Society for Mucopolysaccharide Diseases

ANNUAL REVIEW & ACCOUNTS 2009

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CHARITY INFORMATION

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Wilma Robins	(Vice-Chair)
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Sue Peach	
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TRUSTEES REPORT

The Trustees present their report and financial statements for the year ended 31st October 2009.

Welcome to the Society for Mucopolysaccharide Diseases Annual Report and Accounts for year ending 31 October 2009. The past year has, for the MPS Society and its Board of Trustees, proved to be a mixture of unexpected challenges combined with the rewards of achieving our aims 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 a diverse group of 1200 affected children and adults and their families. The men, women and children with Fabry or Morquio disease have completely different support needs to those with Sanfilippo disease or Mucolipidosis. In Fabry disease it is not unusual to have three or four generations of one family suffering from the condition which, if untreated, leads to progressive renal failure, cardiac involvement and susceptibility to life-threatening TIAs and strokes. Since 2001, when Enzyme Replacement Therapy (ERT) was approved in Europe, our 250 Fabry members have been able to look forward to their disease stabilising and an improved quality of life. Bone Marrow Transplant (BMT) and Cord Blood Transplant has also provided an imperfect treatment option forMPS I, Hurler disease whilst ERT has also changed the course of disease for those suffering from MPS I, Hurler Scheie and Scheie, MPS II, Hunter, attenuated form and MPS VI, Maroteaux Lamy.

This is all good news but where does that leave our members affected by the other seventeen diseases? In 2009 a Phase I/II clinical trial for ERT in MPS IVA, Morquio disease started at three specialist centres in England. The safety trial will continue into 2010 when it is hoped a Phase III/IV clinical trial will prove efficacy. The other sixteen diseases all present huge difficulties for the patients who bear them, the doctors who manage the clinical manifestations, and the research scientists looking for potential breakthroughs. Many of these diseases are associated with progressive neurodegenerative brain disease where the only treatment is palliative. In 2008, funded by the Roald Dahl Foundation, our families were able to rely on the support of a dedicated palliative care and bereavement advocacy worker. Whilst 40 to 50 babies and young children will be diagnosed with MPS each year, another 20 or so will lose their life to MPS. Supporting our 300 bereaved families, many of whom have stayed with the MPS Society for one or two decades, is also important. Families have the opportunity to plant a tree in the Childhood Wood following the death of a loved one with an MPS or Related Disease and each year will be invited to a Remembrance Day in the Childhood Wood.

Support activities and events are an important part of the MPS calendar and included a week at Boreatton Park for MPS siblings in August, a London Zoo family day in July, a weekend in London for MPS young adult sufferers, and a family day at the Hilton Hotel Templepatrick in Belfast. Every two years the MPS Society holds a Weekend Family Conference. In June 2009 we held our biggest one yet. It was so big with over 350 adults and 100 children attending that the gala dinner had to be held in a marquee in the grounds of the Hilton Hotel, Northampton.

The Society is a respected key player in supporting the development of new strategies to clinically manage affected adults and children. During 2009 the Chief Executive Officer and Senior Advocacy Officer have led discussion on the transition of children from paediatric to adult clinical care. Many adult clinics are far from suited to the needs of young adults with no self-help skills, no mobility, no communication and doubly incontinent, all the result of MPS neurodegenerative brain disease. Equally, we have a number of wholly independent young adults less than one metre tall, wheelchair dependent, not needing a carer but unable to be accommodated with dignity when being seen in an adult clinical setting. These are all serious transition issues that affect our members and indeed many others with rare diseases.

Public awareness and communications are paramount to getting the MPS message out. During this reporting period the Society appointed its first full time Communications Officer who is working on improving the accessibility of the website, producing the quarterly MPS Magazine and devising new communication tools for our members. On-going communication with our fundraising supporters has been key to us in these difficult economic times. We have learnt that our fundraisers want to have fun and do something for themselves in supporting the MPS Society. As a result many of the fundraising events offered by the Society in the past year have created a sense of fun or encouraged personal achievement.

Funding research, after providing support and advocacy for our members, is the most important objective. The MPS Society first started funding basic research in 1985 and over the past 25 years has raised nearly £4 million for research that may lead to a therapeutic approach for these diseases. In the last 12 years the MPS Society has received significant funds as a partner in the Jeans for Genes Charity. Regrettably, the net funds available to the Jeans for Genes Charity Trustees to distribute equally between the four partner charities in the 2008 and 2009 fell well short of what might have been expected, due to the high cost / income ratios. As a consequence, the MPS Society apart from its support to the Programme Grant for the MPS Stem Cell Group at the University of Manchester and a second year grant to the Blood Brain Barrier Group at Kings College, London, has only been able to offer support to small research grant initiatives in this financial year.

Mindful of the economic challenges ahead, the MPS Trustees set a prudent budget prior to the beginning of this financial year that provided for all core costs and essential events, and allowed for additional support activities to take place as and when restricted funding for that purpose was achieved. Furthermore, as part of our fundraising strategy and following on from a fruitful and successful three years with a fundraising consultant, the Society appointed its first full time Corporate and Trusts Fundraising Officer.

We end this financial year knowing that our efforts to increase the level of unrestricted income have been rewarded and we have been able to reduce the mortgage on MPS House. Most importantly of all, we have been able to provide a unique and disease specific support service to all those affected by MPS and related diseases including parents, partners, siblings and extended family. This could not have been achieved without the commitment of dedicated staff, volunteers, our members and MPS supporters.

Barry Wilson
Chairman of Trustees
6 February 2010

MPS SOCIETY AIMS AND OBJECTIVES, STRUCTURE AND PUBLIC BENEFIT

Our aims and objectives

- to provide support to individuals affected by Mucopolysaccharide and related diseases, their families and the professionals who care for them to increase awareness of Mucopolysaccharide and related 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 Mucopolysaccharide and related diseases that may lead to improved clinical care, quality or life and new therapies.

In order to carry out these objectives:

- we research the needs of children and adults affected by MPS and related 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 diseases
- we operate in the four countries of the United Kingdom and collaborate with MPS Societies throughout Europe and the rest of the world, raise money and seek ways to grow income.

To achieve these objects, 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 MPS Society

Our structure

The Society was founded in 1983 and is registered with the Charity Commission as an unincorporated association, registered charity number 287034. The Trustees, principal officers, and professional advisors of the Society are listed on the Charity Information page. It is governed by a board of 13 Trustees known as the Management Committee which meets a minimum of five times during the year. The day to day business of the Society is managed by the Chairman, Vice Chairman and Treasurer. There are no sub-committees. 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 10 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.

Recruitment & appointment of Trustees

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

Trustees' Induction & Training

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 Management Committee. 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 Management Committee meetings. Trustees are regularly provided with the latest information on employment and charity law through the provision of the monthly Governance magazine.

Related Parties

The Society for Mucopolysaccharide Diseases is a partner charity of the Jeans for Genes Charity and one of the four beneficiaries of the funds raised by the Jeans for Genes Appeal.

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
- implementation of procedures designed to report on and minimise any potential impact on the Society should any of these risks materialise.

Public benefit

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

- providing advice and support to those affected by MPS and related diseases and /or their families to help them access the disability benefits to which they are entitled
- offering an individual advocacy service through home visits, face to face meetings, support at multi-agency meetings in writing, by telephone or email in areas of home adaptations, special educational needs, independent living and access to respite care
- through our dedicated Roald Dahl progressive neurological palliative and bereavement worker offering in-depth support to families caring for their child at the end stage of their disease, and preparing parents and siblings for loss
- arranging a UK-wide programme of events that included family days, a sibling weekend and a young MPS adult weekend
- organising a National Weekend Conference incorporating three symposia running in parallel on Mucopolysaccharide and related diseases
- recruiting, training and involving over 100 volunteers to provide a child and vulnerable adult care programme at the MPS Conference and event programme
- undertaking Quality of Life studies with the membership to inform the regulators and clinicians on the natural history of the MPS diseases and benefits from new therapies
- continuing to maintain the Childhood Wood at Sherwood Pines, Nottinghamshire facilitating the annual planting and Remembrance Day
- continuing to support the MPS Stem Cell Group at the University of Manchester with a programme grant, fund important research into the Blood Brain Barrier project at Kings College, London and by awarding pump priming research grants.

