

# Newsletter

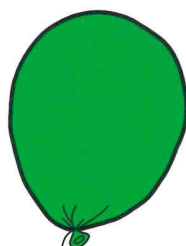
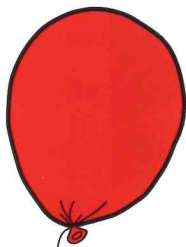
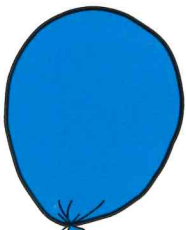


## The Society for Mucopolysaccharide Diseases

National Registered Charity No.287034

### 18th Birthday Edition

Autumn 2000



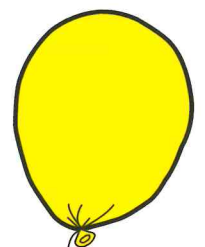
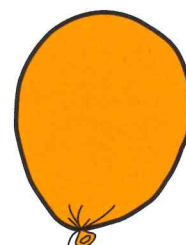
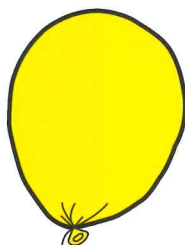
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# 18 YEARS OF MPS



In 1985 the MPS Society facilitated the first cervical fusion for Morquio disease in England using the 'halo' method and bone grafts from the legs. Dr Steven Kopits and his nurse specialist came from Baltimore, USA to operate on Helen at university college Hospital, London and transfer his knowledge to Mr Andrew Ransford, consultant orthopaedic surgeon.



Dr Ed Wraith with America's first Bone Marrow Transplant patient for Hurler Disease at the first International Symposium on MPS and Related Diseases. Minneapolis May 1988.

The photograph on our front cover is of

**Thomas & Louis Gartwaite**  
on their return from the conference outing to  
the American Adventure, aged 6 & 4 years,  
both boys have Hunter disease.



Scott McCarthy who suffered from Hurler Scheie Disease presented with Disabled Scot of the year for 1985. Scott was nominated by the MPS Society.



"A discovery that came too late." Professor John Hopwood from Adelaide Australia, with Robert Culley and Christopher Shorthouse. Research on the two boys led to the isolation of the Hunter Gene.

### Baby's pioneering gene operation

A BABY aged 10 months made medical history today by undergoing the first gene therapy operation of its kind in order to save her life.

The girl, who suffers from a genetic disorder known as Hurler Syndrome, was having her own bone marrow transplanted back after it had been genetically altered in a laboratory. The operation was being conducted at the Royal Manchester Children's Hospital.

July 1997



## '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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Deadline for the Winter Newsletter is 31 December 2000

## CHAIRMAN'S REPORT

*Presented by Wilma Robins at the  
Society's Annual General Meeting Friday 8 September 2000*

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

The Trustees are required to comply with new legislation. The Society has for many years worked to strict confidentiality and equal opportunities policies. Current policies include data protection and increased compliance with Health and Safety, in particular in the organisation and delivery of external activities. The provision of days out and family events have had to be tailored to meet the strict requirements of the Health and Safety legislation. These policies have a major impact on all the services offered to our members. I want to thank all Area Support Families who over the years have organised and provided support for so many enjoyable family activities. Many of you have indicated your willingness to continue to support us in the organisation of regional annual events and for this we thank you.

During the year the Society has continued to develop its Befrienders Scheme. These schemes operate with due regard to the Society's responsibilities to the families' rights to privacy and data protection. Charities like ourselves learn from one another how to develop best practice in applying new legislation but if from time to time our services fall short of the high standard we have set ourselves, we have put in place a complaints procedure that will allow for concerns to be addressed both sensitively and confidentially.

The Trustees continue to monitor the delivery and efficacy of Family Support and Advocacy. We are pleased to inform our membership that during this year the MPS Staff have provided a full and professional service to a record number of families and professionals seeking their help.

In 1999/2000 the Society extended its MPS clinic programme to include Newcastle. This brings to 10 the number of regional MPS clinics held annually. On behalf of the MPS families who benefit from these clinics, the trustees express their gratitude to Dr Ed Wraith without whom these clinics would not have been possible.

From the Society's conception, to this its 18th year, the Trustees have supported over £1,000,000 of aid in scientific and clinical research into MPS and related Diseases. For the last four years all the funds given to research have come from the Jeans for Genes appeal and donations restricted to research given to family and corporate donors. In this year we are very pleased to report the breakthrough in Enzyme Replacement Therapy for MPS type I, which is due to be trialed clinically in the UK shortly after Christmas. The Trustees realise this is only the beginning of a challenging path for scientists given that there is a large number of MPS and related disorders hoping for similar breakthroughs. The MPS Society is here to support the MPS families going forward in the field of research and with renewed vigour we will support the hope for tomorrow for those families waiting in anticipation.

On behalf of all Trustees, I want to thank our staff team for their hard work and total commitment. I know they want to thank you, the member families, for the understanding and support you have given them over the past year.

On a personal note I have had three challenging but rewarding years as Chairman but it is time now for someone else take the reins. I look forward to spending my final two years as Trustee on the 'back bench' of the Management Committee helping to ensure that we can achieve a satisfactory balance between complying with the demands of the data protection and health and safety legislation, with our desire to continue to provide the best possible support in all ways for our families.

The Society having attained 18 years of existence now comes of age. Nothing stays the same forever and the changes in the organisation in the last 2 to 3 years were necessary to ensure maximum value for money from our funding, with increased efficiency of our operations both clinical and family support.

Managing change is never easy but I believe that we have emerged as a stronger organisation fully capable to continue the provision of high level and qualitable support to an increasing and diverse membership, as we embark on the 21st Century.

## TREASURER'S REPORT

*Presented by Vince Hayward at the  
Society's Annual General Meeting on Friday 8 September 2000*

### 1998/99 Accounts

The Income for the Society in this accounting period was £742,588 against £795,261 in the year ending 31st October 1998. Income from corporate donors and trusts held up well as did grants and other restricted income. Restricted money is given by the donor for a specific purpose and may not be used for any other activity.

Unrestricted income in 1998/99 was considerably reduced on the previous year, largely attributed to a loss of fundraising receipts historically raised by membership. In contrast restricted income from Jeans for Genes increased for a fourth consecutive year with an increasing number of MPS families promoting and supporting this appeal of which the Society is one of a consortium of four charities working together. The overall surplus for the year was £137,087 compared with £289,038 in 1997/98.

Costs are increased due to additional amounts spent on direct charitable expenditure in the form of Family Support Services and increased restricted expenditure on Jeans for Genes research, support grants and joint venture funding. I am pleased to report that administration expenditure has been reduced with the Society operating from one office base. Trustees envisage further savings on administration once all the Health and Safety requirements have been met.

This overhead gives a breakdown of Family Support charitable expenditure. The Trustees were pleased to be able to increase expenditure on direct family support by £42,839 in year ending 31st October 1999 compared with the previous financial year.

### Fundraising

Facing another year of reduced unrestricted income the Trustees will be looking at policies that allow the Society to direct its family support services primarily at those families loyal to the Society and who solely rely on the support of the MPS Society.

The Society has a number of fundraising activities in the pipeline and trusts that members will support our 18th birthday annual draw and the sale of our Christmas cards. Responding to member's views we held a competition to design a Christmas card for the year 2000 and would like to congratulate Isobelle Gee aged 8 for her successful entry.

The Society's Web site has continued to be developed over the past year. In the Summer of 2000 the Trustees agreed to set up a secure trader to allow the Society to receive donations on the Internet. We hope to progress this in the coming months so that the Society's publications and Christmas cards can also be purchased on the net.

Finally I would like to impress upon the members that family support remains as in the previous 17 years a major role of the Society but remind families that the Society can only deliver in line with the income and resources of the Society.

## NEWS FROM THE MPS OFFICE

### GREAT ORMOND STREET USERS MEETING

Following the release of the NHS target report from the Government I was invited by Sally Nethercott, Director of Nursing and Family Services at Great Ormond Street to meet to discuss the hospital's strategy for involving the users of the services - the parents and children. The meeting was a great success with discussions based around the hospital's targets for the future. A wide range of people attended including support groups, Directors of care at the hospital and parents of children in long term care both as in-patients and out-patients at the hospital. The next meeting will take place on 25th November. If there is anything you would like me to raise at this meeting please let me know.

*Hannah Crown  
Development Officer*

#### Some questions that were raised:

1. How do parents and children think we could learn from their experiences of Great Ormond Street Hospital?
2. What things could we do to show parents that we are listening to their concerns?
3. Do parents want to be involved in Trust business activities?
4. How do parents think they could be involved in Trust business activities?
5. What do parents think they could offer to enhance the working of the hospital?
6. How should parents be chosen to assist?
7. Is there a role for a Parents' Advisory Council?
8. How can we involve children?
9. What are the training needs of Great Ormond Street Hospital staff and parents for this work?



### MPS CHRISTMAS PARTIES



As Christmas is approaching (only 9 weeks!) the MPS Development Team as well as their day to day work of providing advocacy and support to individual families are busy organising the Christmas parties.

The MPS staff are busy contacting and liaising with volunteer regional event co-ordinators (throughout the UK) to organise Christmas parties.

