

# Newsletter



The Society for  
Mucopolysaccharide  
Diseases

National Registered Charity No.287034

Winter 2000

Jeans for Genes Day



Pages 8  
Jeans for Genes 2001

Pages 16 - 19  
A Personal Experience  
of Caring (Part 2)

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MPS Christmas Parties

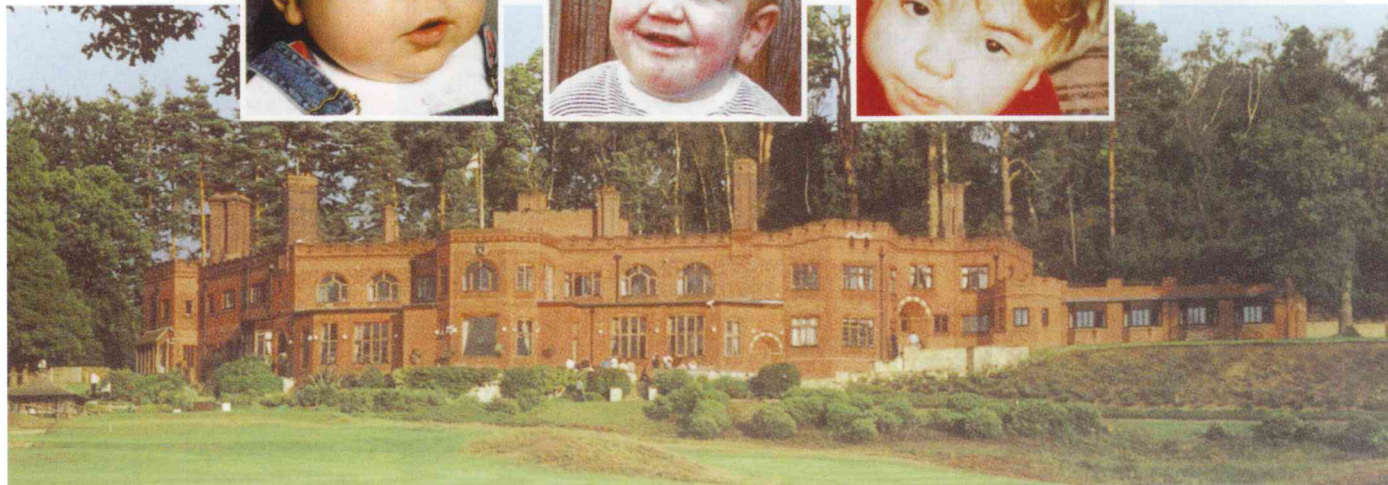
Page 37  
Prizewinners - Grand  
Draw 2000

**£2.5 MILLION  
RAISED TO DATE**



# CHARITY GOLF DAY

ST GEORGES HILL  
SUPPORTING THE SOCIETY FOR  
MUCOPOLYSACCHARIDE DISEASES



**FRIDAY 10 NOVEMBER 2000**

The fifth Charity golf day held by the St Georges Hill Golf Club, Weybridge Surrey raised in excess of **£35,000** towards the work of the MPS Society.

Over 120 members of this prestigious golf club came together for a very enjoyable day of golf that included special fundraisers 'Beat the pro's at the third', 'Birdie ball' and 'Hole in one'. There were special prizes for nearest the pin at the 11th and 14th and longest drive at the 15th. Following a very late lunch, a charity auction was held.

Thank you to Heather Gordon, grandmother to Thomas and Louis who have Hunter disease for nominating the Society to be the beneficiary of this wonderful charity day, to Jeremy Lowe for organising the event and the St Georges Hill Golf Club and its members for all their support. It isn't often the Society starts its financial year with such a boost.



**'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
- To bring about more **public awareness of MPS**
- To promote and support **research into MPS**

## 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 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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## A WELCOME FROM THE CHAIRMAN

Since taking over the Chair of the Society from Wilma Robins at the first Management Committee meeting following the Annual General Meeting, I have been busy ensuring I am fully informed of all aspects of the Society's business and activities. I have met with all the staff at the MPS office and along with my wife, Claire, and son, Ben, hosted the North West MPS Christmas Party.

We are not saying 'goodbye' to Wilma, who fortunately is a member of the Management Committee for 2000 / 2001. Nevertheless I should like to thank Wilma for her service to the MPS Society. As was acknowledged at the MPS Annual Conference Wilma, and her husband, Peter, have devoted nearly two decades to the MPS Society. Wilma has served on the Management Committee since its inception, bringing to it not just a personal experience of MPS, for her only child, Gethin died from Hurler disease at the age of 5 years in 1984, but a wealth of professional advice based on her career in the Civil Service. Wilma has been and continues to be a prolific fundraiser for the Society, particularly where Christmas cards are concerned. She always has a concern for the MPS children and adults of today, and is an enthusiastic supporter of the Jeans for Genes Appeal.

I would also like to thank Jean Leonard who served as a co-opted member of the Management Committee throughout the year.

I should like to welcome two new faces to the Trustees' Management Committee: Judith Evans and Bernie Drayne. Judith is married to Graham and her only daughter, Joanne, is 14 years old and has Morquio disease. Judith and her family live in Scotland. Bernie, who has recently completed a degree in social policy, is married to Kevin. They have two sons, Kilian and Peter, and a daughter, Roma. Roma is 8 years old and has Morquio disease. Bernie and her family live in Northern Ireland.

Now a little about my family. Claire and I have a son Ben, who is seven years old. In 1999 our treasured baby daughter, Alice, died from Mucopolysaccharidosis type II, aged 19 months. Living in Lancashire I work for the Calderstones NHS Trust as Clinical Team Leader in forensic learning disabilities. This background will be a considerable asset in steering the Society forward in areas of support and advocacy and ensuring an equitable service to MPS children and adults, their families and carers throughout Great Britain and Northern Ireland.

The longstanding 'slogan' of the MPS Society is Care Today Hope Tomorrow. Never has there been a time when that saying was more poignant. On 8 January 2001 at the Royal Manchester Children's Hospital the first of 10 children and young adults suffering from Hurler Scheie and Scheie disease started weekly infusions to introduce the missing enzyme, Enzyme Replacement Therapy. As a Society we share in the anticipation that this six month clinical trial will be the start of renewed hope for those not just affected by Hurler Scheie and Scheie but all the MPS and related diseases. At the same time we recognise that this ray of optimism comes too late for the families of many hundreds of children and adults who have died from MPS, as well as those whose loved ones are still battling MPS but perhaps born too soon.

Mark Beniston

Deadline for the Spring Newsletter is 31 March 2001

## NEWS FROM THE MANAGEMENT COMMITTEE

The Trustees met in both October and November 2000 owing to the considerable amount of business to get through.

### ELECTION OF OFFICERS

Mark Beniston was elected Chairman. Angela Brown and Steve Butler Vice Chairs and Vince Hayward, Treasurer. Wilma Robins, the outgoing Chairman was thanked for all her hard work over the last three years.

### HEALTH AND SAFETY

In addition to her current responsibilities for the MPS database, research and therapies, Trustees welcomed the proposal that Angela Ratcliffe become the Society's Health and Safety Officer and Personnel Officer. The Chairman recognised that it is a priority of the Management Committee to ensure all aspects of Health and Safety are adhered to.

### POLICIES

The Trustees agreed a Reserves policy as required under charity law and reaffirmed all previously agreed policies. These included Conduct policies, Financial Controls policies, Data Protection, Confidentiality and Equal Opportunities policies. Mindful of the stakeholder pension legislation to become law on 1 April 2001 it was agreed to introduce a group pension plan for employees. It was agreed that staff will undertake training on the Human Rights Act.

### SUPPORT & ADVOCACY

Data collected throughout the previous 12 months clearly demonstrated a significant increase in the depth and number of advocacy requests from those suffering from MPS, their families and carers. It was agreed that another development officer should be recruited to undertake this area of work.

### REGIONAL EVENTS

Trustees confirmed their commitment to regional events organised by the MPS Society and wished to be involved in the programme of Christmas parties.

### NEWSLETTER

The Trustees warmly received the new layout including the colour pages of the newsletter. It was agreed that the inclusion of colour pages in future issues should continue.

### MPS BUDGET 2000/2001

The Director presented the 2000/2001 budget to Trustees. An expenditure budget of £65,000 was agreed. This includes grants to research from the restricted income of the Jeans for Genes Appeal 1999 and 2000.

### RESEARCH AND TREATMENT

Trustees were appraised of the recent developments in Enzyme Replacement Therapies and welcome these new developments.

## NEWS FROM THE MPS OFFICE

The Millennium year seems to have just flown by. At this time we particularly remember the families who have lost their MPS children during the year. In the week leading up to Christmas there was a real rollercoaster of emotions as we supported two bereaved families and at the same time met with the ten children and young adults looking forward to taking part in the Enzyme Replacement Therapy Clinical Trials in Manchester in the New Year. Throughout this time we received hundreds of Christmas cards many with special messages. These were so appreciated at this time. From myself, Ellie, Angela, Hannah, Kate, Sue, Gina and Alex we say thank you. We know and understand that for many of you Christmas and the coming year will bring mixed blessings.

On 8th January 2001 the first of fifteen British sufferers of Hurler Scheie and Scheie disease received Enzyme Replacement Therapy as a phase III Clinical Trial. Over the next six months these young people will each receive 26 weekly infusions. No one knows who is receiving the ERT product 'Aldurazyme' and who is receiving a placebo.

Through this double blind trial we hope at the end of the 26 weeks that those on the 'Aldurazyme' will see significant clinical improvement in their Hurler Scheie or Scheie disease. This will then allow Biomarin Genzyme to licence the product resulting in its being available to similarly affected MPS I children and adults.

### FIRST TWO MPS I HS AND MPS I PATIENTS RECEIVE ERT



William and mum Rachel



Deborah with Dr Wraith and ERT Nurses Jean Mercer and Jane Roberts

Over the coming weeks another thirteen patients will start the trial and a number of them have promised to keep diaries and share their progress through the newsletter.

Christine Lavery



## NEWS FROM THE MPS OFFICE

### MPS ANNUAL CONFERENCE 2001

HILTON HOTEL  
NORTHAMPTON

14th - 16th SEPTEMBER 2001

SEE THE DETAILS AND BOOKING FORM WITH THIS NEWSLETTER

**BOOK EARLY TO AVOID DISAPPOINTMENT**

#### Dr Martin Bax DM FRCP

Martin Bax retired as senior lecturer in child health at the end of December 2000, after a long and distinguished career as a paediatrician.

Those of you whose children were suffering from Sanfilippo disease in the mid eighties through to the early nineties, may remember Martin for the interest he took in our children's sleep disturbance and feeding difficulties.

I am sure those of you who knew Dr Bax would like to join the MPS Society in sending him our very best wishes for a happy and restful retirement.

*Christine Lavery*

#### NEW LONDON HOSPICE OPENS

Richard House is London's first Children's Hospice and it is now accepting referrals to both the day centre and for the home care team.

The service is available for children aged 0 - 19 years with a life limiting condition and there is no charge.

A child will be offered a maximum of 2 sessions a week for a 10 week period at the day centre.

