MPS

Autumn 2012

Society for Mucopolysaccharide Diseases

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online www.mpssociety.co.uk,
phone 0845 389 9901,
text MPSS01 £2/£5/£10 to 70070
or post your donation
to our office, MPS House.

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. The MPS Society:

Acts as a **support network** for those affected by MPS and Related Diseases

Brings about more **public awareness** of MPS and Related Diseases

Promotes and supports **research** into MPS and Related Diseases

MPS & 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, severe degenerative mental deterioration resulting in death in childhood.

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

Where does your money go?

A donation of ***£2 per month*** could help us to offer so much more support in so many ways:

Access to clinical management and palliative care

MPS Regional Specialist clinics

Support with disability benefits

Paving a child's way in accessing education

Upholding rights in employment

Advising on home adaptations

Bereavement support

Front cover photo:
Elisabeth and Huto D'Souza
at the Chessington MPS Family Day.

Society for Mucopolysaccharide Diseases

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Welcome to the Autumn 2012 edition of the MPS Magazine. Thank you to everyone who took part in our online MPS Magazine survey with Survey Monkey. Many of you had some very positive comments about the magazine. We have taken on board your feedback and have included many more of your stories. We know you like reading them so please do send them to us!

If you have any material to submit, please email magazine@mpssociety.co.uk or phone 0845 389 9901. We would love to hear from you! In the meantime, enjoy the magazine!

Once you have read this MPS Magazine, please pass it on to your family, friends and colleagues. Help us spread the word about MPS and related diseases and the work we do. www.mpssociety.co.uk

Message from the Chief Executive

In the Summer MPS Magazine there was an article on page 4 URGENT BREAKING NEWS – Has AGNSS had its day?

It was back in late May that we became aware that the Coalition Government's New Health Reforms could possibly have devastating implications for adults and children diagnosed and those that will be diagnosed in the future with Lysosomal Storage Diseases.
We started asking a lot of questions and learnt that Baroness Jolly had had secured a Dinner Debate in the House of Lords concerning the future of AGNSS.

I set about drafting a brief on why the 'AGNSS model' for commissioning of national specialised services must not be sacrificed in the new health reforms which was sent to every one of the Members of the House of Lords.
When I and Trustee, Wilma Robins, attended the Debate in the House of Lords on Wednesday 18 July we were humbled that all seven speakers for the motion'To ask Her Majesty's Government what is their assessment of the future of the work of the Advisory Group for National Specialised Services (AGNSS)' had clearly read our briefing and one or two even appeared to use our wording. Responding for the Government was Earl Howe, Parliamentary Under-Secretary of State and Government Spokesperson for the Department of Health. Bent over the despatch box with his right leg swinging behind him Earl Howe proceeded to try unconvincingly to persuade those present and those in the public gallery that the loss of AGNSS will not impact on patients and their families. Having had the opportunity to speak with Earl Howe earlier in the year I found it hard to accept that he really believes this piece of Government Rhetoric that losing AGNSS will have no direct negative effect on Lysosomal Storage Disease patients and their families going forward.

Regrettably the MPS Society and the other Lysosomal Storage Disease Groups were left with no option but to make our voices heard.

By now almost all of you who are patients with or parents of children living with MPS, Fabry or a related disease will have received an email and or letter inviting you to write to your MP, Prime Minister, David Cameron and Deputy Prime Minister, Nick Clegg. We cannot thank the hundreds of members we have heard from to date who have done just that. Your letters to David Cameron in particular have been from the heart and we in the MPS Office have been near to tears on seeing your efforts.

If the Summer holidays have been just too hectic and you haven't had time to act we understand but urge you now to set aside an evening and get writing. We only have a very limited time to get our message over to the Government. It had to be 'The Government' because we knew the ex-Secretary of State for Health, Andrew Lansley was not listening and content to push swathes of our members to one side as he pursued his Health Care Reforms.

One of our Members, Daniella Van de Peer, had the opportunity whilst at Birmingham Children's Hospital with her son, Caleb to speak to Andrew Lansley about her concerns and prevailed on him to meet with me. In front of reporters, the Chief Executive, Sarah Jane Marsh and the clinical team at Birmingham Children's Hospital Andrew Lansley was heard to say he knew me and would meet with me! A week after the event I wrote to Andrew Lansley at the Department of Health as well as his Constituency Office to accept the offer of a meeting and there was a deathly silence right up till he lost his job in the reshuffle. We now understand from Earl Howe that Andrew Lansley wrote to me on 29 August but the response was not received.

Your letters have left a huge majority of Members of Parliament, the Prime Minister and Deputy Prime Minister without a doubt we are worried. The MPS Society with the other LSD Groups (Gaucher, Niemann Pick, Pompe, Krabbe and Battens) have also written to NICE, the Chair of the National Commissioning Board, Professor Grant, and Earl Howe seeking meetings.

Sir Michael Rawlins, Chair of the National Institute of Clinical Excellence (NICE) has agreed to meet with us in October when he starts thinking about strategies for managing the appraisal of new therapies for Ultra Orphan Drugs. This is particularly pertinent at this time to ERT for Morquio disease, Fabry disease in respect of chaperone therapy as well as intrathecal interventions for MPS II, MPS IIIA,MPS IIIB, MPS VII and Mannosidosis.

The response from Professor Grant beggared belief. He is too busy to engage with the LSD patient organisations. It is most concerning that Professor Grant has accepted the position to Chair the National Commissioning Board with all the kudos that goes with it but not interested in whether National Commissioning Board service is 'fit for service' for patients with Lysosomal Storage Diseases.

Earl Howe has kindly responded on 12 September 2012 and strongly suggested we meet with Kate Caston who is leading the design of the specialised services commissioning within the NHS Commissioning Board we are following this up.

www.wickedgenes.co.uk

So what is there to lose?

- Loss of ring fenced funding for this highly specialised LSD service resulting in newly diagnosed patients and those not yet on treatment being unable to receive clinically appropriate treatment of high cost therapy when clinically needed because the budget for highly specialised services budget is exhausted.
- From several sources the LSD Patient Collaborative has heard that the eight LSD specialist centres have been or are to be asked to make 20% cuts in the LSD service budget. It is suggested these savings will come from the high cost therapy budget. Going forward there is concern that the cuts will be a threat to some patients who are on high cost therapies
- Deep concern that the appraisal of high cost therapies going forward will be in the hands of NICE and we will see LSD patients denied access to innovative new therapies by way of cost per Quality Adjusted Life Years. This is currently £30,000 per year per patient.
- Loss of expertise of the National Commissioning Team and the very successful LSD Advisory Group that included clinicians, MPS Society and other LSD patient organisations.

Perhaps our campaign to have our concerns heard turned for the good when David Cameron appointed Jeremy Hunt as the new Secretary of State for Health? Jeremy has been of great help to his local MPS constituents and back in 2005 when in opposition met with me to advise on how the MPS Society might achieve National Specialised Commissioning for LSDs. The rest is history and clinicians, specialist nurses, LSD patient organisations industry, the commissioners and most of all LSD patients and their families have seen the benefit of AGNSS over the past years. We can't step aside and see the 'baby thrown out with the bathwater'.

Finally on this subject we thank you for all your supportive letter writing. MPS is committed to keeping you informed of how the fight to secure key aspects of our LSD highly specialised service is going so if you did not receive your letters by email or post please let us know. If you only received the letters by post that means we DO NOT have your up to date email address. In this case we should be most grateful if you would send us your email to t.ellerton@mpssociety.co.uk as we plan to update members on this matter going forward by email as well as through the MPS Magazine.

News from the MPS office

We have a new face to introduce you to. Many of you will have already spoken to Toni when you ring the MPS office but it's nice to put a face to a name!

Introducing **Toni Ellerton**

Hi My name is Toni Ellerton. I joined The MPS Society in July, on a temporary basis acting as PA to Christine Lavery CEO covering for Joanna Lawley whilst she in on her maternity leave.

I am overwhelmed by the help and support from everyone in the office, they have made me feel a valued member of the team. I have many years' experience in administration and as an Executive Assistant.

My role within MPS is challenging and keeps me on my toes with no two days the same. I am delighted to be working closely with Christine and find it very rewarding.

Outside of work when not exercising my retired Greyhounds, I like to spend my free time with my three grown up children. I also enjoy swimming, reading and watching live music. **t.ellerton@mpssociety.co.uk**

In the next edition of the MPS magazine we'll re-introduce you to some of our existing MPS staff team to give you a brief description of who we are and what we do!

News from the **Management Committee**

The Society's Trustees meet regularly. Here is a summary of the main issues that were discussed and agreed at the Trustee Board Meetings held in April and July 2012.

Generating Income

The Trustees received a report from the Treasurer outlining the current financial position and reviewed the current cash flow mindful of the financial challenges facing the voluntary sector in this time of austerity. The Trustees with regret re-confirmed their decision not to recruit to the fourth Advocacy Officer post until at least one year's funding has been secured. Trustees approved the structure of the Wicked Genes Campaign as a fundraising initiative of the MPS Society. The Trustees recognised that the excellent fundraising efforts by MPS families has to be complemented by attracting funds from the wider public if the Society is to maintain its high level advocacy service and fund pioneering research and clinical trials. It was agreed that our Members are the MPS Society's greatest asset in introducing Wicked Genes to their children's schools. Brothers and sisters could be encouraged to introduce Wicked Genes to their universities and parents, family and friends can spread the word about Wicked Genes to their employers.

Risk Management

The Trustees approved the MPS Society's business continuity plan. The CEO confirmed that there is a detailed work plan for all the Senior Management Team. A discussion on succession planning was had and it was agreed that the Trustees have a dedicated session on this subject prior to the next Trustees' meeting. The risk register was reviewed and no changes made.

Personnel

Trustees had an indepth discussion on performance management and it was agreed the CEO should continue to work on developing a more accessible policy and procedure. The Trustees noted that two members of staff were soon to go on maternity leave and that maternity covers for the two post holders were being sought.

Clinical Management

The Trustees received a report on the current position regarding the disbanding of the Advisory Group for National Specialised Services (AGNSS). The Trustees welcomed the collaborative approach of the Lysosomal Storage Diseases and acknowledged the high level of work this would involve the CEO in. The Trustees were encouraged to send comments on the draft Mandate to the CEO. Trustees were appraised of new developments in the Patient Access Programme which included the start of a non ambulatory study for MPS IVA.

International Collaboration

The CEO reported on the excellent news that Shire Pharmaceuticals is establishing a Humanitarian Aid Programme for MPS II, Fabry and Gaucher disease. The Trustees welcomed this step forward and the benefits it will bring to families in less developed countries.

Fabry International Network

Following a decision taken by Trustees at their April meeting to accommodate the Development Officer Post for the Fabry International Network (FIN), Nawel Van Lin was appointed. Nawel works independently of the MPS Society and is based on full cost recovery from FIN .

General Meeting of Trustees

A General Meeting of Trustees was held at 7.30pm on 13 July 2012 at MPS House, Amersham.

By virtue of company law the Trustees noted the re-appointment of auditors McClintocks , Chester for the coming year.

Trustees were asked to consider, and if thought fit, pass the following as an ordinary resolution that:
Mr Bob Devine, Miss Faith Parrott, Mr Bob Stevens, Mr Tim Summerton, Mr Paul Moody and Miss Jessica Reid be elected as a Director of the Company, The Society for Mucopolysaccharide Diseases.

It was resolved unanimously that all the above persons be duly elected.

It was raised that one Trustee had received an enquiry from a Life Member with a view to becoming a Trustee of the Company. It was agreed that the Life Member would be encouraged to write to the Chair, Sue Peach on this matter.

In the absence of any other business the meeting was closed at 7.50pm

Introducing our New Trustee - Jessica Reid

I am Jessica Reid, a Solicitor specialising in family law, practising in Reading. My brother Daniel (who was 6 years older than me and who was my parents first child) suffered from Hunter disease and sadly died in 1986, when he was aged only 8 ½. I also have a twin brother (unaffected by Hunters) and an older sister.

I became a Trustee of the MPS Society in 2012 for two reasons; 1) I wanted to give something back to the MPS Society after all the support the Society gave my family over the years; and 2) I thought my legal skills could benefit the Society.

The MPS Society gave my family fantastic support throughout the years from the very early days of Daniel's diagnosis, through to Daniel's numerous hospital trips and treatment and after his death. Through the sad times of remembrance and loss, our family has been able to cope with the MPS Society's support.

I went to the family days out as a child whilst my parents attended the MPS conferences. I remember staying in a hotel one night at a Conference and the fire alarm went off (for real!) and we had to get the disabled children out of the hotel without using the lifts and stand outside in our P.J's and watch whilst the fire engines came! We had a sibling's day out and went to a "safari" park and had monkey's climb all over our windscreen and try to get into the vehicle. We planted a tree at the memorial Childhood Wood in Nottingham and we couldn't get the plaque to stick so my sister used her bubble gum!

Sadly, I never really got the chance to get to know my brother. I enjoy hearing stories from my family and their friends about his huge smile, good sense of humour and his unusual character traits (like sitting next to a family friend and scrunching her skirt up right to the top or him making a very bad window standing in front of the T.V!)
I am supporting the MPS Society to raise awareness and help offer those affected by Mucopolysaccharide diseases support, friendship and help - in the same way my family were.

I am into my cycling (originally being from Cambridge!) and have raised money in the last few years for the MPS Society through crazy events like 72 miles in the Peak District and 60 miles in the Chiltern Hills on a Winter's day…and this September I am part of a Team taking part in the London Virgin Triathlon…

I haven't yet had Genetic testing to see whether I am a "Carrier" of Hunter's but it is something I am thinking about doing now that I am 27. In doing so, I know the MPS Society will be there 100% to support me.

I am very much looking forward to offering my assistance to the MPS Society over the coming years as a Trustee and to see the Society continue to go from strength to strength and make a difference to those affected by Mucopolysaccharide diseases both now and in the future.

MPS Society continues to support those affected by Metachromatic Leukodystrophy

The Society for Mucopolysaccharide Diseases continues to welcome members with Metachromatic Leukodystrophy (MLD).

We have an Advocacy Support Officer who supports individuals and their families affected by MLD.

We have a Guide to Understanding MLD fact sheet which is available from the MPS office, and downloadable from the MPS website, plus a range of other information resources which cover issues related to those affected and their carers.

For further information please phone **0845 389 9901** or email **advocacy@mpssociety.co.uk**

Reduce paper consumption!

To cut down on postage and paper so we can put more of our resources into helping our members, we would like to become as paperless as possible.

If you would like to be informed by email of our events and activities, please email mps@mpssociety.co.uk with your current email address.

We will add this to our database to keep you informed and will not pass your details on to a third party.

We understand that this may not be possible or convenient for everyone and if, at any time, you feel you would rather receive information by post or be removed entirely from our mailing list you can email the above address or call **0845 389 9901**.

WHAT'S ON!

SPECIAL EVENTS

Childhood Wood Planting Day: 21 October 2012

Teenage Sibling Weekend: 24 – 25 November 2012
Look out for the booking form in this magazine!

CONFERENCES

MPS National Weekend Conference: 28 -30 June 2013

MPS REGIONAL CLINICS 2012

MPS IV clinic GOSH: 9 October

Bristol clinic: 10 October

Manchester BMT clinic: 12 October, 19 October

Adult Birmingham Fabry clinic: 13 November

MPS III clinic GOSH: 13 November

Birmingham MPS clinic: 23 November

Northern Ireland MPS clinic: 30 November

New to the MPS staff team!

Florence and Sam

Congratulations to Joanne Lawley, PA to Christine, and her family on the birth of baby Sam on 8 August 2012.

Congratulations to Sue and Steve Cotterell on the birth of baby Florence on 24 August 2012. Sue is our Trust and Corporate Fundraising Officer and Steve is one of our Advocacy Officers.

Joanne and Sue are off on maternity leave at the moment and in the meantime we are delighted to welcome Toni and Elizabeth to our MPS team!

New members

Christine has recently been in contact with the Society. She has a diagnosis of Fabry disease. The family live in the South West.

Angela Allen has recently been in contact with the Society. Her daughter Laura has a diagnosis of MLD. Laura is 25 years old and the family live in Derbyshire.

Laurence Watts has recently been in contact with the Society. His son Samuel has a diagnosis of Sanfilippo disease. Samuel is four years old. The family live in the South of England.

Teresa has recently been in contact with the Society. Her daughter Chloe has a diagnosis of Hurler disease. Chloe is 1 year old. The family live in the South East.

Nicola has recently been in contact with the Society. She has a diagnosis of Fabry disease. She lives in the Lancashire area.