Ten parties are planned, in the following regions:-

Northern Ireland	Scotland	Wales
North East of England	Yorkshire	North West of England
Midlands	South East	East Anglia
South West		

You will find an insert with this newsletter giving full details of each event. Each MPS family or individual will be sent booking forms for the Christmas party which falls in their region.

If you are interested in attending an alternative party outside your region, please contact the MPS office.

These events are funded through a grant from the BBC Children in Need Appeal, to whom the MPS Society extends its thanks.

*Ellie Gunary  
Senior Development Officer*

**JEANS FOR GENES**

On Friday the 6th October 2000 it was national Jeans for Genes day. Many people from all walks of life, offices, shops and schools and from all over the UK took part by wearing their Jeans to work or school and paying £1 to the Jeans for Genes appeal.

On the Wednesday before Jeans for Genes day I joined two MPS families plus families from other 3 support groups, PIA, CGD and CF at Topshop at Oxford Circus in London for a press call with pop star Samantha Mumba.

Ashleigh Tomes who is 3 years old and has Hurler disease travelled up from Plymouth on Wednesday morning with his two sisters, his mum and grandmother. As you can see from the photographs below Samantha really did fall in love with Ashleigh.

Maryam Ahmed who is 8 years old and has Morquio disease came along to meet Samantha with her three cousins and her mum. We had a great morning meeting Samantha and the children enjoyed the press call.

I spent the afternoon with Rachel, Emma and Wendy in the Jeans for Genes office. It was a very busy afternoon in the office with the phones ringing constantly but it was also very interesting to spend some time there. I would like to say thank you very much to Rachel, Emma and Wendy for making me so welcome.

By 4.00pm we all went back to Topshop to hear Samantha Mumba sing. By which time Ashleigh had fallen asleep.

Don't forget to send in your Jeans for Genes day stories for us to publish in the next newsletter.

*Hannah Crown  
Development Officer*



**REGIONAL MPS CLINICS**



*MPS office staff  
In their Jeans for  
Genes T-Shirts*

**REGIONAL MPS CLINIC DATES**

<b>Birmingham</b> Birmingham Children's Hospital Thistle Hotel (adults-evening)	Friday	5	January
<b>East Anglia</b> Norfolk and Norwich Hospital	Friday	19	January
<b>North East</b> Royal Victoria Infirmary Newcastle	Tuesday	6	February
<b>Bristol</b> Frenchay Hospital	Tuesday	15	March
<b>Wales</b> University Hospital of Wales Cardiff	Friday	16	March
<b>Northern Ireland</b> Hilton, Templepatrick	Friday	18	May
<b>Scotland</b> Venue to be confirmed	Thursday	7	June
<b>Birmingham</b> Birmingham Children's Hospital Thistle Hotel (adults-evening)	Friday	6	July
<b>Bristol</b> Frenchay Hospital	Thursday	18	October
<b>Wales</b> University Hospital of Wales Cardiff	Friday	19	October

These are in addition to the twice yearly Bone Marrow Clinics held at Manchester and the regular NHS MPS Clinics held in Great Ormond Street, the National Hospital and Manchester.

MPS CLINIC

Bone Marrow Clinic  
Royal Manchester Children's Hospital

Friday 29th September 2000

The bone marrow clinic is held twice a year at the Royal Manchester Children's Hospital. The most recent clinic was held on the 29th September 2000. Ten children aged between two and twelve were seen by Dr Ed Wraith, Dr Andy Will and a team of further doctors and medical staff from the hospital.

The pictures include Sue, the bone marrow transplant nurse specialist, Gill, metabolic nurse specialist and Bernie, nurse auxiliary. Gill and Bernie are based at the Willink Unit and support all the MPS clinics held there. Sue is a familiar face of all the families who have undergone bone marrow transplant.

Many of the children seen were presented with certificates for bravery (Callam Pollock is pictured with his below). By common consensus it was agreed that all the children were very brave by just walking into the clinic room which was filled with people, a daunting experience for anyone!



Emma Slater

Callum Pollock



Angela Ratcliffe, Development Officer Research, attended the clinic with me. While she gained valuable information for the MPS research database, I spoke with families, catching up on how the children were doing and the advocacy support needed. Thank you to those families who took the time to answer Angela's questions.



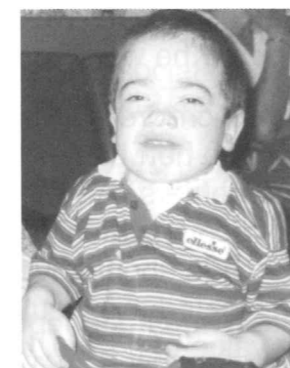
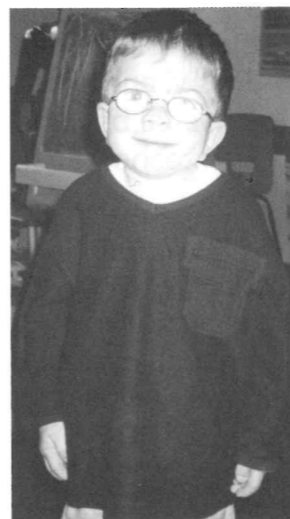
Sue & Gill

Joseph Malone



MPS CLINIC

Bone Marrow Clinic



In between talking with families Angela and I became David Baileys taking photographs of all the children some of which we have included here.

I on behalf of the MPS Society would like to extend our thanks to all the staff at the Willink Unit and the Royal Manchester Children's Hospital for their help in making the clinic such a success. We were especially grateful to Christine and Bernie for arranging all the refreshments. These were very much appreciated by everyone.

We look forward to seeing everyone again at the next BMT clinic in 2001.

Ellie Gunary  
Senior Development Officer



From top left to bottom right: Bradley Evans, Matthew Ingram, Mohammed Razaq, Bilal Mohamed, Alex Cosgrove, Aiden Brown, Jacob Singleton and Bernie

## CONFERENCE PRESENTATION

**I presented the following talk at the MPS Society's 18th Anniversary Conference having first stressed that I was speaking as a family member of the MPS Society and not an employee. My talk in no way reflects my professional role and is to be read as a personal account of my experience of caring. Ellie Gunary**

### A PERSONAL EXPERIENCE OF CARING

#### MEETING

When I met my future husband in 1987 the first things to strike me about him were his beautiful eyes, his winning smile accompanied with dimples and his very mischievous sense of humour. We talked and talked sharing our opinions on all sorts of subjects, putting the world to rights. We enjoyed many mad escapades - camping without a tent in the Norfolk Broads, picnicking in the rain on the coastal path and trying to walk across muddy beaches in the pitch dark after having sat and watched the sun set.

We discussed the future. We met at a residential care home where we were both working as volunteers. Paul hoped to become a manager of a residential home for adults with disabilities and over the next few years gained relevant qualifications. My hope was to become a nurse but I eventually trained as a social worker myself. We both wanted children. Paul held a few concerns as to how he would cope being a father.

Would he be able to physically keep up with children? How would he feel if he could not compete in their games of football? Would he hurt babies holding them with his clawed hands? We discussed the fact that our daughters would be carriers of Paul's disability, Hunter Disease. We accepted a long-term commitment to any future daughters to support them in whatever decisions they made about having children. If they decided to terminate any affected pregnancies we accepted this would be very difficult for Paul with the implicit message this gave about the value of his life, but we would support them and be there or not as they wished.

Three months after we met Paul asked me to marry him. We looked forward to a long and happy future together. In order to complete our studies we waited a further six years before getting married. We saw no reason to hurry; we had the rest of our lives together.

#### INDEPENDENCE

Hunter disease was not part of our lives. Paul was totally independent. He drove a car, worked in a physically demanding job and lived in his own flat. He developed his own techniques for dressing which overcame the limited movement in his arms. His technique for putting on socks for example involved balancing on the edge of the bed with the sock just over his toes and throwing himself backwards. Paul told me about Hunter disease. He had been told he might need a couple of operations in the future a heart bypass and a hip replacement but apart from these he would be well and would lead a long life.



## CONFERENCE PRESENTATION

This is what his parents had passed onto him from what they were told when he was diagnosed in 1973 at the age of seven. With our friends Paul's disability was rarely mentioned. He was taken for who he was and not his physical appearance. We were occasionally aware of stares. Some people expressed shock I was in love with Paul but I brushed these comments aside sorry these people could not see beyond physical appearance.

The first real encounter we had with prejudice was from my parents and their reaction when Paul and I made our engagement official. They hinted at Paul's disability being degenerative and spent the whole of one night trying to dissuade me. Believing they had read up on the wrong disability we did not listen. If we had listened we would have only got married sooner.

#### MPS SOCIETY

Paul made his first contact with the MPS Society in 1989 at the age of 23. His interest was mainly academic. He was writing a college project and needed information. Soon after talking with Christine Lavery he attended an MPS regional event. Paul, when we next met up told me about all the small children he had seen with similar physical characteristics and mannerisms to his own. He went through a difficult few months as he adjusted to the fact that these were associated with his disease and not his character. Paul had after all lived 23 years without meeting anyone else with Hunter disease. We attended our first conference and even then did not take on board what MPS could mean in the future. There was no one to share our experiences as partners rather than parents and much of what we heard did not appear to apply to us.

