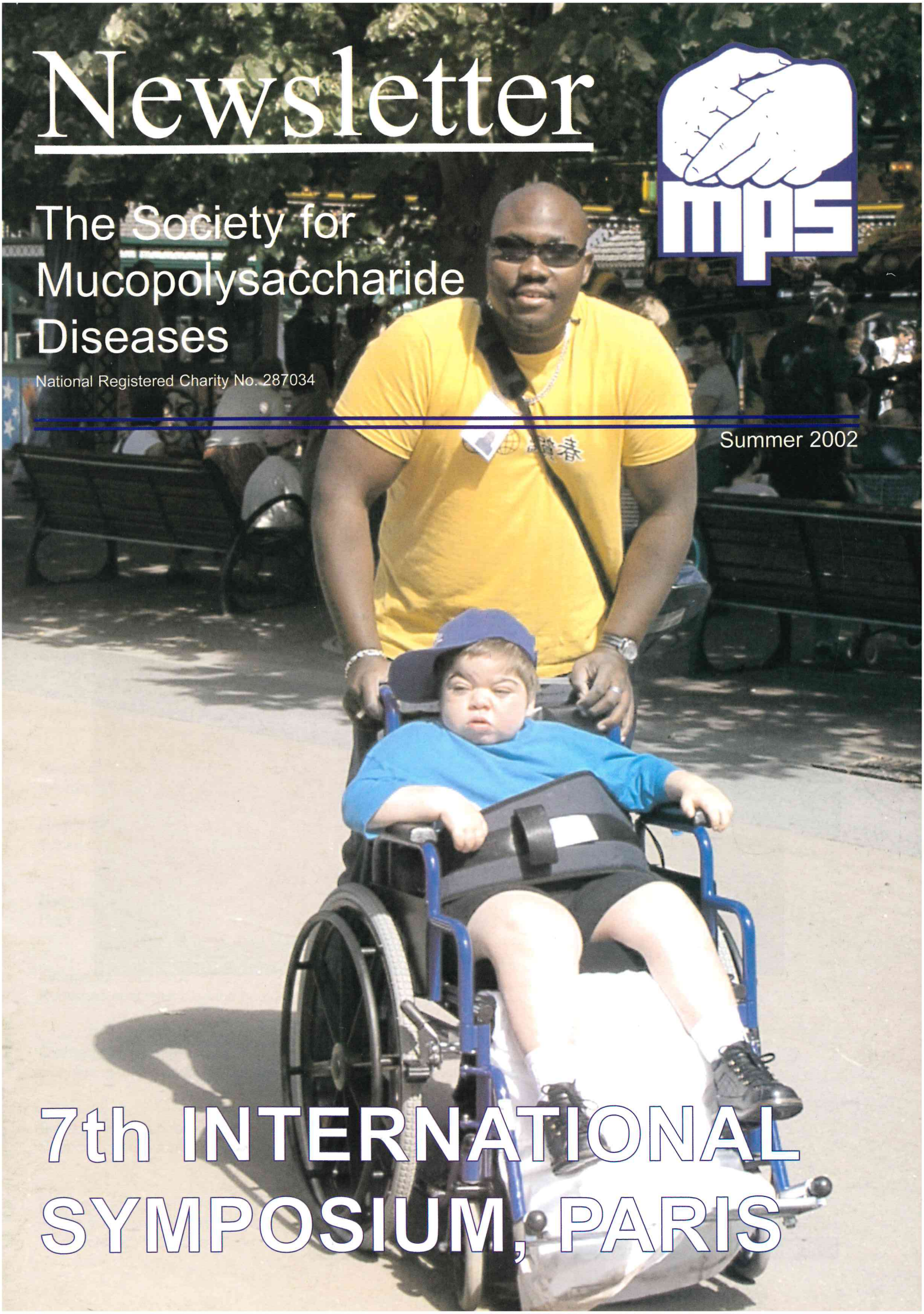
Newsletter

The Society for Mucopolysaccharide Diseases

National Registered Charity No. 287034

Summer 2002



7th INTERNATIONAL SYMPOSIUM, PARIS

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TheSofitel hotel bar proved popular during Friday morning's conference session - England were playing Brazil!

Front cover: Volunteer Olu with Thomas on an outhing in Paris

What is the Society for Mucopolysaccharide 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. It is managed by the members themselves and its aims are as follows:-

- To act as a Support Network for those affected by MPS and related diseases
- To bring about more public awareness of MPS and related diseases
- To promote and support research into MPS and related diseases

How does the MPS Society meet these aims?

Advocacy Support
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 and Adults with MPS
Empowering individuals to gain independent living skills, healthcare support, further education, mobility and accessing their local community

Regional Clinics, Information Days and Conferences
Information days and 11 regional MPS clinics throughout the UK

Regional Events
Social events held throughout the United Kingdom for mutual support

Volunteer Simon with Ben on an outing in Paris

National Conference and Sibling Workshops
Held annually and offering families the opportunity to learn from professionals and each other

Information Resource
Publishes specialist disease booklets and other literature

Quarterly Newsletter
Containing information on disease management, research and sent to members free of charge

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

Research and Treatment
Funds research that may lead to therapy and treatment for MPS diseases as well as furthering clinical management for affected children and adults

'CARE TODAY, HOPE TOMORROW'

Chairman's Report

Once again a great amount of organisation and effort has been put into the past four months in meeting the aims of the Society. We have two new members of staff, who are now quickly settling into life at the Amersham office. They will offer a great boost to the advocacy work of the Society and to that end I am sure a lot of our members will be meeting them in the not too distant future.

The main effort outside of the normal work of the Society since the last Newsletter has been the 7th International Symposium that took place in Paris in June. Seven hundred people from all over the world attended, including professionals, families and MPS and VML staff. The UK MPS Society in particular was well represented. The Symposium has been acclaimed a tremendous success at all levels - from the exchange of vital information by the professionals to the new friendships being forged by young and old alike that will last for years to come.

I would like to say on behalf of all the Trustees and I feel sure the membership as a whole, a special thanks to Christine Lavery and all the members of staff. They have worked above and beyond the call of duty to ensure the success of the Symposium: Well done!

The last Jeans for Genes money is still rolling in, with over £2,700,000 raised. What a success it has been! Well done to everyone that helped to make the event a success. Please keep up the good work.

Enjoy the newsletter

Barry Wilson

New Staff

Helen Heard

Hi! I joined the MPS Society in April this year as a Development Officer. My main role is to offer an advocacy service to clients and families throughout the eastern area of the country and Northern Ireland, London and the South East. I have already attended clinics in East Anglia and Belfast and visited a number of families. It is good to get to know you and I am sure as time goes by I shall either speak to or visit many more of you.

When I was offered this post I was asked if I could cope well with change and challenge! I am only 5'2", but come with experience of dealing with both of these in plenty. My career spans 26 years where I have been lucky enough to enjoy every stage - starting as a Speech Therapist, moving into lecturing and then onto medical research before becoming a Funeral Director. My last post was managing one of High Wycombe's Home Care teams, with Social Services. Now that was a challenge!

I have settled well in Amersham and work with a great team. They are turn are getting to know me - and my sense of humour. Oh yes, I nearly forgot - and I sing, mainly with a local ladies choir but now and again a few notes escape in the office!

Sophie Denham

Hi everyone! For those of you who have not met me, I thought it only polite to formally introduce myself. My name is Sophie and I am the newly appointed Assistant Development Officer.

I joined the Society in March of this year at a very busy and exciting time with lots of clinics planned and of course who could forget the International Symposium in Paris, which was a great success.

In the three months since joining the Society I have been fortunate to meet many families, individuals, and professionals and I hope to meet many more of you in the future. Thank you for making me feel so welcome.

News from the Management Committee

The Trustees met in May to consider the following matters:

Annual Report and Accounts

The Trustees approved the draft of the Annual Report and agreed its publication (a copy is enclosed). The Society's audited accounts were considered in detail and approved.

Financial Trends

Chris Holroyd presented his analysis of the Society's financial trends.

MPS Office

In February 2003 the lease on the MPS office will be up. It was agreed that the Chairman and Director meet with the landlord and at the same time look at alternative options.

Membership of the MPS Society

The Chairman clarified that those individuals who have not returned a signed membership application form are no longer members. It was also reaffirmed that the conditions of membership and receipt of its services are subject to the members being of good standing where the MPS Society is concerned and having occasional participation with the MPS Society.

Staff Recruitment

A Development Officer and Assistant Development Officer were successfully recruited in March.

Policies

The Society's Staff Conduct and Volunteers' Conduct policies were amended and approved. The Society's reserve policy was considered and amendments suggested.

21st Birthday celebrations

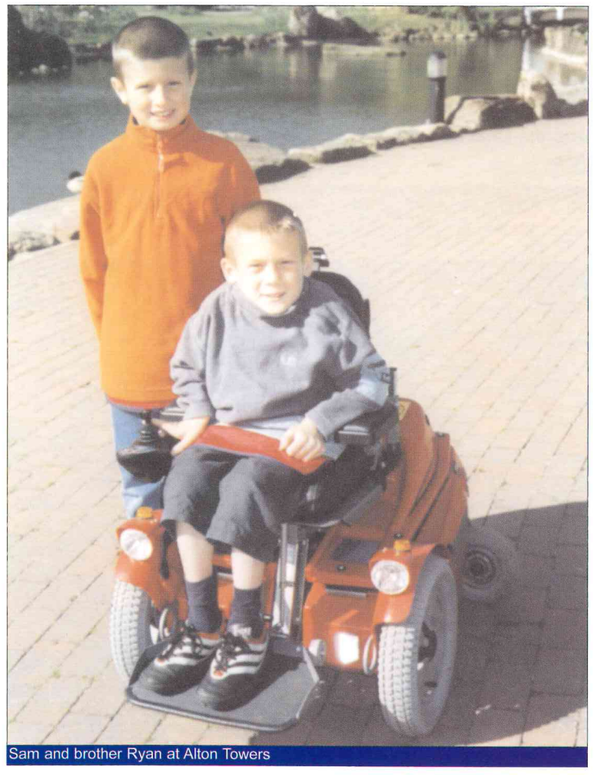
The Trustees agreed a year of high profile events starting in May 2003. These will include conferences in Scotland and Northern Ireland, followed by a National Conference in the autumn.

International Symposium, Paris

The Trustees heard a presentation by Fiona Woodcraft on the Paris Symposium. Arrangements for UK families and volunteers were agreed as well as the children's activity programme.

Jeans for Genes

The Trustees received the excellent news that the October 2001 Jeans for Genes appeal had now reached over £2.6 million.



Sam and brother Ryan at Alton Towers

Annual General Meeting

The Annual General Meeting of the Society took place at the Alton Towers Hotel on 11th May 2002 at 9.30am. Fifty two members and three non members were present. Apologies were received from ten members.

The minutes of the 2001 AGM meeting were distributed in advance to those members present. The minutes were accepted as true and accurate.

The Chairman, Barry Wilson, presented the Trustees' Report. This is published in the Society's Annual Report for the year ending 31st October 2001.

The Treasurer, Judith Evans, presented the statement of accounts for the financial year ended 31st October 2001, the details of which are also to be found in the Annual Report. Judith thanked the membership for their support in fundraising and encouraged the members to help the Society in any way they can.

