

# Newsletter

The Society for  
Mucopolysaccharide  
Diseases

National Registered Charity No.287034



Autumn 2001

## 19<sup>th</sup> National Conference



Page 11 Kirstie's Success  
Story

Page 9 How Life has  
Changed

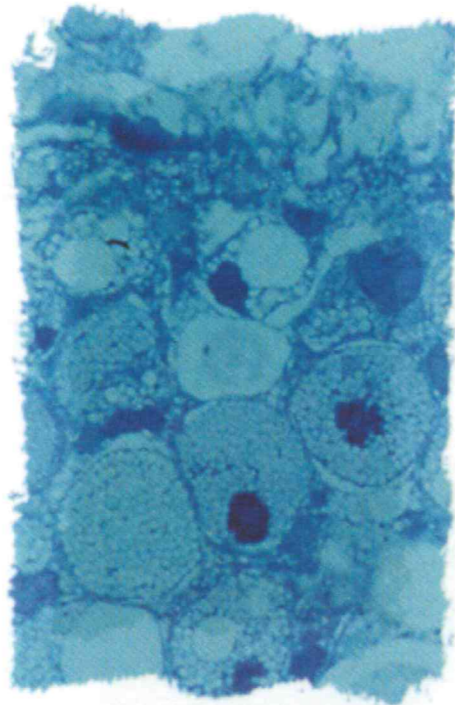
Pages 14-23 MPS Annual  
Weekend Conference

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Christmas Cards

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Paris  
FRANCE

Lysosomal storage in neuronal cells (J.M. Heard)

### Meeting the therapeutic challenges A la rencontre des enjeux thérapeutiques

7<sup>th</sup> International Symposium  
on Mucopolysaccharide  
and Related Diseases  
and 3<sup>rd</sup> Scientific Lysosomal  
Storage Disorders Congress



3<sup>ème</sup> Congrès Scientifique VML  
(Vaincre les Maladies Lysosomales)  
et 7<sup>ème</sup> Congrès International  
des Mucopolysaccharidoses  
et Maladies Associées



## 'CARE TODAY, HOPE TOMORROW'

### 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 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 diseases 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

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

#### Regional Events

Social events held throughout the United Kingdom for mutual support

#### 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 members' news. Sent to all MPS families 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.

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## ANNUAL GENERAL MEETING

*Trustee's report as presented by Barry Wilson at the Society's Annual General Meeting Friday 14 September 2001*

The Board of Trustees has met two-monthly throughout the financial year to monitor the efficient operation of the Society.

The Society has been successful in appointing a second Development Officer to enhance the advocacy support to families living in the North of England and Scotland. The Development Officer post for Southern England, Wales and Northern Ireland vacated in January 2001 was successfully filled in April. Enthusiastic and highly motivated the Development Team has provided needs led advocacy support to a large number of MPS individuals and their families. The Trustees are sensitive to the importance of this area of support and continue to monitor the delivery and efficacy of this service ensuring equality to all areas of the United Kingdom.

During this financial year the Society has organised and funded 10 regional clinics. I am pleased to tell you that in collaboration with Dr Ashok Vellodi a clinic for families in South Essex and Kent is planned. Dr Ed. Wraith and Dr Fiona Stewart have also agreed to a second clinic in Northern Ireland to be held annually.

In October 2000 the Society introduced colour printing to the quarterly newsletter. Following very positive feedback and favourable printing costs the quarterly newsletters from now on will be full colour.

At the Society's budget meeting the Trustees agreed to commission Omnivision to produce a video giving information on the Mucopolysaccharide and related diseases and the work of the MPS Society. This is described through the eyes of affected families and professionals working in the field. Filming started in the Spring and was concluded at the Annual Conference. We are very grateful to Jeremy Bowen of BBC Breakfast News for agreeing to introduce the video and do the voice overs. It is expected that the video will be available in late November.

In June 2001 the Society celebrated 21 years of Bone Marrow Transplantation for MPS and related diseases with an international conference held here in Northampton. We were particularly pleased that 21 families including the first Hurler Bone Marrow patient were able to participate. This specialist conference has provided food for thought in respect of future such meetings.

The Trustees are mindful that for many of us the fruits of many years of research will come too late for our children. However as a Society during 2001 we have been pleased to support the developments of Enzyme Replacement for MPS I Hurler Scheie and Scheie disease. Through the Society's registry it has provided valuable anonymous data to the pharmaceutical industry, the Department of Health and the European Commission. The Society's Development Officer (Research) has supported 12 families whose children have participated in a 6 month world wide clinical trial at the Royal Manchester Children's Hospital.

Genes for Jeans day in October 2000 raised more money than ever before and it is with this money along with the continuing fundraising efforts of MPS families and friends that the Society can continue to develop its support and advocacy services and fund substantial research projects.

In October 2000 the Society awarded the largest ever research grant jointly to the Institute of Child Health, Great Ormond Street and the Willink Genetics Unit, Manchester. Over three years this grant will amount to nearly £600,000.

Finally on behalf of all the Trustees and the members we would like to take this opportunity to thank our staff team for all their hard work and commitment.

## NEWS FROM THE MANAGMENT COMMITTEE

The Trustees met in July and August and considered the following matters

### Trustee Appointments

The Vice-Chairman, Steve Butler announced that Mark Beniston and Sarah Long had informed him that they were unable to continue as Trustees for personal reasons. Both were thanked for all their hard work as members of the Management Committee.

It was agreed to co-opt Barry Wilson as Trustee until the AGM when he would stand for election to the Management Committee. Barry and his wife, Barbara have been members of the MPS Society since their daughter, Joanna, was diagnosed with Scheie Disease in 1996.

### Staff Changes

Trustees agreed the appointment of a full-time member of staff to work temporarily over the summer holidays and conference period.

### Policies

The Director informed Trustees that the Society has received Confirmation of Entry in the Register under the Data Protection Act 1998. It was agreed that the Data Controller is the MPS Society and the Director is the Compliance Officer.

### ERT Party

Trustees agreed the budget for the cost of the party to be held to mark the end of the Enzyme Replacement Clinical Trial for MPS I, Hurler Scheie and Scheie Disease. The Director confirmed that Genzyme had given a grant of £1,500 for this purpose.

### Newsletter

It was agreed to accept a particularly competitive quote to enable the Society to publish the MPS quarterly newsletter in full colour as from October 2001. It was also agreed to purchase a digital camera to eliminate all the rolls of film used at MPS events and when visiting families. This will also enhance the quality of the photos in the Society's publications.

### MPS Clinics

Following proposals from Dr Ed Wraith and Dr Fiona Stewart it was agreed to offer two MPS clinics a year in Northern Ireland. Following requests received from families in the South east of England, Dr Vellodi has agreed to an annual MPS clinic in Kent.

### MPS Video

It was agreed to make a charge of £5 including postage and packing for each MPS video. Further decisions about the launch of the video will be made at a later date.

### NEWS FROM THE ANNUAL GENERAL MEETING

Judy Holroyd, Susan Peach, Adam Turner and Barry Wilson were all elected Trustees at the AGM held on 14 September, 2001.

## NEWS FROM THE MPS OFFICE

### Antonia Crofts - Development Officer

Although I have been working at the MPS Society since February of this year and have already introduced myself in a previous edition of the newsletter, I am pleased to be able to write that I have recently been appointed Acting Development Officer. My new role is to provide advice and support to families living in the South West and the North of England and those living in Scotland.

As part of the Society's network of regional clinics, I am responsible for organising the Bristol and Cardiff clinics held twice a year. The clinics are vital for giving families the opportunity to meet with Dr Ed Wraith and the chance to meet other MPS families in their area. For the Development Team we can use the time to find out how each family is doing and offer our support. The annual sapling planting at the Childhood Wood, Sherwood Pines also comes under my remit.

There are many aspects of my job which I enjoy but I find meeting the families on home visits, at the annual conference and at the regional clinics the most rewarding of all.



### Birmingham Clinic - Friday 6th July 2001

On Friday 6th July I attended the MPS clinic in Birmingham. This clinic was, as always, very busy and gave many families the opportunity to see Dr Ed Wraith. Our thanks goes to Dr Wraith for his continued support to the MPS clinics. We also send our best

wishes for the future to Beryl Holmes who has acted as Birmingham clinic co-ordinator for many years, but who has now recently retired.

*Antonia Crofts*



Top: Antonia with Gina Page's baby Matthew who is 12 weeks old.

Left: Shyam, Kim and Dwain at the Birmingham clinic

## FAMILY NEWS

### The Evans' Family Holiday to Hastings

Dear MPS Society,  
I am writing to you about the holiday we received through React to go to Hastings in Sussex.



Chris and Eleanor at Hastings

We set off from home at 4.00am and did not arrive until 10.30am. As we pulled up into the caravan site it was not what we expected, as the first thing that we saw was a kind of landfill site or dump on a hill looking over the caravan site. We were all very shocked by its presence.

We then arrived at our caravan to unpack all our stuff. Mum, Chris and Eleanor, then went to the supermarket while Laura and I went to go swimming.

As we stepped into the water I looked down and it wasn't the cleanest water I had ever seen nor the warmest so we decided to leave and have a look around the site.

Before we knew it we were halfway through the holiday and had seen many of the tourist attractions which were all very good, such as smugglers Adventure, The story of 1000 and Under Water World.

Then the night had come that we all had been waiting for, the showing of Cannon and Ball.

The whole family went to see the show with another family we met from Portsmouth, they had us in stitches for a full hour and a half.

They were the funniest people we had ever seen and made the holiday for us. We are very grateful for the holiday and look forward to seeing you at the Conference in September.

Lee Evans, Wrexham



Chris, Eleanor, Bobby Ball, Tommy Cannon, Lee and Laura



Laura, Eleanor, Dawn and Lee at the Haven Hastings Caravan Park

### My Special Sister



Eleanor at the MPS Conference

Eleanor was born on the 14th of August 1997, we only found out she was diagnosed with Morquio in November 1998 when she was 15 months old.

We were devastated when we were told, we could not believe it. We did not know what was going to happen to her, but no matter what happens to her she will always be Eleanor who is very special.

