Newsletter

The Society for Mucopolysaccharide and Related Diseases

National Registered Charity No. 287034

Winter Newsletter 2003

Care Today, Hope Tomorrow

What is the Society for Mucopolysaccharide Diseases?

The Society for Mucopolysaccaride Diseases (the MPS Society) is a voluntary support group founded in 1982, which represents from throughout the UK over 1000 children and adults suffering from Mucopolysaccharide and Related Lysosomal Storage 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.

The Society has the following aims:

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

How does the Society meet 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 Young People & Adults 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 including a video

Quarterly Newsletter
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

Front cover photograph: Ben Cooper (MPS II)

Newsletter

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Registered Charity No. 287034

Newsletter Deadlines

Spring	1 Mar 2004
Summer	1 Jun 2004
Autumn	1 Sep 2004
Winter	1 Dec 2004

Subscriptions

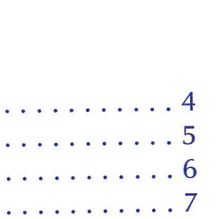
Subscriptions may be taken out from the UK or Overseas by contacting the MPS Society's Office.

The articles in this newsletter do not necessarily reflect the opinions of the MPS Society or its Management Committee. The MPS Society reserves the right to edit content as necessary.

Winter 2003

Contents

Note from the Editor



Dear All

Welcome to the new look Winter 2003 MPS Newsletter. Since the last edition, this publication has undergone a re-vamp to make it more colourful and reader-friendly yet still ensuring it is jam-packed with information and the latest news from the field of MPS and Related Diseases.

We hope you like this new look. Please send in your e-mails to mps@mpssociety.co.uk and let us have your views. Is there anything you would like to see, or anything we can do differently? All comments and opinions are much appreciated and you never know, your letters may appear in the next newsletter!

As always, many of our pages are made up of stories and photos submitted by you, our readers. Although we can't guarantee to pay £250 for each submission (!) we can promise that other readers do benefit from reading about your experiences.

Lastly, check out the back cover for some great fundraising ideas. Don't forget that the Society relies upon voluntary donations to maintain and improve its services.

With all best wishes for 2004!

Antonia Crofts, Editor

Contents

Chief Executive's Report

Another twelve months have gone by and Christmas has been and the year 2004 is well and truly here. Ever mindful that Christmas and the New Year may bring mixed blessings for those affected by any of the MPS and Related Diseases the Staff and Trustees wish you all a peaceful New Year. On behalf of all of us in the MPS Society's office we would like to say thank you for the many, many Christmas cards and kind words we received. They are very much appreciated.

Well, what a year it has been for the Society! A full programme of regional clinics has taken place and our thanks in particular go to the doctors and nurses around the UK that welcome Dr Ed Wraith and members of the Advocacy Support Team to take over for the day once or twice a year. In January 2003 the MPS I under five's clinical trial was fully established and in June we saw the first Enzyme Replacement Therapy for the MPS diseases, for MPS I. In September the MPS VI ERT clinical trial started and, just before Christmas, enrolment for the MPS II ERT clinical trial was almost complete.

On 4 June the Society kicked off its 21st birthday celebrations with an afternoon tea party in the Houses of Parliament sponsored by Andy King MP and courtesy of British Airways. Many extended the celebration by taking a ride on the British Airways London Eye.

The weekend of 20-22 June saw the biggest ever national MPS and Related Diseases conference held at the Hilton Hotel Northampton. The Saturday evening reception gave the MPS Society a further opportunity to celebrate its 21 years by recognising representatives of the scientific, medical and nursing community, the pharmaceutical industry as well as MPS members, volunteers and staff. Recognising regional diversity MPS conferences were also held in Belfast and Edinburgh with MPS Society members enjoying their own 21st birthday celebrations.

Jeans for Genes has again been a wonderful success with to date over £2.6 million raised from the Jeans for Genes day on 3 October 2003. The Trustees have already considered a range of new grant applications and have agreed to fund three innovative projects. Details of these will be given in the Spring 2004 newsletter.

Support continues to be the Society's primary focus and whilst the Advocacy Team is actively supporting the Society's members in a range of areas including palliative care, home adaptations, respite care, special educational needs to name but a few, thought has also been given to collective support activities for the coming year. Do you or your children dream of a family weekend at the new Splash Landings Hotel at Alton Towers? Is the answer yes, but it is too expensive? Well, come and join the MPS Fun Weedend there in May 2004. Arrive on Saturday morning (as early as you wish!). After a private lunch spend the afternoon in the amazing indoor Water Park that makes you feel as if you were in the Caribbean. For more information please see the enclosed booking form. This is an excellent opportunity for MPS Society members to meet and for their children to spend some time together. For brothers and sisters aged 9-18 years the Society has organised two activity weekends at the Pioneer Centre in Kidderminster. This is a one-off opportunity for siblings to come together to be challenged and have fun. For more information please see the enclosed booking form.

Finally, we hope to see as many of you as possible at the International Symposium for MPS and Related Diseases in Mainz, Germany, 10-13 June 2004. Details of this Symposium and of help the Society is offering to members wishing to attend is enclosed separately.

Christine Lavery
Chief Executive

Goodbye to Jeff and Alex

In December we said farewell to Jeff Bawden who had spent six months with the Advocacy Support Team before moving back to Community Nursing. Alex Roberts had been with the Society for nearly four years and in that time brought us into the 21st Century electronically. We wish both Jeff and Alex the very best for the future.

I am Sam

Samantha Vaughan

In my experience, first days at work are never the best; the photocopier eats those incredibly important legal documents you give it, your computer does not do the same for you as it does for the technical support guy, and the printer tends to follow suit. My first day at MPS was not like this at all … I just had to deal with Alison instead (some may deem this worse!)

My name is Sam (hence the title) and I am the new Advocacy Assistant. I can't believe that I only started working for the Society at the beginning of October! You soon learn that the pace is fast in the MPS office – luckily I've managed to keep up so far. In addition to supporting the Advocacy Support Team, I am also taking on the organisation of the regional clinics, MPS regional events, and the management of the Childhood Wood.

Before I started here I was travelling and doing freelance work for an events company. When I saw the advertisement for this job in the paper, I decided that it was perfect for me, so I applied straight away. My obsessive need to be organised, my passion for event planning, and a thirst to break into such a rewarding job sector sealed the deal, and now here I am!

I had the pleasure of meeting some of you at the Cardiff clinic in November, and for everyone else I am sure we will speak soon as I am now the first point of call for the Society. I am really looking forward to working with you all.

Spotlight on... Alison West

Sleep? Who needs it?

I have worked at the MPS Society for just over a year now and would like to share some things I have learned while being here. Sure, I could tell you all about how we can help with benefits, housing, education, grants, respite, holidays, access to clinics and information on current legislation and available treatments. But you know all this already! I want to explain some things you may not know…

For one thing the MPS office is an absolute madhouse. Don't get me wrong, this isn't a bad thing in any way as I believe it's necessary to deal with the immense amount of work which comes our way every week. The old saying *'You don't have to be mad to work here, but it helps'* has never been more apt. Which is why I fit in so well.

In a typical week I will attend a variety of meetings with professionals, members and the rest of the MPS staff, complete an assortment of benefit forms, prepare various presentations, speak to numerous people on the phone about a range of issues and write (what seems like) thousands of reports. You certainly never get bored here!

Travel is also incredibly important as a member of the Advocacy Support Team and my car (Clyde) and I have managed to clock up a fair number of miles, especially as my areas of the country include Scotland, Wales and the South West. Thankfully I enjoy driving and Clyde does me proud every time, although if he could just learn to navigate as well, it would be a bonus!

N.B. For all you sticklers out there I would just like to reassure you that boats and ships are definitely female (father was in the navy!), but my cars have always had male names (dad can't win everything).

Living without proper food or sleep for short periods is something I have perfected at the MPS Society. I'm not a stranger to this as it has been necessary in previous jobs and it's often essential if there's a deadline to be met. Working late is an occupational hazard, but name me one worthwhile job in which it isn't! Thankfully I don't need much food or sleep to keep me going. Now *vodka* on the other hand…

On top of this, being a young(ish), gregarious person, I like to fit in a fairly hectic social life around the times I'm not actually working.

Like I said…sleep? Who needs it?

The Society's Board of Trustees meet regularly. At the November meeting the Trustees reviewed staff salaries, the cost effectiveness of the Society and approved the income and expenditure budget.

Jeans for Genes Research & Support Grants

The Trustees met in September and November 2003 to consider applications for the Jeans for Genes Research and Support Grants. The Trustees approved, subject to clarification of certain details, two scientific research grants and one clinical research grant commencing in 2004. Details of these will be given in the Spring 2004 newsletter.

Policies

The Trustees consider, on a rolling programme basis, all the Society's policies making amendments as appropriate.

International Symposium on MPS & Related Diseases 10-13 June 2004, Mainz, Germany

The Trustees agreed to financially support members of the UK MPS Society to attend this meeting, as well as taking a small number of specially trained childcare volunteers for British children.

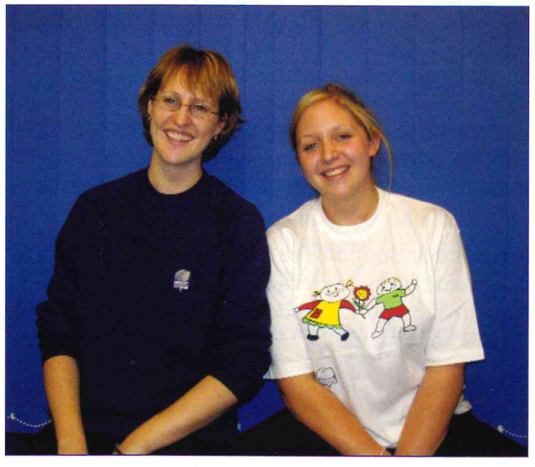
Advocacy Support

Having received such a low number of bookings for the individual regional Christmas parties, the Trustees agreed that no regional Christmas party was viable and that they should be cancelled. The proposal to run just one national party was agreed to be impractical because of the long distances to be travelled.

The Trustees heard from the Assistant Director on the success of the Society's Befriending Scheme with significant links being made on a weekly basis as well as the networking of the conferences and information days which are proving very successful.

In November the Trustees approved an exciting advocacy support programme that includes a weekend MPS Fun Weekend at Splash Landings Hotel and Water Park at Alton Towers and two MPS sibling activity weekends at the Pioneer Centre, Kidderminster. The Trustees expressed the hope that as many individuals, families and siblings will take advantage of these events which are all significantly subsidised by the MPS Society.

Stop press...



New Year Sale!

	Adult	Children
Sweatshirts	£7	£4.50
Poloshirts	£6	£4

Limited stock, assorted colours
Contact Gina for availability

Charity Flowers

15% of the retail price of each order goes to Charity. Order your flowers through Charity Flowers, quote MPS at the time of ordering and they will make a donation to the MPS Society.

Introducing the Society's Trustees

Continuing on from the Autumn 2003 newsletter, we would like to introduce two more members of the Society's Board of Trustees.

Barry Wilson
Chairman

Hello, I am Barry Wilson. I am married to Barbara and have been a Trustee now for three years. I joined the MPS Society some seven years ago when my seventeen year old daughter, Joanna, was first diagnosed with Scheie Disease. Completing my family is our son, James, who is 30 and is a buyer for Argos and Andrew, who died during the war in Iraq when his Sea King helicopter crashed in the Persian Gulf.

Working from home, I am a partner in a small software company that provides systems for the motor trade and related businesses. I have been involved in computers and their systems software for the last thirty plus years. During that period I have worked for such companies as Marconi, N.C.R., Kalamazoo and now my own.

I am now on my run down to retirement and looking forward to the day when my only responsibilities will be my family, my commitment to the MPS Society and, of course, my golf, as opposed to the numerous customer queries that I deal with on a day by day basis.

A recent convert to golf, I am really enjoying the game and hope to go on playing for many years. I enjoy cooking, good wine (actually most wine!), dining out as often as possible and meeting all the wonderful members of the MPS Society.

Barry Wilson

Bob Devine

Bob Devine
Vice-Chair

Hi! My name is Bob Devine. I became a member of the Society in 1996, after our daughter Katie was diagnosed with Hurler Disease. The Society was very helpful and supportive following the devastating news, and through the conference outings etc, our other three children, Andrew, Gary and Laura, were able to meet and talk to other children in a similar situation to themselves. This became particularly important in coming to terms with Katie's illness, and her subsequent death three years ago.

I have been a Trustee for four years now and enjoy it very much. Yes, we do have to give up some of our free time, sometimes working quite late into a Friday evening.

The work is sometimes very challenging, carrying a lot of responsibility, but it is always very interesting. I feel that it has given me an opportunity to give a little back to help the Society to develop and grow in a way that will enable it to continue to be there for people when they need it, providing help and support.

