

MPS

Autumn 2007

Care Today, Hope Tomorrow



Society for
Mucopolysaccharide
Diseases


MPS Volunteer

Mucopolysaccharide and Related Diseases are individually rare; cumulatively affecting 1:25,000 live births. One baby born every eight days will be diagnosed with an MPS or Related Disease. These multi-organ storage diseases cause progressive physical disability and, in many cases, severe degenerative mental deterioration resulting in death in childhood.

What is the Society for Mucopolysaccharide Diseases?

The Society for Mucopolysaccharide Diseases (the MPS Society) is a voluntary support group, founded in 1982, which represents from throughout the UK over 1200 children and adults suffering from MPS and Related Diseases, their families, carers and professionals. It is a registered charity entirely supported by voluntary donations and fundraising and is managed by the members themselves.

What are the aims of the MPS Society?

- To act as a support network for those affected by MPS and Related Diseases
- To bring about more public awareness of MPS and Related Diseases
- To promote and support research into MPS and Related Diseases

How does the Society achieve these aims?

Advocacy Support

Provides help to individuals and families with disability benefits, housing and home adaptations, special educational needs, respite care, specialist equipment and palliative care plans

Telephone Helpline

Includes out of hours listening service

MPS Befriending Network

Puts individuals suffering from MPS and their families in touch with each other

Support to Individuals with MPS

Empowers individuals to gain independent living skills, healthcare support, further education, mobility and accessing their local community

Regional Clinics, Information Days & Conferences

Facilitates eleven regional MPS clinics throughout the UK and information days and conferences in Scotland and Northern Ireland

National & International Conferences

Holds annual conferences and offers individuals and families the opportunity to learn from professionals and each other

Sibling Workshops

Organises specialist activities for siblings who live with or have lived with a brother or sister suffering from an MPS or Related Disease

Information Resources

Publishes specialist disease booklets and other resources

Quarterly Magazine

Imparts information on disease management, research and members' news

Bereavement Support

Supports individual families bereaved through MPS and the opportunity to plant a tree in the Childhood Wood

Research & Treatment

Funds research that may lead to therapy and treatment for MPS and Related Diseases as well as furthering clinical management for affected children and adults

CARE TODAY HOPE, TOMORROW

Cover photograph: Natalie Durkin (MPS Childcare Volunteer) and Alfie Tucker at the Sibling Weekend



MPS Magazine

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Newsletter Deadlines

Winter	1 Dec 2007
Spring	1 Mar 2008
Summer	1 Jun 2008
Autumn	1 Sep 2007

Become a Friend of MPS

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MPS
Awareness Day
Thursday
15 May 2008

International Fabry
Conference in Munich
18 - 21 October 2007

There are five spaces free.
 If you are interested please call
 Miriam Blowers at the MPS
 office as soon as possible.

CHIEF EXECUTIVE'S REPORT



We are delighted to have some good news from Scotland with regards to Enzyme Replacement Therapy. Although the Scottish Medicines Consortium (SMC) has decided not to recommend reimbursement of the treatment Elaprase for MPS II, the Greater Glasgow NHS Trust has agreed to fund Elaprase for a boy with MPS II in Glasgow. This is good news and we hope this will increase the chances of a boy with MPS II in Grampian receiving funding approval for Elaprase in the very near future.

I would like to thank all our bereaved MPS I and MPS II families who have over the past few weeks helped us to bring the MPS I and MPS II registries up to date. If you didn't hear from us it is because you were known to the teams at the Royal Manchester Children's Hospital or Great Ormond Street Hospital and your children were on the registry. This information is so valuable as it will enable the Society and experts in MPS to understand the longevity of these diseases and the primary and secondary causes of death. We would expect to be able to give you feedback from these studies early next year when all the data has been collated.

Later in the magazine you will be able to read about the fantastic weekend some of our MPS brothers and sisters enjoyed at Center Parcs in Sherwood Forest. It was a real privilege to spend the weekend with these young people and our thanks also go to the volunteers who gave their time to ensure the safety of the children and encouraged them on all the activities. We are hoping to run a similar weekend for siblings in 2008.

Recently we had a Family Day to Chessington Adventure Park. We will also be having a Family Day to the London Aquarium and London Eye, and are applying for funding to arrange other activities in other parks of the UK. The next planting in the Childhood Wood will take place on Friday 19th October.

Plans are also in place for our Alton Towers Weekend on 3rd - 4th May 2008 for which you have already received the Booking Form. The early bird booking deadline is 14th December, offering a bargain at £199 per family. Get your booking in early as places are limited and the cost of places after 14th December will rise to £240. Please do book early to avoid disappointment.

We are also in the early stages of arranging MPS conferences in Northern Ireland and Scotland for 2008. Details of the International Symposium on Mucopolysaccharide and Related Diseases which will be held in Vancouver, Canada, 26th – 29th June 2008, are enclosed. Fundraising from the Ollie G Shoot will help families to get to this important conference, but funds are limited and it is important that if you wish to attend you need to complete and return the 'expression of interest form' by the deadline.

Christine Lavery
Chief Executive

News from the MANAGEMENT COMMITTEE

The Society's Board of Trustees meet regularly. Here is a summary of the main issues that were discussed and agreed at the Management Committee Meeting held on 17-18 August 2007.

Governance

The MPS Risk Register was reviewed and agreed. The following policies were reviewed and agreed without amendment: Data Protection, Child Protection, Reserves Policy, Moral and Ethical Policy, Moving and Handling Policy, Careplans Policy, Policy on the Use of Electronic Equipment outside the Office, Policy statement on research, CRB and Disclosure Privacy Policy, Copyright Policy, Managing Stress in the Workplace, Gift Policy, Death of MPS Sufferer, Sickness Absence, Organising Regional Events, DSE Eyecare Policy, Leave for Domestic and Personal Reasons, No Smoking Policy, Policy statement on Board Diversity, Senior Management Conduct Policy.

Election of Officers

Barry Wilson was re-elected as Chairman. Wilma Robins was re-elected as Vice Chair. Bob Devine was re-elected as Vice Chair. Judith Evans was re-elected as Treasurer.

Strategic Plan

Trustees went through the second year objectives of the MPS Strategic Plan 2005 - 2010 and agreed the list of objectives.

Personnel

Trustees were informed that Miriam Blowers had taken on the role of Volunteer and Event Co-ordinator and Sue Cotterell is now the Office Administrator. Sophie Thomas continues on maternity leave following the birth of her son, Harvey in July.

Advocacy Support

The Trustees received a report at the meeting on Advocacy Support to our members. The most common problem was housing, equipment and adaptation followed by educational needs, direct payments, assistance with grants and access to Clinical Management.

International Collaboration

Trustees were advised of the Chief Executive's overseas commitments until December 2007. This is to be an incredibly busy period which will benefit the Society in working collaboratively with other international organisations in the field of lysosomal storage disorders.

Generating Funds

The Trustees were informed that fundraising by MPS members and supporters continues to do well and a number of fundraising events are planned.

MPS Research Grants

The Trustees were informed of the status of all current MPS research grants. Trustees agreed to consider at the next Management Committee Meeting a future strategy for funding research and develop a policy statement on research grants.

Access to Clinical Management and Treatment

Trustees received a detailed feedback on the status of funding for ERT and the challenges presented in Scotland. The Society continues to support MPS members in this area of work.

MPS Staff News: Miriam and Sue have changed roles

Two members of MPS staff, Miriam Blowers and Sue Cotterell, have changed roles within the office. Miriam is now the Volunteer and Event Co-ordinator, and has already organised the Sibling Weekend and Family Day to Chessington, and is looking forward to the Fabry Conference in Munich, as well as many other exciting events in the future.

Meanwhile Sue has taken on the role of Office Administrator, providing support to Christine and the team, and carrying out office management duties. Both Sue and Miriam are enjoying their new roles for the MPS Society. If you wish to contact Miriam about upcoming events, email m.blowers@mpssociety.co.uk or call 0845 389 9901.

Why don't you become a

Friend of MPS?

To promote the Society to a wider audience and encourage more support we launched the Friends of MPS in 2005.

Would you like to show your support by becoming a Friend of MPS?

We welcome relatives, friends, overseas professionals or indeed anyone interested in the work of the Society or the field of MPS and Related Diseases.

This encourages us, helps us plan for the future and brings about more public awareness for this group of rare, genetic diseases.

If you are not eligible to become a member of the Society why not become a Friend of MPS? Download a form from our website www.mppsociety.co.uk or phone us for an application form.

What are the benefits of becoming a

Friend of MPS?

- Membership number and card
- Quarterly colour MPS magazine
- Quarterly colour fundraising newsletter
- Annual review and accounts
- Priority ordering of MPS & Corporate Christmas cards
- Information on and preferential rates at MPS events
- Regular publication updates

If you want to do more than just become a Friend of MPS ask for a fundraising pack to find out more.

Phone us on **0845 389 9901**

or visit **www.mppsociety.co.uk**



ANNOUNCEMENTS

New Members

Karen and Scott Glover have recently been in contact with the Society. Jake has a diagnosis of Fucosidosis. Jake is two years old and the family live in the South East.

Alan and Donna Brown have recently been in contact with the Society. Luke has a diagnosis of Sanfilippo Disease. Luke is two years old and the family live in the South East.

Mr P Jordan has recently been in contact with the Society. Philip has a diagnosis of Fabry Disease. Philip is 38 years old and the family live in the North of England.