It was proposed and seconded that the auditors, McLintock and Partners, Chester, be appointed the Society's auditors for the financial year ending 31st October 2002.

The Director, Christine Lavery, updated members on recent developments in research and treatment for MPS and related diseases. Those present were informed of developments in Enzyme Replacement Therapy for MPS I, II, VI and Fabry disease as well as the Society's 3 year grant programme awarded to the Willink Genetics Unit in Manchester and the Institute of Child Health, London.

Trustee Bob Devine, representative on the Jeans for Genes steering committee, thanked the membership for taking part in the October 2001 campaign and announced that to date £2 677 500 had been raised. In 2002 the four partner charities have selected four guest charities to take part and benefit from Jeans for Genes. The money raised through Jeans for Genes is funding vital research and support projects.

During the election of officers, the Chairman informed those present that there were no new nominations for the Management Committee. Steve Butler, who has served for three years, indicated his willingness to be re-elected for a second three year term. Chris Holroyd, who was co-opted, also agreed to stand for election. Steve and Chris were duly elected.

As there was no further business the Chairman Barry Wilson closed the meeting at 9.50am and wished everyone present a wonderful day out at Alton Towers.

The Society is required to have a least forty members to be quorate at its AGM. The Trustees would like to thank all those members who gave their time to make this meeting possible.

Trustees Sue, Adam and Judith

Scottish Clinic,

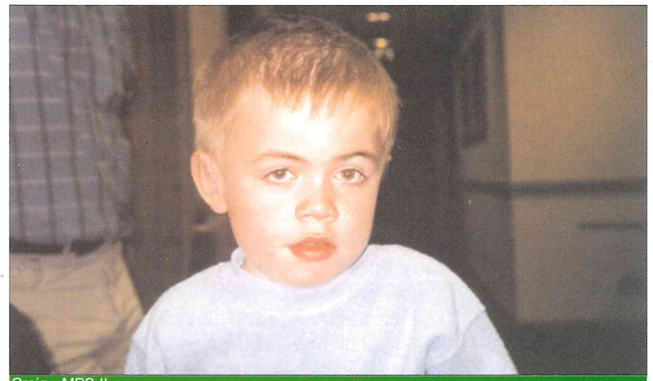
Mounira Hadj-Rehouma, Marketing Development Officer

It is Friday 7th June in Edinburgh. Ellie and I get up bright and early ready for the day ahead. I am a little nervous and excited. It is the first time I attended a clinic … or met children and adults with Mucopolysaccharide diseases!

The clinic is taking place at the Hilton near the Airport and we meet up with Dr Maureen Cleary for breakfast.

Then it is time for Ellie and I to find our bearings. I had not realised we were in a covered maze. We are taken up through the building's first floor, turning left, turning right into the many corridors. Then there are steps!! The first thought was 'How will the patients and families cope?'. 'Someone will accompany them to help them and put them in the right direction' we are told. That's a relief!

We are busy organising chairs in the foyer to make it look like a waiting room when Dr Peter Robinson and Maureen Cleary join us there. Soon the families start arriving. Aidan is first with his Mum Angela, then Rahman's family, Connor and Craig with their parents… Aidan's best friend, little Robyn...
It is delightful, a very nice gathering of people I have been in touch with, I will be in touch with, I work for. I finally feel like I know why I am part of the MPS Society Team and I am even more motivated in spreading the word, promoting MPS and related diseases to enable people to learn about them, support

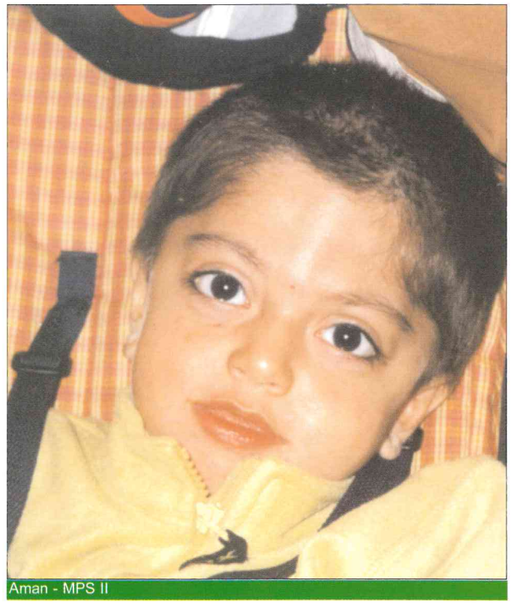


Craig - MPS II

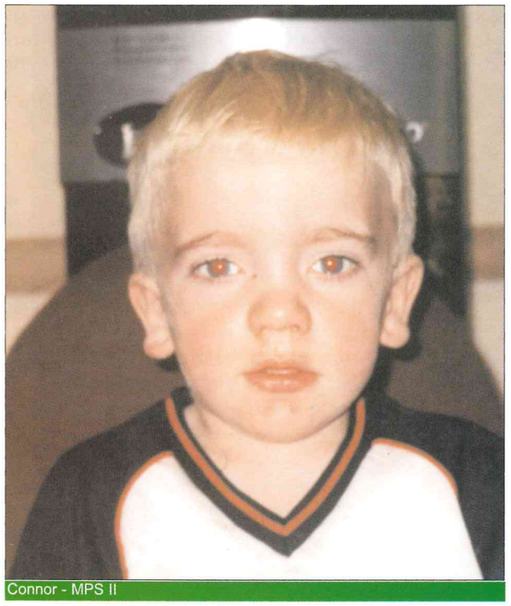
individuals suffering from them and, generally, be understanding.

There are actually a couple of gentlemen at any one time waiting in the same foyer to be called in for an important interview for a promotion. They are curious to find out what the playful children are here for. I speak to couple of these men who are suddenly grateful for what they have and admit that their interview, the stress they are under are put back into perspective.

As with all good things, time has gone by and slowly the foyer is emptying. The families are leaving, one after the other. The bustle, the playing, the conversations are already old souvenirs and we are tidying up anda few minutes later and we are at the airport.



Aman - MPS II



Connor - MPS II

East Anglia, Friday 3rd May 2002

Helen Heard, Development Officer

My first clinic since joining the MPS Society in April. Neither Ellie nor Ed Wraith had been to the newly located Norfolk and Norwich Hospital, so we were all looking forward to using the new facilities. First impression of the Hospital – huge – covering an enormous site and still being built. The Jenny Lind Centre – parking- and lots of it, situated right outside the centre! Ellie had warned me that my biceps might develop as usually staff have to carry boxes some distance to reach the clinic rooms. No such problem here. The building is bright and airy and well set out, and, once the drilling, filling, wiring, decorating is all complete (we were aware of these as we squeezed past ladders and raised our voices over the intermittent drilling/banging which merged with the voices of those waiting to be seen), it will be an excellent venue.

It was great to start putting names to faces, always a steep learning curve in a new job! I was able to talk with families and meet doctors Chris Upton, Uma Ramaswami, and Ed Wraith. I hope Ed's faith in my powers of direction is now established. Ellie and I agreed to drop him off at the station after the clinic, and after an unintentional tour of the town with Ed's "I'm sure it's this way", he decided my route might be right! He caught his train and I was thankful that as the newest Development Team member I hadn't let the side down.

Northern Ireland, Friday 10th May 2002

Helen Heard, Development Officer

Those of you seasoned air travellers can laugh at my discomfort on my first trip to Northern Ireland. I eyed the small British Midlands aeroplane with suspicion and confided in Ellie that I had not flown very much and never in a tiny plane like this.
She was masterful in her distraction techniques – we worked – I gripped the seat simultaneously as we dipped and swayed our way into the air and was eternally grateful that we dropped out of the sky onto Irish soil and were still in one piece!

The clinic was held at the TemplePatrick Hilton Hotel. It was a day when every conference and meeting room was booked and the general melee at coffee breaks was a little overwhelming, however, the greeting to and from the families was warm and I thoroughly enjoyed speaking with them. Many commented on how useful their clinic time with Dr. Wraith had been. We are very grateful to Jeans for Genes for sponsoring this clinic.

Ellie and I carried out advocacy work and tried to keep the children amused. Dean Doherty and I had a wonderful game of chase, as all the doors in the hotel were open because it was such a hot day, and he was determined to sample the sunshine! I have to say a big thank you to Deborah Boyle's Mum, because much as I had fallen in love with Northern Ireland, I did have to get back on that plane on Friday afternoon and go home! She said she would pray me home. Well it worked; an airbus awaited me and the calm voice of an experienced pilot assured me of a smooth trip – and it was. I very much look forward to returning to Northern Ireland in the near future.

Cardiff Clinic, Wednesday 29th May 2002

Sophie Denham, Assistant Development Officer

Ellie asked me if I would like to attend the Cardiff and Bristol Clinic, which were held in May of this year. Of course I jumped at the chance to finally meet some individuals families and professionals who I had been in contact with prior to the clinic.I was informed right from the start that Cardiff was the quieter clinic and Bristol would be extremely busy, but for those of you who attended these clinics we all know this was not the case.

It all started with the day being swapped!
After finally finding the part of the hospital the clinic was being held in (I have never seen a hospital so big!) I was ready for my first clinic. As the clinic was being held on a Wednesday instead of its usual Friday The children's department where the clinic was being held was a lot busier than we have been used to. The waiting area for the clinic was extremely busy throughout the day and finding a seat proved difficult at times.

It was lovely to meet up with so many families and individuals who attended the clinic and I look forward to meeting you all again soon. Our thanks as always go to Dr Graham Shortland and Dr Ed Wraith for another successful clinic.

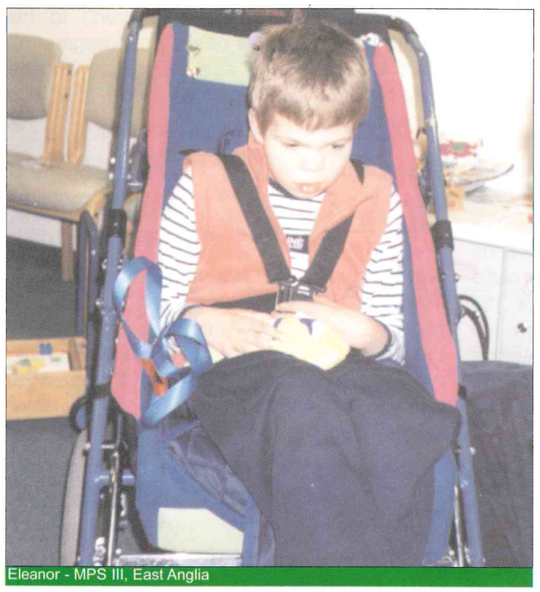
Bristol Clinic, Thursday 30th May 2002

Sophie Denham, Assistant Development Officer

With my multi-map in hand I attempted to navigate Ellie, Dr Ed Wraith and myself to the hospital (if only we had had more faith in the multi map!) after only a few wrong turns we arrived at our destination.