Miss Rebecca Hall and Mr Ben Attree have recently been in contact with the Society. Their son Ethan-Jay and Rebecca Hall have a diagnosis of Fabry disease. Ethan-Jay is 23 months and Rebecca is 20 years old. The family live in the Cheshire area.

Ami has recently been in contact with the Society. She has Fabry disease. The family live in the Surrey area.

Sandra has recently been in contact with the Society. Her daughter Rebecca (who prefers to be called Bex) has a diagnosis of Fabry disease. The family live in the Cambridgeshire area. They joined the Society to find out more about the condition and to not feel alone.

Deaths

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

Sirma Mutlu who suffered from Sanfilippo and who passed away on 31 May 2012 aged 17 years.

Libby Fullalove who suffered from Sanfilippo and who passed away on 6 June 2012 aged 11 years.

Archie Rudham who suffered from Hunter and who passed away on 27 June 2012 aged 12 years.

Sara Hyde who suffered from MLIII and who passed away on 5 July 2012 aged 33 years.

In memory

Libby Fullalove
who passed away on 6th June 2012

Mucopolysaccharidosis, mucoploy xxxx you 'ridosis
You stole our angel, so sadly missed
A sweet angel, that bought us laughter and delight
An angel who ransacked restaurants, kicked and threw
Broke wheelchair and inner tubes - apologies and phonecalls

Consultants, dieticians, gastronomy tubes and pumps,
All bought tears
For which were our delight to spend a day with Libby Lou.
It was heaven to be here with you

We may have held your hands for only a while
But in our hearts you'll always be
Those we love don't go away
They walk beside us every day
Unseen, unheard, but always here
Still loved, still missed and very dear

Libby's life was too short
So sad watching you fade away
Our hearts will always be broken
Our beautiful Libby Lou

Grant Sim
who passed away on 11th July 2011

Sadly our Grant died aged 15 and a half. Grant had Sanfilippo disease. Fortunately he went peacefully. We have many wonderful memories and learned so much from him. He had such joy for life. ***The Sim Family***

Congratulations

Chris Isaacs (MPS IV) carrying the Olympic torch in Dagenham.

Congratulations to Tom Garthwaite
Tom who has MPS II received 2 A*s and an A in his 'A' levels this Summer and is off to Oxford to read biochemistry!

25 years on...

This year, Fer Pidden's son, Anthony got married to his fiancee Mia. Fer shares this story following his sister's birth and diagnosis with Sanfilippo and the legacy this has left behind...

On July 14th, this year, our son Anthony got married to his fiancée Mia to our great joy. It was one of the most proud, memorable days of our lives and equalled the tremendous happiness we experienced on his birth.

Our daughter Natalie was born on 1st October 1980 and was diagnosed with MPS IIIA at the age of three and a half.

In our desperate search for a cure and our reluctance to accepting the prognosis that nothing could be done to change the course of this disease, we were hopeful that bone marrow transplant might answer our prayers.

Soon afterwards, my next pregnancy sadly ended in termination because the tests showed that the foetus had the same condition as Natalie. We were also told that because of the brain-blood barrier bone marrow transplantation would not be an option. Our hopes of having another baby dwindled as time went by. I had a sale at home for MPS and all my baby clothes were sold.

Beginning of 1987, when I nearly gave up hope, I realised I was pregnant. With the collaboration of my then GP and late Dr. Rosemary Stephens, I went to London to have this new pre- natal test called corrion villus biopsy. Until I had the test results, my husband William did not know I was pregnant! The tests were negative and we finally were going to have the baby we dreamt of!

Anthony Efe Pidden was born on 01/08/1987 and made his first appearance on the MPS scene at the MPS Conference Post House Hotel, Heathrow 25 September 1987 at the age of nearly two months!

Ever since then he attended most of the MPS Conferences here and abroad. He also helped with my presentations in the past and even sorted IT problems at the Conferences. He still remembers all the conferences.

Over the years as he became older and stronger and before we had a purpose built extension with hoists for Natalie, he would help me to lift her in the house and in and out of the car.

Very sadly, Natalie passed away on March 10, 2009 at the age of 28 years 4 months. Anthony was there for her last minutes too.

After Natalie's death, even before Anthony got engaged, I had this quest for finding Natalie's DNA sample. My concern and attention was now focused on the future generations and my son's risks of having an affected child. I would do all I could to prevent this happening again.

With the help of pointers from Christine Lavery, I managed to find Natalie's DNA sample in RUH in Bath and wrote to them asking for a DNA mutation analysis for determining Anthony's carrier status.

I was told that because my son was over 16, he had to request it himself. I discussed this with Anthony and there was no doubt in his mind about going through this process and finding out whether he was a carrier or not. He wrote and asked for this test and his sister's mutation analysis.

RUH Bath dragged their feet and the genetic unit was very reluctant to send the sample for analysis quoting general statistics. After several letters, they realised we knew more than they did and that we would not hesitate to have public confrontation.

In the meantime, Anthony was engaged. We also learnt about the MPS IIIA carrier testing for the general population even though it was 50% conclusive.

Finally after a very long period of waiting they asked to see the engaged couple.

After their honeymoon, Anthony and his wife Mia went to RUH Bath and gave blood samples. They were told that Natalie's DNA sample was sent to Manchester Hospital. My husband and I are both going to the surgery to give blood on September 10th for mutation comparisons.

We understand that it would be December/ January time before they will have any results. We will cross fingers and wait until then!

Whatever the outcome of the tests, at least they will be equipped with the knowledge of the results and the options available to them accordingly as and when they decide to have children.

As parents we and as a young married couple they can say they have done all they can with the present scientific knowledge and the testing techniques available.

Anthony was born and grew up in the MPS Community and could reel out information about his sister's disease at a young age when adults had a job to pronounce it! Mia has joined the MPS community because of her ties to Anthony.

I will never know the true extent and the depth of the effect of his sister's condition, life with MPS IIIA and the death of his sister had and will carry on having on Anthony and his life in the future.

I find out things about it in various different ways. He never discussed it with us; although I am aware that he has been doing so with Mia.

On the day of their wedding, Saturday 14 July 2012, at All Saints Church in Westbury, Anthony and Mia decided to put the wedding bouquet on Natalie's grave. Anthony and his best man slipped away quietly and did just that without fuss! I learned about it when I went to visit the grave.

Anthony and his wife Mia, who was qualified as a nurse in Denmark and came here straight away and started work; are still very much of the MPS community. They expressed their wish to help in any way they can in conferences.

As parents we are extremely delighted and excited for them and for ourselves. We are privileged and lucky to have them. We do not take things for granted.

I still can't help asking the question: FOR HOW MANY GENERATIONS WE HAVE TO BE VIGILENT? **Fer Pidden**

Get in touch...
If you would like to share your story and photos in the MPS Magazine please write to us, phone **0845 389 9901** or email **magazine@mpssociety.co.uk**

Fabry in the family

Diane Hughes, her three children and brother all have Fabry but they have very different experiences and approaches to dealing with it. Diane shares her story of taking each day as it comes...

My name is Diane, I am wife to Spencer and mum to Nicola, Thomas and Laura. Here is a little bit about our family

I am 43 and I have known about Fabry since 2001. My brother Ian Hedgecock is a regular contributor to the MPS Magazine and he has already shared our family history with many of you.

Myself and our three children have Fabry disease, all at varying stages. Nik is 21 and is in total denial of Fabry disease, something I find very difficult to understand, but it's her choice. Tom is 19 and has been on Enzyme Replacement Therapy (ERT) since he was 9 years old. His symptoms are under control and managed very well. Laura is 16 and very symptomatic, although she is not on any form of treatment. She was on Fabryzyme for a short time before the production problems, and was doing very well on it. Then with the Fabrazyme shortage she was put on Replagal, as was Tom. He is still on it, however it didn't seem to agree with Laura at all, and it was decided that she should come off it. However, as we expected, the symptoms have come back, so now she just limbers from one Fabry crisis to the next.

I myself have been on treatment since 2001. At that time I was on Fabrazyme, and then about 4 years ago I stopped and went onto the chaperone therapy trial instead.

So as 4 out of the 5 of us in the family have Fabry it throws us a few challenges now and then. As I write this article now, Laura is going through a crisis, which obviously means more work for the rest of us. I know as a mum and wife you are always looking after and caring for all your family, but when you are ill yourself it's not the easiest thing to do.

What we have come to learn and realise though, is that it takes team work for all our family to function properly.

Laura will never complain to me when she is feeling poorly, she is so good. She just sleeps or watches TV. She can sleep for days on end. She always used to have a bed made up in the living room, but now she prefers to stay in her room. It was easier for me when Laura was downstairs, because she was still around us, and we could check if she needed anything, but now we have to go to where she is. I remember doing the same thing when I was young and Ian was ill. We all practically moved into his bedroom to keep him company. Thank goodness for texting now though, this is another way of checking on her.

It wears me down and saddens me to see her like this. Sometimes the emotional stress is worse to deal with than the physical stress. Laura doesn't eat and hardly drinks anything during a crisis, and I feel so helpless. This week I have got some friends trying to tempt her with her favorite homemade foods to get her to eat, but it's just a mouthful every now and again. I do worry about her becoming isolated and withdrawn, because she is not up to seeing her friends - it exhausts her just to talk to them, whereas Laura usually loves a good natter when not in crisis.

I find it very odd that Laura doesn't need much from me when she is like this, but I am exhausted and I can't understand why. I do have extra washing and ironing, due to frequent bed changes, because she overheats which is a typical symptom of Fabry.

One thing I know for sure is that when Laura is back to normal, I will be the one in bed and then the kids will be looking after me. I can have every confidence that when this happens and we are faced with this situation that Nik will do all the cooking and Tom will do all the running around and shopping.

We have all got used to our roles within the family and who does what. Within the three children I can see myself and Ian in them and how similar our health problems were at their age. Myself and Ian were both different with our health when growing up, Laura is the same as Ian was, Tom and Nik are very much the same as I was when growing up. I was only really affected when I got to my thirties, although I did have some Fabry symptoms as a child, mild in comparison to Ian and my mum.

It does upset me very much if I think about it for too long or dwell on Fabry for too long, but we have a great framework of support around us. I don't expect too much from any of us or anybody else really.

Don't get me wrong, it took many years for me to accept that my body won't allow me to do what my head wants it to do. But we take each day as it comes, if it's not a good day, we wait patiently until the next one comes along.
Diane Hughes

Get in touch...
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Amanda's driving battle

Amanda Laycock shares her battle to win back her driving licence after suffering two strokes related to Fabry. With help from the MPS advocacy support team, Amanda won back her independence

My name is Amanda. I am thrilled to be able to say life is going well and it's good. I can work full time, have kept my job, I drive a car, have many wonderful friends, my family is great, and I love to ride a bicycle when I have time. I also feel incredibly lucky to live in Britain where I have been looked after so well by the NHS.

After all it is because of the NHS that I have been able work, and haven't lost my home due to medical bills.
Like many of you, however, who might be reading this, it's not always been so great.

I suffered two strokes (at 38 and 42), without any typical risk factors. After the second stroke, the consultant from my local district hospital (Broomfield Hospital) was determined to get to the bottom of the problem. I was diagnosed 10 months later, 5 years after my first stroke. I started Enzyme Replacement Therapy 4 months after that.

The first month I had really mixed feelings. It was great that I was told that although they can't fix me, they could halt progression of the symptoms. How could I manage (energy wise and cost wise getting into London for my treatments, twice a month?). I was so relieved when the Royal Free Hospital LSD clinic told me that it most probably would be done at home! Although I didn't have any children myself, I am one of 4 children with many nephews and nieces, how would they take the news? Then there were my poor parents grappling with a short period of irrational guilt, ho hum.

After my first stroke, I really struggled with fatigue. I was able to return to work after 12 months, 3 then 4 days per week, I was too tired to do a full week and my employers were so supportive. I managed to get my licence back after a re-assessment within a year.

My second stroke affected me more physically. After 15 months I took a driving assessment, it had been much longer not driving this time around, I was increasingly prone to tiredness and during a 3 hour assessment I was asked to stop before I had completed the assessment.

The DVLA revoked my licence, but they were then to prove to be the most frustrating and difficult obstacle to getting my independence back, and to return to work and be allowed to drive again. At the time I took my assessment I had been on ERT for 2-3 months. I spent the next 9 months having some doctor in Swansea call the shots, not let me have lessons in a dual controlled car with an instructor (to build up my stamina and confidence), whilst not giving me any timescale for when he would let me sit a re-assessment despite my ERT very evidently improving my concentration and energy levels. Needless to say I was fraught, so disappointed and felt that I had fewer rights than any 17 year old whether or not they know they are tired!

Thankfully Rebecca Brandon from the MPS Advocacy Team helped me, by asking on my behalf, and letting me rant gave me support, not being directly involved, but helped keep my sanity.

The DVLA wouldn't budge on letting me have lessons but they did eventually let me go out cold turkey (almost 3 years on now) in the roads of Essex. Fortunately my sister knew of a place in London where you could take a car and drive around a mini road network (on private land) without a licence.
So I went each weekend for a month and drove intensively. I loved doing slaloms with the tyres and cones, avoiding drivers that either muddled their pedals up or forgot to do the steering bit of the driving made for a very eventful time! At least I now had confidence that my stamina was back before I sat my reassessment – even if it was only at up to 30 mph! I passed!

So this year I have started paying back the many car journeys I owe everyone who has been ferrying me about, and this year even did my fair share in France on holiday. I'm not saying I'm free of having off days, Fabry's is like that, but I hope to be free of the DVLA dictating over my life.

I've been back driving now for just over a year, no problems at all. It is so nice to choose to ride my bike when I'm local enough, and it's not raining! I am now so much more optimistic about not waiting for another unexplained stroke, staying well, and even getting to live beyond 50. I cherish every moment, and am grateful. Sure I get frustrated by the things I can't now do because of my strokes but for my Fabry's, I couldn't be in a better place.
Good luck in your journey...

An educational journey

Roma has Morquio disease and in spite of the obstacles this has presented, left school recently with 6 GCSE's and 2 A Levels. Roma's mother Bernie describes their experience...

Roma has had a rather peculiar journey through the education system. The educational milestones that are so important for children, parents and schools are usually the first days at primary school, secondary school, GCSE's and A'Levels…

However, for Roma, each of these milestones was markedly different from her peers. Roma's first day at Primary School and seven years later her first day at Grammar School was truly a big moment for everyone involved. On both those occasions, Roma was recovering from upper cervical spinal fusions, thus for the first 6 months in these new environments - with new staff and new peers - Roma had to wear a large metal halo which was attached to her skull by metal pins at both the front and sides of her head. Not a great way to win friends and influence people…

The same thing happened again at GCSE time when Roma was seriously ill with spinal myeolopathy and following yet another fusion, spent another 6 months in a halo. These were very trying times for all of us but the support from the schools on all these occasions has been truly incredible.

I am highlighting the 'halo experiences' as they always seemed to happen at really important stages of Roma's education. There is one point however, that I want to illuminate - and that was the transition stage between leaving primary school and going to grammar school. This was one of the most trying times for me, I presumed it was not going to be easy but that is an understatement. When Roma was in Primary 5, I started the process of looking at schools in the area to ascertain their accessibility both in terms of physicality and attitude. One would think the first person to ask about this would be the Occupational Therapist. Well the advice there was to go to a school about 40 miles away - all because it had a lift but very low academic attainment…

I wrote to several schools outlining Roma's strengths and weaknesses and asked if I could visit the schools. I contacted 8 schools, and to my horror most were not interested in having Roma and most tried to dissuade me from visiting. Some schools very swiftly rang me back, probably to 'get the thing over with quickly' to explain why Roma could not attend their school. There were many reasons used - usually to do with stairs all over the place, no lifts, bumpy driveways, building works and so on. There were schools that reluctantly agreed to show me around their premises but I soon recognised a familiar pattern – the school tour involved going around the most inaccessible routes.

In Northern Ireland, most children sit the 11+ exam, but children with SEN statements like Roma are prevented from doing this and instead have to undergo an assessment by an educational psychologist. We had massive problems there too, the Education Board would only give us a date for this assessment which would have been 6 months after Roma's peers sat their 11+ exams. Traditionally, after these exams are taken, Primary 7 children relax and spend the remainder of the school year doing extra curricular activities. At this point Christine Lavery from the MPS Society wrote on our behalf to our local representative, and the response was swift. We got our date for the assessment and it was on the same day as the other children sat their exams.

The move to the 'big school' for children with Morquio quite often entails a closer look at wheelchair provision. Where bigger campuses are concerned it is so much more difficult for children whose mobility is deteriorating to walk around these areas or try to self propel manual wheelchairs. Thus the struggle began for Roma to be assessed for a power chair. Here our primary school principal stepped into the breach with a real showdown with our occupational therapist who had brought along to school a 'suitable' wheelchair which the principal considered unsafe and in no uncertain terms told the OT to get it off the premises. It was then that he moved the discussion to the provision of a power chair and 18 months later we eventually received Roma's first Hippo, and a real passport to independence. Roma was also allocated a laptop – again another thing we had to struggle with the OT about.

