38 on this special day, Wear It Blue and our new idea for all those with a guilty conscience!.

Thank you so much to everyone who has fundraised for us and everyone who is currently fundraising for us. Without your help we would not be able to continue doing what we do. Please do remember to tell us about your fundraising, and to include your name and details with any donation you make to us so we can thank you properly. You can contact us either by giving us a call on 0345 389 9901, or by emailing fundraising@mpssociety.org.uk.

Elkie Riches
Fundraising & Communications Officer

Roman Road Primary School Wear it Wicked!

Roman Road Primary School in Gateshead managed to produce a lot of little monsters, ghouls, witches and skeletons last Autumn - and all for a good cause!

The school council loved the idea of our Wear it Wicked campaign so they decided to make it the Autumn fundraiser for the school! 2014 saw them get the whole school involved with a Wear it Wicked breakfast for carers and children. It was a brilliant success, raising a huge amount of awareness throughout the local community, and the children had a truly wicked time!

Our thanks to the staff and children of Roman Road, for their amazing fundraising and their frighteningly fang-tastic costumes! Altogether the children raised £204.

Fancy Dress for Fabry

Glen Cowles recently celebrated his 50th birthday by holding a fancy-dress party at his local leisure centre in aid of Fabry Disease.

Glen and his two nephews, Joe and Josh (pictured above as Batman and the Joker), all suffer with Fabry, so the MPS Society is a charity close to their hearts.

The night raised a brilliant £200, and we were pleased to read in Glen's letter that all his friends and family had a great night.

Matt's Fundraising for Jacob

Before Jacob Carter (MPSI Hurler) underwent seven days of gruelling chemotherapy in the lead-up to receiving his Bone Marrow Transplant, his parents, Jen and Matt, were aware that he would lose his lovely red hair as a result. It was decided that Matt would shave his head to support his son and to raise funds for the MPS Society at the same time.

True to his word, Matt shaved his head on the same day that Jacob received his cells and the sponsorship came flooding in.

Our sincere thanks go out to the Carter family for their incredible effort and to GKN Aerospace for so kindly matching Matt's donation - Matt's head shave raised an astounding €3,211.02!

It just goes to show that the simplest fundraising idea is worth pursuing.

The Haddenham Mummers

Long-term supporters of the MPS Society and unruly band of actors, the Haddenham Mummers, raised a huge amount of money for four different charities over the Christmas period.

Their Treasurer assures us that the money raised was not as a result of their being 'extortionate vagabonds', but rather because many people had given generously after watching one of their traditional Mummers' plays, which they perform in and around Haddenham. One of their biggest supporters is Chiltern Railways, to whom we would also like to extend our thanks.

Thank you to the Haddenham Mummers for donating €570 and for the ongoing support!

Remembering Anabelle

We would like to express our appreciation to Lee and Leanne Shepherd for their incredible fundraising in memory of their daughter, Anabelle, who tragically passed away in 2012.

Over the last two years the Shepherds have raised an amazing €4,963.88 on their Just Giving page.

Thank you to all those that have donated so generously.

Science of the Timelords

The National Space Centre launched Science of the Timelords in 2014, to coincide with the 50th Anniversary of the biggest and, for many, the best science fiction show of all time, Doctor Who.

The Centre is a not-for-profit educational charity, welcoming around 250,000 family and school visitors each year to the award winning visitor centre in Leicester.

The Science of the Timelords event was created for families and fans, who wanted more than a convention, they wanted to meet their heroes, chase Daleks, chat to a Cyberman, find out how the show is made and the science behind the fiction.

In 2015 the event had its second outing and without a doubt, one of the biggest successes was the UNIT live action experience, with visitors young and old being immersed in an environment not that dissimilar to those seen on TV screens all over the world.

Designed and run by the 15th Cyber Legion, the screen accurate costumes and focus on important details - the UNIT scientists having their tea in a UNIT mug being just one of hundreds of little nods to the fans who came through the encounter. All tickets were sold out within a matter of minutes.

With all money going to charity, the group worked tirelessly to get everything right, performing from 10:00-17:00 each day in back to back shows.