I work for Peugeot as a supervisor in the paint shop maintenance department. It is our responsibility to keep all the plant and equipment running efficiently in a safe and reliable condition. I currently work the weekend shift which effectively means I work three long, 13 hour shifts, on Friday, Saturday and Sunday. This allows me to have most of the week free and has helped me to be able to represent the MPS Society as a Trustee for the Jeans for Genes Charity.

Advocacy Support Bulletin Board

Holiday companies with wheelchair-friendly accommodation

Grooms Holidays
08456 584478
www.groomsholidays.org.uk

Leonard Cheshire
01485 543000
park@east.leonard-cheshire.org.uk

Winged Fellowship Trust
0845 3451970
www.wft.org.uk

Ashwellthorpe Hall Hotel
01508 489324
www.ashwellthorpehall.org.uk

Calvert Trust
Devon 01598 763221
Northumberland 01434 250232

Jubilee Sailing Trust
0238 0449138
www.jst.org.uk

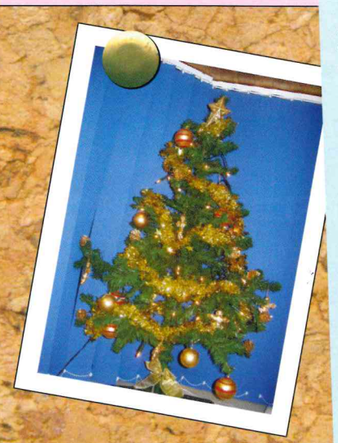
Accessible Travel and Leisure
01452 729739

The Good Access Guide
01582 760733
www.goodaccessguide.co.uk

www.allgohere.com
www.abletogo.com
www.sawdays.co.uk/search

OUT OF HOURS PHONE LINE
07712 653 258
7-9am Mon-Fri
5-10pm Mon-Fri
7am-10pm Saturday + Sunday

Sam on the phone



Hello MPS Staffers

At this festive time of year I have a few messages to pass on to you all! My first is for young Jeff. How are those crosswords coming along? Still stealing them from Sophie? You thief! I hear you are leaving us. We are very sad to see you go but understand that your hands-on skills are needed elsewhere. On to Alison... Well, what can I say? 29? Not getting any younger (one year from the big 30) and sits on tables with other people, apart from me - not very good! Only joking. You are such a fun, friendly person that brightens up the place anywhere she goes.

Ellie, Sophie, Antonia, Cheryl, Gina and Alex - such fab people, all individual with unique qualities that you bring to our Society. Thank you for all your time and effort. Hello to our Society Sam (our new girl). Hope you settle in all right and find the MPS Society friendly. Finally to Christine... Thank you for being such a wonderful charity director - your work never goes unnoticed. We are all touched by the work you do. Hope you have a great Christmas and a happy New Year. Use all your days to come to the full and never regret a thing!!!

All my love

Jo Wilson XXX

Regional Clinics and Events 2004

Sophie

January	
Fri 23	Birmingham Clinic
February	
Tue 17	Newcastle Clinic
March	
Wed 31	East Anglia Clinic
April	
Wed 28	Cardiff Clinic
Thu 29	Bristol Clinic
May	
Sat 1 - Sun 2	MPS Fun Weekend, Alton Towers
tbc	Scotland
Thu 20	Northern Ireland Clinic
June	
Thu 10 - Sun 13	International Symposium on MPS & Related Diseases Mainz, Germany
July	
Sun 11	Childhood Wood, Remembrance Day
Fri 16	Birmingham Clinic
Fri 16 - Sun 18	Sibling Activity Weekend
September	
Fri 3 - Sun 5	Siblings Activity Weekend
Wed 29	Cardiff Clinic
Thu 30	Bristol Clinic
October	
Fri 1	Jeans for Genes Day
Fri 22	Childhood Wood Tree Planting
November	
Thu 18	Northern Ireland Clinic

UK wide information days will take place throughout the year. The Advocacy Support Team remain committed to establishing a regional clinic in the South East of England.

Ellie in her office

Advocacy Support Bulletin Board

Children Style Themselves on Their Parents

Peter Rennoldson

Editor's Note:
Peter was asked to speak at the Society's 21st Birthday conference in June 2003 about achieving independence for children who are physically disabled by a Mucopolysaccharide or Related Disease. Peter gave an assortment of personal views based loosely around living independently.

My daughter Megan has mild alpha Mannosidosis. She is 20 years old, able bodied, active and attends an Information Communication Technology course at the local college of further education. Megan is keen to learn to drive and I recognise this would give Megan the independence she aspires to. But what if she can't learn to drive? What if Megan can't use public transport? What if she can't go to the shops by herself?

No one is independent. How many of us would be independent if there was no petrol? Independence becomes a state of mind.

What other sort of independence is there? There's an independence of spirit, a positive attitude, optimism, assertiveness, determination. All these things can give us so-called independence.

No one is independent. We are all dependent to a certain extent on the state or the law or our friends or family or public transport or the shops where we buy our groceries. How many of us would be independent if there was no petrol?

Christine, Megan & Peter at the House of Commons

Independence becomes a state of mind. So make a list of all the people and things your son or daughter would rely on if you were away for a few days. Some of you may say that as a family we're very lucky, and I believe we are. Some of you may ask 'What do I know about suffering?' as my daughter, Megan, is relatively healthy. We are, all of us, luckier than some and not as lucky as some others.

An example is a man interviewed on television two years ago who had lost all his possessions in the floods. When the interviewer asked, 'What will you do?' he said, 'Oh it's not so bad, I could be living in Bosnia'. Now I am not saying that he was happy to lose everything, that he didn't care and it didn't stop him struggling to make things better, but his attitude was positive.

Now I want to tell you briefly about my experience and my wife Jane's experience that gave us the ability to get on with our lives, which has given Megan the feeling of independence that all young people should have. It wasn't something we consciously did, it just happened.

When Megan was born with what was 'mild talipes', she had a slightly larger than normal head and she spent six weeks in traction to relocate double dislocated hips then three to four months in a plaster cast the shape of an inverted 'T'.

For Jane it was hell. I can't recall how I felt.

Jane's hell turned into guilt and now, 19 years later, she's just beginning to feel ok. Things took a down-turn when Megan was diagnosed but we took a pragmatic approach and saw that in reality nothing had changed. Megan was still the same little girl as before diagnosis.

Everything medical from the moment Megan was born was considered as an isolated, mild condition and not related to any one cause. Each doctor would say 'This is very mild – whatever'. 'Why are you so upset?' Our GP suggested we have another child as soon as possible and that Jane should go back to work. Remember that we did not have a diagnosis at this point.

Jane's a teacher and always good with children. A paradoxical situation which she dealt with, by all outward appearances, very well. Jane went back to work soon after our second child, Tom, was born about two years later.

Had Megan been diagnosed early we might not have had Tom, who, although he carries the same faulty gene that both I and Jane carry, has avoided the double dose that causes Mannosidosis.

Megan had lots of physical and mental tests but nothing was diagnosed until she was about 15 years of age. Her swollen and painful knee was the first clue. Her paediatric specialist, Mr Vic Seal (the surgeon who corrected Megan's talipes), performed some exploratory surgery and, on finding nothing wrong, referred us to others and eventually Dr Ed Wraith at the Royal Manchester Children's Hospital.

I have to say that had it not been for all these minor ailments, Megan wouldn't be in such a strong position. Intellectually Megan's well balanced. Because we realised early that Megan had difficulties, we helped her to become strong intellectually and emotionally and to cope (as much as she is able) with the real world.

Make your child assertive not aggressive. Make sure they can say 'Excuse me, I have a hearing difficulty, please say that again'.

What I am saying to you is that early diagnosis is important in creating a strong, well-balanced child. We didn't have early diagnosis but there were signs that told us that Megan needed extra help. I don't mean kick the child mentally, but don't wrap them up in cotton wool. Teach the child how the world works from the first moment with stimuli (mobiles, noises, lights, interactive toys, card games, patterns and sequences etc). Then later on with more complex things.

Last year I spoke to Dr Dag Malm who is also the father of two children with Mannosidosis and he seemed to agree that a strong intellect will help a child cope as this illness progresses.

This very thing was made more apparent to me when Megan was on her own in her room listening, with headphones, to a cassette tape of Snow White. It was in stereo and the witch was on the right and Snow White on the left. When the witch came round to the other side Megan became frantic because she had no understanding of simple stereo. These sort of things we take for granted. We must take time to analyse and explain instead of saying 'Oh there, there, silly old witch' or 'Don't be daft it's only a tape'.

Megan (Mannosidosis)

Megan has a problem with cause and effect which for some reason is common in Mannosidosis. She may think 'I'm hungry' because 'I'm eating'. Then after a second she turns it around. Although this happens less now, Megan follows the track of the wrong meaning and misses the point of the conversation. Homonyms cause problems if they are not sorted. They can be humorous so long as the perpetrator laughs too. Take the time to explain things that you and I take for granted.

Hearing problems, ear infections, and frequency loss can result in poor language development. Access to speech therapy to improve your child's diction and ensuring that your child has eye contact with you when you speak to them is very important. You may wish to explore digital hearing aids. Megan has really benefited from these strategies.

Make your child assertive not aggressive. Make sure they can say 'Excuse me, I have a hearing difficulty, please say that again'. Or state whatever the difficulty is. At the cinema with Megan, the man at the desk started to get impatient when she mis-heard. When Megan said 'Sorry, I have hearing difficulties', he smiled and became more helpful and friendly.

Don't be afraid to get yourself sorted out. You can't take the world on your shoulders.

There is a lot I could tell you about Megan but that would be an emotional drain on you. I am sure you all have got just as many emotional stories to tell as I have. ■

Fabry Disease in our Family

Suzanne Hill

My husband was diagnosed with Fabry disease at the age of 29 when his Uncle Don found out he had a rare condition called Anderson – Fabry disease. We realised that Graham's symptoms were about the same as his uncle's. The GP found a doctor in London who we went to see. He was the only one at the time who knew anything about Fabry disease.

As a child Graham had moved around the south of England and saw many different doctors. It may have been different if Graham had stayed in one place. Throughout his childhood each time his mum had taken him for pains in the hands and feet, high temperatures and/or lack of energy it had been put down to childhood ailments such as juvenile arthritis. And when Graham as a teenager had a bad spell with paralysis this was put down to bells palsy.

I met Graham through a friend of ours who set us up on a blind date. We were married in September 1985 and at the time Graham was able to do all the things that someone aged 28 years would do although he didn't play sport. The only thing I knew about Graham's medical history was that he had a short stay in hospital in his late teenage years.

I was reassured when his Mum said she had been told it wouldn't happen again although they couldn't find out what could have caused Graham's problems.

Each time his mum had taken him for pains in the hands and feet, high temperatures and/or lack of energy it had been put down to childhood ailments such as juvenile arthritis.

I found out I was pregnant on our first wedding anniversary only to have a cloud come over the happy news as Uncle Don had gone to see a genetics counsellor to be told that he had Fabry disease and that it was passed down through families and that they were not sure how the condition would be passed on in our family. They said they would do a family tree and find out. It was a huge shock being pregnant especially as we found out that the disease would be passed on again if Graham had a daughter. We prayed we would have a boy. Graham and I then had a visit to see a more senior genetics counsellor at Southampton Hospital. Accompanied by Graham's parents and Uncle Don we met a doctor who took blood and told us a lot more about Fabry disease.

Christopher was born in May 1987. When Christopher was born it was such a relief as we knew a boy would be clear of the disease. Christopher was born with a cleft lip/palate so we had several stays in hospital in order to get him feeding properly then, when he was 12 weeks old, he had to go Odstock Hospital to have his lip repair done. Graham, a clerk at the Verne prison at the time, carried on working while I was at home to cope with a very difficult baby. Then a few weeks after Christopher's first operation I had a phone call from Graham's work to say someone was bringing him home because he wasn't well.

Our GP didn't tell me at the time that a stroke is a serious complication of Fabry disease. He didn't think it was anything to worry about.

On arrival home Graham had difficulty walking and was in pain so I called our GP who came to see Graham by which time he had suffered a stroke which paralysed his right side. Graham was also having difficulties speaking so I ended with both a husband and a baby to nurse. Our GP didn't tell me at the time that a stroke is a serious complication of Fabry disease. He didn't think it was anything to worry about. Graham was just 30 years old.

When things had improved enough for Graham to get about again we went to London for tests where, at the end of which, we were told that this was what would happen from time to time with the progression of the disease. Graham was given a life expectancy of 40 years so we thought we would have plenty of time for a treatment to be found. By this time Graham was again well enough to work but not in his previous position. He was transferred to the land registry.

Not wanting Christopher to be an only child we decided that although Graham was not back to his old self we should go ahead and try for another baby. Sarah was born in April 1990. I didn't want any tests to see if Sarah would be a carrier while I was expecting her because we would cross the Fabry bridge when the baby arrived. We knew she would be a carrier but actually did not realise Sarah would have symptoms of Fabry disease. We had been told that females don't suffer from Fabry disease.

