Society for Mucopolysaccharide Diseases

ANNUAL REVIEW & ACCOUNTS 2010

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TRUSTEES REPORT

The Trustees present their report and financial statements for the year ended 31st October 2010.

Welcome to the Society for Mucopolysaccharide Diseases Annual Report and Accounts for the year ending 31 October 2010. The past twelve months have again been a mixture of unexpected challenges combined with the rewards of being a highly regarded patient organisation in the rare disease sector and achieving 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 over 1200 affected children, adults and their families. The support needs vary considerably between the disease groups not least because haemopoietic stem cell transplant is the accepted treatment for babies diagnosed under 18 months with MPS Hurler disease and enzyme replacement therapy (ERT) for MPS I Hurler Scheie and Scheie disease, MPS II Hunter attenuated form, as well as MPS VI Maroteaux Lamy and Fabry disease. At the other end of the spectrum for diseases including the four types of MPS III Sanfilippo disease, the Mucolipidoses and the Oligosaccharide diseases the only treatment is palliative.

During the year we have welcomed the continuation of the clinical trial ERT for MPS IVA, Morquio and a new Intrathecal ERT clinical trial initiative for Sanfilippo taking place at the Royal Manchester Children's Hospital. These clinical trials are invasive and involve huge commitment by the patient and their family. It has therefore been a welcome development for the Society to be awarded the responsibility by the relevant pharmaceutical companies to coordinate the Patient Access Scheme for these trials that involves awareness of clinical trials and organising all logistics and reimbursement for those participating. Weekly or fortnightly infusions of Enzyme Replacement Therapy have proved a lifeline to many of our members and continuing drug development in this field is most important, no less so than the oral therapy being clinically trialled for Fabry disease.

Alongside treatment and clinical management goes support. Roald Dahl's Marvellous Children's Charity has continued to fund our palliative care and bereavement advocacy worker who has made frequent home visits, to those families caring for children and young adults dying from their diseases often helping with care and end of life plans. 16 children and adults lost their lives to MPS and related diseases during the year and a further 60 were newly diagnosed. In October 8 families gathered in the Childhood Wood in Sherwood Pines, Nottingham to plant oak saplings in memory of their children who had lost their lives to MPS and related diseases. They were joined by representatives of Nottingham County Council and the office of the Lord Lieutenant of Nottinghamshire.

Due to new therapies and excellent clinical care an increasing number of children are living into their twenties and beyond. In July 2010 the Henry Smith Charity awarded a grant to fund the appointment of a Transition Advocacy Worker and in September 2010 the Department of Health awarded a QIDIS grant to develop a healthcare transition model for lysosomal storage diseases. The Society will report on this grant in 2011.

The Society has had a presence in Northern Ireland since its beginning in 1982 establishing the twice yearly Belfast MPS clinic and providing individual advocacy from the mainland. In August 2010 with a two year grant the MPS Society and the Primary Immunodeficiency Association (PIA) established a joint All Ireland Advocacy Officer post based at City Hospital, Belfast.

Support activities and events continue to be an important part of the MPS calendar and included a sibling mid week break to Windmill Hill, East Sussex with one of the excursions being a day visit to Boulogne and a visit to a chocolate factory. In August the Society hosted an Expert Meeting on MPS III Sanfilippo Disease the first to be held anywhere in the world. Over 64 professionals and Sanfilippo families from 55 countries came together at the Hilton Hotel, Northampton to share in the science that is hoped very soon will lead to effective therapies for this particularly devastating life limiting disease.

The small number of patients and the challenging environment the Society finds itself trying to work in Scotland was one of the key reasons that the Lysosomal Patient Organisation Collaborative, of which the MPS Society is a member, decided to organise a joint Scottish Conference in Edinburgh in September. The Conference was well attended by professionals and LSD patients and it is hoped for the benefit of the patients and their families that this might be a springboard to a more inclusive relationship with Scottish LSD professionals in the future.

MPS and related lysosomal storage diseases are rare, making ongoing public awareness and communications critical to getting the MPS message out in the public domain and growing support amongst the general public. During this reporting period the MPS Fundraising Newsletter has continued to be developed. The Society's focus in this area for the coming year will be improving accessibility of the MPS website and social networking to increase awareness and introduce new fundraising streams. The Society was most fortunate in January 2010 to receive its biggest legacy to date, £100,000 from one of its member families. The family went on to publicise how the Society can benefit from legacies in the MPS Magazine.