When we were waiting for the results we were really anxious, we were waiting for the leaflets and the yellow booklet. When we got

the yellow booklet, it took a long time for us to read it, but now we have read it all we know what is going to happen and we know what is going to happen and we feel much better.

We have been doing lots of fundraising for the MPS Society, so far we have raised just under £2,000.

We are proud of what we have done for MPS.

Laura Evans, Wrexham

## FAMILY NEWS

### How Life Has Changed

How life has changed. Long gone are the days when I used to get up around 4.00am to give Christopher, David's brother, a chance of possibly sleeping to a normal time. Let me explain.

David has Sanfilippo disease, for a number of parents out there, there will not be much need for explanation. David was diagnosed at the age of six, which by today's standard seems quite late, even ten years ago people were surprised that he had not been diagnosed sooner as he had all the typical Sanfilippo symptoms. Destructiveness, lack of understanding, little or no progress at school, toilet training (what's that?), the list goes on. Above all else, David did not seem to know that going to bed meant you were supposed to go to sleep!

My husband, Andy, was in the Navy, so spent precious little time at home, so I spent much of my time feeling frazzled. Christopher was born into a situation where most of what David did didn't seem to worry him. Being younger than David he just seemed to think it was normal. We were just very fortunate that Christopher didn't follow suit. Perhaps the constant telling off of David was enough to frighten him into not doing it.

This kind of behaviour seems a far cry from the boy that David now is. Now at nearly sixteen years of age, I think he must be making up for all the lost hours of sleep he missed between the age of two and ten. David has not been in school for eight months, his sleep pattern has changed completely. He missed the school bus so many times because he was asleep. I used to take him in at about two in the afternoon and most of the time that was because I woke him up. As I'm sure you can imagine I was very tired, it left me an hour and a half to go into town, or to the bank, shopping or on any other errand.

The problem with waking David before he was ready meant that he was falling asleep by six o'clock in the evening. We were not getting any quality time with David, it seemed unfair that school got all his waking time. After thinking long and hard, we decided that it would be better to take David out of school. I was already very aware how little time I had for myself and wondered whether or not I could cope being almost confined to the house. We talked to our nurse for learning

disability and decided to call a clinical review, to ask for help.

A clinical review was held just after Christmas and I asked about the possibility of getting a sitter in for a few hours a week, just to allow me time to shop etc., I also needed some time out for myself. It was agreed that we needed help and that the health authority would try to find a budget that they could use. Social Services could not help us because David has complex health needs, including tube feeding. The local authority has no insurance to cover tube feeding and classes it as an invasive procedure. It took several weeks, but the health authority managed to provide a temporary service which gives me two, three hour sessions a week to either do chores or just chill out however I see fit.



Eight months down the line, I know we did the right thing taking David out of school. He actually seems better in himself, now that he can wake when he pleases, which is usually around two thirty. He also tires very quickly, usually by eight o'clock he is falling asleep and if I take him out anywhere he is often asleep by six thirty. It seems strange how David has changed so much from the little demon that he was, and how much our lifestyle has had to change over the years. There have been days when I've felt like a total recluse. The knowledge that a nurse will be round to help in a few days has been enough to stop me going round the bend.

The health authority have to hold reviews every three months, to make sure that David still requires the same amount of care, as they have not managed to secure a budget for a permanent nurse. These are much less stressful than they used to be, perhaps that's because we've accepted the change in David now, life is much more settled. Has anyone else had similar experience?

Angela Seymour, Scunthorpe.

angie@seymour.freeserve.co.uk.

## FAMILY NEWS

### Lisa Nurse Celebrates her 30th Birthday

When Lisa was 28 years old, Harry & I decided after much heart searching to allow her to have a Gastrostomy.

We had been advised by doctors in the months leading up to the operation, that Lisa's swallowing was becoming more difficult for her and there was always the chance that she could choke.

The decision still wasn't an easy one, but our options were few. So we decided to take the advice offered to us and allow Lisa to have the operation. The fact of her condition as you know puts her more at risk than most when under anaesthetic, and our concerns were multiplied by that, and the risk factor of the operation. Also I had to know that I would be able to cope with cleaning the area and using the apparatus associated with the operation, as I haven't got the strongest of



medication and fluids and there is always the thought in the back of your mind, that her condition could deteriorate rapidly and then we would have been sorry if Lisa has not had her operation.

Lisa celebrated her 30th birthday on the 29th of July this year with a BBQ party on a beautiful summer's evening joined by family and friends and a good time was had by all. A great achievement in our daughters life, which we hope will continue for some time yet.

*Rosemary Nurse  
Lisa suffers from Sanfilippo Type A*



stomachs. I found this some what unsettling. At first it is scary, but with the help of the nursing staff soon mastered it. Now it is just part of Lisa and we don't take much notice of it.

When the day came for Lisa to have her operation she was in the Theatre for approximately an hour and a half, but our fears were all forgotten when we were told everything was fine and the operation was a success.

At the moment Lisa is still able to be fed by mouth, but the Gastrostomy is useful for

## FAMILY NEWS

### Kirstie's Success Story

Hello everyone,

I am Craig McLean's mum and my name is Karen. I would like to share with you another success story with the help of Ellie Gunnary.

In February of this year I took our daughter Kirstie to an arranged interview for a very good school here in Liverpool. Kirstie was so nervous, she had made up her own folder of awards certificates and other achieving medals she has gained through her present school and outside pursuits.

On entering St. Edwards college Kirstie was taken away with a group of other young hopefuls to complete a questionnaire. When she came back some fifteen minutes later, we were led to an interviewing room. Inside this room was a teacher, Kirstie, myself and a silent witness. I was put some distance away from Kirstie. She was sitting opposite the teacher conducting the interview. He asked Kirstie about her interests, how she achieved her certificates and medals, what subjects she did and did not like at school. The list was endless. I was not allowed to say anything or add anything to what Kirstie had said. We came out, Kirstie was like a jelly fish and I was just so proud as she had given complete answers and not just 'Yes' and 'No'.

We waited a couple of weeks and we got a letter of rejection through the door. Kirstie was like a deflated balloon as she read it. I immediately put in for an appeal. I could not think of any reason why Kirstie was not accepted. Then the penny dropped. I do not go to church as often as they would like me to.

I contacted the MPS Society and spoke to Ellie, who kindly wrote a letter of support to go with my appeal letter. (May I add that this was written while waiting at an airport) I sent everything off and waited and waited. Finally I got the appeal date. I went along answering imaginary questions in my head. I was there too early, but I waited and kept going over and over how I thought I would answer all the questions I thought would be put to me.

It was time to go in. The room was huge. There was a panel of four Independent School Governors, there was the Principal and the head of the school's Board of Governorss, a silent witness and little old me. Introductions were made and the reasons

why Kirstie was not accepted were given. To this day I cannot make head nor tail of what the Board of Governors were talking about. I froze, all these people in this room and just me. This was going to last 20 minutes, what I could I babble on about to make these people change their minds. Then my life line came, the spokesperson for the Board of Governors read out Ellie's letter (all I could think of was thank you Ellie, thank you God). This took ten minutes.

The only piece of information I gave was Kirstie has so much at home to hold her studies back, but nothing does. They were very keen to hear about Craig's condition and how we all coped as a family.

Two weeks passed after the appeal and yes Kirstie got her place at St. Edwards College.

I think Craig will look forward to going to see his big sister in forthcoming plays and choir practices.

I would now like to thank you again Ellie as you made my time at the appeal hearing very short. Most of all, these people took note of how you described Craig's condition and how hard it is for siblings to get full attention from parents. It is not easy but we do try.

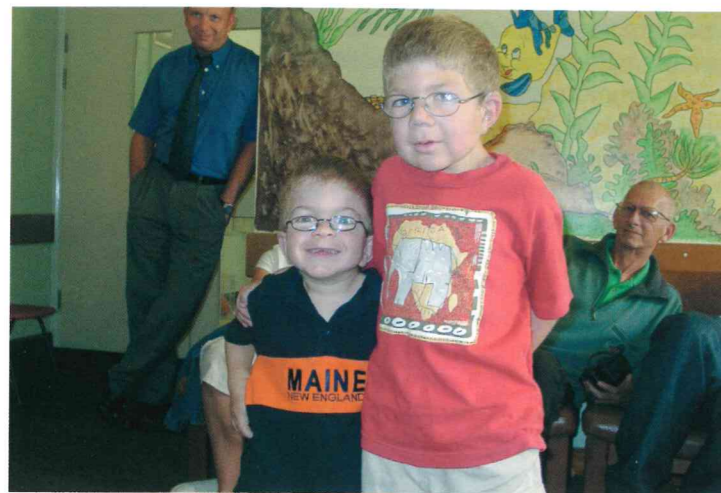
Thank you again.

*Karen McLean*



*Craig Mclean*

# BMT CLINIC



Bradley and Jacob - MPS I



Joseph - MPS I



Alex - MPS VI



Callum - MPS I

## New Families

Mr and Mrs Khan's son, Ali Anwar, has recently been diagnosed with an MPS Disease. Ali is nine months old. The family live in the Midlands.

Mr and Mrs Dacey's son Sam has recently been diagnosed with Hunter disease. Sam is six years old. The family live in the South of England.

Mr and Mrs Richardson's son Ben, has recently been diagnosed with Sanfilippo disease. Ben is nearly three years old. The family live in the Midlands.

## In Remembrance

We wish to extend our deepest sympathies to the family and friends of -  
Jason George who suffered from Sanfilippo Disease 16 November 1989 - 13 July 2001  
Peter Benbow who suffered from Sanfilippo Disease 11 December 1964 - 7 August 2001

# CHILDHOOD WOOD

## Update on the Childhood Wood



On a fine crisp September morning a team of MPS staff members headed up the M1 in Ellie's trusty car, laden down with various gardening implements, cleaning equipment and thermos flasks of hot water. We were on our way to the Childhood Wood in Sherwood Pines, Nottinghamshire to clean, prune, polish and generally spruce it up in preparation for the planting ceremony being held at the end of October.



