

Society for Mucopolysaccharide Diseases

Annual Review 2013



www.mpssociety.org.uk

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REFERENCE & ADMINISTRATIVE DETAILS

Registered Company number

7726882 (England and Wales)

Registered Charity number

1143472 / SCO41012

Registered office

MPS House
Repton Place
White Lion Road
Amersham
Buckinghamshire
HP7 9LP

Trustees

B Wilson - resigned 13.12.13
R Devine - resigned 12.7.13
Mrs J Evans
Mrs W Robins
Mrs S Peach
Mrs J Holroyd
T Summerton
R G Stevens
Prof B Winchester
Ms F Parrott
Ms J Reid
P Moody
J H Garthwaite - appointed 12.7.13
Ms K F Burley - appointed 12.7.13

Company Secretary

Ms C Lavery

Chief Executive Officer

Mrs Christine Lavery MBE

Auditors

McLintocks Partnership Limited
Chartered Accountants
Registered Auditors
2 Hilliards Court
Chester Business Park
Chester
Cheshire
CH4 9PX

Bankers

Barclays Bank plc
United Kingdom House
7th Floor
180 Oxford Street
London
W1B 1EA

Solicitors

Dickinson Dees
St Ann's Wharf
112 Quayside
Newcastle Upon Tyne
NE1 3DX

TRUSTEES REPORT



The trustees who are also the directors of the charity for the purposes of the Companies Act 2006 present their report with the financial statements of the charity for the year ended 31 December 2013. The trustees have adopted the provisions of the Statement of Recommended Practice (SORP) 'Accounting and Reporting by Charities' issued March 2005.

We welcome you to the Society for Mucopolysaccharide Diseases' Annual Report and Accounts for this period. The past 12 months have provided their share of challenges combined with the many rewards of being a highly regarded patient organisation in the rare disease sector and serving the public interest of the charity.

The MPS Society can be proud of the services it has delivered to those affected by these devastating diseases. The support offered within the individual advocacy service is necessarily wide-ranging with the aim of meeting the needs of an increasingly diverse group of nearly 1300 affected children, adults and their families. Across the 24 diseases supported by the MPS Society the support needs vary considerably. In MPS I Hurler disease haemopoietic stem cell transplant is the accepted treatment for babies diagnosed under 18 months of age whereas for the Hurler-Scheie and Scheie forms of MPS II, the attenuated form of MPS II (Hunter), MPS VI (Maroteaux-Lamy disease) and Fabry disease the optimal treatment is currently enzyme replacement therapy. At the other end of the spectrum of diseases including those with severe neurological involvement such as the four types of MPS III (Sanfilippo disease), the Mucopolysaccharidoses and the Oligosaccharide diseases, the only treatment is palliative.

During this period we have continued to provide advocacy support to an increasing number of children and adults participating in Enzyme Replacement Therapy (ERT) clinical trials taking place at Manchester Children's Hospital, Birmingham Children's Hospital, Great Ormond Street Hospital, the Royal Free Hospital, the National Hospital, Queen Elizabeth Hospital and Salford Royal Hospital. The

MPS Society has over the past seven years developed a Clinical Trial Patient Access Programme that has provided our members participating in clinical trials with logistical support on behalf of the relevant pharmaceutical companies. In this reporting period the trustees recognised an opportunity to expand and commercially market the Clinical Trial Patient Access Programme. It was agreed to establish 'MPS Commercial', registered as a limited company in August 2013, as a trading subsidiary wholly owned by the MPS Society for this purpose. As a consequence the level of income in this period received by the Society for expenses paid out to patients has fallen as support for clinical trials has transferred to the subsidiary trading company.

Advocacy support in areas of social care, educational needs, palliative care, transition to adult services and disability benefits alongside treatment and clinical management is a pivotal area of work for the Society and that has tangible outcomes for our members. Bernard Sunley Charitable Foundation, The Shauna Gosling Trust, The Herbert & Peter Blagrove Trust, The Eveson Trust, Leathersellers Company and the Peter Harrison Foundation, and the Simon Gibson Trust are a few of the Charitable trusts who supported the advocacy service in 2013.

17 children and adults lost their lives to MPS, Fabry or a related disease during this time and a further 51 were newly diagnosed. In October bereaved families gathered in the Childhood Wood in Sherwood Pines, Nottinghamshire, to plant oak saplings in memory of their children who had lost their lives to MPS this past year. They were joined by representatives of Nottinghamshire County Council and the Office of the Lord Lieutenant of Nottinghamshire.

Due to excellent clinical care and the new and emerging therapies an increasing number of children who would not have been expected to survive their first decade are living into their twenties and beyond. This has brought about new support areas and challenges not only for young people but the services providing these.

Individuals are faced with having to make decisions and choices in relation to all the health and social care needs and have raised questions for many, such as "Can I live independently, gain employment and start a family?" - questions that many professionals have been unable or have struggled to answer.

Challenges have also occurred within families, particularly for parents where they were told at diagnosis that their child may not make adulthood or would not be able to make informed choices and this is no longer the case for some.

To aid and support young people, the Society has done considerable work looking at transition and gaining insight from members, parents and professionals to better improve practices, expectations and to deliver measurable and achievable guidelines to help this process along. Different ways that this has been achieved include producing some best practice guidelines which have been adopted and approved by the Department of Health (now NHS England) and developing a transition health passport for young people to help facilitate their independence and to inform them of the process in place to alleviate some of the anxieties and uncertainties they may have.

However, for some of our members independence is not possible and therefore we need to look at support and guidance not only for the young person but for the parents / carer and professionals involved in their care and this piece of work is ongoing.

The Society has had a presence in Northern Ireland since its beginning in 1982 by establishing the twice yearly Belfast clinic in 1994 and providing individual advocacy support from the mainland. The All Ireland Advocacy Officer post, which was established in 2010 has proved so beneficial that the Society was awarded grants from Biomarin, Genzyme and Shire to support the expanded advocacy programme across the whole of Ireland. The Northern Ireland Department of Health also renewed its annual grant.

Support activities and events are an important part of the MPS calendar, and in this reporting period included a family day in Edinburgh funded by the Soutar Foundation, a family weekend at Legoland funded by The Gosling Foundation and the Clover Trust, a visit to Warner Brothers Studio to see Harry Potter World funded by Help a Capital Child and UK Lapland funded by BBC Children in Need. It is the policy of the trustees that these events only take place if restricted funding for the whole project can be secured. In June 2013 the MPS Family Weekend Conference took place at The Hilton Hotel in Coventry with 76 families and 131 professionals participating. The Society once again ran a very successful children's programme supported by a team of fully trained volunteers. We were able to support children to go on outings during the day and provided entertainment and childcare on the Saturday evening, giving many parents a much deserved and needed break. All our volunteers undergo a Disclosure and Baring Service check and have to attend a MPS training day which includes moving and handling training.

MPS, Fabry and related diseases are individually rare, making ongoing public awareness and communications critical to getting the MPS message out into the public domain and growing support amongst the general public.

Following a complete rebranding in early 2013, the MPS Society continues to develop support for fundraising and raising public awareness with a number of new initiatives

including "Wear It Blue" for international MPS Awareness Day held on 15 May 2013, and a series of "Wicked Walkabouts" raised in excess of £12,500. The MPS Society was featured in the Independent Supplement promoting promoting the needs of people with rare diseases in February 2013 which was a welcome opportunity for members to tell their stories and promote the work of the MPS Society. We continued to publish our quarterly MPS Magazine and update our range of information resources for children and adults and the wider family affected by MPS and related diseases. This included the production of a children's guide to genetics. In promoting the MPS Society's services and activities we used a variety of communications, including online, social media and print, to ensure we reflected and engaged with the diverse needs of our membership and supporters.

After providing support and advocacy for our members, funding research continues to be the most important objective. In 2013 fundraising for the £650,000 appeal to fund a clinical trial using a high dose of the drug, Genistein aglycone in children with MPSIII Sanfilippo disease continued in earnest. At the year end £495,000 had been raised and plans to start the clinical trial at Manchester Children's Hospital in Spring of 2014 are under way.

In late 2005 the Trustees agreed to purchase MPS House as a suitable facility for the MPS Society to meet its objectives. Only half the building was available at the time but the Trustees saw the potential to enable the society to grow. In July 2013 the other half of the building came on the market and the Trustees agreed to make the purchase.