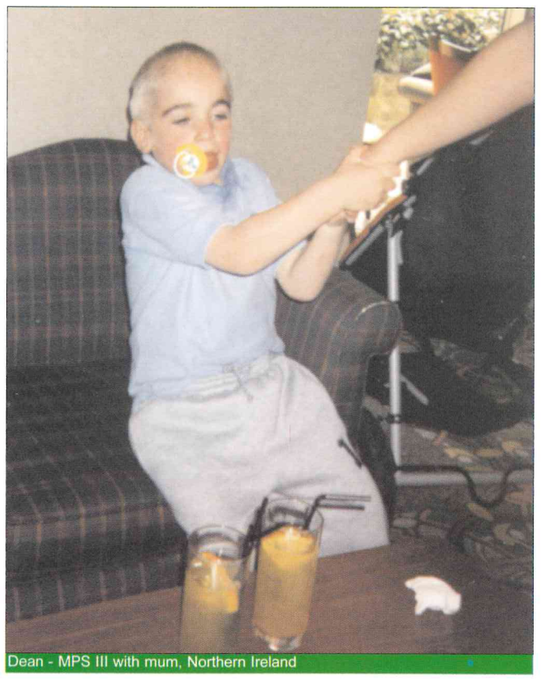
I was all prepared for an extremely busy clinic (even made sure I had my comfy shoes on) but wait this was not to be! The whole clinic went like clockwork and the comment of the day from nearly everyone was "its so quiet what's happened"

It was lovely to see so many of you attend the Bristol clinic and I look forward to meeting you all again soon. We would like to extend our thanks to Deirdre at Frenchay hospital for their her help in organising the clinic and to Dr Philip Jardine and Dr Ed Wraith for another successful Bristol clinic.



Eleanor - MPS III, East Anglia

Terry - MPS I, Bristol



Dean - MPS III with mum, Northern Ireland

Sarah - MPS I, Cardiff

The Tale of the Star with Mannosidosis

Mrs Mathews (Marc's mother)

Marc (24) is living at home in a conversion which is his own bed sit. He is a member of the Shattering Images Theatre Company and currently has the principal role in '*The Threepenny Opera*' as 'Mack the Knife'. As you can see from the photos he started his thespian career at a very early age. He also plays the trumpet and has made a CD.

Despite Marc's difficulties with movement and his hearing impairment he leads a very active life and social life with the theatre group. They tour here and abroad doing performances and workshops in many different places from schools and colleges to outdoor performances in parks and other community venues.

Although Marc does need a lot of rest after performing, he still manages to make the most of the very special gift and talent he has in the performing arts. Marc is also the Promotions Manager for the group so contacts the radio and press to keep them informed of the group's current performances and tours. He also - with some help from Mum – designs and produces all the programmes, posters and fly-sheets to compliment any advertising needs.

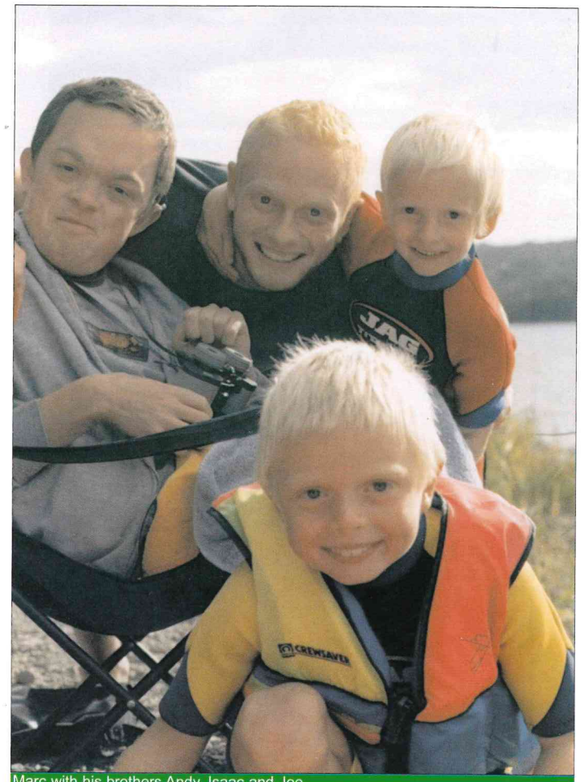
As Marc has got older and his physical capabilities have deteriorated he has made a natural transition in his expectations of what he can do and still remains very optimistic and goal orientated to succeed and do well in everything he sets himself to do.

'Mack the Knife' has been a big accomplishment for Marc over the past 2 years and his success is a credit to his determination and his peers' encouragement. Marc is also a born again Christian and he truly believes that God has made all things possible for him.

The Shattering Images Theatre Company is based in Lancashire. They offer workshops as well as performances.

Already performed are the following plays: *Macbeth*, *Blood Wedding* and *Midsummer Night's Dream*. If you wish to be informed of the future performances or if you would like the Shattering Images Theatre Company to visit you, call 01524 64 857.

Marc - 1987 show



Marc with his brothers Andy, Isaac and Joe

Births

Congratulations to Madeline and Andy King on the birth of their daughter Daisy born 24th May 2002. A sister for Harrison, Harvey, Charlie.

In Remembrance

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

Jake Corcoran who suffered from Hurler Disease
14 December 2000 - 6th May 2002

Philip Davies who suffered from Fabry Disease
21st December 1952 - 17th May 2002

Aaron Martin who suffered from Hurler Scheie Disease
2nd Novemeber 1990 28th May 2002

Michael Armstrong who suffered from Hunter Disease
18th June 1989 - 18th June 2002

Shivahram Selvaranjan who suffered from Mucolipidosis II
3rd July 1999 - 26th June 2002.

'In Dreams'

When the cold of winter comes
Starless night will cover day
In the veiling of the sun
We will walk in bitter rain

But in dreams
I still hear your name
And in dreams
We will meet again

When the seas and mountains fall
And we come to end of days
In the dark I hear a call
Calling me there
I will go there
And with you, be back again

From Marilyn Eggleton, whose daughter Kim passed away on 2nd April 2002

New members

During the last three months the families of 8 affected children and adults with a mucopolysaccharide disease and 8 individuals affected by Fabry Disease have sought the support of the MPS Society. The following families have requested their details to be included in the newsletter.

Elizabeth and Jason's son Jack has recently been diagnosed with Hunter disease. Jack is 2 years old and and is pictured on the right. The family lives in Lancashire.

Peter and Shirley-Ann's daughter Lisa-Marie has been diagnosed with MPS I Hurler Scheie disease. Lisa-Marie is four years old and the family lives in the Midlands.

Kevin and Jucinta's daughter Chloe has been diagnosed with MPS I Hurler Scheie disease. Chloe is five years old and the family lives in Northern Ireland.

Mr and Mrs Broadley's son Lewis has recently been diagnosed with MPS III Sanfilippo disease. Lewis is four years old and the family lives in Scotland.

The Society has recently been contacted by Mrs Hedgecock who has Fabry Disease and lives in Wales.

The Society has also recently been contacted by Diane Hughes who has Fabry Disease and also lives in Wales.

Paris was the place to be

Fiona Woodcraft

After dominating my life for the past weeks and months, the Symposium is finally over! And, to my great relief, it is widely seen to have been a success and a hugely significant event for all those involved in Mucopolysaccharide and other lysosomal storage disorders.

One of the many eminent speakers at the Symposium wrote to us shortly afterwards, saying, "I was quite impressed with the high quality of the conference and the spectacular attendance both by professionals and families." We were certainly inundated with bookings, right up until the day we left for Paris. By this time, we could only accept delegates without children who didn't want accommodation as we had no more volunteers and no more hotel rooms! About 350 professional delegates attended the conference along with adults and children from 33 UK families and 85 families of other nationalities. This made a total of over 550 adult delegates and 85 children.

The Scientific Programme itself covered a wide range of topics and received much praise. For this we must thank the Scientific Committee and in particular its presidents Ed

Mounira and Angela selling T-shirts and booklets on the MPS Society table

Wraith and Irène Maire who put it all together. It really did seem that the Symposium had brought together *everyone* involved in the field of Mucopolysaccharide and other lysosomal storage disorders. I found it amazing that scientists were carrying out research on one of more of these rare diseases in almost every corner of the world. Three Russian scientists and one from Argentina overcame particular difficulties to travel to Paris. To them it meant

so much to meet fellow researchers from all over Europe, the United States, Australia and so on.

Many of these professional delegates submitted abstracts earlier in the year, summarising their recent findings. Some abstracts were selected to be presented orally and the rest – totalling almost 100 – were produced as posters and displayed in a designated area of the hotel. For the first time at such a conference, prizes were awarded to the best posters, judged by an international panel of five highly regarded professionals. The first of the five categories was 'Best experimental study'. This was won by Mark Sands of St Louis, USA, for his poster entitled *Eye-directed gene therapy reduces storage in the brains of MPS VII mice*. Parisian doctor Dominique Germain won the 'Best Clinical Study' category for the poster *Patients affected with Fabry Disease have an increased incidence of progressive hearing loss and sudden deafness: an investigation of 22 hemizygotes*. A group of posters, produced by the team led by Roberto Giugliani in Porto Alegre, Brazil, was awarded the prize for 'Best Professional Presentation'. They illustrated the results of a long-running analysis on Brazilian MPS patients, especially the genotype-phenotype correlation in MPS I and II sufferers. Our own Angela Ratcliffe won the award for 'Best Lay Presentation' for her poster showing the diaries of two mothers whose daughters participated in the ERT clinical trial for MPS I last year. The final category was 'Most Novel Presentation'. This was won by Kémal Azibi from Paris, for his innovative study on *Molecular mechanisms and heterogeneity of Fabry Disease*.

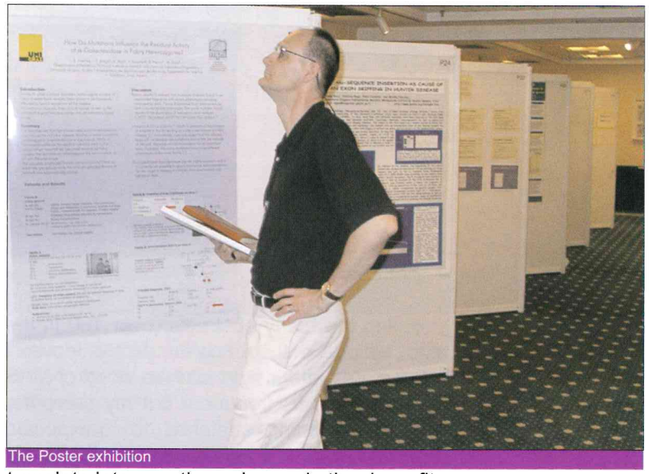
Despite the highly specialised scientific content of some of the sessions, families reported having benefited considerably from their time at the conference. Some sessions were more suited to lay people than others, and there were of course occasions to meet speakers on an informal basis. One family told us, "It was good to have so many specialists together at one time", and another wrote, "It was a wonderful opportunity to meet those who may be instrumental in helping the boys in the future."

For many family delegates, one of the high points of the conference was meeting others in similar circumstances in their own country or abroad. They found they had much in common, and enjoyed making new friends and sharing experiences. One family who had only recently had the diagnosis told us how much they had learnt from families with children 'further on' with the disease, while the parents of a young Morquio sufferer found it useful to talk with families whose children had already had the fusion operation. It was a time for socialising and relaxing too, whilst the children were having fun with the volunteers.

Professional delegates and representatives of pharmaceutical companies took the opportunity to 'network' as well. New ideas, committees, and strategies were discussed and it seemed that people left with renewed motivation. As one delegate put it, "We picked up a real tangible sense of excitement." The conference was so well attended by the pharmaceutical industry that all the main companies had organised their own meetings in the days either side of the main Symposium. Paris really was the place to be!