The principal was well aware of my experience of contacting various schools and he arranged for a visit to the local grammar school - that would have been my first choice - to meet the principal. By this stage my confidence was truly dented but the meeting turned everything around. The grammar school principal was very welcoming, and as long as Roma received an A grade from the educational psychologist she would be more than welcome at the school. Although the school was not physically accessible, the welcome from the principal more than made up for this.

The Principal promised to help Roma and this promise never waned for the whole eight years that Roma attended the school. This exemplifies the school's Quaker ethos and professional commitment to its pupils.

Roma left school in June this year and to my embarrassment, I became very emotional at the last SEN annual review.

There were about 12 people around the table, the school principal, Roma's classroom assistant, our social worker, the SENCO, our MPS advocacy officer, Alison and several other teachers. I am sure many parents of MPS children will understand my sadness but also they will appreciate the embarrassment of 'letting go' at such a formal meeting. I had dreaded this day for so long, and it was every bit as bad as I had anticipated.

So, why was I in such a dreadful state? Well after so many years at the school we were moving away from a warm supportive environment, and into that no-man's land that is transition. I had come to realise that 'education' was our biggest ally and I am sure you will agree with this. Throughout Roma's childhood we have struggled with occupational therapists (who can have a really important impact on the quality of life of physically disabled people), but when it came to education, there was always a can-do attitude, there was always a solution to things, simply there was no messing about. The school had high aspirations for Roma, and they pushed and encouraged her to do her best just as they would with any other student. They were also very flexible, and the principal kept Roma on at school for an extra year following serious illness and yet another halo around the time when Roma was taking her GCSE's.

In the last years at school, Roma was unable to physically attend classes for A Level study but the principal worked out an arrangement where Roma could attend school for about 2 hours per day, and she secured provision from the Education board for home tuition. This was an excellent solution; as often Roma was simply unfit to attend school. Often, the tutor worked with Roma while she was still in bed, and this worked very well.

This is not to say that school was always easy. We all know that there is a poor understanding of rare diseases, and the idiosyncrasies that flow from them. As Roma went through school everyone had to learn that Morquio is so different from the more common conditions or disabilities and misunderstandings often arose because of Roma's poor performance, which was due to her low stamina.

The Principal who invited the MPS Society to give a presentation on Morquio to the staff addressed this. The school had wanted to do their best for Roma, but this went along the lines of 'Roma is no different from the rest of the pupils'. Many people fall into this trap, many think it's all about 'overcoming disability'. Well it's not. The reality is you have to work with the disability; you have to understand and accommodate it.

Everyone worked together on trying to understand Morquio, and it worked. Roma has left school with 6 GCSE's and 2 A' levels.

So far I have not mentioned Roma's classroom assistants. They deserve special mention; they were probably the most important people in Roma's school career. Both of them were excellent and worked in an age appropriate way. During Roma's latter years at school Roma's CA provided great support to both Roma and myself. Classrooms assistants who work with disabled teenagers have a really difficult job. Working within the restraints of health and safety they have to manage their time carefully, they have to know when to be present and when to withdraw. The presence of an adult is off-putting to many teenagers and unfortunately Roma would always have needed adult assistance. Quite often I have felt this placed Roma at a disadvantage.

Many young people with disabilities are socially isolated; this is the elephant in the room, the thing that is never talked about because it is assumed that it is too difficult to deal with. School for many young disabled people like Roma provides the only opportunity to mix with non-disabled peers and it was a great sadness to me when her peer group seemed to disintegrate following Roma's bouts of illness. I spoke to the Principal about this, and she talked to the girls in Roma's year but things never really improved after that. I was horrified when one day Roma told me that the girls who had shared the same table as her for a whole school year had never spoken to her.

I suppose there is no point in dwelling on this, and the lovely thing is that Roma having been granted an extra year at the school met a whole new crowd of young people who were much more welcoming and made her last year at school a happy one. I have also since found out that the original peer group who Roma was with had many strong characters and an unusual mix of hierarchies that isolated other pupils too.

I often think about Roma's student peers, many of who have gone on to study medicine. Only one of those girls has kept in touch with Roma. No doubt some of them will come back into Roma's life when they have do an essay on genetics…

So as we are now in transition land, Roma is looking forward to starting her Open University course. We will always be so thankful for the educational allies who helped Roma along the way, who helped to build her self-esteem and who held my hand too. **Bernie Drayne**

Caring for Sophie

Sophie has Sanfilippo, her parents Tim and Sally care for her changing needs and here Sally shares with us the pressures and issues that round the clock caring means for the family...

My name is Sally, I am married to Tim and we have two children, Will, now 16 and Sophie 15. Sophie has Sanfilippo Type A. It is a while since I wrote an article for the MPS magazine so time for an update! In the past I wrote about living with Sophie, Sophie having a gastrostomy and lastly about buying an adapted vehicle.

All the stages you go through are difficult in different ways and you think you will never cope, but you just get on with it I guess and the new regime quickly becomes the norm.

For us, the loss of mobility has been the hardest thing to cope with, from an emotional and practical point of view. If Sophie is at home, there is no rushing to get out to anywhere, it has to be planned and you always hope that nothing will crop up to delay you! Bowels opening after being hoisted into the wheelchair is particularly hard work as you have to start again from scratch!

Sophie coughs a lot and often at night and this is a big problem as she needs to be checked each time in case she has vomited. It is very tiring to keep checking on her so having a carer in, especially when I have to work the next day, is a real help. They also get her up the next morning for school so that is an added bonus! Sophie's cough has and is being investigated. It has been going on for about two years now, she had tests at Great Ormond Street hospital last November, sadly they were inconclusive. We have an appointment soon to see the ENT team there. She has been put on and off different medications and is on a permanent probiotic dose of antibiotics. It is very hard on her physically and wears her out, this probably exacerbates the amount of sleeping she does.

We have carers in every evening to bath Sophie and now we have carers in for 6 waking nights a month. The overnight sessions are an absolute lifeline and this is something we thought we would never get used to. Having so many people in the home on such a regular basis is still hard to accept sometimes. It has been a real learning curve, especially the overnights, it is very odd having somebody awake downstairs when you all go to bed!

Our carers are wonderful and they all adore Sophie. They carry out all the personal care Sophie requires but they do so much more. They massage her, read to her, paint her nails, make music with her and stimulate her as much as they can. Sophie does sleep a lot more than she used to, so they seize the opportunity when they can.

Sophie still attends school full time and has quite a long day. Transport collect her at 8.30am and she comes home about 3.55pm. She still has a trampolining session once a week after school and swims at school regularly in the hydrotherapy pool. We take her riding every Saturday and she very much enjoys riding Louie, who is a large pony who moves at about the same speed as Sophie! They are well matched!

Sophie is still a very happy girl and enjoys all her activities but like any teenager, she also enjoys being left in bed in the morning to have a lie-in. She can be changed, dressed, fed, washed, teeth cleaned and given her medicines and still not wake up! Sometimes she gets to school and must wonder how she got there as she knows nothing about it! **Sally Summerton**

Living with Fucosidosis

Stephen was a loving baby who seemed to grow normally although he suffered frequently from colds and ear infections. He had a small red mark on the back of one ear, we assumed it was a birthmark. His speech was delayed and at school they thought he was behind and recommended a statement so he could get extra help as he was not learning or retaining facts like his peers.

When Stephen was 6 years old his sister Lauren was born. At about 18 months she started to have a red rash on her buttocks. When Stephen was 13, Lauren 6 at the time, they were referred to genetics at Alder Hey Hospital because of the learning difficulties and red skin marks. It was there that Fucosidosis was diagnosed in both Stephen and Lauren. At home I googled the condition, probably the worse thing I could have done.

Since then both Stephen and Lauren have had supported help at school and Stephen at college.

Stephen is now 20 and Lauren 14. Lauren suffers most physically from angiokeretomas on her body but they do not trouble her too much except for occasional bleeding. They do appear different and unsightly and can attract curious stares from strangers although at school her peer group are good with her.

Retaining information is still an issue. Stephen is just about to start a temporary part time job and does voluntary work.

Lauren is making slow progress, she loves to copy words but her reading and spelling are poor. Both are mobile and enjoy watching sport, Stephen is the more independent of the two.
Linda Bell

Sarah's update

Well the last few months have definitely been hectic. My open university degree is going well. At the time of writing this I am finally on summer break so having a little bit of time to myself is nice again, going out with my friends and family when I can. It's nice not to worry about my next deadline for an essay or a looming exam, at least not for a while anyway.

I think I mentioned last time that I was thinking of looking for a new job, due to cut backs in the job I had. I applied for quite a few and attended a couple interviews with no success, then out of nowhere I got called in to an interview for a job which I thought I had no chance of getting. On the day of the interview I was extremely nervous as this was completely out of my comfort zone, but the interview went well and three days later I was called back in for a coffee with the manager and offered the job. I was to start my training six weeks later, which meant I had to go to work for three weeks knowing I was going to leave but being unable to tell anyone. Finally the day came when I handed in my notice and I felt completely free, I had been there for so long and was so happy to be leaving.

In the middle of June I started my training, which was challenging from the start, I had to travel about two hours away from my home every day for two weeks, having to be there for 9am and leaving at 5pm meant very early mornings and late nights, completely wiping me out for a few days, there was also all of the new information to try to retain.

The first proper day of work however was amazing, everyone was so welcoming and supportive. The only downside was having to sit down with my new boss and explain that I have Fabry's disease. This is always slightly awkward as most people haven't heard of it before. I had to explain what it was, that I was on 2 weekly infusions and had to travel to Cambridge every six months, I was so nervous. However my boss shocked me, he was so supportive, giving me time off every two weeks to have my treatment and guaranteed time for hospital appointments. I know some of you may not be as lucky to have such a supportive boss, and it was definitely a nice surprise and has helped me fit into my first full time job really nicely.

I have now been there nearly three months and still love every minute of it. The next few months when my coursework starts up again may be a little trickier but we will get over that when it comes round. Here's to the next few months. **Sarah**

The MPS Advocacy Service

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

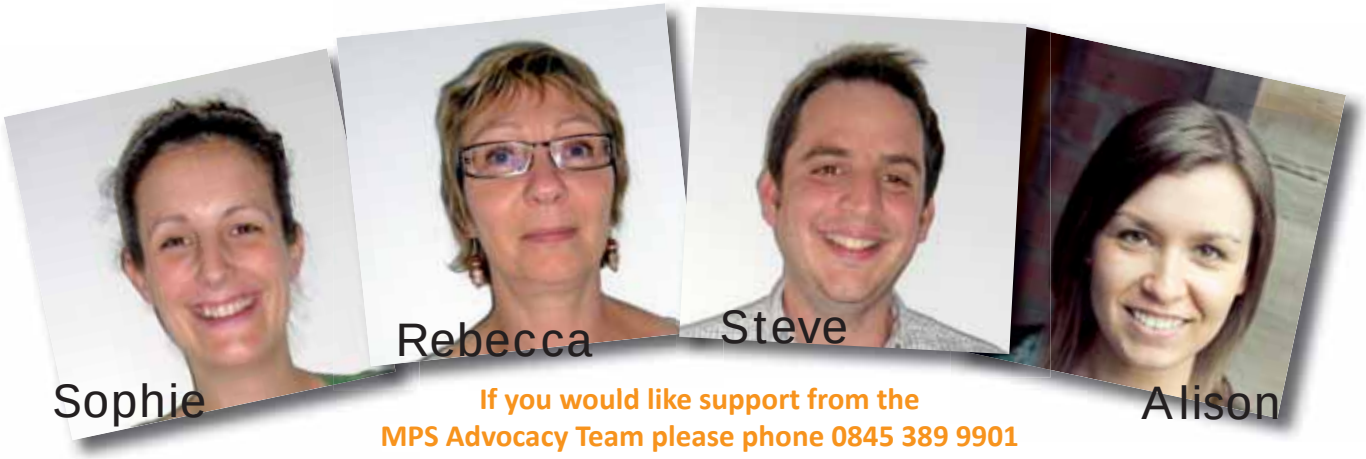
• Telephone Helpline – the Society provides an active listening service, information and support. This includes an out of hours service
• Disability Benefits – in understanding the complexities and difficulties individuals and families have in completing Disability Living Allowance claim forms, the Society 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:
E: advocacy@mpssociety.co.uk
T: 0845 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.co.uk**

- Disability Living Allowance
- 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



If you would like support from the MPS Advocacy Team please phone 0845 389 9901 or email advocacy@mpssociety.co.uk

News from the Advocacy Team

Disability Living Allowance for Adults being replaced by Personal Independent Payment

Disability Living Allowance (DLA) for Adults aged between 16 -64 years is being replaced by a new benefit called Personal independent Payment (PIP).

This is being introduced in some areas of the UK from April 2013 with a view to it being available in all areas from June 2013. All new claims or renewals will be considered using the new PIP. If you are currently in receipt of DLA it is envisaged that you will be written to between October 2013 and March 2016, inviting you to make a claim for PIP

Claiming for the first time

If claiming for the first time, there will be a 3 month qualifying period and your disability must be expected to last for a further 9 months after an application has been made. Please note that the qualifying period starts from when your needs began not from when you apply for PIP.

If you are already in receipt of DLA you will not have to meet the 3 month qualifying period but your needs must last longer than 9 months.

What is PIP?

PIP is similar to DLA in the fact that it still has the care and mobility component but it now only has two rates for both which are classed as standard and enhanced.

PIP is different in the fact it is not based on a person's disability but how it affects them and how it may impact on all aspects of daily living. It is hoped that this new system will be more inclusive as it is more evidence based and looks at a person's ability to carry out daily living and mobility tasks and is not dependant on an individual's condition or disability. The forms include a number of daily living tasks. In order to qualify for PIP you will have to score a certain number of points against each task. The areas covered are;

Care component

- Preparing food and drink
- Taking nutrition
- Managing therapy or monitoring a health condition
- Bathing and grooming
- Managing toilet need or incontinence
- Dressing and undressing
- Communicating
- Engaging socially
- Making financial decisions

Mobility component

- Planning and following a journey
- Moving around

Each task is set against a scoring system and points are awarded for each task that an individual cannot do either 'repeatedly, reliably, safely or in a timely fashion'.

How will claims be decided?

- Information provided by you and other health professionals will be considered and reviewed.
- All assessments will involve a health professional who will look at how your condition / disabilities affect you.
- You may be asked to attend a face to face consultation with a health professional. Please note; you will be able to take someone with you.
- A Health Professional will then advise a benefit decision maker who will then decide if you are entitled to PIP, at what rate and for how long.

How long will I be awarded PIP?

The length of award depends on individual circumstances. You may be awarded PIP for a short term up to 2 years, where it will need to be reviewed. If you are given a long award which could be between 5-10 years or awarded an indefinite or life time award the Department for Work and Pensions (DWP) may contact you at any time to see if your needs have changed.

Please note it is important that you inform the DWP if you condition changes or if there is a change in your circumstances.

PIP for the terminally ill

If you have a terminal illness and are not expected to live more than 6 months, your claim will be dealt with separately to other claims, dealt with quickly and you will not have to meet the criteria for the qualifying period of 3 months or have a face to face consultation.

Will I still be able to get other benefits?

At present it is not envisaged that there will be any impact of claiming other benefits such as carers allowance or being denied access to Motability schemes or applying for a blue badge. Further information will be made available regarding this at a later stage.

MPS Regional Specialist Clinic Programme

The MPS regional clinic programme involves centres including Manchester, Belfast, Birmingham, Bristol, Cardiff, London and Newcastle.

The programme aims to enable individuals affected by MPS and Related Diseases to access a consultation with a tertiary centre consultant without having long distances to travel to their designated specialist centre. The clinics also aim to increase expertise in the regional centres on MPS and related diseases in the clinical management of those affected.

The MPS Society supports the regional clinic programme, which can include arranging and co-ordinating dates of the annual programme and funding the tertiary centre doctors' travel and subsistence costs to the regional centres.

Specific arrangements for each clinic and for organising appointments differ for each of the centres. At least one member of the Society's advocacy support team meets individuals and families face to face to offer individual advocacy support.

You can read more about recent clinics on these pages...

Manchester under 6's BMT Clinic

13th July 2012

Friday 13th unlucky for some but fortunately I am not superstitious. The only unlucky part was the weather!
I was greeted at clinic by a very boisterous, full of energy, Ethan. Not sure what he had for breakfast but I certainly could have done with it.

