MPS

Autumn/Winter 2011

Society for Mucopolysaccharide Diseases

Please donate to
www.mpssociety.co.uk,
phone 0845 389 9901
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: MPS Sibling Weekend 2011

Society for Mucopolysaccharide Diseases

Registered Address: MPS House, Repton Place,
White Lion Road, Amersham Bucks, HP7 9LP
www.mpssociety.co.uk
T: 0845 389 9901, Out of Hours: 07712 653258
F: 0845 389 9902, E: mps@mpssociety.co.uk
Registered as a Company limited by guarantee in England & Wales No. 7726882
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Staff

Christine Lavery *Chief Executive*
c.lavery@mpssociety.co.uk

Antonia Anderson *Communications Officer*
a.anderson@mpssociety.co.uk

Rebecca Brandon *Advocacy Support Officer*
r.brandon@mpssociety.co.uk

Steve Cotterell *Advocacy Support Officer*
steve.cotterell@mpssociety.co.uk

Sue Cotterell *Trust & Corporate Fundraising Officer*
s.cotterell@mpssociety.co.uk

Joanne Goodman
Clinical Trial and Patient Access Officer
j.goodman@mpssociety.co.uk

Fiona Hopson *Events and Office Administrator*
f.hopson@mpssociety.co.uk

Gina Page *Finance Officer*
g.page@mpssociety.co.uk

Joanne Lawley *PA to CEO*
j.lawley@mpssociety.co.uk

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

Alison Wilson *Advocacy Support Officer*
a.wilson@mpssociety.co.uk

Lindsey Wingate *Advocacy Support Officer*
l.wingate@mpssociety.co.uk

Magazine Deadlines

Spring	1 Feb 2012	Summer	1 Jun 2012
Autumn	1 Sep 2012	Winter	1 Dec 2012

To submit content email **magazine@mpssociety.co.uk**

IN THIS ISSUE...

Autumn/Winter 2011

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

A message from the new Chair

Earlier this year, Barry Wilson announced that following the AGM he wished to stand down from the Chair of the MPS Society for personal reasons, although he would still continue as a Trustee. So, after ten years of outstanding chairmanship, Barry stood down at our July meeting and I was elected to try to follow in Barry's footsteps.

I have been a member of the MPS Society since 1982, the year in which the charity started, shortly after our daughter Elisabeth was diagnosed with Hunter's. Sadly, Elisabeth died in 1983 following two bone marrow transplants, our two healthy sons being the donors. However, we continued to be involved with the Society and in 2001 I was invited to become a trustee. Many years later I am still here.

As I have recently retired, although I am still working a couple of days a week, I can now devote more time to the MPS Society and look forward to supporting and promoting the Society as its new Chair. I hope that throughout my Chairmanship it will continue to flourish, support the families that need our help, work with the research departments and pharmaceutical companies towards more effective treatments and continue to educate those many staff in the NHS who know almost nothing about MPS. In short to live up to our motto of "Care Today – Hope Tomorrow".
Although we all hope for better treatment to be developed, we all know that this takes a long time and that we are dependant upon the research scientists and drugs companies to make this happen. However, the Society will continue to support, wherever possible, the research that will lead to a better future for our members.

Meanwhile, as a Society, the most pressing need is to support our families now. As our Society has grown so has the work of our advocacy team and many of you, I know, have been helped by our team. They have to deal with other agencies in all areas of the country to support families with housing needs, educational issues, Social Services problems, medical queries and more recently the problems of transition from child to adult services. This is a huge job which involves our staff having to write detailed reports for each case, traveling long distances to support members in meetings with other professionals, attend sometimes very difficult meetings with the senior management of some organisations on behalf of our members and sometimes appearing as witnesses in some quite distressing cases. All of this is not only physically tiring but can also be emotionally draining. It is also, of course, expensive.

In the present financial climate the Society has had to consider very carefully how it uses the money that it receives through grants and donations. We have sadly had to lose some staff and we have had to turn down requests for funding from some research teams. However, the one area which we are determined not to cut down on is that of the advocacy service that the Society provides to families.

I believe that "Care Today" is the cornerstone on which the Society was built, and I know that our staff at MPS House also considers this to be the most vital part of the Society's work. As Chair I intend to ensure that the service that you, our members, receive from our advocacy team continues to be second to none.

Sue Peach
Chair of MPS Trustees

WHAT'S ON!

CONFERENCE EVENTS

MPS International Symposium, The Netherlands: 28 June - 1 July 2012

MPS II Conference tbc: Mid August 2012 tbc

All Ireland MPS and Fabry Conference: 11 - 13 May 2012

SPECIAL EVENTS

Lapland Christmas Visit: 11 - 14 December 2011

MPS REGIONAL CLINICS

MPS III Clinic (GOSH): 6 December 2011

Northern Ireland clinic: 9 December 2011

MPS IV Clinic (GOSH): 16 December 2011

MPS Clinic (Cardiff): 26 January 2012

12th International Symposium on MPS and related diseases

Dear Friends and Colleagues

We have great pleasure in inviting you all to the 12th International Symposium on MPS and related diseases, which will be held in Noordwijkerhout, the Netherlands, from 28 June to 1 July 2012.

By bringing patients, parents and families together with professionals, the symposium will be able to share information on all aspects of MPS and related disorders. The overall objective is to advance the quality of care and treatment. As well as musculoskeletal disease and MPS, the brain and MPS, and new approaches to treatment, the main topics of the symposium will be pricing and reimbursement. All will be covered in joint sessions attended by doctors, scientists, patients and patients' families. Separately, doctors and scientists will also attend more detailed sessions on the CNS, bone disease and novel approaches to treatment.

Families will not only have opportunities to meet peers from other countries, but will be able to attend sessions on optimizing care, dealing with clinical issues and surgery in MPS, and 'living fully with MPS'.

The symposium will be held at the four-star NH Leeuwenhorst conference centre in Noordwijkerhout, which is approximately 20 minutes from Amsterdam Schiphol airport and 30 minutes from the city of Amsterdam. Noordwijkerhout lies very near to a coast with long sandy beaches, and various major cities and sites of interest are within easy reach. Special activities will be organised for young patients and their siblings, who will be accompanied by trained volunteers. On behalf of the organising committee, we look forward to welcoming you to Noordwijkerhout next June. *Frits Wijburg, Ans van der Ploeg, Hanka Meutgeert*

Further information can be found on the MPS website **www.mpssociety.co.uk** or by visiting **www.mps2012.eu**

The Advocacy Support 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.

At the MPS office, we thought it might be nice for us to share with our families and readers the work that we do. In this edition I have highlighted what the advocacy service is and what we do, as well as introducing you to your advocacy support team. In future additions we hope to give you examples of the work that we are currently undertaking and hope that it will give you a better insight into what we are doing to support our members. If anyone has any suggestions of the type of information that you would like to read about, please do not hesitate to email me directly at s.thomas@mpssociety.co.uk

So, what do we do?

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. It is Needs led and offers empowerment and informed choice by enabling all families and individuals, whatever their situation, to make fully informed decisions as to how they wish to be supported and to access the appropriate and necessary resources to be able to do this.

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. Individuals can also face prejudice as the specific needs of individuals diagnosed with MPS, Fabry or a related disease may be neglected by local policies.

Key aims of support

The key aims of the Individual Advocacy Support Service are:

- To ensure the assessment and provision of services by other agencies are informed by a needs led approach, based on an accurate understanding of the needs of individuals diagnosed with an MPS, Fabry or related disease, their families and carers.
- To ensure that the assessment and provision of services uphold the rights of MPS Society members and their families.
- To provide expert information and advice to MPS sufferers, their families and carers on issues relating to the non-clinical management of individuals affected by MPS, Fabry and related diseases.
- To provide an active listening service to enable individual sufferers, their families and carers to speak about, reflect on and make fully informed decisions in respect of the meeting of their needs.
- By working in partnership with individuals and families and imparting skills and knowledge to promote self advocacy.

Support provided by the team

At present the Society supports over 1200 individuals and families affected by MPS, Fabry and related diseases. The amount of support and contact varies greatly and is dependent on the needs of the individual and their family. We work on a needs led ethos and therefore we are dependant on our members contacting us should they have any support needs. Below is a list of support provided by the advocacy team. Although this list is not exhaustive of the complex and continuing needs of our membership, it highlights the important role that advocacy still has in ensuring best practice and fair access to resources, support and information for all.

- **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**.

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

MPS ADVOCACY SERVICE

As well as the above areas of Advocacy support we facilitate and organise a number of events such as family days, sibling weekends, sufferers events etc...

Members of the Advocacy team

The MPS Society employs a team of Advocacy Support Workers who are appropriately qualified and/or skilled to provide the support requested by members and professionals. Members of this team hold appropriate health, social work or legal qualifications or have relevant experience in these areas. In depth support and training is provided in post into the specific needs of those affected by MPS and Related Diseases and there is a strong ethos of team working within the advocacy team with support and supervision a high priority.