Funding research, after providing support and advocacy for our members, continues to be the most important objective. For the past 15 years the MPS Society has been one of four partner charities benefiting from the proceeds of the Jeans for Genes Charity. These funds have allowed the Society to establish and grow the MPS Stem Cell Research Group at the University of Manchester as well as supporting research projects at the University of Cambridge and Kings College London. The challenge for the Society in the coming months is to identify and establish new streams of research to replace the funds received from the Jeans for Genes Charity following the break up of the partnership by the Jeans for Genes trademark holder in March 2011. The Society has been most fortunate in securing £400,000 to fund a clinical trial to establish safety and effectiveness of the oral preparation, Genistein from a private donor however a further £600,000 is still required.

Mindful that the economic challenges ahead are likely to bite deep into the pockets of our supporters and the public at large the MPS Trustees set a prudent budget prior to the beginning of this financial year that provided for all core costs, advocacy service and essential events, and allowed for additional support and research activities to take place as and when restricted funding for that purpose is achieved.

We end this financial year knowing that our efforts to eliminate the unrestricted income deficit have been rewarded and we have been able to reduce the mortgage on MPS House. Most importantly of all, our unique and disease specific individual advocacy service has been able to reach out to so many of 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, MPS supporters and MPS specialist doctors, nurses and scientists.

Barry Wilson
Chairman of Trustees
4 February 2011

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 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 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 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.

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, 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?

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 Advisory Group for National Specialised Services (AGNSS).

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 AGNSS website www.specialisedservices.nhs.uk

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

Adult
National Hospital, London
Royal Free Hospital, London
Addenbrooke’s Hospital, Cambridge
Hope Hospital, Manchester
Queen Elizabeth Hospital, Birmingham

Wales, Scotland and Northern Ireland have designated specialist hospitals for managing metabolic diseases but MPS patients do not have the benefits of the AGNSS 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 AGNSS 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. In August 2010 the first child in the world received Intrathecal Enzyme Replacement Therapy for MPS III, Sanfilippo disease at the Royal Manchester Children's Hospital as part of a Phase I/II safety clinical trial for MPSIIIA.

The MPS Society is funded by the two pharmacuetical companies which produce the two enzymes to provide support to families participating in these clinical trials 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 Advisory Groups for National Specialised Services (AGNSS).

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 (AGNSS) 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 AGNSS 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

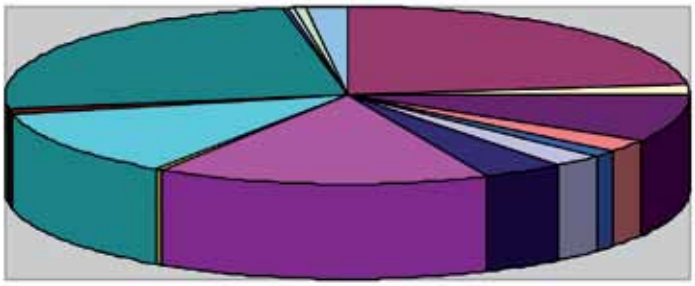
Services for children and young people with life-limiting conditions and who require palliative care varies from locality to locality. Although much has been done to educate service providers there are areas which are still considerably lacking the knowledge, expertise and resources required to carry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

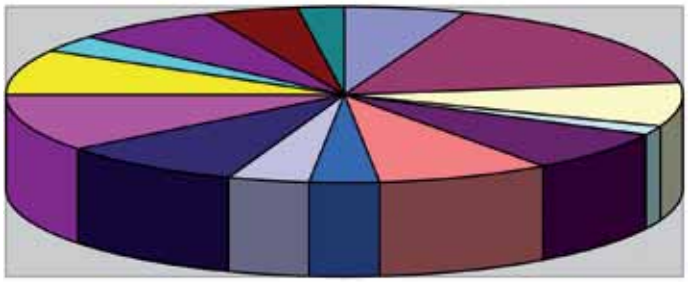
The Society continues to develop and review this service and is in the process of producing some fact sheets in this area of work.

Breakdown of Members Supported by Disease



- MLD
- Sanfilippo
- ML III
- MSD
- Morquio
- Maroteaux Lamy
- Mannosidosis
- ML II
- Hurler Scheie
- Hurler
- ML IV
- Hunter
- Geleo Physic Dysplasia
- Fucosidosis
- Fabry
- AGU
- 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
- Clinical Trial Support
- Home Visits
- Professional Meetings
- Presentations/School Talks/Training

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.