Next to arrive was Jessica with her family, sporting a very patriotic hair ribbon, and a great red with white polka dots rain coat, shame they don't do them in adult versions. Jessica had a great time building the tower of bricks and knocking it down, I think the adults have just as much fun as the kids with the building blocks…

Mikko had an array of stickers on his top for being such a star at the dentist, or that may have been to try and placate him.

Jake came with his new baby sister Sophie Jean, named apparently after our very own Jean Mercer. Jake was sporting a muppet t shirt with Animal on it, despite that he was a little star.

Caught up with Joe just as I was leaving and look forward to hearing how he gets on at college in September.

Well as usual the time flew by and I was soon back on the train home.

Thanks to all the team for looking after me and see you all again in a few months.
Rebecca

Photos top row: Ethan Greening, Second row: Jake Little, Sophie Jean Little, Jessica Stringer, Third row: Morgan Wright, Mikko Astle and his brother, Joe Tucker

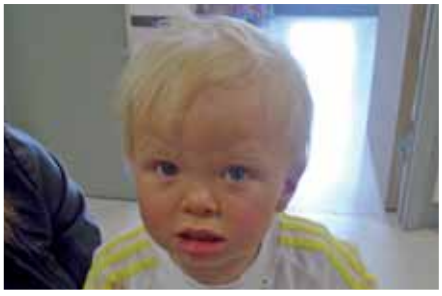
Newcastle MPS Clinic

The MPS Clinic was held at The Royal Victoria Infirmary, Newcastle on the 12th June 2012.

After a very early start, a short flight and car journey I stumbled through to the clinic bleary eyed and in need of coffee.

The clinic went very well and it was a pleasure to meet some of the families from the north east. The MPS Society would like to thank Dr Simon Jones, Dr Rylance and the team at Newcastle for supporting this clinic.
Steve Cotterell




Birmingham MPS Clinic

I always tend to start with the weather and just to say it was ok for ducks… Steve and I arrived at the clinic on 22 June 2012 which was held in the Wellcome Trust Research Facility which was away from the mayhem of general outpatients, no running around like headless chickens trying to track down our families this time.

Nathan arrived with his mum looking very chilled in his baseball cap which disappeared for the photo! Nathan likes singing but would not give me a tune, better luck next time. Alex came with his mum and dad and was looking forward to watching the cricket afterwards. Lisa Marie arrived looking very glam as usual. She had done matching pedicures for her and her mum, usual teenager not taking any notice of being told not to wear such high heels!

Hashim had a lovely photo taken with his little sister Maryam, and mum and dad. Muqadas came in like a whirlwind, everyman, or should I say receptionist, for themselves, phones, computers etc were not safe when this little tornado hit! Will just chilled with his headphones on and watched a DVD. It was a very busy clinic with lots of comings and goings. Soon it was time to make tracks home and an added bonus, it had stopped raining.

Thank you to all the team for looking after us and to the children for keeping us amused. **Rebecca and Steve**





Newcastle Clinic photos clockwise from top left: Laura Fish (Gangliosidosis), Luke Chapman (MPS III), Dominic Clarke (MPS IHS), Jack Baird (MPS III), Daniel Muers (MPS II)

Birmingham Clinic photos clockwise from top left: Alex Dearn (MPS I), Hashim (MPS III) with his Mum, Dad and sister, Lisa Marie Barr (MPS IHS), Nathan Oakley (MPS I), Will Brodie (MPS II)

Manchester over 6's BMT Clinic

22th July 2012

Another early and wet start up to Manchester. For the first time in years Jean was not there and had left the clinic in the capable hands of Clare.

Luke was already and waiting and trying to bring some sunshine to us by wearing his lovely red shirt.
David arrived and looks like he has a passion for motorbike stunts!

Rubina was very happy to sit quietly and do a jigsaw.
Alicia came with her grandparents and she was looking forward to having a MacDonald's on the way home and buying a chocolate muffin for her favourite duck! Just as well I am not around or the duck would have a fight on his hands….

Lyla was very colour co-ordinated, matching hair slide with her glasses etc.

Isaac came with mum and is looking very much the teenager, hence the ' slouched in the chair look.'

Holly didn't have her photo taken as she was having a bad hair day'. She was very impatient to get back to school, being the last day of term they all do lots of fun things.

Leighton was his usual cheerful self, posed with his brothers, they were sporting matching haircuts.

It definitely felt like the end of term, parents dreading it, the kids looking forward to the end of term parties but not so much the long holidays as they get bored!

Thanks to all the team for looking after me and I will see you all again when you have all started in your new classes at school. Enjoy the break… **Rebecca Brandon**

Photos clockwise from top left: Luke Blignaut, Rubina Jalani, Alicia Evans, Lyla May Heppleston, Isaac Turner, Leighton Barker and his brothers

Volunteering opportunities at MPS

Can you volunteer your time caring for MPS children and their siblings at events run by the MPS Society?
Volunteering is fun and rewarding. It could also help you learn new skills and gain valuable work experience.

We are always looking for new volunteers to help out with events and conferences that we run throughout the year. The MPS Society relies on volunteers to assist in the care needed for children and young adults affected by MPS and Related Diseases. All of our volunteers undertake training in moving and handling and are fully briefed prior to the event.

Becoming a volunteer: The MPS Society accepts volunteers from the age of 16 years on a trainee basis. We will require you to undergo an enhanced Criminal Records Bureau check as the Society supports children and vulnerable adults. If you are a new volunteer we also require two references and ask you to attend a compulsory training day at MPS House in Amersham. All new volunteers will be mentored by an experienced volunteer.

Please can you help us? Email: mps@mpssociety.co.uk or phone 0845 389 9901

All Ireland Advocacy Support

The All Ireland Advocacy Support Service is continuing to grow. Alison Wilson, All Ireland MPS Advocacy Support Officer is delighted to have been able to support many more families since she last updated you on this service. As usual she brings just a brief update on the work we do in Ireland and what we hope to do in the future.

When I last updated you on the work of the All Ireland Advocacy Support service we had just completed an exceptionally busy few months with clinics, conferences and family events taking up lots of time. Over the summer months things have been a little less hectic and I have had the opportunity to spend time really focussing on the individual advocacy needs of families across Ireland.

Sometimes people ask 'how can an Advocacy Service help me?'. Rather than me answering this question, I thought you might like to hear it from a few of our friends in Southern Ireland.

June has been supported in applying for an essential piece of equipment and the Smyth's are currently receiving support in relation to housing:

June Elliott (MPS IV)

My name is June Elliott. I live in Slane, County Meath, Ireland. I have Morquio (MPS IV) and I am going to tell you my experience using Our All Ireland Advocacy Officer, Alison.

Since I was 13 years old, I have had hearing loss and I had to get hearing aids. I was in school still and I was able to use a radio aid which would improve my ability to hear the teacher!

When I left school and got through college and eventually getting a job, I noticed that I wasn't hearing my boss as well as I should. About 1½ years ago, I applied through my work to get a Comfort Contego. This consists of a Transmitter and Receiver which would help me to hear more clearly. Unfortunately my application was not a success so I decided to reapply and after numerous phone calls I approached Alison to see if she would help with my application. I felt that if I had the extra support from Alison (e.g. letters explaining what the disease is and how it affects the individual, audiology reports etc) my application would be a success. So in the latter half of 2011 I was awarded the Comfort Contego and I use it mainly in work but also when watching TV and socialising with friends. It has made a huge difference to my life.

I was really grateful for being able to benefit from the All Ireland Advocacy Officer service. Thank you so much.

Geraldine Smyth, mum to Ethan MPS II (Hunter)

The first time we met our MPS advocacy support officer we had some amount of questions for her! We had no one else to help us through the minefield of services within the HSE (Health Service Executive), let alone have somebody who understood MPS! We asked Alison if it would be possible for her to come meet us and Ethan (who has MPS II Hunter disease) in our home in Galway. We personally thought it would be months before she could commit to such a long drive, but to our delight, Alison happily called to see us the following week.

We sat down and had a long chat about what we thought she could help us with, we were unsure about asking too much from one person, but Alison stressed to us that she was there for us and no problem too big or small she would try to help. We felt at ease straight away and began to tell Alison about our long history with the local housing authority. We needed a suitable home for Ethan and had been on the housing list for the past 6 years to no avail, not even a meeting was offered to us... that was before Alison!

Over the next month Alison arranged meetings and even viewings of houses for us. It was a firm step in the right direction for us. Alison attended meetings and viewings with us, even though this meant a long drive for her, she wanted to be there with us.

We feel that Alison's knowledge , professional opinions and experience with MPS has helped us enormously. We feel less like the family who have to prove what we are stating about MPS to be true, when we can just give them Alison's number. This really takes the pressure off us; as any MPS family will tell you, it gets tiring explaining MPS to 'experts' and then having to prove what you are saying just to get a service that your child needs.

We see Alison as more of a family friend who is always at the end of a phone and that is something that was needed badly for Irish MPS families.

Thank you! We appreciate all that you have done and are continuing to do, you have helped us more than anyone we have met since Ethan's diagnosis, you have made this road easier. **Geraldine, David, Ethan and Jack**

Other News...

As well as the usual advocacy work, I have also had the opportunity to represent individuals and families affected by MPS in Ireland at various events and meetings. The MPS diseases may be rare, but this only makes it more important to ensure that those affected are given a voice.

Northern Ireland Rare Disease Partnership

NORTHERN IRELAND RARE DISEASE PARTNERSHIP

In June I attended a planning meeting for the Northern Ireland Rare Disease Partnership (NIRDP). The NIRDP is a group made up of families, professionals and charity representatives who want to improve the lives of individuals with rare disease.

In the NIRDP's three year plan one of the key focus points is education and I have been tasked with heading up this group alongside a few other professionals. It is our hope that by educating medical professionals about rare disease in general, the time to diagnosis will be reduced and the management of patients with rare diseases will be improved. I will be using my experiences as an Advocacy Support Officer for MPS families to illustrate just how critical it is for medical professionals to understand rare disease.

National Rare Disease Plan Strategy Consultation

On 11th June I had the opportunity to attend a consultation day for the National Rare Disease Plan for Ireland. This meeting was an opportunity for relevant stakeholders to hear a briefing on progress to date and to engage in consultation in preparation for the final phase of developing the National Rare Disease Plan. The Department of Health hosted this event in association with the Genetic and Rare Diseases Organisation, The Irish Platform for Patients' Organisations, Science and Industry, The Medical Research Charities Group, the Institute of Public Health in Ireland and the Health Service Executive.

The meeting was an excellent opportunity to voice some of the issues that affect individuals diagnoses with MPS living in Southern Ireland to ensure that their needs are addressed in the final Plan. Some of the key discussions centred around:

- Research and Information
- Centres of Excellence
- Orphan Drugs and Technologies
- Patient Empowerment

I look forward to keeping you up to date with the progress of the National Rare Disease Plan for Ireland.

For more information about the National Rare Disease Plan for Ireland please visit www.ipposi.ie. This is the website for the Irish Platform for Patients' Organisations, Science and Industry.

Shanbally Manufacturing Plant Opening

Photo: Eamon, Elena and Mary McGauran at the Shanbally Plant opening.

Earlier this summer I travelled the LONG journey to Shanbally (Co.Cork) to attend the opening of the Shanbally Manufacturing Plant for a Biomarin Rare Disease Event.

The whole day was fantastic! The sun shone, the factory was fascinating and all the speakers gave an insight into the complexities of managing rare disease, the value of clinical research and what it's like to live with a rare disease. Before being taken on a guided tour of the manufacturing facilities; those who attended heard from David Hackett (Chair of the Irish MPS Society and an MPS parent), Eibhlinn Mulroe (Chair of IPPOSI) and Elena McGauran (Assistant Secretary of the Irish MPS Society, diagnosed with MPS IV).

For me the star of the show was Elena! Elena, who has Morquio, spoke eloquently about her life so far. She described the highpoints and some of the challenges she has faced over the year and finished off by saying: 'I am limited in what I can do, but I make the most of opportunities. I enjoy life and can honestly say I feel fulfilled and happy in myself.'

I was genuinely moved by Elena's zest for life! I hope that all those who attended the event and heard Elena speak, took away with them a sense of just how fulfilling life can be when you focus on the positives and view every challenge with determination and hope. Please read on to hear Elena's story...

Elena McGauran - "Living with Morquio Disease" MPS IVA

I'm Elena McGauran, second eldest of four children and I have just celebrated my 40th birthday and indeed I have had quite a few celebrations!

I attended main stream primary and secondary school and enjoyed it, most of the time. I followed this with a 2 year secretarial and computer course. Since then I work a 20 hour week in our family business, mainly imputing data which is very interesting.

My Mother, Mary, is Secretary of the Irish Society for Mucopolysaccharide Diseases and I am the Honorary Assistant Secretary. I am more than happy to assist with relevant duties including circulating all families on upcoming events etc. and generally being in contact. Indeed I would say that being in touch with other MPS families is invaluable.

I attend our local Irish Wheelchair Association Centre twice weekly. Our activities include arts and crafts, playing cards and bingo or afternoon trips to the beach, weather permitting! I also enjoy going to the cinema, theatre and dancing, well watching other people dance! I am also associated with the Irish Pilgrimage Trust. For about ten years I used to go on a one week respite holiday with them in Galway but this has been discontinued since last year.

Over the years I have been hospitalised many many times usually with severe chest infections. I become very weak but I respond quite quickly with IV treatment. Following hospitalisation in May of last year, my consultant recommended that I use a CPAP at night. This has improved my breathing and energy levels considerably. I should now like to outline some of the many challenges I have encountered and overcome.

My first challenge was stepping up for Holy Communion. Because of my size, I felt the priest would pass me by. However, my parents assured me that they would be standing either side of me, so all would be ok.

With age, it became increasingly difficult for me, to walk any distance. When I was 15, I had to have a Cervical Fusion due to compression of the spinal cord. It was at this point that my parents purchased a scooter, so I said goodbye to being in a buggy, and hey presto, people now said hello and greeted me, in my own right.

In 2003 I graduated to a powered wheelchair. The down side to this was and indeed is access - or should I say restricted access. Venues new to us require a reconnaissance trip by one of my parents to check out the facilities. Able bodied people do not always see 1, 2 or 3 steps!. However to the positive side, this state of the art chair, raises me to counter level – be it at the Cinema, Theatre, Post Office, Bank, Hotel Reception or that all important counter, where I complete my retail therapy!

In 1990, we purchased our first wheelchair accessible car. At the time my siblings reckoned it was like a spaceship. It is great, because it definitely reduces the risk of back ache, for my family and PA. I also feel less of a burden, not that I was ever made to feel that I am a burden.

In November 2003, I had my first PA through the HSE. With the help of my parents, I organised having a lady come into our home, to assist with my personal needs, and drive me to the office or IWA centre.

I wear hearing aids to overcome hearing loss. In 2009, I got a special hearing device, called a Contego. This leaves it much easier for me to join in conversations when travelling by car. It also enables me to tune into, round table chat or discussions, and at approximately 10m distance in the office. So I've heard quite a few secrets.

I have very limited power in my limbs, but I have been introduced to Kurling and Bocccia, for which I have two awards so far. Apart from the social aspect, it is great to be involved in sport – in fact I featured in the Women in Sport 2010 Calendar. Some ladies appear on page 3 – I'm on month 3!

I believe that what I lack in stature I make up for in determination and personality - always ready for a chat, an email, or a text. Thanks to the social dimension of technology - my computer, my mobile phone and with Face Time I can see and chat with my goddaughter Laoise and nephew Ferdia who reside in Amsterdam.

As you can see I am limited in what I can do, but I make the most of opportunities. I enjoy life and can honestly say I feel fulfilled and happy in myself.

My experience of MPS clinics

Jean Mercer MPS I and Gaucher Nurse Specialist
Willink Unit, Genetic medicine, St Marys Hospital, Manchester.

Well I have been asked to write about my varied, interesting, exciting and sometimes amusing (and sometimes sad) Post HSCT clinic in Manchester. In 2004 when I finished the ERT trials at Manchester I took over the Nurse Specialist role for MPS I. The patients in the clinic had been used to Gill Moss and were a little suspicious of the slightly mad me. However we have all worked together well and continued to grow; we've even got to the point that our patients have gone to the adult service – upsetting at times, but fantastic to see the patients thrive.

The clinic ages you in many ways, our patients grow up rapidly, staff retiring and replacements, and hospital changes have happened since 2004. Through it all the children have been amazing, generally happy to see us (even if we use a little bribery with Quavers/colouring and stickers), and ultimately having a true multi-disciplinary review. I am a contact for everyone involved in the clinic and outside it – which is demanding but usually ensures that the children get what they need. The clinicians involved at the clinic have an ever increasing workload and are difficult to coordinate, as they have a full-time role without including our clinic; which is why I sometimes remember to be really thankful to them for their dedication to the cause, namely Professor Wraith, Dr Simon Jones, Professor Clayton, Dr Wynn and Mr Oxborrow.