#### DETERIORATION

My hopes for the future were bright and I had no expectation whatsoever of losing my husband before our fifth wedding anniversary. We bought our first home, tried for a family and pursued our careers. The first indication of Paul's deteriorating health we took in our stride. Paul developed epilepsy. Supporting people through epileptic seizures was second nature to me as a regular aspect of my care role at work. The difference with supporting Paul was that I loved him and found supporting him through seizures emotionally draining. For Paul he lost an important aspect of his independence, being able to drive.



*Paul & Ellie on their  
Wedding day*

## CONFERENCE PRESENTATION

### LEAVING WORK

After four years of marriage Paul began to experience real physical difficulties. It was obvious to me he was struggling. He rarely managed to attend work and when at home did not get out. Paul stubbornly refused to accept my suggestions of giving up work to help him adamant that he was not going to live on Benefits. He had not even applied for Disability Living Allowance previously.

We met with Christine Lavery at an MPS event and having had an opportunity to talk with her Paul agreed to me leaving work. In the months ahead I came to realise that in decisions such as this one I would become the target of Paul's anger and frustration, the enemy in many ways, threatening his wish that everything could remain the same, threatening his denial that he was becoming more physically frail.

Paul would accept other people's observations and advice but not mine. I was too close. Four weeks later while I was working my notice Paul fell and very suddenly lost his ability to walk. Very suddenly I became his carer. For Paul and me this meant that gradually we felt our identities disappearing, our sense of self worth and our health all dissipating, sometimes in quick bursts and sometimes more gradually.

### IDENTITY

I became Paul's carer in place of his wife or Ellie. I became his arms and legs as he became totally reliant on me for the meeting of all his physical care needs and Paul lost the ability to physically act independently. Paul lost the ability to talk more than a few words. His eyes spoke of unvoiced thoughts and feelings but he was trapped by the physical limitations of his body. His words consisted of nothing more than toilet, drink and other single words to this effect. When he needed me he used a bell. Not hearing my name left me feeling I was no longer a valued person. In his insecurity Paul clung to me. I could not leave the room for more than five minutes without him worrying. At night even if there was a nurse present it was I he wanted with him when he felt particularly ill.

### RESPITE

I was allocated six hours respite a week in two sessions. The second session was frequently cancelled due to lack of staff. Before I was due to take a break I felt I was being made to suffer for it. Paul would become sullen, quiet and poorly. This was not intentional but an expression of Paul feeling scared I was not going to be around for a little while. I responded to the guilt I felt in needing a break by trying to make up for my few hours of freedom by overcompensating in meeting Paul's wishes. His wishes became uppermost and mine denied. I for example when with him watched endless hours of cricket on Sky television rather than ask for half an hour to watch a programme I would enjoy.

## CONFERENCE PRESENTATION

### PHYSICAL RELATIONSHIP

We lost our physical relationship. I met Paul's every care need from washing him to wiping him after he had had his bowels open. Paul lost control of the physical functions of his body. He became doubly incontinent and was terribly embarrassed by this. He lost his ability to swallow and became fed by gastrostomy. He reacted to me meeting his care needs by withdrawing from me in many other ways. His physical space was invaded so often through the meeting of his care needs there was no room for a sexual relationship as an expression of our love. Even harder to cope with was his withdrawal emotionally from our relationship. I think he found it so hard to accept that our marriage had ended up with him totally dependent on me rather than him being the provider and supporter he withdrew from thinking of me as his wife. Instead I became his carer. We were living with each other having already lost each other in many ways.

### OTHER RELATIONSHIPS

My relationship with my parents in law changed. They were understandably very worried and wanted to know on a daily basis what was happening and how they could help. No one could help. No one could bring my husband back. Paul's parents as would be expected being parents rather than a partner or wife coped differently to me. They wanted to know all the medical decisions, what the doctors were saying, which tests were being done? They were asking me for answers to questions that I was not ready to ask yet. I was not ready to hear the answers. I just wanted to be with my husband as his wife. This was very hard for them as they lived three hundred miles away and relied on me to communicate what was happening. They began to question whether I was acting in Paul's best interests. Paul relied on me to maintain his independence and carry out his wishes many of which they questioned. It became apparent what was happening after a few months and thanks to a lot of support from Christine Lavery we soon re-established a close relationship.



*Paul, Ellie & friends 1991*

*Due to the space restraints in this edition the second half of this talk will be featured in the next Newsletter (January 2001) - however, if you would like to read the concluding part before January please contact the MPS office and we will be happy to send you a copy*



## FAMILY SUPPORT

### MPS Financial Support Scheme

The MPS Financial Support Scheme is being organised to assist affected individuals and/or their families with some financial assistance. This assistance may be in the form of a loan or a grant and is primarily aimed at providing help in accessing MPS Society support i.e. attendance at events including conferences and regional days.

A small panel will review your application and let you know a decision as soon as possible.

These grants and loans are subject to members being in good standing where the MPS Society is concerned and have occasional participation with the Society (i.e. fundraising, writing letters, contact with other families etc).

If you would like to request funds, please contact the office for a FSS Form. All completed forms will require details of actual costs and for auditing purposes, receipts will be required.

### Carers Grants for 2000-2001

The provision of additional funds to local authorities in England and Wales to provide short-term breaks for carers began last financial year (1999-2000) with £20 million being distributed. The Order laid before Parliament last year was drafted in such a way as to exclude parent carers. However, as a result of representations made by Contact-a-Family, Mr Hutton undertook to ensure that parent carers would be eligible for short-term breaks provided under the £50 million made available this year and the £70 million for next year.

Contact-a-Family are pleased to report that this years order for the local authorities in England specifically includes parent carers and gives local authorities a great deal of flexibility in how to administer the grants. However, our colleagues in Wales cannot find an equivalent direction for their local authorities and this is a matter that will have to be taken up with members of the National Assembly for Wales. Local authorities have been required to produce a plan for the expenditure of these additional funds and so it is advisable for local parents groups to request a copy of that plan.

Please let Contact-a-Family know what is happening in your locality. They and several other national voluntary bodies are determined to monitor the expenditure of these funds and satisfy themselves that Parliament's intentions have been met.

There is a Government web-site for carers at:  
[www.carers.gov.uk](http://www.carers.gov.uk)

Contact-a-Family: Tel: 020 7383 3555  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

### SUPPORT TO MPS FAMILIES

The MPS Society aims to provide a range of support services for everyone who lives with MPS. Support costs money but we aim to provide our services free of charge to the families who need us. And, there are many families who need us - Did you know that the Society supports over 1,000 families affected by these diseases. Did you know that 1 child born every 9 days in the UK will be diagnosed with MPS or a Related Disorder.

#### Costs for this support

It costs:

£50 a day to run our Telephone Support

£6 to send a new diagnosis Information Pack

£21,000 to stage our annual conference  
(net of families and professional contributions)

£270 a week to maintain our befrienders network and provide regional days including Christmas parties and the remembrance day in the childhood wood.

In all we need £270,000 this financial year (Nov 2000-Oct 2001) to maintain our services at their current level. We'd like to do more to help all who live with MPS - can you help us?  
Will you help us?

## CONFERENCE VOLUNTEERS

### *Volunteers*

#### **Erma Bombeck's Dream**

I had a dream the other night that every volunteer in this country, disillusioned with the lack of compassion, has set sail for another country. As the boat moved away from the pier, I reflected, "Serves them right; a bunch of YES people. All they had to do was to put their tongue firmly against their mouth when they were asked to do something and say NO. No more washing smocks, no more saving old magazines, no more time spent in meetings"

The hospital was quiet when I passed by. Rooms were void of books, flowers and voices. The playroom held no children's laughter... the reception desk was vacant. The home for the aged was like a tomb. The blind listened for a voice that never came. The infirm were imprisoned by wheels on a chair that never moved. Food grew cold on trays that would never reach the mouths of the hungry. All the social agencies had closed their doors, unable to implement their programmes. The handicapped, the lame, the lonely, all were abandoned.

The health agencies had a sign in the window, "Cures for Cancer, Muscular Dystrophy, Multiple Sclerosis, Kidney Disorders, Heart Disease, have been cancelled due to lack of interest". I fought in my sleep to regain a glimpse of the ship of volunteers just one more time. It was to be my last glimpse of civilisation..... as we were meant to be.

Day by day, the number of volunteers decreases in the country as more and more of them equated their worth in terms of pounds and pence. Volunteers do not contribute to civilisation. They are civilisation - at least the only part worth talking about. They are the only human beings on the face of this earth who reflect the nation's compassion, unselfishness, caring, patience, need and just plain loving to everyone.

Maybe, like a yacht, the volunteer was a luxury. And luxuries are too often taken for granted. One has to wonder. Did we as a nation, remember to say to the volunteers, "I thank you for our symphony hall. Thank you for the six dialysis machines. Thank you for sitting up with a 15 year old who overdosed and begged to die. Thank you for the hot chocolate at the Scout meeting. Thanks for reading to the blind. Thanks for pushing the wheelchair into the sun. Thanks for being" Did the media stand behind them when they needed a boost! Did the professionals make a point to tell them that they did a good job!. Did the recipients of their time and talents ever express their gratitude! It frightens me somehow, to imagine what the world will be like without them.

**(borrowed from the book "At Wit's End by Erma Bombeck)**

*THANKS TO ALL OUR  
MPS CONFERENCE VOLUNTEERS*

*We couldn't have done it without you!*

## CONFERENCE 2000

### DIARY OF THE 18th ANNUAL CONFERENCE

At last Friday 8th September has arrived. During the previous 4 to 6 weeks, and especially during the last 2, the whole office and all the staff have been working towards this weekend.