The trustees, ever mindful of the difficult economic climate impacting our supporters and the public at large, set a prudent budget prior to the start of this financial year that provided for all core costs, the advocacy support service and essential events it also allowed for additional support and research activities to take place as and when restricted funding for that purpose was achieved.

Most importantly of all, our unique and disease-specific individual advocacy services have been able to reach out to so many of those affected by MPS, Fabry and related diseases, including parents, partners, siblings, and extended family. This could not have been achieved without the commitment of our dedicated staff team, volunteers, our members, MPS supporters, MPS specialist doctors, nurses and scientists.



Sue Peach
Chair of Trustees

STRUCTURE, GOVERNANCE & MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

The Society was founded in 1983 and was registered with the Charity Commission as an unincorporated association, registered charity number 287034. On 2 August 2011 the Society incorporated a company limited by guarantee with the name 'Society for Mucopolysaccharide Diseases'. The assets, liabilities and activities of the Society were transferred into this charitable company on 1 November 2011.

Recruitment and appointment of new trustees

New trustees are elected by the membership and may hold office for six years before retiring. The Board of Trustees (Directors) may co-opt up to three trustees who must stand for election at the next Annual General Meeting.

Induction and training of new trustees

New trustees are provided with information about the Society and its work, the role and responsibilities of trustees, and the composition and workings of the Board. They are given copies of the Society's governing instrument, a folder of all the Society's policies and the minutes of the last five Board of Trustees meetings. Trustees are regularly provided with the latest information on employment and charity law through the provision of the monthly Governance magazine.

Organisational structure

The charity is governed by a board of up to 13 trustees known as the Board of Directors which meets a minimum of five times during the year. The day to day business of the Society is managed by the Chairman, Vice Chairmen and Treasurer and is governed by the Articles of Association. There is a financial oversight committee that meets as needed.

Wider network

One trustee's first language is Welsh, another lives in Scotland and a third is affected by a related lysosomal storage disease. Geographically, the MPS Society provides a UK-wide support and individual advocacy service from MPS House based in Amersham in Buckinghamshire. Our 12 employees are central to providing the support, individual advocacy services and the communication of our cause, while our 5,000 supporters are vital to us achieving our goals and objectives.

Risk management

The trustees have identified the level of risks to which the Society may be exposed and have established the implementation of a risk management strategy which comprises quarterly reviews of the risks the Society may face, systems and procedures to mitigate these risks and implementation of procedures designed to report on and minimise any potential impact on the Society should any of these risks materialise

OBJECTIVES AND ACTIVITIES

Principal activity

To support individuals affected by Mucopolysaccharidosis, Fabry and related lysosomal diseases, their families and professionals who care for them through partnership working, implementation of the individual advocacy service, increasing awareness and raising funds for research into these diseases.

Objectives and aims

- to provide support to individuals affected by Mucopolysaccharidosis and related lysosomal storage diseases, their families and the professionals who care for them
- to increase awareness of Mucopolysaccharidosis and related lysosomal storage diseases amongst health, social care and education professionals
- to extend this to the community at large to secure improved local services and inclusion for affected children and adults and their families
- to raise funds for research into Mucopolysaccharidosis and related lysosomal storage diseases that may lead to improved clinical care, quality of life and new therapies

In order to carry out these objectives:

- we research the needs of children and adults affected by MPS and related lysosomal storage diseases
- we fund cutting-edge, peer-reviewed research that may lead to therapeutic options for those affected
- we campaign for change in government policy and practice
- we deliver services to those affected by MPS and related lysosomal storage diseases
- we operate in the four countries of the United Kingdom and collaborate with MPS patient organisations throughout Europe and the rest of the world, to raise awareness and seek ways to grow income

To achieve these objectives, we rely on:

- funding from voluntary donations, corporate donors, charitable trusts and statutory bodies
- support from the public who fundraise and take part in events organised by the Society

Over the year the Society for Mucopolysaccharide Diseases has worked towards its charitable objectives in the following ways:

- provided advice and support to those affected by MPS and related diseases and /or their families to help them to access the disability benefits to which they are entitled, home adaptations, manage educational needs, transition to independent living, and access respite care
- offered an individual advocacy service in writing, by telephone or email or through home visits, face to face

- meetings and support at multi-agency meetings
- offered in-depth support to families caring for their child at the end stage of their disease, and preparing parents and siblings for loss through our dedicated progressive neurological palliative and bereavement worker
- arranged a UK-wide programme of social events, regional clinics and a National MPS Family Conference
- recruited, trained and involved volunteers to provide a child and vulnerable adult programme at the National MPS Family Conference
- undertook Quality of Life studies with the membership to inform the regulators and clinicians on the natural history of MPS diseases and benefit of high cost therapies
- continued to maintain the Childhood Wood at Sherwood Pines, Nottinghamshire facilitating the annual planting
- continued to support the MPS Stem Cell Group at the University of Manchester with a programme grant
- supported members participating in a wide range of clinical trials

The Trustees confirm they have complied with the duty of Section 4 of the Charities Act 2011 to have due regard to the Charity Commission's general guidance on public benefit, 'Charities and Public Benefit'.

Financial Review

This is the first set of accounts for the incorporated charity that reflects a twelve month accounting period, the previous accounting period having been fourteen months from 1 November 2011 to 31 December 2012. The MPS Society continues to raise and receive funds through applications to grant-giving bodies in support of its advocacy service including the salaries of the senior advocacy officer and four advocacy officers as well as special projects. The Society continues to rely heavily throughout the year on its members' and supporters' efforts to raise unrestricted income by way of donations and fundraising. The fundraising receipts in this reporting period were £167,605 whilst receipts from general donations and legacies were £60,426. The Society's income in these areas held up well. However the Society has the on-going challenge of attracting unrestricted income to enable it to deliver on its governance responsibilities, support activities and other costs related to the individual advocacy service.

WHAT ARE MPS & RELATED DISEASES

Mucopolysaccharide (MPS) and related diseases are rare diseases affecting one baby born every 8 days in the United Kingdom.

MPS and related diseases are a group of 24 rare metabolic diseases, referred to as MPS I-VII or more commonly by the name of the doctor who first described the condition: Hurler, Scheie, Hunter, Sanfilippo, Morquio, Maroteaux Lamy, and Sly.

Mucopolysaccharidoses and other storage diseases also covered by the Society are: ML I, ML II (I cell disease), ML III pseudo Hurler polydystrophy, ML IV, Sialidosis, Fucosidosis, Mannosidosis, Sialic Acid Storage Disease, Multiple Sulphatase Deficiency, Aspartylglycosaminuria, Winchester,

Metachromatic Leukodystrophy and Fabry disease.

Children born with a Mucopolysaccharide or related disease are unable to produce enzymes essential for the continual process of breaking down and replacing used materials. Babies may show no sign of the disease, but as more and more cells become damaged by the storage of used material, symptoms begin to appear. Sadly, these are progressive diseases which lead to an increase in problems as the years go by. Effects of the disease vary but are all associated with progressive physical disability. Over half these diseases cause degeneration of the brain resulting in severe learning difficulties and death in childhood.

HOW ARE THEY MANAGED CLINICALLY?

The Society continues to work collaboratively with the lead specialist centres in MPS and LSDs.

Until 2004 Mucopolysaccharide and related diseases were managed at a variety of District General Hospitals as well as recognised specialist centres in England. This resulted in a significant variation in quality of care and considerable “postcode prescribing” for new therapies. In 2004 the MPS Society initiated the process that led to the 50 lysosomal storage diseases (LSDs), which includes the 24 MPS and related diseases, being managed nationally in England by the National Specialist Commissioning Group. This designation changed almost overnight the patient’s right to be assessed and managed clinically at a recognised LSD specialist centre for children or adults and, where therapy is available to treat their disease and to be assessed against appropriate clinical guidelines.

The highly specialised LSD centres are:

Paediatric

Great Ormond Street Hospital, London
Birmingham Children’s Hospital
Manchester Children’s Hospital

Adult

National Hospital, London
Royal Free Hospital, London
Queen Elizabeth Hospital, Birmingham
Addenbrooke’s Hospital, Cambridge
Salford Foundation Hospital, Manchester

Wales, Scotland and Northern Ireland have designated specialist hospitals for managing metabolic diseases but MPS patients do not have the benefits of national commissioning and access to treatment in the same way as England. This does mean some of our members in these countries are denied treatment or have suffered delays even when they meet the treatment guidelines in England.