Nathan Smith, who organised the event on behalf of the 15th Cyber Legion said; “The group attend many events every year to raise money for charity. We dress up in costumes, entertain crowds and bring to life the characters people love from Doctor Who. The event at the National Space Centre was a fantastic one, because we were given a unique environment to create something a little bit different. It was a lot of hard work, but when a child cries with excitement because he sees a Cyberman in the flesh for the first time, or if you finish the day with a great donation, that can make a real difference to the lives of people less fortunate than ourselves, it is worth every hour of building, rehearsing and deleting visitors!”

Science of the Timelords will return in 2016... prepare to be deleted and upgraded!

www.15thcyberlegion.co.uk

Our thanks to the 15th Cyber Legion for their fantastic donation of £200!

Fundraising Reminder

When paying in your donation as a bank transfer, please remember to use your full name as a reference so we can link it to a fundraising event and pass on our gratitude.

Blake's Genes

Blake's Genes, a group formed by the friends, colleagues and family of the Knaggs family, have been pulling out all the stops to fundraise for little Blake, who suffers with MLII (I-Cell).

From auctions and Wear It Blue, to charity songs and obstacle races, Blake's Genes have done it all and are going strong in support of the MPS Society!

Recently Paul Moody, one of our Trustees, met Blake and his family, as well as other members of Blake's Genes, and collected a cheque for £6,000, which was raised through a charity auction.

Our heartfelt thanks to everyone involved in Blake's Genes and all those who have an event planned - what you all have accomplished so far is amazing!

Take a look at Blake's Genes facebook page for up to date news on the group's activities: www.facebook.com/BlakesGenes

Charity of the Year 2015

Early this year the MPS Society was delighted to have been chosen as Charity of the Year by two different organisations! Both the Nuffield Health Plymouth Hospital and engineering company, HVPD, have selected us as the recipients of their fundraising for the year. Both the Nuffield Hospital and HVPD will also display our posters and leaflets throughout the year, which is great for raising awareness.

What can I do?

If you would like to put forward the MPS Society for Charity of the Year in your place of work, just speak to the staff member in charge of fundraising, and we can always send you out a fundraising pack to help you on your way - just email us at fundraising@mpssociety.org.uk.

If perhaps your work does not run a Charity of the Year scheme you can always suggest a one-off fundraising event, such as a Wear It Blue day for MPS Awareness Day.

Another easy idea is take a look at the Give As You Earn (GAYE) scheme. Give as you earn, also known as Payroll Giving, is one of the easiest ways for you as an employee to give regularly to the MPS Society plus it's both flexible and tax efficient. Employees choose how much they want to give each month and the donation then comes off their gross pay, before the tax man touches it. Have a word with your payroll department if you would like to get started!

Our thanks to HVPD and the Nuffield Health Plymouth Hospital (and especially to Joanna Wilson-Smale for putting our name forward) for adopting us for the year!

The Kindness of Strangers

Earlier this year we were contacted by Lauren Morgan, who had a touching story to relate to us that really illustrated how kind people can be and also the importance of raising awareness.

Lauren Morgan owns a successful family-run Funeral Directors in Kent - she also has a nephew with MPSIII Sanfilippo. As part of her daily work Lauren cares for the various needs of the families that have suffered a loss, and the business is a big part of the local community. She also is passionate about raising awareness for MPS diseases and supporting the MPS Society, and one of the ways she does this is by wearing the MPS Awareness band around her wrist.

When a grieving family came in to speak to Lauren, it was this little blue wristband which caught their eye, prompting them enquire what it meant. Lauren then went on to explain all about the disease her nephew suffered with and the work that the MPS Society undertake to support the affected families and to fund research into treatments. Although devastated by their loss, the family made a decision, having never heard of MPS, to choose the MPS Society as the recipient of any donations collected in memory of their loved one.

The donations we received totalled €1,216.50 - the largest amount ever raised from any of the funerals Lauren has dealt with.

We at the MPS Society were truly touched by the kindness of the family and would like to thank Lauren for raising awareness and passing on this inspiring story.

Thank you to all our supporters who take the time to speak to others about MPS, Fabry or any of the other diseases we support. If you would like to raise awareness for these rare diseases, take a look at our website (www.mpssociety.org.uk) where you can download posters and other resources from the fundraising section and buy MPS merchandise from our online shop (see opposite page). If you have any other queries, drop us an email to info@mpssociety.org.uk.