The home care will be allocated on a needs basis.

If you are interested in accessing this service, please telephone a member of the development team.

#### 21 YEARS OF BONE MARROW TRANSPLANT FOR MUCOPOLYSACCHARIDE DISEASES

HILTON HOTEL  
NORTHAMPTON

FRIDAY 8th JUNE 2001

This conference is open to professionals and MPS families and is supported by the Jeans for Genes appeal

## NEWS FROM THE MPS OFFICE

### JEANS FOR GENES

A little over 3 months ago, on 6 October we were all wearing our jeans to raise money for Jeans for Genes 2000.

As you will have seen from the front cover the money raised to date is £2.5 million and rising.

On behalf of the five charities benefiting from the funds raised through Jeans for Genes we would like to thank you for your support.

#### Now Jeans for Genes 2001 Needs Your Help!

It's simple to do and great fun to join in. Let's get the whole nation wearing their jeans on

### FRIDAY 5 OCTOBER 2001

Jeans for Genes is now in its sixth year on a nationwide scale. This appeal, where everyone across the UK is simply asked to throw aside conventional dress rules for the day and don their jeans to work or to school to raise money for children and adults suffering from Mucopolysaccharide and other genetic diseases, goes from strength to strength!

All we ask is that over the coming months you harness the support of local schools and businesses to support Jeans for Genes.

Visit the Jeans for genes website at: [www.jeansforgenes.com](http://www.jeansforgenes.com)



#### MPS BALLOON UPDATE

In the last newsletter we excitedly announced the senders and finders of the balloons that travelled the furthest in the Great MPS Balloon Race held on 10 September, 2000 at our Weekend National MPS Conference. Life is full of surprises. In late October we received another balloon tag along with the burst balloon. Could we believe it, the balloon had reached the Ukraine! Congratulations to Alexei Riznitsky from the Poltavka region of the Ukraine who found this balloon in a field, and to Steve Butler who released it. Their prizes are on the way to them.



## FAMILY NEWS

### NEW FAMILIES

There have been eight new families seeking the support of the MPS Society since the last Newsletter. This includes the new families below who have given written permission for their details to be published.

Michelle and Karl Preece's daughter Samantha has recently been diagnosed with Sanfilippo disease. Samantha is four years old. The family live in the Midlands.

Adrian and Andrea Tresidder's son Logan has recently been diagnosed with Hunter disease. Logan is five years old. The family live in Cornwall.

### "Dear Santa"

I'm forwarding to you my wish list  
For Christmas is looming near  
My request this year is more complex  
(Thanks for the dust buster last year)  
So I'll try to make it quite clear.

What I want, Santa dear, is a Carer  
To help me look after my child (MPS III)  
They must have specific qualities  
For my child is often quite wild.

A person with two eyes would probably do  
Though one with four eyes would be best  
The two eyes could be alert and on duty  
While the other two eyes have a rest.

A nose that can sniff out a BM  
(Bowel motion for the uninitiated)  
From over 100 metres away  
Is an absolute necessity  
For my child does BM's all day.

They must have the patience of a saint  
And the stamina of Susie O'Neill  
And know every nursery rhyme ever written  
Since the invention of the wheel.

They must love to be constantly showered  
With kisses, bath water and food  
And love cleaning messes and spills all day  
For my child is one messy dude!

Some rodeo skills would be handy  
Like the one lassoing a calf  
That way when my child escapes up the street  
We can get him back extra fast.

I do hope you grant me this wish  
Santa dear  
For I've been a good girl this year  
I'll even share my new Carer around  
With families far and near.

You ask how I possibly ever could  
Achieve this generous feat?  
I'd send them to England for cloning -  
Just like Dolly the sheep.

Then MPS families all over the world  
Would awake Christmas morn with glee  
To find the Carer of their dreams  
Sitting gift wrapped, under their tree.

*By Mrs GIM Exhausted*

*Taken from 'The Linking Hand Across Australia'*

## FAMILY NEWS

### We received this lovely letter and photos from Dallas Rickett - mum to Charlotte and Thomas (14 year old twins)

Both Thomas and Charlotte are doing extremely well. I'm sure that you will be surprised to hear that neither Thomas nor Charlotte are taking any medication at all now. In fact we found that the Melleril was having an adverse effect, and since stopping this, and the anticonvulsant drugs, both are doing a lot better at school. Charlotte has been awarded another class award, and, to our delight, so has Thomas. (see bottom of page)

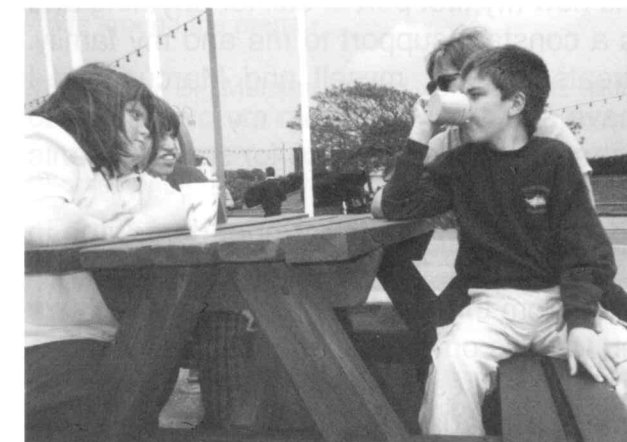
They both still enjoy their really long walks, and Thomas' mobility has actually improved. Charlotte is calmer now, but with it is a more mature, focused young lady who enjoys activities such as swimming, bowling, going to the pictures, dare I say pub meals. At school she is the top of her group, and the work station she was using is all but redundant, as perseverance has meant that she can sit at a normal table with the rest of her group for lessons.

Thomas, what can one say, other than that he's turning into a proper young man, flirting with the girls at school and enjoying all the activities like Charlotte.

There are still no signs of ENT problems, bowel problems or feeding. In fact they would eat you out of house and home.

We are a very determined family as you know, and have always gone with what we feel is right for Thomas and Charlotte, and thankfully the medical profession have always supported our views and wishes.

We feel that all of this, together with the hard work we all put into Thomas and Charlotte, has paid dividends and if other families feel their world has ended, then go with your heart and own gut instincts. I wish you could all see how much Thomas and Charlotte are enjoying life at the moment.



*Thomas enjoying a drink on a school outing to Chapel St Leonards - June 2000*



*Charlotte far left and Thomas far right - with school at Chapel St Leonards - May 2000*



## FAMILY NEWS

### Homeopathy for Victoria

Firstly to introduce my family, my name is Jacquie, my husband is Iain. We have a daughter, Victoria, who is now four and a half years old and a son Marcus who will be two in December. Victoria suffers from Hurlers Syndrome. Two years ago, just after I had Marcus, Victoria came down with a chest infection so we had a trip to the doctors where, as usual, antibiotics were prescribed. We duly followed the course but on this occasion they did not clear up the infection. We returned to the doctors who then prescribed a course of 'adult' antibiotics as he felt that Victoria had become immune to the child strength. I was quite concerned with this and made the decision that Victoria would have no more antibiotics unless it was absolutely necessary. They were destroying her. She seemed to be getting infections more frequently, her skin was very dull and she was always tired. I discussed it with Iain and we decided that the time had come to look outside traditional methods of medicine, so we contacted a Homeopath who had been recommended by a good friend of mine.

We made an appointment and went off to meet Karin. I was a little nervous at first as I had never used any complementary medicine before and here I was about to try it out on our precious little girl. We had a very long consultation with Karin where we went through all of Victoria's medical history, her character, her likes and dislikes, sleeping patterns and so on. Basically we viewed Victoria from all angles.

With Homeopathy I learnt that you treat the whole person and not just the immediate symptoms. Diagnosis is based on their constitution, temperament and their general behaviour at the time of the illness. I very quickly learnt to take on board every detail of Victoria's behaviour so that I could report back to Karin as much information as I could.

Everytime that Victoria came down with something in the early days I would ponder

going to the doctor before going to Karin. I gradually began to build up faith and trust in my Homeopath and the remedies provided as the results I saw were amazing. An ear infection that flared up in the morning had been cleared by teatime! A chest infection disappeared in just a few days!

Victoria responded to the remedies extremely well and we began to see an all round improvement in her general well being. She was taking daily 'Tissue Salts' which is a combination of remedies based on a constitutional type and works to maintain and repair cell growth.

Victoria now has very few ear and chest infections, she has a healthy appetite and sleeps from 7 .00pm to 5.30am. It is now very rare for us to have to attend to Victoria in the night. If we do it is generally just for a drink of water. Her complexion is radiant and she is full of energy; she no longer sleeps in the day and plays very hard for most of it.

We have never looked back on the day we made the decision to try 'something else'. There are still some occasions where conventional medicine is required for minor problems but the important thing is that Victoria has had no antibiotics in those two years for everyday problems only when needing surgery!

Karin is now my first port of call for anything and she is a constant support to me and my family. She treats Victoria, myself and Marcus and I now have some confidence in my own ability to make the right remedy choice for some ailments

I decided to write this after a brief paragraph in the last newsletter. Iain and I felt that we have benefited from this course of action so much we wanted to pass on our experiences. Now our whole family uses homeopathy for everyday ailments like headaches, mouth ulcers and the like.

*Jacquie & Iain Hendry*

## FAMILY NEWS

### Chris gets going!!

Chris Isaac passed his driving test the first time last July, while studying at Lord Mayor Treloar college. He purchased a Renault Kangoo, which has been partly adapted so that he can drive it. Many adjustments have had to be made but as you can see he is now in the driving seat!

Chris can drive independently now but there are still more adjustments to be made to the car to enable him to be independent when he gets to his destination. He is now saving up for adaptations including a hydraulic lift. Being able to drive has given him a new interest in life and more independence.

Chris is 20 years old and has Morquio Syndrome.



*Chris driving his brand new car!*

*If you are reaching the age when you can learn to drive and would like some more information - please contact the MPS Office - we would be very happy to help you!*

### A letter from Faye Longley - Age 10 telling us about **PRINCESS ANNE'S VISIT**

I have been riding at the Cotswold RDA for 2 years. I go every Monday lunchtime and I ride Chips.

A few weeks ago I was asked to ride when Princess Anne came to officially open our new outdoor arena. My Dad was asked to go along as well because his company had raised some money for the RDA.

When the day came I was very excited. My Mum had bought me new jodhpurs and riding boots. We arrived early to get ready and have a practice ride around the arena.

Finally the Big Moment arrived. One by one all the riders rode into the outdoor arena. As I got close, they introduced me and my pony, Chips. I felt excited and nervous at the same time but everything went fine, and all of the horses and ponies behaved.

Afterwards, the Princess came round and presented everyone who is to do with the RDA with a rosette. Next, she cut the cake and everyone had a piece with a drink.

At last, after a long day, the Princess had to leave. On her way out, she stopped to speak to my dad and me. She said that she thought that Chips was too big for me and perhaps Dad would buy me a pony.

I had a fantastic but tiring day and a lot of news to tell Mum when I got home. A few days later, my picture was printed in the local newspaper!