MPS Awareness Day Thursday 15 May 2008

**You are important to us,
please keep in touch.**

Please remember to let the Society know if you are moving and your new address and telephone number. In addition to helping keep the printing costs down, you will help us keep our database up to date. Keep us informed of new addresses, telephone numbers, email addresses and any interesting news about yourself, your child or your family.

Retirement of Margaret Thornley

Thank you to you and the MPS Society for the lovely flowers you sent to mark my retirement. I had a lovely evening out with my colleagues from the Willink Unit, Royal Manchester Children's Hospital and the flowers were an unexpected bonus.

25 of my 36 years with the Willink have been involved with MPS and I have enjoyed the work and the people I have been privileged to meet. I shall still be around on a part time basis and hopefully we will get somebody to carry on my job and I can help train them and keep our service to the high standard I believe we have come to expect. **Margaret Thornley**

Deaths

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

Shabana Khezar who suffered from Hurler Scheie Disease and who died in May 2007 aged 25.

Jess Robertson who suffered from Hurler Scheie Disease and who died on 8 June 2007 aged 1 and a half.

Ayesha Fatima Akhtar who suffered from Sanfilippo Disease and who died on 31 July 2007 aged 3 years.

Louise Hill who suffered from Sanfilippo Disease and who died on 12 August 2007 aged 28.

Sujaid Ali who suffered from Scheie Disease and who died on 15 August 2007 aged 34.

Ann Canton who suffered from Scheie Disease and who died on 15 September 2007 aged 61.

It was with considerable sadness that we learnt of the death of David Leask, father of Christopher Leask (MPS III). Our thoughts are with Margaret, David's wife, at this time.

Your news and views

We are always pleased to receive news, information and letters from all our readers, especially our members. We welcome letters on any subject and your views and comments would be very welcome or perhaps you would like to share some information? Email us at newsletter@mpssociety.co.uk

2007 Dates for your diaries!

13 October	London Aquarium/ London Eye
19 October	BMT Clinic, Manchester
19 October	Childhood Wood Tree Planting
18-21 Oct	International Fabry Conference, Munich
22 Nov	Northern Ireland MPS Clinic

ANNOUNCEMENTS

MPS Awareness Day Thursday 15 May 2008

If you would like help, guidance or information from the MPS Society's advocacy team please do call us on
0845 389 9901



Ayesha Fatima Akhtar

Born on 28 May 2004

Died on 31 July 2007 aged 3 years

Ayesha had Sanfilippo Disease, MPS III, and died of heart failure at home in our arms.

*The grief I feel nobody knows
only I know why the chills blow,
for my child's life is so much to show,
now she is in heaven looking down
at us below.*

*I remember her lovingly as a little girl
I love her, it hurts so bad now she
is gone we're all so sad.
I loved her as a loving father,
She was so happy and so brave,
But now I have to go and look
at her grave. Naveed Akhtar*

**The MPS Society
would like to congratulate
Michael and Ruth Hall on
their marriage which took
place on 17 August 2007.**

**We would like to wish you
both every happiness for
your future together.**

Many congratulations!

We just had to write to thank you and all at the MPS Society for the lovely flowers which arrived today. Over the past few weeks, Steven and I have been completely overwhelmed by the kindness of everyone who knew Jess and about her illness.



Although Jess left us very suddenly, we seem to be gaining strength from her in some way to cope. She was a typical eighteen month old toddler, full of kisses, cuddles and mischief! This seems to get us through the days when it all seems so unfair. All we have to do is think of her making us all laugh and the sorrow lifts. Jess touched everyone who met her. Especially since she was diagnosed with MPS I, Hurler Scheie Disease.

We know how lucky we were to have found a bone marrow donor so quickly and also have NHS Lothian fund the Enzyme Replacement Therapy. Everything was going as well as it could have. We also were painfully aware how hard the years ahead were going to be, but as long as Jess had the strength, we would too.

As I mentioned to you recently, Steven and I are more than willing to keep in touch with the Society. If we can be of use in any way at all we would be more than happy to help. Up until four months ago we had never heard of MPS diseases and now we are more or less experts!

Please pass on our thanks to all at MPS House.
Emma and Steven Robertson

**Jess Robertson passed away on
8 June 2007. Jess was diagnosed
with MPS I Hurler Scheie Disease.**

ANNOUNCEMENTS

Louise Hill

28 April 1979 - 12 August 2007

Louise's Eulogy

Louise came into this world 28 years ago as a beautiful, bonnie baby, being totally unco-operative from the moment she was born.

She ate a lot, cried a lot and slept very little, but nevertheless grew into a healthy, strong toddler with great enthusiasm for life.

We began to realise this enthusiasm was uncontrollable, and within two weeks of starting school she was assessed as needing special schooling. A further blow followed when after nine months of testing she was diagnosed with Sanfilippo Disease, MPS III, a very rare degenerative disease.

Dark years followed as we tried to be a normal family with Louise getting bigger, stronger and more hyperactive. Despite the chaos she caused around her, there was never any malice and everyone who knew her loved her.

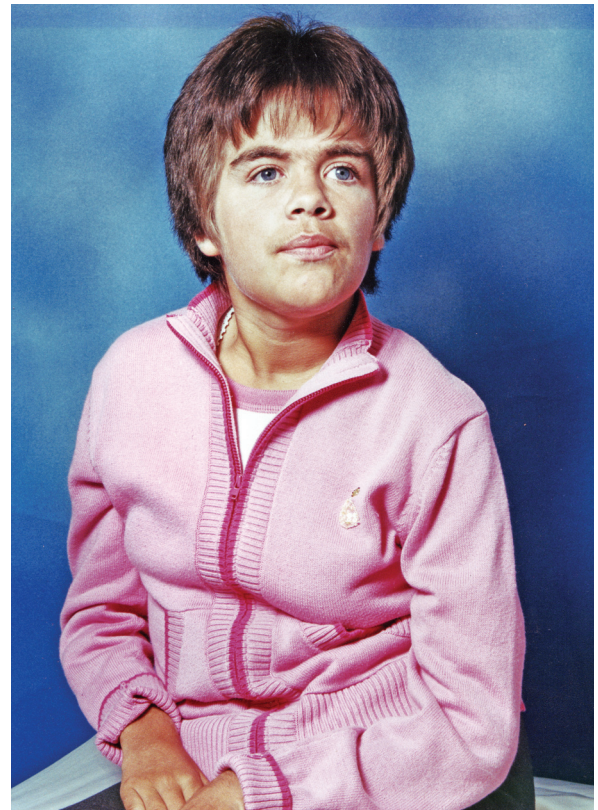
We have endless anecdotes that would fill a book. Food was her greatest pleasure but she would eat anything that she could get into her mouth. How a wrapped entire finger of fudge can pass through a person is still a mystery to us! Balloons and batteries formed a risky part of her diet and she needed constant watching.

Tea time with three little children and Louise became unmanageable and Emma who was a sixth former living around the corner became Louise's carer. She is now a teacher with two children of her own and here are some of the memories she sent to us:

'I remember her lovely smile, her mischievous eyes always on the lookout for an opportunity to escape or eat something she shouldn't, her infectious giggle and the way she never failed to bat her eyelashes at my brother! I spent many happy hours sitting on the sofa with Lou, eating Rich Tea biscuits and trying to persuade her to watch Neighbours after school! I have always thought of her at Christmas time when reading the poem 'The Night Before Christmas' to one of my classes, or more recently to George. I wonder why the line 'like a bowl full of jelly' made her laugh so much. It still makes me smile. I will remember a very happy Louise, pottering around her 'wing' of your home in Hacker Close, crashing out her own compositions on the piano, resisting any attempt to 'row row row your boat' on the floor and looking up, tilting her head and smiling at the next person to walk in the room.'

By her mid teens the illness had progressed and Louise had lost many skills. A spinal curvature made it difficult to balance and walk unaided. Losing her speech was a major sadness but she retained the ability to laugh, giggle and scream for many more years.

After leaving her happy school years behind she attended the Doyle Day Centre until Sanfilippo Disease made even that too difficult. A few years followed when her full time carer Janet would take her out daily in her own little car visiting friends, shopping, taking tea, and her much loved beach hut. She had changed from being like an exuberant puppy to a gentle, sweet soul with only simple needs, and in her final two or three years, rarely left the farm. Living became an effort for Louise, and on Monday morning after spending a weekend surrounded by the love of all her family, she decided to take that courageous new step into her new life whilst no one was watching. She touched the hearts of everyone that knew her and taught us all so much about the important things in life. **Gordon and Anne Hill**



I'll lend you a child

*'I'll lend you for a little time a child of mine,' God said.
For you to love – while she lives
And mourn for when she's dead.
It may be six or seven years
Or twenty-two or three,
But will you, till I call her back,
Take care of her for Me?
She'll bring her smiles to gladden you
And should her stay be brief
You'll have her lovely memories as solace for your grief.*

*I cannot promise she will stay,
Since all from earth return,
But there are lessons taught down there
I want this child to learn.
I've looked this world over
In search for teachers true,
And from the throngs that crowd
Life's lanes, I have selected you.
Now will you give her all your love,
Nor count the labor vain,
Nor hate Me when I come to call to
Take her back again?'*

*I fancied that I heard them say,
'Dear Lord, Thy will be done,
For all the joy Thy child shall bring,
The risk of grief we'll run.
We'll shelter her with tenderness,
We'll love her while we may,
And for the happiness we've known
Forever grateful stay.
But should the angels call for her
Much sooner than we've planned,
We'll brave the bitter grief that comes
And try to understand.'* **Edgar Guest**

David's Story

As mentioned in the Chief Executive's report on page 4, the MPS Society is delighted to have some good news from Scotland with regards to Enzyme Replacement Therapy. Although the Scottish Medicines Consortium (SMC) has decided not to recommend reimbursement of the treatment Elaprase for MPS II, the Greater Glasgow NHS Trust has agreed to fund Elaprase for a boy with MPS II in Glasgow. Here is their story...