The designated specialist hospitals are:

Wales - University Hospital of Wales, Cardiff
Scotland - Yorkhill Children’s Hospital, Glasgow
Northern Ireland - City Hospital, Belfast

TREATMENT & RESEARCH

There is no cure for any of the MPS and related diseases.

In 1980 Bone Marrow Transplant (BMT) was tried experimentally on a young boy with MPS I Hurler disease. Throughout the 1980s a small number of children diagnosed with MPS I Hurler, MPS II Hunter, MPS III Sanfilippo, MPS IVA Morquio, Fucosidosis and Mannosidosis were treated with a BMT. Over time it became clear that except in the case of MPS I Hurler, BMT does not usually offer any therapeutic benefit. Haemopoietic Stem Cell Transplant (HSCT) which includes BMT and Cord Blood Transplant is now the treatment of choice for children diagnosed with MPS I and having two mutations consistent with the MPS I Hurler phenotype. The outcome of HSCT is extremely variable usually only modifying the underlying disease. As a result many MPS I Hurler children who have undergone HSCT may have a degree of learning difficulty. An HSCT in these children does not eliminate corneal clouding or modify the bone disease. As a consequence, the children may continue to have serious spinal complications that require surgical intervention, as well as other joint problems. However, HSCT is the treatment of choice for babies diagnosed with MPS I Hurler under the age of 18 months. HSCT may also be considered in babies under the age of 6 months diagnosed with MPS II where the family phenotype suggests severe neurological involvement.

In the 1990s several pharmaceutical companies started to develop Enzyme Replacement Therapy (ERT) as a potential therapy for the LSDs. The first ERT was given an orphan drug licence to treat Gaucher disease in 1990.

Over a decade passed before ERT became a reality, In the last twelve years Enzyme Replacement Therapy (ERT) for MPS I Hurler Scheie and Scheie, MPS II Hunter (without CNS involvement), MPS IV Morquio and Fabry disease has been clinically trialled and received marketing approval by the European Medicines Agency. ERT for these conditions where the patient meets the clinical criteria is prescribed across England and Northern Ireland. In Scotland and Wales some ERT's are not easily available. Indeed some of our members remain untreated in these countries when if they lived in England they would be treated.

The serious limitation of all Enzyme Replacement Therapies is that it cannot cross the blood brain barrier and, therefore, in their present licensed forms are not a viable option for over half the MPS and related diseases associated with neuro-degeneration. Intravenous enzyme replacement therapy involves a regular infusion, either weekly or every two weeks, lasting up to five hours. Children and adults usually receive ERT through a Home Care Service closely monitored by their specialist LSD centre.

The dose of ERT is based on the weight of the patient making younger children cheaper to treat. It is not unusual for the cost of ERT for a 16 year old to exceed £150,000 per annum!

Clinical Trials for New Therapies in MPS and related Lysosomal Storage Diseases

New therapies require years of pre-clinical work followed by clinical trials before they can be licenced. It can seem forever when you are a patient or the parent of a child or adult with one of these incurable and life-threatening diseases.

Due to the wealth of clinical knowledge of MPS diseases at the eight designated paediatric and adult centres in England almost all phase I/II clinical trials for MPS and Fabry disease have or are taking place in the UK. When it comes to moving on to phase III/IV (pivotal) multi-centre clinical trials English expert centres are major players. In the pivotal clinical trial of Vimizin MAA for MPS IVA, 43 children and adults are on the clinical trial at 7 centres in England out of a total of 171 patients worldwide. The MPS Society plays a crucial role in ensuring that those affected by MPS and Fabry disease are aware of clinical trial opportunities thereby ensuring equitable access. During this reporting period the MPS Society was supporting nearly 80 members on its clinical trial patient access programme. This programme funded by the sponsor of the clinical trial and managed by the MPS Society enables patients to participate in natural history studies and therapeutic clinical trials for their diseases without the burden of booking accommodation, transportation or being significantly out of pocket.

UNIQUE INDIVIDUAL ADVOCACY SERVICE

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

However in 1991, the Society opened its first office and with this the advocacy service we know today was born. The MPS Society provides, through a team of skilled staff, an individual advocacy support service to its members. The service is flexible and a wide range of support is offered on a needs led basis.

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



Support provided by the team

- Telephone Helpline – the Society provides an active listening service, information and support. This includes an out of hours service
- Welfare/disability Benefits – in understanding the complexities and difficulties individuals and families have in completing benefit 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.

Access to MPS / LSD clinical management and therapy

The Society continues to work collaboratively with the lead specialist centres in MPS and LSDs. We embrace an equitable access to all specialist centres and continue to play an important role in promoting the Department of Health guidelines on Advisory Groups for National Specialised Services (AGNSS).

MPS Regional Clinic Programme

MPS regional clinics are held across the UK in Manchester, Belfast, Birmingham, Bristol, London and Newcastle.

The purpose of these clinics is to allow individuals to regularly see a specialist consultant and where possible other medical professionals, hopefully limiting the number of separate appointments individuals and families have to attend.

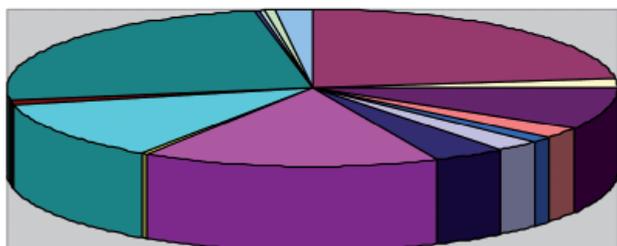
The clinics also allow individuals and families to meet together and to access support from the MPS Advocacy team, who also attend.

Palliative care, pre and post bereavement support

Services for children and young people with life-limiting conditions and who require palliative care vary from locality to locality. Although much has been done to educate service providers, there are areas which are still considerably lacking the knowledge, expertise and resources required to carry out the services needed.

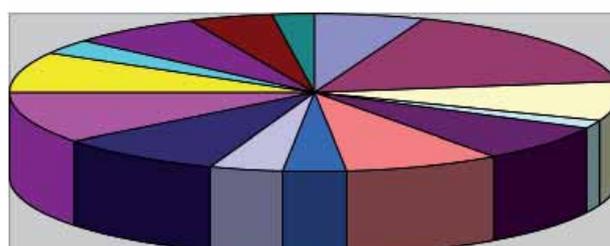
The Society continues to develop and review this service and is in the process of producing some fact sheets in this area of work.

Members Supported by Disease



- | | |
|------------------|--------------------------|
| ■ MLD | ■ ML IV |
| ■ Sanfilippo | ■ Hunter |
| ■ ML III | ■ Geleo Physic Dysplasia |
| ■ MSD | ■ Fucosidosis |
| ■ Morquio | ■ Fabry |
| ■ Maroteaux Lamy | ■ AGU |
| ■ Mannosidosis | ■ Sly |
| ■ ML II | ■ GM I Gangliosidosis |
| ■ Hurler Scheie | ■ Sialic Acid Disease |
| ■ Hurler | ■ Winchester |
| | ■ Scheie |

Support Provided by MPS Advocacy Team



- | | |
|---|---------------------------------------|
| ■ Clinical Management | ■ Befriending Links |
| ■ New Members | ■ Education |
| ■ Disability Benefits | ■ Housing |
| ■ MPS Individual Care Plans | ■ Grants for Individuals |
| ■ Work with Local Authorities & Other Organisations | ■ Clinical Trial Support |
| ■ Palliative Care and Bereavement | ■ Home Visits |
| ■ Transition | ■ Professional Meetings |
| | ■ Presentations/School Talks/Training |

MPS EVENTS

The MPS Society organises a programme of events throughout the year for children, siblings, parents, carers and extended families to come together and share experiences. These events are very successful and generate fantastic feedback from both children and adults.

On behalf of BioMarin, the Society was asked to arrange a **Morquio Focus Group Meeting**, 5 - 6 May 2013 to look at different perspectives of Morquio disease from both an individual's and family viewpoint.



The MPS Society held a **Scottish Get Together** for Scottish families on Sunday 3rd March 2013 at the Hilton Edinburgh Airport, made possible by the kind support of a grant from the Souter Charitable Trust.



On 28-30 June the MPS Society organised the **2013 MPS National Conference** at the Hilton Hotel Coventry. This year's programme was very diverse and included presentations from medical and health professionals and family speakers.



In August 2013 the MPS Society organised a family weekend at **Legoland Windsor Resort** so that MPS families could join us for a weekend of fun-filled activities!