Everyone seemed genuinely to have enjoyed themselves, and it was wonderful to be a part of it. The whole event had been a team effort between all the UK MPS Society staff, our partner charity VML, and the hotel Sofitel, and I want to thank everyone for their part in the organisation.

As for the future, the directors of a pharmaceutical company wrote, "The unique mix of patients and parents with scientists in the field at this meeting we think was very stimulating and motivating and should



The Poster exhibition

translate into new therapies and other benefits for your patients and members." And the representative of one of our sister organisations said, "Without a doubt, lysosomal storage disorders hold a great deal of interest with many scientists, researchers and clinicians worldwide. Knowing this reinforces our support networks as well. We are part of the equation, all working together to one day find a treatment for these diseases."

VML staff Claudine and Brigitte selling foie gras to raise money for their charity

Pharmaceutical company stands

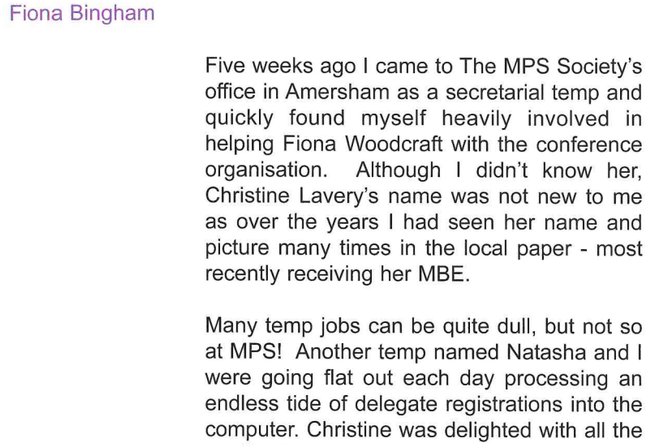
A foot in two camps

Fiona Bingham

Five weeks ago I came to The MPS Society's office in Amersham as a secretarial temp and quickly found myself heavily involved in helping Fiona Woodcraft with the conference organisation. Although I didn't know her, Christine Lavery's name was not new to me as over the years I had seen her name and picture many times in the local paper - most recently receiving her MBE.

Many temp jobs can be quite dull, but not so at MPS! Another temp named Natasha and I were going flat out each day processing an endless tide of delegate registrations into the computer. Christine was delighted with all the applications. With nearly 650 people, including children and volunteers, all to be put in appropriate rooms, fed three times a day, sent on outings etc. and with over a hundred different possible columns of information to be filled in for each delegate, Natasha and I had to keep our wits about us.

My particular job was reformatting and collating the many abstracts (over 160 in the end) which were pouring in. Not only was I having a private insight into the world of MPS research and its treatment but my computer skills were being stretched to unexpected horizons and I could now say the word Mucopolysaccharide without difficulty! I was hugely impressed at the numbers of brilliant people all round the world working so hard, with whom I had become loosely involved. All



Rachel and Fiona helping with enquires

the time the flow of information was being shared by e-mail with the French Association VML, and more information from them was being fed into our giant spreadsheet.

Time was flying and I had by now offered and been accepted as a volunteer, and nominated to care for 11 year old Suet-Li (Rachel), a Morquio sufferer from Malaysia. Goodness

me, what a long journey Rachel and her mother Sharon, like many other families were making to this Conference. I wondered about Rachel and how she would be affected and how I would cope. I took home and read up the Society's information sheets on Morquio. Meantime, masses more detailed work and packing was going on all around me - carefully prepared time tables, room allocations, care plans, provisions of equipment etc.

The Saturday before the Conference was a training day for the volunteers in a nearby community centre. This gave the 53 volunteers from the UK, France and Germany a chance to meet, be briefed on our role, be given care plans and special equipment for our children, and to undergo Moving and Handling Training. I already knew some of the regular volunteers from other local events. It was an exciting day and we felt we would soon be on our way.

Sooner than I expected! Natasha, the other temp had been scheduled to join the MPS team on the Registration Desk in Paris but was now unable to go. Christine asked if I would do this and I jumped at the chance to fly out and join the team who would already be at the hotel - I was to be MPS staff until Friday lunch time then change hats to join the Volunteers. A French Air traffic control strike was suddenly announced, but P&OStena Line saved the day and I arrived in sunny Paris in time by ferry and train. C'est merveilleux!

All hands to the pump to prepare conference material and before we knew where we were IT WAS THURSDAY AND ALL HAPPENING! Rachel and her mum Sharon had already

arrived at the hotel so we had met and said our hellos. It was wonderful to meet her and we were instant friends. I tried to be sure I conversed with her appropriate to her age, despite her size. While Mum went to hear the Symposium in the afternoon, Rachel came and sat with us at the Registration table. I was able to become acquainted with what Rachel could do (everything it seemed!) or couldn't do (nothing!) in preparation for my caring role over the next three days. Rachel was able to size me up too!

Time was whizzing by and my Carer role would soon start but not before the hotel had asked Fiona Woodcraft and me to reorganise the restaurant locations for the next 3 mealtimes i.e. 1800 + meals! Allocating who was to eat in which restaurant had been a major juggling act on our giant spreadsheet as we hoped to facilitate "mixing" by putting professional and family delegates in the same restaurant. Another hour flew by modifying the meal lists on the computer, printing them off and attempting to let delegates know of the changes. Unfortunately, this information did not catch up with many of the professional delegates who surged en masse to their next lunch in the wrong direction! I had to be loud and bossy to get this tidal wave of hungry humanity to change direction. Thankfully the time had come to run upstairs, don my Volunteers gear, and set off on the first outing.

On the Friday afternoon we were off to the Zoo. The three coach loads of children and newly acquainted carers met up to board the coaches. So many new friends to make and names to learn. Rachel had no trouble

Hotel foyer

breaking ice - she was out to make friends and had come armed with name and address slips to give to them. We found ourselves sitting beside 7 year old Wesley from Pennsylvania, USA whose Mum Debra had come as a professional delegate, and had

VML and MPS staff at the Registration and Information desk

brought her Mum Alice to care for him. We pallied up as a foursome and had a great afternoon.

We all took a little while to orientate ourselves, but both children were fantastic. They were both polite, fun, unselfish and considerate to others. Wesley accommodated to Rachel's slower pace, and she was responsible about resting when needed. The excellent little train gave us a great ride round the zoo, with whoops of delight from us all - look at this, look at that! We sat down to have an ice cream right beside the giraffe enclosure with their lovely loping gait and several young feeding from their mothers. What a happy little group we felt even though we'd only met a couple of hours before! - I thought to myself how proud their parents should be of them both at the way they conducted themselves with their many differences - sex, race, physical abilities, religion, nationality etc. and out with a couple of grandmas! Time to head back to meet the coach - now weary and with a long walk - Rachel had a great idea! We wait here and let the coach collect us ..... and that's what happened! I gather this was one of the afternoon's highlights for Rachel - having our own personal coach service!

So, my first caring afternoon was under my belt and my preliminary anxieties as to how I would cope allayed. Compared to some of the other children Rachel was independent and

Continued next page...

...continued A foot in two camps

not difficult to care for and her positive, outgoing nature eased our way. In fact, I didn't hear one grumble or complaint from her the entire time. Her sense of fun caught me out back at the hotel when she insisted on going alone through the giant rotating door! I wish I hadn't agreed to this fearful she may


Volunteer Helen with Joanne and Joanna

stumble. Phew, she'd made it safely into the foyer. Oh no! With laughing eyes she was off on another circuit, only to hop through the last minute gap as the giant door swept round. My heart missed a beat, as did onlookers', and a collective gasp filled the air!

Friday night was the Volunteers' evening off and I joined two others for a fantastic evening in central Paris - music, laughter, street artists, food, wine, le Metro - we couldn't have wished for more!

Over breakfast on Saturday morning I met up with Rachel and her mother, and was able to help her make contact with other Morquio families. While Rachel and I were having fun at Parc Asterix, Sharon met up with Judith and Asma from the UK and had a hugely useful day together sharing information and experiences. Sharon was so buoyant on our return - her long trip from Malaysia had been worthwhile. With no MPS support in Malaysia she told me how isolated they were with their difficulties there, and that she had independently brought Rachel to England when she was 2 years old for the cervical fusion operation by Dr Richard Cowie in Manchester. Now, ten years later he and his diminuitive patient met again and their smiling photo taken in the foyer of the Sofitel will soon be pinned to his office wall.

While these Morquio parents were busy, we were enjoying ourselves at Parc Asterix. At Rachel's suggestion we hired a buggy to help us get around the park. I gathered Rachel only liked being carried if absolutely necessary as she consistently declined offers however tired she was. We had fallen into the same foursome with Wesley and his grandma and found it quite easy to select rides which were suitable ..... well, almost. I felt uneasy about the water rapids ride for Rachel, but we saw Joanne had been on it and decided to queue. Grandma Wesley opted out and headed, with all our bags and buggy to meet us at the ride's exit. The ride was great .... laughter, shreaks, shouting, soaking wet all round!,... bought the photo.... BUT no grandma at the exit! We had quite a worrying, and wet, wait while Wesley's grandma found her way back from getting lost! We were so relieved to see her! Souvenirs were purchased, more photos taken, buggy returned - it was time to gather in the car park for our coach. One of our three coaches had got held up in the Paris traffic, so we were quickly reorganised to make sure the evening outing people got back to the hotel in time. We waved goodbye to our friends and were on our way - glad of a peaceful interlude as a Harry Potter video whiled away the journey.


Volunteer Clare with Maryam and Halima

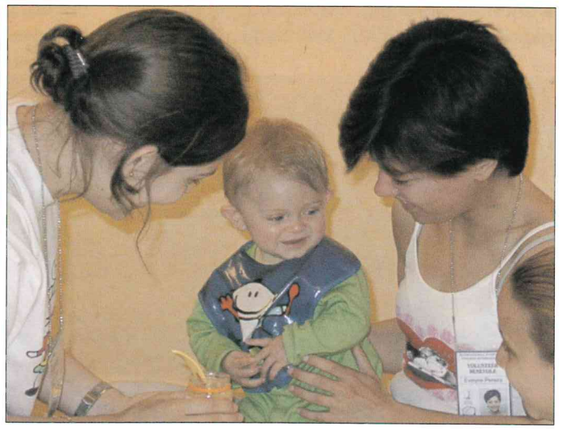
A quick turn round and an hour later 35 of us were off again on the "teenage outing" - a wonderful boat trip down the Seine from the Eiffel tower. Rachel had now palled up with fellow Morquio sufferer Joanne and we all sat together, and enjoyed the romantic ambience, the balmy evening, the beautiful bridges and architecture. Rachel had already "done" Paris with Mum and pointed out many sights. After the boat trip we headed off, walking awestruck under the Eiffel Tower, into the Champs de Mars behind the Tower. Volunteers Ben and Ella had legged it to McDonalds and came back brown bag laden with our pre-ordered meals. Rachel, a non-beef eater had ordered chicken nuggets and fries for the second time that day, and as we ate our meal I wondered how much the disease affected her calorie and nutritional requirements. While we had waited for our meal, "party pieces" were requested for entertainment and I won some brownie points by doing the can-can! As the sun set on the Eiffel Tower our weary group was on its way home. Still enough energy though to chat and play memory games on the coach from which it became clear Morquio has absolutely no adverse effect on memory as Joanne, Rachel, Maryam helped by Halima beat two volunteers hands down in the memory contest!