International Symposium on Mucopolysaccharide and Related Diseases

This three day International Symposium on Mucopolysaccharide Diseases was held at the end of June 2010 in Adelaide, Australia and welcomed over 800 professionals and families from around the world. The theme of the meeting was "Translating research into clinical reality" and showcased the leading research initiatives and treatment outcomes as well as offering families the opportunity to share their experiences during dedicated family conference sessions. The UK MPS Society was fortunate to receive a grant of £20,000 to fund six young adult MPS ambassadors to travel to Adelaide and take part in the Symposium. Five of these young people aged 18 – 25 years were affected by one of the MPS diseases, two being wheelchair dependent. The sixth young person was the sister of a girl with Sanfilippo disease. They were accompanied to Australia by two volunteers who assisted with daily care and managed their health and safety.

Sibling Activity Week

The sibling activity week was held at Windmill Hill, East Sussex, from 12 – 16 April 2010.

This week of structured fun was arranged for children who have brothers and sisters with an MPS or a related disease that are 9-17 years of age. These breaks away from home enable these siblings to have fun with other youngsters in similar circumstances, meet new friends and have new experiences.

As well as various activities at the PGL camp ranging from BMXing, raft building, Zip wires and ludicrous amounts of fun on a giant swing and trapeze, the group also spent a day in France where everyone was taken on a tour of the chocolate factory before going into Boulogne to see the centre of the town and for a bite to eat. Everyone left PGL camp for the Euro tunnel at 8am in order to catch their Eurostar Train… the one and only aspect of the trip that the children mutually disliked!

Here one of our siblings writes are about their adventure:

"I really enjoyed visiting PGL and France. I thought it was really fun. My favourite activity was the giant swing. It was nice being with people my own age and I made some new friends. I just didn't like having to get up so early!"

After this early start the group arrived in France at 12.30 and headed to the chocolate factory ready for their tour to commence at 13:00.

"This week I have really enjoyed myself and made lots of new friends. I really enjoyed my trip to France and the chocolate factory was pure heaven! Getting up that early in the morning is definitely not my favourite thing as I am not an early morning person!"

Family Fun Weekend

Over the May Bank Holiday Weekend the MPS Society held their Family Weekend at Camelot.

On the Saturday afternoon families began to arrive at the Park Hall Hotel, with various stories of their eventful journeys through the ever predictable, ever problematic bank holiday traffic!

After settling into their rooms everyone met in the Park Suite for a buffet dinner where the Children's Entertainer wowed both the children and adults alike. But it was later that evening when the party atmosphere really kicked in resulting in a lengthy conga line and a seamless rendition of the YMCA!

After a hearty breakfast at Brookes Restaurant on the Sunday morning everyone set off to the Camelot Theme Park where the young, and the young at heart, were able to enjoy all the rides on offer. It was a busy day for all, but the fun didn't stop there.

After a short breather it was time to commence with the activities planned for the night ahead.

The children attended their own Gala Tea where they were supported by volunteers and entertained by one of the resident magicians.

As well as having the opportunity to enter a colouring competition to meet King Arthur, the children were also given the opportunity to design a Christmas card for entry into the MPS Society's very own draw. There were plenty of other arts and craft projects on offer as well as a DVD to keep them entertained and amused.

Whilst the children enjoyed their Gala Tea, the adults attended the AGM and Gala Dinner which was held in the Medieval Banqueting Hall.

A little while later the volunteers brought the children to the forecourt outside the Medieval Banqueting Hall to be reunited with their parents and to meet one of Camelot's knights and his trusty steed.

Even after all of this the party continued with a family disco and pass the parcel, which saw the children enjoying the fun bit of unwrapping the layers and eating the sweets and the parents having to do the forfeits… the chicken impersonators were second to none and we do believe that we have found a few X Factor contenders!

The following day everyone had the opportunity to have another day at Camelot Theme Park before making their way home. A marvellous time was had by all.

Regional Christmas Parties

On Sunday 29 November 2009 the MPS Society held a Scottish Christmas Party at the Edinburgh Hilton Hotel.

We all met at 12 noon with drinks, and then sat down for a lovely Christmas lunch with Turkey and all the trimmings.

After lunch, we were entertained with some balloon modelling and a magic show. The balloon models were brilliant - we had a palm tree with a monkey, an alien and a spider, to name but a few. The magic show kept us all entertained, kids and adults alike and some mums and dads were called upon to be the magician's assistants!

Our last guest of the day was Father Christmas who arrived with the reindeers at Edinburgh airport to give the children an early Christmas gift.

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 implemented the grant awarded in 2009 by the Geoff and Fiona Squire Foundation to further develop the Childhood Wood. A second set of Memory Boards were erected in the Wood to accommodate the names of the children and adults going forward from the 2010 memorial planting. At the same time new play equipment and a fifth bench were installed to complement the toad stools and wooden animals installed in 2007.