We were delighted to receive funding from Help A Capital Child to take families from the London area on an exciting group excursion to the **Warner Bros. Studio Tour** "The Making of Harry Potter", on Saturday 20th October.



THE MPS CHILDHOOD WOOD

In 1992, the Society was asked to propose an idea to commemorate children who had died from an MPS or related disease. Out of many ideas, the Childhood Wood was born. The following year the MPS Society was given under licence an area of Sherwood Forest to create a wood of saplings which were cloned from the Great Oak.

In February 1993, 150 saplings from ancient Sherwood Oaks were planted by MPS families, supported by Sir Andrew Buchanan, Lord Lieutenant of Nottinghamshire, along with local MPs and representatives from Nottinghamshire County Council.

Since then, each of the oak trees planted annually celebrate the life of a child whose childhood was destroyed by these cruel, degenerative diseases. The trees which were planted in the early years are now branching out and forming a canopy.

Each year, further saplings have been planted by families and friends of children who have lost their lives to MPS or related diseases.

Over the years and working in collaboration with the Forestry Commission, the MPS Society has put in place memory boards and new pathways, all of which are accessible to visitors to the Childhood Wood. Amongst the pathways, there are wooden animals and picnic areas offering a peaceful setting for those who wish to reflect quietly before leaving the Childhood Wood.

The Childhood Wood Planting

On Sunday 13th October 2013 the families of children and who had lost their lives to an MPS or related disease, came together for the annual Childhood Wood remembrance planting, along with some Trustees and dignitaries to represent families that could not attend.

Starting with lunch and an introductory talk at the Clumber Park Hotel, the group then followed the 'White Route' through Sherwood Forest. After a reading by one of the Trustees, the families released their balloons, each with their child's name attached, and planted their saplings. As has previously been the case, each child's name was inscribed on the memory board, along with a short message of remembrance from their family.



ENGAGING WITH VOLUNTEERS

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, 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.

Photo left: Volunteers and children at the theme park during the MPS Conference 2013. We were lucky in having wonderful weather for the whole of the weekend and the outing to Drayton Manor Park on Saturday was a great success, with the volunteers helping all the children, both MPS affected children and their unaffected siblings, to get the very best from their visit. All the children had a wonderful time at the Park and returned to the hotel in the late afternoon with broad smiles on their faces and many exciting memories to take back home. Some of the older MPS affected children and their siblings and young adults, accompanied by volunteers, were taken to a local bowling alley on Saturday evening; this was another welcome opportunity for relaxed activity and for socialising with others living in similar circumstances.

INFORMATION & AWARENESS

MPS gets a new look - rebranding

In this competitive and uncertain economic environment we simply have to reach out to new and existing supporters. It was decided that after 30 years the MPS branding needed modernising, to remain engaging and to stand up to other charities in a competitive sector.

While it was felt that some modernisation was due, we didn't want to lose the historical integrity of the MPS Society logo and it was therefore felt we should retain the blue colour of the MPS logo and the MPS 'hands' due to the high recognition in the field of MPS/rare /Lysosomal Storage Diseases.

In line with other UK charities, we also moved from our existing web and email address that includes the use of .co.uk to .org.uk to reflect our not-for-profit status. Our website is www.mpssociety.org.uk and our email is mps@mpssociety.org.uk.



MPS online

We continue to develop the MPS website and have increasing engagement with a growing audience on social media, particularly facebook and twitter.

This means that we can impart the latest news on advocacy issues, research and treatment updates as soon as they are announced. We launched our online shop so that information resources, merchandise and seasonal goods can now be purchased online.

Information Resources

The Society continues to develop our range of educational materials and information resources to reflect the changing needs of our membership, available in print and online from the MPS website.

We distributed our quarterly MPS magazine to the entire membership free of charge.

During the year the advocacy team gave school talks and information days throughout the UK. They were at the request of the education authorities, in conjunction with individual families, to provide strategies and understanding so the affected child's school care needs can be met.

MPS Awareness

In 2007 the MPS Society announced its first ever MPS Awareness Day as part of an international campaign to raise awareness of MPS and related diseases. On 15 May 2013 the Society was delighted to hold its seventh MPS Awareness Day.



This year we launched our Wear It Blue campaign for MPS Awareness Day. Many of our members and supporters helped us celebrate this day by organising a number of awareness events and activities throughout the UK.



COLLABORATION

LSD Patient Organisation Collaboration

The patient organisations for those affected by LSDs work collaboratively with the umbrella of the 'LSD Patient Organisation Collaborative' to work and lobby on behalf of LSD patients and their families in the UK. The group is made up of representatives from the Association of Glycogen Storage Disease, Batten Disease Family Association, the Gaucher's Association, the Society for Mucopolysaccharide Diseases, the Niemann-Pick Disease Group UK, Save Babies (Krabbe) and CATS (Tay Sachs). As part of this collaboration, the MPS Society has undertaken to jointly promote and share understanding of their diseases to advance standards of care and to enhance the well-being of those affected.

The LSD Collaborative is now a recognised forum and provides the expert patient perspective to NHS England in respect of procurement of Enzyme Replacement Therapy and Home Care and the approval of new therapies coming to the market.

With the announcement of governmental changes to the National Health Service for April 2013 and the demise of National Commissioning for Highly Specialised Services the LSD Patient Collaborative launched a lobbying campaign through its membership to alert Members of Parliament to the likely impact of the changes. Over 400 LSD patients or their parents wrote to their MP resulting in Earl Howe, Minister of Health to issue a letter confirming that patients on high cost therapies, enzyme replacement therapy, will not be affected and this continues to be case.

What was not addressed is MPS patients on clinical trials when their therapy receives marketing approval and newly diagnosed patients meeting the criteria for treatment with ERT.

MPS International Network

We are members of the MPS International Network which is the official body of the patient associations representing MPS Societies at a European and global level. We are also members of the Fabry International Network the equivalent global body for Fabry disease. These bodies act as an independent forum to promote the well-being of those affected by MPS, Fabry and related lysosomal storage diseases through the best practices of clinical diagnosis, management and treatment. They promote public and professional awareness of MPS and related diseases, identify research priorities and potential collaborations where appropriate, working in partnership with the academic community and pharmaceutical industry.

The MPS International Network meets at least annually and in 2013 had a two day meeting preceding the Japanese MPS Conference held in Kansai in Japan.

FINANCIAL REVIEW

During the first eight months of the financial year the MPS Society continued to provide a Clinical Trial Patient Access Programme for members participating in the MPSII, MPSIIIA and MPSIVA clinical trials. In response to requests from the pharmaceutical industry and trustees recognising the commercial potential of our Clinical Trial Patient Access Programme the trustees agreed to create 'MPS Commercial' as a trading subsidiary wholly owned by the MPS Society for the purpose of growing this programme into a business. From September to December 2013 the management of MPS clinical trials and their pass through costs gradually transferred over to 'MPS Commercial'.

The total Income for the year ending 31 December 2013 was £1,537,658 compared with expenditure of £1,635,096 resulting in a deficit of £97,438. This shortfall has arisen as a result of timing differences on the receipt of outstanding sums due after 31 December 2013. All outstanding sums were received by 31 January 2014.

The trustees continue to work closely with the Senior Management Team to ensure full cost recovery in all areas of work.

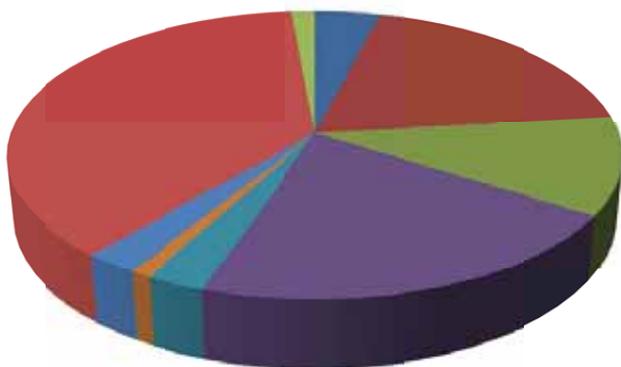
Reserves policy

The trustees have a comprehensive reserves policy, which is reviewed annually to ensure that unrestricted and undesignated funds are maintained at a level that ensures the running costs of the MPS Society can be sustained year on year.