At six months old Sarah had a convulsion so we ended up in hospital for a few days and this was put down to a high temperature due to a virus. We were told how to keep her temperature down and then allowed home. The hospital did not think this was anything to do with Fabry disease but over the next four and a half years Sarah had more and more spiked temperatures which I was able to cope with at home. When Sarah started to walk she would complain about her feet hurting which I didn't make too much fuss over, not wanting her to know that this was due to Fabry disease. When she started school there would be days when I had to put Sarah in the buggy and she would hit out at playtimes because it was impossible for her to run around with friends.

Graham's health has continued to worsen even though he started on Fabrazyme as part of a clinical trial in 1997 and continues today on compassionate use. When the first trial started it was hoped the Enzyme Replacement Therapy would prevent Graham's condition from getting worse but of course Graham's disease was well advanced and he had a major stroke.

Sadly for us Enzyme Replacement Therapy for Graham came too late. Graham has still had several TIA's and his mobility has continued to deteriorate. We have begun to see the effect on his brain with mood swings and memory loss. As a family we have not been able to do very much together in recent years because the children want to be able to run and explore and Graham isn't able to keep up. Now Graham can only go out if he is in a wheelchair.

Sarah has always had frequent spells of high temperatures, pain in the hands and feet, and some gastrointestinal problems.

We had been told that females don't suffer from Fabry disease.

Sarah started on treatment with Replagal three months ago and being of an age to understand what was going on it was her choice to take part in the clinical trial and receive enzyme. Since starting on enzyme Sarah has become a lively teenager with little sign of her previous symptoms. This has hugely improved Sarah's outlook and quality of life.

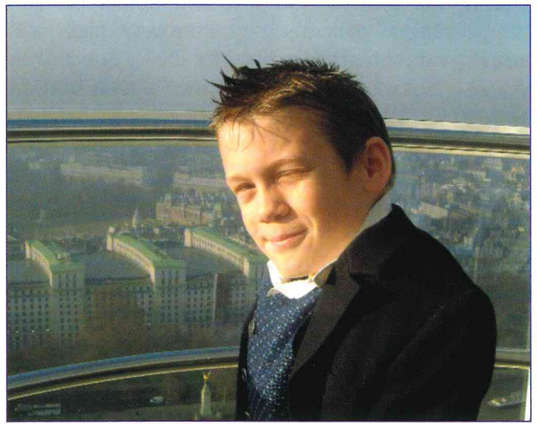
We had another surprise in February 1997 when our third child Andrew was born. I had an amniocentesis so I knew I was expecting a boy. Although there is a big gap between the three children he has been a dream child with no visits to hospital. He is a handful but we all adore him.

Graham doesn't have very much to do with any of the children now. He has no interest in anything anymore and spends his days in an armchair asleep in front of the TV. Although I am disappointed his treatment hasn't made that much difference I hope that, like Sarah, all Fabry sufferers will get treatment before the disease has progressed too far and the damage is irreversible. Fabry sufferers will then be able to look forward to a much improved quality of life with little or no risk of the complications of Fabry disease. ■

Suzanne & Graham Hill (Fabry)

Children of Courage Awards 30th Anniversary

Mark and Rachel Wheeler



Sam (MPS IV) on the Millenium Wheel

Sam was awarded the Children of Courage Award in 1995. As this year is the 30th anniversary of the awards, past winners were invited to the ceremony held in Westminster Cathedral. It was great to meet some of the people we met back in 1995 and other winners.

The event was attended by a great many celebrities. Sam met Chris Eubank, Louise, Helen Worth and David James among others.

After the ceremony the past winners were then taken onto the Millennium Wheel. It was Sam's third trip on the wheel! We were also given free passes to all the major London attractions which we will be using in the very near future.

Letter to the Advocacy Support Team

Mrs Batool, Adikah's Mother

First of all thank you for helping Adikah with her school at St Edmunds. At the moment she is having a transfer to Colton Hills until her adaptations are done at St Edmunds.

We have struggled since half term, but now things look as if they are moving. Secondly thank you with the adaptation to our house for Adikah's bedroom and bathroom, which is in the process of being plastered now. Hopefully it should be ready by the end of November.

Without the support of the Society's Advocacy Support Team I don't think we would have managed this far. I am very grateful to you all. I am sure all the parents that also have your support are grateful for the wonderful job you all do, and the care that is provided for other children with an MPS or Related Disease.

Adikah (MPS IV) in her old bathroom

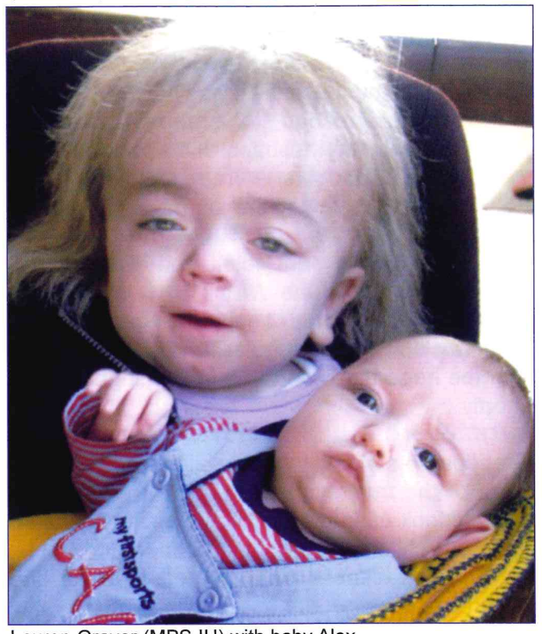
Births

Abdul-Qayyam Zafran was born on 24 October 2003. He is a brother to Yousif Zafran (MPS III).

Toby Richards was born on 11 November 2003. Toby is a brother to Sophie (MPS IH).

Luke David Hope-Gill was born to James and Jules Hope-Gill on 6 November 2003.

Alex Graver was born on 13 October 2003 weighing 7lbs 5½oz. He is a brother to Lauren (MPS IH).



Lauren Graver (MPS IH) with baby Alex

Olivia Perfect was born on 30 September 2003. Olivia is a sister to Ben and Emma (MPS VI).

Sophie Jane Lewis was born on 15 August 2003 to Steven and Joanne Lewis. Sophie weighed 2lbs, 12 oz.

Steven & Joanne Lewis with baby Sophie

Deaths

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

Mary Stacey who died on 22 September 2003. Mary and her husband John have fundraised for the Society since it was founded.

Alan Hughes who died on 19 October 2003.

John McDonagh who died on 26 November 2003.

Karen Naish who died on 17 December 2003.

Thomas Birch who died on 26 December 2003.

Thinking of You

Sue Stuart was critically injured in a motorcycle accident recently and remains in hospital with serious neurological and orthopaedic injuries. Our thoughts are with Sue, her husband Peter, and daughters Hollie and Annie.

Stuart Damen was seriously injured in a cycling accident in October 2003. Our thoughts are with Stuart, Tina, Lorren and family.

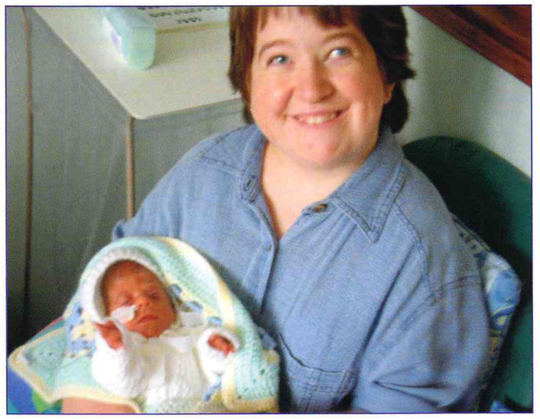
New Members

Roberto and Sarah de Cristofano's daughter Liliana has been diagnosed with Fucosidosis. She is 3 years old. The family live in the South East.

Janet Arrowsmith, who has Fabry disease, has recently joined the Society. Janet lives in the South East.

Joan Chatting has been diagnosed with Fabry disease. Joan is 67 years old. She lives in the South West with her husband Bernard.

Eric Herd writes "My full name is Roderick Cameron Chisholm Herd. I am a former Scot born in Glasgow on 21 February 1944. I like to be called Eric for short."



Joanne Lewis with baby Sophie

A Grandparent's Perspective

Margaret & Graham Moore

Our granddaughter, Samantha, 12 years old, is an MPS I Hurler Scheie patient. She was diagnosed when she was four and it was a horrible shock to all of us to find that she was suffering from a condition with no treatment available.

This is the time when grandparents can provide the stabilising effect while parents (and grandparents) go through the mental traumas of such a diagnosis. The fact that the disease is genetic means that not only the parents but the grandparents all feel responsible for the condition, even though we were not aware of the problems and, let's face it, had never heard of mucopolysaccharide diseases. Another problem is that no one else has heard of it either and find it difficult to relate to such an unknown.

We have always felt that our role is to support and cover for the rest of the family when mother or father are busy with Samantha's treatment.

There can be no finer role than being a loving and supportive grandparent and having the pleasure of watching our family grow into well balanced young people.

I remember a visit to the Willink Unit at Royal Manchester Children's Hospital some years ago when Dr Ed Wraith announced that there was to be an enzyme replacement treatment for MPS I patients and my daughter and I burst into tears at the surprise announcement. Fortunately Samantha was chosen for the trials of Aldurazyme although she was on the placebo for the first six months. This meant that my daughter, granddaughter and I travelled to Manchester up the M6, a 240 mile round trip, whilst my husband looked after Samantha's sister, Daniella. Their father works nights and was not available.

As time went by and my daughter learnt various ways of getting around Manchester, I stopped travelling with her because it was holiday time and I really was needed to entertain Daniella. But periodically my husband and I took over the trip to give our daughter a break and if her father was free he did a few of the journeys.

It is now three years later and we are still travelling weekly to the Willink Unit. With a new baby imminent, once again the grandparents have to step in to do regular runs to Manchester with the hope that we will be in Birmingham very shortly.

Grandparents need to be available to take the brunt of the frustrations; to ensure that they are there to look after the rest of the family; to ensure that both children are getting outings and treats; to treat the patient as a normal person, which she is; and to be the ear for anybody that wants to talk. There can be no finer role than being a loving and supportive grandparent and having the pleasure of watching our family grow into well balanced young people.

Margaret & Graham Moore, Samantha Brockie (MPS IHS) with Crumble the dog

Can You Help?

Do you have a story or experience that you could share to help others deal with their own circumstances? Or, let us know if you have any questions that our readers may be able to answer.

To submit information for the newsletter please send text by e-mail and post original photos which we will return.

Some Memories from a Grandmother

Mr and Mrs Griggs

When our daughter had a baby we were overjoyed. It had been a difficult birth and Natasha's lungs had collapsed, which necessitated her going into intensive care for a while, but after two weeks she was fine and she came home.

She appeared to us to be a normal, happy bright little girl with the most beautiful singing voice. Indeed, I remember when she was on a bus with me, singing 'Frere Jacques' aloud, (very aloud!) and a lady turning round and saying, 'What a beautiful voice your child has!' We were very proud of her.

She had a few health problems, but nothing to worry us unduly. She had grommets fitted in her ears on several occasions, and indeed it was this specialist who suggested that our daughter and son-in-law should see a paediatrician and 'have some tests done'. This they duly did, and it was then requested that both parents should go for a meeting, as the paediatrician wanted a word with them.

I think the bereavement time started there, although we could not really believe this was happening.

Could I look after the children in the waiting room while they went in to see the doctor? Fine. Natasha was now five and a half with a toddler sister Kirsten. I did try very hard to keep the children amused, but after over an hour Natasha was getting really loud and energetic! I began to get worried that they had been so long, when at last they appeared. 'Well,' I said, when we were in the car, 'What did he say?', 'It's a bit complicated, Mum. Wait until we get home and we'll explain.'

I think the bereavement time started there, although we could not really believe this was happening. 'What's MPS? What does it mean? I've never even heard of Mucopolysaccharidosis!'

We watched our Natasha every day and she seemed to be fine. 'Perhaps they've got it all wrong. It's just a mistake.' But then, she wasn't so good on her legs, her attention span became very short, her speech became limited, and she forgot the words to her songs.

The hyperactive years I think were the very worst and really exhausting and draining for her parents

Natasha (MPS III) and her Nan

A life of love, given and received, and never forgotten.

and sister. I well remember when we were unpacking groceries from the car and into the kitchen, Natasha seizing a bottle of dry Martini and smashing it on to the floor with great shrieks of joy. We really needed our Martini that night, but short of licking it off the carpet, there was no way of getting our drink! The bottle of Ribena was sticky and bad news for the carpet on another occasion.