Everything is ready now and we are on our way to the hotel. It is an early start after a late finish the evening before but we know that it is an early start for many of the families also. We are looking forward to seeing the families who have been to the conference before and meeting the new ones. Many of the speakers, volunteers and professional delegates are also on their way.

The hotel is ready for us and we set up our reception table and the mini market. Angela, Ben and Hannah Kubie go off to the Cash & Carry to buy boxed drinks, crisps etc. Christine and Ellie go to Tesco's to buy the wine to celebrate the 18th Birthday and Balloon Release. Conference and Crèche rooms are checked and the MPS staff change into smart clothes in readiness for the first arrivals. The day then rushes by with so many people to meet and greet and book into the hotel. Kate, Sue, Sasha and Alex are on reception. Christine, Ellie and Hannah meet as many of the families as possible and Angela looks after the overseas professionals. There are very few problems and nothing that we can't cope with.

The AGM starts at 7pm. There is an entertainer in the Spencer Suite to keep the children amused while the AGM is in progress but at 7pm he has not arrived - HELP! - there are lots of children, what are we going to do? We are saved by one of our long standing volunteers, Helen Patterson, she walks through the hotel door, is commandeered by Christine and before her feet can touch the ground she is in the Spencer Suite entertaining a hoard of excited and noisy children - that was perfect timing Helen!

Most of the volunteers arrive during the early evening as they have worked all day before driving to the hotel and some of the families arrive very late as they have had long journeys.

Saturday dawns bright and sunny with the promise of a hot, late summer, day ahead. All the staff are down to breakfast very early. Kate liases with Bjorn, the hotel manager, and outstanding matters are dealt with. Families gather to meet up with their volunteers and get the children onto the coaches for their trip to the American Adventure Theme Park. We realise that the 2 disabled coaches are a great asset to the people who need to remain in their wheelchairs during transit but they take longer to load - make a note for next year.

The families and professional delegates prepare for the conference to begin and the children staying in the hotel are delivered to the crèche and their volunteers. The crèche attendance is large this year and we are using all 5 meeting rooms to accommodate everyone. The volunteer crèche leader, Jean Moore, arrived early yesterday to help prepare the rooms and make sure everything was in place for today. This has paid off, and there are very few problems to overcome this morning.

Everyone is welcomed by Dr Charles Pennock and the conference begins. It is the biggest conference so far and the Collingtree Suite is very full. There are many interesting speakers and topics this morning; something for everyone.

Lunch is served and everyone appears happy and sociable. The morning session has gone well. The crèche is running smoothly. There hasn't been any contact with the theme park volunteers, so all must be well.

The afternoon Satallite Seminars begin at 2pm - these are a new concept this year. Each seminar has an international specialist in that particular diseases. The guest speakers have come from Australia, USA and Germany.

The coaches arrive back at 5pm - all in all everyone seems to have had a good day. There are no major problems. The children have their tea.

## CONFERENCE 2000

It is now time for the 18th Birthday celebrations. A crowd has gathered in the courtyard, the Morris Men dance and their cheque for £2000 is handed to the Trustees. Champagne is poured and the birthday cake cut. The balloons are released and while we stand and watch they are carried high up into the atmosphere.

The volunteers and teenagers have their supper. The teenagers are going out to the Megabowl in Northampton. The volunteers are babysitting. Nigel Ratcliffe is going to Patrol the hotel while the parents are enjoying the Gala Dinner.

The evening is a success and everyone relaxes and has fun.

Sunday heralds another early start for the staff. Kate discusses the programme for the morning with Bjorn. The coaches arrive again, this time they are off to Woburn Safari Park.

Conference Session 3 gets underway with the invaluable leadership of Dr Charles Pennock and Dr Ed Wraith talks about ERT. The morning promises more topics to interest everyone.

The children return to the hotel in time for a family lunch of roast turkey and all the trimmings.

The conference weekend is now over. It has gone so quickly! There have been so many interesting, happy people and exciting events.

It's back to the MPS office, unload the cars, tidy up the paper work, pay the bills and start planning for the next conference - if it is anything like as successful as this one we will be very happy people indeed!

*Kate Crown*  
Projects & Information Officer

Thank you to everyone who attended the conference this year, whether family, professional or volunteer you all contributed to making it the best conference yet!



(Pictures: Conference Mini-Market / Claire Garthwaite, Wilma Robins & Angela Brown)



**18th BIRTHDAY BALLOON RELEASE**

To celebrate the Society's 18th birthday 35 blue and white balloons were released into the sky at the same time by children suffering from Mucopolysaccharide and Related Diseases. Each balloon had a tag from the 350 adults and children attending the MPS annual Weekend Conference.

Even though it was a clear evening on 9th September with quite a strong breeze and a prevailing wind from the west none of us gave a thought to just how far the balloons would go. Some balloons did not fly very high and landed in England, East of Northampton. Amazingly other balloons must have gained great height to cross the North sea and the Netherlands landing in Germany and Poland.



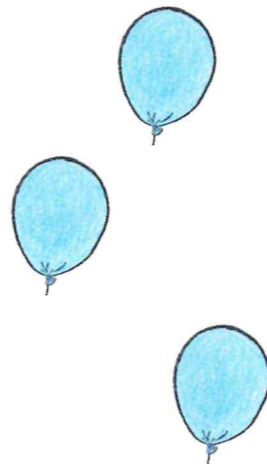
'AND AWAY'

It appears that these balloons must have reached 10,000 metres, where the Jet Stream wind blows West to East, sometimes at 400 - 500 km/hour.

Also, it must have been quite a dry night in all of Northern Europe, because the labels returned to us have not been destroyed by rain.

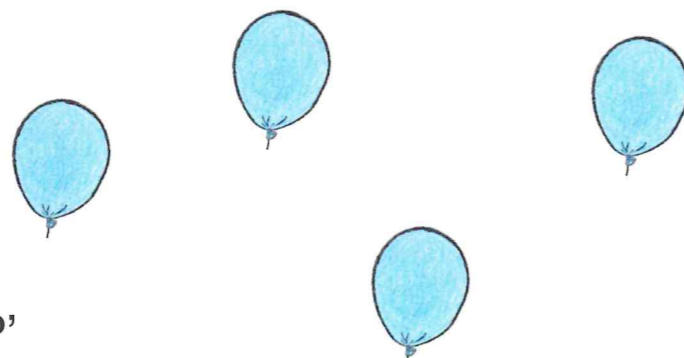


'UP'



Congratulations to Karolina Rog from Wschowa in Poland for finding the ticket of the balloon known to travel the furthest. The sender of this balloon was Monty Russell. Your prizes are on their way. There are also consolation prizes for the senders and finders of the five balloons found in Germany.

'UP'



**18th BIRTHDAY BALLOON RACE**

Ticket 218  
**Louis Garthwaite**  
Found  
Brandenburg, Berlin  
Thomas Strauss



Ticket 136  
**Doreen Russell**  
Found  
Hamburg  
Benjamine Klemme



Ticket 19  
**Sasha Taylor**  
Found  
Nienburg, Germany  
Christa Muller



Ticket 16  
**Alison Gunary**  
Found  
Fulmodeston, Norfolk  
D. Patier



Ticket 202  
**Sheila Bone, TKT**  
Found  
Northampton  
Gavin Chambers



Ticket 135  
**Russell Family**  
Found  
Wschowa, Poland  
Karolina Rog

Ticket 203  
**Dr Kakkis**  
Found  
Neuenkirchen, Germany  
Joset Rehe

Ticket 245  
**Joanne Evans**  
Found  
Luckau, Germany  
Marina Schwale

Ticket 88  
**Hayward family**  
Found  
Litcham, Norfolk  
NA Bertram

Ticket 112  
**Zara Watson**  
Found  
Grafham,  
Cambridgeshire  
Jamie Hart



CONFERENCE 2000 - GALLERY



Hannah chatting to Fiona & Chris

From Patrick, Karen, Emily & Sam

The week before the conference was very stressful but we need not have worried, despite a lot of tears we found the whole weekend very helpful and best of all made so many friends, who we know will be a great support in the future. I have to admit to having a 'wobbly' lately, feeling as if there was no hope, I didn't think I could feel better but I do and we have fallen in love with Emily all over again!!!



Nick Barnett enjoys a cup of tea with Lorraine & Anthony

"More talks by affected MPS sufferers"

"Alternative therapies theory a practical session"

"Genetics for beginners - is it possible to simplify this?"

From Rosemary, Harry & Lisa:

To Christine and all the staff

Once again a successful weekend at the conference

Thank you all



Jo Moore looking after Christopher Leonard

"Carrier Testing - how & when"

"Appreciated meeting other MPS III parents and carers"

Andy Ratcliffe and Ashleigh Tomes - have fun!



CONFERENCE 2000 - GALLERY

Morris Men 'strut their stuff'



"Excellent entertainment Morris Men"

"Many thanks for organising this conference, the contribution from Aiden was reason enough for coming."