We are Robert McDowall and Elizabeth McDowall, a Solicitor and Nurse, and the parents of David. We have two other children Fiona (18) a Dental Student, and Rachel (16) a schoolgirl.

David was diagnosed with Hunter's at the age of three. His older sister Fiona is a carrier. This diagnosis was devastating to our family, due to the severe and lethal affects caused by the condition, and the life expectancy being limited to his teens.

We were aware at a very early stage of the symptoms of this condition, and could see these also in front of our own eyes. Irreversible changes would occur in David's body, resulting in significant reduced mobility and severely restricted quality of life. Hunter Syndrome affects the central nervous system, slowed growth, impaired vision and hearing, upper airway obstruction, reduced pulmonary function, recurrent infections, cardiac disease, joint deformities and reduced range of motion. David suffered all of these symptoms from before the age of three, and the very fact that he was diagnosed at such an early stage

is indicative that the initial diagnosis was that David was suffering from a more severe strain of the condition. David has already undergone surgery at an early age for tonsilectomy, adenoidectomy, grommets in his ears and dental extraction. He continues aside from symptoms and difficulties to have particularly severe bilateral sensory hearing difficulties, a learning disability and limited speech.

We had been involved with the MPS Society, and we learned of a natural history study which was being undertaken at the Willink Clinic at Pendlebury Hospital in Manchester, which is the UK's leading centre for Mucopolysaccharide disorders and screening, under consultant Dr Ed Wraith. Ourselves and David cooperated in this study and through this then heard of a trial being conducted for this new drug called Elaprase by the manufacturers, TKT and then Shire. There had been trials conducted in the USA and we were aware that other treatments such as bone marrow replacement have been unsuccessfully tried. We were not and are not aware of any other treatment that can prevent the degenerative course of Hunter disease and even reverse some aspects of Hunter Syndrome. We felt that due to the up most seriousness and helplessness of David's condition we had nothing to lose and agreed to him undergoing tests with this new drug Elaprase. We were particularly aware that there are always significant risks involved in undertaking tests by any person, in particular a young child such as David with a serious condition.

The trial commenced in January 2004 when David was nine years old. There were 9 UK patients involved in the trial and David was the only patient from Scotland. We had to travel every Thursday to Manchester with David. The infusion of Elaprase would take approximately three hours with a further one hour check regarding any after affects. We saw straightaway a difference in David when he began the trial. This continued for some 18 months until fortunately in July 2005 it was possible to arrange for the treatment to be transferred to Yorkhill Hospital in Glasgow. This was still effectively a day out of our lives but no more 5am rises to drive to the airport, arriving home over 14 hours later! After the initial two year period in the clinical trial, a further one year extension trial followed with the clinical trial ending earlier this year.

MEMBERS' NEWS

We have been asked about the impact of Elaprase on David. The impact has been considerable and has changed his entire quality of life and life expectancy. We have seen a very big difference. Patients with Hunter Syndrome are expected to have significantly restricted growth, however David has sprouted and is now tall for his age which is remarkable. His joints would normally have become extremely stiff, his hands clawed resulting in him having difficulty for example holding a pen. However David's joints have remained supple, he remains agile, and he has become more mobile. He loves football and is even able to play to his great joy. His hair has also become much noticeably softer, as before it was hard and brittle, and his tongue has reduced in size which makes so much difference for his speech and ability to swallow.

Physically, David's cardiac and lung function and mobility has improved and his stomach swelling has disappeared. The effects have therefore been remarkable and life changing. Whilst David continues to have severe difficulties, he has managed to lead a fairly normal life as has the rest of his family. He has managed to attend a mainstream school which before treatment we did not think was in anyway possible and certainly not the picture we were given when David was diagnosed. David is now a second year pupil at St Roch's Secondary School in Glasgow at the Hearing Impairment Unit. He requires a care assistant due to his hearing problems, learning disability and speech difficulties. However, he has in effect a very good quality of life and there is no doubt whatsoever that his life expectancy has been vastly improved beyond his teens. In our opinion if the treatment were stopped, his condition would decline once again as this is a progressive disease, culminating in a very early death. On treatment we now fully expect that David has a future in adulthood and will contribute positively to Society.

We would also mention the psychological effect of his improved physical condition. David has matured and grown in confidence, enjoying a full and active life. This also applies to the rest of his family. Without David being on Elaprase there is no doubt that at least one of us would have by now become a full time carer for David and we can only reflect on the impact of David deteriorating from Hunter disease would have had on his two sisters by looking at other families whose Hunter sons have

already passed away and for whom Elaprase came too late. David's sister Fiona is a carrier for Hunter disease. She is a dental student at Glasgow University. Whether David continues this medication may have a substantial pragmatic effect upon her and her future in having male children. She intends to remain in Scotland to serve the NHS and the public as a dentist.

We have no doubt that the Elaprase has had a significant and quite remarkable positive and beneficial affect upon David in the last 3 and half years, between the vital ages of 9 and 13. Hunter disease is a progressive storage condition, with deterioration affecting most parts of the human form including the skeleton, soft tissue, joints, heart, liver and spleen. It is clear that difficulties in these areas have not only been arrested but reversed and indeed David's condition has improved.

On learning of the decision by the Greater Glasgow NHS Trust to agree to funding Elaprase for David our main emotion was not so much joy as utter relief. The pressure had got worse and worse as the final weeks and days went by. There is no doubt whatsoever that David's life and that of his family has been transformed by ERT and his lifespan prolonged. Now we can just get on with our lives. David being David has of course been utterly blasé about the whole thing. He just enjoys life every day, as he always has.

We wish to thank the MPS Society, Anderson Strathern Solicitors, Dr Robinson and Dr Wraith, all at Pendlebury Hospital and the MPS families who provided testimonials to support David's case. ■

Robert and Elizabeth McDowall

MEMBERS' NEWS

Daniel's Story

While at Royal Manchester Children's Hospital on Tuesday for Daniel's infusions we were speaking to one of the nurses, Jane, and she told us about the little boy in Scotland who has been refused ERT. Jane asked us to write to you about Daniel's treatment, so this is our story.

To begin with we were a little afraid and apprehensive because trying to get Daniel to

sit for a few seconds is a feat in itself, let alone sitting for a three hour infusion. Also we were a little worried about side effects and, in particular, Daniel's breathing which isn't great.

We need not have panicked. This is our seventeenth infusion and apart from a few hiccups at the beginning, things were going great. Daniel sits quite happily watching his videos. He has a friend called Jack who is also having ERT and he loves all the wonderful nurses and especially Ed and Simon.

The most amazing thing is he looks so well. His stomach which was really large and hard like a football has gone right down and is soft. He has started to run around after his football instead of walking. He has far more energy and looks really well, he also has a lovely colour to his skin again. His hair has also got softer. The biggest thing we have noticed is that he says the odd word now and again. This is amazing because he hasn't spoken for about 5 or 6 years.

I just wanted to tell whoever needs to be told that we travel all the way from Coventry to Manchester every Tuesday morning at 6am so Daniel can have this treatment and every single minute of that journey, which is very tiring, is worth it. We have noticed so many wonderful changes in Daniel for the better that it has all been worthwhile. We wouldn't have put him through it if we didn't think it was working. Every child with MPS should be given the opportunity that Daniel and so many other children are getting.

I wonder if the powers that be had children with MPS they would look at it differently.

With warmest regards to all at MPS House.
Sandra, Rash and Daniel Singh (MPS II)



Do you need support from the MPS Advocacy Team?

Please remember that should you wish to speak with a member of the advocacy team do not hesitate to pick up the phone or email if you find it easier. Please bear in mind that at the moment we are a small team covering the entire UK, however we will always return calls and respond to messages as quickly as possible. advocacy@mpssociety.co.uk or **0845 389 9901**

MEMBERS' NEWS

MPS Befriending Scheme

Janice Wilkes became friends with Ann Canton when the MPS Befriender Scheme put them in touch with each other. Ann and Janice both had MPS I Scheie Disease. Ann died on Saturday 15 September 2007. Ann went into hospital for a cancer operation but died due to other health problems.

Ann told Janice about friends she made when she was able to go to the MPS conference, and Janice has requested that we make a special mention of this in the magazine. Janice, her sister Susan Percival and Antony Selwood all have MPS I Scheie and they would like to send their sympathy to her two sisters, family and friends. Ann was 61 and the photo here is of Ann with Janice and Antony in Wales on Ann's 60th birthday. Janice would like to thank the befriending network for putting her in touch with a very good friend.



Please read on for more information about the Society's befriending scheme...

Many families and individuals telephone the MPS Society asking for links with another family or individual in similar circumstances, whether this is by the MPS and related disease affecting the individual or family, geographical location, background etc.