Introducing you to your advocacy support team

The advocacy support team, ensures that it has a wide knowledge of MPS, Fabry and related diseases. However, it has become increasingly apparent that it is more beneficial to our members for individual workers to become more specialised in a small number of specific disease groups.

Below is a list of the diseases each Advocacy worker specialises in.

LINDSEY WINGATE

MPS III Sanfilippo
ML II
Focusing on transition

REBECCA BRANDON

Fabry
MPS II Hunter
ML III / ML IV
Mannosidosis
Fucosidosis

STEVE COTTERELL

MPS III Sanfilippo
MLD
AGU
Winchester
Geleo Physic Dysplasia
Sly
Gangliosidosis
Sialic Acid Disease

ALISON WILSON

Supports all members living in Northern Ireland

SOPHIE THOMAS

MPS IV Morquio
MPS I Huler BMT,
Hurler Scheie, Scheie
MPS VI Maroteaux Lamy
MSD

Overall manager of the advocacy support team and the work it undertakes.

I hope that the above information has given you an introduction into the Advocacy Support Team. In future magazines we hope to give you some examples of the work we undertake and also a glimpse of what it is like to be an Advocacy Support Officer at the MPS Society.
Sophie Thomas s.thomas@mpssociety.co.uk

FAREWELL TO JOLANTA

Sadly it is time for me to say farewell to everyone at the MPS Society. It always has been one of my dreams to experience life in Prague and I believe this is the right time to start a new chapter in my life. As you all know I am Polish and that means that I will be closer to home.

I have been in England for over 4 years, 3 of which I worked for the MPS Society. I greatly enjoyed working with all the families, professionals and being a part of such an amazing team. It has been a privilege to work with all of you and I will miss everyone very much. You all taught me so much, I wish you all the best for the future. **Jolanta Turz**

On behalf of the Trustees I would like to thank Jolanta for all her hard work and enthusiasm supporting our members over the last three years. We are sorry to see her go and wish her well for the future.
Sophie Thomas

New Birmingham Adult Centre for patients with Inherited Metabolic Disorders

Adults with Inherited Metabolic Disorders (IMDs) can now fully access the new outpatient's service at the Queen Elizabeth Hospital, part of the University Hospital Birmingham NHS Foundation Trust.

In April 2010, Birmingham became the most recent NCG-designated service for Lysosomal storage disorders. The Service now sees over 50 patients with a diagnosis of LSD, over half of whom are on Enzyme Replacement Therapy. These patients are seen in multi-disciplinary clinics and at home by the LSD Team. The Service sees over 300 patients in total, with a wide variety of inherited metabolic conditions.

The development of the service for patients with LSD's is a real opportunity to create something which really meets the needs of patients. We aim to develop a comprehensive service, which addresses all the needs of patients and helps them manage these complex conditions in a way which works for them.

Outpatient services based at the old Queen Elizabeth and Selly Oak Hospital have moved to the new Queen Elizabeth Hospital Birmingham during 2011. The IMD team are in the process of moving and the move will be completed by October 18th 2011. Details of the move, including parking, a plan of the new hospital, self check-in information etc. are available and have been sent to all patients. A covering letter assuring our IMD patients that every aspect of care/treatment will remain the same at the new hospital and providing work telephone numbers, mobile numbers and email addresses of the team has also been distributed.

The address of the new hospital is;
Queen Elizabeth Hospital Birmingham, Mindelsohn Way, Edgbaston, Birmingham, B15 2WB. Tel: 0121 371 2000
www.uhb.nhs.uk

Our aim is to continue to develop our Service so that the people of the West Midlands can have access to a local, specialist Metabolic Team throughout their lives, supporting them in hospital and at home and enabling them to access the very best in specialised care. The team at UHB welcomes input and ideas from patients and actively encourages them to make contact with any questions or ideas about their treatment via phone, email, clinic evaluation sheets, surveys etc. If you are worried about finding us in our new home, please do get in touch and we will be happy to help and support you with your first appointment at the new UHB.

Our new hospital represents a £545 million investment in health services for Birmingham and the Midlands. It provides a wide range of benefits that greatly improve the level of patient care our clinical teams can provide. It is built to the very latest healthcare standards and, for the first time, all of our services will be under one roof once the move is complete. This helps to provide care precisely when and where it is required. Despite its size, the hospital is designed to operate on a human scale, putting our patients at ease

Bright, welcoming and calm: the new hospital is designed specifically around the needs of patients and visitors, making coming to hospital easier and more pleasant. Of the 1,213 inpatient beds in the new hospital, 44% are in single rooms and the rest in four-bed, single-sex rooms with en suite facilities.

The new design also greatly improves our ability to prevent infection, as it gives us greater ability to protect or isolate patients who have a higher risk of picking up a bug or passing one on to others. Wards have clinical hand wash stations at their entrances to highlight the need to wash hands before entering and leaving. Building the new hospital has allowed us to invest in the very latest equipment, bringing our services right up-to-date with the latest medical advances available to the NHS. This means the latest diagnostic scanners, new theatre equipment and even robots deployed in our pharmacy and laboratories to make drug dispensing and testing faster and safer.

We are now able to organise services in the most efficient and effective way so patients get the best and quickest service possible. We are able to provide more one-stop clinics, meaning fewer visits to hospital. We are carrying out more day surgery so patients do not spend so long in hospital and specialties are able to accelerate their service improvements. For example, renal patients now have access to dialysis on their ward.

The new Outpatients department is a purpose-built facility and is based on the ground floor of the new hospital. Divided into four areas, each with its own reception, Outpatients has a main waiting area, 18 self check-in kiosks and 200 consulting rooms. Around 200 patients are seen every hour, Monday to Friday.

Appointments are managed by a computer system, created by the Trust's IT Services team in partnership with the outpatient nursing teams.

Called OPTIMS (Outpatient Tracking Information Management System), it uses self check-in kiosks and wall-mounted plasma screens to call patients to their appointments.

The system was successfully piloted at Selly Oak Hospital and the old Queen Elizabeth Hospital before going live at QEHB when the first outpatient services transferred.

It allows staff to more closely monitor the patient flow and improves efficiency in the clinics.

The OPTIMS system relies largely on the patient letter, which carries a barcode unique to the individual.

Patients who turn up with their appointment letter are asked to follow a series of instructions on the self check-in kiosk screen – much like those used for check-in at airports.

Those who don't have their letter with them can still register using the kiosk, although there will be more detail required for registration.

Once checked in, all patients are asked to wait in the main waiting area until their name appears on one of the wall-mounted TV screens. When their name is displayed, the screen directs them to their clinic, where they are greeted by a member of the team.

If you have any questions about or Service or our new Hospital, please contact Liz McAlister on 0121 371 2000.
The UHB IMD Team consists of;
Dr Tarek Hiwot, (Consultant in Inherited Metabolic Disorders), Dr Raashda Suleiman (Specialist Locum Consultant) Jane Lodwig, (Lead Nurse and Clinical Nurse Specialist), Kate Peers (Clinical Nurse Specialist), Louise Robertson (IMD Dietitian), currently on maternity leave but will return in Nov 2011. Sarah Boocock, (IMD Dietitian) Liz McAlister, (IMD Co-Dordinator) Rishender Singh, (Pharmacist) Jeane McGlen, (Medical Secretary)

Team photograph from left to right; Sarah Boocock, Jane Lodwig, Liz McAlister, Dr Tarekegn Hiwot, Rishender Singh, front left Jeane McGlen, Kate Peers. (Missing from the photograph are Louise Robertson (maternity leave) and Raashda Sulaiman.)

MPS Launches Emergency Patient Information Cards

You may remember that our Summer 2011 magazine included an article about Emergency Patient Information Cards and an application form for the cards was sent with the magazine.

An example of how the card looks is shown here. The image shows both the front and the back of the card. Each card is unique to the individual and the particular MPS disease they have.


This patient suffers from a Mucopolysaccharide or Related Disease

Name: A Sample
Date of Birth: 00/00/0000
MPS Disease: MPSIV Morquio
Hospital: Royal Manchester Children's Hospital Oxford Road, Manchester, M13 9WL
Hospital Tel No: 0123 456 7890
Hospital Number: 123456789
Consultant: Dr Sample

Society for Mucopolysaccharide Diseases

Important Medical Information

MPSIVA (Morquio) is a rare genetic disease associated with significant short stature, physical disability and, in many cases, limited life expectancy. Significant skeletal problems include instability of the cervical spine which may have been treated by a cervical fusion. There is currently no therapeutic treatment however some patients may be on a clinical trial for Enzyme Replacement Therapy.