Our Vision

A future where early diagnosis of a Mucopolysaccharide or related disease is routine, and new therapies are immediately available to prevent further multi-organ storage thus avoiding progressive physical disability, and in many diseases, neurodegeneration leading to early death, thereby allowing these children to grow up and achieve their full potential.

WHAT ARE MUCOPOLYSACCHARIDE AND 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 23 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.

Mucolipidoses 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 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?

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 23 MPS and related diseases, being managed nationally in England by the National Specialist Commissioning Group (NCG).

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, to be assessed against appropriate clinical guidelines. These guidelines are available on the NCG website www.ncg.nhs.uk

The NCG LSD specialist centres are:
Paediatric
Great Ormond Street Hospital, London
Birmingham Children's Hospital
Manchester Children's Hospital
Addenbrooke's Hospital, Cambridge

Adult
London National Hospital, London
Royal Free Hospital, London
Addenbrooke's Hospital, Cambridge
Hope Hospital, Manchester

Wales, Scotland and Northern Ireland have designated specialist hospitals for managing metabolic diseases but MPS patients do not have the benefits of the NCG model 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 NCG treatment guidelines.

The designated specialist hospitals are:
Wales - University Hospital of Wales, Cardiff
Scotland - Yorkhill Children's Hospital, Glasgow
Northern Ireland - City Hospital, Belfast

CAN MPS AND RELATED DISEASES BE CURED?

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 1980's 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 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 a HSCT will 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 will continue to have serious spinal complications that require surgical intervention, as well as other joint problems.

In the 1990s several pharmaceutical companies started to develop Enzyme Replacement Therapy (ERT) as a potential therapy for the LSD's. The first ERT was given an orphan drug licence to treat Gaucher disease in 1990. Over a decade passed before ERT became a reality, firstly for Fabry disease in 2001, followed by MPS I Hurler Scheie and Scheie disease in 2003, MPS VI Maroteaux Lamy in 2005 and MPS II in 2006. 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.

Enzyme Replacement Therapy involves a regular infusion, either weekly or every two weeks, lasting up to five hours. Children and adults receiving ERT must be closely monitored, although many children and adults who have been on ERT without any adverse effect for several years are able to be treated at home. 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!

RESEARCH AND TREATMENT

Clinical trials in MPS for new therapies

New therapies require years of pre-clinical work followed by clinical trial before they can be licensed. It can seem forever when you are the patient or the carer of a child or adult with an incurable and life-limiting disease.

Currently, there is a UK multi-centre clinical trial for MPS IVA Morquio to determine the safety of an Enzyme Replacement Therapy in this disease. The MPS Society has played a crucial role in ensuring that those affected by MPS IVA and their families are aware of the clinical trial thereby ensuring equitable access. The MPS Society is also funded by the pharmaceutical company which has produced this ERT to provide support to families participating in the clinical trial including arranging accommodation and travel to the clinical trial centres.

Future treatments

Gene therapy holds the promise of a complete cure for lysosomal disorders like any other genetic disorder. Initial studies have shown that gene therapy is possible but there are a lot of hurdles still to be overcome.

The problems that are to be solved are gene delivery to the target cells and the target tissue in the affected organs and sustainability. Concerns over safety have been aroused by recent experiences in apparently successful gene therapy cases where the recipient has gone on to develop leukaemia. For lysosomal disorders one of the approaches may be the introduction of viral vectors directly into the Central Nervous System (CNS). Another approach that is under consideration is to alter the haemopoietic stem cells from the patient to express the missing enzyme and returning the altered cells by BMT.

Small Molecule Therapy

Inaccessibility of the CNS because of the blood brain barrier and limitations of available forms of therapy, bone marrow transplantation and enzyme replacement therapy, has prompted scientists to think of alternative strategies.

The main attraction of drug therapy is that the small molecules can easily cross the blood brain barrier unlike the enzymes. The principle of using small molecules in lysosomal storage disorders is to keep the production of substrate so that it matches its impaired catabolic rate. This principle is variously named as substrate deprivation, substrate reduction or substrate inhibition.

CHILDREN AND ADULTS FIRST

Individual advocacy service

The MPS Society provides help to its members through an individual advocacy support service. The rarity of MPS and related diseases means affected individuals and their families may experience difficulties accessing adequate needs-led support and services in their local area. The MPS Society's advocacy team provides a support network promoting awareness and understanding of the diseases and works in partnership with members and their families, as well as developing professional relationships with local social care and health professionals.

Support following diagnosis and beyond

The Society provides support to individuals and families where a diagnosis of MPS has been made. Contact can be made by telephone, letter or registering details on the Society's website. On receipt of a new diagnosis, the Society will make contact by providing a membership pack which includes information about the Society and the support it provides, details on how to become a member, copies of the relevant disease booklet and copies of the MPS magazine. Each new member is offered a home visit and will be given information about the centres specialising in MPS and, specifically, the support the Society can provide.

At present the Society supports over 1200 individuals and families affected by MPS and related diseases. The amount of support and contact varies greatly and is dependent on the needs of the individual and their family. This year the advocacy team provided support in a number of areas listed here. 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, employment and relationships
- 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.

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 National Specialist Commissioning (NCG) for LSDs in England.

The MPS regional clinic programme involves centres including Manchester, Belfast, Birmingham, Bristol, Cardiff and Newcastle. The programme aims to enable individuals affected by MPS and Related Diseases to access a consultation with a tertiary centre consultant without having long distances to travel to the NCG (NSCAG) designated clinical centre of excellence. The clinics also aim to increase expertise in the regional centres on MPS and related diseases in the clinical management of those affected.

The MPS Society facilitates and supports the regional clinic programme by arranging and co-ordinating dates of the annual programme and funding the NCG centre doctors' travel and subsistence costs to the regional centres. Specific arrangements for each clinic and for organising appointments differ for each of the centres. At least one member of the Society's advocacy support team meet individuals and families face to face to offer individual advocacy support. Each individual regional clinic is evaluated through the sending and receiving of evaluation forms to each individual and family who attend. These are collected and the feedback taken into account.

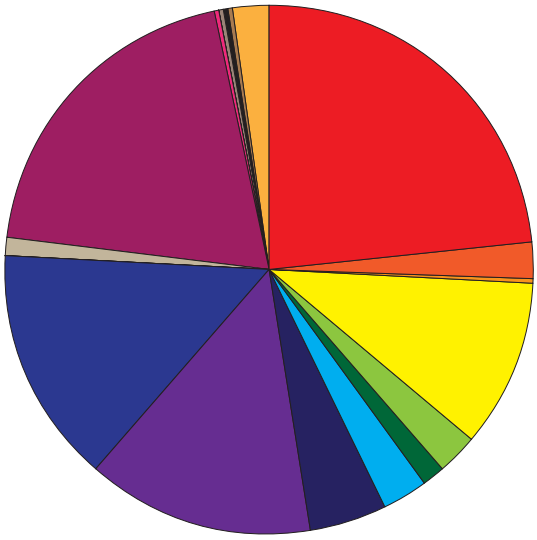
Palliative care, pre and post bereavement support Services for children and young people with life-limiting conditions and who require palliative care varies from locality to locality. Although much has been done to educate service providers there are areas which are still considerably lacking the knowledge,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

Having a dedicated worker with the specialised knowledge and understanding of these complex needs has allowed the Society to respond effectively to the needs of individuals and families.