One of the principal aspects of our work at the wood, was to check that all the trees had plaques and that all of the plaques were clean, in good condition and visible. It is important that families can visit the wood at any time and be able to easily identify their tree.

The wood itself is beautiful, surrounded by the towering Sherwood pines and is approached along the white footpath, which is clearly marked and well maintained so that it is suitable for wheelchairs. Three of the staff team were first time visitors to the wood, including Antonia who has recently taken over the running of the Childhood Wood project.

The facilities in Sherwood Pines are excellent and the park would make a great day out for

the family. There is children's adventure playground with ramps for wheelchair access up on to the mini assault course. The staff team felt that it was necessary in the name of research, to try out a few of the obstacles, however we soon decided that it was time to get back to work when we realised that none of us was fit or agile enough to swing across the monkey bars or climb up the totem pole into the tree house.



In addition to the playground, there were various puzzles and games to be discovered en route to the wood. One of my particular favourites was the collection of "woodland" musical instruments, although no-one else seemed too impressed with my "Cowbell and Oak Tree Xylophone concerto" obviously lacking any musical appreciation.

The visitors centre at the park also has a café and mountain bike hire.

All the staff enjoyed the day out but by 4.30pm, exhausted and coated in mud we decided that it was time to make our way home. I'm not entirely sure that Ellie enjoyed the long drive back as she was accompanied only by the radio and the sounds of the rest of the staff team snoring!

Clare Titcomb



# ANNUAL MPS WEEKEND CONFERENCE

## Friday Fun with Crackers the Clown



Volunteer responsibility does not traditionally begin until 8.30am on Saturday morning, however 6 intrepid helpers, volunteered their services between 7.00 and 9.00pm on the Friday night, to aid Crackers the Clown in his quest to entertain over 30 children armed with nothing more than a few balloons, some plastic plates and an S club 7 album.

I was not officially one of those intrepid volunteers, in fact I was supposed to be helping out at the reception desk, but the desk was quiet so I thought I'd investigate the shrieks of laughter emerging from the



All of the children were sporting rather fetching top hats made from balloons and the sight of them all festooned with this headgear provided plenty of amusement for Faye. Bethany seemed reluctant to ever take off her balloon hat.

Crackers got everyone involved in the fun, those who were able to, competed to become world champion plate spinner and those who were not formed a panel of judges.



Spencer Suite. When I got there everyone looked like they were having so much fun that I abandoned my post entirely to join in ...all in the name of research for the conference of course! (Besides which I already had my eye on a very fetching red and yellow balloon hat).

Crackers was a wonderful children's entertainer, by the time I arrived, the room was already strewn with assorted balloon animals. Amy had at least 3 mice in her possession and Zara had a whole flock of birds. Crackers had also made swords and Thomas and Christopher duelled for the next hour, I am still not sure who emerged victorious.



All the children appeared to love the entertainment, and the volunteers were rapidly becoming reacquainted with their inner child particularly Ben Lavery and Chris Register, who thoroughly deserve the title of Cracker's little helpers.

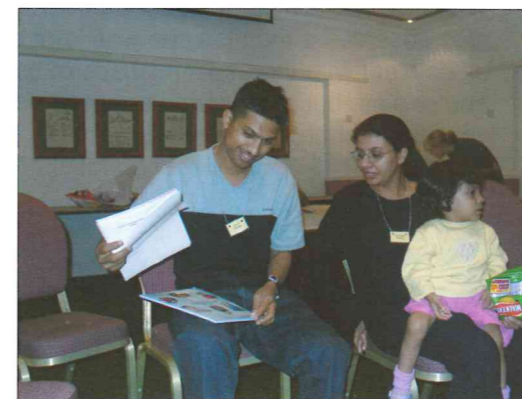
The entertainment ended with everyone dancing or waving balloons to the funky, funky beat of S club 7's "Don't stop moving".

Clare Titcomb



# ANNUAL MPS WEEKEND CONFERENCE

## Children's Entertainment



## Siblings' Workshop





## ANNUAL MPS WEEKEND CONFERENCE

### The Volunteers' View of the Weekend



Saturday morning, and we were off on time for the first time that I remember. This must be due to the MPS staff member helping each coach leader in that crucial 15 minutes before leaving. Off to Drayton Manor we go, a few of us had been there during the BMT conference and we knew what to expect.

On entering Drayton Manor Park Josh says "I want to go on that" pointing to the Apocalypse ride, an enormous vertical tower that is similar to a Bungee Jump, "not with me" says Brin, "I'll find someone else to take you on it": Much to my relief by the end of the day Josh had changed his mind, even for a brave 10 year old it now looked a bit scary: it was scary.



What fun we all had, once we were down the hill near the entrance it was all on the flat, and all the rides were so close together pushing wheelchairs and buggies was no effort at all.

Some of us caring for youngsters that were unable to appreciate the rides set out for the musical shows. Others made the most of the calm tranquil atmosphere in the zoo, the reptile house was particularly suitable for the little ones.

Hannah dragged Tim Anders on to the RNLI water ride three times, not in succession but often enough to make sure that they didn't dry out, she loved it. Every time I saw them they were running from one ride to the other to make the most of the time available: - they didn't even stop for lunch.



Having been told that the Video man would be with us to film the kids during the day, I thought lets have lunch a little early; kids had their Burgers and Chips and were eating quietly, and I'd just paid for mine; - mobile phone rings; - "we're the video team and we are on site, where are you?" - "In the Burger Bar": - "who wants a spare Burger and Chips?"



Find other coach leaders quickly: - a stroke of luck, they are all in the Burger Bar, Helen Patterson has been landed with some extra kids and is laden with Burgers and Chips, and some very hungry children waiting patiently and seated neatly (which is what you would expect from a teacher) for their lunch, Ben's phone is refusing to work, hence I'll have to phone all the volunteers on the trip

so that we can assemble as many of us as possible for the Video.

Wait till you see the MPS video they tell me that the opening scene will be the Carousel at Drayton Manor, it should be good, apart from filming a few of the kids on some of the smaller rides we gathered a carousel full of MPS kids, siblings and volunteers, and they filmed for ages.

I have to say the Carousel staff were brilliant, not to mention the other queuing customers who were so patient with us. We must have commandeered the ride for over half an hour. While we are talking of staff the First Aid lady also deserves a mention she was kept busy all day, not with the usual mishaps of bumps and strains, but a constant stream of volunteers changing nappies. Foot and Mouth Disease sends MPS office into a spin

Sunday is another story, did you know that the Foot and Mouth outbreak sent the MPS office into a gigantic spin. With only a few days (a week and a bit really) to the conference we discovered that as a result of the outbreak the planned visit to Wooburn Safari Park had been complicated by the fact that everyone, buggies and all would have to be disinfected.

Can you imagine the chaos of disinfecting 3 coaches of kids, buggies and wheelchairs, "no chance", we would have been there all day.

Plans had to be changed and quickly: - fortunately our resourceful Director came up with a cunning plan, having seen a sign on the Motorway exit for Gullivers Land: - "we will go to Gullivers Land in Milton Keynes" was the answer.

If ever a cloud had a silver lining this was it, having checked out Gullivers at the last minute (Friday afternoon on my way to the conference), I knew from the attitude of the staff that I met, that this would be a fantastic morning out for the kids.

It was suggested to me that if we arrived a little earlier than their normal opening time of 10:30 we would be welcomed. A very late departure from Northampton, and the coach drivers expressed a wish to take the M1, "OK; - so long as you don't go too fast".

## ANNUAL MPS WEEKEND CONFERENCE

We arrive at Gullivers at 9:50, (just a tad earlier than we hoped), as we were there so early our gang were virtually the only customers in the car park.

Off-loading buggies and wheelchairs, disembarking kids and volunteers took up the next 15 minutes: none of us were anticipating the brilliant welcome we were about to receive at Gullivers.

The surprise welcome show as we entered the park instantly placed really big smiles on every little (and big) face, those smiles stayed on until we left the park. The facilities for the younger members are the best I have seen,

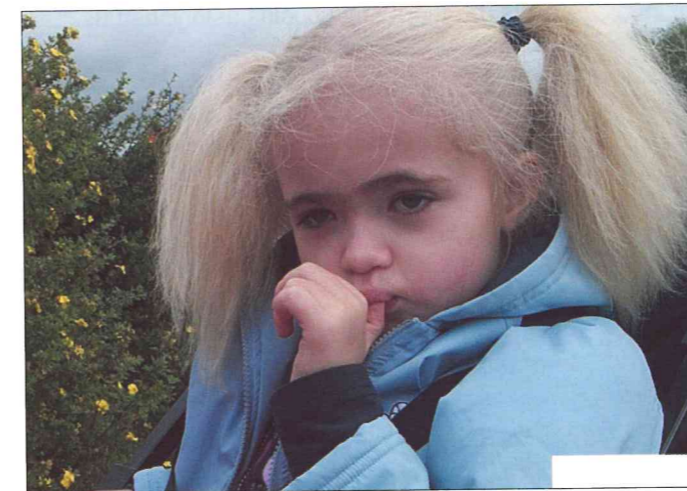
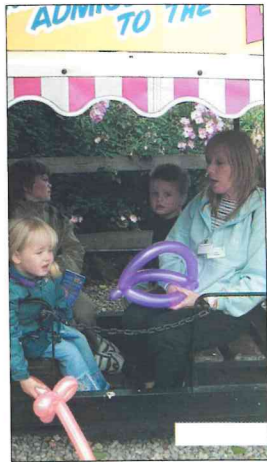
what added to the enjoyment of some of the rides was that you had to make it work yourself, no electricity just muscle power.

Parents: - If you live within travelling distance from Milton Keynes this is a "Must Do" for next year.

Are we going back to Gullivers: - Yes We Are

I asked some volunteers for their help in providing "snippets" from the weekend to include in this report; two that I received appear below and speak for themselves.

Brin



Samantha - MPS III



Louis - MPS II and his sister Pheobe



Killian and Peter

# ANNUAL MPS WEEKEND CONFERENCE

## MPS Apprentice Volunteer's Report

Pearl and I have just attended our first MPS Conference as volunteers.