On receiving such a request, the Advocacy Support Team identify one or more potentially appropriate links and telephone this/these families/individuals to ask whether they would be interested in making such a contact. At this stage only basic information is given about the family or individual requesting the link and their anonymity is maintained.

If the Befriending family/individual agree, the Advocacy Support Team

send a permission form to sign, agreeing that their names and telephone number are released to the family/individual requesting a Befriender, with a stamped addressed envelope for return of the form to the MPS office. On this form, the surname and disease affecting the family/individual requesting a Befriender are given. By only giving this information the anonymity of this family/individual is maintained until a formal link is made.

On receipt of the signed form from the Befriender a member of the Advocacy Support Team contacts the family/individual requesting the Befriender giving them the telephone number and names of the family/individual agreeing to undertake

this role. The family/individual to be Befriended are advised to dial 141 before telephoning the Befriender if they wish to maintain their privacy and not have their telephone number accessible through the Befriender dialling 1471 after the call.

From this point forward any information divulged by either party is at their discretion.

Both participants in a befriending link are advised that if any support is needed as a result of the befriending link they can speak to a member of the Advocacy Support Team at the MPS Office by phone on 0845 389 9901 or by email at advocacy@mpssociety.co.uk

The MPS Advocacy Team

Neisha, Steve and Chris are the current Advocacy Officers for all areas of the UK. We are three at the moment but will soon be back up to four on the return of Sophie from maternity leave. Although at the moment we are all very busy we will always have time to speak to you or answer your emails and help and support in any way we can.

We are here to help with any issue you may have, ranging from education, DLA to funding to name but a few – even if you think it's something we haven't helped with in the

past we are always willing to give it a go. We also offer home visits and will attend meetings with you if required. We all thoroughly enjoy getting out of the office and meeting the families and getting to know that voice on the end of the phone. Another great part of our role as Advocacy Officers is to get involved with family days out and sibling weekends. So keep your eyes peeled for us appearing at these events and don't be shy to come and say Hi to us! **The MPS Advocacy Team - Neisha Hall, Steve Cotterell and Chris Murphy**

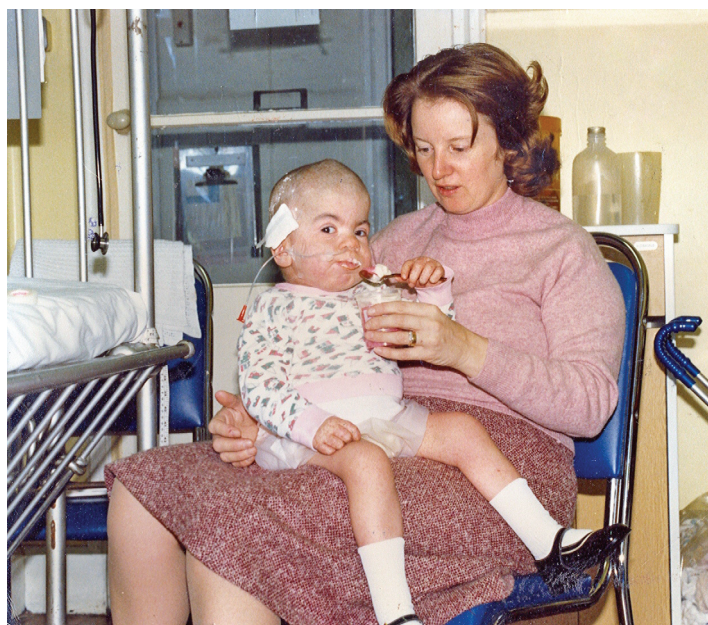
The Skidmore Family - 1982

We are Michael and Pat, and our two children are Richard, 7 and Helen, 3 years and 9 months. To anyone meeting us we are a perfectly normal, run of the mill, family. Nothing particularly exciting or outstanding about any of us and yet like so many of you reading this we have had experiences that have altered our 'ordinary' lives so drastically, we can never be 'normal'. We have a daughter with Hurler Disease.

At this present time I am not going into the detail of Helen's diagnosis, treatment or the traumatic times we have had in the past 3 ½ years, many of which you will be, or have, experienced yourselves. There is such a tremendous difference in communicating with fellow sufferers than with general outsiders. However, I would like to write about the brighter side of a little girl we, as parents, feel very humbled to have as our daughter.

Helen and I were admitted to Westminster Children's Hospital on 17th June 1981 for a bone marrow transplant using Richard as donor. He was not a good match but at least a sibling and the best available. When we made the decision to use Helen for this experimental treatment, only one child had been treated and by the time Helen was admitted, another boy had received a successful transplant from a perfect match donor. Within an hour of being admitted to WCH, treatment began in earnest and we were able to undergo two transplants with Michael being the second donor before success. Helen was dreadfully ill during these months and we lived, and still do, on a day to day basis.

At the end of October, we finally returned home after what seemed a lifetime of having our family separated. Trying to pick up the threads was constantly interrupted by frequent planned and emergency trips to London, but almost 18 months have passed since the second transplant and the obvious question is: How is she? The most effective way to answer that is in a purely medical format.



Helen in cubicle isolation

Liver and spleen: were enlarged and are now back to normal size. This was the first improvement.

Corneas: were quite cloudy although vision was not impaired. They are now brighter and clearer. A forthcoming examination will give more accurate results.

Joints: were stiffening and mobility becoming more difficult, fingers and toes becoming 'clawed.' If I say Helen uses her bed as a trampoline, attempts the splits, walks on tip-toe and generally has very few restrictive movements, it shows they are most certainly not getting any worse but showing very promising signs of improvement.

I.Q.: Groan, groan! A very frustrating thing to assess accurately I feel. A Ruth Griffiths test was carried out in March 1980 which proved her to be 14 months behind (pre-transplant it was approx 3 months) so her period of isolation was taken into consideration. Just before Christmas, another one was done, of which I do not yet know the accurate results, but it seemed she had caught up a great deal and was almost normal.

Facial Features: began to deteriorate at 18 months and are now reversing quite considerably, which the photos may show. During and after the transplant she was almost unrecognisable, due to high doses of steroids and side effects of other drugs.

There are many changes occurring which are difficult to describe. Helen is 'developing'. This seems a totally inadequate word for what is happening, and yet for those of you who have a Hurler's child, you will know what an enormous achievement this is.

Undoubtedly, the biggest miracle must be her hips. When we were finally discharged in October from WCH we were given a 'good-bye' present of – 'Helen, has dislocated hips'. I just didn't want to know, as you can imagine, but after a few months at home, of course I resigned myself to another long spell in London. This was last August. Helen was prepared for theatre for an exploratory operation to decide how to tackle her hip problem. Within 40 minutes she was returned to the ward with the fantastic news of 'nothing to be done'. I just couldn't believe my ears, there must be some catch, but the dislocation was correcting itself and continues to do so.

The programme of bone marrow transplants as a cure for genetic conditions is a long, laborious, heartbreaking team effort. Helen is part of this programme and I hope and pray there will be many others, but we feel very deeply for the many children who have also been part of it, who are equally important and did not survive, and of those who are too old to be treated. There is hope and the work must carry on.

This morning Helen began her second term at our local infant school, in the nursery section. She adores it and we have great moans when Saturday comes. My most proud and happiest moment was watching her perform as a little pig in the end of term concert with all the other normal children. **Pat Skidmore**

MEMBERS' NEWS

The Skidmore Family - 2007

In 1982 Pat Skidmore wrote an article for the MPS magazine about her daughter, Helen, who was diagnosed with MPS I Hurler Disease. Here it is shown on page 14. 25 years on, Pat has now written an update to share with other MPS members the experiences of her family during this time.

At the age of 60 I have a 28-year-old-daughter who was diagnosed at the age of 11 months as suffering from Hurler Disease.

The MPS Society began 25 years ago and of course the above sentence could not have been written then in any magazine or medical journal. In some ways this puts it in perspective in that, 25 years is a very long time and the Society and medical research has achieved remarkable results during that time through determination, persistence, and a lot of hard work. I remember the first meetings to form the Society, the choosing of its slogan, meeting other families for the first time and in those days they were hardly into double figures.

The treatment for Hurler's and associated conditions has also progressed to astonishing levels during this period, but I do not forget the heartache and sacrifice of so many parents who agreed to treatment for their precious son or daughter in the hope of removing the pain and suffering their child was destined to endure.

To introduce ourselves, as a family, we are Michael, Pat, Helen of course, and her brother Richard, now 31, living and working in London and due to marry next year – a time of joy and celebration we are all looking forward to.

It would fill a book to write about the last 28 years, in fact thinking about it, maybe that is not such a bad idea! It seems to be the order of the day to write an autobiography at a very young age when the experience of life is yet to be discovered and therefore the pages are full of emptiness! Perhaps it could be a money making idea for the Society – a collection of autobiographies of parents of MPS children – at least they would have substance, fear, joy, laughter, sadness, and every story told would be different.

I digress, so back to Helen who rules our lives as she has always done, perhaps these days as an adult, it is more intentional. She has never been particularly outgoing but enjoys her small world immensely.

Having endured two bone marrow transplants, do we regret having made the decision, for Helen, to try this experimental treatment? Of course we do not but that does not mean to say the past 28 years have been, on times, frightening, stressful, worrying, ageing and I have shed many tears over the years, but then I have heard Helen giggle over something quite simple and I count my blessings and plod on through the quagmire called life.