The best was yet to come! Back at the hotel, our particular group of parents had had a wonderful evening together. They were glowing in each other's company ... chat, chat, chat! As their daughters joined them their joy was almost tangible. Click, click, click, flash, flash, flash... the celebrities' photos were taken over and over as compact cameras were passed around, promises to email, to meet next year and so on. I thought about the heartache and anguish each of these families privately suffered and what happiness this opportunity to meet was giving them. Sharon was thrilled to have spoken to Dr Wraith and they were meeting up for an assessment early next morning before the family's return to Malaysia.

I waved my lovely new friends Rachel and her Mum off the next morning. Armed with an extra copy of the Abstracts and Delegates' List to give her paediatrician back home, Sharon felt the visit to Paris was everything they had hoped for. Sharon told me that after every outing Rachel had talked non-stop about it before keeling over fast asleep! I was so pleased she'd enjoyed herself so much. As she was leaving Rachel whispered to me, "You know, for a granny you're pretty cool ..... no, not pretty .... REALLY cool"!! We were all winners! I know we'll meet again!

The Crèche

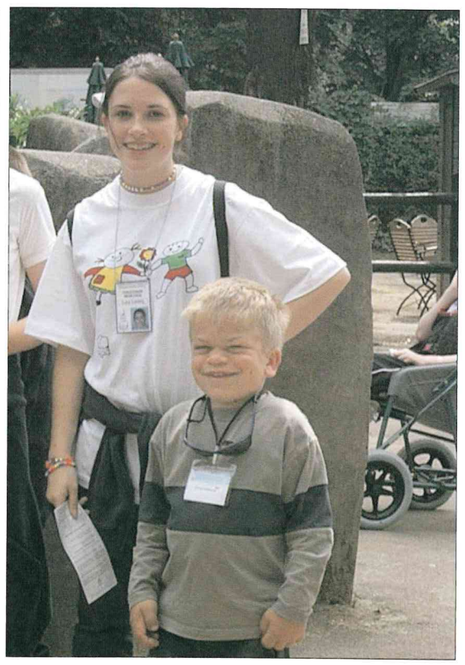
Mattresses replaced the smart conference tables and chairs and a television stood in place of the flipchart. One of the hotel's meeting rooms thus became our crèche for a few days and the base for a small group of English and French volunteers. They were caring for the under 3s and those affected with an MPS disease whose care needs meant they could not participate in one of more of the outings by coach. On several occasions a stately procession of buggies was seen making its way through the hotel foyer – the volunteers were taking their charges out into the fresh air to picnic in the nearby park.



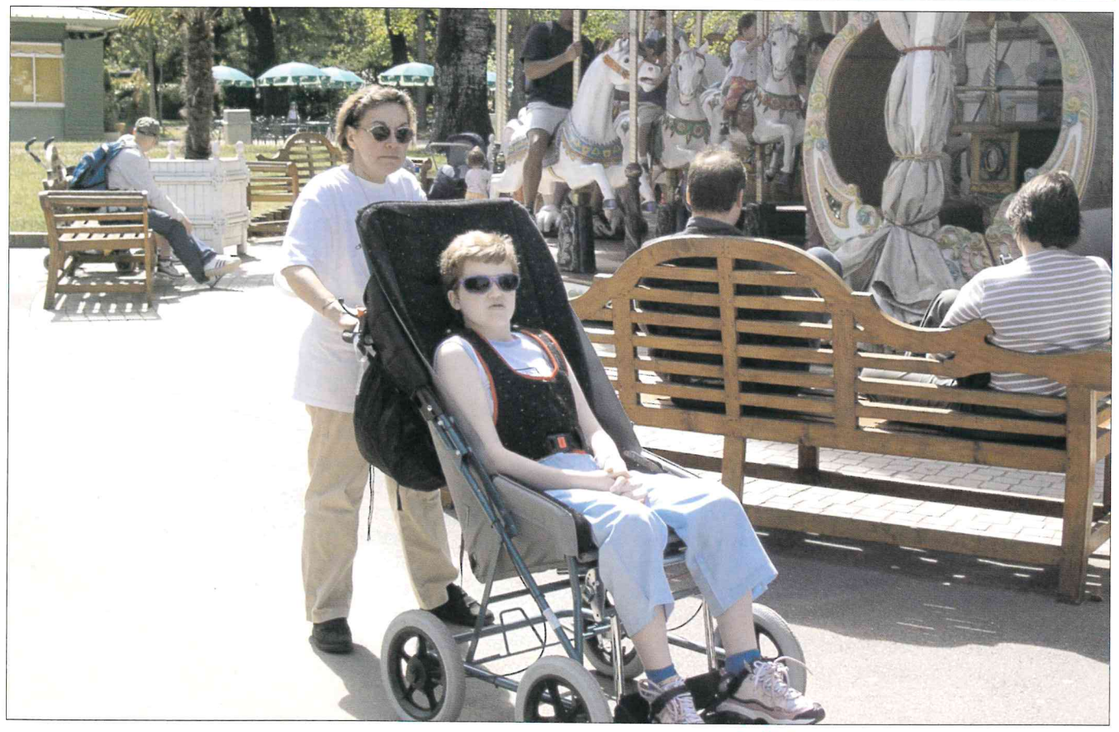
Evening entertainment

While Fiona Bingham was out with the older and more able children, other children, young adults and volunteers were being entertained at the hotel. The varied act included dancing, singing, performing dogs, a rabbit, a dove, and even a flaming torch. There was the opportunity for audience participation at times too. Needless to say it was enjoyed by adults and children alike.

The Zoo and Parc Asterix



The Jardin d'Acclimitation



Dave's Story

David Morgan gave this talk at the Australian MPS Conference April 2002

When first asked to speak at the conference, I wondered what I could possibly have to say that would be of interest to anyone here. I then thought back to the Coffs Harbour conference (2000) and I remembered how listening to the stories of others made me feel less alone. I realised that others were going through some of the same things I was. That to me is what the Society is about. Sharing our experiences, helping each other and working together to help each other cope. So here is my story:

For those who don't know me I am 37. I have a small flat behind my parent' s house. I am the youngest of four boys. Three of us have mild Hunter's. Greg, the eldest at 44, has three young children. Chris, 42, is unaffected and Phillip, 40, has two teenage daughters. We were normal kids growing up. We never suspected that anything was wrong with us. We all played sport. I represented my school in cricket, soccer and even rugby league. I guess the only real obstacle was my size but I was just short, like some people are.

I guess looking back now there were signs like lack of flexibility, etc, but we never thought anything of it and just put it down to individuality. We were just made that way. I am glad because it allowed us to have a normal childhood. I know that if we had known about Hunter's, our lives would have been very different. I can be sure of that because even finding out as adults our lives changed dramatically. For starters going to the doctor was never to be the same. All of a sudden we were different people. It was like suddenly we were given a life expectancy, our worlds were changed forever . I'm glad we were given time to be **normal**.

Our diagnosis came about when at the age of 20 I woke one morning with a screamer of a headache and no vision in my right eye. After a trip to the hospital I was soon found to have glaucoma. It was arranged that I see a paediatrician to help sort out why someone so young might have glaucoma. About the same time Phill was having some health problems. There was a lot going on and the exact details are a bit hazy. But after some tests, etc, we were diagnosed. Later we were contacted by a genetic counsellor. It was a pretty tough time. Phill was newly married and planning his new life. I think it was toughest for him. All of a sudden we were told we were basically different people. We were shown pictures in a book and told that was what we looked like. I guess we all felt our lives were somehow mapped out for us. Everything we had planned and dreamed of was suddenly changed. We all dealt with it in our own way but we all pretty much decided that we would just get on with life, the best we could. Besides there wasn't much help back then and no cure, so what choice did we have?

I think that is why we shied away from the Society for so long. I know, for me personally, I felt it would be admitting that I was different. That I had something wrong with me. That I was one of those pictures in the books I was shown. For me that is one of the many contradictions I have with Hunter's. Yes we do look similar and maybe it is possible to recognise a Hunter person, but we are still individuals and I think it is important for everyone to remember that. Even within my family the three of us with Hunter's are very different people and while the basic symptoms are common (aches and joint stiffness) it affects us differently and the way we deal with it is different. But the way we deal with it also changes from time to time. There are times when you just want to ignore it and other times when you feel you want to know as much as possible. It was through one of these curious times that I decided to make contact with Professor Hopwood. I felt it was time that I knew more about Hunter's. As I said, up until then I just didn't want to know about it. But I thought it was time.

As it happened it was just before the Coffs Conference and after a phone call to Teresa (Australian MPS Society President) and lots of wrestling in my mind I decided I would attend.

It was a life changing experience in a number of ways. It was the first time I had stayed at a resort. The first time I had stayed anywhere on my own really. I had only talked to Teresa on the phone a few times and I knew nobody else. Well that lasted 5 minutes. I was soon one of the family. I now know I have support and that I am not alone and that others are going through many of the same things.

I know that there is research being done by some wonderful people. Not just some mad scientist working away in a dingy lab somewhere (well maybe some are). But I also felt that if I expected help from these people I should make a contribution. That's why I agreed to give this talk. I know I will have struggles in the future but that is what life is all about. And who knows what lies around the comer for anyone of us.

Japanese Society of the Patients & Families with MPS

Shuji Murata, Counsellor

A letter to Christine Lavery.

In Japan it is now the season of weather fine enough for people to remove their coats. How are things with you? I trust that you are more than occupied with all your activities.

The other day I found some very good news. Your face and article were on the front page of a newsletter from the UK. I am truly delighted that you have been awarded an MBE by the UK in recognition of the contribution made to those worldwide concerned with your support activities over many years. Well done. I offer you my most heartfelt congratulations. I believe that people all over the world concerned with MPS, especially patients and their families, have benefited from immeasurable courage and vitality as a result of your activities. Furthermore, thanks to your help in such areas as providing information, the foundations were laid several years ago for the organisation and stability of the Japan MPS Society.

For many years we have been seeking Japanese government designation of MPS as an incurable disease, and at last our wishes have been addressed with recognition. We are delighted that from now on the government is to arrange research study and the lowering of medical fees.

As you are aware, I have resigned as President of the Japan MPS Society and become a counsellor to the Society, being steadily involved in things. On 20 May, together with Dr Orii of Gifu University, I attended the symposium being held for the first time at the Samsung Medical Center in Seoul, Korea.

Unfortunately, I will be unable to attend the Seventh International Symposium being held in Paris. Japan will be represented by Dr Orii and others of Gifu University, Dr Tanaka of the City of Osaka University, Dr Eto and others of Tokyo Public University. Dr Tanaka of the City of Osaka University is the physician in charge of treatment for my daughter, 25-year-old Morquio.

I hope that one day I shall be able to visit the UK and meet you and everyone at the MPS Society.

Once again, my most heartfelt congratulations upon the award of an MBE. Truly well done. Please give my regards to everyone at the UK MPS Society.