But now we look back on these incidents with smiles. We took Natasha into our local café, and pushed her in between the tables (she was in a wheelchair by now). Her little hand reached out with amazing speed and snatched a sausage from a gentleman's fork – horror!! We apologised profusely. 'We will buy another' but luckily he was a real gentleman, very understanding and kind.

Mortification at the time, but smiles in retrospect. As grandparents, we really wanted to help, and found we could do so in the holidays, when we could look after Tasha while Mum and Dad took Kirsty out for treats. Also, we used to take Natasha into Helen House, the children's hospice at Oxford, and stay with her there, while our daughter and family 'recharged their batteries'.

It is very difficult to accept that a grandchild will die before you do. It is alien to the natural order of things, but I think grandparents can help by sharing in whatever ways possible. We were privileged to be at Helen House with the family, when Natasha peacefully ended her days at 21 years of age. A life of love, given and received, and never forgotten.

Members' Perspectives

Emma's Story from an Educational Perspective

Miss S. Hardman M.B.E.

Editor's Note:
Emma Slater is an 11 year old girl with Hurler disease, who has had a Bone Marrow Transplant. She currently attends Gorsefield Primary School in Radcliffe, Manchester.

From a school perspective, we were determined that Emma would succeed in a mainstream school. Her needs centre around ensuring her physical needs are met and her learning problems are provided for. This has meant close liaison with the medical personnel involved in Emma's care and following through their recommendations, such as organising specialist seating, ensuring her fingers remain supple and delivering a carefully structured curriculum using a task analysis approach.

Throughout her life so far, Emma has had to accept that what others take for granted every day, she can only dream about, but she never lets this get her down.

In return we have had the pleasure of seeing Emma blossom in every way into a confident young individual. Emma has approached school with both enthusiasm and commitment. Her medical and physical difficulties have always taken second place to this. She has asked for no special treatment and exists within school on equal terms with her peers. Her zest for life and learning has not been eroded by frequent hospital visits, constant monitoring and high risk surgery twice a year.

Emma has coped with wearing a restrictive spinal support and being denied many of the usual school activities. Most children would welcome a morning off school, but not Emma. Emma hates it when she has to miss even an hour of school to attend a hospital appointment.

Her dream has been to go swimming with school but having arranged for this to happen, Emma needed surgery again and was unable to go. We know she was devastated but she didn't dwell on it, she simply moved on.

Throughout her life so far, Emma has had to accept that what others take for granted every day, she can only dream about, but she never lets this get her down. Instead, Emma treasures the little things in life. She takes great pride in being present for a class assembly. She beams when she is praised for her work. She helps those less able and thinks herself lucky to be able to help.

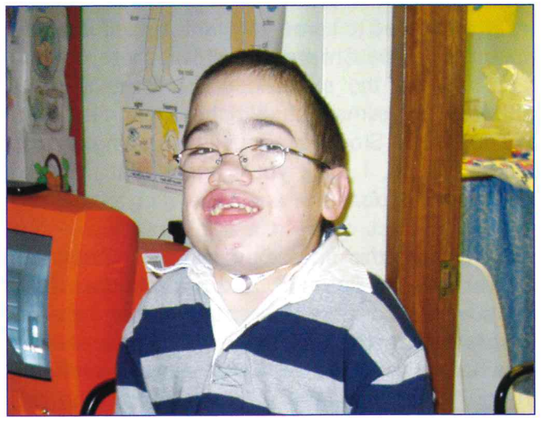
It is for these reasons that Emma is one of the few children in our LEA to have been awarded a Certificate of Achievement from the Director of Education and it is for these reasons that teaching Emma has been both a privilege and a lesson for us all!

Emma (MPS IH)

Bone Marrow Transplant Clinic

Cheryl Pitt

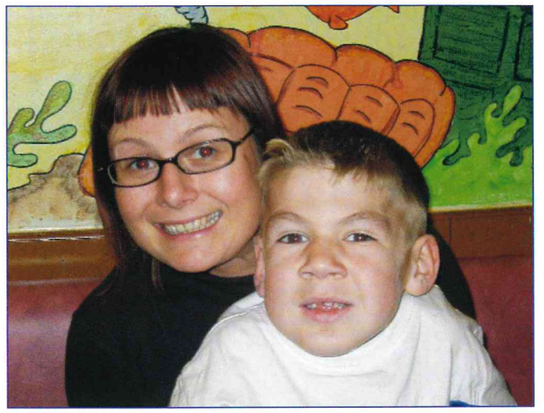
On this occasion the BMT clinic at the Willink was unusually quiet, or perhaps it ran so smoothly the usual chaos didn't get the chance to ensue. It seemed that most of you arrived in such timely fashion that you were ushered into the consulting room almost as soon as you walked in the door. What an efficient team the Willink has!



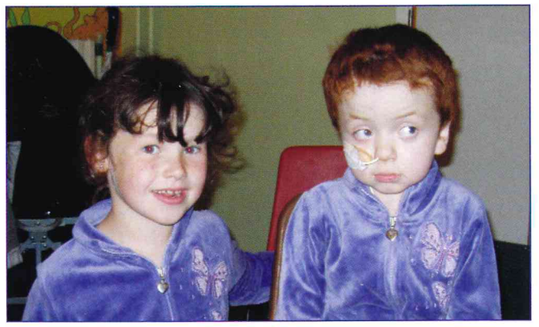
Twelve families attended the clinic, and it was a pleasure to meet some families I haven't met before as well as see the familiar faces again. I was especially encouraged to hear the positive feedback about the Experts' Meeting on Orthopaedic Management of MPS diseases from those of you that attended.

Although such meetings can discuss topics that can be quite frightening for families, I am glad you feel you have gained some essential knowledge that will help you to manage your children's orthopaedic needs in the future.

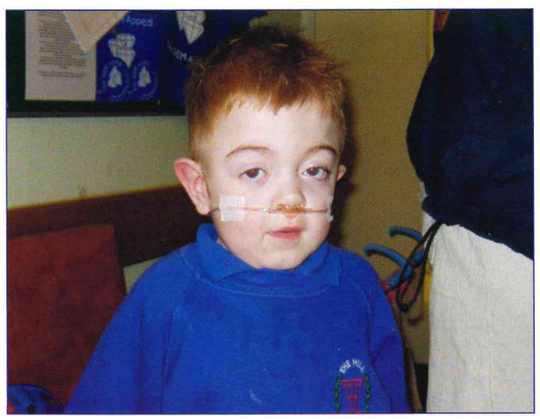
For those of you that could not make the orthopaedic meeting, you have not missed out on the chance to gain insight into the orthopaedic management of MPS diseases, as all the presentations will be compiled and published, and made available to you in the near future.



Staff at the Willink apologise that hot drinks can no longer be permitted in the waiting room. With all the children, toys, buggies, parents, and staff, hot drinks could prove to be a hazard. I hope you agree that this wasn't a problem, and that although the waiting room is small, it has creative and fun entertainment for children of all ages.



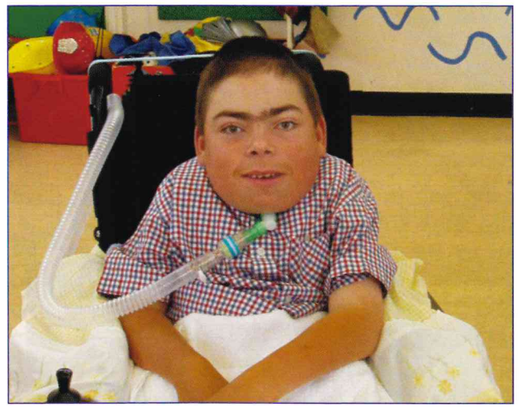
Thank you to my photogenic friends who gave extra large smiles for the MPS camera this time, and to Bernie and Gill for their help and for providing refreshments. Thanks also to Dr Ed Wraith, Dr Rob Wynn, Tim Meadows, and Professor Clayton, who made up the team of consultants, for their excellent work and a successful clinic.

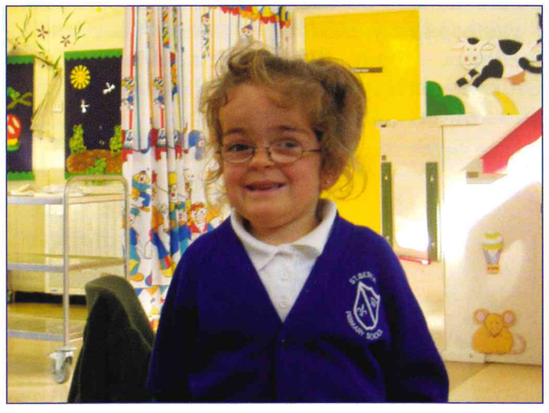


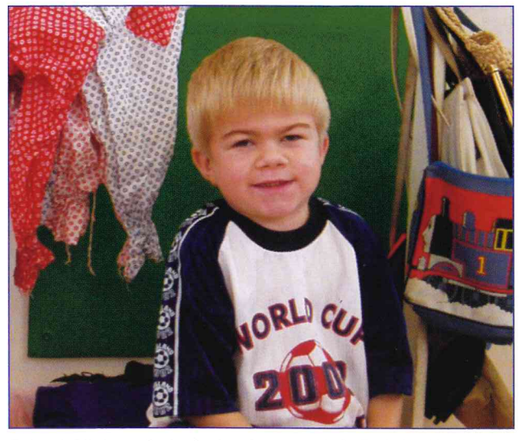
Clock-wise from top right: Cheryl & Callum Pollock (MPS IH); Keira O'Neill (MPS IH) with her sister; Leighton Barker (MPS IH); Isaac Turner (MPS IH); Alex Cosgrove (MPS VI)

MPS Regional Clinics

Bristol, Cardiff and Northern Ireland







Bristol Clinic anti-clockwise from top left: Deirdre Freke, Dr Jardine & Alison; Andrew Hawkins (MPS III); Jimmy Penfold (MPS IHS); Logan Tresidder (MPS II); Terry Butler (MPS IH); Tara Murphy (MPS IH)

As some of you may have noticed, due to circumstances beyond our control, the Bristol and Cardiff clinics had to be changed from their original date in early November. This resulted in Dr Jardine's secretary Deirdre, Dr Shortland's secretary Sue, and Dr Wraith's secretary Christine (and me) all trying to arrange a new date where everyone was free. A few hundred emails later and we were finally agreed!

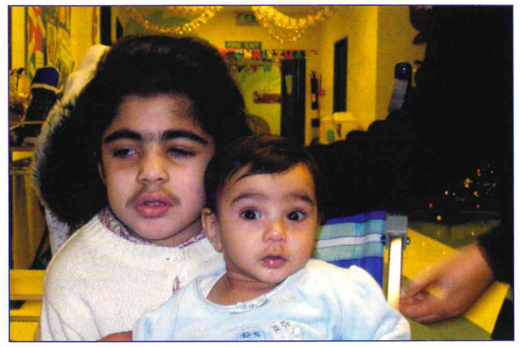
Christmas came early to the Cardiff clinic. We were treated to some truly fantastic efforts from the nurses at the Children's Unit who were working hard to make the place look like Santa's grotto (although at times it did have an element of The Three Stooges about it!) Judging by the photos though, I think you'll agree that they did a magnificent job.

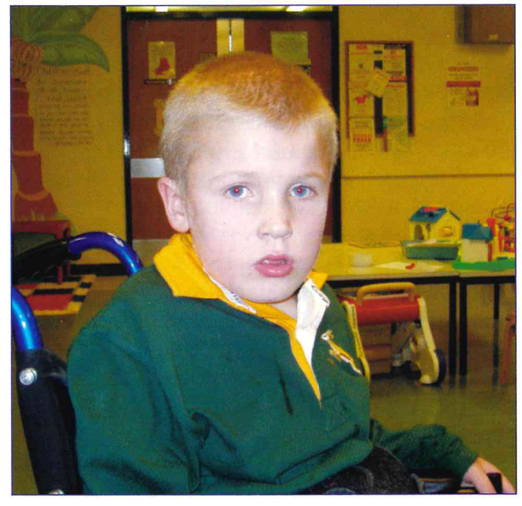
So, what with this impromptu cabaret, Christmas music in the background, and our fabulous array of Christmas cards and wrapping paper for sale, it made for a rather festive clinic. This proved to be quite helpful as, at one point, the clinic was running an hour and a half late! To those of you who had a very long wait, thank you for being so patient.

The Northern Ireland clinic was very quiet compared to normal and, in the end, only six people were seen as two were unfortunately unable to make it. This actually turned out to be quite fortunate as, due to mechanical difficulties, Dr Wraith's plane was delayed and he didn't make it over from the mainland until lunchtime.

Dr Stewart's secretary Sandra proved to be an incredibly resourceful secretary as, once again, she devised a means of blocking off the stairs to make the waiting area safe for the children who came. Hopefully this will be the last time she needs to do this as we are hoping the next clinic will be held in a more 'child-friendly' venue within the hospital.