We have had many towers of bricks built and knocked down, numerous beautiful drawing and adornment with many stickers. Sometimes it can be difficult to listen to the children chatter to us (normally telling us lovely stories about the parents) and keep an ear on the medical opinion whilst updating the clinic excel sheets that we now have for each patient to keep track of their investigations, but hey how what is life without a challenge! These clinics are exhausting for all, including the parents, but ultimately in that room, we are all working towards the best outcome and the best health for the children, enjoying their triumphs and dealing with the disappointments but essentially all on the same team.

P.S – There are too many football discussions in this clinic that I have failed to control up to now!

Thanks to all the team including Clare my wonderful Staff Nurse.

Shared experiences from our members...

Anna Eaton, mother of Archie and Isaac who have Morquio:

I thought I would bring you up to date regarding Archie's new power chair, which has arrived and he is currently trying out during this week's induction program at his new secondary school.

The chair is a Zippie Salsa mid wheel drive, with seat riser. It has been provided by the wheelchair service and funded jointly between the health services and education authority, specifically for the transfer to secondary school. The additional cost of the seat riser was met from the education budget as it proved to be more cost effective than any other way of trying to provide suitable seating at the right height for all the different classrooms. He can use it out of school for general use once he has passed his wheelchair driving assessment - although we don't yet have a car we can take it anywhere in! As the provision is tied to his needs at school, he will no longer be eligible when he leaves and we will have to look for other options at that point in time.

Isaac remains on the waiting list with Whizz Kidz, which we still anticipate may come to something later this year. Otherwise he will be eligible for the same provision as Archie in two years time when he goes up to secondary school.

Our experience may help other families.
Best wishes, Anna Eaton

Autumn 2012

Society for Mucopolysaccharide Diseases

mps children's newsletter

what's inside...

katie's Day Out

Support to siblings

Wicked Genes!

Welcome to our Autumn 2012 children's newsletter. This edition we are asking for your help in fundraising in your school with Wicked Genes - our new fundraising initiative. Check out www.wickedgenes.co.uk for more information and to see how you can get your school involved!

As always, we really want to hear from children that are affected by MPS as well as their brothers and sisters. You can get in touch and have your stories, poems, drawings or messages in the next edition of the children's newsletter. You can email us at magazine@mpssociety.co.uk but don't forget to ask permission first!

Katie's Day Out

My Day Out at Camelot With The MPS Society

One beautiful morning I got up and dressed to go to Camelot. As soon as I got dressed I went downstairs. I had my breakfast then we set off to go to Camelot. When we got there it took 1 minute to find a space. We met Sophie and Steve who gave us the tickets and we gave them to the man at the gates. When we got through the gates I thought this is it! First I got on the caterpillar, then the dragon ride and then the boat ride!

Before lunch we went to the Jousting Show – were I gave my alice band to Sir Lancelot! I thought the jester gave it to Sir Percival instead! It was great.

After a few hours I had lunch in the café then I went on the balloon ride several times! Then I went on the tea cups and the mini train – which no one else was on! After that I got on the mini pirate ship, the flying men ride and the SPOOKEY ghost train – I WAS SCARED!

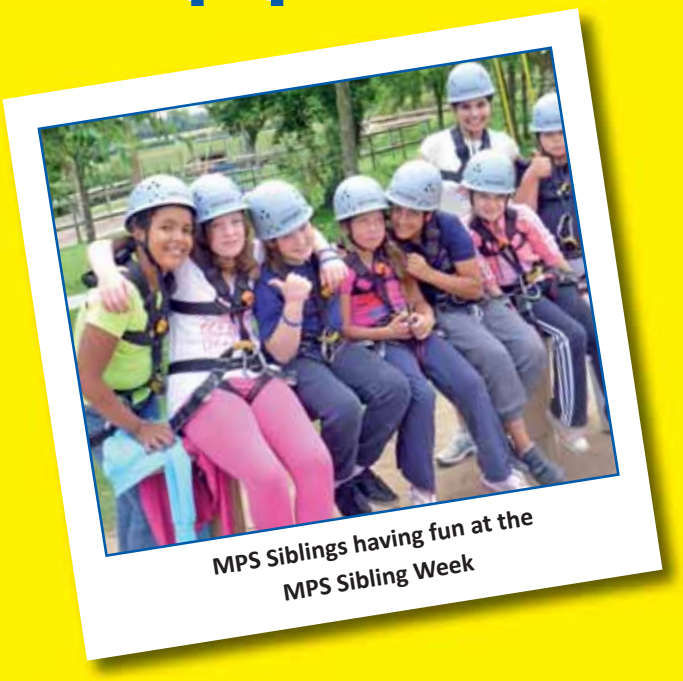
Katie bathing her brother Jack

Soon I went on the Carousel – I went on three times, got off and got on the mini dragon, then I went on the bumper cars.

At the end of the day we said thank you to Sophie and we went to Tesco on the way home to buy some tea and that was the end of my day!

THANK YOU!
by Katie Heath, aged 7 years

support for siblings



MPS Siblings having fun at the MPS Sibling Week

Being a sibling

There are lots of young people growing up with a disabled brother or sister. These young people are called siblings. Sibling is another word for brother or sister.

When you grow up with someone who is disabled, or has a condition like MPS, there are both good things and difficult things about it. It's like this in all families, even if nobody is disabled.

Good things

Many children grow up having brothers and sisters and although this can be a lot of fun, they can be annoying sometimes!

It can be fun to play together, talk about things and share stories about what you did at school or with your friends.

Difficult things

But sometimes things can be difficult if your brother or sister has MPS. Some siblings have said they find the following things particularly difficult:

- Feeling resentful because days out and spending time together as a family doesn't happen very often
- Being embarrassed about their brother or sister's behaviour in public, usually because of how other people may react.
- Not getting a good night's sleep and feeling tired at school
- Finding it hard to get homework done
- Being teased or bullied at school

Different emotions

Even though you always hear people talking about your brother or sister's condition, it can be very difficult to understand what it all means right now and for the future. This might make you worry a lot about your brother or sister and even make you worry about your mum and dad. Sometimes all of this worry and anxiety might make you angry and frustrated with things that wouldn't normally bother you.

Spending time with your Mum & Dad

Even though you love your brother or sister, there might be times where you get a bit annoyed or jealous that they get more attention than you do. You will probably understand that your brother or sister needs more help with things because of how poorly they are, but it still feels unfair. This is understandable because you want to spend time with your Mum and Dad just as much. It is normal to feel jealous.

Ask your Mum or Dad if they can spend a little bit of time with you each day. This may be when your brother or sister has gone to bed.

Write down some things you would really like to do with your Mum or Dad and show them your list.

Getting enough information

Lots of siblings feel that they don't know enough about the disability or illness. Do you know everything you want to about MPS?

You may have heard things from people at school or from relatives about MPS which might not be true. You might not want to ask your Mum or Dad about the condition in case you upset them. Most parents would rather their children asked questions rather than keeping their worries to themselves.

Having someone to talk to

It can be hard to understand what is going on all the time so it is important to make sure that you have someone to talk to whenever you need to get things off your chest.

Sometimes children and young adults that have a brother or sister with MPS or a related disease get worried about asking questions or talking about things with their mum and dad. If you feel comfortable doing so, then maybe you could talk to your teacher or your friends. You could also ask the carers that come to help look after your brother or sister about anything that you are concerned about or don't understand.

Check out our Kids Section on the MPS website
www.mpssociety.co.uk
Don't forget to ask permission first!

Other sources of support

For parents, family members and those working with families affected by an MPS or related disease, there are other sources of support which may be useful.

Sibs is the UK charity for people who grow up with a disabled brother or sister. They support siblings who are growing up with or who have grown up with a brother or sister with any disability, long term chronic illness, or life limiting condition. For more information visit www.sibs.org.uk

Contact A Family produce a range of resources including a fact sheet on Siblings. Visit www.cafamily.org.uk for more information.

Booklets available from the MPS Society

The MPS Society produces special booklets for children. These can be ordered from the MPS office or for more nformation visit our website www.mpssociety.co.uk

I've got Morquio's

I've got Hunter's

I've got Hurler's and had a BMT

Our brothers and sisters have Sanfilippo

I've got Fabry's

I've got MPS VI and I'm on ERT

Ben's ERT Story

Tell us about it!

If you have a brother or sister with MPS or a related disease why don't you get in touch with us and tell us all about yourself. What do you do to help look after your brother or sister? Why are they so special to you? What activities do you do together? Do you get upset or angry sometimes?

There will be lots of other children who will be feeling similar things so why not share your stories and your points of view. You can also get in touch with us and let us know what you would like to see in the MPS children's Newsletter as a sibling?

MPS events

Have you been involved in any of the events run by the MPS Society. Did you enjoy yourselves? Why not share your story here?

MPS Siblings having fun at the MPS Sibling Week

Contact us

Send us an email to: magazine@mpssociety.co.uk
or write to us at: MPS Society, MPS House, Repton Place, White Lion road, Amersham, Bucks, HP7 9LP, www.mpssociety.co.uk

Creating a Future with Hope for Children with Genetic Diseases

Wicked Genes

Hi, my name is Naomi.

I am 12 years old and I have Fabry disease. Having Fabry disease takes up a lot of time. I have to go to lots of hospital appointments. Some of them are in Great Ormond Street Hospital and some are nearer at home in Cornwall. I have an enzyme replacement infusion (drip) every two weeks. This used to be in hospital but now we have a lovely nurse Cherrie who comes to our house. My mum has been taught how to put the cannula in and I don't even need the spray now. I also have other medicines for my Fabry disease. Fabry makes my hands hurt, I also have pain in my joints and in my head, neck and back.

For pain I take paracetamol, iboprufen and gabapentin. Sometimes the Fabry makes me have tummy problems where my tummy hurts and I need the toilet a lot! Since being on the enzyme replacement that has improved so much I hardly ever need to take immodium. Fabry disease makes me also have dizziness – I think it is called vertigo but it isn't about being scared of heights. For the dizziness I take a tablet called cyclizine. After my infusion I start to have more energy and feel lots better but by the time I need my next infusion I'm in lots of pain and am very tired. It would be nice if the infusion would make me completely better but it does make me feel so much better and before I started on it last May I thought nothing would ever help me feel better.

Help kids like Naomi by requesting your school's fundraising pack today!

www.wickedgenes.co.uk
wickedgenes@mpssociety.co.uk
0845 389 9901

Fun day out at **Chessington World of Adventures!**

On Sunday 10th June the families arrived at Chessington World of Adventures ready for a day of fun together. On arrival the families met two of our team who were there to support them – these events provide a good chance for the families to meet our team face-to-face and get to know us, so that they feel comfortable seeking advice and support in the future.

As the families arrived they were invited to have their photo taken to appear in our MPS Magazine; we have included a selection on this page which show how many families benefited from the much-appreciated funding from Barclays.

We had organised an "Adventurer's Pass" for each family which meant that they didn't have to wait in the queues with wheelchairs or with children who find it difficult to stand for long periods: it saved families a lot of time because they were able to use the disabled access to the rides.

The children and their families couldn't wait to explore the many "Lands" on offer, with something for everyone to enjoy. These included Land of the Dragons, Mexicana, Pirate's Cove, Transylvania, Wild Asia, Mystic East, Forbidden Kingdom, the new "Africa", and the Wanyama Village & Reserve. And of course there were the delights of Chessington Zoo and the Sealife Centre which proved very popular. The "Bubbleworks" was also a big hit with many of the children. Families also enjoyed meeting up in the cafes to relax and have a catch up.

At the end of the day the worn-out families headed home having had a super trip, and having met with others to keep in touch with in the future.

International MPS Symposium

On Monday 25 June Sophie and I arrived at the Holiday and Amusement Park Duinrell, Wassenaar, in the Netherlands ready for the 12th International Conference.

That evening we met with the ten families that joined us for a get to know you drink. The weather was mild for all of the week and the families took advantage of the facilities on site which included the waterpark with amazing flumes and slides to the theme park with its heart stopping rides.

The Conference began on Thursday with a reception welcoming all from around the world. This was held about a twenty minute coach drive away at hotel NH Leeuwenhorst, Noordwijkerhout. This gave the families a chance to catch up with our amazing volunteers that we took with us from the UK and in true style they did us proud.

The following two days were filled with family stories and medical (some completely over our heads) talks, while the children went off to Madurodam a local model village and Archeon which includes 43 reconstructions of buildings from three very different periods: the prehistoric age, the Roman era and the Middle ages.

The final evening we had a gala dinner and thanked the families and volunteers and danced away the evening.
Gina Page

Kamal's trip

On 25th June, we flew from Gatwick Airport to Schiphol Airport in Amsterdam. We had rented a car, so we collected it from the airport and drove to Duinrell Park in Wassenaar.

Upon arrival, we collected our keys and made our way to the bungalows. Kamal decided to help with one of the many bags that we brought with us. While we were unpacking, Kamal opted out and decided to sunbathe. As soon as we had finished, we headed straight to the theme park as Kamal was extremely eager to get on the rides. One of Kamal's favourite rides was the mini rollercoaster for children; he was slightly anxious at first, but soon became a little dare devil and lifted both arms off the handle.

We had from Monday until Thursday afternoon free to do as we pleased. We spent some time in the theme park and bought some fresh fruit from the local market. We also went to SEA LIFE in Scheveningen, to the beach, to Rotterdam and to Amsterdam many times. We made sure we made the most of our vacation as the Netherlands was such a beautiful place to be.

On Thursday afternoon, Kamal got to meet his volunteer, Hannah, and we got to meet all the people who had travelled from 48 different countries all around the world. The conferences began the next day, and as the adults were sat in the conferences, the children were taken off the Hotel grounds and went out exploring.

Kamal's favourite adventures were going to Madurodam and being a Roman warrior. Madurodam was Kamal's chance to be bigger than everything and I think he got a little carried away!

The next day, the adults were in the conferences again while the children went out. This time Kamal got to be a warrior, and again he was overly pleased and let off all his anger, just as well the swords weren't real!

The conferences went on from Friday until Sunday; we all travelled from Duinrell Park to NH Hotel by coach, and this was a chance to catch up with the rest of the families.

On Saturday evening, we all went back to the hotel for a special evening and dinner. We got to see what the children had been up to in our absence; we had some dinner and drinks, and the children were entertained with music and jokers. That evening Kamal met Jibreel Arshad, and until this point he had never really spoken to anyone with Morquio (MPS IV A), and he is now aware that he is not the only person who has Morquio. We met Faye (from the UK) and Nic (from Holland) and Kamal and I had our picture taken. These were just a few of the great and inspiring people we had met.

Sunday was our last day, and we said our goodbyes which was very sad as we left on Monday. We met some extraordinary people and Kamal made some great friends which I'm sure he'll be friends with for life. He became very good friends with Jordan (from Edinburgh), Callum and Tara. It was very nice meeting their families as well, and just hearing their experiences and stories. Although they have different MPS conditions, the experiences that we as families have are very similar.

I'd like to thank the MPS Society for giving us the opportunity to meet all these amazing people, and this just proves how a child with any type of disability is unique and special and we are very lucky to have them in our lives.

As soon as we arrived back to Gatwick, Kamal's first question was 'When are we going back to Holland?'
Suzanne Mallah (Mother of Kamal Hoteit, Morquio Disease Type A)

"Sannah and the family had a great time in the Netherlands, Sannah was so happy and enjoyed herself so much. This experience could not have been possible for Sannah and us without the excellent support provided by you Sophie and your team. I just wanted to say a big thank-you to you and your team for supporting us to make this a joyful time for our Sannah."
Feeraz

Information and Education available from the MPS Society

Resources

We publish a number of resources aimed at different audiences – children, parents and carers, grandparents and professionals. They cover a whole range of different topics, including detailed information on each of the MPS and related diseases including Fabry, particular issues covered by the advocacy team such as housing, benefits and travel insurance to guidance on fundraising. There are also general guides on the management of anaesthesia, the pattern of inheritance and challenging behaviour.

Some of these resources are available to download free from the MPS website under Resources and Downloads, or you can order them for a small charge online from our MPS online shop. Check out **www.mpssociety.co.uk**. Alternatively, place your order over the phone on **0845 389 9901** or ask us for a publication order form to be sent to you in the post.