Presentation of cheque to Wilma Robins



"Advice on gaining DLA & Associated help"



Pictures: Joanne and Aiden cut the cake / everyone enjoying the 18th Birthday celebrations / Eleanor Jones finds it all very bewildering / Sam and Marwan meet up again with friends at the conference / the Stuart family promote the MPS Society on a daily basis

CONFERENCE 2000 - GALLERY



Dr Charles Pennock speaking at the Gala Dinner

*"Super atmosphere, good well balanced programme"*



Wilma makes a presentation to Christine & Robin

*"This is our first conference; it has far exceeded our expectations in every aspect, and has been a valuable and positive experience"*



Professor John Hopwood - from Adelaide, Australia



Ellie says thank you to Wilma

*"Many thanks for giving us this opportunity to meet new friends and to speak to some of the wonderful people who want to make our children's lives more comfortable"*



CONFERENCE 2000 - CRECHE

It was a very busy crèche this year with 14 children attending. They were looked after by 7 volunteers who did a wonderful job keeping the children happy and cared for. Many thanks to you all from the MPS Society and the parents.

The crèche commandeered 5 meeting rooms located on the ground floor of the hotel.

There was a Ball Pool in one room, video's in another and lots of toys and equipment in the other rooms.

The weather was very hot and sunny and all the children were able to play outside.

Peter Drayne does a pitch inspection!



Matthew Huntley is sure a career in farming is the way to go!



Jessica Stuart found the warm sunshine very soporific!



Brooke Robjohns helps care for Shavahran Selvaranjan !



Millie Stuart shows her dexterity!



Christian Huntley looks happy and contented sitting on Amanda's knee.

## CONFERENCE 2000

### THANK YOU - From Judy Evans

#### One of the MPS Society's new Trustees!

Dear Everyone,

Just to thank you for all your hard work and planning which must have gone in to organising the Conference last weekend, and to tell you how much Joanne and I enjoyed every moment of it - it surpassed all our expectations and we' had a ball' !

Joanne revelled in having her own activity programme and her independence from me, whilst I was able to relax knowing that she was in Melanie's capable hands.

I thoroughly enjoyed the whole weekend and I am so grateful for the funding which enabled us to attend. All the sessions of the programme were interesting, informative and useful and I even enjoyed doing my own talk, purely due to the friendliness and support of the audience!

As always the patience and good humour of all the MPS staff ensured that everyone had a wonderful time. My abiding memory of the whole weekend is the happy, positive and up-beat atmosphere; not a glum face to be seen amongst the families, all of whom have more than their fair share of heartbreak and anxieties to deal with.

I am very pleased to have been chosen as a Trustee of the Society and only hope that I am 'up to the job'!, I'm sure I am facing a steep learning curve in the next few months, but am relishing the challenge.

It was lovely to see you all again, to renew friendships and to make new friends.

I am looking forward to my first Trustees meeting and to seeing you all soon.

With best wishes and many, many thanks, *Judith Evans*

**Trustees receiving a huge cheque from the Towersey Morris Men - £2000.**

**Thanks to all the Morris Men for their continuing support**

*left to right: Christine, Bernie, Judy, Vince, Angela, Gordon, Wilma, Steve and Rob & Katie, foreground: Joanne & Aiden*



## OVERSEAS

### **WE RECENTLY RECEIVED THESE BEST WISHES FROM AUSTRALIA:**

*I just wanted to extend my very sincere congratulations to the MPS Society on their 18th Birthday. What a milestone Christine, and how proud you and all those who had the vision and the passion to start up the MPS Society in 1982 must feel. Oh! How well I remember those early days and Helen and my visit to the UK in 1984. Some of the names may have changed but the essence of those early years remain and a new era begins. With the advent of Enzyme Replacement Therapy (ERT) the words "CARE TODAY, HOPE TOMORROW" holds new significance. Congratulations.*

#### **Ros Smith**

Ros is the mum of Adrienne who died from Sanfilippo disease aged 17 years in 1991 and founder of the Australian MPS Society. Pictured Ros at the wedding of Adrienne's sister Catherine and her new husband Shane on 1 April 2000.



### **ITALIAN MPS SOCIETY ANNUAL CONFERENCE**

The Italian MPS Society held their annual conference in Alessandria between the 9th and 11th June 2000 and Christine and I were lucky enough to be invited. We were made very welcome and made the best of the opportunity to catch up with the European MPS organisations. The conference was attended by representatives from Austria, Germany and Hungary along with the Italians and ourselves. We had a productive European Working Party meeting that ran alongside the conference.

Angela Ratcliffe  
Development Officer  
(Research)



From right to left: Suzanna (Hungary)  
Christine(UK), Suzanna R (Hungary)  
Dr Michael Beck, Michela Ubelis (Austria)

## FAMILY NEWS

### DEBY & MARK'S STORY

Jade was diagnosed in April 99 with "Sanfilippo" aged 1 year and 4 months, and as every parent of an MPS child, you feel your world has fallen apart and you're on a rollercoaster ride and can't get off, gradually you realise life does go on and you feel you have so much to cram in.

We decided we wanted Jade to have company, and I became pregnant in September 98, which was very stressful for the first 12 weeks as we knew I would have a CVS done to check the baby was okay. After two days of jumping every time the phone rang Dr Fiona Stewart's call confirmed everything looked healthy for the baby. What a relief, baby was due on 1st June 2000.

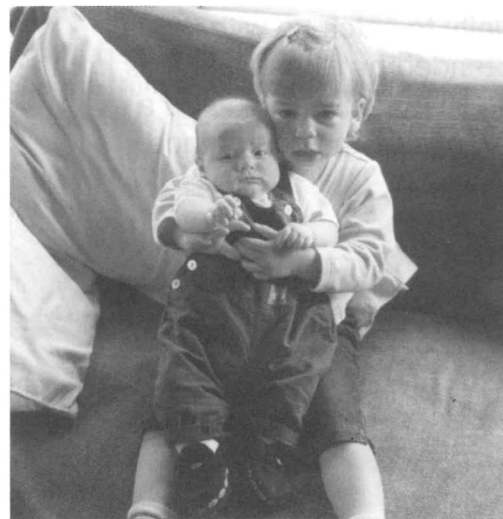
Meanwhile, we started to send Jade for a little respite which I felt guilty about and it took 6 months to work on, we started with half an hour and have now it built up to six hours twice a week, I still feel guilty and lost when I leave her, but she loves her respite worker Margaret and looks forward each week to going. I couldn't have asked for anyone better to care for Jade, and it has helped her so much with her social skills, and me mentally to cope.

Jade also had a lot of E.N.T problems and at the end of June she got her tonsils and adenoids removed and vents replaced in her ears. Straight away we could see an improvement in her breathing and no more discharge from the noes, also the puffiness in her face disappeared, now she looks great and at present is pain free.

Jake arrived 2 and a half weeks early and is doing very well and Jade loves to nurse him, help me bring his wind up and is constantly hugging and kissing him, she is such an affectionate and loving child, by having Jake I hope we have given her a very special little friend.

I should tell you why he's called Jake. Jade loves to watch the "Tweenies" and when you asked her who do you like? Her reply was always "Jake", so his name is very special as it was picked by his big sis a very gifted child Jade.

To finish my letter I have written the words of a favourite song of mine, which always touches a soft part of the heart.



Its amazing how you can speak right to my heart  
Without saying a word you can light up the dark.  
Try as I may I can never explain  
what I hear when you don't say a thing

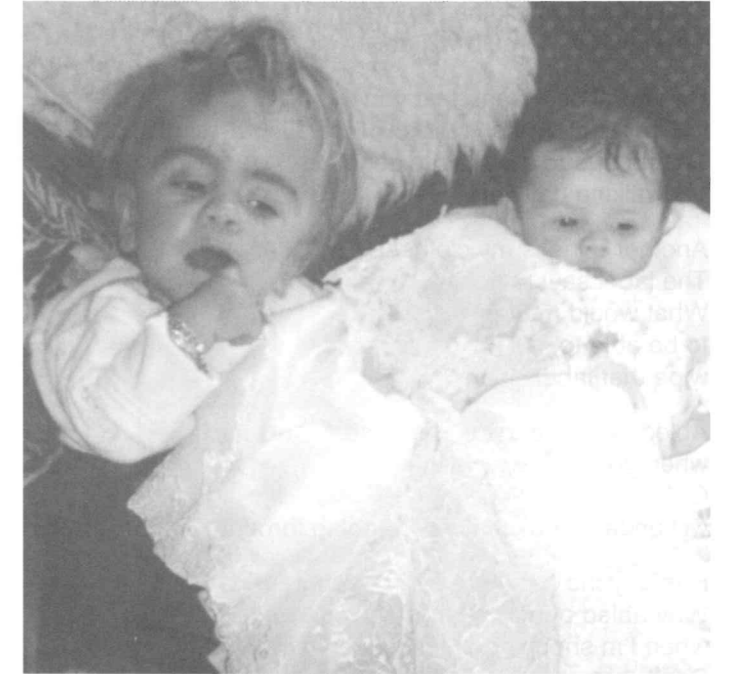
The smile on your face let's me know that you love me  
There's a truth in your eyes saying you'll never love me  
The touch of your hand says you'll catch me wherever I  
fall.

You say it best when you say nothing at all.