Through our work it is evident that individuals and families feel confident knowing that they have a dedicated worker who can support them from diagnosis to bereavement. This is a critical area of work as these diseases are degenerative, complex and multi-organ in nature, causing continual changes to the affected individual's physical and mental condition.

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

Breakdown of Members Supported by Disease



- Sanfilippo
- ML III
- Multiple Sulphatase Deficiency
- Morquio
- Maroteaux Lamy
- Mannosidosis
- ML II
- Hurler Scheie
- Hurler
- Hunter
- Geleo Physic Dysplasia
- Fucosidosis
- Fabry
- Aspartylglycosaminuria
- Sly
- GM I Gangliosidosis
- Sialic Acid Disease
- Winchester
- Scheie

Areas of Support Provided by the MPS Advocacy Team

- Clinical Management
- New Members
- Disability Benefits
- MPS Individual Care Plans
- Work with Local Authorities/Other Organisations
- Palliative Care and Bereavement
- Transition
- Befriending Links
- Education
- Housing
- Grants for Individuals

MPS SUPPORT EVENTS

The idea of families coming together is to share support, to give support and to enjoy each other's company. The idea was first conceived in 1986 and by 1987 it became a reality. Every year since then, the Society has had the privilege to offer families and individuals the opportunity to support each other in this way.

Many individuals and families suffer isolation when a rare condition like one of the MPS or related diseases is diagnosed. They can often feel shut off and very much alone. Imagine for one moment telling someone your child has MPS or Fabry disease, the normal response is a total blank, confusion or even embarrassment. The result can be isolation. MPS Society events for families and individuals affected by MPS and related diseases break down the isolation, enable experiences to be exchanged, bring understanding, care and support and for many, the development of lasting friendships.

National MPS Conference

The 23rd National MPS Conference was held at the Hilton Hotel, Northampton on 26 – 28 June 2009, and was a great success with nearly 400 people attending for all or part of the weekend. Seventy UK MPS Society families were represented, along with 6 Irish MPS Society families and 4 Spanish MPS Society adults. Also present were Fabry family representatives from Ireland, Australia and the USA, and two MPS family representatives from Saudi Arabia. Nearly a hundred UK professionals from the fields of Healthcare, Science and the Pharmaceutical industry attended, along with nine international professionals from Poland, France, the Netherlands, Ireland, and the USA.

Over 80 children enjoyed the Children and Young People's Programme this year, supported by 43 volunteers.

On the Saturday the children headed off to Drayton Manor Park for a fun day out with their volunteers. A great time was had by all. On Saturday evening the children had childcare in their rooms watching a DVD. The teenagers enjoyed an evening out bowling.

On the Sunday morning a whole host of activities had been organised on-site. In the marquee the children could build a "Be My Bear", have their face painted, make dinosaurs or create some stylish jewellery. There was also balloon modelling and canvas painting and printing. Just outside the marquee there was a bouncy castle, a very exciting Laser Quest, and a 4-car Racing Challenge for the kids (and some of the volunteers!) to compete to be the fastest. There was also a Simulator which could take up to 17 people at a time on a variety of whirlwind rides such as rollercoasters, racing cars and a journey into outer space.

MPS Young Adult Weekend

The MPS Adult Weekend took place on 29 - 30 November 2008. The weekend kicked off on Saturday lunchtime as MPS individuals, volunteers and MPS staff met at the London Hilton Tower Bridge. Having had time to catch up with old friends, meet new ones and generally get to know each other, everyone headed off to Covent Garden to hit the shops. After dinner in a restaurant in Covent Garden the girls and boys split into two groups for the evening's entertainment. The boys went to see 'Avenue Q' at a nearby theatre, whilst the girls intrepidly ventured across London to see 'Wicked'. We then met back at the hotel for a nightcap and swapped stories about our evening.

The next morning was a morning of leisure, it was Sunday after all! We all met up for pizza at lunchtime then took a spin on the London Eye in the chilly, dusky afternoon before heading back to the warmth of the hotel to say our goodbyes. The weekend was an enormous success.

"I am writing to thank you for inviting me on the adult weekend trip to London. I had a fantastic time and have to admit that seeing the theatre production 'Wicked' and travelling on the London Eye have been the highlights of my year. Going on the trip has given me the confidence to venture out on my own without the support of my family."

Sibling Activity Weekend

The sibling activity weekend was held at Boreatton Park, Shropshire, from 14 - 17 August 2009. Here one of our siblings writes about his weekend.

"I travelled by train to the PGL camp along with two of the MPS staff. We got to the camp where we met our group leader and she took us to our cabins. At around 5pm we went for dinner. The evening activity was 50/50 where we were split into two teams and we had to do different challenges such as peel an orange with our teeth or create clothing from three bin bags. After that our group leader left us and the boys played football until it was time to get into our rooms.

After breakfast the following day we had our first activity which was a challenge course which included climbing a flat 3 metre wall, balancing along beams, climbing through a tyre tunnel and a slanted climbing wall. We then swapped with the other group and went on to the big swing in pairs which was great. We went back to the canteen to have our lunch and after that we went canoeing along a river with four in the boat. Our final activity of the day was called 'Passport to the World' where we had to find a flag and answer the questions to get points.

Our first activity on the Sunday was archery where we had to hit different parts of the board to get a particular item to eat with that lunch. This was one of my favourite activities along with fencing. The rest of the day we did abseiling, fencing and giant zipwire. After dinner we played a game called 'Robot Wars'. We were put into teams and had to dress someone up like a robot then they were put in an arena and were blindfolded. The rest of the team had to direct them to pick up flour or water to throw at the opposition.

On the last day we had two activities which were quadbiking and leap of faith (trapeze). After we had finished our activities we went back to the white marquee to collect our packed lunches.

It was a great weekend and I think everyone really enjoyed it." Will, brother of Sophie

Regional Family Days

We have some wonderful feedback from families about our events…

"On 1 July 2009, we got up early and prepared for a trip into London for a day out at the London Zoo with the MPS Society.

We met the MPS team outside the gates at 10 am, quite a feat to be up, ready and in London by that time – especially on a Saturday. We all met up and had drinks in the zoo before splitting up and going off in various groups.

Meeting up at the beginning of the day was excellent as it gave us the opportunity to meet up with all the other families and get to know them. This was great as we were then able to stop and chat as we bumped into various families during the day. At this point it looked like the sun was going to shine for us.

We started with the Aquarium, as did most people, and spent quite some time viewing the fish and chatting with the other families. By the time we had completed this it was time to retire for coffee. We settled down outside the café with another MPS family and rearranged the tables to accommodate ourselves. It was great to see another pair of families arrive and rearrange the remaining tables, the takeover of the outdoor seating was complete! With a collection of buggies and wheelchairs, siblings and parents there was no room for anyone else!

Before long, we realised that we had spent far too long talking and we went off in search of the big cats. We detoured to view the butterfly tunnel, such amazing creatures and they kept us all entertained.

We met two new families both with Sanfilippo children and spent some time chatting and comparing notes before moving on to finally see the tigers, stopping en route for a very late lunch.

As time was running out we again bumped into the other MPS families and spent a while discussing the joys and problems of living with Sanfilippo.
It is great to meet families at these gatherings and realise you are not alone and the problems you face are not only yours." Tim, father of Sophie

Regional Christmas Parties

"On 7 December 2008 the MPS Society held a Christmas party at Newcastle United's football ground and we were lucky to be given a box which gave a great view of the pitch.

The room was decorated with hats and crackers, all sporting the Newcastle logo, and gifts. We had our own personal bar and waiting staff. Once everyone had arrived and taken in the view we sat for a carvery lunch with a festive twist. While everyone was taking coffee, the magician set up his box of tricks ready to entertain the children as well as the adults. He was fantastic and kept us all entertained with magic tricks which included a customary rabbit in a hat and two white doves.