Urgent Patient Specific Information:

Cervical Instability
Intravenous Enzyme Replacement Therapy

MPS Society Number: 08453 000001 www.mpssociety.co.uk

MPS Society Out of Hours Office Number: 07712 653259

By carrying this card, accurate, clear and useful information about the disease you or your child suffers from can be given to the emergency team and hospital immediately, saving precious time. The card is free of charge and we believe it will be of great use to our members should they need to attend a different hospital from the one they are registered with.

We have already received application forms from some of you and the feedback has been very positive. Here are a couple of your comments: *'Very impressed with the new information medical card for Jade, which we have attached to her wheelchair.' 'Received my Emergency Patient Information Card today, it's great, thanks. I think the card is a great idea, it gives peace of mind. Hopefully, it will never be needed, but if it is, then it's good to know people will be directed to professional help quickly.'*

If you are interested in having a card for you or/and your child(ren), please complete the form included with this magazine and return it to: Jo Goodman, MPS Society, MPS House, Repton Place, White Lion Road, Amersham, Bucks, HP7 9LP.

You can request more forms by email at j.goodman@mpssociety.co.uk. Additional cards are available but may incur a small charge; please contact us for more information.

THE NHS COMMISSIONING BOARD AND NHS REFORM

The NHS in England is changing and it is the MPS Society's responsibility to its members to follow the progress of the Health and Social Care Bill closely as it progresses through Parliament. The second reading should have taken place before you read the MPS Magazine and we would want you to know that we are watching the components of the Bill important to National Commissioning and in particular the area where MPS and Fabry patients most benefit currently, National Specialised Commissioning.

The duties of the NHS Commissioning Board are:

- To agree and deliver improved outcomes and account to Ministers and Parliament for progress. There will be a clear mandate, setting out expectations for the Board and the broader commissioning system;
- To oversee the commissioning budget, ensuring financial control and value for money;
- To develop and oversee a comprehensive system of clinical commissioning groups with responsibility for commissioning the majority of healthcare services;
- To commission directly around £20bn of services including specialised services and primary care services (including holding around 35,000 contracts for primary care services).
- To support quality improvement by promoting consistent national Quality Standards, a culture which promotes research and innovation and providing world class support for clinically led service improvement and leadership;
- To promote innovative ways of demonstrating how care can be made more integrated for patients;
- To promote equality and diversity and the reduction of inequalities in all its activities;
- To develop commissioning guidance, standard contracts, pricing mechanisms and information standards;
- To engage with the public, patients and carers, champion patient interests and ensure patients have access to a wider range of information about services;
- To develop a framework to make choice a reality for patients, setting out guidance in consultation with Monitor about how choice and competition should be applied to particular services;
- To oversee planning for emergency resilience and lead the NHS operational response to significant emergencies; and
- With its partners, develop a medium term strategy for the NHS, which alongside the local priorities developed through health and wellbeing boards, helps form the basis for local commissioning plans.

Taken from 'Developing the NHS Commissioning Board' 8 July 2011
www.dh.gov.uk/en/publicationsandstatistics/publications

One of our key demands is that the budget for the LSD specialised service be protected and allocated with the future in mind. Although the numbers are relatively small there will be a cohort of newly diagnosed patients each year who will meet the clinical guidelines for new therapies including enzyme replacement therapy. There are new drugs in clinical trial which may offer a treatment option for new groups of MPS patients in the future. Clearly the budget for the LSD specialised service needs to reflect this small growth area in patient need.

MPS Awareness Day

15 May 2012

One baby will be born every eight days in the UK with an MPS or related disease

Each year the Society celebrates International MPS Awareness Day on 15 May. This is a day devoted to raising awareness of MPS and Related Diseases

Help us celebrate International MPS Awareness Day on Tuesday 15 May 2012

In 2012 we're asking all our members, Friends and supporters to do something, big or small, to mark MPS Awareness Day

Visit **www.mpssociety.co.uk** for more information or give us a call on **0845 389 9901** to find out how you can support us…

Treatment Therapies

MPS I

Aldurazyme®, administered once weekly, has been approved in the European Union for the long-term enzyme replacement therapy (ERT) in patients with a confirmed diagnosis of MPS I, to treat the non-neurological manifestations of the disease. Aldurazyme was developed by BioMarin and Genzyme under a joint venture agreement that assigns commercial manufacturing responsibilities to BioMarin, and worldwide sales and marketing responsibilities to Genzyme. Additional information can be obtained at **www.aldurazyme.com**

MPS II

Elaprase®, is a a long term ERT for patients with a confirmed diagnosis of MPS II which has been approved for use in the European Union. Elaprase was developed and is produced by Shire Human Genetic Therapies (formerly TKT), and is given as weekly infusions to replace the missing enzyme that Hunter syndrome patients fail to produce in sufficient quantities. Additional information can be obtained at **www.shire.com**

MPS VI

Naglazyme®, is the ERT for individuals with a confirmed diagnosis of MPS VI and has been approved for use in the European Union. It was developed and is produced by BioMarin Pharmaceuticals, Inc. Additional information can be obtained at **www.bmrn.com**

Fabry

Replagal® and Fabrazyme® are Enzyme Replacement Therapies for Fabry disease both approved in the European Union. Replagal was developed and is produced by Shire Human Genetic Therapies. Fabrazyme was developed and is produced by Genzyme. For additional information please visit **www.shire.com** and **www.fabrazyme.com**

EUROPEAN UPDATE

Alpha Mannosidosis

A Phase 1 trial has recently been successfully completed and demonstrated that the enzyme, Zymenex, is safe and well tolerated. A Phase 2 dose-finding clinical trial is now underway. The biotechnologically derived human enzyme product rhLAMAN (LamazymTM), is produced by the Scandinavian biotech company Zymenex and developed for the treatment of patients suffering from the rare disease alpha-Mannosidosis. The clinical trial has now entered a new phase with the 10 patients from the Phase 1 trial, drawn from around Europe, moving forward into a Phase 2a dose-finding clinical trial, with the aim of indentifying the most optimal dose to achieve the desired clinical benefit.
www.zymenex.com/pressreleases

Enzyme Replacement Therapy for MPS II and MPS III:

Where we have come from, and where we might be going?

A Brief Summary of a Presentation given by **David Whiteman**
Principal Medical Director
Global Medical Affairs and Medical Lead
MPS Programme at Shire Pharmaceuticals

Dr Whiteman explained that animal data does not necessarily prove efficacy in humans with MPS II and MPS III.

He proceeded to explain the genetics and clinical manifestations.

The team explained how Shire is engaged in the large scale manufacturing of Elaprase and spoke of the Phase I/II and Phase II/III and extension trials. Taiwan has carried out an under 5s study (PMC038 and 042) and this will be reported on in early 2012. Data shows that prepubertal MPS II children on the clinical trial had a normal growth rate.

Hunter Disease with CNS involvement

It is generally agreed that two thirds of the MPS II population have CNS involvement. The focus of Intrathecal ERT for MPS II is to get past the blood brain barrier by direct administration. Shire chose to focus on using a surgical catheter (portacath) into the lumbar central spinal fluid below the start of the spinal cord. In 2011 Shire began the clinical trial in the USA and UK and focusing on safety. Patients recruited will receive one of three different doses or no treatment.

MPS IIIA Sanfilippo Disease A

A 12 month longitudinal natural history study involving 25 patients carried out by the University of Minneapolis found children losing 12 developmental points a year under the age of 6 years.

Phase I/II Safety, Tolerability, Ascending Dose and Dose Frequency Study
Study Sites are Manchester and Amsterdam. This is very early work and there is a need to prove the drug works before distributing the drug more widely and establishing clinical trials.

MPS IVA – Enzyme Replacement Therapy:
Update on Clinical Studies

An observational study was started in 2008 and will continue to 2018.

Phase I/II Study – MOR002
The objectives of this study were to:
- Establish safety
- Establish optimum dose
- Establish treatment response

20 patients were recruited in the study in three centres in England, Manchester, Birmingham and London. They were aged 5 years to 18 years. At the time of starting the study, 16 patients used a wheelchair. At 24 weeks of the study there was significant improvement in the 3 minute stair climb and 6 minute walk tests. Maximum Voluntary Ventilation (MVM) showed approximately 11% increase from baseline to week 24 and week 36. Forced Vital Capacity (FVC) similarly showed improvement by approximately 11% at 24 weeks. There was also a steep decline in urinary keratan sulphate and there was evidence of correlation to dose dependency. 17 of the 20 children recruited completed the study and entered the Phase III Extension Study.

Phase III Study – MOR004
The Phase III Study started in the UK in February 2011. It is now a multinational study with currently 40 sites in 15 countries.