During Helen's treatment days we met and were assisted by many wonderful medical personnel in all departments but so often I have had to argue, cajole, and write many letters to various medics and authorities to obtain necessary treatment, after care, or facilities for Helen but for most of her life it still seems we have provided for and cared for her needs in all aspects. When Helen had her transplants the Paediatrician in charge of her case was Dr Hugh Jones and I clearly remember him saying to his team on morning rounds, "Listen to what Mum has to say, she's nearly always right". Why can't many more department leaders and medics have the same attitude? Who knows more about their every breath, every movement our child makes other than a parent. I only have to look at Helen's face to know what she is thinking or what she needs. I have to admit however, this does have its drawbacks in that it has made her quite dependent and me old before my time!

In hindsight would I change anything in the past 28 years? Yes of course I would, I would have made more effort in encouraging Helen to be more independent, but times move rapidly as I have said and so many years were spent coping with today and not thinking whether tomorrow was going to come. All those years ago it seemed inconceivable that Helen might outlive me – now I have to plan for that possibility.

Good Luck to the Society for the next 25 years.

Pat Skidmore





To order your MPS Awareness Day promotional goods please complete the reply slip below and return it to the MPS Society

To make a Donation

☐ I wish to make a general donation of £

Gift Aid

Contributions to charities are eligible for tax relief. This means that if you pay income tax or capital gains tax, and you make a donation during the year, the Society can claim tax on this donation. To make this possible just tick the box and complete this section.

I wish for all contributions I may make to the Society for Mucopolysaccharide Diseases to be treated as Gift Aid donations.

Signature

Date Postcode

If your circumstances change, please let us know.

To Order Goods

MPS Awareness Ribbon	49p	Qty
MPS Trolley Key Ring	£1	Qty
MPS Awareness Wrist Band	£2	Qty
MPS Dog Tags	£2	Qty
TOTAL	£

☐ Please send me a free MPS Fundraising Pack

Address and payment details

Mr/Mrs/Miss/Other (please delete as appropriate)

Name

Address

Postcode

☐ I enclose a cheque/postal order made payable to the MPS Society (UK Sterling only)

☐ I wish to pay/donate by (please delete as appropriate)
Mastercard/Visa/Visa Electron/Maestro/Solo

Card No

Last three digits on signature strip

Valid From / Expiry Date /

Issue No Name on Card

Numbers in address

Numbers in postcode

MPS Awareness Day

Each year the Society will celebrate MPS Awareness Day on 15 May. This will be a day devoted to raising awareness for this group of 21 rare, genetic diseases.

You can help support MPS Awareness Day by ordering some of our great promotional goods:



Photo above appears courtesy of
The Buckinghamshire Examiner
www.buckinghamshireexaminer.co.uk



Thursday 15 May 2008

The Society celebrates MPS Awareness Day on 15 May each year. This will be a day devoted to raising awareness for this group of rare, genetic diseases. **Can you help us raise awareness in 2008?**



What can you do to get involved?

Help us spread the word about MPS and raise valuable funds to provide vital services. Read on for inspiration...

Spreading the word...

Use MPS Awareness Day to tell everyone you know about MPS. If you suffer from MPS why not tell your story, talk about jobs and careers, family life, local issues or campaigns you may be involved in, pursuits you enjoy or sports you are passionate about.

If you can't help yourself, may be you can approach your place of work. MPS is eager to explore more ways of working with our supporters in the corporate sector. Here are some of the ways in which companies have supported us in the past and can continue to support us in the future...

Charity of the Year

Payroll giving

Sponsoring events

Staff fundraising

Matched company giving.

Raising funds...

Does your workplace, friends, relatives or neighbours support a chosen charity. Why not tell them about MPS? Or are you organising a fundraising event? Email fundraising@mpssociety.co.uk to tell us what you are doing and to order your fundraising pack. Tell your supporters where the money is going and what it will support.

Try to get some coverage in your local media by giving them a call or writing them a letter. Local press like to feature inspirational stories so let them know about your event. Make use of your local amenities, for example, pubs, restaurants and shops as they are great places for promoting awareness but remember to check whether you need permission from anyone to use their venue.

Ask small companies to donate gifts as they will benefit from the publicity and supporting worthwhile causes.

Do you have your own place in an event and haven't told us or are you still looking for a charity to support? Set up your own fundraising web page. For collection boxes, stickers, balloons and other support materials contact us. You can also call us for tips on organising an event or advice on how to publicise it locally.

For all activities remember to check the legal insurance requirements and health and safety regulations.

For more information please visit www.mpssociety.co.uk, email us at fundraising@mpssociety.co.uk or phone the MPS office on **0845 389 9901**



Have you thought about being a volunteer with the MPS Society?

Do you or anyone you know want to spend some time caring for MPS children and their siblings at events run by the MPS Society?

We are always looking for new volunteers to help out with events and of course the Conferences that run throughout the year.

If you know anyone that may be interested please contact Miriam Blowers, Volunteer and Event Co-ordinator, at the MPS Society by email at m.blowers@mpssociety.co.uk or by phone on 0845 389 9901. Miriam can then send you an application form to complete. Volunteers must be over the age of 18.

Natalie Durkin - Current MPS Volunteer

'Volunteering with the MPS Society is fantastic. You get to visit some amazing places, meet some awesome kids and make great friendships. I have recently been to the Sibling Weekend which was an adventure to say the least... we took the Siblings quad biking, swimming, bowling and bike riding and loads more. I have been involved with many other events including MPS National Conferences, and Alton Towers.'

'Being a volunteer involves encouraging and getting alongside the MPS kids and their siblings, making sure they are safe and most importantly having fun. The MPS Society provides training, support and reimburses expenses incurred to the volunteers. Overall I can't think of a more rewarding and worthwhile experience and would recommend everybody to give it a go. Please get in touch with Miriam, she rocks my world!'

Natalie and Milly Stuart at the Sibling Weekend



Thank you

from Alfie Tucker

I was a bit nervous when Neisha and Steve picked us up in Chester because I've never been on a Sibling Weekend before. But I knew we were going to have a great time and we did!

The best part was when we went swimming for the first time because we went on lots of different rides. The second best was when we were in the restaurant by the driving range, but the third best was on the quad bikes or on the bike journey.

I would like to thank all the volunteers for their hard work and especially Tom and Natalie for being such fun.

Natalie and Alfie are pictured on the front cover of this magazine.

SIBLING WEEKEND

Sibling Weekend at Center Parcs

31 August - 3 September 2007

A volunteer's perspective

Both of us were excited and a bit apprehensive of the weekend, but our apprehension was soon dismissed as we met our fellow chalet companions Steve, Tom and our four young lads, Alfie, Abraham, Sam and Will.

The weekend was crammed packed with activities which were all well organised and resulted in everyone enjoying themselves, even us adults. Loads of swimming, biking, rope adventures, raft building, tenpin bowling, quad biking, so much for everyone to take part in, with of course time for the odd TV viewing sessions. Hope our four lads did not report of any 'late night TV' or 'card games' as this never happened during the weekend. (PS - Will, have you still got the pack of cards and have you tried out that card trick on anyone yet?).

The choice of venues for the evening meals were excellent, only trouble is Rich now expects this standard of food and service back home (some chance of that happening!).

I am sure that everyone who attended that weekend is still talking about his or her experiences, because we are. Thanks to everyone for a memorable weekend at Center Parcs, hope to meet up with you all again sometime.

Message for Tom: Rich says remember to pack your socks next time. **Richard and Christine Syrda**

Neisha Hall, Milly Stuart, Christine and Richard Syrda

Sibling Weekend was enjoyed by all...

Siblings from all over the country joined together for a weekend away at Center Parcs in Nottinghamshire. Activities were booked in advance which meant there were going to be very tired and worn out siblings and volunteers at the end of the weekend. There were loads of swimming and group activities aimed to build teamwork amongst those attending. Some brilliant volunteers spent time caring for the siblings and encouraging them in the activities.

Story after story has been told in the office to me about all the adventures that were had by all... A certain number of ducks entering a villa? The girls involved will remain unnamed although I have heard that the volunteers were woken to hear giggling and hysterics from the girls trying to get them out of the villa...

A very brave Alfie Tucker in the high ropes, as well as the rest of the 8 - 10 year olds climbing through the high rope course which was as high as the tree tops.

Canoeing and raft building seemed to be quite good fun with everyone, of course, getting very wet but some good healthy competition involved with races to a point in the lake and then some clever swapping of places while standing on the raft.

Plenty of yummy food was eaten at a number of restaurants at Center Parcs. Go Ape and quad biking to finish off the weekend.

Overall a fantastic time away for the siblings (as you will see from the photos and stories on the next few pages) and a great break... anyone up for another one? **Miriam Blowers**



SIBLING WEEKEND

A weekend without parents!

Hi, my name is Becci Home and I am ten years old. My older brother Matthew has Hunter Disease, MPS II. I was recently lucky enough to go on the Sibling Weekend to Center Parcs. This is what we got up to...

Chris Murphy, from the MPS office, came to collect me from Rownhams Service Station at 10am on Friday morning. We headed up to Newbury to collect three other girls.