The day was coming to an end but we still had one visitor to arrive. With a knock at the door and a loud Ho! Ho! Ho! Father Christmas entered the room bearing gifts for all the children, even the big ones.

The day ended on a high and a good day was had by all." Sophie Thomas, Senior Advocacy Officer

THE 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.

In this financial year the Society has received a grant from the Geoff and Fiona Squire Foundation to further develop the Wood.

The Childhood Wood Remembrance Day

Families who have lost a child were invited to the Bereaved Family Remembrance Day in June 2009 at the Childhood Wood. This was organised in conjunction with the MPS National Conference programme for bereaved families. The families enjoyed lunch at the Saville Restaurant in the beautiful surroundings of Rufford Country Park before traveling to the Childhood Wood for a time of remembrance and a balloon release to remember 23 children and adults.

The Childhood Wood Planting

Those families who had lost a child in the previous 12 months were invited to plant a tree, in their memory, at the Childhood Wood planting day on 23 October 2009. Following lunch at Clumber Park Hotel, families and dignitaries gathered at the Wood to read the names of the children and adults being remembered and to listen to a reading of the poem ‘Remember’. Families and friends were then able to take their time to plant the sapling trees and release balloons in memory of loved ones.

ENGAGING WITH VOLUNTEERS

MPS Childcare Volunteers

The Society made use of over 150 childcare volunteers who generously gave their time to care for children and young adults affected by MPS or related diseases, and their siblings, at activities and events organised during the year. Recruiting volunteers to assist at our events and conferences provides parents and carers an opportunity to listen to presentations and learn more about MPS and related diseases and to have time to relax, while their children are looked after by our trained volunteers in a supported and happy environment.

We organise a programme of activities for all children, sufferers and their siblings, from babies to teenagers. Volunteers are assigned to a specific child or children and these may be children suffering from an MPS or related disease, or their healthy siblings. Children and their volunteers are put into groups according to age and well-being, and are supported by volunteer group leaders. New volunteers are always supported by an experienced volunteer. Volunteers are provided with care plans specific to the children in their care, along with any additional information or equipment necessary.

All volunteers are required to register with the Society and attend training prior to the event including a briefing on MPS and related diseases, childcare arrangements, details about the event, roles and responsibilities as well as appropriate Health and Safety guidance, Child Protection and Moving and Handling training. Volunteers will also have undergone a Criminal Records Bureau check carried out through the MPS Society.

We have some wonderful feedback on our volunteers from the individuals and their families…

"Our son had an excellent volunteer who listened to us and responded well to his needs."

"Our volunteer was superb. She took on all the MPS issues without any problem. She was quick to learn and gave me a high level of confidence."

"A very conscientious and helpful young man. My son enjoyed himself thoroughly. Many thanks."

"The carers were fantastic and our children really enjoyed being with them."

"Lovely rapport with the children - very caring. We felt very relaxed leaving the children with her."

MPS Office Volunteers

The Society made use of three office volunteers to provide secretarial support, pack the quarterly MPS magazine and continue to develop an access database for maintaining epidemiological data on MPS diseases.

One of these volunteers has given half a day a week throughout the year to continue to develop and maintain the MPS Registry that provides valuable demographic and epidemiological data on MPS diseases. Over the past year the work has concentrated on updating and verifying data on all registrants entered with a diagnosis of MPS III and MPS IVA as well as producing reports to support presentations made by the Chief Executive and Senior Advocacy Officer.

MPS INFORMATION AND AWARENESS

MPS Publications

As part of our aim to continually update and develop our range of educational materials and information resources, the Society devised five new fact sheets on the rarer of the MPS and related diseases. These are downloadable from the MPS website or available in printed form from the MPS office for a nominal charge.

Over the coming months we plan to turn our existing publications in the 'Guides to Understanding' series into fact sheets to make them more accessible to our membership and those who work with them.

We distributed our quarterly MPS magazine and fundraising newsletter to the entire membership free of charge. For the next year we are revising our fundraising strategy. Mindful of increased printing and postage costs the Fundraising Magazine will be reduced to an A5 publication going out twice-yearly in March and September.

During the year the advocacy team gave 10 school talks and information days in the South West, South East, North West and the Midlands. 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 Website

The development and management of the MPS website is ongoing and is attracting considerable positive feedback. The secure log in facility to enable trustees to access policies and Management Committee papers continues to work well.

For next year we aim to have developed a Kids Section of the MPS website to encourage the younger generation to share their experiences of living with these diseases.

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 2009 the Society was delighted to hold its third MPS Awareness Day. A number of events were organised throughout the UK by the Society's members and supporters.

Plans are underway to launch the MPS Society on Facebook to develop awareness amongst a new generation of individuals and supporters.

LSD Patient Organisation Collaboration

The patient organisations for those affected by LSDs created a new action group 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 Diseases, Batten Disease Family Association, the Gaucher's Association, the Society for Mucopolysaccharide Diseases and the Niemann-Pick Disease Group UK. 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 working to stimulate interest, and working to establish a forum in which members can discuss matters of common interest and contribute to the development and dissemination of good practice.

INTERNATIONAL COLLABORATION

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.

It acts as an independent forum to promote the wellbeing of those affected by MPS and related lysosomal storage diseases through the best practices of clinical diagnosis, management and treatment. It promotes public and professional awareness of MPS and related diseases, identifies research priorities and potential collaborations, where appropriate, working in partnership with the academic community and pharmaceutical industry.

The International Network is responsible for overseeing the nominations to host the International Symposium for MPS diseases and preside over the decision-making, forward planning and reporting.

INFLUENCING RESEARCH

The Society's overarching research objective is to 'Promote and Support Research into MPS and related diseases.'

It's purpose is to play a leading role with clinicians, scientists and academics in initiating and funding innovative research projects which may have a therapeutic benefit to those affected by MPS and related diseases.

Initially, the MPS Society funded one-off projects because it could not rely on regular funding. In 1995 the MPS Society entered into a partnership with the Jeans for Genes charity that generated regular income for research. As a result of this income, the Society undertook to develop an MPS Stem Cell Group at the University of Manchester with an initial programme grant of over £300,000. As you will read here, support to this group has grown and many research projects have been funded.

The Society's Research Strategy 'Making a difference 2005-2010' set out how this was to be achieved:

- promote and fund research into the causes and effect of these severely life-limiting diseases with particular emphasis on getting enzyme into the brain
- extend the psychological research programme identifying the impact of MPS and related disorders and publish the results
- continue to develop the MPS registry

Between 1985 and 2010 the Society has funded and participated in innovative projects that have advanced the knowledge of MPS and related diseases. Unfortunately, due to the decline in income for research, many important research projects remain unfunded.

In this reporting period the Society awarded the following grants:

Dr David Begley £75,000
Kings College London, London, UK
One year extension grant to research involvement of the blood brain barrier in MPS IIIA and MPS IIIB.

Dr Brian Bigger £20,000
MPS Stem Cell Research Group, Uni. of Manchester
First year of a two year grant for improving enzyme secretion and tracking in lentiviral mediated stem cell gene therapy of MPS III. NOTE: Made possible by a grant from the Irish MPS Society.

Dr Chris Hendrickz £4,000
Birmingham Children's Hospital, Birmingham, UK
Year one of a three year project looking at new imaging techniques and to develop appropriate assessment scales to measure cognitive decline by use of new psychological methods in children with lysosomal storage diseases.

Professor Elsa Shapiro $49,500
University of Minnesota in Minneapolis, USA
To investigate the cognitive, adaptive, quality of life and psycho-social outcomes of children who are at least one year post Haemopoietic Stem Cell Transplant for MPS IH, Hurler disease. This investigation will build upon the data collected in the Society's previous three year psycho-social research project and result in publications.