Press release 12th June - TKT Announces Positive Preliminary Findings in Development of Iduronate-2-Sulfatase for Hunter Syndrome

Transkaryotic Therapies, Inc. announced preliminary results of the first clinical trial of iduronate-2-sulfatase (I2S), its investigational enzyme replacement therapy for the treatment of Hunter syndrome, also referred to as mucopolysaccharidosis type II or MPS II. The results indicate that treatment with I2S is generally well-tolerated and is clinically active. The Company expects the full clinical findings will be presented at a medical meeting in the Fall of 2002. Based on the results, TKT intends to advance the program into the pivotal stage of clinical testing.

A randomized, double-blind, placebo-controlled Phase I/II study was conducted at the University of North Carolina at Chapel Hill to assess the safety and clinical activity of I2S enzyme replacement therapy in patients with Hunter syndrome. Twelve patients participated in the study. The primary focus of the study was to assess the safety of I2S enzyme replacement therapy. Patients were randomized to receive one of three doses of I2S (0.15, 0.5, or 1.5 mg/kg) or placebo as an intravenous infusion every other week over six months.

All patients completed the Phase I/II clinical trial, and infusions of I2S were generally well-tolerated. All patients who participated in the study have elected to participate in an open-label maintenance study, with many patients receiving treatment for at least one year. The data demonstrated reductions in glycosaminoglycan (GAG) levels, the toxic substrate that accumulates in patients with Hunter syndrome, indicating that the enzyme is biochemically active. There were also reductions in liver and spleen size, as well as evidence of clinical activity in several areas, including pulmonary function and joint mobility.

"These Phase I/II data are very encouraging, and I look forward to expanding the scope of I2S clinical testing," said Joseph Muenzer, M.D., Ph.D., Associate Professor of Pediatrics at the University of North Carolina at Chapel Hill and principal investigator of I2S clinical testing. "Currently, patients affected with Hunter syndrome have no treatment options. With continued success in the development of I2S, I am optimistic that a therapeutic will become available to treat patients suffering from this devastating disease."

"We are very pleased with the results of this study and believe we are on the right path to developing an effective therapy to treat this debilitating disease," said Thomas J. Schuetz, M.D., Ph.D., Vice President, Clinical Affairs of TKT. "We believe we have determined an appropriate dose and gained an understanding of the clinical activity of our I2S product, and we are very much looking forward to advancing the clinical development program to a pivotal Phase III study."

In 2001, I2S was designated an orphan drug in both the United States and Europe.

Press release 24th June - BioMarin and Genzyme Announce Positive Findings from Phase 3 Trial and Extension Study of Aldurazyme for MPS I

BioMarin Pharmaceutical Inc. and Genzyme General on June 24 announced detailed results from the six-month double-blind Phase 3 clinical trial of AldurazymeTM (laronidase) and preliminary six-month findings from the trial's ongoing open-label extension study. Aldurazyme is an investigational enzyme replacement therapy for patients with mucopolysaccharidosis I (MPS I). Data from the extension study indicate that patients who received Aldurazyme for twelve months continued to improve upon the results seen in the first six months of treatment.

Ed Wraith, M.D., of the Willink Biochemical Genetics Unit at the Royal Manchester Children's Hospital, Manchester, UK, and one of the trial's clinical investigators, presented findings from both the double-blind and extension study portions of the Phase 3 trial on Saturday, June 22 at the International Symposium on Mucopolysaccharide and Related Diseases in Paris, France. BioMarin and Genzyme will submit the six-month interim extension study data to the U.S. Food and Drug Administration (FDA) in the third quarter to complete their "rolling" Biologics License Application (BLA).

"The data presented on Saturday indicate that this is a promising treatment for the complex array of symptoms experienced by MPS I patients, who currently have no specific treatment available to them," said Dr. Wraith. "I am particularly encouraged by the results seen in patients who have now been on treatment for a full year."

Extension Study Results

All 45 MPS I patients from the six-month, randomized, double-blind, placebo-controlled Phase 3 trial were enrolled in the open-label extension study in order to further evaluate the safety and efficacy of Aldurazyme. Patients who were previously on placebo were switched to Aldurazyme for the extension study, while those patients who received Aldurazyme during the first six months of the trial continued to receive Aldurazyme via weekly infusions in the extension study.

The extension study includes analysis of the same two primary endpoints that were evaluated in the double-blind portion of the Phase 3 trial: pulmonary function, as measured by forced vital capacity (FVC), and endurance, as measured by the distance covered in a six-minute walk test. Patients who received Aldurazyme in the double-blind portion of the trial and who continue to receive treatment in the extension study maintained improvement in FVC, moving from a 5.3 percentage point mean increase in percent of predicted normal FVC during the first six months of treatment to a 5.9 percentage point mean increase after an additional six months of treatment as part of the extension study. These same patients improved from a 19.7 meter mean increase in the six-minute walk test over the first six months of treatment to a 42.9 meter mean increase after six additional months of treatment as part of the extension study.

During the extension study, patients who were switched from placebo to Aldurazyme experienced a slight decline in FVC compared to baseline (-0.6%) but began to improve during the second half of the six-month extension period. In the six-minute walk test, patients who were switched from placebo to Aldurazyme showed a mean improvement of 23.8 meters, which is consistent with the increase seen among patients who received six months of treatment with Aldurazyme during the double-blind portion of the trial.

Additional findings from the extension study have been generally consistent with results seen in both the Phase 1 trial and the double-blind portion of the Phase 3 trial: statistically significant reductions in liver size and in the excretion of urinary glycosaminoglycans (GAGs), the carbohydrate substances that accumulate in patients with MPS I. Patients who received Aldurazyme in both the double-blind and extension study periods maintained the reductions in liver size and urinary GAG excretion that were seen in the first six months of treatment.

The safety profile in the extension study has been comparable to the double-blind period. The most commonly reported reactions were fever, headache, rhinitis, and rash. One patient in the extension study died of causes considered by the principal investigator to be unrelated to treatment.

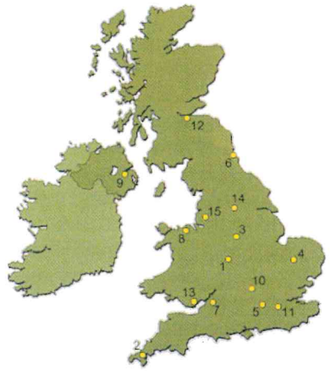
Mobility

Motability's contract hire scheme for cars offers many disabled people the best value available.

Anyone in receipt of the higher rate mobility component of Disability Living Allowance, with more than three years to run, can commit that benefit to hiring a car usually all the allowance. For larger cars an additional advance payment is required.

The scheme pays for the car, insurance, recovery and breakdown services from the RAC and routine maintenance. Driving is limited to two named drivers, but a third can be added at extra cost. The contract runs for three years, then the car goes back and a new contract starts. There is no extra charge for young or inexperienced drivers, but there are some insurance restrictions for young drivers and those with a history of insurance claims. An extra charge is made for exceeding 12,000 miles a year. The only extra costs are petrol and a contribution, usually £75, to the cost of each insurance claim. The scheme is open to disabled drivers and disabled people who prefer to be driven. Motability can offer grants towards the cost of advance rental and conversions.

Motability also runs a hire purchase scheme for new and used cars and for motorised wheelchairs and scooters. It is available to disabled people regardless of their credit history. For details of the Motability scheme, tel: 01279635666 or go to www.motability.co.uk



1. Regional Driving Assessment Centre, West Heath Hospital, Rednal Road, Birmingham B38 8HR, tel: 0121 627 8228, fax: 0121 6278629.

2. Cornwall Mobility Centre, Tehidy House, Royal Cornwall Hospital, Truro, Cornwall TR1 3LJ, tel: 01872254920, fax: 01872254921.

3. Derby Regional Mobility Centre, King sway Hospital, King sway, Derby DE22 3LZ, tel: 01332371929, fax: 01332 382377.

4. Kilverstone Mobility Assessment Centre, 2 Napier Place, Thetford, Norfolk IP24 3RL, tel: 01842753029, fax: 01842755950.

5. Mobility Advice and Vehicle Information Service (MAVIS), "0" Wing, Macadam Avenue, Old Wokingham Road, Ccowthorne, Becks RG45 6XD, tel: 01344 661000, fax: 01344 661066.

6. Mobility Centre, Regional Neurological Rehabilitation Centre, Hunters Road, Newcastle upon Tyne NE2 4NR, tel: 0191 2195694, fax: 0191 2195665.

7. Mobility Service of the Disabled Living Centre (West of England), The Vassall Centre, Gill Avenue, Fishponds, Bristol BS16 2QQ, tel: 01179659353, fax: 0117 965 3652, email: mobserv@dlcbristol.org

8. North Wales Disabled Drivers Assessment Centre, The North Wales Resources Centre, Glan Clwyd Hospital, Bodelwyddan, Oenbighshire LL18 5UJ, tel: 01745584858, fax: 01745582762, email: info@drivemobility.org

9. Northern Ireland Mobility Centre, Disability Action, Portside Business Park, 189 Airport Road, Belfast BT3 9ED, tel: 028 9029 7880, minicom: 028 9029 7882.

10. Oxford Driving Assessment Service, Mary Marlborough Centre, Windmill Road, Headington, Oxford OX3 7LD, tel: 01865 227600, fax: 01865 227294.

11. Queen Elizabeth's Foundation Mobility Centre, Damson Way, Fountain Drive, Carshalton, Surrey SM5 4NR, tel: 02087701151, fax: 020 87701211.

12. Scottish Driving Assessment Service, Astley Ainslie Hospital, 133 Grange Loan, Edinburgh EH9 2HL, tel: 01315379192, fax: 01315379193.

13. South Wales Disabled Drivers Assessment Centre, Rookwood Hospital, Fairwater Road, Llandaff, Cardiff CF5 2YN, tel: 029 2055 5130, fax: 029 2055 5130.

14. William Merritt Disabled Living Centre and Mobility Service, St. Mary's Hospital, Green Hill Road, Armley, Leeds LS12 3QE, tel: 0113305 5288, fax: 01132319291.

15. Wrightington Mobility Centre, Wrightington Hospital, Hall Lane, Appley Bridge, Wigan, Lancs WN6 9EP, tel: 01257256409.

When a Child's Brother or Sister Dies

Dr. Alan D. Wolfelt, *Source: 'The Connection' Canadian MPS Society*

Next to the death of a parent, the death of a sibling can be the most traumatic event in a child's life. Why? Because not only has a family member died, but a family member for whom the child probably had very strong and ambivalent feelings.

As those of us who have brothers and sisters know, sibling relationships are characterized by anger, jealousy and a fierce closeness and love - a highly complex melange of emotion. This complexity colors the surviving child's grief experience.

A Caring Adult's Role

How adults respond when someone loved dies has a major effect on the way children react to the death. Sometimes, adults don't want to talk about the death because they want to spare children from some of the pain and sadness. And for the same well-intentioned but misguided reason, adults hide their own feelings of grief from children.

What bereaved siblings really need is for adults to be open and honest with them about the death. They need to see that grief is as natural a part of life as loving. Children need adults to confirm that it's all right to be sad and to cry, and that the hurt they feel now won't last forever.

When ignored, bereaved siblings may suffer more from feeling isolated than from the actual death itself. Worst yet, they may feel all alone in their grief.

What a Surviving Sibling Feels

Each person's grief is unique and changes from day to day. So, it is impossible to predict what a specific child will feel after her brother or sister dies. If you want to help, the most important thing you can do is to listen and to accept any and all feelings the surviving sibling expresses.