## FAMILY NEWS



### Hoping for a Dream to Come True!

Kerry Parker, aged 9 years and her brother Alfie who is 7 years old are hoping to visit Disneyland next year, for a holiday for themselves and their family. They love Disney toys and videos and it would be a dream come true for them to have the opportunity of this special trip. We wish them luck!

The Parker family live in the South West of England.

### The Special Rainbow

Emma Slater, aged 8 years suffers from MPS I Hurler syndrome (for which she had a bone marrow transplant in 1994), she also has a severe curve of the spine (scoliosis) for which she has had several operations, and there are a lot more to come. Emma also wears a spinal brace to protect the metal rods either side of her spine. Despite all of this Emma never lets it get her down and will have a go at anything she possibly can. Emma has been a member of Rainbows for a couple of years and has been on various trips and attended various events and has even carried the Rainbow shield on the St George's Day parade.

### Badgers Award

Emma joined Badgers (junior section of St John's) in January 2000 and has attended regularly, gaining badges for basic safety and basic first aid. At a recent St John's ambulance presentation evening, Emma was presented with an award for the best newcomer and most determined, as she does everything to the best of her ability, despite her disability.

Emma's parents, Emily and John, write to say: "We are so proud of Emma, we thought we would share it with the Society".

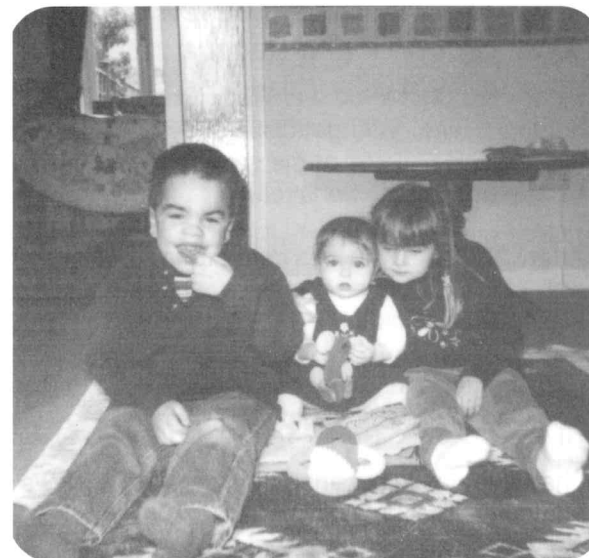
*Well done Emma, you are an inspiration to us all. Since writing this article Emma has joined the Brownies - watch this space!!*

### Matthew, Rebecca and Charlotte Home

Jacqui Home, mum to Matthew, Rebecca and Charlotte has written to say how much they missed meeting everyone at the conference this year but they will try to come again next year, when Charlotte is that much older!

Matthew is very well at the moment. He had T-tubes put in at the end of September and seems much happier now that he can hear again and has started singing and speaking single words again. He can now say Charlotte!. He is very lively and loves playing football in the garden. He also loves his school and visits to Naomi House.

Here is a photo of the children at home.



*These are lovely photos and articles. Thank you for sending them to us.  
Please keep your family articles coming into the office - everyone loves to read them!*

## OVERSEAS

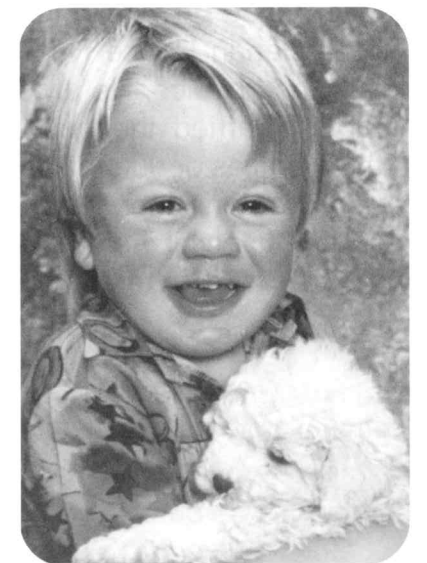
### TJ'S STORY

*We recently received this story about TJ, written by his mum Lynn Pienaar from South Africa. It is a very touching insight into this special little Hunter boys short life. We felt sure that you would like to read it. The second and final part of this story will be in the next Newsletter (Spring 2001), please contact the office if you would like to receive a copy before the Spring)*

My husband and I were looking forward to the birth of our new baby. Our son was born on the 23rd of February 1990 and we named him Tristan Jonathan. Shortly after his birth, he was placed in the Intensive Care Unit for 60 days. On 18th day he had a heart operation which was called a 'PDA'. The nurses in the hospital got to know him so well because of the long period he had to stay there, they affectionately called him 'TJ'.

TJ was one and a half when he got pneumonia. He stayed in hospital for 14 days, during which time it was discovered that his liver and spleen were enlarged.

At that stage, my husband and I got divorced. Numerous tests were done and finally I was told that TJ suffered from a Mucopolysaccharide Disease. They had made the diagnosis but didn't know enough about the disease to give me any more information. It was suggested that I contact Dr. Ed Wraith at the Willink Unit in Manchester England. I took TJ to Manchester where Dr. Ed Wraith diagnosed him as a Hunter boy which is a Mucopolysaccharide disease. He showed me leaflets and explained to the best of his ability what was happening, but at that stage, it was impossible to imagine that my little boy, so healthy and active, would follow the pattern set out in the literature.



When back in South Africa, I had come to terms with being told that TJ would get ill and he would die. I was working full days and my neighbour (Connie) was looking after TJ. After his 2nd Birthday we had his tonsils and adenoids removed. There were problems with the anaesthetic and it took about 5 hours before he came around. After 2 weeks in hospital we took him home and TJ was smiling and laughing again. I soon realised that TJ was a very special child. He always went to bed with a smile and, in the morning, woke up with a smile. He was a very busy little boy. He tried to do everything at the same time. HE would not go to bed until I did - and even then he would not sleep. He couldn't sit still - There were some days when by 10am Connie and I felt that we had done all we possibly could, taken him to visit my sister at 6am, took him to the park, had a bath, had breakfast, been shopping - you name it and still he was full of energy. However we felt, it was practically impossible to feel cross or annoyed with TJ who made us laugh, looked like an angel and was the most loving sweet little boy. Everything he did was with energy and untold strength and a joy for life. I went to see Dr. Ed Wraith in Manchester again the following year and I told him that TJ was very hyperactive and demanding. We couldn't leave him alone for 5 minutes! Ed Wraith just smiled at me and said, "Of course he is a busy boy Lynn, he has got so much to do and he has so little time to do it." With these words, I viewed his hyperactivity with renewed respect. He told me that I must try not to be sad but to enjoy TJ as much as I could in the time that we had. He also said that although TJ's needs and care took up a lot of our time, we were all equal in his heart. Through these wise words I learnt to treat TJ as a gift to be treasured, not as a burden. However, there were some days when I craved to do things by myself, for myself. I felt angry that I couldn't go out with some friends and have some fun.



## OVERSEAS

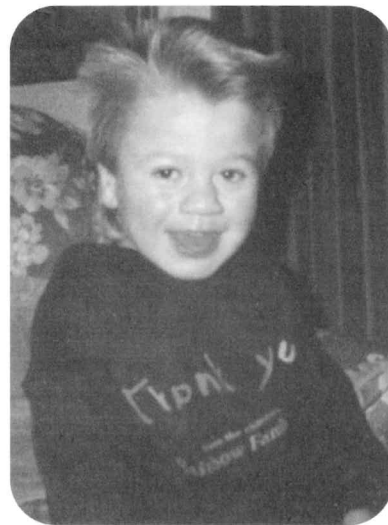
Having these feelings made me know because I knew that TJ only wanted to be with his brain and his body were letting him down. On the other hand TJ made it very easy for us to look after him because he was a joy, he never moaned, he laughed all the time and made you feel so special and lucky to be part of his life, and loved by him.



We made every birthday special for him. He enjoyed playing with the adults and entertained and amused them. He never used to play with children his own age. Every year when we visited Ed Wraith in Manchester we stayed at Derian House Hospice in Chorley. TJ loved the hospice. He always helped with the babies, carried their nappies and gave them their bottles or dummies. He really cared for the babies and took his role seriously. He also helped in the kitchen with the food and was brilliant with packing away of the clothes and linen. We had lots of fun there. TJ used to open the gate so that the rabbits could run away. He then laughed at all the care team while they ran around trying to catch them again.

TJ had a very special gift, he could 'see' people. He always knew when people were sad or happy. His intuition was finely attuned to people's emotional well being. TJ never liked 'animated' movies. His favourite movie however was 'ROBIN HOOD' (with Kevin Costner). TJ watched this movie twice a day and his favourite song was 'Everything I do' (Bryan Adams). Every night he listened to the song before he went to sleep. He loved it to put his fingers through my hair until he dozed off. TJ was a very lovable child, but he would never kiss or hug just anybody. He had his favourites. He never used to talk to strangers, although he would greet and be friendly with the black people in our country. Somehow they fascinated him. Maybe his intuition telling him that they accepted him for what he was, without judging?

He used to play cricket, rugby and soccer. He was very good with sport although he got tired quickly when running around. He always accepted a gift with gratitude and looked after it. He always liked to play with his old toys, although he preferred his soft toys, and his many balls. He sometimes went to bed with the cricket ball under his pillow.



The Reach for a Dream Foundation approached me and asked me what TJ's dream was. I explained to them that TJ just wanted to live, he did not have a dream. I knew that he just wanted to be happy for the short time that God had given him. He didn't want to go to Disney World, or meet a soccer star - No, TJ was content with what he had. He had me, Connie and he had love! They however arranged to take him on a weekend trip to Durban where he could see the dolphins. TJ really enjoyed that. He was always happy in his own backyard where he could play with his toys, in familiar surroundings, and be with people that he loved. TJ was very demanding when it came to give everything of yourself, but he returned it tenfold.

## CONFERENCE PRESENTATION

### AN EXPERIENCE OF CARING

*As promised in the last Newsletter (Autumn 2000) here is the concluding part to the talk presented by Ellie Gunary at the 18th Annual MPS Conference. If you missed the first part please contact the MPS Office for a copy.*

#### CONTROL

Our lives before MPS took over were our own. As Paul's health deteriorated it felt as though we lost this control. Decisions we would previously have made alone, perhaps asking for help from friends were suddenly analysed by and involved a whole variety of other people. Before we had decided what we needed and had arranged this. It felt at times as though we were on trial, having to justify our rationale behind every decision we made.

#### PRACTICAL

We considered moving to an adapted house. This was the rational thing to do, as our home was not easy to adapt. It became apparent that Paul did not want to move and we were both very attached to our home. It was our first home, full of memories, hopes and dreams. The decision to stay was purely emotional. There was nothing practical about our home. The toilet and bathroom were upstairs where Paul could not access them. There was a deep step up to the front door and only two small rooms downstairs. It took nine months for social services to install a ramp giving Paul the opportunity to use it just three times before he died.