Website

Thank you to everyone who took part in our survey on the MPS website. The majority of you found it easy to navigate and were able to find the information you were looking for. If you have any further thoughts on how we can improve the site, please do email **website@mpssociety.co.uk**.
Don't forget you can download many of our resources and materials directly from the site. There is plenty of information on our different activities and how you can get involved, either by volunteering or helping us with fundraising. We also update our latest news regularly so don't forget to have a look to see what's new.

Online shop

Our online shop was a big hit in the run up to MPS Awareness Day with lots of you ordering MPS merchandise. If you have any suggestions for how we can improve our online shop, or if there are particular items that would be like to see available, please email **webmaster@mpssociety.co.uk**.
Our seasonal collection for 2012 is available this year to purchase through the shop too, so please place your orders for Christmas cards etc early to avoid disappointment!

Fundraising resources

Have you checked out our fundraising pages on the MPS website recently? You can download fundraising packs, sponsorship forms, sample press releases etc. If you can't find what you're looking for, need some more information or just want to chat through your fundraising ideas drop us a line at **fundraising@mpssociety.co.uk**. If you don't have easy access to a computer or want multiple copies, please phone us on **0845 389 9901**.

As well as our general fundraising resources, we can send you extra leaflets, posters, balloons, stickers, collection boxes plus a T-shirt for each individual fundraiser. Everyone running for MPS can choose to receive a T-shirt or a running vest plus a couple of banger sticks for your supporters to wave and cheer you on!

Your feedback

Your comments, suggestions and feedback are really important to us and we always take your comments on board. Where resources allow, we will also try to change things! Please get in touch with us at **magazine@mpssociety.co.uk**, **webmaster@mpssociety.co.uk** and **fundraising@mpssociety.co.uk** depending on the nature of your feedback! Thank you.

MPS Magazine

The MPS Magazine goes out quarterly to all our members, supporters and subscribers. It is our main way of communicating with you, telling you all about what's been happening with our events, research, treatment updates, fundraising, and for you to share your stories and news.
You can sign up to receive the Magazine by email as a pdf by completing the MPS magazine sign up box on the MPS website homepage, **www.mpssociety.co.uk** and download it too from our Resources and Downloads section.

We do get a few people suggesting we should send the magazine out by email, rather than wasting money on printing and postage and to be kinder to the environment and this is something we continue to consider. However, our membership is very diverse and the majority still like to receive their copy in the post to pass on to our family, friends, colleagues etc. We obtain very competitive quotes which we review each edition and the grants we receive for the printing are restricted for that particular purpose so can't be used for anything else. Again, if you have any suggestions for how we can improve the MPS magazine, or would like to submit an article please email **magazine@mpssociety.co.uk**.

Father Writes Kids' Book To Save His Terminally Ill Children

Fairfax, VA - Matt McNeil's daughter, Waverly, just wasn't getting the hang of it. Toilet training had come so easily to so many of their friends, and many of them much younger than her. She was lagging behind in her speech too, and what words she did use were difficult to understand. At first, her doctor diagnosed a hearing loss, which seemed to explain so much. But after a few months of working intensely with audiologists and speech therapists, it became apparent that Waverly was facing something much more serious.

By the spring of 2008, doctors figured out what was wrong. Waverly's developmental delays were caused by MPS III, a degenerative and ultimately terminal genetic condition. The doctors advised that there was no cure and no treatment available for this rare disease. Even more bad news came just one month later: Waverly's little brother, Oliver, also had MPS III.

Stunned by the fact that he would lose both his children by the time they were teenagers, McNeil felt himself being pulled down by depression. He started writing as a way to put some space between himself and his overwhelming grief. After a few years, he finished a book, THE STRANGE TALE OF BEN BEESLEY, about a fly named Ben who sets out to save his friends from a cruel spider's deadly venom.

"I drew on our experience with MPS to make Ben's quest as difficult as possible," said McNeil, "and it was extremely cathartic to give him a fighting chance to succeed. But once I finished, I realised the book was actually quite good and could be just what I needed to help my kids. That's when I decided to sell it and that every penny raised would be donated to the National MPS Society to support research programs."

Although BEN BEESLEY is an outpouring of a father's hope for his children struggling against a terminal illness, it is first and foremost an exciting adventure story for middle grade readers (age 9-12). The book was released nationally in the US on MPS Awareness Day, May 15, and will be available in paperback and Kindle editions. For more information visit benbeesleybook.com.

Coming soon - EASIER TOGETHER!

The MPS Society is pleased to announce 'EASIER TOGETHER – bring your own story' - a brand new patient support project designed specifically for Hunter disease patients and their support communities.

The project has been developed through the support and commitment of Shire, in collaboration with the MPS Society. To ensure that it really captures the experiences and needs of patients, a range of Hunter disease experts, including healthcare professionals, the MPS Society, Shire and of course you, patients and families, are helping to shape the project and materials. The work is ongoing but we hope to be able to launch this initiative before the end of the year.

We'll be sharing the full details of the project shortly, but today we can tell you that Easier Together will feature a range of informative materials and tools (available online and in print formats), which we hope will support, motivate and empower patients and the wider Hunter community.

Once Easier Together has launched, we'll certainly be seeking your feedback, suggestions and ideas to help us make the project even better throughout next year! We want the project to grow and evolve with the needs of our Hunter patients and their families.

We'll be sharing more information very soon so please stay tuned to the MPS Society website!

Clinical trial update

MPS II Intrathecal ERT

Shire Human Genetic Therapies is sponsoring a clinical trial at Birmingham Children's Hospital. The phase I/II safety and ascending dose ranging study of idursulfase administration via an intrathecal drug delivery service in paediatric patients with MPS II is designed to learn whether direct administration of recombinant enzyme into the fluid around the brain and spinal fluid is safe and a possible treatment for children cognitively impaired by MPS II. All participants must be receiving treatment with Elaprase prior to participating in this study. This study is closed now.

MPS IIIA Intrathecal ERT

Shire Human Genetic Therapies is sponsoring a "Phase I/II Safety/Tolerability, Ascending Dose and Dose Frequency Study of Recombinant Human Heparan N-Sulfatase (rhHNS) Intrathecal Administration Via an Intrathecal Drug Delivery Device in Patients with MPS IIIA". The Phase I/II Clinical trial began in June 2012 and is currently coming to an end. Patients who have completed all study requirements in this clinical trial are being invited to participate in an open-label extension study that is designed to evaluate long-term safety and clinical outcomes of intrathecal administration of rhHNS. **www.clinicaltrials.gov.uk**

MPS IIIB Observational Prospective Natural History Study

Shire HGT announced in January 2012 that it will sponsor a natural history study for individuals with MPS IIIB. Ethical approval for this study has now been received and the study will take place at Great Ormond Street. This study is expected to begin recruiting within the next few weeks. Details of the inclusion and exclusion criteria will be posted on **www.clinicaltrials.gov.uk**. The objective of this study is to evaluate the natural unaltered disease progression of MPS IIIB and has been designed similarly to an interventional clinical trial. This is a longitudinal, prospective, observational, natural history study to identify end points that may be used for future ERT trials via standardised clinical, biochemical, neurocognitive, developmental, behavioural and imaging measures. It is expected that the outcome from this natural history study will provide key disease insights, similar to what would be treated in an untreated control group of patients in an interventional clinical trial.

MPS IVA Enzyme Replacement Therapy

In February 2012 BioMarin Pharmaceutical Inc. closed the access gate to its Pivotal Phase III trial for N-acetylgalactosamine b-sulfatase (GALNS or BMN110) intended for the treatment of MPS IVA having recruited over 160 patients in 40 centres of the world. Recruitment is continuing for the MOR-006 study for non-ambulatory individuals with MPS IVA For further information go to www.clinicaltrials.gov.uk

Other clinical trials:

MPS I Intrathecal ERT, Los Angeles Biomedical Research Institute, Harbor – UCLA, California, USA
MPS I Intrathecal ERT for Children Being Considered for Transplantation - University of Minnesota, Minneapolis,US

Alpha-Mannosidosis Enzyme Replacement Therapy

Zymenex's enzyme is in Phase 2 clinical trials inpatients with the rare disease alpha-Mannosidosis. A Phase 1 trial has just demonstrated that the enzyme is safe and well tolerated and the Phase 2 dose-finding clinical trial is now underway.

The biotechnologically derived human enzyme product rhLAMAN (LamazymTM), which is produced by the Scandinavian biotech company Zymenex and developed for the treatment of patients suffering from the rare disease alpha-Mannosidosis, has successfully completed Phase 1 trials and has now entered Phase 2a clinical trials. The patients were recruited into the Phase 1 trial from around Europe, where the initial goal of demonstrating that the enzyme is safe and well tolerated, has been achieved. This now allows the 10 patients to be moved forward into a 6-month Phase 2a dose-finding clinical trial, where the aim is to identify the most optimal dose to achieve the desired clinical effect.

MPS Awareness Day in Turkey

In Turkey, MPS Awareness Day was marked by an event on 20th of May in Istanbul.

350 people; patients, their families and friends, doctors and press attended the event which was held in a Conference Centre made available free of charge by the local mayor. A well known showman, author and poet entertained all who attended for one and a half hours. A sociologist gave a speech on how to improve the quality of life for people with these diseases and disabilities. Finally, the day ended with music and a meal.
Fer Pidden

Research

Amicus Therapeutics Presents Updated Patient Screening Profiles From Phase 3 Fabry Study

Majority of Subjects Screened in Phase 3 Fabry Study 011 Had Missense Mutations Considered Amenable to Migalastat HCl Monotherapy Based on a Cell-Based Assay

CRANBURY, N.J., Sept. 6, 2012 (GLOBE NEWSWIRE) -- Amicus Therapeutics (Nasdaq:FOLD), a biopharmaceutical company at the forefront of therapies for rare and orphan diseases, today announced updated details on patients screened for one of the global Phase 3 registration studies (Study 011) to investigate the pharmacological chaperone migalastat HCl for Fabry disease. These results were presented in a poster1 at the Society for the Study of Inborn Errors of Metabolism (SSIEM) Annual Symposium 2012 (SSIEM 2012).

Migalastat HCl is in Phase 3 development for Fabry disease in patients with genetic mutations that are amenable to this chaperone as a monotherapy. Study 011 - also referred to as FACETS - is one of two ongoing Phase 3 studies of migalastat HCl monotherapy being conducted by Amicus and GlaxoSmithKline (GSK). Updated screening profiles at SSIEM included the following:

- A total of 180 Fabry patients (60 males and 120 females) were screened for Study 011. Prior to screening sites could have used genotype information when available to enrich for Fabry patients with amenable mutations who were more likely to be interested in participating.
- Approximately 86% (154/180) of patients screened had missense mutations (compared to a current estimate in the Fabry population of approximately 60%)
- Approximately 88% (136/154) of those patients, or 76% of patients screened, had alpha-galactosidase A mutations amenable to migalastat HCl monotherapy, and were potentially eligible for enrollment.
- Approximately 50% (67/136) of those patients, or 37% of all patients screened, enrolled in Study 011 upon meeting all entry criteria, including: 1) naïve to ERT or had not received ERT for at least 6 months prior to study entry; 2) genetic mutations amenable to chaperone monotherapy and; 3) for study purposes, urine globotriaosylceramide (GL-3) levels at least four-times the upper limit of normal at baseline.

Pol F. Boudes, MD, Chief Medical Officer of Amicus Therapeutics stated, “Not all Fabry patients have been genotyped and new patients continue to be diagnosed. During screening for Study 011, we discovered 15 unique missense mutations that contribute to the growing database of new mutations within the broader Fabry population. We continue to believe the randomized population in Study 011 is fairly representative of a broad range of Fabry patients by gender, disease burden, and genotype.”

Study 011 is a randomized study with a 6-month, double-blind, placebo-controlled primary treatment period and a 6-month, open-label follow-up period in which all subjects receive treatment with migalastat HCl. The primary endpoint in Study 011 is a change in interstitial capillary GL-3 as measured in kidney biopsy at 6 months versus baseline. The 6-month primary treatment period in Study 011 was completed in the second quarter 2012 and the 6-month follow-up period is expected to complete in the fourth quarter 2012. Amicus and GSK expect to unblind and analyze data from the primary 6-month treatment arm during the fourth quarter 2012. Both companies remain blinded to all results at this time.

John F. Crowley, Chairman and Chief Executive Officer of Amicus stated, “Screening results from Study 011 suggest that migalastat HCl monotherapy may address a substantial portion of the Fabry population on the basis of genotype. In addition, these screening results may provide the Fabry patient and physician community with valuable information on a wide variety of different mutations, including newly discovered mutations.”

1. Migalastat HCl, an Investigational Pharmacological Chaperone Therapy: Screening Results from FACETS, a Phase 3 Study in Male and Female Fabry Patients. —Nicholls, K., Castelli J., Winkler R., Sitaraman, S., Benjamin E., Wu, X., Duke C., Boudes, P., on Behalf of FACETS Study AT1001-011 Principal Investigators.

Creating a Future with Hope for Children with Genetic Diseases

Wicked Genes is the new fundraising initiative of the MPS Society

Wicked Genes has been moving from strength to strength since its launch in the last edition of the MPS Magazine. We are delighted to have received such positive feedback about the initiative.

A buzz has certainly been created and people are beginning to use Wicked Genes to raise money for researching treatments and to provide support to our MPS families.

We have fundraising packs, press releases, posters and sponsor ready to download or post direct to YOU!

Thanks to Medco for a great day of Wicked Fundraising!

Medco Health Solutions arranged several events with our staff members. We had a cake stall in our canteen with donations from the staff which were sold throughout the day, a raffle that local businesses and staff members donated to, an auction of high value items such as Spa vouchers and an extra days annual leave and also a Wicked Genes Jeans competition.

Our Van Drivers and Nursing team also took part and handed flyers to our patients explaining why they were wearing pink and Jeans and some of the patients even donated!! All of our staff commented on how much they enjoyed the day and some even went home with some brilliant prizes!!

In total from the event Medco raised £974.64!!

Get in touch now!

0845 389 9901

www.wickedgenes.co.uk

wickedgenes@mpssociety.co.uk

Our Creative Wicked Elves have been busy behind the scenes developing an exciting schools charity fundraising calendar.

The big idea:

- Schools are invited to fundraise with Wicked Genes by people like you.
- Each school is given a year's charity planner full of fun and exciting ways to encourage pupils and staff to take part.
- A member of the Wicked Genes team will be in touch with the school to assist with planning fundraising events.
- A Wicked Genes ambassador will visit and present to the school to share their own personal story of living with genetic disease.
- The schools will have lots of fun throughout the year and raise loads of money to save children's lives!

"Do something **Wicked** for Wicked Genes!"

What are we up to next?

The new school term has started and schools are preparing for the year ahead. It's the perfect time to introduce Wicked Genes as a great way for your local school to raise much needed funds.

We believe that personal connections and relationships are by far the most powerful way to engage people. We need you to speak to your local schools (and your friends and families to do the same) about Wicked Genes. We will provide you with the Wicked Year charity planner and welcome pack to support your first contact and we will follow this up ourselves to each and every school who shows an interest.

We need to move on this fast! Please request your very own wicked school charity calendar pack and speak to your local schools today!

Fundraising

Welcome!

The MPS Society supports children and adults affected by MPS and related diseases throughout the UK, their families, carers and professionals.
As you will have read earlier in this magazine, we provide a unique needs-led advocacy service, organise and manage events to enable those affected to come together to share experiences and learn about the latest developments in clinical management and treatment, and fund and encourage research into these devastating diseases.

But to do this we really do rely on the generosity of people like you to help us continue our vital work.
We have a whole range of resources available to download from the MPS website including our **Fundraising Pack** which gives you plenty of ideas and guidance on fundraising for MPS plus template forms for you to download, from organising an event, to simply making a donation online or via text.

We can send out T-shirts, balloons, stickers, posters and leaflets to promote your fundraising and we have a range of merchandise to raise awareness of MPS.

You can make a difference today.
If you would like to get involved with MPS Fundraising, please email **fundraising@mpssociety.co.uk** for more information...
We would love to hear from you!

This section of the MPS Magazine is devoted to your fundraising stories, opportunities and thank yous! Please read on...

Walk/run and ceili raises over **£17,000**

At the start of May 2012 my family and I got together with alot of ideas to raise monies for the MPS Society. We came up with a 5km walk/run followed by a ceili on 3rd June in Keady Co Armagh.

This was a huge success and over 400 people showed up on the day to show their support for the walk/run and 150 took part in the ceili. Alot of the schools and sports clubs in the area held their own events like mini walks from the bus to school, a creche that Shannon-Rose attended had a dress up morning for the kids and a coffee morning for the parents. Football teams had charity games and donated all the money to the MPS Society. So the whole community got behind our wee campaign. **Sheena Mallon,** mother of Shannon-Rose who has GM 1 Gangliosidosis.