"What a magnificent and rewarding experience!"

Being honest, we were both a little apprehensive before arriving at the Hilton in Northampton. However, we soon learnt that these were normal feelings for first-timers.



In the event, two glorious days were spent in the company of some extremely wonderful youngsters. There was Roma, her two brothers; Killian and Peter, Thomas, his brother Thomas and his cousin Alec, as well as Matthew and sister his Siobhan.

On Saturday, we tried to ensure that all in our

care had maximum possible fun at the Drayton Manor Theme Park. Certainly, many were fast asleep within minutes of settling onto the coach for the return journey!

For me, the highlight of the day was to see a broad smile of joy developing on Thomas' face on the vintage car ride: - it made everything so worthwhile.

MPS Office Thomas Birch pic.?? We boarded the coaches again on Sunday for another fantastic visit, this time to nearby "Gulliver's Land". Once more, the weather was kind and loads of fun was had.

Roma waited patiently for a turn on the "mini-digger" and then, with quiet determination, showed the boys how it's done! The level of maturity, devotion and love displayed by all sisters, brothers and cousins astonished us. This made our part so much simpler.

The professionalism and dedication in organising the whole weekend was outstanding. Please invite us again!

*Richard & Pearl Hirst*

from the old film goes, with a few word changes,



"OF ALL THE HOTELS IN ALL THE WORLD, WE WERE ALL GLAD THAT ADIKA CAME TO OURS".

*Jo Rikalans*

## MPS Apprentice Volunteer's Report

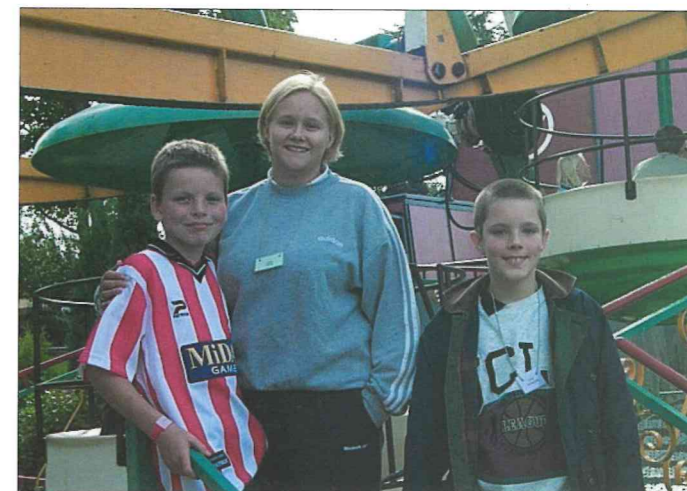
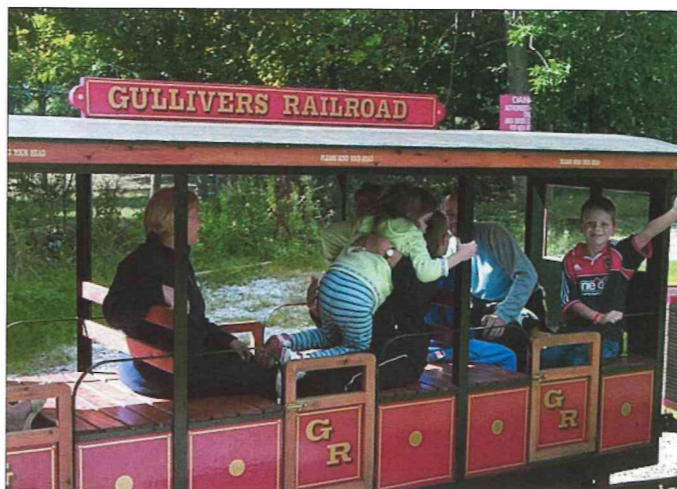
I had the pleasure of looking after Adika, her brother Hassan and sister Atiya. I find it hard to put down the right words for Adika as she was such a pleasure to have. She was such a happy girl and I've never known anybody young or old say please and thank you so much to everybody. I was lucky that she didn't like the fast rides. We teamed up with Sue Hodgetts and Bethany and if I could not go on a ride Adika would go on with Bethany and look after her.

On the coach she had everybody in stitches with the things she was saying, especially Eileen Smale and Max Howlett. She made friends with Azeem but as she kept saying, they were just good friends.

The only upset we had was on Saturday when she could not go bowling as she wasn't yet 11 years old. She said it was not fair and she is going to put a complaint in to Christine Lavery and I would not be surprised if she did. After I calmed her down she asked if she could go to the Reception and play the Piano, which we did and met Brin and Val. She had a drink and some crisps and as the saying

# ANNUAL MPS WEEKEND CONFERENCE

## Children's Outing to Gulliver's Land



# ANNUAL MPS WEEKEND CONFERENCE

## Children's Outing to Drayton Manor Park



Jo Moore & Alison Rowe



Faiza and her volunteer



Samantha with Chris Edwards



The Pirate Boat



Eleanor with Stephanie Anders



Samantha

# ANNUAL MPS WEEKEND CONFERENCE

## Volunteer's Moving and Handling Training



Sue Elder & Laura Patterson



Nigel Ratcliffe, Graham Ratcliffe and Ben Lavery



Gemma Talbot trying out a walking belt



Gemma Talbot, Clare Titcomb, Chris Regester and the Trainer



Chris Regester and Clare Titcomb

# ANNUAL MPS WEEKEND CONFERENCE

## Conference Programme



Jackie Edwards speaking at the Conference on a personal experience of pre-natal diagnosis



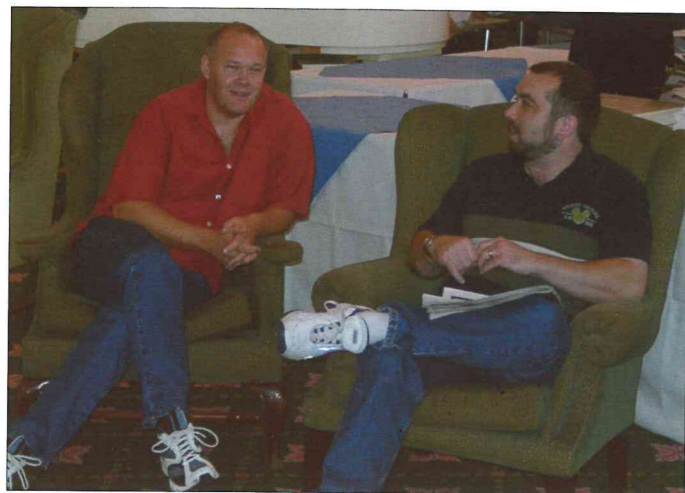
Speaker Ian Bruce talking with Barry & Barbara Wilson



Conference Hall



Claire Moraidi who spoke on her experiences as a sibling



Bob Devine and Graham Cawthorne



Gordon Rowe and Harry Nurse

# ANNUAL CONFERENCE

## Conference Programme



Completing the evaluation forms



Jean Rondeau from VML with Angela Ratcliffe



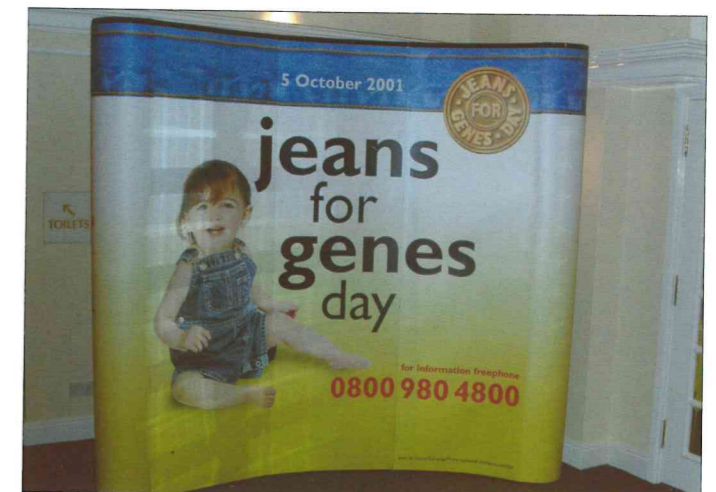
MPS Mini-Market



Alison Gunary with the Nuse family



Dawn Cawthorne with Lauren - MPS I



Jeans for Genes display

## ENZYME REPLACEMENT THERAPY

### ERT Party

On 8th January 2001 12 children from England, Scotland and Northern Ireland suffering from Mucopolysaccharidosis Type IHS and IS (Hurler Scheie and Scheie disease) started on the first world-wide Stage 3 Clinical Trial for Enzyme Replacement Therapy. This was the first Clinical Trial of its kind for an MPS disorder and it is hoped that this may lead to further therapies becoming available for the thousands of children suffering from Mucopolysaccharide and other lysosomal storage diseases.

It is hoped that this Clinical Trial, now complete, will build on the encouraging results of the initial US safety trial. BioMarin Genzyme LLD conducted this confirmatory phase II clinical trial of Aldurazyme enzyme replacement therapy for Mucopolysaccharidosis Type IHS and IS prior to seeking marketing approval from the Food and Drug Administration (FDA). Aldurazyme has been granted fast track status by the FDA. Regulatory filing in Europe will quickly follow the US filing.

The 12 patients on the trial in the UK ranged from 6 years to 22 years and came



from 11 families. During the 26-week trial each patient received a weekly infusion at the Willink Biochemical Genetics Unit at Royal Manchester Children's Hospital. The world-wide trial involved half the patients receiving Aldurazyme(tm) and the remaining patients receiving a placebo. At the conclusion of the 26-week on 31st July 2001 trial all patients continued their treatment on Aldurazyme(tm).

To celebrate completion of the trial and to recognise the contribution of all those taking part the MPS Society held an End of Trial party in the grounds of the Novotel, Worsley, Manchester on Wednesday 1st August 2001. It was attended by the participants and their families as well as the medical team from the unit and also MPS Society staff and a Jeans for Genes representative.