The Childhood Wood Remembrance Day

Families who have lost a child or children were invited to the Bereaved Family Remembrance Day in July 2010 at the Childhood Wood. Eight families attended from as far away as Scotland and the South Coast of England. Two trustees and the Chief Executive hosted a lunch at the Saville Restaurant in the beautiful surroundings of Rufford Country Park before the whole group travelled down the road to Sherwood Pines and the Childhood Wood. On arriving in the Wood each family was given a coloured balloon. A few words were said and the names of the children being remembered read out before the balloons were released up into a clear blue Nottinghamshire sky and the families left to explore the wood and reflect at the Memory Boards.

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 22 October 2010. 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 80 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 when appropriate Moving and Handling training. Volunteers will also have undergone a Criminal Records Bureau check carried out through the MPS Society.

Hannah's Story

"I've been volunteering for the MPS Society for a few years now and I love it. One of my brothers (Dan) and my sister (Amy) both have Sanfilippo and when I was younger I really enjoyed coming along to the MPS conferences. Our family used to need quite a few volunteers and I have really happy memories of fun volunteers who gave us all such a great time.

As a volunteer now, seeing the younger MPS children and their siblings brings back happy memories of when Amy and Dan were little and needed fast runners to chase them! It feels really good to be able to give something back now. The weekends are always such good fun. What could be more fun than a hotel full of MPS kids running around and causing chaos!

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

It's satisfying too; I really enjoy getting to know the kids and their siblings over the weekend. Seeing them enjoy themselves whilst knowing that their parents are able to appreciate a bit of a break is great. It's nice to feel like you've really been a help and its really rewarding to have a parent say to you "Wow you can come again, she's gone straight to sleep she was so worn out!"

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

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

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

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

The Society is continually updating and developing our range of educational materials and information resources to reflect the changing needs of our membership. The Society has developed a new range of fact sheets on each of the MPS and Related. These are downloadable from the MPS website or available in printed form from the MPS office for a nominal charge.

In the last year we have published a factsheet for Grandparents looking at the important role played by the wider family in supporting those affected by MPS and Related Diseases. In the coming year we look forward to developing a similar factsheet aimed at healthy siblings.

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

During the year the advocacy team gave 12 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.

A Kids Section of the MPS website has been developed alongside the quarterly Children's Newsletter to encourage the younger generation to share their experiences of living with these diseases. We have expanded on the information provided to include sections on the Society's Governance and History, History of the Research Programme and a breakdown on how funds are spent. In the next year we are looking forward to announcing the launch of the online shop.

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 2010 the Society was delighted to hold its fourth MPS Awareness Day. The Society's members and supporters helped us celebrate this day by organising a number of awareness events and activities throughout the Country. In the next year we have plans to celebrate our fifth MPS Awareness Day coinciding with the start of our Thirtieth Anniversary year with a family day.

The Society launched it's online presence on Facebook to actively engage and develop awareness of the Society's work and fundraising activities 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 Disease, 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 has now achieved the status of a recognised forum and has been invited to participate in the Brains for Brain European Task Force Meeting in the European Parliament in Brussels in December 2010.

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 meets at least annually and in 2010 had a one day meeting preceding the International Symposium on MPS diseases in Adelaide at the end of June. In August following the Expert Meeting on Sanfilippo Disease the UK MPS Society hosted an International Network dinner and breakfast meetings to discuss an international strategy for funding vital research into Sanfilippo disease.

INFLUENCING RESEARCH

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

Its 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:

Prof Ed Wraith; Dr Rob Wynn and Dr Brian Bigger
MPS Stem Cell Research Group, Uni. of Manchester
Final year 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, Dr Brian Bigger, is responsible for leading and developing the group in stem cell therapy for the Mucopolysaccharidoses

Dr Brian Bigger
MPS Stem Cell Research Group, Uni. of Manchester
Final year of a two year grant for improving enzyme secretion and tracking in lentiviral mediated stem cell gene therapy of MPS III

Dr Chris Hendrikz
Birmingham Children's Hospital
Year 2 of a three year project looking at new imaging techniques to develop appropriate assessment scales to measure cognitive decline by use of new psychological methods in children with lysosomal diseases

Dr Brian Bigger
MPS Stem Cell Research Group, Uni. of Manchester
One year funding to investigate Genistein and Synaptic Decline in MPS IIIB

Dr Brian Bigger
MPS Stem Cell Research Group, Uni. of Manchester
1 year grant to research Non Myeloblative Bone Marrow Transplantation for MPS I

James Blundell
University of Birmingham
Year one of a three year grant to fund a post graduate studentship to develop of sensitive and efficient methods for measuring cognitive abilities in the areas of memory, language, attention and motor control in children with MPS and related diseases