Leaving a Legacy

None of us want to spend much time thinking about our own death, but there can also be great satisfaction and peace of mind in knowing that your personal affairs are organised in the way you want.

Of course when considering Wills, family comes first, however many people also want to ensure that the causes they care about will also be helped in some way.

Legacies are extremely important to any charity, and the MPS Society is no exception. We want to be able to continue our work, supporting families and funding research, well into the future - until, we hope, a cure is found for these devastating diseases.

If you would like to know more about how to leave a legacy in your Will to the MPS Society, and what your money would be spent on, please email us at fundraising@mpssociety.org.uk or visit www.mpssociety.org.uk.

Thank you.

New MPS Merchandise

Take a look at the recent additions to our merchandise list. If any of these goodies catches your eye, you can make an order online by visiting www.mpssociety.org.uk for our full merchandise list, or drop us an email and we can send you out an order form.

Shopping Bag
£3.50

This 100% cotton shopping bag is an eco-friendly way to support the MPS Society.

Photo/Memo Holder
£3

Ideal for your desk to hold business cards, memos or family photos.

Pen £1

This black ink rollerball pen bears the MPS hexagon and 'Society for Mucopolysaccharide Diseases' in silver.

These are just the few new additions we have on our merchandise list. You can still order our MPS T-shirt, trolley token, teddy bear, awareness ribbon, piggy bank, awareness band and lanyard on our online shop or merchandise form.

Wear It Blue!

MPS AWARENESS DAY

Friday 15th May 2015

It's coming up to that time again! Last year our members and supporters really got behind our Wear It Blue campaign and helped us to mark MPS Awareness Day - blue cake sales, Wear It Blue selfies and 24-hour radio shows are just a few ways that you all helped to make the day special.

We need your help to make this year's MPS Awareness Day as, and even more, successful than last year. We've got a couple of ideas (one familar, one not so familiar), but you're not limited to these - if you have an idea for a fundraiser to help mark the day, give it a go! But don't forget to let us know what you are doing by emailing fundraising@mpssociety.org.uk or calling 0345 389 9901.

Wear It Blue!

Our main fundraising campaign, this is an easy, fun and popular way to mark the day and raise awareness for MPS, Fabry and related diseases.

All you have to do is wear blue and donate to the MPS Society - and of course, get as many other people to do the same thing as possible! Last year you involved work colleagues, fellow pupils and students, friends, family and even neighbours. It's a great opportunity to speak out about MPS diseases and also about the significance of the day.

Order your Wear It Blue fundraising pack from our website (www.mpssociety.org.uk) to get everything you need to set your plans into motion! If in doubt - email us at fundraising@mpssociety.org.uk.

How can I make a donation?

There are any number of ways you can make your donation for Wear It Blue or any other fundraising event you choose to organise or take part in:

- Send us a cheque (made payable to the MPS Society
- Visit our www.mpssociety.org.uk and download a donation form to post back to us
- Donate through Just Giving or Virgin Money Giving
- Text MPSS01 €2/€5/€10 to 70070
- Call 0345 389 9901 to donate over the phone

However you decide to make your donation, please don't forget to include your name, contact details and what you did so that we can say thank you!