The weather was very kind to us and after the formalities were over many of the children cooled off in the pool.

*Angela Ratcliffe*

## ENZYME REPLACEMENT THERAPY

### ERT Party

On Wednesday 1st August I was very pleased to be able to represent the Trustees at the ERT End of Trial party held at the Novotel Hotel, Worsley. Along with the other members of the Trustees Board, I have followed with interest, the progress of the drug trial and have been delighted with the success of it.

It was good to meet the members of the ERT team from the Willink Unit, and to talk with some of the families involved and learn a little of how it has impacted on their lives.



Naturally it is wonderful to reach the stage of being able to test a potential treatment for one of the MPS diseases, but it certainly necessitates a major commitment by the young people involved and their families.

The venue for the party was perfect, a marquee in the lovely grounds of the hotel, alongside the swimming pool and children's play area. Angela had done a superb job and had organised everything, including the weather! (We must bear this in mind when organising future outdoor MPS events!). Who would have thought that at 10 pm on an English summer evening, we could still sit outside by the pool, we could easily imagine we were somewhere in the Mediterranean!



To say that a good time was had by all may be an old cliché, but it was certainly true of that evening. Everyone met up at 5pm (Christine and Ellie almost made it by 5pm, having spent the day filming at the Childhood Wood for the MPS video, followed by a frantic dash across the M42 in rushhour!). We then sat down for a delicious meal followed by presentations to the ERT patients and members of the Team at Willink; afterwards, the DJ did his best to run a disco, but on such a beautiful evening, the swimming pool proved far more tempting!



As always when MPS families get together for a party, there was a tremendous camaraderie, much laughter, reunions for old friends and new friendships made; I, for one, was very glad to be part of such a happy and memorable evening.

*Judith Evans, Trustee*

## RESEARCH UPDATE

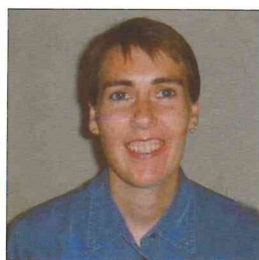
### Report to the MPS Society for Jeans for Genes Grant

Over the last four years, Jeans For Genes money from the MPS Society has funded Dr. Clare Beesley at the Institute of Child Health, London to screen for mutations in three MPS disorders -MPS I, MPS IIIA and MPS IIIB. Just over 100 families have been analysed and the disease-causing mutations have been found in 94 cases. Approximately 100 different mutations have been identified, 50 of which have not been reported before. During the fourth year, the project concentrated on investigating the precise effect of some novel mutations on enzyme function. When a mutation alters a single amino acid in the protein chain it is termed 'missense'. However, changing an amino acid can either be disease-causing or have no effect on the protein (termed a 'polymorphism'). We have many sequence changes that alter amino acids and we need to investigate if they are disease-causing or not. This is carried out by creating the sequence change in a normal copy of the gene and transferring it into cells

that can manufacture the enzyme. By measuring the enzyme activity in cells with the mutant protein, we can determine if it is functional or not. Studies have been carried out on eight novel missense mutations found in MPS I patients. Seven of the eight mutations did not produce any functional enzyme and can be classified as disease-causing. However, one missense mutation did produce enzyme activity at levels similar to normal. This mutation is therefore not disease-causing and is referred to as a 'polymorphism'. Three missense mutations found in MPS IIIB patients were also investigated and all were shown to produce no functional enzyme. This work highlights the need to investigate missense mutations further and fully characterising the genotypes of MPS patients will be a prerequisite when selecting patients for the most appropriate form of treatment in the future.

Clare Beesley

### An Introduction to Clare Beesley



I was born in Formby, near Liverpool on 28th October 1968. I attended Holy Family High School in Thornton from 1980-1987 where I obtained 10 O'levels and 4 A'levels.

Between 1987 and 1990 I did a BSc degree in Biochemistry at the University of Sheffield. Between 1990 and 1994 I was a Research Assistant at the University of Lancaster and obtained a PhD on the Molecular Genetics of Cyanobacteria.

I moved down to London in 1994 to work at Imperial School of Medicine at the National Heart & Lung Institute, Harefield Hospital. I helped to set up a project to identify

mutations in the acid a-glucosidase gene from patients with glycogen storage disease type II (a lysosomal disorder). The project was funded by an independent charity The Hal Brodhurst Trust.

I moved to the Institute of Child Health in 1997 to work on the identification and expression of mutations in 3 MPS disorders, Sanfilippo type A, Sanfilippo type B and MPS I.

I live in Watford and I am a keen hockey player, I am an active member of Chess Valley Hockey Club in Rickmansworth.

### Jeans for Genes Research Grant Applications

The deadline for receiving research applications is 14 November 2001. In the first instance please contact the Society's Director, Christine Lavery to discuss your

research needs. Only research directly related to Mucopolysaccharide and Related Lysosomal Storage Diseases can be considered.

## INTERNATIONAL CONFERENCES

### 7th International Symposium on Mucopolysaccharide and Related Diseases

20 - 23 June 2002 - Professional Delegates

21 - 23 June 2002 - Family Delegates

Paris Porte de Sevres

France

The MPS Society and Vainacre Les Maladies (VML) are jointly organising this major conference to bring together those affected by MPS and other Lysosomal Storage Diseases, their families and carers, alongside doctors, scientists and representatives of the biotech industry from around the world, in the field of Lysosomal Storage Diseases.

This long weekend follows the success of previous International Symposiums organised by MPS Societies in other countries but with several unique features. To allow flexibility and a greater choice of presentations, two conferences will run in parallel on Friday and Saturday. One conference will concentrate on the Mucopolysaccharide diseases whilst the other the related Lysosomal Storage Diseases including Fabry Disease.

#### What about the Children?

The MPS Society in the UK is working with our dedicated team of trained volunteers to raise the funds to sponsor one volunteer per UK family attending the International Symposium.

A very exciting children's activity programme is planned for Saturday and Sunday. Hopefully the weather will be glorious, the activities different but the volunteers, standard of childcare and attention to issues of health and safety the same as if we were in the UK. For overseas families attending the International Symposium the British MPS Society is happy to provide a trained volunteer. However the Volunteers costs can't be met by our Society. A creche for very young children and those too unwell to take part in the children's activity programme will be available.

#### How will we get to Paris?

The Society is currently looking at group travel by air from different airports around the UK, coach travel and rail eurostar. For those who can combine the International Symposium with a holiday the MPS Society

has information on Canvas Holidays, Eurocamp etc. and may also be able to help with ideas on caravan or campsites.

#### How much will it cost MPS families?

The registration fee for families attending the International Symposium including meals is £200 per adult plus £100 per night for the bedroom in the Sofitel. Children's costs will be kept to an absolute minimum. The Society is raising funds to enable it to apply its 50% subsidy to these costs and is willing to help with applications to local charities for families needing additional financial help. It should also be remembered that the Family Fund will usually help with a holiday.

#### What do we do now?

If you have already completed a form expressing an interest in attending this international meeting you need do nothing more. Over the coming weeks the MPS office will call you to discuss your plans and needs further. If you have not to date expressed an interest either ring the MPS Office, e-mail us or drop us a line.

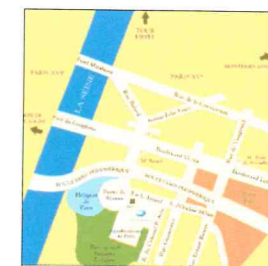
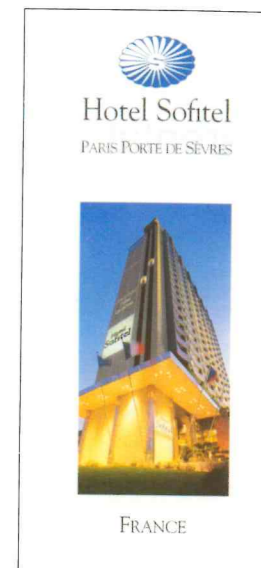
If there is sufficient demand the Society is also prepared to look at a group departing on Wednesday 19 June and spending one day (2 nights) at Disney Land Paris.

If you are a family reading this from outside the UK we are pleased to provide advice and share our knowledge of the Symposium Programmes, Children's activities and hotel. Just call or e-mail us.

See you in Paris for the Event of the Year!

p.s. Don't tell your teenagers that whilst the gala dinner is on we're planning a visit to the Champs Elysee and Eiffel Tower for them on Saturday night.

p.p.s. Did you know its Festival night in Paris on the Friday evening, we are planning a family night out.



## INFORMATION EXCHANGE

### Action on Entitlement

Thank you to everyone who has supported this campaign. The latest news is very positive and encouraging. On 11 July 2001 the Government withdrew the Code of Practice which had raised concern. In this code the Government changed the wording in statements from specify to set out and advised that LEA's may quantify the provision to be provided for a child as necessary. Such wording gave parents very few rights in ensuring their children were receiving

adequate support at school.

As soon as there is more news from the Action on Entitlement campaign it will be printed in the newsletter and those MPS members who have signed up to supporting this campaign will hear directly from me.

*Ellie Gunary*  
Assistant Director

### Parental Leave

The Development Team has been receiving regular enquiries about parental leave.

Parental leave entitlement is to be extended from thirteen weeks to eighteen weeks for parents of disabled children later this year.

Until this time, the present parental leave arrangements are as follows:

- \* Each parent of a child born or adopted after 15th December 1999 can have thirteen weeks off work to care for a child during the first five years of his or her life. Parents of disabled children are able to use their leave over a longer period, up until the child's eighteenth birthday.
- \* The leave is unpaid
- \* The employee remains employed while on parental leave; some terms, such as contractual notice and redundancy terms still apply
- \* At the end of the parental leave an employee is guaranteed the right to return to the same job as before, or, if that is not practicable, a similar job which has the same

or better status, terms and conditions as the old job; where the leave taken is for a period of four weeks or less, the employee is entitled to go back to the same job.

\* The leave is applicable to parents across the whole of the UK

The consultation period for extending the leave entitlement ended in August 2001 and new information will be produced on how the practical arrangements for this additional leave will be implemented.