Those participating will have to take the study drug or placebo every week via infusion for approximately 6 months. The participants will also undergo clinical examinations, blood and urine tests, vital signs, height and weight, x-rays, lung function tests and the 3 minute stair climb and 6 minute walk endurance tests. These tests may be part of a weekly or quarterly schedule as outlined in the informed consent form.

There are 27 scheduled visits including 24 weekly infusions. An infusion visit will usually take 6-8 hours plus travelling time. A few visits will require several hours during each of 3-5 consecutive days.

The study participants will be provided with the study drug and all tests and procedures free of charge. Reasonable travel and accommodation costs will be provided. In the UK, this is managed through the MPS Society. The key eligibility requirements are:
- Have a documented clinical diagnosis of MPS IVA.
- Be at least 5 years old.
- Be able to meet the study entrance requirements for the 6 minute walk test.
- Have never received treatment with the Study Drug BMN110.
- Have never had a stem cell transplant.
- Have not had major surgery within 3 months prior to study entry or planned major surgery during the 24 week study period.
- Not have participated in a study that involved any investigational drug or device within the last 30 days.
- If sexually active, must use birth control, have a negative pregnancy test and not be breast feeding or planning to become pregnant during the study.

Further Studies Planned
Under 5s Study – MOR007
Non Ambulatory Study – MOR006

Experimental Gene Therapy Treatment for MPS III

Lysogene has been approved to start clinical trials of gene therapy for the treatment of MPS IIIA, Sanfilippo disease. The first treatment took place in France in September.

This gene therapy programme is aimed at introducing a functional version of the defective SGSH gene directly into the brain of four young patients.

The objectives are to slow down, stop, and/or even reverse the symptoms of Sanfilippo disease and demonstrate a high level of tolerance to the treatment.

Data will also be gathered to design the next phase which will be primarily aimed at evaluating the treatment.

The same clinical trials for MPS IIIB Sanfilippo are pending within the year.

Amicus Therapeutics Announces Close of Patient Recruitment in First Phase 3 Study of Amigal™ for Fabry Disease: Final Enrollment on Track for 4Q11

CRANBURY, N.J., October 19, 2011 – Amicus Therapeutics (Nasdaq: FOLD), a biopharmaceutical company at the forefront of developing therapies for rare diseases, today announced that patient recruitment has closed in the first Phase 3 global registration study (Study 011) of Amigal™ (migalastat HCl) for Fabry disease. Participating sites have stopped screening new patients, and Amicus and its collaborator GlaxoSmithKline (GSK) continue to anticipate full enrollment this quarter upon initial dosing of the last patient.

John F. Crowley, Chairman and Chief Executive Officer of Amicus Therapeutics stated, "I am proud to announce that we, along with our collaborator GSK, have closed recruitment for the first phase 3 study for Amigal. This is a significant accomplishment given the strict entry criteria for Study 011. I am confident in the strength of our Fabry program and impressed with the coordinated effort at Amicus and GSK as we continue to progress."

Study Design
Study 011 is a six-month, placebo-controlled Phase 3 study of migalastat HCl for Fabry disease at 37 centres worldwide to support marketing applications for the U.S. Food and Drug Administration (FDA) and other regulatory agencies. The study is expected to randomise approximately 60 male and female Fabry patients, with an equal number to receive migalastat HCl 150 mg or placebo on an every-other-day (QOD) oral dosing schedule for a six-month treatment period.

Patients enrolled in the study must meet the following entry criteria: naïve to enzyme replacement therapy (ERT) or have not received ERT for at least six months, a genetic mutation that may be addressable with migalastat HCl, and elevated urine globotriaosylceramide (GL-3) levels at least four times the upper limit of normal.

European Authorities Approve New Manufacturing Facility for Shire's REPLAGAL® (agalsidase alfa)

Dublin, Ireland and Lexington, MA, US – June 24, 2011 – Shire plc (LSE: SHP, NASDAQ: SHPGY), the global specialty biopharmaceutical company, today announced that the European Medicines Agency has approved the purification of REPLAGAL® (agalsidase alfa) drug substance at its new manufacturing facility in Lexington, MA, US. REPLAGAL, Shire's enzyme replacement therapy for the treatment of Fabry disease is the first product that will be made available to patients from the new facility.

With this approval, the company now has two approved facilities – Alewife, which is located in Cambridge, MA, as well as the new Lexington facility – in which to purify REPLAGAL, thus providing increased manufacturing flexibility. The cell culture portion of the REPLAGAL manufacturing process will continue to be conducted at Alewife.

"We are pleased that we were able to accelerate the construction and approval of our new manufacturing facility in order to provide rapid access to important therapies for patients in need," said Bill Ciambrone, Senior Vice President of Technical Operations, Shire HGT. "This new facility allows greater flexibility to meet global demand for our products, including REPLAGAL."

Shire reiterated that it has sufficient product inventory to continue to meet the needs of Fabry patients worldwide currently receiving REPLAGAL and that it can meet anticipated additional demand. The Company is committed to continuing to provide uninterrupted long-term access to the product.

Home treatment with intravenous enzyme replacement therapy with idursulfase for MPS II – data from the Hunter Outcome Survey

Authors on behalf of the HOS Investigators -Barbara Burton – Children's Memorial hospital, Chicago, USA; Nathalie Guffon – Hospices Civil de Lyon, France; Jane Roberts & Simon Jones – St Mary's Hospital, Manchester, UK; Ans T van der Ploeg – Erasmus Medical Centre, Rotterdam, Netherlands

This paper uses experiences of patients in the observational database HOS – Hunter Outcome Survey to evaluate the feasibility of home infusions of Elaprase for patients with MPS II. The data of 421 patients who had received infusions at home or in an alternative, approved non hospital setting was analysed.

The findings were that patients started home treatment after an average of 9 months on Elaprase. Most were aged between 5 and 11 years at transfer. The average age being 8 years but nearly 20% were under 5 years of age. The children had disease manifestations typical of the wider population; over one third had cognitive impairment, in some cases severe. Illness was the most frequent reason for missed home infusions. Six children stopped home therapy and four of them subsequently resumed home infusions. Five infusion-related reactions occurred in 2 of the 59 patients who had received home therapy for at least 12 months. Reactions were classified as mild to moderate. All reactions that occurred at home were readily managed at home.

The authors' conclusions were that providing appropriate factors are considered, it should be feasible for patients with MPS II including those who are severely affected, to receive infusions at home.

Genzyme Fabrazyme® (agalsidase beta) Supply Update: Frequently Asked Questions

October 3, 2011

FABRAZYME GLOBAL ALLOCATIONS

How is Fabrazyme supply allocated?

Fabrazyme is approved and used by patients in over 50 countries worldwide. Globally, Genzyme has tried to maintain product allocations (amount of vials, types of vials or product) that are, overall, proportional to available supply and demand (the number of patients currently using the product, irrespective of commercial or charitable status) in a particular country.

Are all countries affected by Fabrazyme supply constraints?

All countries where Fabrazyme is used continue to experience significantly restricted supply of Fabrazyme. Genzyme is currently unable to meet worldwide patient demand. Each country manages their limited supply allocation in different ways.

Why are patients treated differently in different regions globally? Why are patients in Europe treated on full dose and not in the USA?

Fabry disease is a complex condition presenting differently in different patients. The choice of treatment where available, remains the decision of the treating physician and patient; as a manufacturer of a product, Genzyme does not make treatment recommendations. Differences in regional distribution logistics, availability of alternative treatment options, treatment practices and regulatory guidelines mean that that the timing and amount of Fabrazyme available to patients may vary significantly from country to country.

- In the European Union, regulatory authorities recommend that patients be treated at a full dose or switched to an alternative product. Genzyme has worked to accommodate such a request within the region or country's allocation. Approximately 70% of European patients treated with Fabrazyme as of mid-2009 have by now been switched to an alternative treatment. This allowed for a smaller number of patients to be treated with a full dose of Fabrazyme. In turn this led to an overall decrease in the proportion of Fabrazyme supplied to Europe. Currently there are a handful of European patients who are on a reduced dose of Fabrazyme.

- In the USA, where no other approved treatment for Fabry disease is currently available, the FSWG (Fabry Stakeholders Working Group) recommended that no group of Fabry patients should be designated to receive full dose, as this would require a significant further reduction in dose or no treatment at all for other US patients treated with Fabrazyme.

Why did I miss my recently scheduled infusion?

Because there is very low inventory, supply is vulnerable and delays are possible. A recent example is the delay in the shipment of August 2011 Fabrazyme allocation for patients in the US due to a manufacturing release delay; Genzyme supplied the product allocated for August in September 2011. When such delays occur Genzyme will try to inform the Fabry community as quickly as possible.

MANUFACTURING & SUPPLY

Genzyme previously communicated a return to full doses in Q4 2011, now this has been postponed until Q1 2012. Why the delay?