After a very long car journey, we finally arrived at Center Parcs. We found our villa, chose our bedrooms and settled in. I shared a bunk bed with Millie Stuart. We met up with the rest of the MPS group for dinner at Huckleberry's. The food was delicious! After dinner we wanted to go for a swim, but whilst we were getting changed the fire alarm went off. The fire engines came and unfortunately swimming was cancelled.

On Saturday morning we were woken up by some ducks quacking, which had managed to get into our villa! After breakfast, we went to the High Ropes centre. We were

attached onto a safety line and walked across wooden beams and ropes, high in the trees. Some parts were a bit scary but everyone agreed it was great fun. Later, we set off for the subtropical swimming paradise. The best things were the family raft ride, which was great and the outdoors rapids, which were really fast.

After breakfast on Sunday we found a family of swans outside our villa. We also saw loads of rabbits and squirrels. Later, we took the minibus to Sherwood Forest and hired some bikes. We rode our bikes for miles and miles through the forest. We were all hungry by lunchtime! In the afternoon we went ten-pin bowling and Natalie was the winner. Then it was back to the pool for a swim.

Monday was our last day. We checked out of our villa and went Quad biking for the morning. After lunch we said goodbye to our new friends and travelled home.

Thank you so much for a fantastic weekend, I really enjoyed myself. Also a special 'thank you' to Chris for driving so many miles to make it possible for me to come.



Photos above: Bike riding through Sherwood Forest. Photos page 21: Attempting the High Ropes

SIBLING WEEKEND

'I wish I could do it all again'

It was great fun at the Center Parcs Sibling Weekend. I shared a villa with three other boys of a similar age and we became good friends. All of the volunteers who were with us were great too, kind and friendly and they joined in with everything.

I really enjoyed swimming - it was fantastic! There were several water slides, some of which were long, curvy and steep and there was also some rapids to ride down.

On the Saturday, after getting to know everyone the night before, the 8 - 10's attempted the High Ropes, including the 'Leap of Faith' - climbing up a pole on to a high platform and then jumping across to grab a bar - it was seriously cool!

On Sunday we all went bike riding. We went on a long circuit that included lots of hills that were very high and long and quite rough terrain. The circuit took a long time to complete but I had a great time doing it although I was relieved to get back! Later that day we went bowling and I got a pretty high score and after trying a million times to get a strike I finally got a spare on my final throw.

On the Monday morning the 8 - 10's went Quad Biking. It was serious fun - plenty of races and I didn't fall off once.

The whole Center Parcs weekend was packed full of excitement and I made some great friends. I enjoyed it so much I wish I could do it all again - I can't wait for the next Sibling Weekend! **Sam Otway**



'The best weekend I've had in ages'

When my Mum opened the letter and asked if I wanted to go on the Sibling Weekend trip I immediately said yes. I couldn't wait for it. All the activities sounded great such as raft building, swimming, Go Ape, bike riding and quad biking for the little kids.

I packed my bag on the Thursday night ready for the Friday morning pick up. The morning arrived and I was really excited. My Mum had to work so I got a lift to Chester services where I was being picked up by Neisha and Steve. The car journey was alright but a bit too long. When we arrived we put our stuff in a villa and went to the information desk. We waited for everyone else to come but that was really boring.



Unfortunately we couldn't do any activities on the Friday night because there wasn't enough time. So everyone went back to the villas with their volunteers. I was put in a room with Mark and Heshan and our volunteers were Rosie and Dave. Everyone in our villa was really cool.

The next morning we had our breakfast and then we went raft building - what a laugh that was! In my group was Tom the volunteer, Jasmine, Kate and Mark who didn't even get in the water. We built our raft and put it in the water. I was amazed to see it float. The other group put theirs in the water and unfortunately that also floated. So the race began, and it was so funny because our raft started to sink and we just kept falling off. It was great! At the end we lost but we all had a load of fun.

After our dinner we went swimming. The place was fantastic, there was a huge pool that had a wave machine, hot pools and even a plunge pool. Me, Heshan, Emma, Jasmine and Kate all went into the plunge pool. It was freezing! We said that we were going to have a competition to see who could last the longest. We were in there for about 10 minutes when the girls said that they were getting bored so they wanted to get out. Personally I think it was because they were getting too cold. The rapids were amazing. You either got stuck or crashed into people, either way you knew you were going to have fun. That day was a great day and I never will forget it.

The next day we went to Sherwood Forest where we were going to have our bike ride. We all got our bikes and went riding off in front of the volunteers. The bike ride was really fun but also very tiring. Everyone finished the bike ride and well done to the little kids for

doing that because it was very hard. After we got back me and Lucy went to the Childhood Wood where we both have trees planted for our brothers. The last time I was there was when me and mum and dad were planting it. The tree has grown loads and all of the trees look like a proper forest now. I would like to thank Neisha for letting me go to see it and to Lucy for taking me.

When we got back to Center Parcs we had our dinner and went swimming again. It was even better than the day before. We did the rapids, slides and wave pool - it was awesome! We spent three hours in it - wicked! That night we had to pack because we were leaving in the morning and because we were going to Go Ape. Go Ape was wicked. It is even more fun when you're scared of heights. I was paired up with Dave. I think he was a bit gutted but anyway we had a laugh. We went on all of the stages and we both never fell off. The best one was Activity 5. You had to go over some ladders which were wobbly and then climb up a pole and wait for this thing to come back. You then connected yourself to it by some ropes and a pulley. You pushed off and crashed into a net. It was ace. At the end of it we all had some dinner and then went our separate ways. I said my good byes to everyone and went.

That weekend was the best I've had in ages and I would just like to thank everyone at MPS who organised it. I would like to thank the volunteers, especially Rosie and Dave who had to put up with me for the whole weekend, also Tom, Sasha, Lucy before she went home and Natalie. Sorry if I forgot to mention anyone.

My biggest thank you goes to my Mum who let me go on it.

Thanks Mum, love always and forever. **By Ian Grandidge**

SIBLING WEEKEND

Dear all at the MPS Society

I am writing to say thank you very much for a great weekend at Center Parcs. Thank you for organising it, you made it so much fun.

I would love to go again if you ever do another one.

Lots of love

Emily Rudham



'Anybody that didn't go, really missed something'

I went to Center Parcs, Sherwood on 31st September with the MPS Society. I got on the minibus at 9.45am at MPS House. We went to Euston to pick up some people then we went on the M1 and at junction 13, the services, picked up the last of the people. We finally arrived at Center Parcs at 3.45pm.

That night we went to Hucklebury's, which is an American restaurant. I had a rack of ribs. Lots of people had very tasty food.

On Saturday 1st September we got out of bed eventually then we had breakfast. After that we went to the high ropes and we did the leap of faith. We had to go along a wire around 6 metres from the ground with one rope to hold on to, then we went up a couple of metres, then we had to go across another wire with only being able to hold on to a couple of ropes dangling from the top. We went across three wooden poles. At different heights we had to do different things on each one. After that we got lunch and I had a burger. Then we went swimming.

It was fantastic, we went on the rapids and down the slides. It was great! That night we went to Hucklebury's again, I had another rack of ribs and it was fantastic. Afterwards we went night swimming, which was brilliant. The rapids were faster and the waves were bigger than in the day time. The first whole day at Center Parcs was great.

On Sunday 2nd September we went bike riding and we went really far then we had a picnic. After that we went bowling, but I didn't win! Then we went swimming. Later we went to Hugos and we played in the play area. I had scampi but it wasn't that nice.

On the last day we went quad biking which was great fun. We took it in turns then we did relays and time trials. After that we made the long journey home.

The sibling weekend was great and I really enjoyed it. It was brilliant and great fun and anyone that didn't go was missing something! **By William Summerton**



MPS Family Day



Chessington - A World Full of Adventure! Well, the day, 15 September 2007, started that way as Neisha had trouble in finding Chris's house to pick her up!

We were truly lucky with the weather. The sky was blue and the sun was shining, perfect for our planned day at Chessington. We met with all the families at 10am at the main gate to the park where tickets were handed out so that the families could go around the park and enjoy the day.

It had been years since either of us had been to Chessington and we admitted to each other that we were getting excited the nearer we got!

After we had met all the families and ensured everyone had their tickets, it was off into the Park for some fun and to see what rides we could get on before meeting up at 2pm with everyone. Sadly we didn't get to go on any rides at that time but we were very impressed to see Will going whizzing round on one of the rides.



Photos clockwise from top right: The Oyawale Family (MPS IV), the Gremo Family (MPS III), the Bown Family (MPS III), the Williams Family (ML III), the Zadok Family (MPS III)

CHESSINGTON

at Chessington

2pm soon came and we all met up in The Market Square. It was a perfect photo opportunity and a chance for families to catch up with old friends and make new ones. I'm sure you will agree the photos turned out brilliantly. It was also a great opportunity for new families to meet some of the other families that are going through similar experiences to them and be able to show each other support and encouragement. Getting everyone in the one place facing the camera was a bit of challenge but as you can see there are some great photos and well worth the wait.

I hope everyone who came enjoyed the day as much as we did and have fun looking at the photos of the day. We really look forward to meeting you again at another event. Keep your eyes on the magazine where new events will be advertised.

Neisha Hall & Chris Murphy
Advocacy Support Officers



Photo top: The Summerton Family (MPS III)

CLINICS

Sanfilippo and Morquio Clinics at Great Ormond Street

The Sanfilippo Clinic was held on 21st June at Great Ormond Street and a Morquio clinic was held on 16th August at Great Ormond Street. Both clinics went well and I enjoyed the opportunity of meeting new families.