Dr James Edmond Wraith, Dr Rob Wynn & Dr Brian Bigger £63,183
Willink Biochemical Genetics Unit, Royal Manchester Children's Hospital, UK
Year four of a five year programme grant to establish the Stem Cell Therapy Group with funding for a Senior Research Fellow at the University of Manchester. The post-holder was to be responsible for establishing and leading a research group in stem cell therapy in inherited disorders of Mucopolysaccharide metabolism.

Professor Bob Jolly £2,750
Massey Uni., Palmerston, North Island, New Zealand
One year grant to fund physiological principles underlying Intrathecal ERT in lysosomal storage diseases.

Dr Brian Bigger £6,500
MPS Stem Cell Research Group, Uni. of Manchester
Travel grant to the MPS Stem Cell Group.

MPS Quality of Life Surveys

Particularly as new therapies have been licensed for MPS I, II, VI and Fabry disease it has become increasingly necessary to find appropriate ways of measuring quality of life and clinical outcome. The MPS Society has undertaken two quality of life studies in this reporting period and is working towards a poster looking at the correlation between four quality of life tools.

The research element of the Quality of Life Study for MPS I has been completed and is now in the process of being analysed in anticipation of submitting an abstract for the International Symposium on Mucopolysaccharide and Related Diseases in Adelaide and the WORLD Conference in Miami in 2010.

The research element of the Quality of Life Study for MPS II has been completed and submitted to the University of California for statistical analysis.

Brains for Brain

The Brains for Brain foundation is an international taskforce formed by researchers, expert clinical scientists, leaders in the neurological field and supported by patient organisations. The MPS Society is represented on the Brains for Brain advisory board by its Chief Executive. During 2009 the MPS Society supported an international meeting of experts to identify research initiatives on the blood brain barrier which may lead to therapeutic benefit for those affected by lysosomal storage diseases. During this period, an application was made to the EU 7th Framework Grant Programme of which the MPS Society and its CEO had a work package. We are currently awaiting the outcome of this application.

POLICIES

Restricted Funds

The Society receives grants for activities, which are considered to be restricted funds as such funds can only be used for the purpose for which the funds were given. Restricted funds held by MPS at 31st October 2009 represent unspent grants at the end of our financial year. This position has arisen as not all the grants run co-terminus with our financial year and so balances are taken forward into the following financial year. The unspent restricted funds of £329,071 in respect of the Jeans for Genes appeal reflect grants awarded to research institutions but not yet drawn upon.

Grant-Making Policies

The Society's charitable grant making policies include offering support to children and individuals with MPS and their families and fund research. The Society allocates a small budget each year to provide financial assistance to families in genuine need for the purchase of essential equipment, and to access events organised by the Society.

There is a thorough application process for applying for MPS research grants. All but small grants are peer reviewed, and short-listed applicants are required to present to the Management Committee.

Investment Policy

The Trustees have the power to invest surplus funds as appropriate under the constitution as they see fit. The Trustees have sold any investments in favour of holding all such funds in low-risk bank deposits. Consequently, the Society no longer holds any fixed asset investments, and bank deposits are classed as current assets as appropriate.

Reserves Policy

The primary aim of the Society's Reserves Policy remains that we will hold adequate funds, which may include any equity on the building MPS House, to maintain the long term sustainability of the Society's support and advocacy service, its research projects and to manage short-term volatility in income of liquidity.

This policy is designed to ensure that the Society can:

- continue to meet its financial commitments
- deploy funds promptly, in a planned way and react to new opportunities
- balance sound investment, in a planned way and react to new opportunities
- not be forced into short-term decisions to the detriment of its long-term vision.

The bulk of the Society's charitable expenditure is by way of provision of the Society's support and advocacy service and its commitment to research projects funded from the restricted income from grant-givers and fundraising donors. In respect of the support and advocacy services, which provides a lifeline to over 1200 affected families, the Trustees wish to hold sufficient free reserves to ensure that, in the event of the worst case scenario, they could continue to meet the costs of the service for at least 6 months whilst action is taken to increase income and/or reduce other expenditure in an orderly and controlled manner.

Based on the budget for 2009/2010 and having deducted restricted funds received for these essential care services in this financial year, the reserves required amounts to £420,000. Currently the MPS Society owns 58% of a building valued at £824,000.

During the year the Trustees have reviewed the Reserves Policy and have re-examined MPS' requirements for free reserves in the light of the predominant risks to the organisations and its working capital requirements. The three major risks are:

- the impact of the economic climate
- loss of reputation resulting in the loss of corporate and trust support
- loss of fundraising income due to the severity of MPS diseases and the demands on families and carers

Auditors

McLintocks have signified their willingness to continue in office and a resolution to re-appoint them will be proposed at the forthcoming Annual General Meeting.

Barry Wilson
Chairman of Trustees
6 February 2010

FINANCIAL REVIEW

Incoming Resources

As well as applications to grant giving bodies for special projects, the Society relies heavily throughout the year on its members and supporters to raise the restricted and unrestricted income required in each financial year. During this financial year the Society has appointed a fulltime Communications Officer to engage with our members and supporters in order to grow the Society's income, particularly in areas of events and gift aid. Meanwhile, our newly appointed Trusts and Corporate Fundraiser has been focusing on achieving grants. Overall income decreased by £100,409 to £1,131,401 and is in proportion to expenditure on charitable expenditure. In general, and taking into consideration the current climate and falling property prices, all income streams held up well. The reduction in income was mainly due to reduced fundraising, donations and legacies which are on the whole unrestricted income.

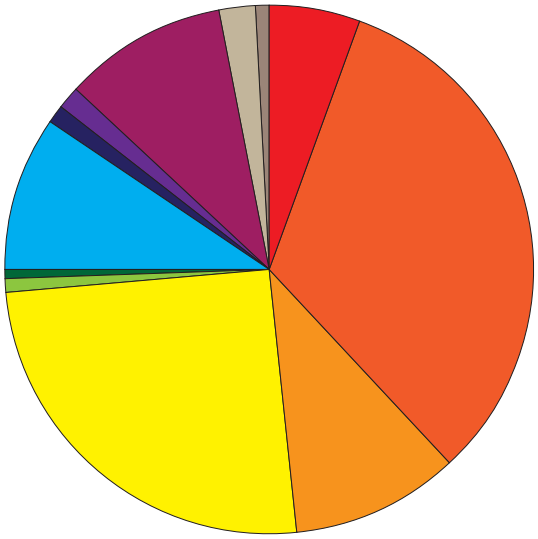
Charitable Expenditure

The total charitable spend decreased by £239,157 to £1,184,239 in this financial year. This follows two years of an increasing charitable expenditure deficit incurred by a lack of unrestricted funds. There was a drop in support salaries due to two maternity leaves and one member of staff opting for reduced working hours and interest payable. The Society's core activities are sustained and developed year on year. The Society has also seen a significant decrease in the interest received on its bank income. However, special support projects and events tend to fluctuate depending on the restricted funds secured.

The cost of generating funds rose by £11,935 due to the costs of securing additional fundraising events including marathons, 10Ks and Great Runs. Governance expenditure fell by £23,366 in this financial year due to one part time administrative post being made redundant. The Trustees' strategy agreed in November 2008 to reduce the deficit by 50% by greater efforts towards full cost recovery resulted in a reduction of £138,748 to £52,838.