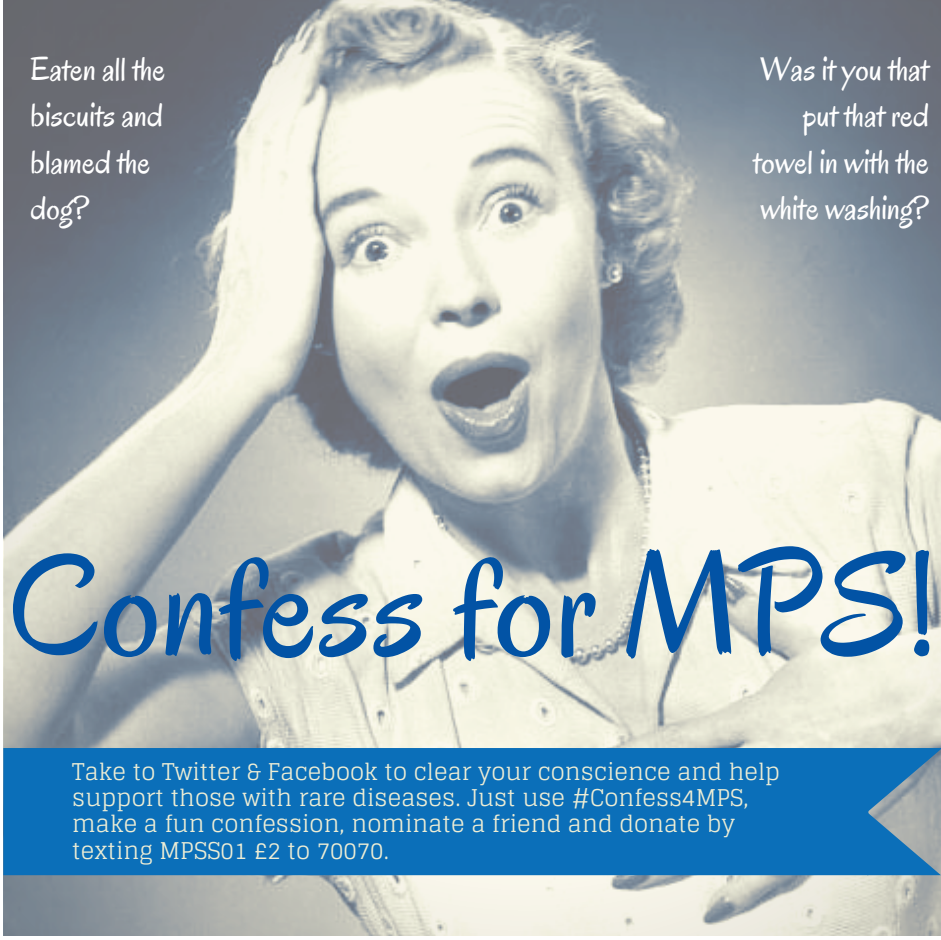
Confess for MPS!

New for 2015, this social media friendly campaign is sure to get people talking!

Quick, easy and fun, we will be launching this campaign on MPS Awareness Day to raise awareness and funds. All it takes is for people to make a fun confession using the hashtag #Confess4MPS, nominate someone you know to do the same, and make a donation to the Society using our text donation service.

To give you some idea, a member of the MPS Society staff (remaining nameless) has already made a confession: *"I ate all the kids' Easter chocolate in front of the telly on Saturday night.In the spirit of karma I've texted to donate £2 to the MPS Society to help children and adults affected by life limiting MPS Diseases. An amazing cause!"*

Keep it light-hearted and see how many people you can nominate!



MPS Donation Envelopes

If you have a wedding, party or any kind of function coming up, you might want to get some of our new donation envelopes in. Measuring 9.5cm x 12.5cm, these envelopes fit nicely in a place setting to catch the eye of your guests. A Gift Aid form on the back ensures that we receive the most out of every donation.

If you think you could make use of this resource, please drop us an email to fundraising@mpssociety.org.uk.

Using eBay to Fundraise

Lots of people use eBay to sell unwanted items or to get a bargain. Did you know that you can also use eBay to support the MPS Society? One of our supporters has written this article to show you just how easy it is

EBay charity sales has two great uses – extra valuable funds for the MPS Society and it also creates awareness of MPS related conditions which in turn will give the Society more publicity.

You can sell your unwanted items through eBay and donate from 10% up to 100% of any sales to the MPS Society. You also receive a proportionate refund on your selling fees. For example, if you donate 100% of the selling fee to MPS Society then eBay will waive the listing and selling fee totally. If you donate 50% then it will charge you 50% of the listing and selling fee. 100% of the percentage you donate will go to the MPS Society directly through PayPal.

So why not get all those items listed and help a great cause – it's just a different way to donate.

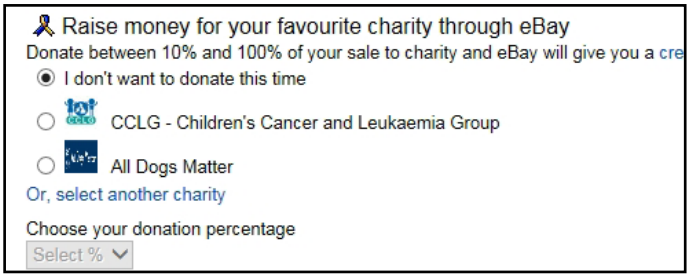
Why not get all your friends to sell an item too, its just some spare time they need to find and free up some valuable storage space!