The new right to parental leave applies to employees who have completed one year's service with their employer. Parents are able to start taking parental leave when the child is born or placed for adoption or as soon as they have completed one year's service with their employer, whichever is later.

Further information on parental leave can be sought from the Parental Leave Enquiry Line Tel: (020) 7215 5986. Website: [www.dti.gov.uk](http://www.dti.gov.uk)

### VALUING PEOPLE: a New Strategy for Learning Disability for the 21st Century

A new White paper sets out the Government's commitment to improving the life chances of people with learning disabilities. It is generally recognised that most people with learning disabilities who receive services have a poor quality of life. Compared with people with no learning disabilities, people with learning disabilities are less healthy, have more limited sexual relationships and live lives that are more routine and less stimulating.

One of the key reasons why services remain poor for so many people with learning

disabilities is that traditionally they have little power and control over their lives.

The White paper gives details of plans from the Government for improving the lives of all people with learning disabilities

The plan is based on four main beliefs.

- \* Having Legal and Civil Rights: "people with learning disabilities are citizens too"
- \* Supporting Independence: "All this can be done by believing that people with learning disabilities can move on and be independent"
- \* Having More Choice; "People with learning

## INFORMATION EXCHANGE

disabilities have been saying for a long time that they can speak up for themselves"  
\* Being Included: "People with learning disabilities can live just as good a life"

Key points of the plan are

- \* To enable more people to get direct payments to buy in support services.
- \* To ensure that disabled children get good early support, particularly in the areas of education and health care.
- \* To ensure parents of children with disabilities are well supported by a key worker
- \* A new service called Connexions is proposed through which a personal adviser can help young people with choices of further education and ensure people with higher support needs get expert help working closely with adult services.
- \* Independent advocacy to be more widely available
- \* For plans to be written for each person with a learning disability with their wishes and ideas at the centre of this to include all areas of life including health, social care, education, work, leisure, housing and communication.
- \* More support to family carers of people with learning disabilities who live at home
- \* Improved access to information with the setting up of a new National Learning

Disability Information Centre and telephone advice line

- \* Equal access to health care services with improved training to all medical staff on supporting people with learning disabilities.
- \* Improved choices on where to live
- \* A change to traditional day centres with a greater emphasis on people with learning disabilities being integrated into local community services
- \* More employment opportunities for people with learning disabilities

The MPS Society will keep all its members informed about the progress of this white paper, as further information becomes available.

A full copy of "Valuing People: a new strategy for learning disability for the 21st Century" is available free of charge from DOH publications PO Box 777 London SE1 6HX

Fax: 01623 724 524  
Email: [doh@prolog.uk.com](mailto:doh@prolog.uk.com)

It is available on CD-ROM, cassette and an easy to read booklet.

### Managing Personal Assistants

Rough Guide to Managing Personal Assistants which is written and edited by Sian Vasey, a member of the Muscle Power committee.

Produced in a very easy to read format, including some clever cartoons, the book is in chapters. Covering such topics as recruiting, (Chapter 1- Desperately Seeking) relationships with your PA's, (Chapter 3- We Can Work it Out) guarding against dishonest PA's (Chapter 5- The Sting) and holidays, (Chapter 6- We're All Going on a Summer Holiday). Finishing with Chapter 8- Reason's to be Cheerful!

Each chapter is based around the

contributor's experiences and thoughts, and finishes with a check list of quick tips. Aimed at those new in this 'game' I felt it is still relevant to us 'old timers' as I found it good for comparisons, and that- "Oh, I've always felt that, too" factor.

This is a useful publication, which puts the whole employer/employee situation in perspective, in a straight forward and, sometimes, humorous way.

Priced £7 + £1.50 postage (cheques payable to BCODP) 250 Kennington Lane London SE11 5RD  
Tel: 020 7587 1663  
Email: [ncil@ncil.org.uk](mailto:ncil@ncil.org.uk)

## INFORMATION EXCHANGE

### Winter is Nearly Here.....

It is well documented that a major contributory factor to the annual winter crisis that the NHS and social care services suffer is due to people not being able to afford to heat their homes adequately. Those most at risk are older people and those with disabilities, two groups of people who are often dependent on benefits for income.

There is help available through the home energy efficiency scheme (Hees). This is run by government but in practice the day-to-day work is carried out under contract, being administered by private company the Energy Action Grants Agency (EAGA). This scheme provides grants for work to be carried out to ensure that a home's heating system is as efficient as possible. Hees has been massively revamped in the last year, and more people may now qualify for grants. Also people who had grants under the old system may qualify for extended grants under the new one - for example, they could now increase loft insulation to an eight inch thickness, whereas before this was set at a lower limit. The new Hees can also provide new heating controls, draughtproofing, cavity wall insulation, pipe insulation and, in some cases, installation of central heating or upgrades to existing heating systems. The precise items that can be grant aided depend on a combination of income and the actual heating efficiency needs of a property. The scheme is open to tenants and owner-occupiers alike.

Devolution has led to there being four Hees schemes operating in England, Northern Ireland, Scotland and Wales. There are differences in how each of the schemes operates.

For example in Scotland, the Warm Deal for

Scotland enables anyone over 60 to get a grant of up to £125, and for anyone of any age on a disability or income based benefit - including tax credits - to get a grant of up to £500.

In England, the criteria for people over 60 are tighter, as they have to be on an income based benefit but may get up to £2,000 or up to £1,000 if they are on a disability-related benefit but not also a means tested benefit. Householders under 60 can also get up to £1,000 if they are on an income-based benefit or disability-based benefit.

In Wales, the maximum grant for anyone of any age on an income-based or disability-related benefit is £2,700 with a grant of up to £175 for anyone over 60.

In Northern Ireland, the Domestic Energy Efficiency Scheme maximum is £2,000, but households in the private sector on a disability-related benefit can also get a lower grant of £750.

Because of these differences it is best to get details of the specific scheme operating in your area. You can do this by visiting Eaga's website - [www.eaga.co.uk](http://www.eaga.co.uk) - which not only sets out the different schemes and offers down-loadable leaflets, but also carries information on local authority and other grant schemes to supplement the Hees. Alternatively you can ring Eaga directly England - 0800 952 0600, Scotland - 0800 0720150, Wales - 0800 316 2815, Northern Ireland - 0800 181 667.

If you have any questions which cannot be answered by Eaga please contact the MPS Society's Development Team.

### New Helpline for SEN Advice

New Helpline for SEN Advice IPSEA, the Independent Panel for Special Education Advice, has set up a help line in Northern Ireland to provide help and advice on Education and Library Boards' legal duties towards children with special educational needs. They seek to guide parents and guardians through the assessment procedure, helping them make written contributions to their child's assessment and

to understand professional reports.

Contact Geraldine McAvoy, Tel. (028) 9070 4606. IPSEA also runs an appeals helpline, designed to help parents and guardians challenge decisions made by Education and Library Boards.

The Appeal Helpline is open Wednesday to Friday, Tel. (028) 90705654.

## INFORMATION EXCHANGE

### Equipment Boosts

The Government has pledged £10m in ring-fenced money for communication aids for disabled children.

The money will be provided by the Department for Education and Employment over two years from 2002. Youngsters will be able to keep the equipment once they leave education and look for work.

Meanwhile, guidance on the provision of community equipment including communication aids has been published by the Department of Health. It is backed by £105m over the next three years and will also help those using equipment like bath rails and hoists.

The announcements, made in March, were

welcomed by Scope, which has been calling for more provision of communication aids since it published its report *Speak for Yourself* last year. This revealed a "postcode lottery" in the provision of communication aids. Scope chief executive Richard Brewster said the move was "tremendous news."

The Disabled Living Centres Council also welcomed the guidance, which emphasises user involvement in planning services.

Director Maggie Winchcombe said: "This is a significant initiative for everyone who relies on disability equipment in the course of daily life." But she warned that many Disabled Living Centres, which advise on equipment, had faced financial problems. She hoped new money would help support them.

### Genetic Testing - Insurance Companies to use Genetic Information

From the Newsletter of the Trades Union Disability Alliance comes this disturbing report. "The Government has announced that insurance companies are to be allowed to use genetic information to identify people with hereditary diseases."

The controversial decision will allow insurance companies to penalise against those suffering from inheritable diseases that science can screen for, by raising the premiums of those individuals or denying cover altogether. By approving the plans Britain will become the first country to sanction the use of genetic technology for these commercial ends.

The first disease to be approved for screening will be Huntington's Chorea, an inherited disease causing progressive dementia and behavioural changes. Other diseases likely to be screened for in the future will include hereditary breast cancer, Alzheimer's and Duchenne's muscular dystrophy. Further proposals include allowing access to individuals' genetic information to help in deciding who to hire.

The plans have sparked a fierce ethical debate amid fears of marginalisation of those most vulnerable in our society, leaving them unable to get mortgages or obtain long-term financial security for themselves, partners and children.

### Advice for Unpaid Carers

The government's website at [www.ukonline.gov.uk](http://www.ukonline.gov.uk) now includes a section for unpaid carers.

Called *Looking After Someone*, in the site's Life Episode section, it provides access to information on services offered by central government, statutory service providers and key organisations in the voluntary sector.

It is divided into three segments; taking a caring role (for those new to caring); help in looking after someone (for those already in a

caring role); and when your role ends.

Information is provided on subjects such as financial support, breaks and respite care, alternative caring options and emergency care.

e-Envoy Andrew Pinder said: "This is the latest in a series of exciting new initiatives we are undertaking to harness the benefits of new technology in delivering services to people."



## INFORMATION EXCHANGE

### Home Responsibilities Protection (HRP) for Parents and Carers

In order to qualify for your full basic Retirement Pension, you need a certain number of qualifying years (years you have paid enough National Insurance contributions) over your working life. Years you have been getting National Insurance credits through the benefits system can be taken into account as long as you have actually paid some National Insurance in the past.

Gaps in your National Insurance record, that is, years you have not paid enough National Insurance nor been credited by the benefits system, can mean you get less than the full basic Retirement Pension when you reach retirement age.