The photos of the Morquio clinic are unfortunately not available for the magazine as they mysteriously disappeared from our MPS camera following the Sibling

Weekend. This was very sad as the families had to have great patience with me at the clinic whilst I was still trying to get to grips with how to use it!

Both clinics were successful and our thanks go to Dr Vellodi and Niamh for organising the clinics.

Chris Murphy



Jamie Macfarlane, Yasin and Haris Mahmood at the MPS III Clinic

MPS 25th Anniversary Balloon Race



Ticket 424 belonging to Milly Stuart found in the back garden of Edward aged 11 and Issie aged 9, 40 miles away from the Hilton Northampton. Unfortunately the weather was not on our side.

Chris & Steve run for MPS!

Some of you may be aware that Chris Murphy (MPS Advocacy Officer), John Simpson (my friend) and I have been duped into participating in the Great South Run... 10k indeed! It will be a 10 mile sprint to the finish on 28th October 2007 in Portsmouth, hopefully with knees still intact! Gina has kindly set up a Just Giving site (see link below) and funds raised will of course be for the MPS Society, any sponsorship or donations are very much appreciated. **Steve Cotterell, MPS Advocacy Officer**

<http://www.justgiving.com/steveandchris>





10th International Symposium on MPS and Related Diseases

26-29 June 2008

Vancouver, British Columbia, Canada

Conquering MPS

Learn. Live. Cure.

Welcome to the 10th International Symposium on Mucopolysaccharide and Related Diseases, being held in beautiful Vancouver, Canada, June 26-29, 2008. We encourage you to join us for what we believe will be the most informative and enjoyable MPS Symposium to date.

Learn:

We are gathering the world's leading scientists to explore what we know about the underlying science of these diseases, in particular, the effects on the brain, the skeleton and the connective tissue and the challenge of the blood-brain barrier.

Live:

More and more children and adults are living with MPS. We will be exploring coping mechanisms and assistance, as well as presenting best practices in management and care so that all affected can live life to the fullest.

Cure:

We will also be devoting sessions to what cures are being investigated, the feasibility of such cures and the timelines involved.

We are extremely excited to offer a spectacular and professionally run child and youth programme. This will allow your children, both affected and unaffected, an opportunity to visit Vancouver's wonderful sights and form lasting friendships, while you take advantage of all that the Symposium has to offer.

We would not find a more beautiful city in which to hold our conference and to showcase our country. Vancouver is a cosmopolitan city of two million people, nestled between the Pacific Ocean and Canada's spectacular coastal mountains. We suggest you add some vacation days to the end of the conference and take this opportunity to see all that Canada's west coast has to offer.

We look forward to seeing you!

Kirsten Harkins, Canadian MPS Society

Expression of Interest

Overleaf is an **Expression of Interest Form** for you to complete and return to MPS if you are interested in being a part of the Symposium in Canada in June 2008.

Please return this form ASAP to ensure that you get a place with financial assistance from the MPS Society. We are unsure as to what the expense will be to our MPS members as yet as we are waiting for confirmation as to how much money has been raised towards this. Please be aware that you may need to

pay towards your flights or accommodation. So please do start budgeting now if you want to be a part of this conference.

The deadline for returning this form to us is **16 November 2007**. If you have any questions please contact Miriam Blowers, Event and Volunteer Co-ordinator at the UK MPS Society.

Please feel free to browse the following website about the conference
www.mpssymposium2008.com

10th International Symposium on MPS and Related Diseases

26-29 June 2008

Vancouver, British Columbia, Canada

Expression of Interest

First name	<input type="text"/>
Surname	<input type="text"/>
Address	<input type="text"/>
	<input type="text"/>
Postcode	<input type="text"/>
Daytime	<input type="text"/>
Telephone No.	<input type="text"/>
Email Address	<input type="text"/>

Surname Adults	First Name	DoB	MPS
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Children 0 - 17 years			
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Please return your completed form by 16 November 2007 to:

Miriam Blowers
Volunteer and Event Co-ordinator
Society for Mucopolysaccharide Diseases
MPS House, Repton Place, White Lion Road, Amersham, Bucks, HP7 9LP
Tel: 0845 389 9901, Fax: 0845 389 9902
Email: m.blowers@mpsociety.co.uk, www.mpsociety.co.uk



INFORMATION EXCHANGE

Criminal Records Bureau checks available through the MPS Society

The MPS Society is registered as an umbrella body with the Criminal Records Bureau (CRB) to provide a service to other organisations and individuals wishing to apply for Disclosure Certificates through the CRB.

How the MPS Society can help if you need a CRB Disclosure Check

Application forms and booklets explaining how to apply for disclosure are available from the MPS Society. Once you have completed the application form and sent it to the Society together with documents showing proof of identity as required by the CRB, these will be checked to ensure they comply with the CRB's stringent requirements. If they do, the application will be forwarded to the CRB; if not, the Society will contact you to explain what is required.

The CRB then processes the application and issues a Disclosure Certificate. One copy of this is sent to the Society and one to the individual at their home address. The Society will then confirm to the organisation in writing whether the applicant is suitable for the position for which they have applied, based on the information given on the Disclosure Certificate.

Based on the information provided on the Disclosure Certificate, if the Society is unable to assess the individual's suitability for the position, the Society will write to the organisation to this effect and explain that the organisation may ask the applicant for sight of the Certificate but this is at the applicant's discretion.

The organisation is responsible for checking the level of disclosure required (for example, standard or enhanced). Information and guidance on the different levels of checks

can be found on the CRB and Disclosure Service websites. It is also an applicant's responsibility to ensure compliance with the provisions of the Rehabilitation of Offenders Act 1974.

The MPS Society is not involved in, nor does it take responsibility for, any recruitment decisions made as a result of the Disclosure information received.

Data Protection, Confidentiality and CRB Code of Practice

All paperwork and communication with individuals, organisations and the CRB remains confidential to those members of staff at the MPS Society who undertake the administration of this area of work.

The MPS Society fully adheres to the regulations of the Data Protection Act 1998 and the Rehabilitation of Offenders Act 1974. The Society also complies with the CRB Code of Practice and requires adherence to the Code by any parties using the Society's service as a registered umbrella body.

For more information please contact the MPS office.

Our charges

Enhanced Disclosure Service for paid employees
£55.00

Standard Disclosure Service for paid employees
£50.00

Enhanced and Standard Disclosure Service for volunteers
£10

MPS I Survey

The UK MPS Society, in collaboration with Genzyme UK and USA, is sponsoring an MPS I Disease Management Survey. All living MPS I individuals and their families should have received a letter from our student researcher, Natalie Durkin, inviting you to participate in a telephone interview. The survey enquires about your experiences with MPS I, Hurler Disease, including treatment and care received.

If you haven't received the letter from Natalie or responded, and would like to participate in the survey, please do email me at c.lavery@mpssociety.co.uk, call the MPS office and speak to Sue or drop us a line.

The information you provide, as well as that provided by other individuals with MPS I participating in this study, will

help advance the patient and their families' perspective of clinical management and treatment as well as understanding of the course of the disease.

We would hope to share the highlights of the survey results on the UK MPS website early in 2008.

I would like to reassure you that your responses will remain strictly confidential. Nothing that identifies you will be attached to your responses.

Over 80 individuals and their families have already taken part in the survey but we would still like to involve the other 20 families.

Christine Lavery

genzyme

INFORMATION EXCHANGE

POSTAGE

Please ensure that you use the correct postage. As a charity we do not collect undelivered items due to the expense incurred.

All figures shown here reflect the new pricing system, which is based on size as well as weight.

LETTER FORMAT

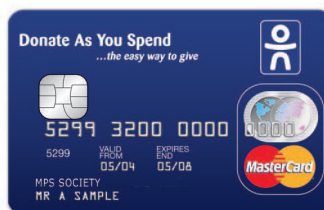
C5+ or under. Up to 100g.
Less than 5mm thick.
Max weight 100g
Max dimensions 240 x 165 x 5mm
For example: Most letters, bills, statements, greetings cards, some brochures and catalogues

LARGE LETTER FORMAT

B4 or under. Up to 750g.
Less than 25mm thick.
Max weight 750g
Max dimensions 353 x 250 x 25mm
For example: Letters containing unfolded A4 paper, most brochures, CDs and DVDs

Any questions please visit
www.royalmail.com

'Donate As You Spend' MasterCard



Donate As You Spend is an organisation founded to help smaller charities raise funds in ways only previously available to the largest charities. MPS are one of the first charities to take advantage of their new MasterCard.

Donate As You Spend Donations to MPS

£10 (plus Gift Aid £2.80) to MPS when you first use your card, 25p (plus 7p Gift Aid) to MPS for every £100 you spend on your card (N.B. balance transfers and cash withdrawals do not generate donations).

plus

A **voucher** for a FREE HOTEL BREAK FOR 2 with a choice of 200 hotels (subject to availability) once you activate and spend on your card three times!

Exclusive offers and discounts with your account statements

- Accepted in over 24 million outlets worldwide
- No interest to pay for up to 50 days
- 0% interest on Balance Transfers for 6 months
- 24/7 access to cash at over 56,000 ATMs in Britain alone
- Typical APR 16.9% variable

Ask us for an application leaflet now.