In summary the trustees have considered advice and have agreed that the equity from MPS House is considered as a part of MPS' reserves. The trustees recognise that it may take a period of time for the equity held in the property to be realised through the sale of MPS House. The trustees have considered what funds would be immediately available and what funds would not be immediately available for the costs to be met should MPS be in immediate financial difficulty. The trustees regularly review the buoyancy of the market in the area of MPS House in order to understand the potential for realising these funds. In this financial year the trustees have set an objective to start securing a modest unrestricted reserve and continue to build this over the coming years until the charity has liquid equity to cover 6 months running costs

Where the money came from

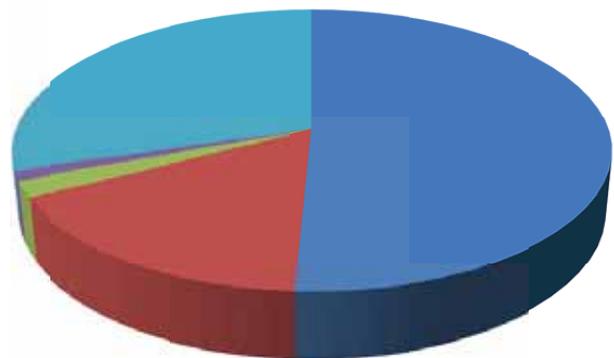
The MPS Society's income was £1,537,658 and was generated in the following areas:



- Donations and Legacies
- Research Grants
- Fundraising
- Support Service
- Investment Income
- Magazine/Info Resources
- Support Events
- Clinical Studies Trials
- Other

Where the money was spent

The MPS Society's expenditure was £1,635,096 and was generated in the following areas:



- Charitable Activities
- MPS Research and Support Grants
- Governance
- Cost of Generating Funds
- Clinical Trials

FUNDRAISING FOR THE MPS SOCIETY

We recognise and appreciate the enormous effort that goes into fundraising and would therefore like to convey our appreciation to all our members, donors and fundraisers for their support to the Society over the year. 2013 saw us launching our 'Wear it Blue' and 'Wear It Wicked' fundraising schemes, designed to be used in conjunction with, but not limited to, MPS Awareness Day and Halloween respectively. These schemes have proved to be successful in promoting fundraising ideas and have helped to the charity's profile and increase awareness. Schools, universities and businesses have utilized these schemes successfully. Fundraising that our supporters have taken part in over the past year have, as always, been diverse and imaginative. Below is a snapshot of some of these events...

Early in 2013 Nick Travers raised £400 in memory of his friend's brother who suffered from Hunter disease. The money was raised from donations and from the proceeds of a gig by his band at the o2 arena in Sheffield.



In aid of MPS Awareness Day in May 2013, Arriva buses in Aylesbury held a Wear It Blue fancy dress day for their staff. Not only did staff give donations, but they also had collection boxes on their buses and advertised with posters and boards. A local newspaper and radio station covered this event and staff even handed out MPS leaflets and helped to raise awareness. They raised £1800.



In January 2013, the Berkshire, Buckinghamshire and Oxfordshire Junior Lawyers Division hosted a charity quiz night in Reading. Twenty-two teams representing law firms across the three counties came together and managed to raise £1000 for the MPS Society.



Sophie Longley ran the Virgin London Marathon 2013 raising £1300 for the MPS Society. She trained in all weathers for over 3 months, with the motivation that she would be helping others like her sister Faye who suffers with Morquio.



In August 2013, the village of Frimley Green held a Wicked Walkabout for MPS after discovering that a local boy had Hunters. The fundraiser began with a 3-legged race and ended with a ball at the local pub, which boasted a Dixieland jazz band and food. The whole community came together for this wonderful event and raised £7500.



CORPORATE SUPPORT, TRUSTS & GRANTS

Corporate Giving

Our biggest group of corporate supporters are the pharmaceutical companies which are working in the fields of research and therapeutic treatments for MPS and related diseases. We value their contributions but are careful to maintain our independent position and acceptance of a donation does not imply endorsement by the MPS Society of the company's products.

We also have a number of businesses and companies which fundraise regularly for us because a member of staff has a relative with MPS, or knows someone who is affected. Their efforts on our behalf are much appreciated.

We are keen to engage with any companies which are interested in working with us in the following ways: payroll giving, matched funding of staff fundraising efforts, magazine sponsorship, 'in kind' donations of goods or services, and recruitment of volunteers.

Trusts and Grants

As the MPS Society continues to improve and expand its services in response to members' needs, grant-making bodies are playing an increasingly important role in providing the funds to make this happen and giving us an increasingly important source of income.

We make carefully-targetted applications to suitable trusts and foundations for specific areas of our work including our support service, literature and family events to name a few, 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. Grants for medical research are sought whenever we need funds for our ground-breaking programme of clinical studies which are leading to new treatments for MPS and related diseases. 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 they 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 provide regular reports on whatever aspect of our work they choose to support.

The MPS Society would like to thank all MPS members, families and subscribers, corporate donors and charitable trusts for their invaluable support this year. Some of our benefactors are included here:

The Rothschild Foundation
The Enkalon Foundation
The Fitton Trust
The Felicity Wilde Charitable Trust
The Gosling Foundation
The Clover Trust
The City Bridge Trust
Department of Health - Social Services, Northern Ireland
Baron Davenport's Charity
Summerfield Charitable Trust
BBC Children in Need
The Joseph Strong Frazer Trust
The Bernard Sunley Charitable Foundation
The Shauna Gosling Trust
Lloyds Banking Group Community Fund Award
Chiltern District Council
The Christopher and Elspeth Thomas Charitable Trust
The Reuben Foundation
Peter Harrison Foundation
The Eveson Charitable Trust
The Albert Hunt Trust
Sir George Martin Trust
Goldsmiths Company Charity
The Neighbourly Charitable Trust
James T Howat Charitable Trust
Associated British Ports - South Wales
Adamson Trust
Sovereign Healthcare Charitable Trust
Shire Human Genetic Therapies
Genzyme
BioMarin
Arriva Buses
Norton Rose LLP
Asda Eastbourne
GE Power Conversion

TIMELINE OF THE MPS SOCIETY

1982

The MPS Society is founded. The first meeting of the MPS Management Committee is held on 13 October. The first MPS newsletter is dispatched on 31 October to 70 families and 12 hospitals.

1983

The Society is granted trusteeship and registration as a UK national charity in May. The first 40 founding member families come together for the first weekend conference in Birmingham in September.

1984

The Society produces its first formal annual report and statement of accounts.

1985

The MPS Society first starts funding basic research. The MPS Society facilitates the first cervical infusion for Morquio disease in England using the halo method and bone grafts from the legs. The surgery is carried out at University College Hospital involving British and American doctors. The MPS Society receives a grant to establish the first MPS registry collecting incidence data and epidemiological data for the UK and Europe.

1986

Whilst the newsletter continues to be produced by a member family in a domestic environment, the first tentative embrace of new technology is made by the production of the newsletter on a home computer linked to the printer purchased by the Society in 1985.

1987

At the Society's annual family weekend conference at the Posthouse Hotel, Heathrow, bloods from over 50 MPS II Hunter families were taken to enable research being conducted by Prof John Hopwood from the Women's and Children's Hospital, Adelaide, Australia to be carried out.

1988

The MPS Society announces four year funding of Dr Ed Wraith's post as Consultant Paediatrician specialising in MPS at Royal Manchester Children's Hospital (RMCH). In May the first MPS family day in the Republic of Ireland is held.

1989

The first disease booklets are published by the MPS Society. Prof John Hopwood isolates the gene for MPS II Hunter disease making the path clear for potential treatment.

1990

The first international symposium on MPS diseases is hosted by the MPS Society at the University of Manchester. It brings together over 150 families and 300 professionals to share experiences from all parts of the world.

1992

The Society celebrates its tenth anniversary year with a Reception at the House of Commons in June.

1993

Inaugural planting takes place of 150 saplings from the ancient Sherwood Oak planted by MPS families. The Rt Hon Michael Howard, then Secretary of State for the Environment, plants the first oak in memory of Simon Lavery. Christine Lavery is appointed by Trustees to the post of Chief Executive.

1995

The number of newly diagnosed families seeking support from the MPS Society doubles.

1997

Following three year funding to the RMCH and Christie Hospital Manchester the first gene therapy trial for MPS I Hurler disease is carried out at RMCH.

1998

The MPS Office moves to Woodside Road, Amersham from Hill Avenue. In December the Rt Hon Gordon Brown MP as Chancellor of the Exchequer hosts a children's party at No. 11 Downing Street.