Where the money came from

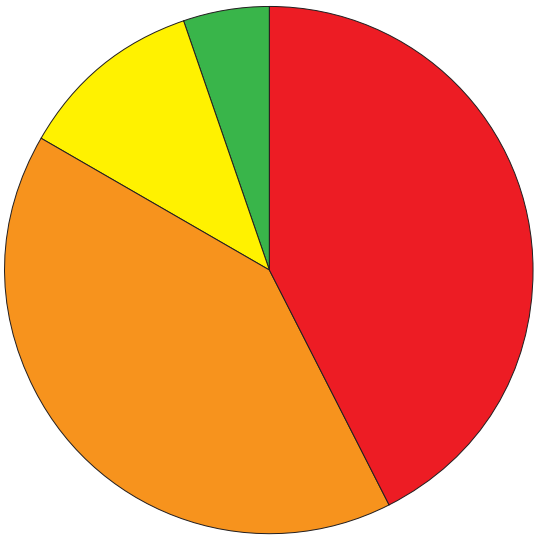
The MPS Society's income was £1,131,401 and was generated in the following areas:



- Donations and Legacies
- Jeans for Genes
- Fundraising
- Grants
- Investment Income
- Information, Magazine and Other
- Conferences
- Childhood Wood
- Family Support of Special Events
- International Symposium Vancouver
- Research Studies
- Other

Where the money was spent

The MPS Society's expenditure was £1,184,239 and was spent in the following areas:



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

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. This will help us strive to meet the needs of the increasing number of MPS families and in finding a cure for these devastating diseases. Our supporters have held many events for us in the last twelve months. Look out for forthcoming events in the fundraising newsletter which is packed full of inspirational fundraising ideas. Don't forget to send in your stories and photographs which we can include in the newsletter to fire the imagination for others!

Here are stories from some of our fundraisers

Michelle Worsford *"My son, Nathan, was diagnosed with MPS II, Hunter Disease. On 3 May 2009, myself, my husband Eamonn and my son Nathan travelled to Lurgan in Co. Armagh, to meet my family and friends to take part in our annual sponsored walk on behalf of the MPS Society. We managed to raise the grand total of £1000.*

We would like to take the opportunity to sincerely thank everyone who participated and helped out in any way to raise this fantastic amount of money. I wish to extend my appreciation to everyone in Our Lady's Grammar School, Newry, for their continued support."

Russell Lyon *"My name is Russell Lyon and I have a wife and two children with Fabry's. The NHS and doctors have been very good to us, providing support and information. We attend the MPS meetings and find these useful.*

Me and my brothers were planning a camping trip and to climb Mount Snowdon. This was about the same time Chris Moyles was climbing Mount Kilimanjaro for Comic Relief. A week or two before my climb, I decided I could climb Snowdon for charity too and of course the MPS Society was my choice of charity.

It did not leave me much time but I managed to raise £282 from friends and family. People thought I would not be able to do it; I never walk anywhere and I sit at a desk all day, I have never tried anything like this before.

The day of the climb, 21 March, was warm and sunny. We were at the foot of the mountain by 9am and started our climb. The views were great and we took our time. We were about an hour away from the top when the weather got bad. My father was with us, and he was finding it difficult. Therefore we decided to turn round and try again (without my dad) the next morning.

We were up at 6am and had to be at the top and back by lunch time. We decided to take a different route called the miners route. This route was easier but did not have the views. However I was finding it difficult because my legs were hurting now. Towards the top we came across snow and the visibility was now down to a few metres. The wind was very cold and I could not feel my toes or fingers. However we got to the top and quickly took our pictures. It was too cold to hang around and we could not see anything so we went back down as quickly as possible. It took about 3 and a half hours to reach the top and only an hour and a half to get back down.

I would like to thank everyone for sponsoring and helping me and my family."

Donna Halleron *"The planned walk of 24th May 2009 was much more of a climb! Everyone who participated got to the top in 3 or 4 hours. When I reached the top I saw some people nearly running with their sticks, putting me and others to shame, but with little or no training, I think everyone did amazingly well. Obviously this was a round trip so everyone was walking up to 8 hours, the views were breathtaking at every turn. I know that I could have given up numerous times, the only thing keeping me going was the cause. It was extremely difficult but very worth it as we have raised in the region of £2500.*

The people who participated were myself and Enola's big sister Cora, my sister Melissa, my mum Christine and her partner Colin. My very good friends Claire, Julie and Rowena and their families. My Nan, Joan, looked after Enola at the campsite.

We received support from Enola's school (St Paul's RC Primary School) who organised a cake stall and the cakes were baked by all classes and donated by parents. They were sold in the hall by year 6. The pupils, staff and parents purchased and raised £227 in support. *(Continued over page)*

A big thank you to the support we received from the rest of my family, staff from TBE Blackburn who supported Colin with over £400 of sponsor money, Hollytree Hair, staff at TNG Bolton and those on the PGDE numeracy at Bolton University who sponsored Christine £250, Isaac Centre Burnley, Dugdales and neighbours of participants. I am eternally grateful for the support of family and friends, without it, it would not have happened."

"**Marina Foster** has raised £4752.43 from the sale of second hand items and recycling items from her shop in Bristol. This brings the collective figure to £49001.46. A big thank you to Marina and her colleagues."

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 will be launching a number of corporate fundraising initiatives in 2010 and are keen to begin discussions with any companies which are interested in working with us in the following ways: payroll giving, match funding of staff fundraising efforts, magazine sponsorship, 'in kind' donations of goods or services, and recruitment of volunteers.

Give As You Earn

Contributions by way of regular direct debit have increased and Give As You Earn through employers' schemes have risen enabling the Society to plan for the future. When you donate to the Society a Gift Aid form allows the Society to claim an extra 28p in every pound.

Department of Health Third Sector Investment Programme

In April 2009, the MPS Society was awarded a three year grant by the Department of Health under its Third Sector Investment Programme 'Innovation, excellence and service development' fund. The grant was awarded to establish national standards of care and guidelines on clinical management of the 17 lysosomal storage diseases for which there is no treatment. The resulting 'best practice model' will be made widely available to other organisations providing services to patients and families with rare diseases.

Relationship with the Pharmaceutical Industry

Since the development and approval of the first Enzyme Replacement Therapy for lysosomal storage diseases by Genzyme there has been a rapid growth and interest in the development of new therapies for MPS diseases. Although the number of diseases that currently benefit from treatments is very small, this progress is very much welcomed by the Society and its members. There are now at least six pharmaceutical companies actively involved at pre-clinical and clinical trial stages to develop treatments for other MPS disorders. As a result the MPS Society works independently but collectively with the pharmaceutical industry to promote the MPS diseases, facilitate clinical trials and ensure that new therapies reach the patients.

CORPORATE SUPPORTERS & FUNDERS

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. In 2009, 24% of our income was in the form of grants - up from 22% in 2008.

We make carefully-targeted 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. 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 grants can help us improve the lives of individuals with MPS and related diseases, and the families who care for them.

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

Amicus
Asda - Bexhill-On-Sea
Asda - Eastbourne
The Barbour Charitable Trust
Benham Charitable Settlement
Bernard Sunley Charitable Trust
Bexhill-on-Sea Lions Club
Biomarin Europe
Biomarin MORCAP
Bridge House Trust
Bruce Wake Charitable Trust
The Bryson Corbett Charitable Trust
Bunney Reckitt Trust
Roald Dahl Foundation
DHSS – Northern Ireland
DHSS – England
The Doyly Carte Charitable Trust
The Earmark Trust
Enkalon Foundation
Genzyme Therapeutics
Greggs Trust
The Headley Foundation
Healthcare At Home
Imagination Technologies Limited
The John Ellerman Foundation
Joseph Strong Frazer Trust
The Magdalen and Lasher Charity
The Mary Webb Trust
Mazars Charitable Trust
Mercers' Company
National Commissioning Group
Norton Rose
The Oakley Charitable Trust
Ollie G Ball
The Pamela Barlow Charitable Trust
Reuben Foundation
Rotary Club of Rickmansworth
Rotary Club of Sale
SCOPE
The Shauna Gosling Trust
Shire Pharmaceuticals
Soutar Charitable Trust

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.