Our thanks go to everyone who makes these clinics successful: Drs Ed Wraith, Philip Jardine, Graham Shortland, and Fiona Stewart for their continued hard work and support; Sue, Deirdre, Sandra and Christine – the tireless secretaries who make the arrangements; and all the staff at the hospitals who help the clinics run smoothly. ■





Clockwise from top right: Cardiff Clinic - Ayesha Ghaffar (MPS III) & sister Aaminah; Carley Dickinson (MPS III); Steven Jones (MPS III); Christopher Jones (MPS III); Melanie Jones (MPS III): Northern Ireland Clinic - John McDonagh (ML II) & parents

Childhood Wood Planting

Alison West

On October 24 a group of families and MPS staff gathered at the Childhood Wood in Nottingham for our annual tree planting to remember those who have lost their lives to an MPS or related disease. The weather provided us with a beautiful autumnal day, if a little cold, and the day ran very smoothly.

We all gathered at the Clumber Park Hotel for a buffet lunch where we met with Councillor Nellie Smedley, Vice Chairman of Nottinghamshire County Council, who had been invited to support the planting.

She gave a lovely welcoming speech to all the families who were participating in the day and, after lunch, was presented with a beautiful bouquet of flowers by Jack Johansson. He also managed to give an impromptu speech of a few words thanking Councillor Smedley for coming and both were rewarded with a warm round of applause.

Everyone then moved down to the Wood where we held the traditional ceremony by the MPS information board. Councillor Nellie Smedley shared some personal reasons for feeling privileged to be included in this day, Barry Wilson read the names of all the children who were to be remembered, and I read the poem 'Remember' before the families each collected their oak saplings and planted them together with their individual plaques.

Byron, the Forestry Ranger who is soon to be taking over from Andrew as our contact at Sherwood Pines, and Andrew both kindly assisted with the planting and helped us take some photographs. I would like to extend a personal thank you to them for all their support and hard work.

I would also like to thank Sophie for making all the arrangements, allowing us to focus on participating fully in the day, and Councillor Nellie Smedley for her valued support.

Clock-wise from top right: Daniel Wainman's family; Mrs Louie Bean, Cllr Nellie Smedley & Barry Wilson; Daniel Wainman's family; Mrs Louie Bean, Cllr Nellie Smedley & Jack Johansson

South West Social Evening

Alison West

A Social Event? Show me my best frock and lead me to it!

Following a disappointing response to our request for interest in our Christmas Parties, it was decided that we hold a couple of ad hoc Social Events to see if this would engender any interest. We recently held such an event for families living in the Hants/Dorset area and below is an article written by one of the families who attended.

If anyone feels that they would like an event like this in their area, please contact the Society to register your interest.

A Plea from the Quiet Side of Dorset

Stephen Home

I'll quickly introduce myself. I'm Steve, father of Matthew, who is now 9 years old and has severe Hunter's, Rebecca who is 6 and Charlotte who is 3 (going on 24, for all those fathers with daughters you know exactly what I mean!)

We all cope with our personal situations in our own unique ways, so this is just my personal view on the world, and I am sure that there are many of you to who this will mean very little.

Recently Jacqui and I were invited to a local MPS Society meeting for parents and carers in our area. It dawned on us that it had been a significant period of time since we had last had this sort of opportunity.

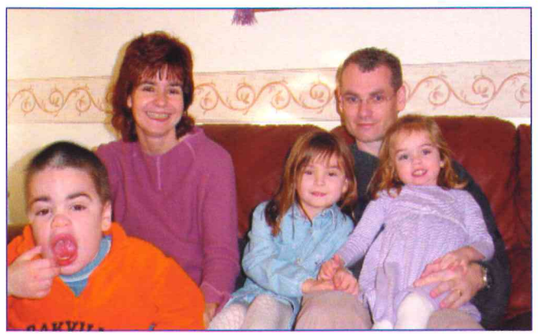
I remember the first few meetings, where Jacqui and I were asking all the probing questions, trying to piece together what our lives would be like as Matthew grew older. Five to six years on and we have moved a significant way down that road. We can now talk about how we have overcome problems, what is important to fight for, and what not.

There is of course the annual conference. Don't get me wrong, I am sure that when Matthew enters the next stage of his condition, we will attend again, with the same trepidation, fear and nerves of that first ever conference. I am also confident that we will come away with the comfort and angst associated with that peek into the future, what lies ahead for Matthew and for us. It's that knowledge that helps me plan and cope. But I always find these very impersonal, and as I said quite harrowing.

However the regional events offer that more personal and intimate touch, for myself (you may have guessed) I am not a very gregarious animal. We all stand up and get counted when we need to fight for our children's needs, but in more social situations I am really rather shy.

So when we recently attended a small meeting at a local hostelry it was like a breath of fresh air. It was simply great, it allowed everyone to talk in an informal environment, we all had similar concerns and issues but the conversation always had that local relevance (Southampton is obviously the place to go and live!). The ability to discuss, listen and just be in the company of others in a similar situation had a strangely calming effect.

So to the crux of this letter, a burdened plea from the quiet side of Dorset, more please?



Stephen, Jacqui, Matthew (MPS II), Rebecca & Charlotte Home

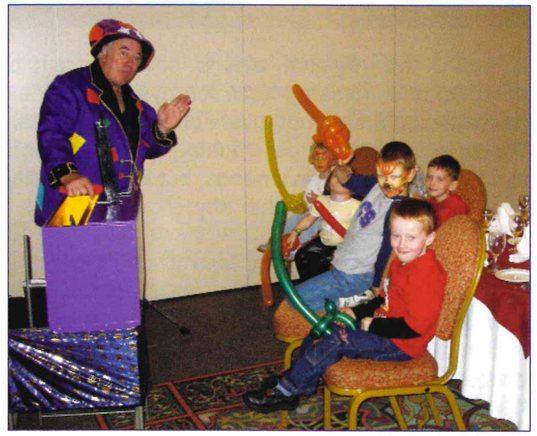
Celebrating 21 Years of the MPS Society in Northern Ireland

Jeff Bawden

The MPS Society has organised a number of celebrations for this, its 21st birthday year, and in November it was the turn of Northern Ireland to celebrate. Last, but by no means least.

Over two days we held a birthday party and a conference for all families, individuals and professionals wishing to learn more about the various MPS diseases. Both these events occurred at the Hilton Hotel Templepatrick and we would like to extend our thanks to everyone there who helped make both the events so successful.

The 21st birthday party was quite a small affair although it certainly wasn't quiet. In fact the hotel staff asked us to keep the noise down as we were disturbing the conference next door! Needless to say we behaved ourselves after this (yeah right!).



The entertainer with the children

Three families came to the party bringing with them a total of 6 children and we had a face painter and a magician to entertain us. Unfortunately the face painter didn't have much to do as most of the kids were boys who didn't think it would be cool to have their faces painted, although in the end one agreed to be a very cool tiger!

The magician however was a great success with all the children and kept them occupied whilst the adults enjoyed their meal. It has to be said that not many of the children ate their birthday tea because of this fun distraction. The magician was very good at entertaining the adults too with some cunning magic tricks and we all got to go home with a balloon animal! I am sure Christine and Ellie had great fun packing their's the next day.

Barry Wilson with the children cutting the cake

We would like to thank Bernie Drayne for recommending the entertainment company. She also recommended the cake company and that cake was delicious.

After a slow start with the bookings the conference 'Caring Today, Looking to the Future' went very well indeed, in fact a quick head count halfway through showed that a total of forty three individuals attended.

The speakers were all very good and the topics were very varied including clinical clues to diagnosing MPS diseases, orthopaedic management, challenging behaviour, making successful Disability Living Allowance claims and an update on Enzyme Replacement Therapy. There was also a very informative speaker from Horizon House, the Northern Ireland children's hospice.

Most importantly all the speakers ran to time as they were far too scared of Dr Alex McGee and Dr Fiona Stewart, who so ably chaired the meeting, to even think about over-running. We would like to thank both Alex and Fiona for this. We would also like to thank Fiona for promoting the MPS sales goods so effectively. She certainly got the sympathy vote going.

Finally we would like to thank all the families, individuals and professionals who attended both these events, without you it would not have been possible. Many thanks for making the last official 21st birthday celebrations of the year such a success.

Enzyme Replacement Therapy Christmas Party

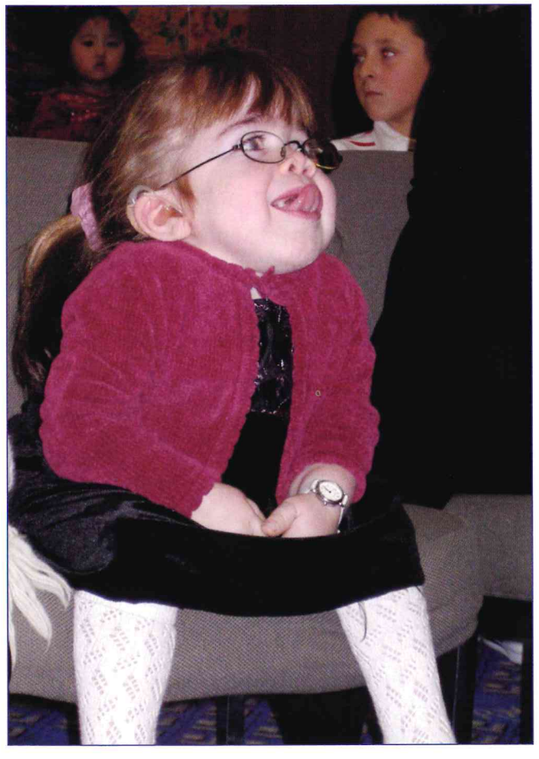
Ellie Gunary

On Tuesday 9 December children with metabolic diseases, patients receiving treatment at the Willink Unit, their families, staff of the Royal Manchester Children's Hospital and guests came together to celebrate Christmas.

The party, organised by staff at the Willink Unit, began with an entertainer who got everyone (including the adults present!) into the party spirit with dancing.

He followed with magic tricks, talking puppets and, after a break to eat, children's party games. The evening had an international feel with patients present from throughout Europe. The party ended with a visit from Father Christmas who had a gift for each child.

Of real note was the energy of those children who had been on Enzyme Replacement Therapy, children who a year ago would have been tired out much earlier in the evening.



Children at the ERT Christmas Party

Experts' Meeting on Orthopaedic Management of MPS Diseases

2-4 October 2003, Manchester Airport Hilton Hotel

This consensus meeting was jointly hosted by Dr Ed Wraith of Royal Manchester Children's Hospital, and Dr Charles Peters of the University of Minnesota. The aim of the meeting was to bring together experts in the field of orthopaedics, paediatrics, and physical therapy from around the world in order to discuss and reach agreement on the optimum way in which to manage the bone and joint problems that are seen in children and adults affected by MPS diseases.

Tim Meadows & Jim Ogilvie

Throughout the two-day meeting, experts shared their experiences of both the non-surgical and surgical procedures that they have carried out on MPS patients in order to correct their bone and joint problems. The use and effectiveness of braces to correct spinal curvatures was discussed, along with a number of surgical procedures used to correct neck instability, spinal curvatures (kyphosis and scoliosis), genus valgum (knock-knees), acetabular hip dysplasia, carpal tunnel syndrome, and trigger digits. The pros and cons of different surgical techniques were discussed, along with the appropriate time at which surgery should be performed in order to prevent bone deformity from progressing, to ease pain, and to prolong mobility.

The issue of quality of life was also discussed, together with appropriate ways in which to measure such a concept, and the pilot project exploring the psychosocial outcomes of Bone Marrow Transplant for MPS I was introduced.

Since a great number of issues were discussed, it is not possible to give a full account here. However, the Society, together with Charles Peters of the University of Minnesota are currently putting together a special supplement to the Journal of Inherited Metabolic Diseases, which will be available to you soon.

The supplement will include all the presentations from this Experts' Meeting as well as those from the COGENT Hurler meeting that took place in September 2002. So those of you that were unable to attend either of these meetings will get the chance to soak up the experts' knowledge and experiences.

We would like to thank all the speakers and chair people for their valuable contributions to this meeting, especially Dr Ed Wraith and Dr Charles Peters for kindly hosting it. We would also like to thank Jean Mossman for successfully carrying out the difficult task of facilitating the consensus discussions, and last but certainly not least we would like to thank all the professionals and families that attended the meeting for their contributions to the discussions.

It was a very successful meeting, which we hope was the first of many 'Experts' Meetings' to come. Since MPS diseases are rare, and specialists in the field even rarer, it is essential that we continue to bring them together so that patients and their families can receive the best possible care and attention.