Paul and I, despite the unorthodox arrangements of his bedroom in the living room and his makeshift bathroom in our dining room, were determined to keep it looking like a home our friends and family could relax in. Paul was fiercely proud and wished to hide his care needs from all our family and friends who visited. This meant constantly moving things, putting equipment away, moving the commode in and out of a cupboard. Because of this, supporting Paul took twice as long. His bed became a sofa during the day; his clothes were housed in a hall cupboard rather than a wardrobe. His wash things and medical equipment were kept hidden behind a screen in the corner.



## CONFERENCE PRESENTATION

Where cupboards had been filled with china and coats they now housed gastrostomy feed, medicines, dressings and so on. Our garage housed beds, wardrobes, chairs, dining table and sofas. I could have rented it out but decided that explaining the rental income to the benefits agency would be too difficult.

### SOCIAL AND HEALTH CARE

One positive thing arose from Paul's need to be gastrostomy fed. It brought an end to meetings where social services and health service staff debated whether Paul's needs were considerable enough to be now met by the health service rather than social services. The need for health care was now indisputable. These meetings had taken place in our home with us present. Paul being fully aware and alert had to sit through those demeaning discussions. Looking back I would now walk out, but I was then physically and emotionally exhausted, suffered very low self-esteem and felt a failure in not being able to cope alone without services' help. I did not have the strength or presence of mind to walk out.

Some of the nursing staff who supported us we valued greatly. They acknowledged us as people, sussed out how we worked and adapted to this. For Paul they respected his right to make choices and supported him to eat at his request despite all the medical advice to the contrary. For me if Paul had not lost the ability to walk he would be at the shops buying his own food so just because he was physically unable did not deny him the right to go against medical advice. Food was one of Paul's loves and for him the risks incurred to his health by eating was worth taking.

The worst type of nurse for me were those who tried too hard. Those who stood over me as I said goodnight to my husband. Our home seemed constantly invaded with different people coming and going and we both got little enough space on our own as it was. The "dear dear" type were the worst for Paul. Their characters clashed with his blunt down to earth character and sense of humour. Paul gained what control he could. Paul had always enthusiastically brushed his teeth, taking ages over this. With these nurses he took twice as long, testing their patience. If they asked whether he had finished before he put his toothbrush down he would stop, glare, say "be patient" and carry on for even longer. We had a few battles before the care services accepted that although they could only provide evening support at 8 p.m. this really was too early for Paul at thirty-one to go to bed.



## CONFERENCE PRESENTATION

### FRIENDS

We were lucky in having some very good friends who helped keep our sense of humour intact. One friend in particular who shared Paul's blunt sense of humour phoned up asking whether he had got through to the Hunger Hills hospital and was he speaking to the Matron. With The Patient Paul he asked direct questions, did not avoid awkward issues and it was Scott to whom Paul spoke his last words. Not repeatable I'm afraid.

### PAUL'S DEATH

Paul was stoical, denied ever being in pain despite it screaming at me through his body language. When asked if he was in pain he would angrily deny this, claiming I was misreading him. I began to question even my ability to read Paul and advocate for him. His words and his actions did not concur. Paul eventually admitted painkillers would help and gained relief taking these. His facial expressions and body relaxed. Paul died eleven months after his fall. By this time I was physically exhausted. I slept very well after his death. I had a lot of catching up to do. I was unable to sleep in my bed. I lay there, trying to hear Paul's breathing and expecting to hear the bell at any moment to summon me. I moved onto the spare bedroom floor and it was some months later before I was able to relax in my bed. My world emptied when Paul died. Everything I had known for the last year had gone.

My role had gone. Paul no longer needed me. It took a long time to adapt to the fact that I could go shopping everyday and did not need to stock up on food, that I could leave the house when I wanted, accept invitations to go out and that when I returned I would not find Paul sitting in his chair with the nurse waiting for me. I searched for something familiar from the last twelve months. One daily task had been the laundry and getting through the three daily loads of soiled linen. Now there was not enough for one load a day. I put clean sheets in the wash just for something familiar to do. That did not last long! Guilt carried on, especially for the times I had shouted when I felt I could no longer cope and when things had got really bad and I had shouted "You are going to die anyway so why don't you now." My anger spilling over. Paul forgave me for those times, did not take it lightly, gave some pretty straight answers and we made up.





## CONFERENCE PRESENTATION

### FINALLY

There are some things that particularly remain with me from my experience of caring.

The things it taught me:

*Gratitude for many things I had previously taken for granted, the ability to walk, the ability to talk and the ability to eat for example.*

*To value and make the most of each moment.*

*How many varieties of chocolate mousse exist (this became Paul's favourite food, he ate about five a day, choking his way through them and it was a challenge to keep this diet varied)*

There were many things I missed when caring for Paul but those I missed most were:

*Being able to walk with Paul holding his hand. I always had to walk behind him to push his wheelchair.*

*Having a long, relaxing, uninterrupted bath - usually I had to go downstairs dripping wet after being rung to support Paul.*

*Drinking a whole hot cup of tea.*

I now very much take these for granted again except when I remember those times of caring. Paul will always hold a very important place in my heart and the hole in my life will always be there in some form.

Paul always looked towards the future even when he was extremely poorly and held onto the hope that future generations of children with MPS would have the opportunity to access treatments not available when he lived.

I hold onto that hope, the hope Paul lived with knowing it would never arrive in time for him.



## MPS CHRISTMAS PARTIES



### MIDLANDS

The Christmas party for the families in the Midlands was held on November 25th, a very wet and gloomy Saturday.

Sue Hodgetts was the family organiser and I went along as a representative of the staff team. My job changed at the beginning of the year, so it was a lovely opportunity to meet up with the families again!

The room we had booked at the hotel was perfect, just big enough for a few particularly energetic children to let off a bit of steam but small enough that we could keep an eye on them and also to create a cosy, friendly atmosphere.

The hot buffet was a success, especially as it was such a miserable day outside. We had party hats and crackers, pass the parcel and Christmas songs and the highlight of the day - Barney - a children's entertainer who performed magic tricks, told jokes, made balloon sculptures (which were popular with both the adults and the children) and managed to involve everyone.

Snow White did the rounds, looking after everyone and helped to make the day very special and before everyone left to start their journeys home, we had a visit from Father Christmas who had a present for all the children and was the perfect ending to a very successful afternoon.

I look forward to seeing all the old faces and maybe some new ones next year!

Angela Ratcliffe  
Development Officer ( Research)





### MPS CHRISTMAS PARTIES

#### NORTHERN IRELAND

Six families gathered together at the Aldergrove Airport Hotel for this year's Christmas party.

The atmosphere was lively and seasonal with music and entertainment provided throughout the party by Mr Majestik who enthralled the children with magic tricks, jokes and balloon modelling.

With the tinkling of chimes and dimmed lights, Santa arrived, trudging in with his heavy sacks. There was great excitement as the children waited for their private audience with Santa who took time to speak individually to each child and gave them their well deserved gifts. We send a big thank you to Santa's agent, Mr Dee Bruce who arranged this.

The party was most enjoyable and provided an excellent opportunity for the MPS children and young people, their brothers, sisters and parents to meet and share experiences.

We would like to thank Bernie and Kevin Drayne for kindly being there on the day to welcome all the families. We hope to see even more families at the Northern Ireland Christmas Party in 2001.

Ellie Gunary



The McDonagh family



The Shields and McAfee families



Lucia Dawson, mum Rosemary, and friends at the Northern Ireland Christmas Party

### MPS CHRISTMAS PARTIES



#### YORKSHIRE

The Yorkshire Christmas party was held at the Ship public house in Mirfield. We all met there at 12 o'clock and enjoyed a lovely afternoon.

It was a small party with 5 families attending but this did not make any difference to everyone's enjoyment.

The Robjohns unfortunately had to leave early as Paula was taken ill and had to go home. We hope you made a quick recovery Paula.

The children had a great time, this is a Brewers Fayre pub and there is lots for the children to do. Ellie came along to party with us (and to make sure we behaved ourselves!)

We were looked after really well and the food was delicious, although we didn't think there would be much left after Adam Brown had finished!!

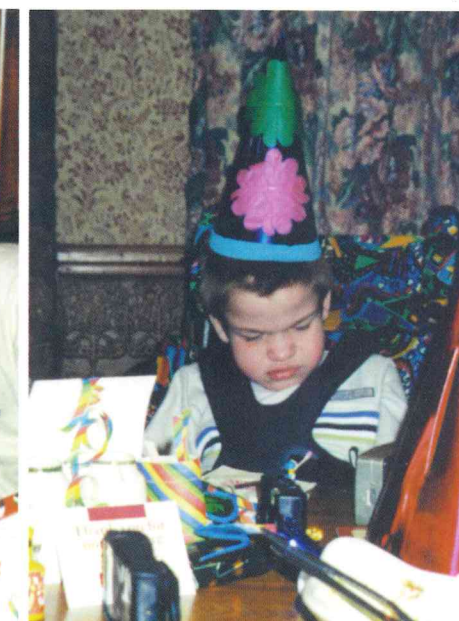
Every child received a gift and left full of food and looking forward to Christmas.

We would like to wish all MPS families a happy New Year.

*Becky, Steve, Sally and Daniel Ellis*



Joanne and Steven Lewis



Daniel Ellis



Steve and Jordane Robjohn



## MPS CHRISTMAS PARTIES

### SOUTH EAST CHRISTMAS PARTY

The Party was held at the Maidstone Hilton Hotel on 10 December 2000 between 12 midday and four pm. This new venue and location attracted a record number of MPS families, 54 adults and children in total. Soon after arrival families were served a choice of hot and cold buffet followed by dessert and coffee or tea. Volunteers organised musical chairs and pass the parcel where irrespective of disability every one could take part. There were surprises throughout the parcel. However Emma Perfect's face was a picture when she won the cuddly toy concealed by the final wrapper of pass the parcel.

At two o'clock the entertainer Aero took over and by the end of the afternoon nearly all of us present could spin a plate on a stick! To bring the afternoon to a conclusion we enjoyed a visit from Father Christmas. It was wonderful how he had time to meet with each of the children before sending them off with a small gift.



*Look I can spin plates too*



*Faye Rowe with her sister meeting Father Christmas*



*Ben and Emma Perfect enjoying the party*

## MPS CHRISTMAS PARTIES

### NORTH WEST CHRISTMAS PARTY

A great time was had by all at the North West Christmas Party at the Thistle Haydock. We started with a brief introduction prior to a hot buffet meal. The children then enjoyed traditional party games, such as pass the parcel and musical chairs, and a dancing competition. This gave the adults time to socialise and get to know each other over coffee. We were all then entertained by Percy Piecrust with a combination of magic and games which we all joined in and was great fun.

The day was rounded off by a visit from Father Christmas with presents for all, with Santa receiving a cheque on behalf of the Society from the Jones family. Mark and Claire would like to thank everyone who attended for making the day such a great success and allowing us to make so many new friends - we are really looking forward to seeing you all again next year.

Mark Beniston

*We had a great time at the Haydock Thistle. We have never been with such a great bunch of people. They were all so friendly.*

*Chris and Dawn Jones*



*Chris, Dawn and Eleanor Jones presenting a cheque for MPS to Father Christmas and Santa's elf*

### SOUTH WEST CHRISTMAS PARTY

The South West Christmas Party was held on 9 December 2000 at the Bristol Hilton. It was a small affair after several families who had booked were unable to come due to illness in the family.