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.

INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES OF THE MPS SOCIETY

We have audited the financial statements of The Society for Mucopolysaccharide Diseases for the year ended 31 October 2009 which comprise of Statement of Financial Activities, the Balance Sheet and the related notes. The financial statements have been prepared under the accounting policies set out herein.

This report is made solely to the charity's trustees, as a body, in accordance with Sections 43 and 44 of the Charities Act 1993 and regulations made under Section 44 of that Act. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's 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 charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Respective Responsibilities of Trustees and Auditors

The trustees' responsibilities for preparing the Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) are set out in the Statement of Trustees' Responsibilities.

We have been appointed auditors under Section 43 of the Charities act 1993 and report in accordance with regulations made under that act. Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and International Standards on Auditing (UK and Ireland).

We report to you our opinion as to whether the financial statements give a true and fair view and are properly prepared in accordance with the Charities Act 1993. We also report to you if, in our opinion, the Annual Report is not consistent with the financial statements, if the charity has not kept proper accounting records, if the charity's financial statements are not in agreement with these accounting records, or if we have not received all the information and explanations we require for our audit.

We read the Trustees' Report and consider the implications for our report if we become aware of any apparent misstatements within it.

Basis of Opinion

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the trustees in the preparation of the financial statements, and of whether the accounting policies are appropriate to the charity's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming an opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

Opinion

In our opinion:

- the financial statements give a true and fair view, in accordance with United Kingdom Generally Accepted Accounting Practice, of the state of the charity's affairs as at 31 October 2009 and of its incoming resources and application of resources for the year then ended, and
- the financial statements have been properly prepared in accordance with the Charities Act 1993.

McLintocks
Chartered Accountants and
Registered Auditors
2 Hilliards Court
Chester Business Park
CHESTER
CH4 9PX

6 February 2010

STATEMENT OF FINANCIAL ACTIVITIES

Incorporating an income and expenditure account for the year ended 31 October 2009

	Notes	Unrestricted Funds £	Restricted Funds £	Totals 2009 £	Totals 2008 £
INCOMING RESOURCES					
Incoming resources from generated funds					
Voluntary income					
Donations		45,851	-	45,851	90,762
Legacies		25,000	-	25,000	-
Jeans for Genes Appeal	4	-	412,521	412,521	403,823
		70,851	412,521	483,372	494,585
Activities for generating funds					
Fundraising		129,110	-	129,110	179,613
Charitable Activities					
Grants Receivable	5	-	321,577	321,577	266,814
Research Studies			25,300	25,300	5,724
Conferences			121,476	121,476	170,324
Childhood Wood		-	11,117	11,117	7,161
Family support of special events			18,173	18,173	36,374
Resource materials and magazine		4,949	-	4,949	20,147
		4,949	497,643	502,592	506,544
Other Incoming Resources		5,895	-	5,895	5,814
Investment Income		10,432	-	10,432	45,254
Total incoming resources from generated funds		221,237	910,164	1,131,401	1,231,810
RESOURCES EXPENDED					
Costs of generating funds					
Costs of generating voluntary income					
Jeans for Genes Appeal	4	-	7,257	7,257	9,498
Costs of Generating Funds					
Fundraising		59,823	-	59,823	45,647
Charitable Activities	6	61,358	920,335	981,693	1,209,419
Governance costs	7	135,466	-	135,466	158,832
Total Resources Expended		256,647	927,592	1,184,239	1,423,396
NET (OUTGOING) RESOURCES -MOVEMENT OF FUNDS		(35,410)	(17,428)	(52,838)	(191,586)
Total Funds brought forward		544,457	542,785	1087,242	1,278,828
TOTAL FUNDS CARRIED FORWARD		**£509,047**	**£525,357**	**£1,034,404**	**£ 1,087,242**

All amounts above are derived from continuing operations and the Society has no recognised gains or losses other than those passing through the Statement of Financial Activities. The Society has not received any gifts or intangible income during 2008 or 2009.

BALANCE SHEET AT 31 OCTOBER 2009

	Note	2009	2008
FIXED ASSETS			
Tangible Assets for use by the Charity	8	808,088	839,749
CURRENT ASSETS			
Debtors	9	100,000	200,000
Short Term Deposits	10	544,933	472,398
Cash at Bank and in Hand		4,137	717
		649,070	673,115
CREDITORS - Amounts falling due within one year	11	80,261	35,633
NET CURRENT ASSETS		568,809	637,482
TOTAL ASSETS LESS CREDITORS DUE WITHIN ONE YEAR		1,376,897	1,477,231
CREDITORS – Amounts falling due after one year	12	342,493	389,989
NET ASSETS		£1,034,404	£1,087,242
FUNDS OF THE CHARITY			
Unrestricted Funds-General Funds	13	23,529	58,939
Unrestricted Funds-Designated Capital Fund	13	485,518	485,518
Restricted Funds	14	525,357	542,785
		£1,034,404	**£1,087,242**

Approved on behalf of the Trustees on 20 March 2010

Barry Wilson
Chairman of Trustees
20 March 2010

Notes to the Financial Statements for the year ended 31 October 2009

1. ACCOUNTING POLICIES

a) Basis of Accounting

The financial statements have been prepared in accordance with the historical cost convention and in accordance with the requirements of the Statement of Recommended Practice on Accounting by Charities (SORP). The following is a statement of the principal accounting policies adopted in the preparation of the accounts, which have been consistently applied.

b) 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 income and expenditure account in full as soon as it is received.

c) Grants Receivable and Payable

Grants receivable and payable are included in the income and expenditure account 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.

d) Jeans for Genes

The funds are raised by MPS working together with three partner charities with genetic diseases, Great Ormond Street Hospital for Sick Children (GOSH); Chronic Granulomatous Disease Research Trust (CGDRT); and the Primary Immunodeficiency Association (PIA). The Trustees Board (made up of one trustee from MPS and the three above charities and five independent Trustees) appointed guest charities for the 2009 Jeans for Genes campaign. Funds are raised by holding a day once a year, when everyone is encouraged to wear jeans. Hence 'Jeans for Genes Appeal'. In the five year agreement signed by the four partner charities in March 2006 at least 60% must be spent on genetic research. The remaining funds may be used to support those suffering from genetic diseases, in our case Mucopolysaccharide and related diseases. Most of the research grants awarded by MPS are of three or more years in duration and paid in arrears. As a consequence the Society has considerable reserves allocated for Jeans for Genes research grants awarded by monies not yet drawn.

e) Restricted and Unrestricted Funds

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.

f) 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. Any gifts and intangible income that can be quantified are recognised in the Statement of Financial Activities.

g) Investment Income

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

h) Expenditure

Expenditure is included in the income and expenditure account on the accruals basis. Expenditure on discretionary research programmes is charged to the income and expenditure account in the year in which the expenditure is incurred. All items containing the Society's logo, which are bought for resale, is written off in the year in which they are purchased. Costs of special events organised by the Society are included in the expenditure section of the income and expenditure account; donations and fund raising receipts relating directly to the staging of such events are included in the income section.

i) Fixed Assets

Expenditure on fixed assets costing over £250 has been capitalised. Expenditure on computers and office furniture is depreciated on a straight-line basis over 3 years.

j) 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

k) Reserves Policy

The trustees have agreed to maintain unrestricted and undesignated funds at a level that ensures at least one future year's running costs can be sustained.

2. (DEFICIT) FOR THE YEAR	2009 £	2008 £
(Deficit) for the year is after charging:		
Depreciation	31,661	47,155
Auditors Remuneration	1,939	1,939
Trustees Reimbursed Expenses	10,862	10,105

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.