The total raised was over £17,000 and we would like to thank everyone who was involved in the organisation and took part in the events. Thank you to all the community for donating to the Society.

shareagift.com

2 year old Jack's £600k Shareagift campaign for Genistein

This little golden-haired ray of sunshine is Jack. He's 2 years old and has Sanfilippo MPS IIIA. And in a little over 3 weeks, his story has prompted members of the public to donate over £3,000 towards a new campaign for the MPS Society in a drive that we hope will help children with Sanfilippo everywhere.

As many of our readers will know, the MPS Society and Wicked Genes fundraising initiative are trying to raise nearly £600,000 to fund clinical trials of the Genistein drug used to help treat Sanfilippo disease. A few weeks ago, with the help of the MPS Society, Jack's family set up a personal Gift Page on a new website, Shareagift.com, to help with the campaign, and we've been absolutely amazed by it's success.

Jack's page, www.shareagift.com/jack, has already collected over £4300 in donations and received heartfelt messages of love and support from all sorts of people, many of them strangers, all over the UK. We've received some fantastic press coverage, particularly in Jack's home region in the northeast and the public response has been incredibly touching.

Snowballing the campaign

The success of Jack's page has lead to more families coming forward to start their own Gift Pages, with all of the proceeds going towards the Genistein clinical trials. 4 year old Ella and 7 year old Bobby and their families have now also set up Gift Pages to help attract public support in their local areas. Families have posted videos on YouTube linking to their Gift Page, asked people to post the link to their Facebook Walls and put it out on Twitter to help spread the word. All of us at the MPS Society are hugely optimistic that this snowballing effect will help spread awareness and collect those funds we so urgently need.

How you can help

We are asking everyone to spread the word about Jack's page throughout their own social networks online – by posting to Facebook, tweeting on Twitter, sharing the YouTube video and any other means available. If you have any contacts with the media and are able to help us get the story in the press please get in touch, and of course, if you would like to make a contribution to the fund please go to www.shareagift.com/jack where you can donate online from anywhere in the world.

Creating your own Gift Page

We are also asking any other families of children with MPS to contact us if they would like to create their own Gift Page to help. Anyone can create a Gift Page on the site, which is more commonly used for group gifts, but we are helping individual families set up their pages to ensure they are all linked to the Genistein fund. If you would like to set up a page for your child, or perhaps in memory of a loved one, do please contact C.Lavery@mpssociety.co.uk.

We know that £600,000 is a lot of money. But we also believe that with the power of public support we can raise it. It's all about spreading the word – from the media, to our family and friends, to our social networks. If 600,000 people went to Jack's Gift Page, and if everyone of those donated just £1, we'd be there. That's the goal – one that will ultimately make a huge difference to children suffering from MPS all over the world. Now we just need your help to make it happen!

Phoenix Bar Fundraiser for the MPS Society

A fundraising evening was held at the Phoenix Bar with family and friends of James Stewart who has Hunters. The event raised £750 for the MPS Society. We would like to thank the Phoenix Bar, all the retailers who kindly gave donations and a special thanks to Jim O'Donnell for his very generous donation to MPS. £400 of the £750 total was raised in the Bar itself. Big appreciation is also extended to all the customers in the bar who bought raffle tickets.
Sharon Hartwell on behalf of James Stewart

Zack's day out at Arbury Carnival

Zack had a day out at the 35th Arbury Carnival Cambridge on June 9th 2012.

In the theme of kings and queens to also celebrate the jubilee it was sure to be a success. What a great time to have a stall to raise funds for the MPS.

It started the night before with a sleep over at grandads which went fine until it was time to go to sleep. Zack didn't want to and one and a half hour later he finally dropped off. Although he said he didn't want to go to the carnival, I knew he would enjoy it.

So to Saturday morning. Plans into action - two car loads from three houses had to meet at 9am to set up stall. Zack was with me and the plan was for everyone else to load and get ready without Zack's help which he always wants to do.

All loaded we met up and the convoy began to the carnival. There we set up stall, gazebo up,tables out and bags and boxes of everything we could find to sell unloaded with Zack's help.

After a week of rain we were a little worried about how it was going to go. Although very windy on Saturday morning, it was dry and not to cold. We all had our MPS T-shirts on but it was not warm enough to take our coats off. Rip in the gazebo as we were putting it up but we cracked on, blowing our MPS balloons up and attached to the gazebo.

Jar of sweets ready to guess how many in the jar to win them, lucky dip bags for boys and girls and the tombola prizes arranged to pull in the crowd. We were already to go.

Zack was being unhelpful at being helpful by now so it was time for him to go for a walk with nanna. He had a go on the car fair ride then crazy golf and a big blow up giant slide, after a few more attractions he came back with his face painted which he loves to have done. The stall was doing really well and there were no let up of people. Then it was lunch time for Zack so to the chip van.

The afternoon gave us the procession of floats and the crowds were swelling. Time for another walk for Zack so we could get everyone spending their money without Zack picking everything up and putting it in his back pack.

So off for some more rides. Zack had mum, dad, nanna, grandad, auntie Izzy, Shannon and their friends Sarah, Laurie, Georgia, uncle Phil and Eddie helping at the stall. Zack was worn out by the end of the day and after packing away from 4.30 we headed home at 5pm.

A big thank you to all our helpers on the day which we raised a total of £296.00 for the MPS Society. A great day and great result. **Zack's Grandad**

Sherborne Inner Wheel raises £1700

Edgar Zaldua very kindly came along to our meeting in June to receive a cheque for £1700 raised by the ladies of Sherborne Inner Wheel for MPS. It was a pleasure to meet him. He spoke very movingly about his son, Daniel, and how the benefits his family has derived from the great work that MPS do. The ladies were most appreciative that he took time out to speak to them and afterwards said that it made their fund-raising efforts seem so much more personal and worthwhile. June Alexander (pictured right with Edgard Zaldua)

The Sherborne Inner Wheel donated a wonderful £1700 being the proceeds of their fundraising. We would like to thank the Zaldua family very much indeed for kindly representing the MPS Society at the cheque presentation. Thank you!

Valerie Casey wrote to tell us about a recent Sportsman Dinner which raised £750 for the MPS Society. The event was organised by her uncle John Casey and the MPS Society is very close to their hearts as their nephew Jordan Mount has MPS I.

In Memory - Linda Collett

Keith and Shirley Bown recently wrote to the MPS Society to inform us of the sad news that Shirley's twin sister Linda Collett had recently passed away. They write: 'Linda was 59 and is greatly missed by all her family, friends and everyone who knew her. Our grandson Luke Bown has MPS which was not confirmed until he was two and a half years old. The news was devastating for all of us. We made a decision as a family to raise as much money as possible for research into his condition praying that progress would be made to assist Luke as he got older.

Linda was so supportive and apart from her personal donations she also ensured that as many people as possible saved stamps, including Tesco Eastbourne where she worked. She stood on street collections with me rain or shine greeting everyone with a smile however she felt.

It was only in the last two and a half years that ill health prevented this. Even to the last when arranging her funeral Linda requested donations to go to MPS instead of flowers on behalf of Luke who she loved so much.

Linda has achieved so much on behalf of MPS. Although as a family we will go on, however difficult, and will continue to support MPS on behalf of Luke and in her memory.'
The MPS Society would like to thank the Bown family and friends for donations received in Linda's memory.

Dorothy Robinson held a second card workshop on 18th May raising £175 for the MPS Society.

Thank you to **Mr and Mrs Des Hope** for donating £345 collected in lieu of wedding presents.

London 10k

On March 11th 2011 our life changed completely, we had an appointment at GOSH to see Dr Vellodi. After nearly four years of doctor and hospital visits, we were finally going to get some answers regarding what was going on with our youngest daughter Lily.

She was going to be 5 in the May and it had been a long time to finally get an answer to all her health problems.

Although we new a visit to GOSH meant something was not quite right, nothing could prepare us for what he was going to say.

After a short history of Lily's symptoms, we were told Lily the reasons behind this was that Lily has MPS IIIA Sanfilippo.

Both myself and my husband were completely deverstated, although we had expected some bad news, a statement this harsh was not well recieved.

It's very difficult to explain what thoughts circulate around your head when you hear your child has a life limiting illness, and although there are various areas of support , there is no proven remedy to make things better.

Over the last year we have slowly started coming to terms with everything involved with the illness and have met some fabulous new families that also have children with Sanfilippo through the MPS society.

This referral has been a great comfort to us and meeting other families has helped to understand the illness and the challenges presented to us all.

Over the last year we have seen in the magazine people who have done various fundraising activities and I decided that this year I was going to run in the British 10k run in London, in July.

As a full time mummy, I have never done anything like this before in my life so challenged my mum, sister in law and brother in law to do it with me too, all for Lily's charity of which they agreed to without hesitation!

Team Lily was ready for training so in the evenings starting in January myself, Tina Brogden (Mum), Danielle Hayes (Sister In Law) and Nicholas Brooker (Brother in law) along with a group of friends ran each week locally like a mini marathon team!

In the heat and cold we trained, and omg did I hurt afterwards for the first couple of weeks, but finally my body started getting used to it. I just knew that if I didn't train, I wouldn't be able to do the run and that wasn't an option. As the run got nearer we went out running twice a week and started to look forward to our charity fundraising event.

The week before the run we all received our T-shirts, vests and running numbers and this made it all so real although now we were so excited and nervous at the same time.

I got everyones t-shirt and put a picture of lily on it to remind us on the day who we were doing it for and that face would keep us all going.

Race day finally arrived my husband got a mini bus to transport both our families up to London for our big event. Whilst our families waited on Westminster bridge to cheer us on , at 9.35am the race begun and we all started off together and gently jogged around the start of the course. About half way round the heavens opened. Down came the rain but it was very much appreciated as we were so hot and I've never drank so much water in all my life, I'm more of a coca cola girl myself!

We all supported each other all the way along the course and as we went over Westminster bridge the markers said we only had 1k left to go, and then we saw our families and of course my Lily , all of them cheering us on.

That was a great motivator and made me emotional seeing them all , and I knew I was doing this for all the right reasons :). The finishing line was in sight, and I thought, omg I have just run the British 10k run !

As I crossed the line I just cried with emotion, I had achieved just a little something to help the charity , and the rest of the team crossed not long after and we all just hugged and congratulated one another, and got another drink! We walked back exhausted towards Big Ben to meet the family to be greeted with cheers and hugs, and some excitement from Lily which was heartwarming.

A huge thank you to all that supported and sponsored us. Between the four of us we have managed to raise a fantastic £1,461.00 for the Society.

The funds shall help all our children enjoy life, as much as we enjoy them.
Michelle Brooker

Parachute for Free!

If you have ever wanted to do a parachute jump here is your chance. The MPS Society is looking for adventurous volunteers to make a fundraising parachute jump and if you raise enough sponsorship you will get to jump for free!

There are three types of jump available - an accelerated freefall where you can experience the thrill of skydiving solo from up to 12,000 feet, a tandem skydive from 10,000 feet attached to a professional instructor and a static line jump which is performed solo from up to 3,000 feet - and you can jump from any one of over 20 British Parachute Association approved airfields across the UK.

No experience is necessary as all training is given and if you raise from £360 (depending on the type of jump you choose) you will receive your jump for free.

For a full information pack and everything you need to take part in the experience of a life time, please email **fundraising@mpssociety.co.uk** or phone the MPS office on **0845 389 9901.**

Gemma Hall raised £415 from her participation in the Virgin London Marathon 2012.

Michael Krause raised £182.50 from his participation in the Great Manchester Run and £223 on his Justgiving page.

Lindsay Webb completed a skydive on 30 July 2012 in Spain raising £220.

Michelle Rayner completed a skydive on 20 March raising £313. Michelle says that she thoroughly enjoyed the day and she was pleased to be able to raise some donations to help with all the hard work the Society does for children with MPS diseases such as her grandson Blaise.

Hayley Lever raised a further £110 from her participation in the Edale Skyline fell race in March.

Louis Garthwaite and his sponsored cycle team mates from the RGS 5A Sponsored Cycle have raised a further £670 for the MPS Society - thank you to the team and everyone who sponsored them!

Chris Taylor has raised a further £375 from his Jogle for Joseph challenge.

Stuart Walker raised £120 being the proceeds of a tandem skydive for MPS.

Giving Calcs

By Aura Creative Communications
Open iTunes to buy and download these apps.

A simple, easy to use tool to calculate the cost and value of tax-effective gifts.

This app, commissioned by the Institute of Fundraising, is designed for both donors and charities alike to calculate the benefits for different forms of tax-effective Giving.

The calculators include:

- Gift Aid
- Share Giving
- Payroll Giving
- Legacy Wealth

For any further information, please visit **http://www.tax-effectivegiving.org.uk**

Donate by Text

The Society for Mucopolysaccharide Diseases supports individuals and their families affected by MPS and related diseases throughout the UK.

We rely on your generous support to enable us to provide a unique advocacy support and information service including access to clinics, conferences and events.

Donations can be made online at www.mpssociety.co.uk.

We are also now delighted to accept donations by text...

Text MPSS01 £2 / £5 / £10 TO 70070 to donate now!

Thank you!

JustTextGiving by vodafone

Once you have read this MPS Magazine, please pass it on to your family, friends and colleagues. Help us spread the word about MPS and related diseases and the work we do. www.mpssociety.co.uk

AGCO Salsa raises £1000

AGCO Ltd have raised £1000 from a charity BIG SALSA & KIZOMBA PARTY they held on Friday 29th June 2012 at the Massey Ferguson Social Club, Broad Lane, Coventry.

We chose this charity because of our connection with our work colleague Sue Hallissey. Sue is one of the local Service Desk team here at Abbey Park and it was through Sue that we first became aware of the condition. Sue's nephew Daniel was diagnosed with MPS at the age of 4 and Sue often spoke about Daniel and of the love and joy he gave to all the family. But whilst this was true the disease presented many challenges and it was during these times that the MPS society was able to offer additional support, experienced advice, or just a shoulder to cry on. Sadly Daniel lost his battle with the disease in December 2011, aged 20. **Lynne Cooper**

McKesson Information Solutions UK Ltd held a dress down day and raised £366.80. The MPS Society was chosen to receive this money after being nominated by one of their employees, Dewinder Bhachu.

NATS IS Team support MPS Awareness Day

An IS member of staff (Sally Palmer) at NATS has recently been affected by the tragic news of a her little baby niece, Anabelle (pictured above), who has been diagnosed with a rare incurable genetic disease called MPS Type 1, Hurlers.

MPS (Mucopolysaccharide Disease) is a genetic disorder that results in the build up of glycosaminoglycans (known as mucopolysaccharides) due to a deficiency of alpha-L-iduronidase, an enzyme responsible for the degradation of mucopolysaccharides in lysosomes. Without this enzyme, a buildup of heparan sulfate and dermatan sulfate occurs in the body. Symptoms appear during childhood with death frequently occurring by the age of 10 years.

Although there is no cure for this disease there are treatments which can slow down the disease and give Anabelle a better quality of life. She is regularly receiving a weekly ERT (Enzyme Replacement Therapy) infusion, which take around 5 hours each week.

On Tuesday 15th May, IS held an event at the CTC & Swanwick sites to raise awareness and some funds for the MPS Society. NATS IS continue to encourage their employees to support the MPS Society by purchasing MPS merchandise, participating in events planned throughout the year and adding the MPS Society to their list of chosen charities for the Give As You Earn scheme.

Thank you to everyone at NATS for your continued support and for raising over £2700 so far for the MPS Society. Thank you also to Sally Palmer at NATS for co-ordinating this support.

Gentoo Living regularly hold small, informal fundraising events and donate the proceeds to charity. This Summer the MPS Society was nominated by a member of their staff. A donation of £12 was raised by a small office Dress Down Day.

Corporate Giving

In these challenging times, the MPS Society is looking to increase the number of companies that we talk with to gain their financial support. We would really appreciate your help with this as a personal contact and introduction is the most effective to introducing our charity, the work we do and how we would benefit from a company's support.

Many companies have a really positive attitude to supporting charities that their employees are involved with. If you, a family member or a friend work for a company work for a company please see what you can do to help…

Corporate Responsibility

Fundraising at work is a great way to boost your employer's reputation and image with shareholders, suppliers and the community. Many companies now have Corporate and Social Responsibility Programmes and welcome the chance to work with charities as part of this.

Charity of the Year

Many companies have a charity of the year. Not only can it generative positive local and national PR opportunities attracting valuable media attention, it can boost staff morale, encourage team building, and gives you something to talk about with your customers, clients and partners!

The selection process, although different for each company, usually requires an employee to nominate their charity. Sometimes the nomination process is simply emailing the name of the charity (the Society for Mucopolysaccharide Diseases) to the Committee. However, if they require supporting information, please direct them to our website www.mpssociety.co.uk or contact fundraising@mpssociety.co.uk.