Nevertheless there was plenty to eat and the children were entertained by Martin the Magician, Father Christmas was delayed, but he did arrive just in time to deliver a small gift to each of the children.



**CHILDHOOD WOOD**

The annual sapling planting of the Childhood Wood took place on Friday 27th October at Sherwood Pines in Nottinghamshire.

The Chairman of the County Council Mr Jim Napier joined Paddy Tipping MP, myself, Angela and four families to plant the oak saplings for children who have died this year from an MPS or related disease.

Three trees were planted on behalf of families who were unable to make the day.

We picked a very autumnal day for the planting but the rain held out just long enough to allow us to plant the trees.

Prior to the planting the families and guests enjoyed a light lunch at the Clumber Park Hotel.

If you would like a tree in the Childhood Wood for a relative who has died from a Mucopolysaccharide or related disease please let me know at the MPS Office.

Hannah Crown  
Development Officer

**The Children and Adults Remembered**

Daniel Kaye	Samuel Mayhew
Kerry Little	Michael Copeland
Bernadette Smyth	Kerry Graham
Baby Mayhew	Carissa Aggett



Sarah Little presenting gifts to Councillor Napier and Paddy Tipping MP



Families planting their trees in the Childhood Wood

**IN REMEMBRANCE**

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

<i>Katie Devine who suffered from Hurler</i>	<b>24.10.95 - 17.12.2000</b>
<i>Ronda Brierley who suffered from ML III</i>	<b>10.05.74 - 26.10.2000</b>
<i>Lee Brown who suffered from Hunter</i>	<b>12.05.77 - 31.10.2000</b>
<i>Brian McDonagh who suffered from Hurler</i>	<b>23.11.99 - 2000</b>
<i>Sean Osment who suffered from Sanfilippo</i>	<b>21.5.86 - 15.12.2000</b>
<i>Katie Martin who suffered from ML II</i>	<b>18.5.89 - 08.01.2000</b>

**In Memory of Lee**

*How lucky we were to have known him  
All who knew this beautiful boy  
How lucky we were when he showed us  
Everyday is a gift to enjoy  
How lucky we were he was special  
Endless courage and strength he portrayed  
But he couldn't stay any longer  
He has to leave us today  
So remember the lessons Lee taught us  
No matter what life may hold  
Face your fears and problems as he did  
Head on, forever bold.*

*sent in by Trevor and Shirley Brown*

**Colin Thompson**

The MPS Society sends its sincere sympathy to the Thompson family in Australia on the recent death of Colin.

Colin died on 8 August 2000 aged 30 years. Colin had Hunter disease.

In the past we have enjoyed Colin's company at our MPS conference, he has contributed to the MPS Newsletter and shared his life experiences speaking at the MPS International Symposium in Wollongong, Australia.

**Katie Devine's favourite hymn**

If I were a butterfly,  
I'd thank You, Lord, for giving me wings.  
And if I were a robin in a tree,  
I'd thank You, Lord, that I could sing.  
And if I were a fish in the sea,  
I'd wiggle my tail and I'd giggle with glee;  
But I just thank You, Father,  
For making me 'me'.

*For you gave me a heart  
And you gave me a smile,  
You gave me Jesus  
And You made me Your child,  
And I just thank You, Father,  
For making me 'me'.*

If I were an elephant,  
I'd thank You, Lord, by raising my trunk.  
And if I were a kangaroo,  
You know I'd hop right up to You.  
And if I were an octopus,  
I'd thank You, Lord for my fine looks;  
But I just thank You, Father,  
For making me 'me'.



## KIDS PAGE



### CHRISTMAS CARD COMPETITION

Following the huge success of Isabelle Gee's winning entry for the MPS Christmas card competition for the year 2000 Millennium design, it is now time for you to submit your entries for the year 2001 Christmas Card Design Award.

We have to agree designs six months in advance of the event, and we are sure you would rather produce your Christmas designs now than try to think Christmassy in May!

What we need is drawings, painting, collages etc. with a Christmas theme.

There will be a prize for the winner or winners, and their design will be printed as the MPS Society 2001 Christmas card.

### GET BUSY & GOOD LUCK

#### COMPETITION RULES

Entries should be on an A4 sheet of white paper.  
The entrant's name, age and address should be on the back in the top left hand corner.  
Entry is open to all MPS children, young adults and their siblings.  
Closing date for receipt of entries at the MPS Office is February 28 2001.  
Winners will be notified by post.

#### A CHRISTMAS TALE

Don't forget to send in your stories about what happened to you over the Christmas holidays and send photos as well so that we can put them in the next Newsletter.

#### IDEAS !

We would love to have your ideas for future articles on this page. If there is anything you would like to see included in future Newsletters please send your suggestions to the MPS Office and we will do our best to include them.



## RESEARCH AND THERAPY

### CLINICAL TRIALS

Clinical trials are used to determine whether new drugs or treatments are both safe and effective. Carefully conducted clinical trials are the fastest and safest way to find treatments that work. Many new medicines and treatments are found to be helpful and safe in test tubes and animals. They must also prove safe and effective in humans before doctors can prescribe them.

Ideas for clinical trials usually come from researchers. Once researchers test new therapies or procedures in the laboratory and get promising results, they begin planning Phase 1 trials. New therapies are tested on people only after laboratory and animal studies show promising results.

#### What are clinical trial phases?

Clinical trials of experimental drugs proceed through four phases:

In **Phase I** clinical trials, researchers test a new drug or treatment in a small group of people for the first time to evaluate the safety, determine a safe dosage range, and identify side effects.

In **Phase II** clinical trials, the study drug or treatment is given to a larger group of people to see if it is effective and to further evaluate its safety.

In **Phase III** studies, the study drug or treatment is given to large groups of people to confirm its effectiveness, minor side effects, compare it to commonly used treatments, and collect information that will allow the drug or treatment to be used safely.

In **Phase IV** studies are done after the drug or treatment has been marketed. These studies continue testing the study drug or treatment to collect information about their effect in various populations and any side effects associated with long-term use.

#### What is a Placebo?

A placebo is an inactive pill, liquid, or powder that has no treatment value. In clinical trials experimental treatments are often compared with placebos to assess the treatments' effectiveness. In some studies, the participants in the control group will receive a placebo instead of an active drug treatment.

#### What is a blinded or masked study?

A blinded or masked study is one in which participants do not know whether they are in the experimental or controlled group in a research study. Those in the experimental group get the medications or treatments being tested, while those in the control group get a standard treatment or no treatment.

#### What is a protocol?

All clinical trials are based on a set of rules called a protocol. A protocol describes what types of people may participate in the trial; the schedule of tests, procedures, medications and dosage; and the length of the study. While in clinical trials the participants are seen regularly

by the research staff to monitor their health and to determine the safety of their treatment.

#### Who can participate in clinical trials?

All clinical trials have guidelines about who can get into the programme. Guidelines are based on such factors as age, type of disease, medical history and current medical condition. Before you join a clinical trial you must qualify for the study. Some research studies see volunteers with illnesses or conditions to be studied in the clinical trial, while others need healthy volunteers.

The factors that allow someone to participate in a clinical trial are called inclusion criteria and the factors that keep them from participating are called exclusion criteria. It is important to note that inclusion and exclusion criteria are not used to reject people personally. Instead, the criteria are used to identify appropriate participants and keep them safe. The criteria help to ensure that researchers will be able to answer the questions they plan to study.

#### What is a control or control group?

A control is the standard by which experimental observations are evaluated. In many clinical trials, one group of patients will be given an experimental drug or treatment, while the control group is given either a standard treatment for the illness or a placebo.

#### What protections are there for people who participate in clinical trials?

The government has strict guidelines and safeguards to protect people who choose to participate in clinical trials. Every clinical trial must be approved and monitored by an Ethics Committee in the UK to make sure the risks are as low as possible and are worth any potential benefits. An Ethics Committee is an independent committee of physicians, and lay people that ensures that a clinical trial is ethical and the rights of participants are protected. All institutions that conduct or support biomedical research involving people must have an Ethics Committee that initially approves and periodically reviews the research.

## INFORMATION EXCHANGE

### Disability Law Service

The disability Law Service offers free confidential legal advice and representation to disabled people, their families, enablers and carers. The service is made up of solicitors, advisers and trained volunteers who provide up to date, informed legal advice on such subjects as benefits, community care, consumer issues, discrimination, education and employment. To make an enquiry call their advice line on 020 7791 9800, minicom 020 7791 9801, fax 020 7791 9803 or email: [advice@dls.org.uk](mailto:advice@dls.org.uk), or write to them at 39-45 Cavell Street, London E1 2BP.

They also offer the following fact sheets, all available free of charge if you send them a stamped addressed envelope.

*Disability Discrimination Act 1995:  
Employment - a guide*

*Appealing the Special Education Needs Tribunal  
a guide for parents/guardians*

*Changing Schools - a guide for  
parents/guardians of a child with special  
educational needs*

*Special Needs Education for Children under 5*

*Guidelines for trusts where there is a family  
member with a disability*

### In Good Repair

If you are considering making adaptations to

your home, you maybe interested in a new booklet called *In Good Repair*.

*In Good Repair* is a practical guide for people who need repairs or adaptations to their homes. It takes the reader through the various stages involved, and includes information on finding a good builder, sources of finance and what to do if things go wrong.

Scope, a national disability organisation whose focus is people with cerebral palsy, and Care & Repair England, a charitable organisation which addresses the needs of people living in poor or unsuitable housing, have worked in partnership to produce this booklet, and copies are free to individuals. Copies can be obtained from Scope, 6 Market Road, London N7 9PW, tel 020 7619 7100. Copies are also available on audio cassette disc, computer disc and in large print.

### Promise of a Legacy

Legacies now give rise to a very substantial part of the income of many charities. If you or anyone you know, is making a will, a bequest to the MPS Society large or small could make a lot of difference to the level of support offered to individuals suffering from MPS, their families and carers as well as the speed with which research can be carried out leading to therapy.

All that is needed in the will is a sentence 'I bequeath to the Society for Mucopolysaccharide Diseases' Registered Charity No. 287034, the sum of £\_\_\_.

Call the WINTER WARMTH ADVICE LINE for advice, a copy of the Keep Warm Keep Well winter guide and for help with winter heating costs.

Winter warmth advice line →

You can also visit our website at  
[www.doh.gov.uk/kwkw](http://www.doh.gov.uk/kwkw)

or write to:

PO Box 777, London SE1 6XH.

Fax: 01623 724 524

**FREEPHONE**  
**0800 085 7000**

**TEXTPHONE 0800 085 7857**  
**8am to 8pm Monday to Friday**

## INFORMATION EXCHANGE

### A Better Deal for Working Parents

The Government wants to encourage more parents back into work and to guarantee working parents a minimum household income. What is the deal? From October, Working Families Tax Credit (WFTC) replaced Family Credit and it is much more generous. If you think you wouldn't be eligible, the truth is you might well be. To qualify a family must have:

1. one or more children under sixteen years (or 19 years if in school)
2. one parent working at least sixteen hours a week
3. less than £8,000 in savings
4. parent(s) resident in the UK and entitled to work
5. a low or middle income

A family can be a lone parent, a married couple, or a man and a woman living together as if married with the care of at least one child. Single parents or other extended family are treated as lone parent, maintenance payments are disregarded as income and you only need to be working sixteen hours a week to get help with childcare costs.