3. STAFF COSTS AND NUMBERS	2009 £	2008 £
Wages and Salaries	266,991	281,253
National Insurance	26,534	28,574
Pension Scheme	9,686	10,000
	£303,211	**£319,827**

No trustee or related person received any remuneration from the Society
No employee earned £60,000 pa or more.
The average monthly number of employees during the year, calculated on the basis of full time equivalents, was as follows:

	2009 No	2008 No
Director	1	1
Administration	1	1
Advice, information and support services	8	9
	10	**11**

4. JEANS FOR GENES APPEAL (RESTRICTED)		2009 £	2008 £
INCOME:			
Appeal Funds		387,521	203,823
Joint Venture Loan		25,000	200,000
		£412,521	£ 403,823
EXPENDITURE			
Research and Support Grants		484,767	465,914
Capital Fund Designated for Capital Projects	Note (a)	-	50,000
Financial Assistance Scheme	Note (b)	-	2,186
Advocacy Support Services		-	5,000
Joint Venture Loan		25,000	200,000
Management Expenses		7,257	9,498
		£517,024	**£732,598**

(a) Subject to the continued success of the Jeans for Genes appeal the Trustees in agreeing the budget designated £50,000 to be paid as a capital sum off the mortgage.
(b) The Society subsidises all its organised events to members by at least 50%. However that even modest financial contributions may prohibit some families from benefiting from the support offered, the Society operates a means tested Financial Assistance Scheme.

5. GRANTS RECEIVABLE	Unrestricted Funds £	Restricted Funds £	Total 2009 £	Total 2008 £
J4G 07 Campaign	-	-	-	104,863
Agnes Hunter	-	3,000	3,000	-
Amicus	-	1,320	1,320	-
Bailey Thomas	-	-	-	35,000
Biomarin Europe	-	10,000	10,000	15,000
Biomarin - MORCAP	-	6,500	6,500	-
Bridge House Trust	-	4,250	4,250	8,500
Christadelphian Sasm Fund	-	300	300	-
City Bridge	-	-	-	4,250
Cotton Trust	-	-	-	500
Roald Dahl	-	37,340	37,340	-
DHSS – Northern Ireland	-	3,953	3,953	3,857
DHSS – England	-	48,500	48,500	-
Enkalon Foundation	-	4,500	4,500	-
Eveson Trust	-	-	-	15,000
Genzyme Therapeutics	-	15,485	15,485	23,000
Research Management	-	-	-	20,000
John Ellerman Foundation	-	38,000	38,000	-
JTH Charitable Trust	-	-	-	500
Mercers	-	2,000	2,000	-
National Commissioning Group	-	15,000	15,000	-
Oakley Charitable trust	-	500	500	-
Ollie G Shott	-	2,632	2,632	-
Ollie G Ball	-	20,400	20,400	-
Percy Bilton	-	-	-	4,733
Scope	-	5,000	5,000	10,000
Shire Pharmaceuticals	-	40,000	40,000	2,916
Soutar Family Day	-	1,000	1,000	-
Bernard Sunley	-	5,000	5,000	-
The Adamson Trust	-	-	-	2,250
The Shauna Gosling Trust	-	30,000	30,000	-
Toy Trust	-	-	-	4,733
Individual Grants to families via MPS	-	19.884	19,884	7,411
MPS Research Grant	-	2,412	2,412	-
Overseas Co-operation Grants	-	4,601	4,601	3,622
Training Grants	-	-	-	679
	£ -	**£321,577**	**£321,577**	**£266,814**

6. CHARITABLE ACTIVITIES	Unrestricted Funds £	Restricted Funds £	Total 2009 £	Total 2008 £
Jeans for Genes Research & Support Grants	-	484,767	484,767	465,914
Jeans for Genes Joint Venture Loan	-	25,000	25,000	200,000
Research Study Costs		39,547	39,547	487
Conferences	-	115,667	115,667	134,329
Family Support Special Events		12,301	12,301	42,253
Overseas Co-operation	-	12,100	12,100	7,068
Grants and Donations	-	25,722	25,722	18,352
Childhood Wood	-	1,281	1,281	2,651
Magazine and Resource Materials	-	6,851	6,851	18,163
Support Services	-	197,099	197,099	267,362
Office Support Costs	59,766	-	59,766	46,670
Training	1,592	-	1,592	3,984
MPS Financial Assistance Scheme	-	-	-	2,186
	£61,358	**£920,335**	**£981,693**	**£1,209,419**

7. GOVERNANCE COSTS

	Unrestricted Funds	Restricted Funds	Total 2009	Total 2008
	£	£	£	£
Depreciation	31,662	-	31,662	47,155
Mortgage Interest	10,885	-	10,885	28,341
Professional Fees	5,856	-	5,856	3,346
Management Committee Expenses	10,862	-	10,862	10,105
Office Running Costs	11,461	-	11,461	18,848
Payroll Costs	60,922	-	60,922	46,570
Recruitment and Advertising	3,818	-	3,818	7,586
	£135,466	**£-**	**£135,466**	**£158,832**

8. TANGIBLE FIXED ASSETS

	Freehold Property	Property Improvements	Computers and Equipment	Office Furniture	TOTAL
COST					
At 1 November 2008	824,000	51,524	143,042	20,606	1,039,172
Additions	-	-	-	-	-
At 31 October 2009	824,000	51,524	143,042	20,606	1,039,172
DEPRECIATION					
At 1 November 2008	49,440	2,356	127,021	20,606	199,423
Charge for Year	16,480	1,030	14,151	-	31,661
At 31 October 2009	65,920	3,386	141,172	20,606	231,084
NET BOOK VALUE					
At 31 October 2009	£758,080	£48,138	£1,870	-	£808,088
At 31 October 2008	£774,560	£49,168	£16,021	-	£839,749

All fixed assets are held for charitable purposes.

9. DEBTORS

	2009	2008
	£	£
Jeans for Genes Appeal	100,000	200,000
	£100,000	£200,000

10. SHORT TERM DEPOSITS

	2009	2008
	£	£
Cash on Bank Deposit	519,933	472,398
Treasury 4% Consolidated Stock	25,000	-
	£544,933	£472,398

11. CREDITORS - Amounts falling due within one year

Bank Loans and Overdraft	74,842	30,214
Accruals	5,419	5,419
	£80,261	£35,633

12. CREDITORS – Amounts falling due after one year

Bank Loans and Overdraft	£342,493	£389,989

Bank loans comprise of primarily a mortgage on the premises at Repton Place purchased on the 16 December 2005. The mortgage represents approximately 42% of the Property Value and is secured on that property.

13. UNRESTRICTED FUNDS

	£	£
General Funds		
At 1 November 2008	58,939	(15,490)
Net incoming (outgoing) resources	(35,410)	74,429
At 31 October 2009	23,529	58,939
Funds designated for Jeans for Genes capital projects		
At 1 November 2008	485,518	435,518
Transfer from Restricted Fund	-	50,000
At 31 October 2009	485,518	485,518
	£509,047	£544,457

14. RESTRICTED FUNDS

Jeans for Genes Appeal	329,071	433,574
Other Grants and Donations	196,286	109,211
	£525,357	£542,785

Restricted Funds comprise unexpended balances of donations, bequests and grants received from donors subject to restrictions on the purposes for which they may be used.

15. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Tangible Fixed Assets and Investments	Short Term Deposits	Other Net Current Assets	Total
RESTRICTED FUNDS:				
Jeans for Genes Appeal	-	483,246	(154,397)	329,071
Other Grants and Donations	-	-	196,286	196,286
		483,286	42,111	525,357
UNRESTRICTED FUNDS	808,088	61,687	(360,728)	509,047
	£808,088	£544,933	£(318,617)	£1,034,404
(DEFICIT) OF INCOME OVER EXPENDITURE			**£(52,838)**	**£(191,586)**