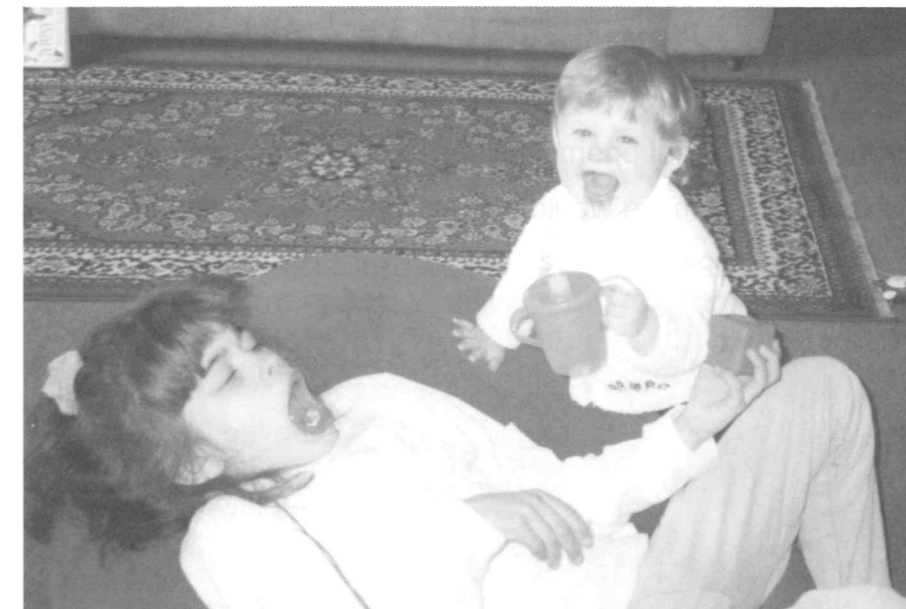
To close I just want to add something my sister told me,  
God must think we are very special parents to give us  
such a special child to love and care for, and those  
words are embedded in my head, they are words of  
comfort.

## FAMILY NEWS

Thank you to the Mongan family from Belfast and Nicole and Anna Pickard's grandma for sending these super photo's of their treasured children.



*This picture shows Shannon and Naomi Mongan on Naomi's Christening day. Naomi was born on 11 May 2000 and Shannons birthday is on 27 August when she will be having a BIG party with her friends - she will be 2 years old.*



Nicole and Anna  
Pickard

Grandma is not sure if  
Anna has 'nicked' the  
mug from Nicole  
(usually) or if she is  
being a kind sister!!

Please keep the family photo's coming - we love to include them in the newsletters

## FAMILY NEWS

### Morquio Syndrome

Social workers, wheelchairs.  
Occupational therapists too.  
Crutches, kids' clothes to wear,  
That's what Morquio will do.

Deterioration means that you  
will suffer more as you grow older.  
That is true to a certain extent,  
My walking days are over.

Another thing is my clothes.  
The label says 4 not 14.  
What would I not give,  
to be able to,  
wipe that label clean?

Abled people don't understand,  
when you cry, "why is that?"  
Only those like you,  
will understand what you're going through.

Has anyone out there ever thought,  
Why abled people sit and gawp,  
when I'm shopping, going to school.  
Don't they realise I find it cruel?

Just because I'm that little bit different,  
Just because I have Morquio Syndrome.

*By Joanne Evans*

Thank you Joanna for these wonderful poems. Please keep them coming!

If you would like to send a story or poem we would be very happy to publish them.

Joanne and June Elliott enjoying each others company at the Balloon Release in September.



### The MRI Scanner

Bang bang! Bang bang!  
I'm lying here all alone.

Bang bang! Bang bang!  
How much longer I'll be in here.  
I just don't know.

Bang bang! Bang bang!  
Mum's peeping in from behind.  
Bang bang! Bang bang!  
when it's over she'll let me know.

Bang bang! Bang bang!  
It's driving me mad now.  
Bang bang! Silence.  
And now my ears are ringing with  
the sound!

*By Joanne Evans*

## FAMILY NEWS

### BIRTHS

Cathy and Andy Flaig are proud to announce the arrival of Oliver who was born on Wednesday 21st June 2000. He is a very welcome brother to Joseph and Thomas.

Christine and Terry Vigus are delighted to announce the safe arrival of their new son Daniel George on 14 September 2000.

#### Belated Birth Congratulations!

Our congratulations and apologies for the delay go to:

Helen and Ricky Montgomery on the birth of their daughter, Charley Louise, on 13 January 2000, weighing in at 7lb 5.5oz.

She is a very welcome sister for Ashleigh.



### NEW FAMILIES

There have been 3 new families seeking the support of the MPS Society since the last Newsletter. This includes the new family below who have given written permission for their details to be published.

Mr & Mrs Selvaranjan's son Shivahram has recently been diagnosed with Mucopolipidoses Type II. Shivahram is one year old. The family live in Middlesex.



## IN REMEMBRANCE

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

<i>Vilma Vanni who suffered from Morquio</i>	<i>03.12.47 - 01.07.2000</i>
<i>Michael Copeland who suffered from Hurler</i>	<i>08.03.90 - 18.07.2000</i>
<i>Kerry Little who suffered from Hurler</i>	<i>12.04.92 - 06.08.2000</i>
<i>Kerry Graham who suffered from Sanfilippo</i>	<i>16.06.86 - 20.08.2000</i>
<i>Carissa Aggett who suffered from Hurler</i>	<i>19.12.90 - 18.09.2000</i>

### HEAVEN'S VERY SPECIAL CHILD

*A meeting was held quite far from earth  
"It's time again for another birth"  
Said the angels to the Lord above,  
This special child will need much love.*

*His progress may be very slow,  
Accomplishments he may not show  
And he'll require extra care  
From the folks he meets down there*

*He may not run, or laugh or play,  
His thoughts may seem quite far away.  
In many ways he won't adapt  
And he'll be known as handicapped.*

*So let's be careful where he's sent  
We want his life to be content  
Please Lord find the person who  
Will do this special job for you.*

*They may not realise straight away  
The learning role they're asked to play,  
But with this child sent from above  
Comes stronger faith and richer love.*

*And soon they'll know the privilege given  
Their precious child so meek and mild  
Is HEAVEN'S VERY SPECIAL CHILD*

### CHILDHOOD WOOD PLANTING DAY

The annual sapling planting will take place on Friday 27 October 2000 at the Childhood Wood in Sherwood Pines.

Trees are being planted for eight children who lost their lives to MPS or Related diseases over the past 12 months.

Prior to the planting there will be a light lunch for everyone attending at the Clumber Park Hotel.

Councillor Jim Napier, the Chairman of Nottinghamshire County Council will be joining us for the afternoon.

*Hannah Crown  
Development Officer*

## EDUCATION

*The following information only applies to England and Wales. The Society is keeping a close eye on developments in Scotland and Northern Ireland.*

### URGENT - YOUR CHILD'S SPECIAL EDUCATIONAL NEEDS PROVISION IS AT RISK

All MPS families with a child of school age should have already received a letter and documentation from the MPS Society highlighting proposed changes to the law and guidance on special education which threaten the rights of children with disabilities to the extra help they need in school. For over 17 years now the law has required Local Education Authorities (LEA's) to specify a child's special educational provision in their Statement. Despite this many LEA's still fail to state clearly how much help a child should receive. What does it mean if your child's Statement uses phrases like "access to support" and "regular help"? Christmas is regular!

The Government is proposing to remove the current legal duty, which states that a child's special educational provision should be specified and quantified. This will leave parents with no way of knowing exactly what support their child has been assessed as needing and whether this support is being received.

The MPS Society is campaigning against the Government's proposal to weaken statements arguing instead that there is a pressing need to strengthen the law by:

First making it legally binding on professionals to state in their reports on children their opinion not just on the type of provision a child needs, but also on the amount of provision. This will mean that you as a parent or carer will have a clear idea of the professionals views on how much help your child needs.

Second, making it legally binding on the LEA when writing a Statement not only to specify the type of provision, but also to quantify the amount of provision to be arranged. You as a parent or carer would then know exactly what provision your child is being offered and is entitled to.

It is vital that as many politicians as possible hear from concerned parents as well as the organisations that support you. Your personal story, being personal has an impact that organisational support cannot generate. Please write to your MP and if possible go and see him. Numbers also count! You may also wish to write to the Secretary of State for Education David Blunkett MP, House of Commons, London SW1.

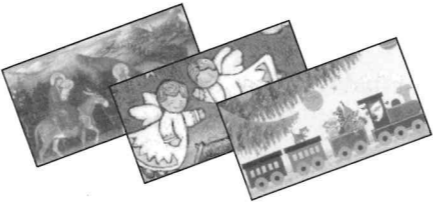
The MPS Society is one of a number of organisations supporting this change. We believe that with the support of parents this an argument we can win, but only by working together and everyone doing their bit.

If you have not received the information on proposed changes to the law and guidance on Special Education and are interested in supporting the campaign please phone the MPS office and ask for the details.

All those registered to support the campaign will receive news and updates, as they become available.