Dr Chris Hendrikz
University of Birmingham
Contribution to grant by the LSD Patient Collaborative to the LSD Clinical Study Group

Dr Patrick Deegan
University of Cambridge
1 year grant to research Therapeutic targeting of lysosomal enzyme glycoforms in Hunter syndrome and Fabry disease

Dr Brian Bigger
University of Manchester
Grant to research 'The brain degeneration in Sanfilippo mice reversible after long term substrate reduction therapy'

Dr Brian Bigger
University of Manchester
Grant to research 'The effect of heparan sulphate on stem cell homing and engraftment in MPS I'

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. In recent years the MPS Society has carried out a number of quality of life surveys using a variety of validated Quality of Life measures. From this work it has become apparent that these measures are not effective in measuring quality of life in children and adults with physical and/or neurological degenerative disease. At the International Symposium on Mucopolysaccharide and related diseases in Adelaide the Chief Executive made an oral presentation of her poster 'a pilot assessment of four questionnaires for accessing functional status and quality of life in Mucopolysaccharidosis Type I.'

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.

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 2010 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 £957,963 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 2010/2011 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 a building with a book value of £741,600, which had an outstanding mortgage of £280,493 at 31 October 2010.

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
4 February 2011

FINANCIAL REVIEW

As well as applications to grant giving bodies for special projects and advocacy support worker salaries, the Society relies heavily through the year on its members and supporters to raise unrestricted income by way of donations and fundraising. Fundraising receipts were up by £7,171. That may be attributed to the new downloadable fundraising materials available on the MPS website and the support members are receiving in their fundraising efforts from the Communications Officer. In contrast general donations are down by £17,284. Whilst compared with many charities the Society's income in these areas held up well but the Society still has the ongoing challenge of attracting unrestricted income to enable the Society to deliver its support and individual advocacy service.

Overall income increased by £682,783 to £1,814,184 compared to overall expenditure of £1,292,226. The total charitable spend increased by £107,987 to £1,292,226 in this financial year with the Society's core activities being sustained and developed year on year. The Society has, as is to be expected, seen a significant decrease in the interest received on its bank income.

The income increased substantially for two reasons:

- Receipt of £100,000 legacy (unrestricted)
- Receipt of £834,367 in restricted grants for research

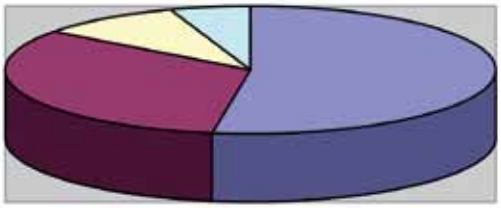
At the year end the Society has £521,958 surplus brought about because of the significant rise in income in this financial year restricted to specific research projects (see page 19), and where the funds have not been drawn down in the year they were received. The largest single grant being not yet drawn down is that of the £400,000 to develop therapies for Sanfilippo disease.

Where the money came from

The MPS Society's income was £1,814,184 and was generated in the following areas:

Where the money was spent

The MPS Society's expenditure was £1,292,226 and was spent in the following areas:



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:

"My neice Nadine Murty is two years old and suffers from MPS I Hurler disease. She is such a fun loving little girl, she has a go at everything. She loves to play with her sister Chloe and once she's out playing, it's hard to get her back in again.

Myself and my family wanted to do something for MPS Awareness Day on 15 May, it was also Nadine's granddad's special day as it was his 70th birthday. We had a special lunch and all the family wore blue MPS awareness ribbons. Also on15 May Nadine's Aunt Marlene and her friend Katie walked the West Highland Walkway and raised a lot of money for the MPS Society.

My two sisters, Helen, Josephine, brother-in-law Kevin, Nadine's sister Chloe, friends Amanda and Shirley, and their kids, Maureen and Aiden, all cycled around the Isle of Cumbre, Millport on 22 May. We all had a great day and the weather was very hot and sunny. My sister Helen had a great day with Nadine down on the beach and the play park in Millport, while we all cycled 10.25 miles around Millport. It took us all 2 hours. We stopped off for ice creams and drinks and also to give 8 year old Chloe and 10 year old Aiden a little rest.

We raised £1003.50 for the MPS Society. We were all very proud of each other for raising this amount. The monies were all donated from Caledonian University, McVitie's Biscuits, Forest Furnishings, Golden Jubilee Hospital and many family and friends. We would like to thank you all at the MPS Society for the hard work that you do to help the sufferers and families affected by MPS diseases."
Sandra Irvine

"Whilst attending ante-natal classes in 2007 I met and became really good friends with Caroline. Our sons are now best friends and both start pre-school together in September. They both love the same things and are crazy when they get together and you can't tell the difference between them. However Caroline's little boy, George, was diagnosed with Hunter Syndrome a couple of years ago and now has to have life saving medicine dripped into him for two hours once a week.