The payment is weekly and it has four elements:

1. a basic tax credit of £52.30 per family
2. an extra credit of £11.05 for a family where one parent works at least thirty hours a week
3. tax credit for each child of between £19.85 and £25.95 depending on their age
4. the Childcare Tax Credit (CCTC) worth, 70p for every pound you pay out, up to £100 for one child and £150 for two or more children.

To qualify for Childcare Tax Credit, be sure to have evidence of the childcare arrangements you have made. This must be either with a registered childminder or an out of hours club or school premises, run by a school or local authority, and must be set up before you apply.

### How might it help parents with children with disabilities?

Although Invalid Care Allowance is counted, your child's Disability Living allowance (DLA) is disregarded as income. The qualifying age for help towards the costs of childcare is extended up to the September following the child's sixteenth birthday if they are in receipt of DLA.

Parents can still offset childcare costs at a rate of 70p for every pound spent up to £100 whatever the hourly rate, whether the costs are £3.50 per hour or £35 per hour. This should help families of severely disabled children with high care, or complex medical needs, meet the higher costs of specialist childcare.

### Severe Disablement Allowance - Apply Now!

Severe Disablement Allowance is a non-means tested, non-contributory benefit paid to people under 65 who cannot work through disability and have not paid sufficient National Insurance Contributions to qualify for Incapacity Benefit. From April 2001 the SDA will no longer be available to anyone who is not already claiming it before that date. Disability campaigns have therefore launched a campaign to ensure that all those entitled to SDA claim the benefit before it is abolished.

According to Lorna Reith of the Disability Benefits Consortium (DBC), 'It is vital that people apply for SDA now before the benefit is abolished. A successful claim now guarantees SDA into the future. SDA is paid regardless of income, savings or National Insurance contributions. After April 2001 severely disabled people who have not paid National Insurance contributions will only be able to apply for means tested benefits such as Income Support.'

The DBC has produced an information pack, available from the RNIB helpline on 0845 766 9999. This is, however, good news for anyone under the age of twenty who currently receives SDA as they will be able to go straight on to Incapacity Benefit.

### Increased Financial Help for Carers and Disabled People

The Secretary of State for Social Security has recently announced a new £200 million annual package of extra financial help for carers and disabled people. The carer premium is now increased by £10 on top of the normal up-rating - the weekly premium will rise from £14.15 to £24.40. Additionally, a £7.40 rise to the disabled child premium which is paid with Income Related Benefits will increase the benefit from £22.25 to £30 per week. For further details contact the Benefit Enquiry Line, Freephone 0800 882200.



## INFORMATION EXCHANGE

### Education gets boost

Disability campaigners have welcomed the Government's announcement that it will introduce the Special Educational Needs and Disability Rights in Education Bill during this parliamentary session, and provide £220m to improve access in schools over the next three years.

But campaigners are concerned about whether children should be compensated if they are discriminated against, amid fears that schools might see payments as an easy way out.

The Government also announced it would give a further £172m to colleges and universities to spend on lifts, ramps and equipment between 2002 and 2004.

Brian Lamb, chair of the Special Education Consortium, said disabled children can now 'look forward to equal rights in education and an end to discrimination in schools.'

The legislation will require schools to make reasonable adjustments to improve physical access barriers to disabled students.

Campaigners are divided over whether children should be compensated if there is proof they have been discriminated against.

The Department for Education and Employment said 'For schools cases we judge that the most appropriate remedy is an educational one - putting right the situation, stopping the discrimination.'

Solicitor David Ruebain, vice chair of Rights Now!, said compensation was important because it would show the public that discrimination shouldn't happen.

In some cases - if a child had not been allowed to go on a trip because of their disability, for example - compensation could be the only way of making amends, he added.

But Caroline Cooke, policy officer at Scope, said: 'Financially compensation may be, for some institutions, an easier and less expensive way out. We want to see schools and colleges forced to change their policies and practices to stop discrimination against current and future disabled pupils.'

### Draft Code of Practice on SEN

The MPS Society is a member of the Special Education Consortium. This is a group of 247 organisations and individuals concerned to protect and promote the interests

of children and young people with special educational needs and disabilities, particularly when there are proposals for change in legislation. The Special Education Consortium has drafted a response to the Draft Code of Practice on Special Educational Needs.

The Consortium has serious concerns that the revised Code of Practice, as currently drafted, could undermine much of the positive direction given to SEN by the Green Paper, the Programme of Action, and the SEN and Disability Rights in Education proposals, on which the DfEE consulted earlier this year. The Consortium has particular concerns in four main areas:

1. Loss of specificity and lack of clarity about the use of resources for a statement
2. The lack of support for a more strategic approach to meeting SEN
3. The Lack of coherence with proposals for Disability Rights in Education
4. The function of the Code and its relationship to the Good Practice Guide

If you would like to find out more about the work of the Special Education Consortium, or would like a full copy of the response to the Code of Practice, contact: Special Education Consortium c/o National Children's Bureau, 8 Wakley Street, London EC1V 7QE tel. 020 7483 6318. Alternatively, you can contact Ellie Gunary at the MPS Office.

### The Juggling Act - A Conference for families of Children with Special Needs

Saturday 31st March 2001, 10am - 4.30pm at Meeting Point House, Telford

When you care for a child with special needs, life can sometimes feel like a Juggling Act. This conference will explore ideas for helping parents balance the needs of all the family - including their own! The day will offer a variety of guest speakers, workshops, a relaxation zone, and children's entertainment.

The day is for parents and families. Professional workers are invited, but priority will be given to parents. The conference fee is £5 for parents and £25 for professional workers. Children can attend free of charge.

For further information and a booking form please contact the Contact a Family North West England Office.

Tel. 0161 743 0700

## INFORMATION EXCHANGE

### New Student Rights

The Disability Rights Commission (DRC) is to launch a conciliation service for cases of disability discrimination in education, after the Government announced new rights for disabled students.

The Government confirmed in the Queen's Speech that it would introduce the Special Education Needs (SEN) and Disability Bill.

It means schools and colleges must not treat disabled children and students less favourably without justification and that they must make reasonable adjustments to improve access.

The DRC's conciliation service will help people enforce their rights without having to take the full legal route.

Bert Massie, chairman of the DRC, said: 'Disabled children and students will have a fair and impartial service to resolve disputes.'

### Education of Sick Children

The DfEE is undertaking consultation on producing a new guidance document on the education of sick children/young people. The previous document 'The Education of Sick Children' dates back to 1994. The DfEE is keen to sound out all interested parties to ensure as wide a consultation process as possible. The guidance is entitled 'Consultation on the Education of Sick Children' and can be obtained from DfEE Publications, PO Box 5050, Sherwood Park, Annesley NG15 0DJ Tel. 0845 602 2260 or from the website at [www.dfee.gov.uk](http://www.dfee.gov.uk) Questionnaires should be returned by 5th February 2001.

### Protests at SEN code

Parents and disabled children have demonstrated against proposed changes to the special educational needs (SEN) code of practice.

Protesters from umbrella group Action on Entitlement gathered at 10 Downing Street on 13 October to hand a letter to Prime Minister Tony Blair, claiming the revised code which advises local education authorities on SEN provision and funding is misleading.

Protesters are also concerned that, as SEN funding will no longer be earmarked for individuals, children's provision may be cut.

Sally Capper, education advocacy worker at the Down's Syndrome Association, said: 'We think the code could be improved, but so far the changes are not satisfactory. It just doesn't say what the professionals are supposed to do.'

The consultation period has now finished. A government spokesperson said: 'The changes we propose in the code aim to make it clearer for parents and others. We are taking time to consider all the responses we have received very carefully before reaching our decisions on the text of the final version.'

### Parents for Inclusion

Parents for Inclusion have launched an Inclusion Helpline, Tel. 020 7582 5008 (Tue, Wed & Thur, 10.00am - 2.00pm). Calls are taken by trained and experienced parents who aim to help other parents so that their disabled children can learn, make friends and have a voice, in ordinary school and throughout life. The group believes that all children should be allowed to be together whatever their disability, ability, race, class or gender.

## INFORMATION EXCHANGE - 16+

### Helping You to Stay Independent

#### A guide to long-term care services and benefits for people who live at home

One of the key commitments of the Modernising Government White Paper was to improve access to public services and make them more responsive to the needs of customers. Five groups, called Service Action Teams, were set up to address the problems facing individuals in trying to access services. One of these was the Service Action team on long-term care at home.

The team identified the need for a guide for users and carers that 'sign-posted' the key long-term care and support services that they might need to call on to help them continue living at home.

Copies of this guide are now available and can be requested by email at [doh@prologistics.co.uk](mailto:doh@prologistics.co.uk) or by post from Department of Health, PO Box 777, London SE1 6XH. The guide is also on the Department of Health's website: ([www.doh.gov.uk/scg/sat/htm](http://www.doh.gov.uk/scg/sat/htm))

**"Leaving Home - Moving On"** is a booklet produced by The Foundation for People with Learning Disabilities. It is intended for parents of a young person with learning disability, living at home with them. It offers guidance with planning the process of leaving home and gives some ideas of what housing options may be available. It includes several useful checklists. Single copies are free with a 31p SAE. Multiple copies at £2.20 incl p&p. Contact: Publications, Mental Health Foundation, 20-21 Cornwall Terrace, London NW1 4QL

### "After 16 - What's New? Choices and Challenges for Young Disabled People"

A lively new information guide for teenagers and young people with disabilities has recently been published by the Family Fund Trust. For every young person with a disability, there is a unique set of challenges, decisions and choices to be made during the teenage years and beyond.

"After 16 - What's New?" is intended to help young people with disabilities work through some of these important choices including further education, where to live, daytime activities and changes in income. It is also about the rights and responsibilities that go with them. The book stresses the importance of good information; it signposts the readers towards people they need to talk to, useful voluntary organisations, books, internet sites and lots more.

The book is available free to young people with disabilities, their parents and carers, and £10 to others: Information Office, Family Fund Trust, PO Box 50, York YO1 9ZX - email: [info@familyfundtrust.org.uk](mailto:info@familyfundtrust.org.uk)

**"A Practical Guide for Disabled People"** is a new updated guide on where to find information, services and equipment if you have a disability or if you care for someone with special needs. It covers travel, work, holidays, relationships as well as a whole host of other information.

Copies are available free from: Department of Health, PO Box 777, London SE1 6XH

### Transition to Adulthood for Young Disabled People with Complex Health and Support Needs

Published by the Joseph Rowntree Foundation, Publications Office, The Homestead, 40 Water End, York YO30 6WP - Tel:01904 615905  
A full copy can be found at website: [www.jrf.org.uk](http://www.jrf.org.uk)

This is the title of a recent set of findings based on a report by Jenny Morris. Some of the conclusions include:

Information about medical conditions, treatments and impairments was important to young people but they did not always receive the information they needed, or in ways that were useful to them.