Subject to status. Applicants for credit must be aged 18 or over and UK resident. The DAYS MasterCard is issued by Sygma Bank UK, Equipoint, Coventry Road, Birmingham B25 8FE

Our Christmas Collection 2007 is available now.

To order cards please complete the form enclosed, phone 0845 389 9901

or visit www.mpsociety.co.uk
to download an order form.





MPS House

Conference and Library and facilities for hire

The MPS Society's headquarters, MPS House, is built over two floors. The first floor provides ample space for the Society to provide all its advocacy and support services whilst the ground floor provides a conference area and training resource plus library area. We offer out our conference facilities to other voluntary organisations and businesses at very reasonable and competitive rates as our main aim is to raise awareness of MPS diseases within the local community. If you would like to consider using the facilities of MPS House for your meetings, please read on for more information.

Conference Rooms

MPS House has a fully equipped conference room which can be used for a number of activities including board meetings, AGMs, and training days. The room can seat 60 delegates theatre-style, or 30 delegates boardroom-style. LCD projector, flip charts, video/DVD player are all available.

If you have a smaller meeting but would still like to take advantage of all our facilities, the conference room can be divided in half with a sound-proof dividing wall.

The Library

The Library is open during normal office hours, 9am to 5pm, Monday to Friday by prior appointment. Individuals and small groups are welcome to use the library facilities for a small donation to the Society. High speed broadband internet access is available.

The Library houses a range of publications and resources on all aspects of rare, genetic diseases, lysosomal storage diseases, working in the voluntary sector and charity management. If you have a specific area of interest or enquiry please do contact us. The library can also be used for small meetings for up to six delegates.

Accessibility

The MPS centre is fully accessible to visitors and we offer a warm welcome to everyone either contacting MPS remotely or visiting MPS House in person. There is suitable access and ground floor facilities for disabled individuals.

Transport and Parking

MPS House is ideally situated for motorway access and public transport to all parts of the United Kingdom as well as to London, Heathrow and Luton airports.

Depending on when you want to visit, parking can be limited. Please contact us to discuss your travel and parking requirements and we will be happy to assist you.

Booking Enquiries

Quotes, bookings and further information on our full hospitality package or just room hire is available. Please contact us.

Email: meetings@mpsociety.co.uk

Phone: 0845 389 9901



INFORMATION EXCHANGE

Mobility Nationwide

Mobility Nationwide is a small family company that has grown to become one of the UK's largest specialist providers of Wheelchair Accessible Vehicles. www.mobilitynationwide.co.uk
Tel: 01824 707773

Safe spaces

Safe rooms and sleep systems.
Flexible alternatives to room padding for those with autism, epilepsy, challenging behaviour and other special needs www.safespaces.co.uk

Dreams come true

Dreams Come True is a charity that makes the dreams of terminally or seriously ill children become a reality.

No dream is too big or too small and the only limit to the dream is the child's imagination.

How do I apply for a dream?

If you know of a child or a young adult who deserves a dream, please write to us (address as below) giving a brief outline of their illness together with the type of dream in mind, we will then forward you our Dream Packs with more detailed information.

Please do not hesitate to call our free phone number if you have any queries.

Dreams Come True Charity
Knockhundred House, Knockhundred Row, Midhurst,
West Sussex, GU29 9DQ

Tel: 01730 815000
Fax: 01730 813141
freephone: 0800 0186013
www.dctc.org.uk

Daisy Chain Project

This is a block of apartments situated on the South Shore of Blackpool about 5 - 10 minutes from the Pleasure Beach, set on different levels, for example ground floor, first floor etc. They have three ground floor apartments. None of the apartments are equipped with disability aids however they can arrange the hire of portable hoists. The apartments consist of two bedrooms (one double room and the other either a single or bunk beds - a 'Z' bed can be asked for if required), a bathroom which has a shower over the bath, a lounge area and a fully equipped kitchen. All apartments are themed for the children.

The bookings go from Monday to Sunday and cost £45.00 for administration. This remains the same price whether there are two or five people in an apartment.

There is someone from the Daisy Chain Project available to speak to - a telephone call away if you need to speak to someone about something, which many families would find reassuring.

More information about the Daisy Chain project can be accessed through the following website
www.kensingtonfoundation.com

MPS Information Materials

The MPS Society has been working on developing and updating its range of information materials for individuals affected by MPS and Related Diseases, their families and those working with them. To place your order please

complete the form opposite and return it to the MPS Society. Alternatively, you can download a publication order form from www.mpssociety.co.uk





Society for Mucopolysaccharide Diseases

Publication Order Form

The Society is pleased to have published a range of information resources for individual members, their families, carers and professionals. As the Society is only a small charity with considerable commitments to both research programmes and advocacy support, whilst we seek to reach as wide a readership as possible, we simply cannot absorb the growing costs without charging a contribution towards printing and postage.

Specific disease booklets

Each booklet in this 'Guide to Understanding...' series introduces the disease, its causes and inheritance. A detailed clinical presentation with options for managing and treating specific symptoms is given with guidance on general management of issues including diet, drugs and physiotherapy. There are sections on living with a child or adult affected by the particular disease and a final section which covers specific treatments for the condition where these exist.

UK £2.00 Europe £3.00 Overseas £4.00

Qty

_____ Aspartylglycosaminuria (AGU)
 _____ Fabry
 _____ Fucosidosis
 _____ Hunter (MPS II)
 _____ Hurler, Hurler Scheie, Scheie (MPS I)
 _____ Mannosidosis
 _____ Maroteaux-Lamy (MPS VI)
 _____ Morquio (MPS IV)
 _____ Mucopolipidosis II (ML II)
 _____ Mucopolipidosis III (ML III)
 _____ Sanfilippo (MPS III)

Disease progression booklets

These booklets are produced specifically for professionals working with children and adults affected by an MPS or Related Disease. Through photographs of the same child at different ages, the booklets demonstrate the progressive nature of each disease.

UK £2.00 Europe £3.00 Overseas £4.00

Qty

_____ Jessica: Hurler (MPS I)
 _____ Lauren: Hurler (MPS I)
 _____ Hunter (MPS II)
 _____ Sanfilippo (MPS III)
 _____ Sarah: Maroteaux-Lamy (MPS VI)

Booklets for children

Written for children with an MPS or Related Disease, or their siblings, these booklets are designed for children aged 5 years and over. Each colourful booklet uses large print to give age appropriate information about the disease and its effects. They are an invaluable tool for use in schools to support children in understanding more about these diseases.

UK £2.00 Europe £3.00 Overseas £4.00

Qty

_____ I've got Morquio's
 _____ I've got Hunter's
 _____ I've got Fabry's
 _____ I've got Hurler's and had a BMT
 _____ Our brothers & sisters have Sanfilippo
 _____ I've got MPS VI and am on ERT

Information Sheets

These sheets are written by the Advocacy Support Team to provide further important information on key issues on which the advocacy service provide support.

Qty

_____ Travel Insurance
 _____ Disability Living Allowance (DLA)
 _____ MPS Diseases and Life Insurance

Other publications

Qty

_____ A Chance to Live - Isaac's Story	UK £4.95	Europe £5.95	Overseas £6.95
_____ Anaesthetic Management in MPS	UK £2.00	Europe £3.00	Overseas £4.00
_____ 21 years of BMT, Conference 2001 Report	UK £10.00	Europe £12.50	Overseas £15.00
_____ MPS Video	UK £5.00	Europe £7.50	Overseas £12.00



Please turn over to complete the payment and delivery instructions

Delivery Address

Name:

Address:

Postcode: Country:

Gift Aid

Use Gift Aid and you can make your donation worth more. Just sign below! It's that simple! To qualify for Gift Aid, what you pay in income tax or capital gains tax must at least equal the amount we will claim in the tax year.

Signature: Date:.....

Please ensure that you include your address and postcode details above.

Payment Details

Amount payable £.....

Donation £.....

Total payable £.....

I enclose a cheque/postal order payable to 'The MPS Society' for £

I wish to pay by Master Card/Visa/Maestro/Visa Electron/Solo (Delete as appropriate)

Card No:

Valid From:/..... Exp:/..... Issue No

Security Code (last 3 digits on reverse of card)

Name on Card

Numbers in Address (e.g. if you live at Flat 41, 315 Any Street, write 41315)

Numbers in Postcode (e.g. if your postcode is AB12 3BA, write 123)

Please return this form when completed with your chosen method of payment to the address below:

Society for Mucopolysaccharide Diseases

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

Tel: 0845 389 9901, Fax: 0845 389 9902

Email: mps@mpsociety.co.uk, www.mpsociety.co.uk

Registered Charity No. 287034



Fundraising for MPS

Contact us now for your fundraising pack
www.mpsociety.co.uk

Across the United Kingdom, over 1200 individuals and their families turn to the Society for emotional, practical, financial and social support.

Not only does the Society provide valuable help to its members, we also raise vital funds for medical research and promote awareness of these diseases through conferences, regional events and information resources.

The efforts and contributions of voluntary fundraisers and donors are fundamental for the Society to continue providing these services.

**Every little counts and we need your help
 to carry on raising money...**



Fundraising for MPS

CAN YOU LEND A HAND?



Only £199 if you book before Friday 14 December 2007!



Society for Mucopolysaccharide Diseases

Fun Weekend

& Annual General Meeting

Saturday 3 May and Sunday 4 May 2008