Jim Ogilvie, Brad Williamson & Christophe Garin

International MPS Societies Organisers' Meeting

4-5 October 2003, Manchester Airport Hilton Hotel

Following the experts' meeting, the Presidents, Chief Executives and Assistant Directors of MPS Societies from around the world got together to hear about each other's work, share experiences, and agree ways of taking forward issues and ideas which would benefit from an international approach. Twelve countries were represented, and the opportunity to meet both formally in the structure of the meeting and informally over lunch and dinner was invaluable.

International MPS Societies Organiser's Group

Enzyme Replacement Therapy was a hot topic, due to distinct differences between countries on the ability of patients to access funded treatment. Of equal importance were discussions on the support needs of those individuals and families for whom there is no therapy available. Whilst all the MPS Societies offer Advocacy Support Services, this varies greatly both because of the resources available, but also because of differing levels of state support and health service provision.

Representatives from the American & Canadian Societies

The need for state of the art accessible information on MPS diseases was identified, with most countries having published booklets on the specific diseases. These were shared and everybody left with considerably heavier suitcases than they arrived with!

The future direction of research into MPS diseases was an important subject and much collaborative working came out of the meeting with each group agreeing to share details of the research and its funding, to prevent duplication between countries.

Governance was addressed with the representatives sharing the need for policies. I was struck by how the younger groups, developing in a different climate than that which the MPS Society started 21 years ago, have embraced this need.

Whilst there were some very serious discussions, there were humorous times shared as well. We all failed to keep a straight face when one country told of a fundraising event it had organised involving a field marked into measured squares and a cow. The cow is allowed to roam the field and people sponsor a square of the field. The winner is the sponsor of the square of the field where the cow does a pat. Any farmers in the MPS Society?...I'm sure the telling of the story was funnier than my writing up of it!

As always, when meeting with members and staff of other MPS Societies, I was struck by how much we all have in common and how this overcomes any other differences such as language and culture.

MPS and Related Diseases are an international concern and I for one came away from the meeting feeling we had learnt and shared a lot and agreed future areas in which we can work together to benefit all members of the UK MPS Society as well as those MPS individuals and families sharing similar situations throughout the world. A universal agreement was made on the need for regular meetings, and we look forward to seeing everyone again next year.

Representatives from the Austrian & German Societies

International Collaboration

Second International Meeting of Patients with Fabry Disease

Jeff Bawden

Once again the MPS Society was asked to support this International Patient's Meeting which took place 23-26 October.

This was on a larger scale than last year with a total of thirty nine individuals with Fabry disease and family members/carers attending. This year the conference was held in the town of Sitges just outside Barcelona rather than in the city centre. The meeting certainly tested my organisational skills and I was greatly relieved when everyone arrived safely.

The first day of the meeting concentrated on the latest results of Enzyme Replacement Therapy in the morning followed by various perspectives on home therapy in the afternoon. The second day concentrated on the more social aspects of having Fabry disease including genetic counselling, carer's issues and employment issues.

There were also a number of group sessions where participants were able to raise issues and questions among themselves and with relevant professionals.

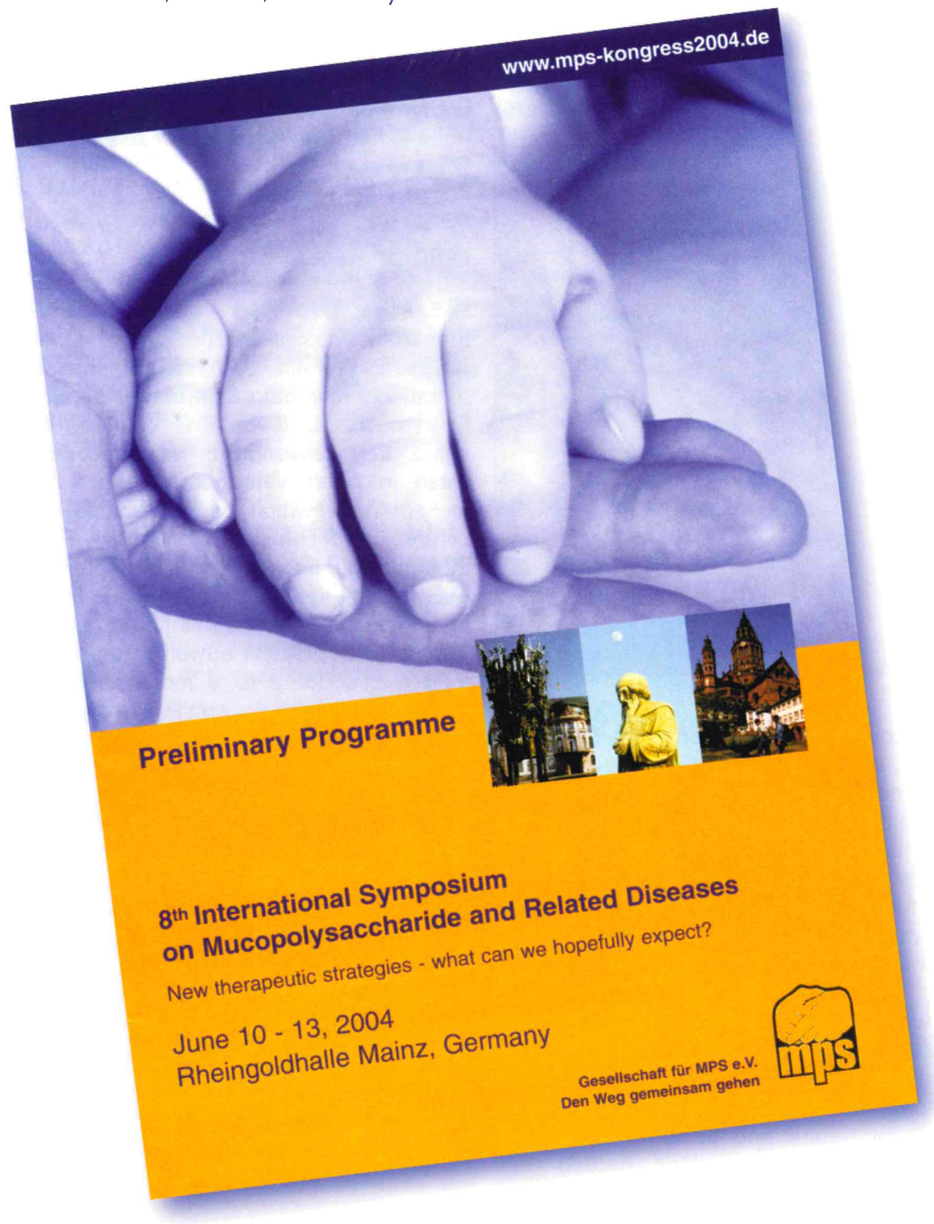
Certainly all the feedback I received about the meeting was positive and I am sure everyone had a good time. I also hope that lasting friendships were made among everyone who came.

From L-R: Juanita & Matthew Davenport, Sharon, Glennon & Lyndon Chatting, Laura Davenport in Sitges

In 2003 and 2003 European Fabry Patient Associations organised exclusive Fabry Patient Meetings in Barcelona and Sitges, Spain. These two meetings were funded by a single pharmaceutical company. For each meeting the Society received an invitation to send 38 British Fabry patients and their carers to participate. All costs from leaving a UK airport to arriving back four days later were met by the conference organisers. To enable the Society to make an informed decision as to its level of participation in any future exclusive Fabry Patient Meetings organised on the lines above we need to have our Fabry patients' views. A questionnaire is included with your newsletter.

8th International Symposium on MPS & Related Diseases

June 10-13 2004, Mainz, Germany



Enclosed with your newsletter is the Preliminary Programme for the 8th International Symposium for MPS and Related Diseases, June 10-13 2004, Mainz, Germany.

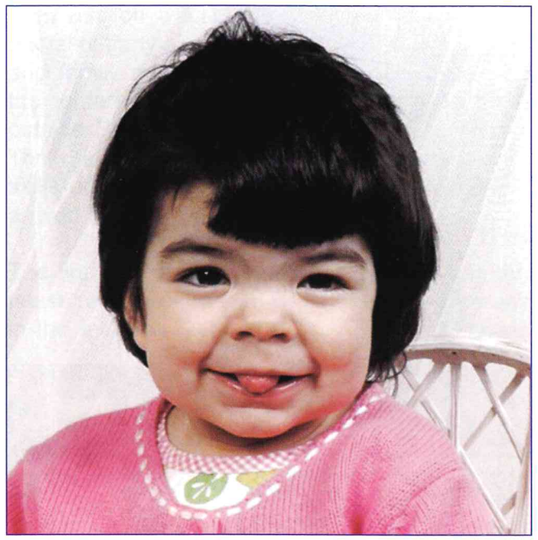
The Society is able to offer to fund the registration fee for up to two adult members per family. If you would like to take advantage of this subsidy please complete the enclosed registration form for families and affected patients and accompanying children, accommodation and additional optional excursions. The Society will then process your application and once confirmation is received, authorise your payment and the registration fees to be paid by the Society.

The Society is planning to take its own childcare volunteers who are CRB checked, and will have undergone training in moving and handling and care plan management. The Society volunteers will provide evening childcare Thursday 10 June and Saturday 12 June, as well as throughout the children's programme.

The Byrne Family

Judy Byrne

Editor's Note: This article first appeared in the Canadian MPS Society's Newsletter and permission has been granted for it to appear here.



Sarah (MPS IH)

Sarah's recovery from her transplant has been remarkable. We were released on July 11, 2002, only 5 ½ weeks after her transplant. In the whole first year, she only spiked a fever once, and by the time we made the decision to bring her to Sick Kids, the fever had gone down by itself. This child has had fewer illnesses than our whole family. Her donor must have the immune system of a mountain man!

Sarah was off her cyclosporine (immune suppressant) in the first week of December, and as a result, she was taken off a number of other meds to deal with the side effects. Sarah took her last doses of Septra and penicillin in the first weeks of July, shortly after getting her immunizations restarted. I can't believe it - this girl is on NO medication. She is a wonderful thriving two year old – although tiny. Her only detectable developmental delay at this point is her speech. We got tired of being on the waiting list for the county speech therapist (13 months and counting), so we have decided to pay for a private speech therapist ourselves. We are very glad we did as she is showing improvements already.

We do have a few crosses to bear in the future though. Sarah underwent a small surgery on July 17, to have a thyroglossal duct cyst removed. This is a condition completely unrelated to Hurler syndrome - just luck I guess. It is a small sack of fluid that collected in her neck, which had to be removed. Although it is a pretty minor operation, they were very concerned about being able to intubate her, as MPS kids can be notoriously hard to do. Also, because of her mitral valve prolapse, they had all kinds of heart machinery ready. Well it turned out to be much ado about nothing, and she was done in less than an hour!

> Life is gloriously normal. I have a two year old girl who is very stubborn, opinionated and hilarious.

We have also seen our cardiologist, who thankfully, has seen no progression in her prolapse. We did learn though, that it is only a matter of time before Sarah will be put on some heart medication, even if the prolapse remains the same. It is preventative, as the constant back wash into her valve could cause her heart to enlarge, which would cause all sorts of problems. The next big thing we are facing though, is her back surgery. On September 3, she will have her kyphosis straightened. It is currently about 60 degrees, and it is time to have it done. The surgeon predicts a twelve hour surgery, and then a cast for 3 to 6 months. (Can we say stinky?) Hopefully, we won't have any other bone issues to deal with for a while.

Despite this, life is gloriously normal. I have a two year old girl who is very stubborn, opinionated and hilarious. She lives and breathes Winnie the Pooh, and follows her big brother around like a lost puppy. As soon as the back is healed, I envisage ballet and swimming lessons!

Finally, we received our first letter from Sarah's bone marrow donor, and it was wonderful. He did say that he was willing to release his identity to us after the two year waiting period. We cannot wait! From his letter, he appears to be the caring and compassionate man that we always assumed he must have been.

Sarah (MPS IH)

Psychosocial Outcomes of BMT for MPS I Research Update

Cheryl Pitt

I am pleased to announce that we have Multi-Centre Research Ethics Committee (MREC) approval to go ahead with a pilot study as planned. The MREC comprises a board of professionals and operates within the NHS. Its role is to ensure that all research carried out in the UK is conducted by qualified professionals and is ethically sound. Specific guidelines are set in place to ensure that research participants are fully informed of the aims and procedure of the research, and that they fully understand their role in the research should they decide to take part. They also ensure that participants are made aware of their right to confidentiality and anonymity, and that they can withdraw from the study at any time.

Getting approval can be a lengthy process. Firstly, because the MRECs are very busy, but also because making an application is a painstaking exercise. When the application is made, a slot is allocated for the research to be assessed, and this alone may involve a two-month wait. Once the board have met and discussed the project, the researchers are informed of any changes the board feel should be made, and are invited to make their case against these changes if they feel they are not justified. In some cases, this process can swing to and fro until all are in agreement that the research protocol meets all requirements, without hindering the research.