Young people sometimes lose contact with specialist healthcare services when they cease to use paediatric services.

Some young people would benefit from health services specifically geared to transition to adulthood. However, there is very patchy provision of such services across the country.

## INFORMATION EXCHANGE - SCOTLAND

### GRAMPIAN HELP - is at hand from your local Health Council

Your Local Health Council cares about your health and are there to make sure you get the best deal from the National Health Service. Your needs and concerns are represented by 15 ordinary members of the public from across Grampian.

Would you like to know more about -

Your rights as a patient?  
Getting the best from the NHS?  
Health Services in your area?  
Family Doctor and Dental services?  
etc. etc.

Get the facts! - contact the MPS office for a leaflet and more information.

### SCOTTISH CHARITY MAY BE REVIVED!

Disability Scotland could be brought back from the dead if merger talks with RADAR and the Enham Trust are successful.

Disability Scotland folded in the summer with debts of £40,000.

### THE WARM DEAL FOR SCOTLAND

The Scottish Executive is providing grants up to £500 to make your home more energy efficient and keep you warmer during the cold winter months!

Please contact the MPS Office for a leaflet !!

### Education of children with severe and low incidence disabilities

This report, from an Advisory Committee chaired by Professor Sheila Riddell of Glasgow University, arises from a review of SEN provision in Scotland for children with severe and relatively rare disorders. Although the Committee's remit was confined to Scotland, and several of its recommendations are specific to Scotland, it is believed that many recommendations are of much wider importance within the UK, the EU and beyond. For example:

The report adopts a strongly 'inclusive' approach to meeting these children's educational needs within mainstream schools but also recognises that specialist provision will be necessary for some time.

Considerable emphasis is placed on the need to obtain parents' and children's views.

The importance of the role of the voluntary sector is recognised, as is the need for good inter-agency working practice by all statutory authorities - education departments, social work, housing and health. Clear identification of responsibilities within Children's Service Plans is also identified as essential, combined with a specific statement of proposed action.

The in-service training and professional development of all staff involved with these children should be reviewed.

Post-school provision for these children should also be reviewed.



## INFORMATION EXCHANGE

### DISS

DISABILITY INFORMATION SERVICE SURREY

DISS is a disability information service. They give free, confidential and impartial information on anything to do with living with disabilities.

Including information on self help groups, equipment, employment, holidays, education, benefits, recreation, access and transport.

**Anyone can use DISS and it's FREE**

Enquire by phone, post, fax, e-mail or you are welcome to visit

**Tel: 01306 875156 / Fax: 01306 741740 e-mail: [info@dis.org.uk](mailto:info@dis.org.uk)  
webbpage: <http://www.diss.org.uk/diss/>**

### Changes in Access to the Attractions of Disneyland Paris

Do not tell your child that they will be able to go on this or that ride as this may not be the case.

On entering Disneyland you go to the Town Hall with your orange badge or proof of disability. You will now be asked to fill in a questionnaire consisting of about 10 questions, eg, Can the disabled guest climb a ladder or run thirty metres? Depending on your answers, you will be given a white, blue or green passport. The holder of this card has to acknowledge having read and understood the restrictions concerning access to the attractions described in the Disabled Guest Guide and accept them unconditionally. "The Cardholder will in no instance hold EuroDisney SCA responsible for restricting his/her access to any attractions other than those listed on the reverse side. The card has been created to meet your needs with regard to safety and comfort." A green card allows access to everything, and a blue card to several attractions. A white card is very limiting.

We suggest that you contact Disneyland Paris before you purchase your tickets to make sure your child will be able to go on the rides of their dreams.

### CARERS WEEK 11 - 18 JUNE 2001

Contact a Family is part of a UK-wide consortium of carers organisations which successfully bid for lottery funding to organise a bigger and better Carers Week in 2001. The consortium comprises: Carers National Association, Contact a Family, Crossroads Care, Black Carers Workers Forum, and the Princess Royal Trust for Carers.

The theme of the week will be Health and will highlight the need for carers to look after their own health, and for health professionals to be more responsive to their needs. All groups are being actively encouraged to get together with local carers organisations to plan some kind of event during the week.

Carers Week resource packs for groups are available in the new year, and these will include lots of ideas about how to run an event and get local publicity.

For more information contact: Patricia Orr or Amy Hodgson on tel: 020 7828 7720

## INFORMATION EXCHANGE

### DID YOU KNOW?

THAT WHEN YOU START  
RECEIVING THE STATE  
PENSION YOU ARE NO  
LONGER ENTITLED TO  
INVALID CARE ALLOWANCE

IF YOU FEEL THIS IS  
TOTALLY UNREASONABLE

(AS WE DO)

PLEASE CONTACT YOUR  
LOCAL MP  
TO REGISTER YOUR  
OBJECTION TO THIS CHANGE  
IN THE LAW

AND LET THE MPS OFFICE  
HAVE A COPY OF YOUR  
LETTER

### A Free "2000/2001 Toy Catalogue"

has been produced by the Royal National Institute for the Blind, which includes toys which have been specially selected for their suitability for blind and partially sighted children. The toys featured are available in many high street shops and can be enjoyed by all children, so brothers, sisters and friends can enjoy them too.

To order copies of the catalogue please contact:

Customer Services  
RNIB  
224 Great Portland Street  
London  
W1N 6AA

Tel: 0845 702 3153

### CASH FOR CARERS

Carers on Income Support (IS) will receive extra money and people on Invalid Care Allowance (ICA) will be able to earn more without losing their benefits, the Government has announced.

The £191m package was announced by the Social Security Secretary, in October.

The carer's premium claimed by 220,000 people on IS will increase by £2 a week. People on ICA will be able to earn £67 a week (previously £50) before losing benefit.

The Carers National Association (CNA) has been at the forefront of the campaign to improve the financial lot of carers. A CNA survey published in June found that one in five carers were cutting back on hot meals and buying out-of-date food.

Diana Whitworth, CNA chief executive, said that the new measures would make a significant change to the lives of many carers, but that the campaign would continue to ensure that the carer premium is doubled and that all carers are recognised for the enormous contribution they make to society.

### KEEP WARMER THIS WINTER

Have a warmer, healthier home with a grant from the Government's Home Efficiency Scheme (HEES)

This scheme is funded by the Department of the Environment, Transport and the Regions. It provides a grant of up to £2,000 to make your home warmer, more energy efficient and more secure.

HEES will focus on households with the greatest health risks - older people, people with children under 16 and people who are disabled or chronically sick.

The scheme is run by The Eaga Partnership in the West Midlands, South West, London, South East, North West & North East on behalf of the Government. It has been specifically targeted towards households on certain benefits who may need help to keep warm.

Please contact the MPS Office for more information.

## FUNDRAISING

### PRIZEWINNERS - GRAND DRAW 2000

PRIZE	WINNER	TICKET NO.
<b>1<sup>st</sup> Prize £650</b>	<b>Mr &amp; Mrs Harper, Dartford</b>	11773
<b>2<sup>nd</sup> Prize £350</b>	<b>Andrew Weedall, Runcorn</b>	10648
Pocket Computer	M Eggleton, Redhill	29368
Canon Camera	Mrs C Comber, Rugby	31362
£50 Leisure Vouchers	Davy Hancock, Chester	51971
£50 John Lewis Vouchers	Steve Hutton, Hammersmith	4233
£50 John Lewis Vouchers	Jack Thomas, Farndon	56153
£50 Argos Voucher	Lesley Hawkings	58350
P&O Travel Pass to France	A Obonna, London	23321
Manchester United football	Vicki Broderick, Runcorn	10690
£20 Chessington Park Voucher	Eileen Dooker, Wigan	16330
Middlesbrough F.C. Tour x 2	Mr & Mrs Harper, Dartford	11767
Audioline 13 memory phone	C J Wilkes, Brierley Hill	12778
£10 M & S Voucher	M Gillespie, Glasgow	41593
£10 Sainsbury's Voucher	Amanda Gregory, Cheshire	47413
£10 Sainsbury's Voucher	Marie Pattison, Burstwick	54080
£10 Sainsbury's Voucher	J Walker, Frizington	20066
£10 Wyvedale Garden Centre	Walter, East Goscote	0936
£10 M & S voucher	S Simmonds, Minerva	53697
Large Teddy Bear	John Russell, Glasgow	51796
Travel Bag and Flask	Mrs Hosking, Ebbw Vale	26080
Lego Bucket Age 3 - 12	L Windsor, Knaresborough	51319
Lego Bucket Age 3 - 12	M Murphy, Bristol	19915
Lego Bucket Age 3 - 12	Andrew Shields, Kilkeel	38036
Lego Bucket Age 3 - 12	A Stuart, Reading	9114
Silver Euro Calculator	D Chartrey, St. Leonards	52003
Clock/Photo Frame	Helen Stokes, London	25422
Child's Rucksack & filofaxes	C Campbell, Lockerbie	42534
Document Bag and Portfolio	W A Stuart, Reading	50311
Travel Bag with wheels	Una Dawson, Antrim	37692
Easel Photo frame	R Hatton, Pimperne	47682
Desk Clock and mini fan	A Hall, Winterbourne	47488

#### 1st PRIZE WINNERS

We received the following letter from Jenny and Allan Harper who were the 1st Prize winners in the Grand Draw:

*"Thank you for the cheque for our prize in the MPS Raffle. After thinking long and hard about what to do with it, we decided to make a donation to Little Bridge House, in Femington, as our niece spends time there. Also a donation to Cancer Research, as I have cancer (Jenny) and then treat ourselves to a holiday in the spring"*

Thank you for this letter - it is so nice to know that the prize money is going to make such a difference to so many lives - we hope you do get a holiday in the spring and wish you both well.

## FUNDRAISING

### COFFEE MORNING RAISES CASH

Dawn Jones, mum to Eleanor who is three years old and has Morquio syndrome, and Dawn's own mother recently held a coffee morning for the MPS Society and raised a staggering £165 !!

*Well done to you both, thanks for all the hard work and thank you to everyone who made the event such a huge success.*

### FUNDRAISING IDEA!

Samantha Huntley whose little brother Christian has Morquio syndrome is hoping to raise money for MPS by running the Reading Mini Marathon - she has explained to her school friends about Christian and several have said that they would like to sponsor the MPS Society as well.

### WELL DONE UNCLE IAN !!

We received a cheque for £114 from Sam Walker of Blackpool who told us that her Uncle Ian, who has special needs himself, raised the money by doing a sponsored walk around a local beauty spot near to his home in South Yorkshire. Sam went on to explain that her uncle raises quite a lot of money for different charities (mainly local) and that he never worries about himself, only about the help he can give to others.

*Our sincere thanks go to Uncle Ian for raising that great amount of money and to Sam for writing to tell us all about it.*

### Fundraisers - Please Keep In Mind

The MPS Society is a registered Charity and the Society's Management Committee are responsible under the Charities Act for all funds that are raised.