However, I have had the privilege to counsel hundreds of bereaved siblings. Among many other special lessons, they have taught me they often feel:

Guilt - For a number of reasons, bereaved siblings often feel guilty. Their power of "magical thinking" - believing that thoughts cause actions - might make them think they literally caused the death. "John died because I sometimes wished he would go away forever" is a common response among children who haven't been given the concrete details of the sibling's death and who haven't been assured that they were not at fault.

Relief - A child may feel relief as well as pain when a sibling dies. Responses such as "Now no one will take my things" or "I'm glad I have a room to myself' are natural and do not mean the child didn't love his or her sibling. It is important that you provide an atmosphere in which the child feels safe to express whatever he or she may be feeling.

Fear - When a child's brother or sister dies, another young person has died. So, for a child, confronting this reality can mean confronting the possibility of one's own death. Be prepared to honestly but reassuringly answer questions such as "Will I die, too?" The death of a sibling can also make a bereaved child fear that his other family members will die, too, leaving him alone.

Confusion - One eight-year-old girl I counselled after the death of her brother asked me, " Am I still a big sister?" This little girl was obviously struggling with the confusing task of redefining herself, both within the family unit and the world at large. The answer to her question, of course, is both yes and no, but ultimately it is a question the child must answer herself. Adults can help, however, by letting the child teach them what this confusion is like.

Siblings Can Be "Forgotten Mourners"

When a child dies, most of the grief support from family members and friends gets focused on the parents. Indeed, losing a child may be the most painful experience in life, and those of us who are parents readily empathize with and offer our support to the dead child's parents. And the parents themselves are often so overwhelmed by their loss that they can barely help themselves get through the day.

So what about the surviving siblings? Though we can't quantify grief, we can say that siblings are often as profoundly impacted by the death as their parents are. And in some ways they are even more deserving of our attention because they are *children*.

Let's not allow bereaved siblings to be forgotten mourners. If you are a bereaved parent, share your grief with your surviving children and make time to understand theirs. If you just can't make yourself emotionally available right now, gently explain this to the child and appoint another adult as grief helper for now.

Can insurers ever ask to see the results of a genetic test?

Association of British Insurers

Background

The development of genetic testing has led to concerns that test information might be used by insurance companies to set premiums, so creating a 'genetic underclass' of people unable to obtain or afford life or health insurance.

In fact, insurance companies do not and will not ask individuals to take genetic tests as a condition of taking out insurance. The issue is whether and under what circumstances the results of a relevant genetic test that has already been taken should be given to an insurer.

Code of Practice

The Government-appointed Genetics and Insurance Committee is the body that decides which genetic test results can be used by insurance companies. The industry supports the Committee and will implement its decisions in full.

The ABI developed a Code of Practice on Genetic Testing that was first published in December 1997. This sets out the procedures to be used if insurers wish to use the results of certain genetic tests that have already been taken. It also includes comprehensive guidelines on confidentiality.

The Moratorium

Following discussions with the Department of Health, the ABI published an agreement with the Government in October 2001 setting out the terms of a five year moratorium on the use of DNA genetic test results by insurers.

The agreement covers all but the largest quantities of insurance, enabling consumers to obtain up to £500,000 of life insurance, and £300,000 of critical illness, income protection and long term care insurance, without having to disclose any genetic test results. The ABI moratorium is longer than the three years suggested by the Human Genetics Commission. Its purpose is to provide the breathing space required in which to agree a consensus on long term policy.

This means that only in a small proportion of cases of high value insurance will the results of relevant tests that have already been taken need to be disclosed. In this minority of cases, only the results of genetic tests that have been authorised specifically by the Genetics and Insurance Committee need to be disclosed.

The five year moratorium came into effect on 1 November 2001. Under the terms of the agreement, there will be:

- A review of the financial limits after three years;
- An impartial and independent complaints mechanism;
- An annual public report on compliance.

Recruitment

Rare Disorders Alliance

Christine Lavery, Director

On November 27 Ellie and I attended a meeting of the Advisory Group of the Rare Disorders Alliance UK in London. Facilitated by CaF, the RDA.UK is a network of groups and individuals who support the aims of the alliance. It values the expertise of those affected and those working with rare disorders and is a vehicle to influence policy and exchange information.

The aims of RDA.UK are:

- To share good practice and information relating to all aspects of rare disorders;
- To promote the well being of those affected by a rare disorder;
- To raise awareness of rare disorders;
- To raise awareness of and influence medical professionals and industry about rare disorders;
- To raise awareness of professionals working with those affected by rare disorders;
- To act as a consultative body on all policy issues relating to rare disorders;
- To work collaboratively with other European Global Alliances;
- To give guidance to CaF on all issues relating to rare disorders.

This initial meeting was to re-establish this group and provide a focus for the members. Much of this meeting involved a development of a draft terms of reference. The proposed role of the group is to:

- Share information and experience relating to any aspect of rare disorders;
- Support the views of anyone affected by a rare disorder;
- Ensure that the needs of the wider rare disorder community remain a priority;
- Offer guidance and advice to CaF on current issues relating to rare disorders;
- Act as a consultation body for relevant policy issues;
- To be responsible for directing any work programme for the RDA.UK;
- Represent the RDA.UK at UK, European or worldwide meetings on any matters relating to rare disorders;
- Be involved in any decisions relating to the development of the RDA.UK.

Whilst still in its early days this group has the potential to not only raise awareness, but also affect policy in relation to rare disorders and it is important that we take an active part in its work. Future meetings will discuss potential involvement in the National Service Framework External Working Group on Disabled Children. If any of you have views about how the work of the RDA.UK should represent families, or if you would like to feedback to the Government's newly developed National Service Framework about how services are delivered and how they can be improved, please let me have your thoughts (again in writing) and I will pass them back via RDA.UK.

London Marathon

Neil Carey

Neil Carey, the cousin of Lisa Nurse (Sanfilippo), ran the London Marathon on 14th April raising £1,305 for MPS.

"The whole day was a great event. During the run I ran very comfortably until the 18 mile mark when the dreaded brick wall hit. The last 8 miles were very tough especially doing it on my own, but the crowd kept me going until the end. When I saw the finish line in sight it was the greatest feeling of achievement.

"My nephew Garry age 7 jumped the barrier to run the last 100 metres with me. (He is in the bottom right hand comer of the photo). I hope the total amount I raised will help MPS a great deal."

Sheffield half Marathon

Steve Robjohns

Steve Robjohns writes,

"This photo of us with Jordane was taken just after we had completed the Sheffield half marathon.

"Dean Vellam is on the left, I am on the right, and the guy in the middle standing behind Jordane is Darren Ferguson.

"We have raised just over £500 and the time we finished the run was 2 hours 9 minutes."

The Three Peaks Challenge

Trevor and Shirley Brown

Trevor Brown joined a team of nine men and took on the 'Three Peaks Challenge' over the weekend of 10th - 13th May. They were supporting another charity but felt it apt to raise money for MPS as well, since the Browns' late son's birthday fell on 12th May.

Thanks to the generosity of their friends, family and work colleagues they raised £1,030 for the MPS Society.

Trevor was the eldest member of a ten man team the only preparation being every other weekend going for long walks over a four month period, but with the proper equipment.

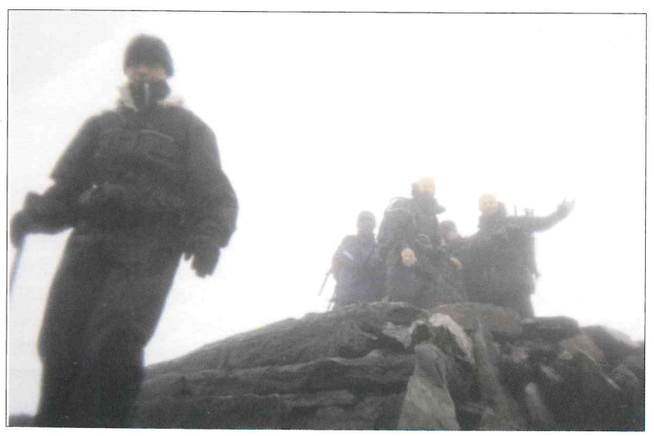
Friday 10th May
A twelve hour bus trip to Fort William arriving at 6.00pm which was tiring in itself. They stayed overnight in a Hotel ready for the next morning.

Saturday 11th May, Ben Nevis
After a delay because of the weather they started. It proved very hard. Ben Nevis saw off two people, one with a knee injury and the other exhausted, both that much younger than Trevor. He carried on and after four hours reached the summit very cold and in 3ft of snow, but very rewarding. It took a further 3 and half hours to get back down then the drive to the Lake District.

Sunday 12th May, Scafell Pike
4.45am was their start time only having had a few hours' sleep on the bus. Seven team members started the climb. It took three and a half hours of very hard terrain to reach the top and although very exhausted everyone marvelled in all the sights they had seen up to then. It took a further two and half hours to walk down. The organiser decided that to drive to Wales and then climb Snowdon on the Sunday would have been madness. So it was decided that they would drive to Wales stay overnight in a Hotel and rest ready to climb Snowdon.

Monday 13th May, Snowdon
All the team wanted to climb Snowdon but the weather was atrocious - torrential rain, high winds and mist. They started out at 12.00 midday. It took two and half hours to climb and three and a half hours to descend, but because of the weather conditions it seemed much longer. They were all freezing, soaked through and very tired, but loved every minute.

Trevor is very proud of himself, as are we all. He enjoyed it so much he wants to do it again. He arrived home at 1.00am Tuesday morning with no injuries, but very tired. It took him a week of early nights to catch up. Trevor's driving force was why he was doing it. It just goes to show what you can achieve when your mind is set. All our children have that drive everyday. It's quite remarkable what they achieve and that is why we are so proud of them.



Flora Women's Challenge, 1st September 2002

Light FLORA WOMEN'S CHALLENGE asics

ENTRY FORM

Please complete in CAPITALS and send to the address below

For office use only. Race No:

First Name

Surname

Address

Post Code

Date of Birth

Telephone - Home Work

Signed Date

Please give details of the charity you wish to benefit from your donation

Name of Charity .....

Charity Address .....

Post Code .....

Please note if you do not give the full name and address of a charity your donation will go directly to The London Marathon Charitable Trust which supports sports and recreational projects in the Capital.

For office use only.

Please send your entry form together with your £12 entry fee to:
Flora Light Challenge for Women, PO Box 1998, London SE1 8ZW.
The closing date for entries is 2nd August 2002
OR EARLIER SHOULD THE ENTRY LIMIT BE REACHED.
Please make cheques payable to The London Marathon Limited.

The Flora Light Challenge for Women is organised and operated by The London Marathon Limited. By signing this form I declare that I will abide by the rules of the event and that I shall be, at the date of the event, fit and that the details given in the form are correct in all particulars. I accept that, to the extent permitted by law, the organisers and sponsors shall have no liability to me for any injury, loss or damage, nor any consequential loss or damage suffered by me at or by reason of the event. Your name and address may be used in connection with other London Marathon services and may be also given to other reputable companies to contact you. Should you not wish to receive any such mailings, please write to: Entry Co-ordinator, Flora Light Challenge for Women, PO Box 1998, London SE1 8ZW. Please note, entry fees are non refundable.

Whatever your age, your fitness levels or running ability, signing up to take part in the Flora Light Challenge for Women is a great incentive to keep fit and feel healthier.