Hunter Syndrome is a rare, genetic disease. It has a wide spectrum of severity and which often involve both physical and mental deterioration. In many cases it can lead to death in childhood. There is no cure, only treatment for the symptoms as they arise.

Hunter's comes under the umbrella of the Society for Mucopolysaccharide Diseases who represent and support over 1200 affected children and adults in the UK and desperately need donations. So, I did the Keswick to Barrow 40 mile (yes 40 miles) walk on Saturday 8 May followed by the Manchester 10k on Sunday 16 May. Charlie and George are also putting on their tiny trainers and are going to do the Manchester Mini." ***Cali Pickens***

"About two years ago my nephew and niece were diagnosed with Morquio. This as the readers already know, is devastating news not only for the children but for parents and extended family. Very soon after this dreadful discovery the MPS got in touch with the family. They provided support for the parents and have helped them come to terms with their new life, which by the way, they have discovered is still a good one!! This support has been ongoing and very much appreciated.

Now I am not a New Year's Resolution kind of girl, but on New Years Eve 2008 I decided to set myself a goal for 2009 which was to do something to raise money for the MPS, by way of repaying some of the kindness and support they have shown our family. At this stage I must point out that I am also not the athletic type, I'm more of a sitting on the sofa with a glass of wine type.

However for some mad reason, (or maybe too much alcohol), the idea of running in the Grim Challenge seemed a fantastic idea. The Grim Challenge is an 8 mile run, over an army driving assault course in Aldershot. The Challenge takes place in early December which as you can imagine is fairly cold, but the "Grim" part is that in order to complete the course you must run through puddle after puddle up to your waist, slide up and down muddy hills and generally get as wet and as dirty as humanly possible. Whilst running the course I questioned my own sanity constantly but I finished in 1hr 29mins and with a huge sense of personal achievement.

Friends and family had sponsored me for this challenge and I was able to raise just over £1000 for completing the course, so well done them! The next time I organise something to raise funds for the MPS, it will not involve me doing something quite so unpleasant but there will be a next time because the MPS is a great charity and worthwhile supporting." ***Sarah Vickery***

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, 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.

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. In March 2010 the Society reported on its first year's work which resulted in draft clinical and social care guidelines for children and adults diagnosed with Sanfilippo disease. These guidelines are now out for peer review and the second year's work to develop clinical and social care guidelines for the Mucolipidoses is underway.

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

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:

Alliance Bernstein
Amicus Therapeutics
ASDA - Eastbourne
Bank of America
Bernard Sunley Charitable Foundation
Biomarin Europe
Dave Kelly
Eveson Charitable Trust
Heather Gordon & Anne Cotton
Roald Dahl's Marvellous Children's Charity
DHSS – Northern Ireland
DHSS – England
Genzyme Therapeutics
Henry Smith Charity
Hobson Charity
Holly Nowell - Kent
Leathersellers Company Charitable Fund
Mercers Company
Norton Rose LLP
Rok - Devon
The Pearson Family & Friends - Gloucestershire
The Shauna Gosling Trust
The Towersey Morris Men
Shire Pharmaceuticals
Soutar Charitable Trust
Wills & Trust IFP Ltd

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.

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 2010 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 the Charities and Trustee Investments (Scotland) Act 2005 and the Charity Accounts (Scotland) Regulations 2006. 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 Section 44(1)(c) of Charities and Trustee Investments (Scotland) Act 2005 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 2010 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 for England and Wales and the Charity Accounts (Scotland) Regulations 2006.

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

4 February 2011

STATEMENT OF FINANCIAL ACTIVITIES

Incorporating an income and expenditure account for the year ended 31 October 2010