In order to increase the supply of Fabrazyme, a new manufacturing plant with additional bioreactor capacity has been built in Framingham, Massachusetts. This plant is undergoing validation and the current expectation is that Genzyme will begin to be able to supply Fabrazyme produced at this plant to patients beginning in the first quarter of 2012. This timeline depends on successful completion of validation procedures and also requires subsequent regulatory approvals.

When will Fabrazyme supply return to normal?

The new Framingham facility remains on track to supply product from that facility in the first quarter of 2012. The approval of this plant will allow the return to "normal" supply of Fabrazyme (that is, no restrictions on dose or patient numbers and a reduced risk of supply disruptions). However, due to the complexities of global regulatory approvals, global distribution, and release timing, approval to release product from Framingham is not expected to immediately enable return to full dose treatment for all Fabrazyme patients globally; such increase to full dose is expected to be gradual. Genzyme is following a conservative approach and need to be confident that they can sustain higher levels before increasing supply levels - i.e., they do not want to increase supply and then have to decrease it in subsequent months.

What is Genzyme's contingency plan if approval of the Framingham plant is delayed?

Approval of the Framingham plant is necessary to restore and sustain normal, uninterrupted supply of Fabrazyme (that is, no restrictions on dose or patient numbers and a reduced risk of supply disruptions).

What is the plan for the Allston and Framingham facilities in the future?

Genzyme will continue to support global markets with Fabrazyme originating from both the Allston and Framingham facilities until they can establish significant inventory levels and have the necessary regulatory approvals and a plan to consistently supply global markets. Only then would the Framingham facility become the sole production site for Fabrazyme.

Can Genzyme switch bioreactors around to make more Fabrazyme?

Given the ongoing supply constraints of Thyrogen® (thyrotropin alfa for injection), Fabrazyme and Cerezyme® (imiglucerase for injection), Genzyme are unable at this time to change the allocation of bioreactors. They are continuously assessing their long-term manufacturing capacity plans and are taking this into consideration.

European Platform for Rare Diseases

The European Platform for Rare Disease (EPIRARE) is a three-year project co-founded by the European Commission within the EU Program of Community Action in the field of Public Health that started officially on 15 April 2011.

EPIRARE's primary aim is to build consensus and synergies to address regulatory, ethical and technical issues associated with the set up and management of registries for Rare Disease patients in EU and to define possible policy scenarios. Its specific objectives organised in eight work packages are as follows.

Define the needs of the EU registries and databases on rare diseases; to define the state of the art of existing registries with reference to their legal basis; organisational and IT measures used; type of data collected; compliance with the rules on personal data protection; quality assurance; operational and financial support.

Identify key issues to prepare a legal basis to assess the feasibility of an EU legal instrument to allow the integration of national information sources and the collation and exchange of data at the Community level in compliance with the EU Directive 45/96 and with other relevant provisions.

Agree on a Common data set, elaborate procedures for quality control to define a minimum data set for all rare diseases; to define criteria for quality assessment of data, data sources and procedures in the registries.

Agree on the Register and Platform Scope, Governance and long-term sustainability to define the scope, operation and governance model of the platform, balancing the interests of relevant stakeholders and ensuring long-term sustainability of the platform. To identify tools and other facilities to support the operation for platform users.

The MPS Society has over 28 years of experience in building a registry that collects demographic data, defines the natural history of MPS diseases, clinical manifestations, treatment received and quality of life outcomes. It is therefore a considerable honour that representing the MPS Society I was invited to the first EPIRARE meeting to present aspects of the MPS registry and show some outcome data. Going forward I will be attending to next EPIRARE meeting in London in October.
Christine Lavery c.lavery@mpssociety.co.uk

Fabry International Network

The Fabry International Network (FIN) was founded five years ago and registered under Dutch law to offer support to the national Fabry patient organisations around the world and offer a global voice to patients with Fabry disease and their families.

Early 2011 I was invited to join the FIN Board. Before joining I thought long and hard as to what difference I could bring to FIN and most importantly how working collaboratively on the Board I might encourage FIN to reach out making a real difference in the lives of the Fabry patient organisations and their members. One thing I was conscious of in joining the Board was FIN's lack of regular meaningful communication with its members. Yes we had received an invitation to the FIN Annual General Meeting but that was about it. The MPS Society felt it had not benefited from any leadership by FIN over the years particularly in advocating for the Fabry patient over the shortage of Fabrazyme. I was keen to see leadership and communication worked upon because if this was the MPS Society's experience how many other groups feel the same.

As the months have gone by and I have got to know the FIN Board it became clear that others shared my aspirations around improved communication and the need for FIN to be seen to be making a real difference. I am pleased to say that the FIN e-News is now as of September being sent out to all members monthly and will contain up to date and valuable information for Fabry patient organisations. How FIN communicates with all its stakeholders is currently under review led by FIN's new acting President, Megan Fookes. Another area the FIN Board is keen to develop and advocate support to Fabry patients in countries where there is no Fabry support group.

If you have any thoughts on how FIN can make a difference in the lives of Fabry patients globally please do send your thoughts to president@fabry.com.au or me c.lavery@mpssociety.co.uk
Christine Lavery

25th Anniversary Conference of the German MPS Society

It was of considerable honour to be invited to participate in the German MPS Conference, 9 – 10 September 2011 Marriot Courtyard Hotel, Gelsenkirchen, Germany and I am most grateful to Michaela Giel, Georg Schetter and Carmen Kunkel and the organising team for making me so welcome.

On arrival in Gelsenkirchn, it was a warm, balmy evening and many of the families with their children and volunteer carers were congregating at the front of the hotel. I realised this was clearly going to be a big conference. From a distance I saw two familiar faces, Prof Michael Beck from the University of Mainz and Dr Susanne Kircher from the University of Vienna. Dr Kircher first attended a UK MPS Society meeting back in 1984 in Harrogate, Yorkshire so we go back along way.

That evening we were invited to hear the results of a competition to find out what MPS children wanted to be as they got older. The winning children had been photographed reflecting their wishes and the images of the five winners were truly amazing. I took a special shine to the little boy with Sanfilippo who wants to fly aeroplanes! On the quiet I was told the boy did not cooperate in 9 hours of filming so some artistic discretion was used; but you would not know and this photo was quite memorable.

On Saturday morning the conference started with a panel discussion on access to clinical management and new therapies. Although a majority if not all patients in Germany receive enzyme replacement therapy as appropriate there was a lively debate on concerns for funding of these treatments in the future and whether clinical guidelines would be a way forward. Encouraging more collaborative working between MPS specialist centres was called for as were multi disciplinary clinics.

In the afternoon I spoke on access to MPS clinical trials and presented the outcomes of some of the quality of life studies the UK MPS Society has been involved in or organised. I then attended a session where Dr Brian Bigger from the MPS Stem Cell Group at the University of Manchester spoke on Genistein in the mouse model and plans for a clinical trial in MPSIII A,B and C patients in the UK. He shared the challenge facing the University and the MPS Society of raising the necessary funds as quickly as possible.

The Gala Dinner on Saturday night was held at the nearby Gelsenkirchen Stadium, also called Arena Auf Schalke or Veltins-Arena. It is the home of the Bundesliga club FC Schalke 04 and was completed in 2002 in particular for the World Cup. Whilst not a football fan it was very interesting to see the driveoutable lawn field allowing the area to be used for other events including ice hockey. The banqueting room featured coal brick work to reflect the prominence and history of the mining industry. Indeed a retired miners band marched and played at the Gala Dinner.

However without question the highlight for me was meeting up with Jurgen and Brigitte Zumbro the founders of the German MPS Society. Jurgen and Brigitte whose daughter Natalie died from Sanfilippo disease two years ago devoted many years of their lives to establishing the German MPS Society and between 1986 and the early 2000s were regular participants at the UK MPS Conferences. The evening was quite memorable and again I'd like to say thank you to everyone for making my time in Gelsenkirchen so pleasurable.

Christine Lavery c.lavery@mpssociety.co.uk

EUCERD/EMA Workshop

Towards a public – private partnership for Registries in the field of rare diseases

This workshop on 4 October 2011 was organised in the context of the ongoing scientific activities of the EU Committee of Experts on Rare Diseases (EUCERD) dedicated to registries in the field of rare diseases. The workshop set out to build on the Rare Disease Task Force Report 'Patient Registries in the field of rare diseases' that the MPS Society was involved in. The aims of the workshop were to:

- foster the establishment of quality data repositories
- to avoid any duplication of efforts so as not to waste resources and expertise in a field where resources are scarce
- to provide unified sources of data for diseases where several products are available, the aim being to favour disease registries over product registries

The first session Dr Ségoléne Aymé described how there are 569 registries as strategic tools. Most are run by academic teams but a few like the MPS and related disease registry are run by patient organisations. The common issues are scarcity of carers and limited resources. There is a considerable waste due to duplication in developing tools. There is a waste of data, waste of expertise and waste of opportunities. The objectives of Orphanet is to foster establishment of quality data to speed up clinical research and provide data to regulatory and reimbursement bodies.