You can have a gap of up to five years over your working life without affecting your Retirement Pension. However, parents and carers can further reduce the number of qualifying years they need to get the full Retirement Pension because of something called Home Responsibilities Protection (HRP). Home Responsibilities Protection can also help you to qualify for Widowed Parent's Allowance and Bereavement Allowance.

#### What do you need to do to get Home Responsibilities Protection?

A parent who has been the main person receiving child benefit does not need to claim Home Responsibilities Protection. It will be given to her/him automatically when child benefit stops or her/his youngest child reaches sixteen years (whichever is earlier).

A person who has been getting Income Support as a carer, will be given Home Responsibilities Protection automatically at the end of the tax year.

Other people with caring responsibilities who are worried about gaps in their National Insurance record may still qualify for Home Responsibilities Protection. However, they will need to make a claim.

Home Responsibilities Protection was introduced in 1978 and you can claim for any tax year from then. However, new rules expected in 2002 will restrict the number of years you can have backdated -so check it out now!

For an information sheet on Home Responsibilities Protection, call the Helpline or write in to the City Road office.

### Farbrazyme & Replagal Approved in European Union

On August 3, 2001 both Genzyme Corp. and Transkaryotic Therapies, Inc. received marketing authorization from the European Commission. This means that both drugs have been approved in Europe for long-term enzyme replacement therapy in patients with Fabry disease. Both therapies also received joint status as orphan drugs giving them 10 years of protection against competition from similar products. With this done now both

companies can begin obtaining pricing and reimbursement approval. Soon EU physicians will be able to prescribe these two therapies to Fabry disease sufferers. French authorities have allowed this since late last year but now it is official for all fifteen European Union countries. This is great news. Finally a real treatment rather than simply addressing problems resulting from this disease.

### Training & Employment Opportunities for Disabled People in Theatre

Birds of Paradise Theatre Company are a professional theatre company providing training and employment opportunities for people with physical disabilities who wish to work in theatre, film or television. From January 2001 onwards, the company will be running a series of training programmes in Performance and Technical Skills for individuals who would like to pursue their interest in these areas. Training and support will also be given to individuals who seek to pursue their interest in going on to further education colleges. Tutors for the training

programmes will include Theatre Directors and practitioners from a variety of Scotland's theatre companies, and a number of Scotland's venues will be used for on-site training facilities. If you have a physical disability and think you might be interested in participating in this training please contact Birds of Paradise Theatre Company, 333 Woodlands Road Glasgow G3 6NG  
Tel: 0141 3391155

E-mail: [all@birdsofparadisetheatre.co.uk](mailto:all@birdsofparadisetheatre.co.uk)  
Website: [www.birdsofparadisetheatre.co.uk](http://www.birdsofparadisetheatre.co.uk)

## INFORMATION EXCHANGE

### Reading List

"Dealing with Separation and Divorce" is a pack produced by the Lord Chancellor's Department aimed at helping children through this difficult time. It provides guidance and advice for parents and carers on how best to support children, a booklet for young children and a booklet for young people. Copies are available free from FREEPOST, PO Box 2001, Burgess Hill RH15 8BR. It is also available on the web at: [www.lcd.gov.uk](http://www.lcd.gov.uk)

"Use of Oxygen on Holiday" is an information sheet produced by Holiday Care. It gives vital information on obtaining oxygen supplies in the UK, hire of equipment in the UK, travelling abroad and also a list of useful contacts. The cost of the sheet is 50p payable in stamps to Holiday Care, 2nd Floor Imperial Buildings, Victoria Road, Horley RH6 7PZ Tel. (01293) 774535 Website: [www.holidaycare.org.uk](http://www.holidaycare.org.uk)

"Directory of Child Development Services 2001" has been compiled by the Royal College of Paediatrics and Child Health.

Copies are priced at £6.00 including p&p from the Royal College of Paediatrics and Child Health, 50 Hallam Street, London W1W 6DE Tel. (020) 73075600 e-mail: [enquiries@rcpch.ac.uk](mailto:enquiries@rcpch.ac.uk)

"Muddles, Puddles and Sunshine" is an activity book for children to help them deal with the death of someone close. It is priced at £4.99 plus £1.00 p&p from Winston's Wish, The Clara Burgess Centre, Gloucestershire Royal Hospital, Great Western Road, Gloucester GL1 3NN Tel. (01452) 394377 e-mail: [admin@winstonswish.org.uk](mailto:admin@winstonswish.org.uk)

"The Gabbitas Guide to Schools for Special Needs" is a comprehensive guide to schools and also to special education. It is priced at £14.99 plus £3.00 p&p from Gabbitas Educational Consultants Ltd, Carrington House, 126-130 Regent Street, London W1B 5EE Tel. (020) 7734 0161 e-mail: [admin@gabbitas.co.uk](mailto:admin@gabbitas.co.uk) Website: [www.gabbitas.co.uk](http://www.gabbitas.co.uk)

### Social Care Council - NISCC

The NISCC will be established from October 1st 2001. The Council aims to increase the protection of those who use Social Care Services, their carers and the public, by ensuring staff and employers meet agreed standards of conduct, practice and training. The Council will have two key responsibilities:

To register and regulate the Social Care workforce and draw up Codes of Practice for Social Care Workers and their employers

To ensure that staff are properly trained and qualified to do their jobs.

The functions of the Central Council for Education and Training in Social Work (CCETSW) will be transferred to the new

Council, as will the functions of the Training Organisation for Personal Social Services (TOPSS). The ultimate aim of the Council is to raise the quality of the services provided and put in place better safeguards for the protection of people being cared for.

The NISCC will be relevant to you whether you are a user of Social Care Services, a carer, a social care worker, a provider or purchaser of Social Care Services.

Contact: Ms Pat McAuley, Chair, NISCC Communications Sub Group, C3.2, Castle Buildings, Stormont Estate, Belfast BT4 3SJ Tel. (028) 9262 7552


Website: <http://www.dhsspsni.gov>

## INFORMATION EXCHANGE

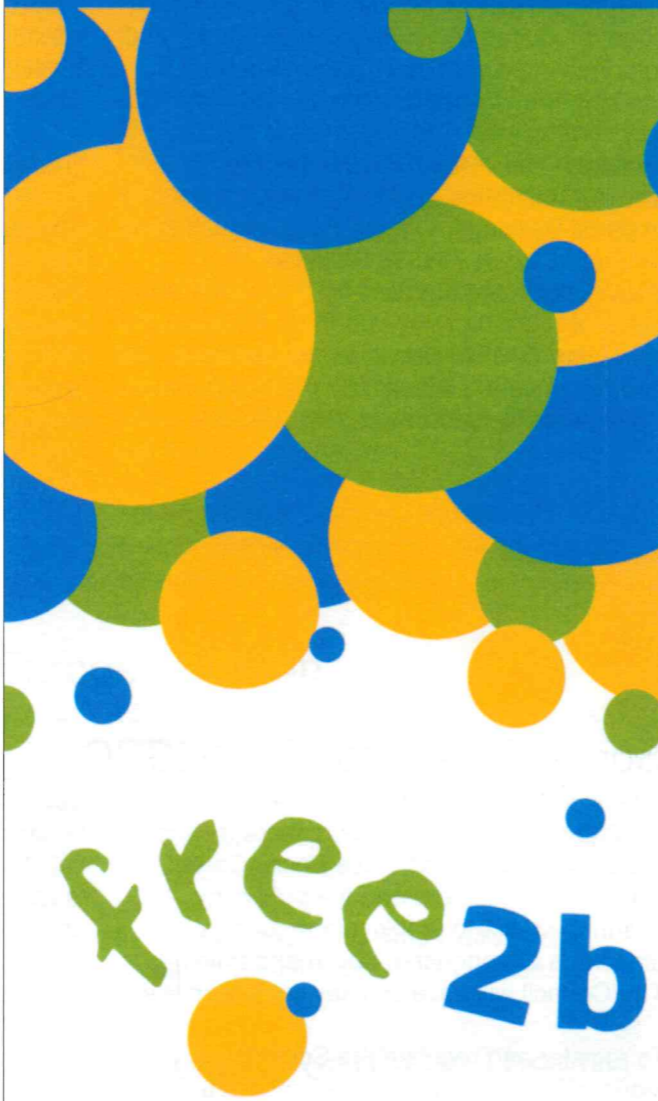


**How to get help in looking after someone**  
A Carers guide to a carers assessment

*If you look after a relative, disabled child or friend and caring has a major impact in your life then a carer's assessment could help you.*

**Young disabled people challenging attitudes**



**free2b**

22 October 2001 Ocean, Hackney, London

## FUNDRASING

### A New Fundraising Idea

I just want to give everyone a good fundraising idea which I did last December in my office.

In remembrance 'Sarah Bear' I got the idea from The Blind Society, but adjusted it to fit my needs. In December the Blind Society came into our office with a gorgeous big teddy bear. They gave me a card with 40 names on and everyone paid a pound per name and tried to guess the name of the bear. As soon as the card was completely sold, you broke the seal at the back and revealed the name.

Later that week the Society came back and picked up their £40.00. Such little effort! Soon after I went into my local toy shop, just by chance, and saw the cutest pair of singing teddy bears. I couldn't refuse them, so bought them for £20.00. Vic groaned and said not more bears. Realising then, we have too

many bears, I said, I'll take them into work and raffle them. That's exactly what I did. I sat them in the reception area and sold £100.00 of raffle tickets. We drew the raffle just before Christmas. Hence I donation. made £100.00 for the Society.

So if anyone works in an office or place where there's plenty of people to help generate a raffle or name guessing, go out and buy a really great teddy! In fact you don't even have to work, take teddy into your local school and raffle him for 50p a ticket.

Our Sarah who died in 1994 at the age of 19 and suffered from Maroteaux Lamy, was a great teddy bear collector, her room is still full of all her bears. So think of Sarah and go out there and get bear and raise 'loads of money'.