We are very grateful to those people who fundraise for the MPS Society regardless of the amount.

Please remember though, that it is very important when you are embarking on a fund raising venture, on the MPS Society's behalf using the MPS Society's name and/or any number of our materials, booklets, etc., that the total amount of monies raised must be sent directly to the MPS Society.

It is not legal to fundraise for something for yourself, a family member or friend in the name of the MPS Society, nor is it legal to use the MPS Society's materials if the monies raised are not being raised for the MPS Society.

### FIRE STATION OPEN DAY

Rosemary & Harry Nurse have been very busy raising money for MPS at their local Fire Station open day.

From the photos it looks as though they had lots of help from Lisa Nurse and Thomas Birch!

*Well done to everyone who helped and supported this event.*





## FUNDRAISING

### FUNDRAISING EVENTS

The Society is grateful to the following who held fundraising events

Nigel Taylor – Running London Marathon  
 Jenny Hardy's mum – Sale of marmalade  
 Pam Ballard – Sale of old MPS stock  
 Lakeside Infants School – Harvest Festival  
 Andy and Jenny Hardy – In lieu of Silver Wedding presents  
 Mrs Tilley – Collection  
 Charity Flowers – Commission  
 Ian Lane – Five Mile Sponsored Walk  
 Dawn Jones – Coffee Morning  
 Midlands Xmas Party – Raffle  
 Mrs T Stokoe – Webb Ivory Catalogue sales  
 Occasions – Selling spare envelopes  
 Coronation Dental Practice – Boat trip/raffle  
 Rebecca & Peter Caplan – Charity Clay Pigeon Shoot  
 St Georges Hill Golf Club – Charity Golfing Day  
 Marston Institute Ladies Bowling – Collection in lieu of sending Xmas Cards  
 Mrs Carol Westland – Sale of Bric-A-Brac  
 Pearl & Tony O'Neil – Auctioning Marrow Wine at Folk Festival  
 Stonelaw High School – Sponsored Swim  
 Graham & Margaret Moore – Coffee Morning

#### KINDLY DONATED TO THE MPS SOCIETY IN MEMORY OF

Grant Pollard  
 Agnes McBride  
 Edward Nowell  
 Dennis Rowan  
 Mr Skidmore  
 Gethin Robins

## DONATIONS

The Society is grateful to the following who made donations

BP Chemicals  
 Mr & Mrs Stuart  
 Burghley Charitable Trust  
 Anne Cock  
 Blythe Liggins  
 Jane Heritage  
 M G & P Hammond  
 K Williams  
 Linda Pack  
 Mrs Davison  
 Mrs Hodgkins  
 D Rickett  
 Slater  
 Gulam Seedat  
 Adam Sutcliffe & John Dansey  
 Rotary Club of Amersham  
 Mrs Garthwaite  
 Amtrade International, Amersham  
 Linda Saunders  
 J & Mrs Hancock  
 Joseph Strong Frazer Trust  
 J & E Heisig  
 Mayor of Hyde Trust Fund  
 Mrs Sheridan  
 W McGinn  
 Angela Seymour  
 E Temple  
 Carl Major  
 Mr & Mrs Arnold  
 Mr & Mrs Brown  
 Go-Ahead Group plc  
 M J Beane  
 D Holmes

Dr McIndoe  
 Gibbs family  
 James & Jeanette Reid  
 Mr Norseworthy  
 Mr Ritchie  
 Milton Keynes Japanese Women's Club  
 TKT Europe  
 R.A.O.B. Dereham Lodge 9142  
 Norwest Holst Group plc  
 Douglas Heath Eves Charitable Trust  
 Mr & Mrs Blanch  
 Mr Roy Moody  
 UCI Cinemas, High Wycombe  
 Elizabeth Jenkins  
 John Nicholson  
 Relief Chest Scheme, Grand Charity of  
 Freemasons  
 Susan Lowry  
 Jessica Stuart  
 MIAA, Liverpool

#### **STAMPS**

Anne Kelly  
 Rebecca (Australia)

#### **FOREIGN MONEY**

The Jones Family

#### **COLLECTION BOX**

Gillingham Fire Station  
 Rectory Meadow Surgery



## MANAGEMENT COMMITTEE

<b>Chairman</b>	Mark Beniston 17 Hameldon Close Hapton Burnley BB11 5QY
<b>Vice-Chair</b>	Angela Brown Steve Butler
<b>Treasurer</b>	Vince Hayward
<b>Members</b>	Rob Devine Bernie Drayne Judith Evans Gordon Hill Sarah Long Wilma Robins

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

Tel: 01494 434156  
Fax: 01494 434252

**OUT OF HOURS HELPLINE: 07712 653268**

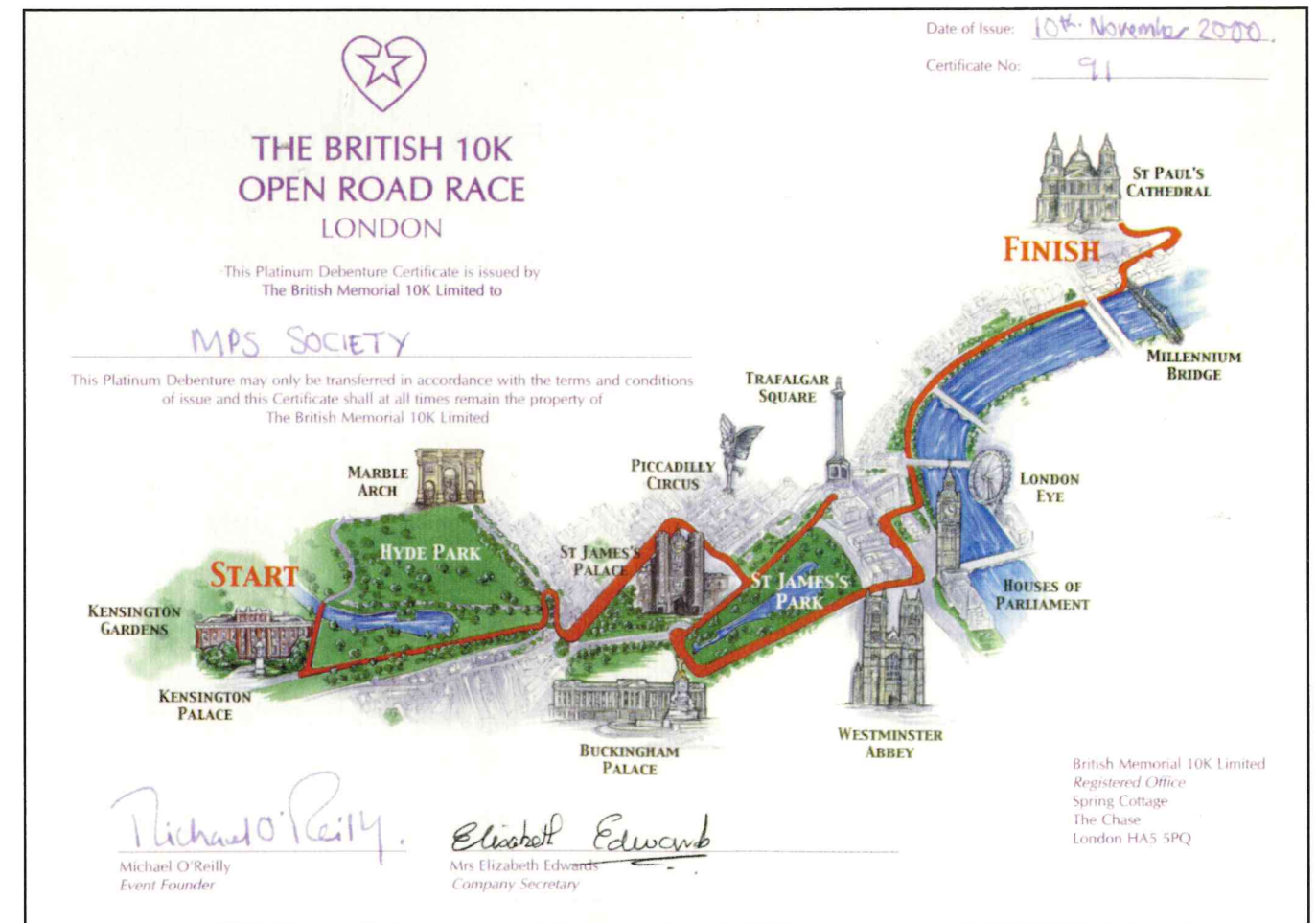
email: [mps@mpssociety.co.uk](mailto:mps@mpssociety.co.uk)  
Home Page: [mps@mpssociety.co.uk](http://mps@mpssociety.co.uk)

<b>Staff</b>	Christine Lavery Ellie Gunary Hannah Crown Angela Ratcliffe Kate Crown Alex Roberts Gina Page Sue Taylor	Director Senior Development Officer Development Officer Development Officer (Research) Project & Information Officer Development Assistant Administration Officer (Finance) Administration Officer (Finance)
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### NEWSLETTER DEADLINES

<b>SPRING</b>	31 March 2001	<b>SUMMER</b>	30 June 2001
<b>AUTUMN</b>	30 September 2001	<b>WINTER</b>	31 December 2001

## SUNDAY 22 JULY 2001 10K / 6.2 Miles Sponsored Run



### Raise money for the MPS Society 12 Guaranteed Places for 2001 Race

For all you sporting MPS members who think a full marathon is beyond you, how about something a little shorter? The road race, taking place for the first time this year, will pass through some of the most scenic parts of London, and bands will be lining the route. Places are limited. If you are interested, please give either Sue or Gina a ring at the MPS Office - they will be allocated on a first come first served basis, and there is no minimum sponsorship, although we would hope that all participants would be able to raise at least £100.

**Sponsorship forms are available from the MPS Office**





# REGIONAL MPS CLINIC DATES



**North East**  
Royal Victoria Infirmary Newcastle

Tuesday 6 February

**Bristol**  
Frenchay Hospital

Tuesday 15 March

**Wales**  
University Hospital of Wales

Friday 16 March

**Northern Ireland**  
Hilton Templepatrick

Friday 18 May

**Scotland**  
Venue to be confirmed

Thursday 7 June

**Birmingham**  
Birmingham Children's Hospital  
Thistle Hotel (adults evening)

Friday 6 July

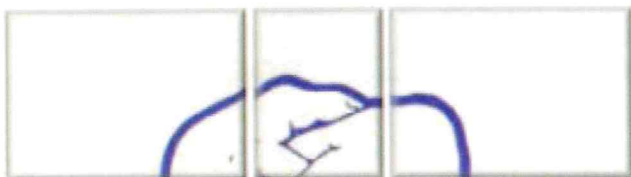
**Bristol**  
Frenchay Hospital

Thursday 18 October

**Wales**  
University Hospital of Wales

Friday 19 October

The Society For Muscopolysaccharide Diseases  
46 Woodcote Road, Atherton, Buckinghamshire, HP16 6AL, England



[www.mpsociety.co.uk](http://www.mpsociety.co.uk)

Please click a link on the top above to access an area of the site. Hover your mouse over above for a description of the contents.