	Notes	Unrestricted Funds £	Restricted Funds £	Totals 2010 £	Totals 2009 £
INCOMING RESOURCES					
Incoming resources from generated funds					
Voluntary income					
Donations		28,567	-	28,567	45,851
Legacies		100,000	-	100,000	25,000
Jeans for Genes Appeal		-	108,010	108,010	412,521
		128,567	108,010	236,577	483,372
Activities for generating funds					
Fundraising		126,401	9,880	136,281	129,110
Charitable Activities					
Grants & Research Funds Receivable	4	7,000	1,114,350	1,121,350	321,577
Clinical Studies Trial Support		-	112,702	112,702	25,300
Conferences		-	165,930	165,930	121,476
Childhood Wood		-	2,208	2,208	11,117
Family support of special events		-	20,726	20,726	18,173
Resource materials and magazine		11,196	-	11,196	4,949
		18,196	1,415,916	1,434,112	502,592
Other Incoming Resources		6,063	-	6,063	5,895
Investment Income		1,151	-	1,151	10,432
Total incoming resources from generated funds		280,378	1,533,806	1,814,184	1,131,401
RESOURCES EXPENDED					
Costs of generating funds					
Costs of generating voluntary income					
Jeans for Genes Appeal		-	9,066	9,066	7,257
Costs of Generating Funds					
Fundraising		60,387	-	60,387	59,823
Charitable Activities	5	11,105	1,092,134	1,103,239	981,693
Governance costs	6	119,534	-	119,534	135,466
Total Resources Expended		191,026	1,101,200	1,292,226	1,184,239
NET (OUTGOING) RESOURCES - MOVEMENT OF FUNDS		89,352	432,606	521,95	(52,838)
Total Funds brought forward		509,047	525,357	1,034,404	1,087,242
TOTAL FUNDS CARRIED FORWARD		£598,399	£957,963	£1,556,362	£1,034,404

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 2009 or 2010.

BALANCE SHEET AT 31 OCTOBER 2010

	Note	2010	2009
FIXED ASSETS			
Tangible Assets for use by the Charity	7	788,708	808,088
CURRENT ASSETS			
Debtors	8	35,000	100,000
Short Term Deposits	9	1,114,609	544,933
Cash at Bank and in Hand		1,870	4,137
		1,151,479	649,070
CREDITORS - Amounts falling due within one year	10	143,332	80,261
NET CURRENT ASSETS		1,008,147	568,809
TOTAL ASSETS LESS CREDITORS DUE WITHIN ONE YEAR		1,796,855	1,376,897
CREDITORS – Amounts falling due after one year	11	240,493	342,493
NET ASSETS		£1,556,362	£ 1,034,404
FUNDS OF THE CHARITY			
Unrestricted Funds-General Funds	12	112,881	23,529
Unrestricted Funds-Designated Capital Fund	12	485,518	485,518
Restricted Funds	13	957,963	525,357
		£1,556,362	**£1,034,404**

Approved on behalf of the Trustees on 4 February 2011.

Notes to the Financial Statements for the year ended 31 October 2010

1. ACCOUNTING POLICIES

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.

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.

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.

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 2010 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.

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.

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.

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.

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.

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.

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

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.	SURPLUS/(DEFICIT) FOR THE YEAR	2010 £	2009 £
	Surplus /(Deficit) for the year is after charging:		
	Depreciation	19,380	31,661
	Auditors Remuneration	1,939	1,939
	Trustees Reimbursed Expenses	10,352	10,862

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	2010 £	2009 £
	Wages and Salaries	249,150	266,991
	National Insurance	27,714	26,534
	Pension Scheme	10,130	9,686
		£276,994	£303,211

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:

	2010 No	2009 No
Director	1	1
Administration	1	1
Advice, information and support services	8	8
	10	10

4. GRANTS AND RESEARCH FUNDS RECEIVABLE

	Unrestricted Funds £	Restricted Funds £	Total 2010 £	Total 2009 £
Miss Agnes H Hunters Trust	-	-	-	3,000
Amicus Therapeutics	-	1,394	1,394	1,320
Biomarin	-	17,000	17,000	16,500
Bridge House Trust	-	-	-	4,250
Christadelphian Samaritan Fund	-	-	-	300
Roald Dahl's Marvellous Children's Charity	-	28,005	28,005	37,340
DHSS – Northern Ireland	-	4,052	4,052	3,953
DHSS – England	-	48,960	48,960	48,500
Enkalon Foundation	-	-	-	4,500
Eveson Charitable Trust	-	15,000	15,000	-
Genzyme Therapeutics	-	15,100	15,100	16,485
Gill Turner	-	1,000	1,000	-
Henry Smith Charity	-	30,000	30,000	-
Hobson Charity Ltd	-	20,000	20,000	-
John Ellerman Foundation	-	-	-	38,000
Leathersellers Company Charitable Fund	-	3,000	3,000	-
Mercers Company	-	-	-	2,000
National Commissioning Group	-	-	-	15,000
Oakley Charitable Trust	-	-	-	500
Ollie G Shoot	-	-	-	2,632
Ollie G Ball	-	-	-	20,400
Scope	-	-	-	5,000
Shire Pharmaceuticals Ltd	7,000	20,000	27,000	40,000
Souter Charitable Trust	-	-	-	1,000
Bernard Sunley Charitable Foundation	-	10,000	10,000	5,000
Sir Jules Thorn Charitable Trust	-	600	600	-
The Shauna Gosling Trust	-	30,000	30,000	30,000
Walter Guinness Charitable Trust	-	500	500	-
Individual Grants to families via MPS	-	-	-	19,884
MPS Research Projects	-	836,485	836,485	2,412
Overseas Co-operation Grants	-	13,074	13,074	4,601
Shire Pharmaceuticals Ltd	-	20,000	20,000	-
Training Grants	-	180	180	-
	£7,000	£1,114,350	£1,121,350	£321,577