You can then publicise the items you are selling through social media sites like Facebook and twitter which could help you significantly raise the selling price.

If you share some of the posts amongst your friends (Hey look what I'm selling.....) they may also share the post and help to sell the item and also publicise the MPS Society and the good work it does for all those children with rare and life limiting conditions. It shows up on the listing which charity you are supporting.

Here's what you need to know.

Just create your listing as you would normally do by clicking "sell" once you have logged into your account. Select your category and proceed with your listing as normal. When you get to "Choose a format and price" below Duration it will show:



PayPal Giving Fund

eBay for Charity

Click on "Or, select another charity" and search for "Society for Mucopolysaccharide Diseases". Click the "select" button when your chosen charity appears. Fill in the remaining parts and finally click "submit".

How much does the charity receive?

Paypal Giving Fund delivers 100% of your donation to your chosen charity, plus any applicable Gift Aid.

If you sell for charity on eBay, not only will you be doing something to help support families affected by MPS and related diseases, but eBay will also reduce your fees *and* items with a donation will also generate 34% more sales

**** Be careful on starting price or buy it now as if the item does not sell then you will have to pay the listing fee (usually 35p for a private seller in most categories) – which is the only sting in the tail. However, all private sellers currently have 20 free listings each month so always use up your allowance and sell your unwanted items.

If your item does not sell, you've done all the hard work already by filling in the listing form and all you need to do is go to your unsold section and relist with a few clicks of your mouse.

If you don't have an eBay account then it's really easy to setup and it's completely free.

So what are you waiting for - get those dusty items out and sold! Believe you me, virtually anything sells on eBay.

Yarko

If you use eBay, remember to set the MPS Society as your favourite charity!

MPS Charity Places

Challenge events are a great way to support the MPS Society and to achieve personal goals too. These big events provide participants with a fantastic atmosphere and an unforgettable day, and many of our supporters come back year on year to enjoy the experience. If you would like to give yourself a challenge for 2015, take look at the list below and get in touch with us at fundraising@mpssociety.org.uk

Morrisons Great North Run – 13th September 2015
We still have some places left for this event, so please drop us an email to start your registration. Charity places for this popular run will be filled quickly, so get in touch today! Starting in Newcastle and finishing in South Shields, this run is the premier event in the Great Run series, and holds the title of Britain's biggest participation event.

Previous runners include some of the most famous names in distance running: Mo Farah, Paula Radcliffe and Haile Gebrselassie.

Morrisons Great South Run – 25th October 2015
We still have one place left for this iconic race, so email us to register your interest today!

This is a fast and flat 10 mile route, where you will pass Portsmouth Dockyard and Cathedral, Spinnaker Tower and the HMS Victory. The final straight offers the perfect opportunity to get that elusive personal best!

Morrisons Great Manchester Swim - 4th July 2015
If running is not your thing, why not take one of our charity places for the Great Manchester Swim, and experience a new challenge.

Staged at the vibrant Salford Quays, this 1 mile swim is great for swimmers of all levels, with expert kayakers on hand to ensure your safety.

Virgin London Marathon
Although our places for the 2015 London Marathon are all now filled, there's always next year, so register your interest with us early. This event is phenomenally popular, and with very limited places we have to work on a first come first served basis.

Alternatively, we do urge those who wish to enter to try their luck with the ballot later this year - you can still fundraise for the MPS Society. Just let us know how you get on so that we can support your fundraising!

Morrisons Great Manchester Run
All our charity places for this event have now been taken, but if you would like to register your interest for 2016, just let us know.

If you need more information for any of the above events, or would like to register your place or your interest in a place, please email fundraising@mpssociety.org.uk. Available places will be allocated shortly.

Even if you are unsuccessful in obtaining a charity place, for some of these events you can still enter yourself as an individual and fundraise in aid of the MPS Society.

How we can support you
Fundraising packs and MPS running vests will available to all our challenge events participants for 2015. If needed we are always happy to provide you with advice on fundraising and how to make the most of the sponsorship opportunity.