*Ellie Gunary  
Senior Development Officer*

**MPS NOTICE BOARD**

<p>CONFERENCE 2001  THE NEXT MPS ANNUAL CONFERENCE  WILL BE HELD ON  14 - 16 SEPTEMBER</p>	<p>MERCHANDISE  Full list of merchandise and Order forms are available from the office.  Promote the Society's logo and raise funds at the same time</p>	<p><b>Blue Badge Map</b>  The Transport Committee for London has issued a free map for Blue (formerly Orange) Badge holders showing disabled parking spaces in central London.  It's available on 020 7747 4767</p>
<p><b>Rail Services</b>  The Rail Regulator has launched a consultation on a new code of practice for disabled passengers, which will set standards of service and access for disabled passengers.  The first code of practice was published in 1994 and the Disability Discrimination Act 1995 imposed a duty on the Rail regulator to revise it, taking into account the legal requirements now imposed by the DDA.  The document "Train and Station services for Disabled Passengers" is available in audio cassette, standard and large print and other formats from:-  Sue MacSwan, Office of the Rail Regulator, 1 Waterhouse Square, 138-142 Holborn, London, EC1N 2TQ Tel: 020 7282 2001 Fax: 020 7282 2045 e-mail: <a href="mailto:orr@dial.pipex.com">orr@dial.pipex.com</a> Website: <a href="http://www.rail-reg.gov.uk">www.rail-reg.gov.uk</a></p>		<p><b>GIFT AID</b>  You may be aware that from the beginning of April 2000 the government reduced the £250.00 limit on donations before we could claim the tax back. This means that every donation is eligible for tax relief so long as the donor is a current UK tax payer. This means an extra 22% towards donations to the MPS Society, which will dramatically increase our income.  Contact the office for more details.</p>
<p><b>MYSTERY SHOPPING</b>  The Grass Roots Group (Disability Research and Training) runs 'Disabled Mystery Shopping' market research studies. Such projects basically involve inviting disabled people to visit or telephone companies to ascertain how well or badly they serve people with disabilities.  For example they may ask you to buy a loaf of bread at a local supermarket or have a meal for two in a local Pizza restaurant. Following every visit a questionnaire has to be completed about the experience. How well did the staff deal with the request? To what extent did the premises meet your needs ?  Many companies commission Grass Roots to report on their standard of service and assess how their premises and staff measure up to the standards of new disability legislation.  Disabled people are required from across Britain to take part in this ongoing research. A proper rate for the work is paid as well as expenses.  For further details contact Grass Roots on 0870 870 4483</p>		 <p>Christmas is coming.....  You have already received your Christmas card order form. Do please get your orders in early - we can offer packs on sale or return.  Why not show the flyer around your office or to your friends and neighbours.  MPS cards not only raise much needed funds but also create awareness of MPS to everyone who receives one.  Please see the back page of this Newsletter !</p>

**INFORMATION**

**DIRECT PAYMENTS**

**"Katy takes control as Direct Payments puts her in the driving seat"**

After an 18 month pilot, Direct Payment will go live in Buckinghamshire from 1st October 2000. Katy Etherington, 27 from Iver Heath has been part of the pilot and describes the difference that Direct Payments (DP) has made to her life.

Katy, a talented graphic designer, applied to receive DP because of difficulties she had been experiencing with care agencies in the past. Katy, a wheelchair user, requires assistance with personal care early in the morning to get her ready for work as well as a driver to take her to work. In the past there were many occasions when this could not be provided - either the carer was not able to be with Katy early enough for her to get to work at the proper time, or frequently there were problems with finding an insured driver.

"The care agencies tended to provide what they had on offer rather than what was actually needed, and direct payments seemed to offer a possible solution" said Katy who first became aware of DP through former college friends.

Katy approached her care manager who contacted the co-ordinator of the DP Support Service in Buckinghamshire. The care manager visited a couple of times to complete the necessary forms and Katy received her first payment in May.

Katy admitted that it could seem a little daunting at first but urges people not to be put off.

**What are Direct Payments ?**

The Community Care (Direct Payments) Act 1996 gives Social Services the power to make cash payments in lieu of community care services. The money is then used to purchase services to meet assessed needs. A DP can be given for any service currently a community care service for example residential respite care, day services, meals, escorting, transport, shopping services and social activities. A DP cannot be used to employ a close relative or someone living in the same household.

A support and advice service is essential to explain the DP arrangements and the user guidelines. These sorts of services provide help with staff recruitment, health and safety advice and help in the setting up and management of the scheme.

One essential requirement if receiving DP is that a separate bank account is maintained. Independent Living Fund (ILF) monies cannot be paid into the same account into which DP are made. Quarterly returns have to be forwarded to social services, in addition to any PAYE or NI records that need to be kept is a personal assistant (for example) is employed. The user guidelines and support service can help with all these issues.

**INFORMATION:**

Contact the MPS Office for a list of recommended guides to help you.

## INFORMATION

### AN INTRODUCTION TO REIKI

A couple of months ago I was having coffee with my friend Jean, and noticed a book entitled 'REIKI FOR BEGINNERS' - mastering natural healing techniques' on her coffee table; and, being curious, I started to read it while she was taking a phone call.

She then went on to tell me how she started having Reiki treatment during a difficult time in her life and how it helped her. She had been so impressed, that she decided to be attuned to First Degree in Reiki healing in order that she could pass on the benefits to others.

Reiki is a form of hands on healing, with its origins in India and the East dating back many thousands of years. However the ancient art was lost in the passage of time until it was rediscovered by a Japanese scholar and monk named Dr. Mikao Usui in the 1800's. Reiki is a Japanese word for the vital energy which flows through all living things and can be activated for the purpose of healing. It's literal translation is 'life force energy'.

However it does not claim to effect cures, but rather provides a support system in tandem with conventional medicine. It works through the seven main CHAKRA points of the body to re-balance the flow of universal life force around the body; I know this sounds like new-age mumbo jumbo, but I can only speak of the positive effect it has on Joanne, who has been receiving treatment once a week over the past two months; she finds the sessions relaxing and afterwards feels energised. It is said that the Reiki goes where it's needed and we have noticed that no matter where Jean places her hands over Joanne's body, she feels most sensation in her neck, arms and legs which are her 'weak' areas.

I have only had one Reiki session so far and it was on a day when I was feeling really 'down in the dumps' but afterwards found my mood had lifted completely.

Like many people who have been introduced to Reiki, we feel it has been beneficial to us both in different ways. I am now considering an attunement for myself, mostly in order to treat Joanne and other members of my family - including Tara, our ageing Golden Retriever! I will also benefit from this, since it is possible to do self-treatments and also the person giving the Reiki receives energy at the same time.

There are Reiki practitioners all over the country and they often hold Open Days when anyone can go along to find out more about it and try a treatment if they wish. If you have the opportunity, it's well worth an hour or two of your time.

*Judy Evans*

### HOMEOPATHIC REMEDIES - REDUCTION OF UPPER AIRWAY SECRETIONS

During the Saturday afternoon Hurler session at the Conference, discussion turned to the reduction of upper airway secretions. Homeopathic remedies were mentioned, and I could not recall at the time, but a friend of mine who is a nurse and has a son with Downs, recommends Echinacea Drops or tablets. Apparently these should not be used on a daily basis, nor on immuno-compromised children, but are suitable for a week's use approximately once per month. This probably excludes most MPS children, but I did say I would pass on the information to the MPS office. During the discussion, Lindsey Devine was describing a homeopathic drink that she gave her child each morning and reported that this had reduced the number of colds in the last year. Perhaps the newsletter could have more practical tips for a nursing column?

*Jean Leonard*

## INFORMATION

### **Getting Involved in Research**

#### Clinical Trials

All patients, whether their condition is a common or a rare one, have a right to expect that the medicine they take will be safe, effective and reliable. In order to establish this a process of clinical trials has evolved over the last forty years. The process is tightly controlled by legislation and regulation and must be followed before a new drug is allowed to be put on the market and prescribed for general use by patients.

Much of the legislation is nationally biased. In addition there are a number of international measures set up to ensure a consistent approach to establishing safety and effectiveness wherever the trial is undertaken. The International Conference on Harmonisation (ICH), involving Europe, the USA and Japan has produced guidelines on Good Clinical Practice (GCP) considerations which must be met if clinical trials are to incorporate current best practice in their procedures. These GCP guidelines provide general standards, to ensure the protection of those taking part in trials from unnecessary risk or from exploitation. Other more specialised notes for guidance also give specific advice with respect to the particular design and conduct of trials for certain types of disease (e.g. cancer, heart disease) or population categories (e.g. children, the mentally ill) designed to protect those taking part in trials from unnecessary risk or from exploitation.

A clinical trial is a late step in the Research and Development process. It is established after a great deal of preliminary research in the laboratory and on animals. A detailed dossier has to be drawn up prior to the trial which justifies the **need** for the trial and explains the **rationale** underpinning the proposed course of action. This information is scrutinised for its technical adequacy and also to ensure that it is ethically sound. If approval is given by the regulatory agencies in the country where it is proposed to hold the trial then it can proceed.

Clinical trials proceed by distinct stages which have to be completed satisfactorily before the next step can be taken:-

- Phase 1 is to look for the effect of the new substance (the drug) on the human body. This will normally involve a small number of healthy volunteers.
- Phase 2 looks at the question of the appropriate dose and the activity of the drug in people with the condition it is intended to treat. (This may include placebos where this is ethically justified). Phase 2 trials are usually undertaken with a few hundred patients participating.
- Phase 3 trials are usually carried out across many centres, often in different countries. This stage is to compare the new treatment with existing practice and it can involve several thousand patients.

Phases 1-3 may take 5-10 years. Once they are complete the drug is submitted to the regulatory agencies (e.g. the European agency for the Evaluation of Medical Products - EMEA) and if the authorities are satisfied then the new product is put on the market.

Phase 4 trials follow, monitoring the use of the product when administered according to its authorised therapeutic indications for patients, to increase knowledge of how the drug works in the context of current medical practice, and to spot any previously undetected adverse consequences.