Dr Carla Hollak followed presenting the academic view by setting out the different categories of registries. She highlighted how essential requirements for these registries varies. Data needs to be complete and data validated for regulatory registries. The view was expressed that there is a need for registries for orphan diseases and should be able to evaluate the effectiveness and cost effectiveness of orphan drugs. Of the 16 registries run by private companies, eight are for lysosomal storage diseases. An example of Fabry was given with two product registries. There is absolutely no collaboration. The result of this is a delay in understanding the long term outcome and cost effectiveness of these treatments. Dr Hollak used the example of Gaucher disease and the Genzyme registry and how still the information needed to judge cost effectiveness and efficacy was not available.

The need to have a regulatory registry was presented to address the following:

- Appropriate use of all treatment
- Cost effectiveness
- Safety Profile
- Long term complications

Dr Hollak concluded stating then need to assess patients, not drugs. That the data should be subject to independent analysis requiring complete and detailed data and there should be an obligation on physicians that if they want to treat patients with an orphan drug they have to complete the detailed data. She proposed that Government and Industry should work together.

Samantha Pakter gave an industry perspective stressing Industry only runs a very small number of registries. The majority are global registries. The primary objective of an Industry is a post marketing regulatory commitment. If the registry post marketing is to be used to collect drugs data, and cost effectiveness of the patient, patients will need to be re-consented. Clear rules are required on data transfer.

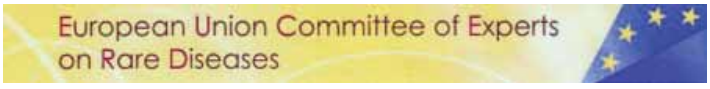
Dr Fabrizio Bignami (Eurordis) offered the point of view of Patient Representatives and set out the Evolution of the Rare Disease Environment. In the past very few researchers and clinicians were interested in the rare diseases. Now more researchers are interested in rare diseases, there is an increase in interest from larger pharma companies and new drugs are emerging. Patients invite all stakeholders and in particular policy makers and regulators to work together for the long term sustainability of registries. Patients can contribute with governance, preparation of information and documents and support the recruitment of patients. Patient groups want to benefit from the analysis of the data and be able to disseminate to members.

Dr Stella Blackburn speaking on behalf of the regulatory agenies explained that there are 61 Orphan drug products on the market. In respect of sharing data the biggest issue is data protection. Whilst the concept of one registry per disease is ideal maybe there is a need to think about registries sharing data. All have desire to do what is best for the patient and for public health.

In Session two the workshop looked at the usefulness of registries for regulatory purposes and the opportunities and challenges. We heard the experiences of Swedish rheumatology registries and in a roundtable discussion it was agreed that a vital ingredient is well defined minimum data set, minimum data quality and disease course on individual patients.

Session three focussed on European Community initiatives identified to provide high quality and unified sources of data to all stakeholders. This included the EPIRARE perspective which the MPS Society is also involved in. The issue of quality of Life measures and data was raised by Dr Carla Hollak and Dr Anil Mehta. This always makes me nervous as the UK MPS Society has wide experience of many of the validated tools used to measure quality of life are not sensitive enough for lysosomal storage diseases. In fairness to patients what is really needed is a Research Project to look at the effectiveness and limitations of validated measures.

We finished off the afternoon with 5 minute summaries by a representative of the EMA, Academia, Industry, regulators and the patient followed by a roundtable discussion where it was agreed that all stakeholders need to work together to make registries work for the patients. **Christine Lavery**



MPS 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 the **MPS 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 and posters 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!**

How to raise £2000 and enjoy it!

September 17th was quite a rainy dank evening here in Lisburn, but in Dinah and Damien Adair's house the champagne was flowing and the 'craic was 90'.

Dinah and Damien who are Roma Drayne's aunt and uncle kindly provided their house for a fundraising curry night. This was a great venue, with the dining room being used as a bar and the living room provided the space for everyone to get together for a good yarn.

The guests were all really well attended too. They were greeted with a champagne reception, followed by barmen always on hand to fill glasses up and waiters who served canapés whilst a chef worked away in the utility room providing a wonderful array of salads to serve with the hot curries that were arranged in the kitchen for self- service.

For this occasion we used the services of Posh Nosh, a local top-notch caterer, and their presence certainly added to the wonderful ambience of the evening. Normally we would have asked guests to bring a salad but this occasion was different. In March we had been to a fundraising ball with Dinah and Damien in aid of Northern Ireland Childrens' Cancer Fund and we bid in an auction for the services of Posh Nosh so that we could run an event for MPS.

So, having secured the services of Posh Nosh, we were able to run an MPS event charging our guests £50 each for a ticket to the curry night. This meant that guests did not have to bring any food and all the ticket charges went straight to MPS.

We do have a good band of committed MPS supporters who were eager to get their tickets. Some of the guests travelled quite a distance to the event, even as far as England. We really do appreciate everyone's loyalty to MPS and we offer our sincere thanks to everyone. We were delighted to raise £2000 for MPS.

Finally we would like to thank Damien and Dinah for doing this for MPS. It was a really busy landmark weekend for them particularly as their son Paul was about to leave home for the first time to go off to university. It was also Damien's birthday, 21 again and as generous as ever!
Bernie and Kevin Drayne

The **Towersey Morris Men** donated £700 to use towards research into finding a cure for MPS. They had a lovely evening in July with three other guest sides, many spectators, representatives from the Multiple Sclerosis Trust and Jenny Hardy who received the cheque on behalf of MPS. The MS Trust also received a cheque for £700.

The men have had one of their busiest seasons ever this summer, dancing at fetes, weddings and regular pub spots as well as the MPS Awareness Day festivities held at The Hampden Arms in Great Hampden. They opened the Towersey Festival at the end of August and held a day of dance raising money for the Wooden Spoon Trust, based at Stoke Mandeville Hospital. For more information please visit **www.towerseymorrismen.org.uk**

We would like to extend our thanks to the Towersey Side for their support over the last ten years during which time they have raised over £10,000 for our charity.

Grants make things happen

As the MPS Society improves and expands its services in response to members' needs, grant-making bodies are playing an increasingly important role in providing the funds to make this happen.

We make carefully-targetted applications to suitable trusts and foundations for specific areas of our work and understand the desire of grant-makers to see exactly where their money is going and what it is achieving. This might be to give a group of young carers a respite holiday, provide support to patients and their families at regional MPS clinics or offer bereavement support.

We also welcome contributions towards the core costs of providing our nationwide advocacy service and are particularly keen to establish long-term relationships with trusts and foundations whose aims and mission are a close match with ours.

We welcome visits and discussions to explore the different ways in which you can help us improve the lives of individuals with MPS and related diseases, and the families who care for them. We have an effective range of monitoring and evaluation processes in place and will provide regular reports on whatever aspects of our work you chose to support.

Previous grants have enabled us to set up new services, such as our telephone helpline, and to organise events such as regional family days and sibling breaks.

If you would like to know more about the difference a grant can make to our work or know of a Trust or Foundation which we could apply to for a grant, please contact us on 0845 389 9901 or email **grantsandtrusts@mpssociety.co.uk**.

A grant of £10,590 from the Geoff & Fiona Squire Foundation is funding improvements to our Childhood Wood. Being able to plant a tree and add a personal inscription to our memorial boards gives great comfort to bereaved families and creates a lasting legacy.

Fundraising Standards Board

The Society for Mucopolysaccharide Diseases is a member of the Fundraising Standards Board (FRSB). The FRSB is a self-regulatory body for UK fundraising organisations, members of which agree to adhere to the highest standards of good practice in their fundraising activities. For further information please visit our website www.mpssociety.co.uk

Fundraising resources available from MPS

Fundraising pack; School fundraising packs; Fundraising fact sheets; Sample press release; Sponsorship forms; Merchandise Order Form; Publication Order Form; T-shirts, posters, balloons, plus more…

Please visit **www.mpssociety.co.uk**

The Long Ride Home

How I come to be riding a tandem home from Edinburgh to Teynham in Kent is a story of an overactive imagination and a loose tongue when my wife asked if there was anything I could do to raise money for the MPS Society. She asked the question as a friend's 5 year old daughter had just been diagnosed with MPS. As always, when I volunteer for these things my old school pal Matt gets roped in. He far too eagerly agreed, for a normal sane person, to join in.

Once we decided we were to tackle the ride the planning started. A short conversation with another friend secured us the loan of Tommy the Tandem. It is worth pointing out at this stage neither of us had ever ridden a tandem! So the ride was on, route planned, B&Bs booked and tandem borrowed. All we had to do was the training.