1999

Significant research in ERT has led to clinical trials for Fabry and MPS I disease. The MPS Society receives its largest grant yet to fund the MPS advocacy service for the coming three years.

2000

The MPS Society celebrates its 18th birthday.

2001

Enzyme Replacement Therapy is approved in Europe for Fabry and the Fabry Patient Support Group is amalgamated with the MPS Society.

2002

Christine Lavery is awarded the MBE for services to metabolic diseases. The MPS Society jointly hosts with the French patient association, VML, the International Symposium on Mucopolysaccharide Diseases in Paris, France.

2003

The Society celebrates the start of its 21st birthday year with a tea party at the House of Commons. Enzyme Replacement Therapy for MPS I Hurler Scheie and Scheie disease is launched.

2004

The MPS celebrates the close of its 21st anniversary celebrations with a Tea Party at Downing Street. Lysosomal storage disorders including all MPS and related diseases receive National Specialist Commissioning designation by the Minister of Health. No more “post-code prescribing” or legal challenges in England.

2005

Friends of MPS is launched. Launch of Naglazyme ERT for MPS VI. The MPS Society awards its largest programme grant in its history, £308,000, to fund a research fellow at the University of Manchester to develop the MPS Stem Cell Group working towards therapeutic outcomes for MPS.

2006

The MPS Society moves into MPS House. Elaprase ERT for MPS II is launched.

2007

The MPS Society celebrates its 25th anniversary. The first MPS Awareness Day is launched on 15 May. The Society achieves NHS funded ERT for three children in Scotland.

2008

The MPS Society hosted a 2 day international expert meeting on MPS IVA, Morquio disease.

2009

A Phase I/II clinical trial for ERT in MPS IVA disease is started at three specialist centres in England. The MPS Society becomes a charity registered in Scotland.

2010

A Phase I/II Intrathecal Enzyme replacement Therapy Clinical Trial is started at the Royal Manchester Children's

Hospital. The MPS Society hosted a 2 day international expert meeting on MPS III, Sanfilippo disease. An extension clinical trial with patients from the MPS IVA Phase I/II MPS IVA Clinical Trial started in September 2010.

2011

A Phase I/II intrathecal Enzyme replacement Therapy Clinical trial was started at the Birmingham Children's Hospital. The MPS IVA phase III/IV continues with adults over the age of 18 years being admitted. The MPS Society becomes a company limited by guarantee in August.

2012

In May 2012 the MPS Society celebrated its 30th Anniversary year with a reception at the Palace of Westminster hosted by the Rt. Hon. Jeremy Hunt MP currently Secretary of State for Health, and attended by members of the Society, representative from the LSD medical and nursing fraternity, the pharmaceutical industry as well as supporters, volunteers, donors and fundraisers. 2012 saw over 30 UK children and adults with MPSIVA recruited to a clinical trial for Morquio disease at seven LSD expert clinical centres across England. With over 170 patients worldwide recruited this is the biggest clinical trial yet for an ultra-orphan disease.

2013

In October 2013 the MPS Society moved its Fundraising and Communications teams into the newly expanded ground floor of MPS House. 41 years after Dr William Sly first described MPS VII, the first MPS VII patient received enzyme replacement therapy and a Phase I/II clinical trial at the Manchester Children's Hospital.

STATEMENT OF TRUSTEE RESPONSIBILITIES

The trustees (who are also the directors of Society for Mucopolysaccharide Diseases for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

select suitable accounting policies and then apply them consistently;
observe the methods and principles in the Charity SORP;
make judgements and estimates that are reasonable and prudent;
prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

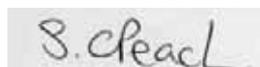
In so far as the trustees are aware:
there is no relevant audit information of which the charitable company's auditors are unaware; and the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website.

Auditors

The auditors, McLintocks Partnership Limited, will be proposed for re-appointment at the forthcoming Annual General Meeting.

ON BEHALF OF THE BOARD:



Mrs S Peach - Trustee
28 March 2014

We have audited the financial statements of Society for Mucopolysaccharide Diseases for the year ended 31 December 2013 on pages fourteen to twenty-eight. The financial reporting framework that has been applied in their preparation is applicable law and the Financial Reporting Standard for Smaller Entities (effective April 2008) (United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities).

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, and to the charitable company's trustees, as a body, in accordance with Section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members and trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members and trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of trustees and auditors

As explained more fully in the Statement of Trustees Responsibilities set out on page ten, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

We have been appointed as auditors under Section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Report of the Trustees to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

Opinion on financial statements

In our opinion the financial statements:

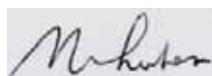
- give a true and fair view of the state of the charitable company's affairs as at 31 December 2013 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Opinion on other matter prescribed by the Companies Act 2006

In our opinion the information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements.

Matters on which we are required to report by exception
We have nothing to report in respect of the following matters where the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) requires us to report to you if, in our opinion:

- the charitable company has not kept proper and adequate accounting records or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Report of the Trustees.



Michael Caputo (Senior Statutory Auditor)
for and on behalf of McLintocks Partnership Limited
Chartered Accountants
Registered Auditors
Eligible to act as an auditor in terms of Section 1212 of the Companies Act 2006
2 Hilliards Court
Chester Business Park
Chester
Cheshire
CH4 9PX

28 March 2014

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

**STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
for the Year Ended 31 December 2013**

				Year Ended 31.12.13	Period 2.8.11 to 31.12.12
	Notes	Unrestricted funds £	Restricted funds £	Total funds £	Total funds £
INCOMING RESOURCES					
Incoming resources from generated funds					
Voluntary income	2	60,426	-	60,426	62,489
Activities for generating funds	3	166,335	1,270	167,605	171,775
Investment income	4	41,200	-	41,200	4,682
Incoming resources from charitable activities					
Research grants	5	-	295,669	295,669	152,080
Clinical studies trial costs		-	575,366	575,366	765,510
Conferences		-	72,449	72,449	20,038
Family support special events		-	38,184	38,184	71,282
Overseas co-operation		-	9,560	9,560	9,684
Childhood Wood		-	1,456	1,456	1,554
Magazine and resource materials		14,287	-	14,287	6,445
Support services		45,680	194,468	240,148	360,323
Other incoming resources	6	<u>21,308</u>	<u>-</u>	<u>21,308</u>	<u>1,653,641</u>
Total incoming resources		349,236	1,188,422	1,537,658	3,279,503

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

**STATEMENT OF FINANCIAL ACTIVITIES - CONTINUED
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 DECEMBER 2013**

	Notes	Unrestricted funds £	Restricted funds £	Year Ended 31.12.13 Total funds £	Period 2.8.11 to 31.12.12 Total funds £
RESOURCES EXPENDED					
Costs of generating funds					
Costs of generating voluntary income	7	<u>18,346</u>	<u>-</u>	<u>18,346</u>	<u>70,797</u>
Charitable activities					
	8				
Research grants		-	270,655	270,655	277,578
Clinical studies trial costs		-	482,889	482,889	739,857
Conferences		-	113,548	113,548	15,462
Family support special events		-	22,825	22,825	57,660
Overseas co-operation		-	17,507	17,507	13,754
Donations		-	29,055	29,055	2,740
Childhood Wood		-	1,565	1,565	2,069
Magazine and resource materials		18,199	-	18,199	18,445
Support services		61,427	310,705	372,132	393,440
Office support costs		-	111,234	111,234	38,445
MPS Financial Assistance scheme		108	-	108	-
Governance costs	10	33,509	-	33,509	21,235
Other resources expended	11	<u>157,429</u>	<u>(13,905)</u>	<u>143,524</u>	<u>137,282</u>
Total resources expended		<u>289,018</u>	<u>1,346,078</u>	<u>1,635,096</u>	<u>1,788,764</u>
NET INCOME/(EXPENDITURE) FOR THE YEAR					
		60,218	(157,656)	(97,438)	1,490,739
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>478,824</u>	<u>1,011,915</u>	<u>1,490,739</u>	<u>-</u>
TOTAL FUNDS CARRIED FORWARD		<u><u>539,042</u></u>	<u><u>854,259</u></u>	<u><u>1,393,301</u></u>	<u><u>1,490,739</u></u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

BALANCE SHEET At 31 December 2013

	Notes	2013 £	2012 £
FIXED ASSETS			
Tangible assets	15	1,280,517	757,701
Investments	16	<u>6,100</u>	<u>6,100</u>
		1,286,617	763,801
CURRENT ASSETS			
Debtors	17	126,379	139,117
Investments	18	25,000	25,000
Cash at bank and in hand		<u>679,869</u>	<u>779,385</u>
		831,248	943,502
CREDITORS			
Amounts falling due within one year	19	(51,192)	(70,751)
		<u> </u>	<u> </u>
NET CURRENT ASSETS/(LIABILITIES)		<u>780,056</u>	<u>872,751</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		2,066,673	1,636,552
CREDITORS			
Amounts falling due after more than one year	20	(673,372)	(145,813)
		<u> </u>	<u> </u>
NET ASSETS		<u>1,393,301</u>	<u>1,490,739</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

BALANCE SHEET - CONTINUED

At 31 December 2013

	Notes	2013	2012
	24	£	£
FUNDS			
Unrestricted funds:			
General fund		539,042	478,824
Restricted funds:			
Other grants and donations		465,057	546,526
Research		<u>389,202</u>	<u>465,389</u>
		<u>854,259</u>	<u>1,011,915</u>
TOTAL FUNDS		<u>1,393,301</u>	<u>1,490,739</u>

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies and with the Financial Reporting Standard for Smaller Entities (effective April 2008).