5. CHARITABLE ACTIVITIES EXPENDITURE

	Unrestricted Funds £	Restricted Funds £	Total 2010 £	Total 2009 £
Research and Support Grants	-	425,805	425,805	484,767
Jeans for Genes Joint Venture Loan	-	37,500	37,500	25,000
Clinical Studies Trial Costs	-	109,836	109,836	39,547
Conferences	-	180,337	180,337	115,667
Family Support Special Events	-	3,485	3,485	12,301
Overseas Co-operation	-	9,664	9,664	12,100
Grants and Donations	1,178	-	1,178	25,722
Childhood Wood	-	14,025	14,025	1,281
Magazine and Resource Materials	8,038	-	8,038	6,851
Support Services	-	220,010	220,010	197,099
Office Support Costs	-	91,372	91,372	59,766
Training	1,889	-	1,889	1,592
MPS Financial Assistance Scheme	-	100	100	-
	£11,105	£1,092,134	£1,103,239	£981,693

6. GOVERNANCE COSTS	Unrestricted Funds £	Restricted Funds £	Total 2010 £	Total 2009 £
Depreciation	19,380	-	19,380	31,662
Mortgage Interest	5,624	-	5,624	10,885
Professional Fees	5,047	-	5,047	5,856
Management Committee Expenses	10,352	-	10,352	10,862
Office Running Costs	22,524	-	22,524	11,461
Payroll Costs	50,452	-	50,452	60,922
Recruitment and Advertising	6,155	-	6,155	3,818
	£119,534	-	£119,534	£135,466

7. TANGIBLE FIXED ASSETS	Freehold Property	Property Improvements	Computers and Equipment	Office Furniture	TOTAL
COST					
At 1 November 2009	824,000	51,524	143,042	20,606	1,039,172
Additions	-	-	-	-	-
At 31 October 2010	824,000	51,524	143,042	20,606	1,039,172
DEPRECIATION					
At 1 November 2009	65,920	3,386	141,172	20,606	99,423
Charge for Year	16,480	1,030	1,870	-	31,661
At 31 October 2010	82,400	4,416	143,042	20,606	31,084
NET BOOK VALUE					
At 31 October 2010	741,600	47,108	-	-	788,708
At 31 October 2009	£758,080	£38,138	£1,870	£-	£808,088

All fixed assets are held for charitable purposes.

8. DEBTORS	2010 £	2009 £
Jeans for Genes Appeal	35,000	100,000
	£35,000	£100,000

9.	**SHORT TERM DEPOSITS**	**2010**	**2009**
		£	**£**
	Cash on Bank Deposit	1,089,609	519,933
	Treasury 4% Consolidated Stock	25,000	25,000
		£1,114,609	£544,933

10.	**CREDITORS - Amounts falling due within one year**		
	Bank Loans and Overdraft	135,426	74,842
	Accruals	7,906	5,419
		£143,332	£80,261

11.	**CREDITORS – Amounts falling due after one year**		
	Bank Loans and Overdraft	£240,493	£342,493

Bank loans comprise of primarily a mortgage on the premises at Repton Place purchased on the 16 December 2005. The mortgage represents approximately 34% of the Property Value and is secured on that property.

12.	**UNRESTRICTED FUNDS**	**£**	**£**
	General Funds		
	At 1 November 2009	23,529	58,399
	Net incoming (outgoing) resources	89,352	(35,410)
	At 31 October 2010	112,881	23,529
	Funds designated for Jeans for Genes capital projects		
	At 1 November 2009	485,518	485,518
	At 31 October 2010	485,518	485,518
		£598,399	£509,047

13.	**RESTRICTED FUNDS**		
	Jeans for Genes Appeal	167,033	329,071
	Other Grants and Donations	790,930	96,286
		£957,963	£525,357

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.

14. **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	-	167,033	-	167,033
Other Grants and Donations	-	947,576	(156,646)	790,930
		1,114,609	(156,646)	957,963
UNRESTRICTED FUNDS	788,708	-	(190,309)	598,399
	£788,708	£1,114,609	(346,955)	£1,556,362