*Sue Lowry*



Sent in by Julia Hope-Gill who sent in money for the 10K run, photo of Andy Hardy and his Morris Men taken at the Welsh Lacrosse

## FUNDRAISING

### The British 10K Open Road Race - July 2001



Congratulations and a big thank you to everyone who took part in the inaugural British 10K Open Road Race to raise funds for the MPS Society. The event was a great success with 20,000 people running the route through the heart of London, taking in some of the city's best sights such as Big Ben, the Houses of Parliament, the London Eye and St Paul's Cathedral. Seventeen people ran on behalf of MPS, Chris Jones and Alison Britton share their experiences:

It was an early Sunday morning and after months of hard training the time had come. We arrived outside the Hard Rock Cafe at about 9.00am.



Kevin Grace, Nigel, Graham, Andy, and Alastair Ratcliffe

It was very busy, I was now very anxious as I looked around me and saw all the people warming up for the run. I even managed to see a few famous people before I went over to the start line. While I was standing at the line I chattered with Alison Britton from the MPS Society for about 15 minutes, she recognised me as I had a t-shirt which said 'Running for MPS' on it.



Chris Jones

The race was started and we were off I saw the spectators which were supporting me but I just concentrated on the race ahead. Now I would like to say thank you to them, Dawn, Lee, Laura, Eleanor, Kieran, and Franchesca but most of all to my sister in law Teresa and her husband Joe whom kindly let us stay at their house for a few days before the race.

There was a great atmosphere amongst all the people who were running, people were coming up to me and asking me what MPS was about, all the people were friendly.

The best feeling I had was coming up towards Enbankment Station where all my supporters were standing with a big banner saying 'Go Chris for MPS' cheering me on.



Eleanor supporting her dad

When I had finished the race I went over and collected my medal although I was tired I felt great knowing I had done something to help MPS.

*Chris Jones*

When's the next one? I had an absolutely brilliant day right from trying to find the start line through to eating my MacDonalds meal afterwards! The friendliness and atmosphere before and during the race was incredible.

At the beginning I was a little nervous, firstly because I had never attended a large race like it and more importantly because I had not run 10K before. (Unfortunately I didn't quite find the time in the weeks building up to the race to fit in a trial run). Luckily for me there were plenty of things to keep us all going such as London's great attractions, people playing music along different parts of the route and generally a great sense of togetherness, especially when we were running through the tunnel and everyone started shouting. I've never enjoyed running so much, and I was raising money for MPS too!

When I crossed the finish line it was a very strange but amazing feeling. It was as if a big wave rushed over me. I also felt a bit dizzy, probably shock! It's as if when your body is ready to give up your mind takes over and you keep going. I felt a real sense of achievement. My time was 58mins 57secs which I was pleased with as someone had offered to double their sponsor money if I did it under an hour!

My knees ached for a week afterwards and walking was an effort but I would still definitely do it again, maybe try a longer distance. ...and definitely train for it!

*Alison Britton*



## FUNDRAISING & DONATIONS

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

Contract Flooring Association – Dinner Dance Raffle  
Kingswood and Hanham Bowls Club – Charity Weekend  
Scottish Widows – Dress Down Day  
Pauline and Josey – Collection at their Wedding in Masonic Hall  
Claire Garthwaite – Wintershall Tennis Tournament  
Carol Lilestand – Bits and Pieces Sale  
Fardon Sports & Social Club – Ticket sales at Casino night  
Lynn Longhorn – Lunch Party  
Julia Hope-Gill – 10K Open Road Race  
Chris Jones – 10K Open Road Race  
P Claridge – Sponsored Bike Ride  
D Foster – Sponsored Bike Ride  
Diane & friends at the Sandringham – Sponsored Bike Ride  
Marina & Dave – Car Boot Sales  
Karl Preece – 10K Open Road Race  
Alison Britton – 10K Open Road Race  
Marie and Ray Thomas/Chris & Dawn Jones – Car Boot Sale  
Michelle Langton – Car Boot Sale  
Deggy's Fishing Tackle Shop/Pirelli Angling Section – Junior Fishing Match  
Jeanette Hogg – 10K Open Road Race  
Daniel McGinn – Aquathlon Event  
Helen Sydenham – Sale of Bike  
Andy Flaig – 10K Road Race  
Alison Britton - 10K Road Race

Thank you also to Alison & Doug Gunary, Pam & Ken Ballard, Lucy Lavery and Sue Lowry for their help with the Mini Market at the MPS Conference, which raised over £1000.00

### COLLECTION BOX

Mills Newsagents  
C.M.L Jones and Partner – Swindon  
Oversley Mill Service Station – Alcester  
Newark Advertiser

### STAMPS/FOREIGN COINS

Garthwaite Family  
Ernest Butler

### The Society is grateful to the following who made donations

The Sobell Foundation  
Judy Holroyd – Bristol  
M J Gleeson Group PLC  
James and Janette Reid – Argyll  
Clifford Chance  
Wilkinson Hardware Stores – Nottinghamshire  
Laxdale Ltd – Stirling  
Catholic Women's League  
Tomkins  
Stanley Leisure PLC  
Lions Club – Wigtonshire  
Mrs Cockman  
Catriona Ogilvie  
G McKee – London  
P Hammond – West Yorks  
Mrs K M Skene – West Sussex  
J V Freeman – Buckinghamshire  
Martina McParland – Northern Ireland  
Fyffes  
Mrs Sue Stuart – Ely  
M Haigh – Huddersfield  
Mr & Mrs Hall – Bristol  
Mrs W Turner – Stockton  
Yvonne & Kevin Puddy – Somerset  
Wessex Water  
Willow Farm Trust  
Kirkhill Golf club  
MJE Borrett – Portsmouth  
Dave & Beth Frederick – Monmouth  
Doreen – Alcester  
Mrs S Peach – Rugby  
Christine Incedon – Weybride  
The Sir Jules Thorn Charitable Trust  
Duni Limited  
Brenda Weston – Greenfield  
Friends of Alice Ida Haslam – Bolton  
Pauline Summerton-Lladudno  
Sandy Sandison – Saltford  
Mr & Mrs Burkenshaw  
Mr & Mrs Lacey  
T. Lewis – Isle of Whithorn  
New College – Oxford  
Mr & Mrs Garthwaite – Jersey  
Jaguar Cars – Birmingham  
Community Relations – London  
The Christopher Laing Foundation  
Mrs C Brown – Croxley Green  
Mr. D. Brooks-Daw – Taunton

## MANAGEMENT COMMITTEE

### NEWSLETTER DEADLINES

#### WINTER

17 December 2001

#### SPRING

31 March 2002

#### SUMMER

30 June 2002

#### AUTUMN

30 September 2002

**Chairman** Barry Wilson

**Vice-Chair** Steve Butler  
Judy Holroyd

**Treasurer** Judith Evans

**Members** Angela Brown  
Rob Devine  
Vince Hayward  
Sue Peach  
Wilma Robins  
Adam Turner

**Staff** Christine Lavery Director  
Ellie Gunary Assistant Director  
Angela Ratcliffe Development Officer - Research  
Antonia Crofts Development Officer - Support & Advocacy  
Alex Roberts Project & Information Officer  
Gina Page Finance Officer  
Alison Britton Assistant Development Officer

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 below.

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.

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OUT OF HOURS HELPLINE: 07712 653258

email: [mps@mpssociety.co.uk](mailto:mps@mpssociety.co.uk)  
Home Page: [www.mpssociety.co.uk](http://www.mpssociety.co.uk)



Sold in aid of  
The Society for  
Mucopolysaccharide  
Diseases  
Registered Charity: 287034

# Christmas Cards 2001

Mucopolysaccharide and Related Diseases cause progressive physical and mental disability usually resulting in death in childhood.

The Society for Mucopolysaccharide Diseases is the only National Registered Charity, providing information, advocacy, and practical help to families of affected children and young adults. At present there is no cure and the monies raised from the sale of these cards will help towards supporting nearly 1000 affected families in the UK

## ORDER FORM 2001

Card Code	Size (mm)	Description	Pack Size	Cost per Pack	Quantity Ordered	Value
A052/01	100x100	Polar Bear Knitt	10	£2.25		£
A037/01	100x100	Moon & Mistletoe	10	£2.25		£
A032/01	100x100	Christmas Cherub	10	£2.25		£
9/3059	230x90	Flight into Egypt	5	£1.30		£
00/3925	111x111	Santa & hole in Sack	10	£2.50		£
K0431	120x120	Robins in Postbox	10	£2.75		£
69338	180x140	Santa's Animals	5	£1.60		£
M2/1064	100x152	Angels Watch	10	£2.75		£

## PAYMENT DETAILS

Postage and Packing	All Card Sizes Approximate	Postage and Packing	£
1-4 Packs £1.00		Donation	£
5-10 Packs £1.75		Total	£
11 Packs or more £3.00			

1. Please fill in your name, address and phone number and indicate your card selection on the order form.
2. All payments should accompany orders. Please make Cheques/P.O. payable to "The MPS Society", or pay by Credit Card.

## BLOCK CAPITALS PLEASE

Contact Name:

Address:

Postcode:

Tel No.:

## CREDIT CARD DETAILS

Cards Value ..... Card No: - - - - / - - - - / - - - - / - - - -

Post & Packing ..... Cardholder Name .....

Donation ..... Card Type ..... Visa etc

Total Amount Due ..... Expiry Date - - / - -

PLEASE RETURN YOUR ORDER FORM TO:

The MPS Society, 46 Woodside Road, Amersham, BUCKS, HP6 6AJ

TELEPHONE: 01494 434156 FAX: 01494 434252

# Christmas Cards 2007



A052/01 : Polar Bear Knitting  
Size: 100mm x 100mm



A037/01 : Moon & Mistletoe  
Size: 100mm x 100mm



A032/01 : Christmas Cherub  
Size: 100mm x 100mm



G/3059 : Flight into Egypt  
Size: 230mm x 90mm



M2/1064 : Angels Watch  
Size: 100mm x 152mm



CO/3925 : Santa has a Hole in his Sack  
Size: 111mm x 111mm



IC0431 : Robins in a Postbox  
Size: 120mm x 120mm



69338 : Santa's Animals  
Size: 180mm x 140mm