The Flora Light Challenge, in association with Asics, is a 5 kilometre fun run... or walk... for women. It takes place in London's Hyde Park on Sunday 1st September 2002. It is an event for all women, of all ages, fit or not-so-fit.

Training and taking part in the Challenge may be even more fun if you team up with friends. You can walk, jog, run - it's your choice. The main thing is to have fun and enjoy your achievement.

It is all in a good cause too. £5 from your £12 entry fee will be donated to the charity of your choice. All you need to do is clearly identify the charity you want to support on the entry form overleaf and we will make sure it is forwarded to them. If you do not identify a charity your donation will go to the London Marathon Charitable Trust which supports sports and recreation projects in London.

Flora have teamed up with Asics to provide tips on training and you will find these in the information booklet obtained from the organisers. Once entered you will next hear from us in early August when you will receive your running number and final instructions magazine. Although we will not acknowledge receipt of entry, your cheque will be cashed within 14 days and your next bank statement will show that we have received your entry. On the day every finisher will receive a goody-bag which will include a finisher T-shirt and a medal. To enter please complete the entry form overleaf and send it with the £12 entry fee to: Flora Light Challenge for Women, PO BOX 1998, LONDON SE1 8ZW Cheques should be made payable to: The London Marathon Limited. Photocopies of the entry form will be accepted or go to: www.london-marathon.co.uk/other_events/raceentryform.pdf

Donations

The Society is grateful to the following who made donations

A S Rowe
Alton Towers
Andreas Charalambous
Belvoir Park Golf Club
Benham Charitable Settlement
BioMarin Pharmaceutical Inc.
Brentford Football Club
Britannic Assurance plc
Catholic Women's League
Charities Aid Foundation
Clover Trust
Clydesdale Bank Plc
Coty Manufacturing UK
Dr R B Silhi
Electrolux
Fenwick Ltd
GKN Plc
Go-Ahead
Homebase
Jane Heritage
Joan Thompson
John Lewis
Joseph Strong Frazer Trust
Lifeline for Lorren Appeal
L'Oreal
Macfarlane group
Manchester Airport
Mars U.K Ltd
Masterfoods
Mattel Europa B.V.
McBride
Michael J Lonsdale
Middlesborough Football Club
Morgan @ Morgan
Mr & Mrs Barnham
Mr & Mrs Heanue - Taunton
Mr & Mrs Sager
Mr P Stoughton
Mr S Blanch
Mr T Raferty
Mrs P C Gluckstein Charity trust
Mrs Thurairajah
Northgate Information Solutions
Open Text
P Bennett
Peter Mason
Robert Kenton
Sainsbury's - Beaconsfield
Saudi Petroleum Overseas Ltd
Securicor
Sovereign Health Care
Steria
Stoke Row Beavers
Strasser Foundation
Susan Lowry
Sylvia McAulay
Tesco - Amersham
The Good Neighbours Trust
The Grammar School for Girls - Wilmington
Tracy Taylor
Tungscarb Products Ltd
V Lazenby
Whitbread Retirement Association
Wyevale Garden Centre

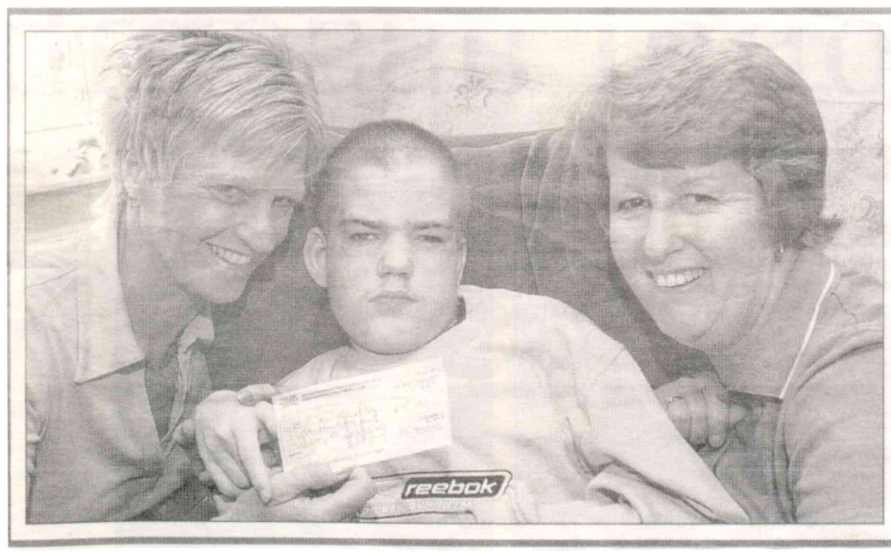
Fundraising

The Society is grateful to the following who have held fundraising events

YES Group - Golf Day
Lynn Longhorn - Skittle Evening
M I Stimpson - Webb ivory Commission
Tom & Margaret Brennan - Dance Show Northgate
The Cock Hotel Social Club
Brenda Weston - Coffee Moring
B.C.S - Xmas raffle
Andy Hardy - Morris Men
Wells City Football Club - Fun Day
Neil Carey - London Marathon
Dave Keyworth - Sheffield Marathon
Sponsored Beardathon - Sheffield
Andrew and Vivienne Culley - Car Boot
Graham Jobes - Charity Walk
Elizabeth Heath - Golden Jubilee Street Party/Prize Draw
Eric Musgrove - London Marathon
John Scott
Trevor Brown and friends - Three Peaks Challenge
Eileen Smale

In Memory

Jade Robinson
Jake Corcoran
Alan Coates
Annette Puddy
Kim Eggleton
Shivahram Selvaranjan



THANKS: A charity race night held at Brumby Hall, Scunthorpe, raised £1,241 for the MPS (Mucopolysaccharide) Society. MPS volunteer and race night organiser Eileen Smale (left) is pictured presenting the cheque to MPS sufferer David Symour and his mother Angela Symour. Eileen and Angela wanted to thank all the comanies and local organisations which offered their support with sponsorship and donations, plus all who contributed to the final total.

MANAGEMENT COMMITTEE

Chairman	Barry Wilson		
Vice-Chair	Steve Butler Judy Holroyd		
Treasurer	Judith Evans		
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	Alex Roberts	Project & Information Officer	a.roberts@mpssociety.co.uk
	Fiona Woodcraft	Project & Information Officer	f.woodcraft@mpssociety.co.uk

Do let us have your family stories and any helpful hints you would like to share with our newsletter readers. If you have a question that you would like to see answered in a future edition of the newsletter, please do write to us.

To submit information to the newsletter please send materials (preferably via e-mail for text) and mail photos to the address on the left.

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.

NEWSLETTER DEADLINES

AUTUMN
30 September 2002

WINTER
17 December 2002

SPRING
31 March 2003

SUMMER
30 June 2003

CONTACT US

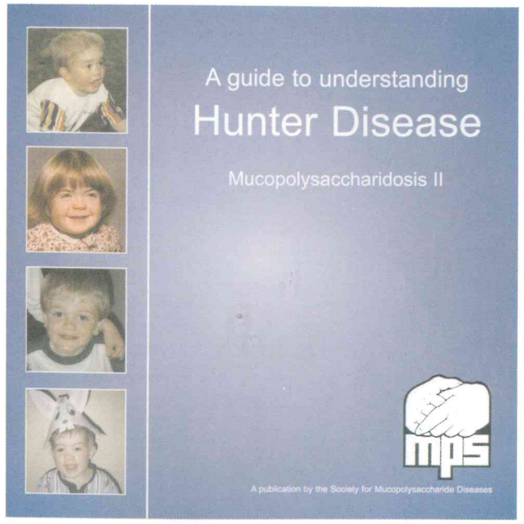
MPS OFFICE: 46 WOODSIDE ROAD, AMERSHAM, BUCKS HP6 6AJ

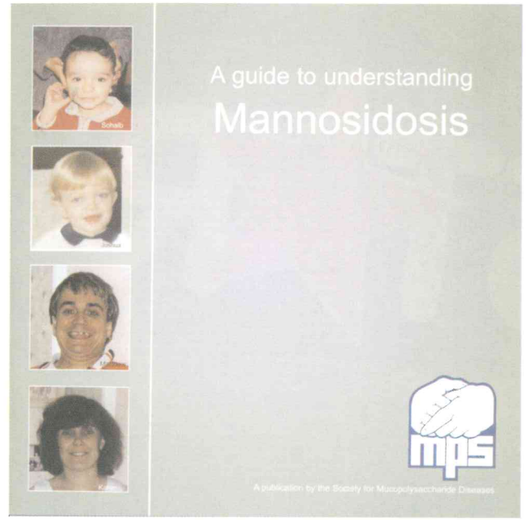
Tel: 01494 434156
Fax: 01494 434252

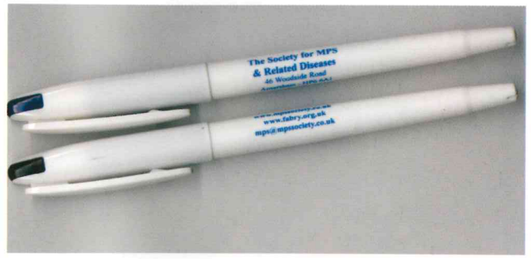
OUT OF HOURS HELPLINE: 07712 653258

email: mps@mpssociety.co.uk
Web site: www.mpssociety.co.uk
Fabry: www.fabry.org.uk

The MPS Society has recently published information booklets on Hunter Disease and Mannosidosis. They are priced at £2 each. Other items for sale include yo-yo keyrings (75p each), whistle top pens (£1 each) , biros (£1 for a pack of 2), and pencils (£1 for a pack of 4). Pencil cases, each containing a ruler, bookmark and keyring, are also available at only 70p each. Contact Gina at the office.







Always wanted to be a star?

Now you can be, simply by selling badges to support the national Jeans for Genes Appeal!

Be a STAR for Jeans for Genes!

It will cost you nothing and you'll be helping to raise vital funds for research into genetic disorders and to provide support services for families across the UK.

This year's **Jeans for Genes Day** is being held on Friday 4th October when everyone across the UK will once again be invited to play a starring role by simply throwing out the usual dress code, jumping into their jeans and donating £1 to the appeal.

Many supporters want to wear Jeans for Genes badges – this is where we need YOUR help!

We are asking you to take a supply of badges to sell to your family, friends or colleagues for £1 each. Or order a supply for your local shops, library or leisure centre. When you place an order, we will also send a collection box, posters and additional fundraising ideas!

Don't miss out on your moment of stardom, order your badge supply today!

Simply return the coupon below or telephone Julie on

0207 813 8103

Eight national charities working together to help sick children

- Great Ormond Street Hospital Children's Charity
- The Society for Mucopolysaccharide Diseases
- The Chronic Granulomatous Disorder Research Trust
- The Primary Immunodeficiency Association
- Alström Syndrome UK
- The Ataxia-Telangiectasia Society
- The Haemophilia Society
- The Jennifer Trust for Spinal Muscular Atrophy

www.jeansforgenes.com

I would like to support the Jeans for Genes badge campaign.

Please send a supply of badges to:

Name

Name of organisation (if applicable)

Address

Postcode

Telephone

Email

☐ Each pack will contain 50 badges in 8 designs, a display box, collection box and fundraising ideas. Please state how many packs you require.

You will receive your pack in early September