The first attempt at riding the tandem wasn't very successful, with lots of shouts of "stop wobbling" we made it about 10 metres before having to stop with a fit of the giggles. It was going to be a long ride. We did master the tandem and though the first few training rides had to overcome a few unforeseen mechanical problems.

As the weeks went by we didn't get as many miles on the bike as we would have liked, but one final 95 mile training ride, with double the uphill that we would face on the first day in the Borders, blew the cobwebs away and gave us a new respect for the challenge ahead.

The day before we actually started we travelled up to Edinburgh, with travel reports quoting cancelled ferry crossing and bridge closures due to high winds. These were winds that would be a feature of the week's riding. It didn't bode well for the Indian Summer we had hoped for in early September.

Day One Edinburgh – Corbridge

Day one dawned and all the planning and talking was over and we set off from Edinburgh Waverly Station. We had hoped to leave the city on the A7, but it wasn't as well signposted as we had hoped and took a few wrong turns. This was fortunately the only time in the whole ride we would be a little lost. The first climb of the day was Soutra as we ventured down the A68. This was surprisingly easy going and things felt good at the top, we were finally truly on our way. The morning was bright but the cross winds were making riding really difficult on the tandem. Being on the back I had to suppress all natural reactions to the wind and allow Matt to steer us through. It did mean we couldn't build much speed up on the downhills as a wobble at speed would have put us in difficulty. The climb up to the border at Carter Bar was the biggest of the day, but was well worth it. Through the afternoon the temperature dropped and the cloud came down and it started raining. Stopping in a bus shelter in Risdale, on another of Northumberlands seemingly endless hills, putting full waterproofs on we both realised just how tough this ride was to be. The end of the day couldn't come soon enough. We plugged on until finally reaching Corbridge late in the afternoon. 95 miles and the worst day for climbing on the ride done.

Day Two Corbridge – York

The second day was brighter but still very windy. We knew we had most of the climbing to do in the morning to get over the Darlington, but could look forward to flatter roads in the afternoon. As the miles went by we found ourselves approaching Darlington. A quick stop for a Pasty at the bakers for lunch and we headed for the Thirsk office on the promise of a nice cup of tea.

The constant rain of the first afternoon had gone but was replaced with very sharp showers, one in particular was so hard it was difficult to see where we were going, but with brightness on all sides we knew it wouldn't last long and pressed on. We stayed at a pub that evening called the Saddle Inn, very appropriate. Another 95 miles done.

Day Three York – Folkingham
This was to be the longest day in terms of miles but with the flatlands of Lincolnshire ahead we were in tandem territory. The miles really flew by through the morning, through Goole, the busiest place I'd never heard of, and on to Lincoln. We got delayed through the centre of Lincoln as we got caught at the level crossing and every red light in the centre. As we pressed on south on the A15, the road seemed narrower and the lorries ever closer. We took the decision not to continue on this road and found some back roads to take us to our final destination for the day. Injuries were starting to mount, from the obvious soreness, muscle fatigue and both suffering from painful knees. 107 miles closer to home.

Day Four Folkingham – Cheshunt
With most of the climbing done and 107 miles the previous day, we approached day four thinking the worst was over and with only 90 miles to do, it would be an easier day. We were wrong. On my travels for work I am regularly up and down the M11/A14/A1, on the fourth day our route was to run a similar path. In the car I never noticed the endless rolling hills of Cambridgeshire and Hertfordshire. With the cross winds increasing again day four was the toughest of the ride. The hills weren't big but tired legs were finding them harder and harder to crest. As the afternoon drew on we knew that the next day would be the last and was much shorter. The end of hurricane Katrina that had been forecast to batter us the next day seemed to have been slower making its way over to the UK and we should get home before the full effects were felt. These thoughts kept us going through to our final night stop. Another 90 miles done only 63 to go.

Day Five Cheshunt – Teynham
When we planned the route we spent some time deciding how we would cross the Thames. Our plan was to ride straight down through London and over Tower Bridge. Being Sunday morning we hoped the roads would be quieter, as they proved to be. Still I had my busiest day on the back of the tandem signalling to cars and busses where we were going and making room in traffic to pull out across lanes. The route through London seemed to pass quickly and before we knew it we were at Tower Bridge. A welcome sight indeed. Once across the bridge we picked up the A2 and turned to head for home. Once on the A2 I was back on familiar ground. Despite the tiredness the closer we got to home the quicker we were riding, adrenaline overcoming fatigue. As we rounded the last corner we were greeted by a much larger crowd than we had expected all turned out to see us home.

So that was it, 450 miles ridden in 5 days, Edinburgh to Teynham complete. Our final fund raising total was £1120.
Chris Pike www.justgiving.com/chrismatt

EVENTS & CHALLENGES

Are you thinking of participating in a sponsored challenge or organising an event? Read on...

Find us on Facebook

Sponsored fundraising events are very popular and an easy way of raising money. We can supply promotional materials to support your event including posters, balloons, stickers, t-shirts, collection boxes and buckets. Set up a page on justgiving.com so that people can donate at the click of a button.

You can be sponsored for almost any type of event. You may like to try a walk, swim, or something a little different such as holding a tea-party, getting sponsored to shave or jumping into a bath of baked beans. If you work for a company, ask them to match funds received pound for pound that their employees raise for registered charities. The more original or difficult your event, the more money you are likely to be sponsored! For example, giving up smoking or even chocolate, giving a five minute massage in your lunch break, holding a quiz night, sponsored slim or a fancy dress party! Ask yourself whether there is anything you have always wanted to do, or wanted to give up. Do you have a particular hobby that is interesting and fun?

Try to get some coverage in your local media. They like to feature inspirational stories so let them know about your event. This will raise awareness of both MPS and your event or organisation. If you need to write a press release or would like some advice talking to the media do give us a call. There is a sample press release available as a download from our website.

Make use of your local amenities, for example, local pubs, restaurants and shops as they are great places for holding events, displaying posters and promoting awareness. Check whether you need permission from anyone to use their venue. Ask small companies to donate gifts as they will benefit from the publicity and supporting worthwhile causes. An excellent place to begin your fundraising is at your place of work. Use staff noticeboards, pigeonholes and email to spread the word. If you belong to any clubs or societies, get them involved.

You can do your sponsored event on your own as an individual, or you could persuade your friends and relatives to take part with you. This may be more fun and you could raise even more money if there is a group of you. Those who want to get involved, but who do not want to actually take part, may be willing to take a sponsor form to their school or workplace. Never feel guilty asking people to sponsor you.

Once the event is over, you need to start collecting the sponsorship money, chase any late donations and total up the final amount you have raised. Send it to us along with the sponsorship forms and a story and photo for our fundraising magazine.

Ask us for a fundraising pack which contains more information and points to consider. Phone 0845 389 9901 or email fundraising@mpssociety.co.uk

Health and Safety is an important issue that must be considered whenever you arrange an event. Here are a few things to bear in mind.

The Society does not authorise organisers of fundraising events to act as agents of the Society.

Whilst the Society appreciates your support, it is not responsible for organising, supervising or hosting your event. Individuals taking part in activities do so at their own risk.

We do not accept any liability for your event, loss or damage to yourself, property or personal effects, so if you need insurance you must arrange this yourself. Inform your insurance company in plenty of time.

Please do not do house to house collections. The Society does not support this. Please be aware there are strict rules and regulations which you must observe. Please ensure you have made yourself aware of these and follow them.

Health and safety is a serious issue. Give your local Red Cross or St John's Ambulance a call if you intend to organise an event.

Supervise children and don't let them collect money from strangers.

Only get sponsored by and collect donations from people you know and trust.

No one under the age of 16 should be collecting sponsorship money without adult supervision.

Children should always have permission from a parent or guardian to participate in a fundraising activity.

Always wear safety equipment if required.

Ensure you have enough volunteers to control the crowd that may arise.

Be careful if you are carrying money. Put it in a safe place and keep it out of sight.

Legal aspects

All your fundraising and publicity materials need by law to include the words 'Society for Mucopolysaccharide Diseases', our logo, registered company no. 7726882, registered charity no. 1143472 and Scottish charity no. SC041012. These should only be reproduced with our prior written permission.

If you are considering holding an event that is open to the public, whether the admission is free or not, you may require a licence.

Please note you cannot use any of the Society's materials for raising funds for an individual i.e. raising funds for a holiday or piece of equipment. All money raised, less expenses, must come to the Society. If you need help with specific funding, please contact our advocacy team for advice **advocacy@mpssociety.co.uk**

Sporting Events for MPS

Take up a challenge and push yourself - it's all in a good cause!

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.**

Jamie Pollard took part in a Skydive on behalf of MPS and collected £566 in sponsor money.

Dan Taylor, whose daughter has MPS I Hurler, has raised £1355 on his justgiving.com page for a sponsored skydive.