Thank you to all our donors including...

Sally Jones and the team at LG Optical raffled a Christmas hamper and raised £287.50 for the MPS Society.

Paul, Trevor, Ryan and Simon all grew festive Christmas beards and raised an amazing £825 on their JustGiving page.

Kerri Shaw's husband, Jae, grew his hair and will be then shaving it all off to raise money to support Jack (MPS I). So far he has raised £576.25 on his JustGiving page.

Dorothy Robinson, Nanny to Hannah Shannon (MPSIII), raised an amazing £500 from not only holding a card-making workshop, but also from the sale of hand-made cards and various bird boxes and bird tables that herself and her husband made.

Lucy Miller and Charles Clark from Curzon C of E Combined School, gave up their netball time to polish people's shoes in their school playground. Within the hour they raised £20.80 for the MPS Society.

Dr Husain recently spoke at for the Medics Society at Dr Challoner's Grammar School and asked for his fee of £50 to be donated to the MPS Society.

Alison Glover organised a friends and family camping event, where she held a raffle and other fundraising activities, and raised £80.

Angela Hollingworth and the Yorkshire Bowling Association held a number of different fundraising activities throughout 2014, such as quizzes and raffles, and managed to raise £500 for the MPS Society. Angela chose to support us as her grandson Ryan has MPSII.

CB Imports in Leeds held their annual company Christmas raffle and raised a fantastic £167. Our thanks to Joan for organising the raffle and to Elliot for passing it on!

Valerie Evans took part in a Tapathon and raised £15.

Hemsworth & District YMCA held a ladies' coffee morning and raised £50.

The staff at **Portland Medical Practice** donated the money they would have spent on Christmas cards to the MPS Society, raising a total of £90.

Marina and Friends have donated £5,383.16 from the sale of second-hand goods from their shop in Bristol - £46 of which was kindly donated by the South Bristol Methodist Church. Marina and her volunteers have now made a staggering total of £135,538.54 towards research into MPSIII Sanfilippo.

Jude Butler and the North Herts and Stevenage SEN team donated £80 in lieu of buying Christmas cards. Jude's grandson, Jacob, suffers from MPSI Hurler.

The Year 2 class at **St Thomas More Catholic Primary school** held a nativity play in 2014 and managed to raise £277.33 for the MPS Society.

Darryl Brook organised a bake sale and raised £307.52.

Long-term fundraiser **Louise Lucas,** landlady of The Hampden Arms, held a Boxing Day pub quiz and raised £200.

Pat Isaac recently gave a talk to the Fiddington Women's Institute and received £30, which she donated to the MPS Society.

The Sandford Brownies took part in a Swimathon arranged by the local Lions Club and managed to raise £95 for the MPS Society. Some of the Brownies go to school with Josh, who has MPSVI, so they were eager to help their friend!

The Pavilion Ladies Luncheon Club held a Christmas dinner fundraiser and raised £300. The ladies club is friends with Tillie-Mae Mawdsley, who suffers with MPSIII Sanfilippo.

MPS Society Trustee, **James Garthwaite, and his wife Claire** held a 'Not the Antiques Roadshow' fundraising event and raised an incredible total of £2,040.

Sacha Knight held a glamorous ball for her 30th birthday and took the opportunity to raise lots of awareness about MPS, Fabry and related diseases, and she also raised £185.60 for the MPS Society. Sacha suffers with Fabry disease.

Lymington Infants' School raised some money by selling handmade woolly hats and their school choir sung at their community tea. One of their pupils suffers from MPSIII, Sanfilippo.

Halifax Bank in York held a Wear It Blue fundraising day in support of Blake's Genes and raised £159.53 for the MPS Society.

Margaret Yallop and the members of Slimming World group at Newark Hill School collected £100 for the MPS Society.

The Finance Department of Best Western Hotels donated the proceeds from a charity tuck shop, which amounted to £100. The MPS Society was nominated to receive this by Toni Beattie.

The Friends of the P.O.W. held a raffle and raised £100.

Maria Murphy ran the Bath Half Marathon and raised a fantastic £476.25 on her JustGiving page. Maria's daughter, Tara, has MPSI Hurler and has been supported by the MPS Society.