The financial statements were approved by the Board of Trustees on 28 March 2014 and were signed on its behalf by:



.....
Mrs S Peach -Trustee

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

Notes to the Financial Statements for the Year Ended 31 December 2013

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements have been prepared under the Companies Act 2006 and in accordance with applicable accounting standards, the Charities Act 2011 and the Statement of Recommended Practice on Accounting and Reporting by Charities: the Charities SORP 2005 (Revised May 2008). The financial statements have been prepared under the historical cost convention as modified by the adoption of market value for investments held as fixed assets.

Accounting convention

The financial statements have been prepared under the historical cost convention, with the exception of investments which are included at market value, and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008), the Companies Act 2006 and the requirements of the Statement of Recommended Practice, Accounting and Reporting by Charities.

Exemption from preparing a cash flow statement

Exemption has been taken from preparing a cash flow statement on the grounds that the charitable company qualifies as a small charitable company.

Voluntary income

Voluntary income, which is received by way of restricted and unrestricted donations, gifts, legacies and special fund raising events, is included in the SOFA in full as soon as it is received.

Grants receivable

Grants receivable are included in the SOFA in the year in which they relate. Grants received relating to future projects are dealt with as grants received in advance and are carried forward as a creditor in the balance sheet at the year end.

Donations in Kind

The MPS Society appreciates the level of active support it receives from volunteers who spend a considerable amount of time supporting our objectives, fund raising and administering our activities. Without this voluntary support the MPS Society would incur considerable additional expense. It is not considered practicable for the purposes of these financial statements to put a monetary value on this support; the trustees can but offer their heartfelt gratitude to all its volunteers and supporters. Gifts and intangible income that can be quantified are recognised in the SOFA.

Investment Income

Investment income comprises gilt, building society and bank interest receivable. This is included in the income and expenditure account in the year in which it is received.

Legacies

Legacy income is recognised when it is certain to be received and can be measured with sufficient reliability.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED **for the Year Ended 31 December 2013**

1. ACCOUNTING POLICIES - continued

Resources expended

Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources. The irrecoverable VAT is included with the item of expense to which it relates. Grants payable are included in the SOFA in the year in which they relate. Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

Allocation and apportionment of costs

75% of all office overheads are allocated to charitable expenditure to allow for full cost recovery on all direct support costs. Grants awarded for research attract full costs recovery, 5% on grants under £100,000 and 10% on grants over £100,000 and over. All restricted MPS fundraising received for research attracts 20% full cost recovery.

Tangible fixed assets

Expenditure on fixed assets costing over £250 is capitalised. Expenditure on property and property improvement is depreciated on a straight-line basis over 50 years. Expenditure on computers and office furniture is depreciated on a straight-line basis over 3 years. Investment assets are included at market value. Investment assets are valued at open market value at the date of donation and subsequently revalued to open market value at least every 5 years.

Taxation

The Society as a registered charity is not considered to be liable to taxation. VAT incurred is not recoverable and is included in relevant expenditure.

Fund accounting

The financial statements distinguish between restricted and unrestricted funds. The former is received from donors and is subject to restrictions on the purposes for which they may be used. Unrestricted funds are those where there are no externally imposed restrictions. They include those funds freely available to the charity for expenditure or appropriation to reserves for internally designated purposes, such as research programmes. The designated fund represents amounts put aside for capital projects.

Pension costs and other post-retirement benefits

The Society contributes 5% of gross salary to individual employees' pension schemes. Contributions payable to individual pension schemes are charged to the SOFA in the period to which they relate.

Operating leases

Rents payable under operating leases are charged to the SOFA on a straight-line basis over the period of the lease.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2013

2. VOLUNTARY INCOME

	Year Ended 31.12.13 £	Period 2.8.11 to 31.12.12 £
Donations	60,426	42,692
Legacies	<u>-</u>	<u>19,797</u>
	<u>60,426</u>	<u>62,489</u>

3. ACTIVITIES FOR GENERATING FUNDS

	Year Ended 31.12.13 £	Period 2.8.11 to 31.12.12 £
Fundraising events	<u>167,605</u>	<u>171,775</u>

4. INVESTMENT INCOME

	Year Ended 31.12.13 £	Period 2.8.11 to 31.12.12 £
Rents received	38,477	-
Deposit account interest	2,223	3,682
Interest on Treasury Stock	<u>500</u>	<u>1,000</u>
	<u>41,200</u>	<u>4,682</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2013

5. INCOMING RESOURCES FROM CHARITABLE ACTIVITIES

	£
Research and support grants	295,669
Clinical Studies trial costs	575,366
Conferences	72,449
Family support special events	38,184
Overseas Co-operation	9,560
Childhood Wood	1,456
Magazine and resource materials	14,287
Support services	<u>240,148</u>
	<u><u>1,247,119</u></u>

6. OTHER INCOMING RESOURCES

	Year Ended 31.12.13	Period 2.8.11 to 31.12.12
	£	£
Sundry income	21,308	5,002
Funds transferred from unincorporated charity	<u>-</u>	<u>1,648,639</u>
	<u><u>21,308</u></u>	<u><u>1,653,641</u></u>

7. COSTS OF GENERATING VOLUNTARY INCOME

	Year Ended 31.12.13	Period 2.8.11 to 31.12.12
	£	£
Staff costs	-	51,946
Fundraising expenses	<u>18,346</u>	<u>18,851</u>
	<u><u>18,346</u></u>	<u><u>70,797</u></u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2013

8. CHARITABLE ACTIVITIES COSTS

	Direct costs	Grant funding of activities (See note 9)	Totals
	£	£	£
Clinical studies trial costs	482,889	-	482,889
Conferences	113,548	-	113,548
Family support special events	22,825	-	22,825
Overseas co-operation	17,507	-	17,507
Grants and donations	29,055	270,655	299,710
Childhood Wood	1,565	-	1,565
Magazine and resource materials	18,199	-	18,199
Support services	372,132	-	372,132
Office support costs	111,234	-	111,234
MPS Financial Assistance scheme	108	-	108
	<u>1,169,062</u>	<u>270,655</u>	<u>1,439,717</u>

9. GRANTS PAYABLE

	Year Ended 31.12.13	Period 2.8.11 to 31.12.12
	£	£
Research grants	270,655	277,578
	<u>270,655</u>	<u>277,578</u>

Grants payable to institutions

	£
King's College, London	26,352
University of Manchester	231,290
Other	<u>13,013</u>
	<u>270,655</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2013

10. GOVERNANCE COSTS

	Year Ended 31.12.13 £	Period 2.8.11 to 31.12.12 £
Legal fees	20,042	7,864
Auditors' remuneration	2,650	2,820
Management committee expenses	<u>10,817</u>	<u>10,551</u>
	<u>33,509</u>	<u>21,235</u>

11. OTHER RESOURCES EXPENDED

	Year Ended 31.12.13 £	Period 2.8.11 to 31.12.12 £
Staff costs	37,049	48,888
Recruitment and advertising	7,133	11,444
Office running costs	60,644	50,269
Interest payable and bank charges	7,949	6,616
Support costs - depreciation	<u>30,749</u>	<u>20,065</u>
	<u>143,524</u>	<u>137,282</u>

12. NET INCOMING/(OUTGOING) RESOURCES

Net resources are stated after charging:

	Year Ended 31.12.13 £	Period 2.8.11 to 31.12.12 £
Auditors' remuneration	2,650	2,820
Depreciation - owned assets	<u>30,749</u>	<u>20,065</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED for the Year Ended 31 December 2013

13. TRUSTEES' REMUNERATION AND BENEFITS

No trustee or related person received any remuneration from the Society other than in respect of services as an employee of the entity.