In our case however, the study was passed with relative ease. So, I am excited that we can finally start on this valuable journey of discovery. For those of you who have volunteered to take part in this pilot study, I apologise for the delay, but I hope I have now explained the reason for this. With regard to the rest of the sample, participants have been randomly selected from the MPS Society database, and a total of eight families have been invited to take part.

In the very near future we will be able to use the information gathered from this pilot study to design a main study, which will include all families of children with MPS I post-BMT in the UK.

The Quality Control Scheme - Appeal for Help

Margaret Thornley, Royal Manchester Children's Hospital

The MPS Quality Control Scheme is run from the Willink Laboratory in Manchester. We send out sets of 3 samples 3 times a year to all labs in our scheme, at present about 40, in the UK and Europe. These samples are from known MPS patients and also from non-MPS children. Labs test samples in the same way as if a child was referred from a doctor who suspected that their patient may have MPS or if they didn't know what was wrong with the child and wanted to rule out MPS before going on to do other tests.

Some of the MPS diseases are more difficult to identify than others and, as these diseases are rare, many general labs do not normally see a positive sample, and do not know if they are missing some things because their method is not sensitive enough or the interpretation of the results is not accurate.

This scheme gives them positive samples to find and also gives feedback in the form of reports so that the labs know that their testing is proficient. We feel this work is important in ensuring that children with MPS are detected as early as possible by labs that are able to give meaningful and reliable results to their tests.

Our problem is in getting samples, especially from MPS III patients, one of the more difficult of the MPS's to diagnose. Each lab requires 5-10 ml of urine to test, depending on the method they use, We need about 350 ml of each urine to divide up and send out. This volume does not need to be provided at one go, urines collected at different times can be pooled together. They do, however, need to be kept reasonably fresh and this can be done by freezing them. We can provide large (500ml) plastic bottles if anyone is willing to help us. All we we require is the age and sex of the child and which form of MPS s/he has. The samples are sent out 'blind', the labs are only given the sex and age. Age is important as MPS levels measured in the urine are age-related and the sex can help with interpretation of the results.

We realise that transport of any samples to the lab may be a problem but regional MPS clinics occur regularly. If parents are willing to help collect a sample for us and take it along to a clinic, frozen in the bottle, we will be able to get it back to the lab. Anyone interested in helping us to carry on this important part of our work (not just MPS III parents) can contact the lab direct or the MPS Society with details and we can send them an empty bottle in the post.

Contact: margaret.thornley@cmmc.nhs.uk

New Forms for DLA (Disability Living Allowance)

There are plans to replace the current Disability Living Allowance (DLA) claim forms with new shorter forms. Good news? This is uncertain as testing for a new disability living allowance claim form for adults began in the north Thames area in September 2003.

The new form is around half the size of the previous pack. The Department for Work and Pensions claim that, to make up for collecting less evidence from claimants in the shortened packs, they will phone more people for additional evidence. There are fears that having to give more evidence over the telephone will discriminate against some people.

The MPS Society's Advocacy Support Team has direct experience of working with members who find it really difficult sharing the true extent of their disabilities and the difficulties they encounter in managing day to day tasks. Having to give this evidence over the telephone to complete strangers we can predict is going to be extremely difficult. Collecting evidence in this way may also discriminate against some people including those with mental health problems.

There are fears that having to give more evidence over the telephone will discriminate against some people.

We recognise the difficulties of the current forms, which are long, complex and difficult to complete. Time will tell if the new system of assessment is an improvement or if, like the current system, it will be inherent of difficulties.

Remember that the Society's Advocacy Support Team can help you to complete Disability Living Allowance claim forms. For more information contact the Society.

Achieving Funding for ERT (Enzyme Replacement Therapy)

In June this year during the National Conference the launch of Aldurazyme (now called Laronidose), the first Enzyme Replacement Therapy for MPS I was celebrated.

The hope of tomorrow, from the MPS Society's motto 'Care Today, Hope Tomorrow' had arrived for some of the Society's members.

Aldurazyme is the third ERT product available for the diseases covered by the MPS Society. For the treatment of Fabry disease, Fabrazyme and Replagal were granted a licence in August 2001.

The hope of tomorrow, from the MPS Society's motto 'Care Today, Hope Tomorrow' had arrived for some of the Society's members.

Unfortunately since approval by the EMEA (European Medical Evaluation Agency) many patients in the UK have experienced considerable barriers to accessing these treatments. Whilst applications to some Primary Care Trusts have been successful and patients are now receiving funded ERT treatment, other PCTs are refusing to fund and the Society is being called upon to support an increasing number of appeals.

The reasons being given for refusing funding vary widely, and of deep concern is that many of these reasons are erroneous and unacceptable.

The reasons being given for refusing funding vary widely, and of deep concern is that many of these reasons are erroneous and unacceptable. They include deferring of decisions until the development of regional policy, awaiting a report from a review being undertaken by the Chief Medical Officer at the DoH, a review that does not exist, and inaccurate assessments of the efficiency and safety of ERT.

The MPS Society is expressing its deep concern with the delays and refusals in granting ERT for those patients for whom it has been clinically prescribed.

These therapies concern treatment for life-limited children and adults who suffer degenerative diseases and who do not have time on their side. In addition the psychological distress for both the individual and their family in being refused treatment is incalculable.

Whilst rigorously pursuing the appeals procedures within individual PCTs, for each member who approaches the Society for support and for whom treatment has been clinically prescribed, the Society also recognises the need for a national approach to the funding of treatments for lysosomal storage diseases.

Given the low prevalence of MPS I and Fabry disease, and looking towards MPS II and MPS VI in the future, there are a small number of expert centres to which individuals and families are referred to for treatment. In these centres, clinical expertise in the care and management of patients is high. Decisions about the suitability of any individual patients for ERT is based on detailed knowledge of the condition. Recognising the difficult position of PCTs in becoming knowledgeable about lysosomal storage diseases in order to make informed decisions about treatment, the Society is pursuing several lines of support to take this forward.

A meeting has been held with relevant patient support groups for whom ERT is an issue to which commissioners from all the PCT and consortia in the UK were invited (some PCTs have approached the issue of funding for therapies for rare diseases by joining other local PCTs and pooling funding to share risk).

Expert medical practitioners were invited to speak about MPS I, Fabry disease and Gaucher disease, and then patients and parents of children with these diseases spoke about living with the diseases and their experience of receiving or not receiving treatment.

In its work on each appeal, with the individual or family's permission, the Advocacy Support Team write to the constituency MP and inform them of the difficulties being experienced, requesting their support.

In the second week of December, MPs of constituents for whom funding for Enzyme Replacement Therapy is not being made available were invited to a meeting at the House of Commons hosted by Linda Gilroy MP for Plymouth Sutton who has a constituent who is being refused funding for ERT. Dr Ed Wraith and Dr Atul Mehta supported this meeting and spoke to MPs about lysosomal storage diseases and the benefits of Enzyme Replacement Therapy. Dr Ashok Vellodi and Dr Uma Ramaswami also attended.

Although the number of MPs attending was small the discussion that took place was most productive. It was agreed that five MPs, Dr Ed Wraith, Dr Atul Mehta and Christine Lavery request a meeting with the Parliamentary Under Secretary of State at the Department of Health, Lord Warner, to take forward the issues.

In undertaking appeals for ERT the Society's Advocacy Support Team is working in close partnership with the medical teams of the tertiary centres and relevant individuals and their families, as well as the wider community of professionals and organisations involved in the commissioning of treatments for rare diseases. Until recently, with the difficulty in securing funding for ERT, it had appeared to some of us as though the research funded by the MPS Society over the last twenty one years had been in vain. It is this research that has contributed to the development of ERT treatments and without this we would not be in the position of having these treatments available today. It remains disappointing however that there are still so many hurdles to be overcome and for many patients by virtue of where they live, they are still waiting.

Until recently, with the difficulty in securing funding for ERT, it had appeared to some of us as though the research funded by the MPS Society over the last 21 years had been in vain.

The Advocacy Support Team is supporting individual appeals to PCTs and Health Authorities for ERT and is reliant upon the individual or family concerned driving the appeal process. Our experience to date is that practices amongst PCTs vary greatly with little commonality between both the processes followed in considering applications and appeal.

If you are asking the Society to support you in achieving funding for ERT, regular contact is needed with the Advocacy Support Team about the next step to take. The Society does not always hear the outcome of the appeals submitted and is reliant upon members to give this information. Working in partnership in this way has proved to be the key to achieving funding for ERT at appeals.

Whilst it has been disheartening to learn of applications being refused and to work on appeals where success has seemed very distant a boost was received recently when a West Midlands appeal was successful. The success of this appeal has opened the door to many other individuals awaiting ERT who live in this area of the country, an area which has appeared to have a blanket policy of not funding Enzyme Replacement Therapy.

The success of this appeal was due to the family taking an informed proactive approach working closely with the Society. Through partnership and consultation the family drove their line of the appeal and the Advocacy Support Team backing this up took it to the appropriate levels and placed it in the wider context of human rights and equal opportunities. ■

Copyright

The Society's range of booklets are an important means through which the MPS Society provides information and raises awareness of MPS and Related Diseases. These booklets are used by a wide variety of people including parents of children and adults with MPS and also professionals who work with these families such as social workers and occupational therapists. The recently revised specific disease booklets in the 'A guide to understanding…' series and the 'I've got …' series for children have been particularly successful.

Recently the Society has received several requests from overseas MPS Societies for permission to translate our booklets into other languages. In many cases, our booklets are written by the Society but draw closely upon the personal experiences of individual members and their families and with significant input from medical professionals.

In order to protect both the Society and our members we have copyrighted many of our new booklets and formalised the procedure by which we allow their reproduction by other individuals and organisations. The Society will not consent to any of the booklets being translated by a third party either as a whole or in part without our prior written agreement nor will we consent to any unauthorised lending or copying.

These safeguards mean that when members agree to having their photographs or personal stories published in our booklets they can be reassured that the information they provide will be used only by the Society and will not be passed on by us to anybody else without prior written agreement.

BT 195 Service

For disabled individuals who cannot hold, handle or read a phone book a free directory enquiries service is still available. To register for the BT 195 service telephone 0800 587 0195.

Fairer Charging Guidelines

A coalition of charities has warned the government that local authorities are illegally trying to charge for the provision of essential care services to disabled children. The fairer charging guidelines were put into practice in October 2002 to ensure that local authorities review the way they charge adults for care. However, the coalition says that these guidelines are in fact being used as an excuse to extend charges to children.

The organisations Scope and Contact A Family are awaiting a decision by Department of Health lawyers on whether such charges are legal. In the meantime a survey is being carried out by the coalition to discover the impact of fairer charging Guidelines. For further information visit www.disabilityalliance.org.

Handbook for Disabled Parents

Through funding from the Department of Health the Disabled Parents Network has published a handbook for disabled parents. This draws on the experiences of disabled parents and gives useful sources of information on assessments of need, accessing healthcare and other mainstream services. Further information on this handbook can be obtained from the Disabled Parents Network. www.disabledparentsnetwork.org.uk.

SEN Action Plan

As part of a ten year Special Educational Needs action plan due to be launched later this year, the government has released details of three new projects aimed at helping schools improve access to education for disabled children. The projects will involve the Disability Rights Commission, the Department of Education and Skills, Disability Equality in Education and the Institute of Education. Details will be released as the Disability Rights Commission celebrates its first year of the Educating for Equality Campaign.

Free Fare Campaign

Disability groups and the Equality Commission are campaigning for the disabled individuals in Northern Ireland to travel free on buses and trains. Although some disabled individuals currently do travel free of charge, the government plans to introduce half price concessions from next year.

Jeans for Genes Day 2003

Summary from the Jeans for Genes Campaign Office

Amount raised so far: £2,689,966!

Thousands of you Did it in Denim on Friday 3rd October, when a record-breaking number donned their denims and donated those vital pound coins on the 8th annual Jeans for Genes Day!

A huge thank you to all of you that have made your donations and helped us to smash our £2.5million target. If you have still to pay in your donation, please do so as soon as you can so we can start making a real difference to the lives of children affected by some of the most devastating genetic conditions.

Whatever you did on Jeans for Genes Day thank you for Doing it in Denim and we hope you will join us for more fun next year.

Doing it in the media!

2003 was an amazing year for press coverage. Jeans for Genes supporters were photographed in newspapers up and down the country and the day was covered by hundreds of local radio stations. The campaign also made TV! Jeans for Genes Day was covered on London Tonight, Central News, BBC Look East, Belfast and Wales, while the Head of Jeans for Genes was invited on Living TV's 'Loose Lips' by Melinda Messenger!

All information on the Jeans for Genes campaign can be found on our website www.jeansforgenes.com - including a page of wacky supporter photos and activities from 2003 J4G Day.

Date for your diary

Friday 1 October, Jeans for Genes day 2004!

www.jeansforgenes.com

Delegates at the Orthopaedic Meeting celebrating Jeans for Genes Day

21st Birthday Draw 2003

The first and second prizes were drawn by Mr Paul Sagoo. The remaining prizes were then drawn by each of the Trustees, who also witnessed the logging of names and ticket numbers.