We can provide press releases, case studies and photos which companies can use to put up on their websites, publish in internal magazines etc to give ongoing exposure and advertising. We always write to say thank you and try to offer a local MPS representative to collect cheques where asked.

Events

Here are some fun ideas for getting your workplace involved...

- Dress up, or down, or choose a fancy dress theme - those who take part donate £1, those who don't pay £2 (as a penalty for not getting involved)
- Guess the baby competition - get everyone to bring in a photo of themselves from a particular decade, or under the age of 3 for example, and pay to guess who each photo is of. The person with the most matches wins
- Pack your lunch - save money by bringing in your lunch instead of buying it, and ask people to donate what they would have spent into the collection pot. Designate a week to do this and watch how the money builds up!
- Swear box - any container will do. Every time you or a colleague swears on a designated day means that a £1 penalty must be paid
- Use the stairs - have a forfeit box near the lift and ask people to make a donation every time they give in and the use the lift
- Abandon your car - get sponsored to walk or cycle to work
- Guess the number/weight - either fill a jar with an item and ask people to guess the quantity or display something and ask people to guess the weight
- No email day - get everyone walking and talking and impose a penalty fine for those who cheat
- Ask us for an MPS Collection Box and have this on display so you can collect up all that loose change
- Recycle old mobile phones, ink cartridges - ask us for a freepost envelope
- Send us used old stamps from incoming post - we can exchange these for money to MPS
- Plan a sponsored challenge such as a skydive, cycle ride, trek or run with a group of colleagues. Ask us for a fundraising pack or check our website for the latest opportunities www.mpssociety.co.uk

For more information about how you can get your workplace involved, why we value corporate support and how we use the monies raised please visit **www.mpssociety.co.uk**. You can also download a fundraising pack and other useful materials.

Matched Giving

https://www.cafonline.org/giving-as-a-company/engaging-employees/matched-giving.aspx

Many larger companies now operate a matched funding scheme, whereby they will match all the funds raised by one of their employees up to a specified limit. So, if you raise £200, you may find that your company will match that money with another £200.

Payroll Giving

http://www.hmrc.gov.uk/businesses/giving/payroll_agencies.htm

Payroll giving is one of the easiest ways for employees 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 charities they want to give to. The donation then comes off their gross pay, before the tax man touches it.

Charities benefit from payroll giving because receiving regular donations means that they can make financial plans for their long-term future – knowing they can rely on the regular gifts of their payroll donors. Employees can give as much or as little as they like, and because the donation is taken from their pay before tax, it actually costs them less.

Payroll giving is completely flexible - you can change the amount you give or which charities you donate to at any time. If you want to stop making donations then simply contact your payroll department.

Ask your Payroll Department whether or not your company offers the scheme. If they don't, they can set up a Payroll Giving Scheme by signing up with an approved Payroll Giving agency as listed on HM Revenue and Customs.

Gifts in Kind

If appropriate, your company might be able to support us by providing gifts as donations in kind for our annual prize draw!

Further information

For further information or to discuss any of these opportunities further please contact **fundraising@mpssociety.co.uk** or phone the MPS office on **0845 389 9901**.

Diane Kolassa, a piano teacher, and her students held a small concert on 19th May and the money collected totalling £150 has been donated to the MPS Society. Diane knows of Oliver Moody, MPS VI.

Wicked Genes

www.wickedgenes.co.uk

SCHOOL FUNDRAISING PACK AVAILABLE NOW!

Laura Hodd recently carried out a fundraising cake sale at her school, Lytchett Minster. She wishes the money to go towards MPS II Hunter. Laura decided to raise the money when a child she knows, Josh Cutler, was diagnosed with Hunter.

Priory School raises £4000 for MPS

My son Luke broke up from school today, and as his school have yet again been supporting the MPS Society this term, I was asked to say a few words and collect the cheque on behalf of the MPS Society.

The school has raised the money throughout the term through "Cake Sales", "Sponsored Cross Country Runs", "Mufti Days", "24 hour Football", and as many ways as they can think of.

It was very nerve wracking having to speak on stage in front of a packed hall of boys, parents and grandparents. (Something I hate!)

However it was moving to see the tears and emotions from the audience/teachers and hear the rapturous applause I received when I'd finished telling my story. I'm delighted to tell you the cheque was for £4000!

Needless to say Luke too has done me proud also today, winning a cup for effort, and a certificate for reaching Grade 2 in his Drum Exam.

Here is a picture of Luke and I on stage holding the cheque.
Ita Vickery

Thank you to Marina and Friends

We would like to extend a special thank you to Marina Foster and friends. Marina runs a charity shop in Bristol, Marina and Friends Fundraisers, donating the proceeds from the sale of second hand items to the MPS Society. So far, the cumulative total raised by Marina and Friends for research into Sanfilippo disease is **£88,092.53**
If you would like to support the MPS Society by providing items for Marina to sell, please find below the address for the shop: Marina & Friends Fundraisers, 44 Sandy Park Road, Brislington, Bristol, BS4 3PF.

You can also follow Marina and Friends Fundraisers on facebook.

Project Sanfilippo

The concept of Project Sanfilippo was developed by Karen Robinson, mother of Oliver who has Sanfilippo. Project Sanfilippo raises vital funds for the MPS Society to put towards research into Sanfilippo Disease. Here is an update of what's been happening so far. A further update will be given in the next edition, Winter 2012.

Craig Dudley becomes Ironman
for Project Sanfilippo

A FAIRFORD barman has taken on an Ironman triathlon to raise awareness for a rare terminal disease suffered by a youngster in his hometown.

Craig Dudley, 22, had always wanted to take-on the strenuous swimming, cycling and marathon challenge. And when he met teenager Ollie Robinson he was determined to complete it for him.

Ollie, from Fairford, is only 13 but has already reached his expected lifespan.

The former Meysey Hampton Primary School pupil has a degenerative disease called Mucopolysaccharidoses (MPS), which varies depending on its form but causes learning difficulties, speech and hearing loss and a dramatically shortened life span.

Craig, who works at The Bull in Fairford, said: "Ollie is doing fantastically well because he should be in a wheelchair by now, but he's cycling and having fun.

"I really wanted to raise awareness for the disease – not enough is known about it."

Although Ollie was not diagnosed with a rare form of MPS called Sanfilippo until he was seven-years-old, his mum Karen said she always knew there was something wrong.
"He was quite a physically able child when he was young but that started to slow down," she said.

She said he also displayed very challenging behaviour which, before moving to Meysey Hampton Primary School, had been labelled as "naughty".

With the help of teachers at Meysey Hampton Primary School Karen fought for answers.

Now she has them, she said it is a waiting game because Ollie's symptoms are set to get progressively worse.

"A lot of the children who have Sanfilippo are dead by 13," Karen said. "It's a horrible, horrible disease."

Karen said any money raised for "Project Sanfilippo" at the MPS Society, would help to find a treatment of the genetic disease, which she fears her other 10-year-old son Sam may be a carrier of.

"It will probably be too late for Ollie," she said. "But hopefully one day there will be a cure for it."

Former Farmor's School student Craig completed the 2.4 mile swim, 112 mile cycle and marathon event at Bolton last week in 12 hours and 55 minutes, raising £746 for charity on his Justgiving page.

To donate visit justgiving.com/Craig-Dudley and for more information on Project Sanfilippo visit www.mpssociety.co.uk

Here at the MPS Society we love to support fundraising ideas that you may like to take on, or to hear of any ideas that you think we should be considering. The MPS Society is only able to exist and develop with your help so please do contact us by email at fundraising@mpssociety.co.uk.
Thank you!

Further information
There will be further updates about Project Sanfilippo in future editions of the MPS Magazine.

To sign up to receive our MPS Magazine by email, please visit our website www.mpssociety.co.uk

Fundraising Standards Board (FRSB)
The MPS Society is a member of the FRSB. For further information please visit our website www.mpssociety.co.uk

Gift Aid Q&A

www.wickedgenes.co.uk

What is Gift Aid?
It's a scheme introduced by the government which allows charities like the MPS Society to reclaim the tax that supporters have already paid on their donations. For every £1 donated, the taxman gives us an extra 25p, so our income from your donations increases by almost a third. We can only claim on donations made within the last six years', tax unclaimed before this will be lost forever, so please act now.

Why 25p per £1?
It's linked to the current basic rate of income tax (which is currently 20 per cent). As a basic rate taxpayer, for every £1.25 you earn, you will pay 25p to the taxman and receive £1 in your pocket. It is this 25p we claim.

Am I eligible?
If you are a UK taxpayer and have paid enough income or capital gains tax in the financial year to cover the amount we'll reclaim, then yes: please complete a Gift Aid declaration.

Where can I get a Gift Aid declaration form?
You can download a Gift Aid declaration form from our website or we can post one to you. Please complete one of these forms and return it to the address specified on the form. If you require assistance please call 0845 389 9901.

What if I'm a pensioner?
We can still claim the full 25 per cent on your donations, providing you pay at least as much tax as we will be reclaiming in the year in which you made your gifts. As a pensioner, for example, you may still pay tax on a private pension scheme or a savings account, or pay Captial Gains Tax if you sell property or shares.

What if I'm a higher-rate taxpayer?
We can only claim the basic rate back, but this is still extremely valuable. You will also be able to claim additional personal tax relief on your self-assessment form.

I'm not eligible; should I still return the form?
Yes please. It would be a huge help if you could return a declaration to us letting us know not to claim. This way, we won't contact you about Gift Aid again in the future, saving us time and money.

I've already completed a declaration for another charity. Do I need to complete one for The MPS Society?
Yes. You will need to complete a separate form for each charity you want to benefit from Gift Aid.

What else does ticking the Gift Aid box commit me to?
Nothing at all. It just ensures that, if you donate to us, we can claim money back from HM Revenue and Customs.

How long does my declaration last for?
Until you tell us to stop. At the moment, and as long as you remain eligible, your declaration lets us reclaim past (up to six years), present and future donations.

What do I do if I need more information on Gift Aid?
If you would like to find out more, or if you would prefer to make your Gift Aid declaration over the phone, please contact us on 0845 389 9901 and we will do our very best to help.

What if I change my mind, or am no longer paying tax?
Please contact us either by letter to The MPS Society, or by e-mail to fundraising@mpssociety.co.uk, and tell us that you no longer wish us to claim the tax on your gift.

What if I'm an events participant?
If you have received a benefit by participating, although anybody can sponsor you, MPS Society may not be able to claim Gift Aid from all your sponsors, including family members ('Connected Persons'). Please check with us for further details.

Will it really make a difference?
Yes. You will be increasing the value of your donation which will go the extra mile for those who need our support.

giftaid it

Making a donation

By post: Send us a cheque or postal order. Don't forget to enclose your address so we can reply and send you a thank you. Please don't send any cash by post.

At a bank: Pay in your cash or cheque at any branch of Barclays. Our account number is 33986306, sort code 20-02-06. Just let us know who you are and what you've done!

By credit card: Phone us or visit our website to donate online. Please ensure you let us know your details and how you have raised the money. Most major credit cards accepted.

Online: You can donate online through our secure server by visiting www.mpssociety.co.uk

For other ways of making a donation, please ask us for our Making a Donation factsheet.

Please let us know when you are making a donation or paying in money directly into our bank account and please include a reference for the payment. This way we can confirm safe receipt of the funds and say a big thank you. If we can't identify where the funds have come from then we can't thank you! **fundraising@mpssociety.co.uk**

The Hyde family kindly sent in donations totalling £305 in memory of Sara Hyde who passed away on 5 July 2012.

Lynn Longhorn donated £320 to be used for research into Sanfilippo disease. This money was the proceeds of a lunch and raffle held in August.

Ann Parsons at Asda Eastbourne raised £225 from the sale of MPS keyrings.

The MPS Society has received £125 from the sale of used stamps.

Joyce Bridges donated £50 in memory of Archie Rudham.

Nathan Oakley organised a raffle at his family's Jubilee party and raised £30.

The librarians at Pontefract Library held a coffee morning and raised £100 in donations to MPS.

Linda Allen donated £60 online being the proceeds of fundraising for MPS.

Jennifer Barclay donated £200 online being the proceeds of wedding favours in the name of Aiden Brown.

Denise Main has donated £25 to Morquio research.

The MPS Society received £30 in donations from **Ipsos MORI** after survey respondents nominated the Society to receive donations.

Caroline Ferrier sent in a donation of £200 on behalf of the Educational Psychology and Behaviour Support Team and the SENCOs and schools in the East Riding of Yorkshire on behalf of William Mason Ferrier.

Jackie Lowe has raised £34.60 on her justgiving page from cake sales for MPS.

A Band night on 5th July in memory of Gareth Evans at **Haven on the Hill** in Cwmfelinfach raised £290 for MPS.

Elizabeth Heath held a Diamond Jubilee street party and raised a fantastic £1200. £500 of this was kindly donated by Elizabeth's godfather, Mr B C Campbell and his business partner.

The Co-operative on Sandford Road in Wareham, Dorset have raised £535 through the sale of MPS merchandise and donations from their customers. We would like to thank everyone who kindly supported the MPS Society in this way.

Thank you to **Shimal Patel** at Day Lewis plc for raising £2576 being the proceeds of a Golf Day.

Stamps, foreign coins, mobile phones, ink cartridges, jewellery: S Melville-Smith; Donna Bown; Janet Gremo; Langlea House Care Home; Karen Robinson; Molly Griggs; Children and Young People's Service – Lambeth; Dorothy Robinson; Mr J Casey, Susan Wilkinson; Lifebuild; Sarah Swayne; Ruth Hall; Susan Swayne; Ruth Hall; Jo Goodman

In memory: Colin Arrowsmith; Archie Rudham; Michael Copeland; Linda Collett

Donations: Janet Warriner; Mrs A Baker; Residents of Ruxley Court; Dr and Mrs Bansal; Laura Morris; Brendan Dalligan; Lauren Kreisler; Miss M S Taylor; Ms M Knowles; Mr and Mrs McKane; Mr and Mrs Eaton; Mrs Baker; Ann and Colin Booker; Melanie White; Caroline Gardner; Revd. Andrew Dean; Susan Williams; Caroline Copeland; Marian Henshell; Pauline Headland; Peter and Jean Hawkins; Boys from Boglena; Elizabeth Gillespie; Lauren Kreisler

Legacies: Ms Deborah Jayne Plummer

Collection boxes: David Haskell; Mrs J M Dine; Marcia Burnett; Haven on the Hill Cwmfelinfach; Frances Gee

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; G Simpson; William Cavanagh; L Brodie; Jackie Dalligan; M Malcolm; E Mee; K Brown; E Brock; M Fullalove; McCann; R N Taylor; K & S Bown; S & G Home; E P Moody; V Little; S & D Greening; M Reeves; L Wood; J Casey; E M Lee; D Palmer; J & V Hastings; R & K Dunn; S Littledyke; N Saville; M Barralet; L Twaddle; S Bhachu; Cullen; G Simpson; W Cavanagh; L Brodie; Cadman; Wilson; J & F York; M Rigby; K Robinson; A Tressider; K Osborne; Mr Thompson; M Wood; E Cox; C Lunnon; S Hill; B Weston; M Peach; R Arnold; J Ellis; I Pearson; C Gibbs; D Peach; S J Brown; Andrew Cock; Alan Dickerson; M Kalsi; P Summerton; John Scott; E White; C Hume; A Weston; Gordon Ferrier; D & A Gunary; Marcia Tosland

Requesting more information by post

If you would like to receive more information by post, please tick the appropriate boxes, complete your contact details and return the form to us in the post.

- ☐ Fundraising Pack
- ☐ Wicked Genes School Fundraising Pack
- ☐ Publication Order Form
- ☐ Merchandise Order Form
- ☐ Ink cartridge re-cycling Envelopes
- ☐ Jewellery Recycling Envelopes
- ☐ Cardboard Collection Box
- ☐ Gift Aid Form
- ☐ How to make a regular donation
- ☐ Leaving a Legacy leaflet
- ☐ Payroll Giving
- ☐ Information on becoming an MPS Childcare Volunteer

Name: .....

Address: .....

..... Postcode: .....

Email: ..... Tel. No. .....

Creating a Future with Hope for
Children with Genetic Diseases

Wicked Genes

Wicked Genes is a fundraising initiative of the Society for Mucopolysaccharide Diseases

Jack is two years old and has Sanfilippo Disease.

Help us save the lives of children like Jack by visiting the Wicked Genes website to find out how you can get involved

"Do something **Wicked** for Wicked Genes!"

www.wickedgenes.co.uk
wickedgenes@mpssociety.co.uk
0845 389 9901