Trustees' expenses

All trustees are reimbursed for their expenses which are necessarily incurred in attending management committee meetings and in performing their duties as trustees. The Chief Executive of the Society approves the reimbursement of such expenses.

14. STAFF COSTS

	2013	2012
	£	£
Wages & salaries	396,144	406,330
Social security costs	37,582	40,051
Other pension costs	<u>15,958</u>	<u>16,466</u>
	<u>449,684</u>	<u>462,847</u>

No employee earned £60,000 p.a. or more.

The average monthly number of employees during the year, calculated on the basis of full time equivalents was as follows:

	2013	2012
	No.	No.
Director	1	1
Administration	2	2
Advice, information and support services	<u>10</u>	<u>9</u>
	<u>13</u>	<u>12</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2013

15. TANGIBLE FIXED ASSETS

	Land and buildings £	Fixtures, fittings and equipment £	Totals £
COST			
At 1 January 2013	875,524	170,218	1,045,742
Additions	<u>553,565</u>	<u>-</u>	<u>553,565</u>
At 31 December 2013	<u>1,429,089</u>	<u>170,218</u>	<u>1,599,307</u>
DEPRECIATION			
At 1 January 2013	121,837	166,204	288,041
Charge for year	<u>28,581</u>	<u>2,168</u>	<u>30,749</u>
At 31 December 2013	<u>150,418</u>	<u>168,372</u>	<u>318,790</u>
NET BOOK VALUE			
At 31 December 2013	<u>1,278,671</u>	<u>1,846</u>	<u>1,280,517</u>
At 31 December 2012	<u>753,687</u>	<u>4,014</u>	<u>757,701</u>

16. FIXED ASSET INVESTMENTS

	Year Ended 31.12.13 £	Period 2.8.11 to 31.12.12 £
Other	<u>6,100</u>	<u>6,100</u>

There were no investment assets outside the UK.

Investments (neither listed nor unlisted) were as follows:

	Year Ended 31.12.13 £	Period 2.8.11 to 31.12.12 £
Donated jewellery - transfers in from unincorporated entity	<u>6,100</u>	<u>6,100</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2013

17. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2013	2012
	£	£
Other debtors	<u>126,379</u>	<u>139,117</u>

18. CURRENT ASSET INVESTMENTS

	2013	2012
	£	£
4% Consolidated Treasury Stock (valued at cost)	<u>25,000</u>	<u>25,000</u>

19. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2013	2012
	£	£
Bank loans and overdrafts	47,500	40,000
Taxation and social security	-	8,718
Other creditors	<u>3,692</u>	<u>22,033</u>
	<u>51,192</u>	<u>70,751</u>

20. CREDITORS: AMOUNTS FALLING DUE AFTER MORE THAN ONE YEAR

	2013	2012
	£	£
Bank loans	<u>673,372</u>	<u>145,813</u>

21. OPERATING LEASE COMMITMENTS

The following operating lease payments are committed to be paid within one year:

	2013	2012
	£	£
Expiring: Between one and five years	<u>1,356</u>	<u>1,356</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2013

22. SECURED DEBTS

The following secured debts are included within creditors:

	2013 £	2012 £
Bank loans	<u>720,872</u>	<u>185,813</u>

Barclays Bank PLC have legal charges over the two properties Nash House and MPS House.

23. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted funds £	Restricted funds £	2013 Total funds £	2012 Total funds £
Fixed assets	1,280,517	-	1,280,517	757,701
Investments	-	6,100	6,100	6,100
Current assets	(20,603)	851,851	831,248	943,502
Current liabilities	(47,500)	(3,692)	(51,192)	(70,751)
Long term liabilities	<u>(673,372)</u>	<u>-</u>	<u>(673,372)</u>	<u>(145,813)</u>
	<u>539,042</u>	<u>854,259</u>	<u>1,393,301</u>	<u>1,490,739</u>

24. MOVEMENT IN FUNDS

	At 1.1.13 £	Net movement in funds £	At 31.12.13 £
Unrestricted funds			
General fund	478,824	60,218	539,042
Restricted funds			
Other grants and donations	546,526	(81,469)	465,057
Research	<u>465,389</u>	<u>(76,187)</u>	<u>389,202</u>
	1,011,915	(157,656)	854,259
TOTAL FUNDS	<u>1,490,739</u>	<u>(97,438)</u>	<u>1,393,301</u>

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

NOTES TO THE FINANCIAL STATEMENTS - CONTINUED
for the Year Ended 31 December 2013

24. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	349,236	(289,018)	60,218
Restricted funds			
Other grants and donations	993,954	(1,075,423)	(81,469)
Research	<u>194,468</u>	<u>(270,655)</u>	<u>(76,187)</u>
	1,188,422	(1,346,078)	(157,656)
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>1,537,658</u>	<u>(1,635,096)</u>	<u>(97,438)</u>

25. ULTIMATE CONTROLLING PARTY

The charity is controlled by the trustees.

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

DETAILED STATEMENT OF FINANCIAL ACTIVITIES for the Year Ended 31 December 2013

	Year Ended 31.12.13 £	Period 2.8.11 to 31.12.12 £
INCOMING RESOURCES		
Voluntary income		
Donations	60,426	42,692
Legacies	-	19,797
	<u>60,426</u>	<u>62,489</u>
Activities for generating funds		
Fundraising events	167,605	171,775
Investment income		
Rents received	38,477	-
Deposit account interest	2,223	3,682
Interest on Treasury Stock	500	1,000
	<u>41,200</u>	<u>4,682</u>
Incoming resources from charitable activities		
Research grants	295,669	152,080
Support services	240,148	360,323
Overseas co-operation	9,560	9,684
Clinical studies trial support	575,366	765,510
Conferences	72,449	20,038
Childhood Wood	1,456	1,554
Family support of special events	38,184	71,282
Resource material and magazine	14,287	6,445
	<u>1,247,119</u>	<u>1,386,916</u>
Other incoming resources		
Sundry income	21,308	5,002
Funds transferred from unincorporated charity	-	1,648,639
	<u>21,308</u>	<u>1,653,641</u>
Total incoming resources	1,537,658	3,279,503

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

DETAILED STATEMENT OF FINANCIAL ACTIVITIES for the Year Ended 31 December 2013

	Year Ended 31.12.13 £	Period 2.8.11 to 31.12.12 £
RESOURCES EXPENDED		
Costs of generating voluntary income		
Wages	-	51,946
Fundraising expenses	<u>18,346</u>	<u>18,851</u>
	18,346	70,797
Charitable activities		
Clinical studies trial costs	482,889	739,857
Conference costs	113,548	15,462
Family Support special events	22,825	57,660
Overseas co-operation	17,507	13,754
Grants and donations	29,055	2,740
Childhood Wood	1,565	2,069
Magazine & resource materials	18,199	18,445
Support services	372,132	393,440
Office support costs	111,234	38,445
MPS financial assistance scheme	108	-
Research and support grants	<u>270,655</u>	<u>277,578</u>
	1,439,717	1,559,450
Governance costs		
Legal fees	20,042	7,864
Auditors' remuneration	2,650	2,820
Management committee expenses	<u>10,817</u>	<u>10,551</u>
	33,509	21,235
Other resources expended		
Wages	34,006	45,068
Pensions	3,043	3,820
Recruitment and advertising	7,133	11,444
Office running costs	60,644	50,269
Mortgage interest	5,436	4,397
Bank charges	<u>2,513</u>	<u>2,219</u>
	112,775	117,217

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
for the Year Ended 31 December 2013

	Year Ended 31.12.13 £	Period 2.8.11 to 31.12.12 £
Depreciation		
Freehold property	27,551	16,480
Improvements to property	1,030	1,030
Computer equipment	<u>2,168</u>	<u>2,555</u>
	<u>30,749</u>	<u>20,065</u>
Total resources expended	1,635,096	1,788,764
	<hr/>	<hr/>
Net (expenditure)/income	<u>(97,438)</u>	<u>1,490,739</u>