## INFORMATION

### Getting Involved in Research - continued

Central to the conduct of clinical trials is the fact that all patients are volunteers. They have the right to withdraw at any time and their access to other medical services must not be influenced by their participation, or non participation in a clinical trial. Participants have the right to information about the trial, must not have their confidentiality compromised by their participation; and medical care during the trial must be provided.

Clinical trials always involve an element of uncertainty. If the outcome was known already, there would be no need for the trial.

These requirements and other issues to ensure trials are ethical and, as far as possible safe are laid down in the ICH guidelines. To give them the force of law and to standardise the proceedings for the conduct of clinical trials in Europe, the EU is currently bringing a new Directive into effect. This is not yet law. But when it is adopted, it is intended to ensure that the standards set throughout Europe are applied fairly and consistently and that adequate methods exist for inspection and verification of the procedures followed. It is hoped that a bureaucracy that will stifle research and slow drug development is not created. Ideally the approval of the protocol by the relevant Ethics Commission will remain the determining factor for allowing clinical trials to start.

One aspect of the traditional model for clinical trials will be immediately apparent to patient groups supporting families with rare genetic disorders - the numbers involved! A traditional clinical trial may involve several thousand patients - which may be more than the total number of affected individuals in a country, or even in the whole of the EU. If the rules were to be applied rigidly this would inhibit or even prevent the development of products for the treatment of rare disorders, even if basic research produced promising results. Fortunately this paradox has been recognised and the dilemma of establishing efficacy whilst also demonstrating safety is being addressed through the Orphan Medical Products regulations.

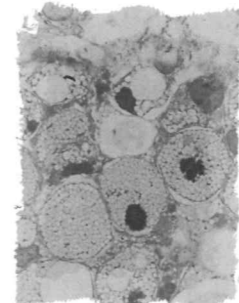
The Orphan Medicinal Products Regulations give the European Agency for the Evaluation of Medical Products (EMA) the authority to advise on the conduct of clinical trials for products designed for use with rare disorders. This means that the nature and quality of evidence necessary to obtain permission for the new product to be put on the market can be established before the start of the clinical trial and the study designed in such a way that it can provide the necessary information in ways that reflect the needs of patients and the prevalence of the condition in the population.

Patient groups, scientists, clinicians and their industrial partners who are aware of the pending need to set up clinical trials for rare conditions should be in conversation with the relevant official of EMA as soon as the need becomes apparent. This communication will ensure a smooth passage through the approval procedure and on to the market for the benefit of those affected.

## INFORMATION


17 18 19 20 21 22 23 24 25 June 2002


Paris  
FRANCE



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

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





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

For more information contact:  
VML - 9, place du 19 mars 1962 91035 Evry Cedex France  
MPS Society - 46, Woodside Road, Amersham Bucks HP8 6AJ UK

Would you like help with learning 'IT'  
or buying or installing a computer?

**This group can help.**

#### THE BRITISH COMPUTER SOCIETY DISABILITY GROUP

is a voluntary network of computer professionals willing to visit disabled people in their homes and give advice and help.

What they can do:

- Advise on what computer technology can offer
- Help you select equipment and get you started
- Install hardware or software
- Solve technical problems
- Suggest alternatives if you can't use a keyboard or mouse
- Get you connected to the Internet
- Help you use standard software packages such as Word or Excel

**If you'd like help OR if you'd be interested in becoming a volunteer contact:**

**07944 541773**

**or 01753 893793**

for more information

## DONATIONS

The Sobell Foundation  
Fitton Trust  
Inner Wheel Club of Cheshunt and  
Waltham Cross  
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Miller Hendry  
Sue Stuart  
Mrs Skene  
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### Conference Donations

Philip Barker Charity  
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Lions Club of Gillingham  
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The Boyton Charity  
Blatchington Court Trust  
Barbara A Shuttleworth Memorial Trust  
Nottingham County Council - Fund for  
the Disabled  
Douglas Hay Trust  
Leicester Charity Organisation  
Kensington & District Nursing Trust  
Thorngate Trust

## FUNDRAISING

### FUNDRAISING EVENTS

The Society is grateful to the following who held fundraising events

Sally Ellis & Harriet Holman - Beard Shave by History Teacher  
Strabane Golf Club - Golf Tournament  
The Rowe Family - Penny jar collection  
Jenny Hardy's mum - Sale of marmalade  
Lincoln Sports and Social Club - Summer Raffle  
Swanage Parochial Church Council - Parish Fete at St. Mary's Church  
P Claridge & D Foster - Sponsored Bike Ride  
Marina and Dave - Car Boot Sales  
Lyn Longhorn - Fundraising Lunch  
Kirkhill Golf Club - Invitation Greensome Competition raffle  
Egremont & District Sunday League - Football March  
Crosby Hotel, Scunthorpe - Beer jug collection  
Rachel Todd - Pony and Trap Cavalcade  
Oversley Mill Services - Collection box  
The Nelson Family - Coin collection  
Charity Flowers - Commission  
Caversham Folk Festival - Annual Festival  
Mrs Jean Cockman - Recycling cans & re-using bags  
William Durrant School, Chesham - Sale of pencil cases  
M Stimpston - Webb Ivory Catalogue fundraising  
6th Form College, Farnborough - Charity Jar in reception  
Northgate Information Solutions UK Ltd - Sale of obsolete furniture  
Sue Lowry - Stall at annual Conference  
Pam and Ken Ballard - Stall at annual Conference  
Lucy Lavery - "Guess the name of the Bunny at Conference"  
Eileen Smaile - Sale of Bubble Pens  
Marlow Twinning Association - Towersey Morris Men

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

Vilma Vanni  
Susan Cox  
Gordon Smith  
Liam Taylor  
John Leonard  
Edward Nowell

### MANAGEMENT COMMITTEE

<b>Chairman</b>	Wilma Robins 77 Hillview Avenue Hornchurch Essex RM11 2DN Tel: 01708 443157	<b>Chairperson</b>	Sarah Long 5 Selworthy Terrace Coobe Down Bath BA2 5QZ Tel: 01225 835104
<b>Vice-Chair</b>	Angela Brown	<b>Treasurer</b>	Vince Hayward
<b>Members</b>	Mark Beniston Steve Butler Rob Devine Bernie Drayne Judith Evans Gordon Hill		

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

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Fax : 01494 434252**

**OUT OF HOURS HELPLINE : 07712 653268**

**e-Mail : [mps@mpssociety.co.uk](mailto:mps@mpssociety.co.uk)**

**HOME PAGE : [www.mpssociety.co.uk](http://www.mpssociety.co.uk)**

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

<b>WINTER</b>	31 December 2000	<b>SPRING</b>	31 March 2001
<b>SUMMER</b>	30 June 2001	<b>AUTUMN</b>	30 September 2001

### ORDER YOU MPS MERCHANDISE NOW!!

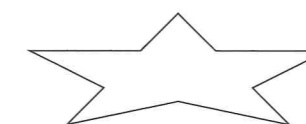
#### 2001 MPS DIARY

*Price each: £3.00*

*Price for 2: £5.50*

*Orders of 3 and over : £2.50 each*

**Inclusive of post/packing**



**UMBRELLA - £5.00 incl p&p**



**SWEATSHIRTS - £13.50  
various colours & sizes**

**STATIONARY - please contact the office**

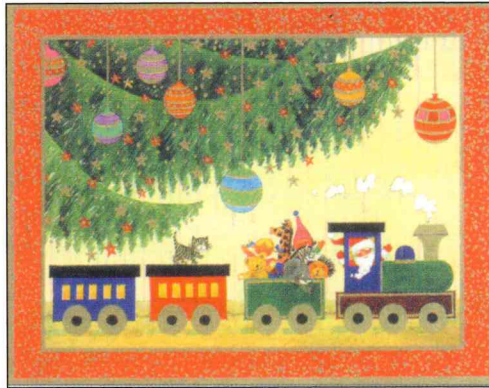


**PLEASE CONTACT THE MPS OFFICE FOR ALL YOUR MERCHANDISE REQUIREMENTS**

# Christmas Cards 2000



'Santa has a hole in his sack'



'Toy Train'



'Santa's Animals'



'Santa's Journey'



'Flight into Egypt'



'Angels Watch'

Card Code	Size MM	Description	Pack Size	Cost per pack	Quantity ordered	Value
M2/1064	100 x 152	Angels Watch	10	£2.75		£
	111 x 111	Santa has a hole in his sack	10	£2.50		£
9/3059	230 x 90	Flight into Egypt	5	£1.30		£
69338	180 x 140	Santa's Animals	5	£1.60		£
67015	100 x 130	Santa's Journey	5	£1.00		£
67022	130 x 100	Toy Train	5	£1.00		£
Postage & Packing		All card Sizes Approximate			P&P	£
1-4 Packs	£1.00				Donation	£
5-10 Packs	£1.75					
11 Packs +	£3.00				Total	£

Contact Name:

Address:

Tel No.

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

Please charge my Access, Mastercard or Visa (delete as appropriate)

Cards number \_\_\_\_\_ Expiry Date \_\_\_\_/\_\_\_\_

**Please Return your order form to:**  
**The MPS Society,**  
**46 Woodside Road,**  
**Amersham,**  
**Bucks. HP6 6AJ**