The draw raised a total of £6,483.25. We extend our thanks to everyone who purchased a ticket and helped raise funds for the Society.

Prize Winners

Prize	Winner	Ticket
Park Lane Hilton	C A Howell, Norfolk	18058
Chicago Tickets/£150 John Lewis	Chris Cooke, Surrey	50632
£100 Next Vouchers	Catherine Love, Glasgow	8725
Sony DVD Player	Mrs D Smith, Lichfield	50786
CanoScan Lide 30 Scanner	A Mather, Derby	3991
Personal CD Player	James Jennings, Preston	48697
Mattel Toys	Paul Watson, Dunoon	24583
Mattel Toys	Caroline Grant, Glenavy	12860
£25 Marks & Spencer Voucher	Marjorie Taylor, Wales	11272
£20 Sainsbury's Voucher	Mr Davies, Radstock	24874
Stainless Steel Toaster	R Kenton, Worthing	17305
Kitchen Knives/Scissors/Cutlery	Janice McIntyre, Holy Town	21918
Fruit Juicer	Jones, Llanelli	17511
Roller Suitcase	Mr Taylor, Fareham	50078
L'Oreal Products/Make-up Case	Mr West, Hampshire	33330
4 Piece Luggage	Laura Patterson, London	11128
Global AM/FM Alarm Clock	R Arnold, Isle of Wight	14871
Briefcase/Clock	Jodie, Llanelli	17555
£15 Oddbin's Voucher/Cork Screw	Fiona Kendall, Cumbria	29384
Black Holdall/Clock	Zoe Waymont, Essex	46412
£10 Tesco Voucher	Mr R Lambley, Sleaford	50893
Debenham's Teddy Bear	P M King, Fakenham	18050
Mr Fothergill's Seeds	K Rowan, Sheffield	23689
Small Cool Bag/Flask	Anne Fitz Gibbons, Somerset	22111
Calendar Calculator	B Harriss, Rochester	9615
World Calendar Organiser	E Porte, Scotland	6252
Flashlight with Case	D McEntee, Cheshire	30837
Black Holdall	P Thomas, Marlow	50202

Barry Wilson, Judith Evans & Wilma Robins

Paul Sagoo, Bob Devine & Judith Evans

Donations

Mrs J D Matthews
Mrs Kelly – West Sussex
Carole Fisher – Doncaster
City of Edinburgh Lions Club
Caerdydd Lodge No 3959
F E Woods
Field Group plc
L Harrington
S K Bates
E Heisig
Communisis plc
Mr & Mrs M Russell – 25th Wedding Anniversary Celebrations
Allison Hancock
Mrs B Klaber
Bellway plc
Elizabeth McDowall
Towersey Morris Men – Haddenham
Murtaza Moledina
Pam Hughes
Mrs M E Davison
Mr & Mrs Arnold
Susan Swayne
Rachel Howell
Mrs Linda Rowland
The Furlongs Fund
Huby Methodist Church – York
The Robertson Trust
Mr J Rogers
Cooper Gay
Mr & Mrs Gallagher
Pat Skidmore
Richard Matthews
Mrs J Norsworthy
Cadogan
John Menzies plc
Mrs Ann Canton
Mr & Mrs Culley
Williams Family

Collection Boxes

Ms B Davies
Andrews Family & Friends
N C & B Lunt Pharmacy

Fundraising

Mr & Mrs Williams – Underground Cooking
Mrs Fleur Thomas – Wintershall Tennis Tournament
Mr J Sands & Mr J Ross – Signed Football Shirt
Cattriana Amott – Pampered Chef Party
Ted Robbins – Raffle
Caversham Folk Festival
Mrs M I Stimpson – Webb Ivory Sales
TLC Day Nursery
Biochrom Ltd – Sponsored Breakfast
Northgate Information Solutions – Recycled Paper Sale
Tony Sumner – National Rally
Pip Hardy – National Rally
Jason Plevey – 24 Hour Bike Ride
John Sanderson – Rossendale Mountain Bike Challenge
Occasions – Sale of Envelopes
The Terry School of Dance - Evening of Dance
Castings Social Club – Social Night/Bingo
Mr & Mrs Russell – Raffle, School Dance Show

Stamps & Foreign Coins

Bob & Claire Stevens
Andy & Jenny Hardy
Miss N Williams, Family & Friends
Mr Preece and Ms Langton
Letitia Ricketts
Karen & Andrew Weedall

Donations In Memory

Nancy Sagoo
Mary Stacey
Edward Nowell Memorial Fund
Faye Rowe
Mr Maurice Podmore
James Bernard Edwards
Denis Rowan
James Kilpatrick
Kim Eggleton
William Broadley

Caversham Folk Festival

Jeff Bawden

Caversham Folk Festival has been a long-standing supporter of the Society and this year has been no exception. It was my pleasure to recently represent the Society at their cheque presentation evening. This year they were able to raise £500 for the Society for which we extend our thanks. The evening was great fun with real ale and music/singing with a good family atmosphere. If the evening is anything to go by I would strongly recommend anyone with an interest in folk music to attend this event.

Caversham Folk Festival Cheque Presentation

National Motorcycle Rally in Aid of MPS

Pip Hardy

Ellie Gee first entered my life in the spring of 1998. I had recently moved to a village just north of Cambridge and to a house requiring, as they say, 'some attention'. A mutual friend had recommended Ellie's father, Steve, as a cabinet-maker extraordinaire and, as shelves were one of my preoccupations at the time, he agreed to come and inspect the building site that passed for home at the time. He appeared, to my surprise and delight, on a motorcycle - a pink, Honda CBR1000, to be precise - and wearing a pink shirt to match! As I was learning to ride a motorcycle at the time, and about to take my test, we quickly agreed on my shelving requirements and spent the next hour happily chatting about motorcycles.

I knew before we met that Steve and Franny had a daughter with a serious degenerative disease. Steve spoke a bit about Ellie that evening, and during our subsequent meetings. It wasn't long before we were introduced and I was struck, as were many, by Ellie's air of serenity. She was still quite mobile when I first knew her and I used to look after her sometimes while Steve took Ellie's sister, Issy, swimming or shopping.

I was then, and continued to be, impressed by the way Steve and Franny managed their lives: with charm and wit and good humour tempered by an openness and willingess to talk about their feelings in relation to Ellie and the effects on family life of having an increasingly ill child. Tenderness and attentiveness characterised their care of Ellie and yet they managed (and continue to manage) to do interesting things with Issy and make time for friends and family. The shared motorcycle rides of that period have become an enduring feature of our friendship and we were well pleased when Steve eventually succumbed to the purchase of a sensible bike - a Suzuki Bandit, like ours.

Ellie's sister, Issy, with Pip's step-daughter Lauren

We became friends and our families saw one another regularly. We agonised with Steve and Franny over the decision to have a gastrostomy and watched with sadness as Ellie's condition deteriorated. A terrible sense of helplessness alternated with guilt at having five healthy daughters.

I remain convinced that it is not possible to understand the level of suffering experienced by a parent of a seriously ill child or a child who dies, and so words are of little use.

Our attempts at friendship, therefore, have focused on trying to enjoy the times we had together and offering, at the very least, a shared understanding of love for one's children and frustration at the unfairness of life. Our daughters played together and we marvelled at the way Steve and Franny coped with the sudden death of Franny's mum, followed by the death of her best friend, and then her father. Her strength and courage continue to astound me.

Ellie died the day before her 13th birthday, in August of 2002 while we were on holiday in California. We had last seen her less than a month before at our summer party and had been struck by how quickly she had deteriorated since we had seen her last. We hadn't, however, expected the end to be quite so soon. Steve and Franny thoughtfully waited to tell us when we returned, hoping not to spoil our holiday.

It is difficult to know how to be a good friend in such circumstances. Nothing anyone can say can really be of any comfort. There is only sadness and an aching desire to do something, almost anything, to ease the pain. We continued to encourage Steve, and Franny when she felt like it, to come for motorcycle rides and to attend concerts with us. If nothing else, such activities provide some distraction for a while, together with a reminder that the world does carry on, albeit in a way which is altered forever.

Every summer for the past five years, Tony and I have ridden in the National Motorcycle Rally - a weekend navigational scatter rally testing the wit and endurance of motorcyclists around the country. Participants are encouraged to raise money via sponsorship for MENCAP and we have raised the better part of £1000 over the years. This year we felt it would be appropriate for our efforts to benefit the MPS society.

So our 400 mile ride between 14.00h on Saturday and 10.00h on the Sunday morning enabled us to raise £600. We are grateful to friends, relatives and work colleagues (including our accountant!) for their support and hope that the money may go towards research into a cure for Sanfilippo disease.

I feel privileged to have known Ellie and honoured to count her parents as my friends. She brought joy to almost everyone who knew her in her short life. Her picture sits on our mantelpiece and she will not be forgotten. ■

Pip & partner Tony, leaving home to start the ride

Coffee Morning in Aid of MPS

Graham and Margaret Moore & Jim, Victoria, Samantha and Daniella Brockie

Saturday, June 28th dawned bright and sunny after a day of continuous rain on Friday. It looked as if coffee would be served on the lawn – what a relief! Our house would not be bursting at the seams.

Today was to be our coffee morning in aid of the MPS. Our granddaughter, Samantha Brockie, Hurler Scheie, was to be in charge of the tombola and her sister, Daniella, was in charge of the 'how many sweets in the bottle' competition. Samantha's mother, Vicky, had been busy baking and so had her grandmother. Her father and grandfather were ready to serve coffee. With the rest of the family on various stalls we waited with baited breath to see if anyone would come.

I don't know why we worried. At ten o'clock people started to arrive and quickly filled the house and spread out into the garden. What wonderfully generous friends and neighbours we have. Those that couldn't come gave us donations and the others spent liberally on the tombola and raffle.

The result of this effort was £421 for the MPS Society, which we were delighted with, especially when nobody can pronounce mucopolysaccharide and certainly do not understand the implications of it!

Terry School of Dance

Teresa Ferguson

Following the success of our previous 'Evening of Dance' the Terry School of Dance in Renfrewshire again staged a performance on 21 and 22 November 2003. Following sell-out performances last time, this year we staged three performances and I am delighted to enclose a cheque for £850 for the Society.

The show included all 110 pupils from the ballet school from 3 years to 18 years. Parents of pupils and many personal friends donated prizes for the raffle, which contributed significantly to the total proceeds.

The Society was chosen to receive these funds due to one of the first pupils being Joanne Evans who suffers from Morquio disease, who is now 17.

24 Hour Bike Race

Jason Plevey

In August I completed a 24 hour Bike Race which I decided to get sponsored for, because my girlfriend's nephew had just been diagnosed with Morquio disease. It was a very hot day when the race started but the atmosphere was great as in past years. I did not do as well as I had hoped, but still managed 13 laps. This has not put me off and I will enter again next year.

I enclose a cheque for £760 raised and hope this small amount goes some way to helping you in your goals.

Our thanks go to members of Castings Social Club in Falkirk who held a social night with prize bingo and raised £3,150.00 for the Society.

Fundraising Can you help?

The Society for Mucopolysaccharide Diseases relies heavily upon voluntary donations in order to continue its high level of service to individual members and their families, raise awareness and promote research into MPS and Related Diseases.

We need to raise at least **£600,000** this year in order to continue our work. You can help us reach this target in a number of ways. Just check out the ideas below.

Through the government's gift aid scheme we can get more money from your donations at no extra cost to you! **Last year this scheme raised us an extra £4,200!** If you are a UK tax payer and complete a gift aid declaration the Society will receive an extra 28p per £1 donated. This also applies to sponsorship forms so encourage your sponsors to tick the necessary box.

Tobogging, Bungee jumping, Mountain climbing, Computer gaming... Darts night, Belly dancing, Swimming, Pub quiz, Dog walking, Bingo, Cycling, Cake eating, Fashion show, Goal scoring, Head shaving, Throwing pies, Leap f

Organise and get sponsored for almost any type of event, such as a bowling tournament, raising money for MPS.

We can supply sponsor forms, posters, collection boxes and t-shirts. All you need to do is ensure your event is safe, and make it clear for whom you are raising the money.

These are just a few ideas of ways you can raise money for the Society. If you would like help or advice in organising an event, or for further information, just give us a call. We hope you can help...

mps@mpssociety.co.uk

☎ **01494 434156**

Don't stash your cash.
Let go of your dough.
Fundraise for us...
... just give it a go!

Plan an idea
(However funny!)
Anything goes
Just raise us some money

You don't have to take part
You can sponsor a mate
Help raise awareness
And help educate

Working as one
We might raise enough
Awareness and money
To make life less tough

So call Gina now
For more information
Let's do our bit
What better invitation?