Michelle Petersen has been fundraising in support of her daughter, Chiara, who suffers from MPSI Hurler. Michelle has raised an incredible £2672.89 on her JustGiving page!

Donations

Teresa Vockins; Hayley Rodzoch; Jacqueline Mount; Mrs S. Malik; Mrs M. Henshell; Jane Hufton; Denise McPhee; Terra Hold; Shirley Brown; Portakabin; Mrs Horn; Sue and Vic Lowry; Joan Crespin; Mrs Shirley Stewart; Teresa Alvarez Pino; Mr & Mrs Charlesworth; Charles & Elsie Sykes Trust; Mrs A. Baker; Dorothy Robinson; Mr & Mrs T. Watts; Mrs D. Duckett; The Hospital Saturday Fund; Rachel Martin; Mrs D. E. Peirson; Pam and Ken Ballard; Mr Lavelle; Brian Taylor; Andy and Jenny Hardy; Samuel William Farmer Trust; S. Winzar; Janet Hillier; John Avins Trust; Philippa Green; Katherine Ide; Phil Powell – Bids & Pieces; Mrs E.J. Hirons; Melanie Marcinkowski; The Sir Arthur Black Trust; The Stafford Trust; The Hedley Foundation; Dave & Laura Brodie; Dr C.A. Pennock; Mrs Jane Hart; Bowen Lodge; Jacqueline Best; Mrs Caroline Garthwaite; Heather Gordon; Dr C.J. Osborne & Partners; The Whartons Primary School; Eammon Drayne; Marsh Christian Trust; The Florence Turner Trust; The F C Burgess Sunday Appeal Fund; Mr C.D. Folkes; Neil Shaefer; Sue Standish

In Memory

Mrs Valerie Howard Hollings; Daniel Allen; Mr Gardner; Ben Wilton; Jack Stuart; Joan Tame; Craig Stephen McDougall; Gracie Bella Sims; Peter Lavender; Joan Donal Wheeler; Jack Heath; Mrs Eileen Drayne; Jessica Hambly; Julie Hopper; Mark Cambridge; Anabelle Shepherd

Collection boxes, stamps, foreign coins, mobile phones, ink cartridges, jewellery

Sally Summerton; Lucy Brock; Mrs M. Griggs; Victoria Bernard-Hayklan and staff at HSBC in Cheltenham; Mrs A. Baker; Glyn Goodman; Melanie Marcinkowski; Alan & Marilyn Eggleton; B. Harriss; D. Bown; Christopher Croft's family

The Society would like to thank the following donors for their regular contributions by either Standing Order or Give As You Earn

S Bhachu; C Cullen; S Brown; I & A Hedgecock; D Forbes; V M Lucas; P & R Shrimpton; P Summerton; A Weston; G Simpson; William Cavanagh; Barbara Harriss; L Brodie; A Sabin; A Ephraim;P Summerton; A Weston; A Byrne; C L Hume; D M Robinson; Dalligan; M Macolm; E Mee; Elliot Moody; Mr Hahner; K Brown; E Brock; M Fullalove; E Parkinson; Michael Reeves; Gordon Ferrier; Margaret Leask; R Taylor; R & N Gregory; L Stillwell; R & K Henshell; K & S Bown; S & J Home; V Little; S & D Greening; Z Gul; K Hiller; J Casey; J & V Hastings; E Lee; R & K Dunn; S Littledyke; Norman Saville; M Tosland; N & S Cadman; J York; J Wilson; J & M Wood; A Tresidder; E Cox; Mr Thompson; K Robinson; K Osborne; M Rigby; M Peach; C Garthwaite; P Raymond; J Ellis; I & V Pearson; D & S Peach; C & M Gibbs; J Garthwaite; S Winzar; W Cavanagh; A Sabin; C M Pierce; L Stillwell;

Wear It Blue!

MPS AWARENESS DAY

Friday 15th May 2015

MPS support research awareness Wear It BLUE

HELP RARE DISEASES STAND OUT BY WEARING IT BLUE FOR MPS AWARENESS DAY!

It's easy to join in, just wear blue & donate!

Text MPSS01 £2/£5/£10 to 70070

Visit www.mpssociety.org.uk

Call 0345 389 9901

Or hand your donation to the event organiser

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