Priti Chapaneri did a skydive on the 27th August 2011. On her justgiving.com page ,which raised £365, Priti writes 'My aim is is raise as much money as I possibly can and all my proceeds will go to the MPS Society.This rare and genetic condition has a special meaning to myself. Aisha Seedat (13) from Manor High School in Oadby suffers from Morquio's. I regularly support Aisha in alot of her classes, she is a true inspiration and a wonderfully gifted child who never looks or gets down from this disease.'

MPS Charity Places available on events for 2012

For more information and to register your interest
please email **fundraising@mpssociety.co.uk** or phone **0845 389 9901**

BUPA Great Manchester Run	20 May 2012, Manchester city centre, 10km
BUPA Great North Run	Date TBC, Newcastle-upon-Tyne,13.1 miles
BUPA Great South Run	28 October 2012, Southsea, Portsmouth, 10 miles
BUPA Great Birmingham Run	28 October 2012, Birmingham City Centre, 13.1 miles
Great North Swim	22/24 June 2012, Windermere
Great South Swim	Date TBC, London

For more information about each of these events, please visit **www.greatrun.org**.

Running isn't just for adults - it's for kids too!

There are a number of children's races featured in the BUPA Great Run series.
For more information visit www.greatrun.org/junior

justgiving
fundraising made easy

Are you taking part in a sponsored challenge or event.
Use **www.justgiving.com** to encourage online donations.

The MPS Society has teamed up with justgiving.com so all our runners and events' participants can raise money quickly and easily online with their own personalised web pages. For more information visit **www.justgiving.com** or contact them as detailed here.

The JustGiving helpdesk is now available every day of the week.
If you or your supporters need expert fundraising advice, support and more, we'll be there, ready and waiting.
t: 0845 021 2110
e: help@justgiving.com

Volunteering opportunities

Hannah's Story

I've been volunteering for the MPS Society for a few years now and I love it.

One of my brothers (Dan) and my sister (Amy) both have Sanfilippo and when I was younger I really enjoyed coming along to the MPS conferences. Our family used to need quite a few volunteers and I have really happy memories of fun volunteers who gave us all such a great time. As a volunteer now, seeing the younger MPS children and their siblings brings back happy memories of when Amy and Dan were little and needed fast runners to chase them!

It feels really good to be able to give something back now. The weekends are always such good fun. What could be more fun than a hotel full of MPS kids running around and causing chaos!

It's great to meet some amazing families and spend the day with fantastic kids in the hotel or taking them out for the day to a theme park or zoo. It's definitely hard work and challenging at times and you need to be prepared to run fast and have hands that can be in 4 places at once!

Sometimes things don't always go to plan either… like when fire alarms go off and you have to evacuate all the children out of the hotel! But it's all great and by the end of the day a good night's sleep is always guaranteed! It's satisfying too; I really enjoy getting to know the kids and their siblings over the weekend. Seeing them enjoy themselves whilst knowing that their parents are able to appreciate a bit of a break is great. It's nice to feel like you've really been a help and it's really rewarding to have a parent say to you "Wow you can come again, she's gone straight to sleep she was so worn out!"

Being trusted to look after someone else's child for the day does feel like a big responsibility, but the weekends are always so well organised. The volunteers are like a big team and all work together and help each other out. It's been good coming back year after year, catching up with all the other volunteers and seeing the families that I've got to know before.

This last year it's been really nice to volunteer on the young adult weekend too. This was in Blackpool and was quite a bit different to the other weekends I'd volunteered on before. It was good to spend time talking and getting to know each of the young people and I was inspired by their positive attitude towards life, especially with the many challenges that they face and overcome every day.

I've really enjoyed volunteering at the MPS weekends, getting to meet some amazing people, experience some really interesting situations and have a great time! MPS weekends are definitely the most exhausting weekends of my year but also some of the most rewarding and fun ones too. **Hannah Donegani**

Volunteering opportunities at MPS

Are you interested in becoming a childcare volunteer for the MPS Society? Perhaps you're not able to support us through fundraising, but maybe you can spare some time and energy to be one of our childcare volunteers? Maybe your work place and colleagues could donate some time to support our childcare programme at events?

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

To become a childcare volunteer we would need you to complete an application form. 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. Once we have obtained satisfactory references and your CRB check, you will then receive an acknowledgement that your application has been accepted and you will be added to the volunteer mailing list. All new volunteers will be mentored by an experienced volunteer.

The MPS Society organises a programme of events and activities throughout the year. These include sibling weekends for brothers and sisters of children affected by MPS and related diseases, adult weekends for adult individuals affected by the diseases and family weekends, expert meetings and conferences for the whole family to participate in.

Our event programme is exciting and we rely on our childcare volunteers to keep our children and vulnerable adults safe whilst ensuring they have a happy and memorable time.

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

Don't forget to check out the fundraising section of our website for further information and ideas www.mpssociety.co.uk

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

Mission Fish and ebay for Charity

Background: We aim to help charities get the most out of online commerce.

We want to make it possible for any charity to benefit from any gift from any donor. To achieve that vision we're trying to make it easier to give as a part of daily life online, and working to change the way people think about philanthropy. We are a registered charity (No 1110538).

Our major initiative is **eBay for Charity**, a unique programme that helps charities raise money on eBay. eBay for Charity helps charities of all sizes to raise funds by trading on the eBay marketplace.

The MPS Society is registered with Mission Fish eBay for Charity.

eBay sellers can donate 10%-100% to the MPS Society whenever they sell an item (there is a £1 minimum donation per listing). Pick the MPS Society as your favourite charity to see when you are buying and selling on eBay. You can make this selection on the 'My Favourite Charities' page in your eBay Donation Account.

To learn more about how you can support the MPS Society on eBay, visit *www.ebay.co.uk/charity*

ebay for Charity

Any individual leaving 10% or more to charity will have their inheritance tax reduced from 40% to 36% from 6 April 2012. The relief is designed so that the benefit of the tax saving is reflected in the bequests received by charities and not in payments to other beneficiaries. The Chancellor said in his speech 'we want giving 10% to charity in legacies to become the norm'.

Please donate

online: www.mpssociety.co.uk

phone: 0845 389 9901

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

IDEA: Creating a *Justgiving.com* page in memory of a loved one is a powerful way for friends and family to honour them by donating to a cause they cared about. Create your page in aid of the MPS Society, you can write a personal message, add your favourite photos and invite people to make a donation.

www.justgiving.com/sfmd/remember

Seasonal Fundraising

Christmas

Here are some fun ideas for fundraising at Christmas time

- Guess the present:
- Guess the weight of the Christmas cake
- Donations in lieu of sending Xmas cards
- Fancy dress or mulled wine & mince pie party
- Donations for kissing under the mistletoe
- Order from our MPS Christmas Collection (leaflet shown to the left) by visiting **www.mpssociety.co.uk**

Jenny and Andy Hardy recently raised £716.02 for MPS. They raised £591.02 through the sales of cards, gift wrap and reindeer food and the additional £125 is half the amount people generously donated at their card sale, held at the start of November. Jenny and Andy sent the other half to Helen and Douglas House as they also sold some of their cards. As well as selling cards, they provided coffee and biscuits in the morning, tea and biscuits in the afternoon and mulled wine with nibbles in the evening - an exhausting but thoroughly enjoyable and profitable day.

Would you like to volunteer for us?

Volunteering is fun and rewarding. It could also help you learn new skills and gain valuable work experience. The MPS Society relies on volunteers for our events and conferences 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. Volunteers should be 16 years or over, will need to provide two references and undergo a Criminal Records Bureau check and attend a training day in Amersham. Those volunteering for our conferences will receive accommodation and all meals throughout the weekend.

Contact us now to register your interest and availability. **mps@mpssociety.co.uk**

Help us care for today and give hope for tomorrow, leave a gift in your Will

It is vital that the MPS Society has sufficient funding to be able to look forward to the future with confidence. One way in which you can support the Society achieve its long term objectives is to include the Society when drawing up your Will. For more information please contact us for our Leaving a Legacy leaflet or for more information please visit **www.mpssociety.co.uk**

Find us on Facebook

The MPS Society Facebook page is a means of providing information to our MPS Members and Friends quickly and efficiently. In the future we hope to feature some of our events and activities and recognise those that contribute to the Society and the work that we do.

You can find us by entering *MPS Society* into the facebook search engine.

As well as aiming to provide you with news from our fundraising activities and MPS events to coincide with our quarterly MPS Magazine we are also hoping to encourage greater awareness of the MPS Society.

If you have any ideas or suggestions for our facebook page please email **facebook@mpssociety.co.uk**

Do you have a story to share?
Please email
magazine@mpssociety.co.uk
or phone **0845 389 9901**

Gift Aid Q&A

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**