

# Newsletter

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The Society for  
Mucopolysaccharide  
Diseases



National Registered Charity No.287034

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Summer 2000



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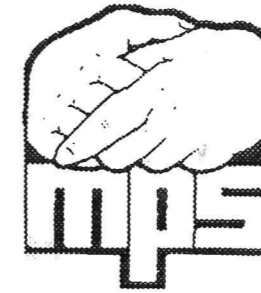
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<b>Kate Crown</b>	<b>Project &amp; Information Officer</b>
<b>Sasha Taylor</b>	<b>Development Assistant</b>
<b>Gina Page</b>	<b>Administration Officer (Finance)</b>
<b>Sue Taylor</b>	<b>Administrative Assistant (Finance)</b>

**NEWSLETTER DEADLINES**

<b>Autumn</b>	<b>30 September 2000</b>
<b>Winter</b>	<b>31 December 2000</b>
<b>Spring</b>	<b>31 March 2001</b>
<b>Summer</b>	<b>30 June 2001</b>



**The Society for  
Mucopolysaccharide Diseases**

**46 Woodside Road, Amersham Buckinghamshire HP6 6AJ**

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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 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**

The Society offers an information and advocacy service for affected individuals, their families and professionals. At the present time the Society supports two specialist MPS centres at the Royal Manchester Children's Hospital and at the Hospital for Sick Children, Great Ormond Street, London. It co-ordinates a network of regional events and links families through it's befriending scheme.

The Society also funds research projects at the Christie Hospital, Manchester; Royal Manchester Children's Hospital and the Institute of Child Health, London. It encourages and assists contact and co-operation between parents and professionals and maintains links with sister Societies in Europe and throughout the world.

There is at present no cure for MPS Diseases but much can be done to improve the treatment and care of sufferers. The slogan of the Society is:-

**"CARE TODAY, HOPE TOMORROW"**

*The photograph on our front cover is of*

**ROBYN WATTERSON**

*Aged 3 years who suffers  
from Hurler Disease*

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Deadline for the Summer Newsletter is 30 September 2000.

## CHAIRMAN'S REPORT

Over the last three months the Society has provided individual advocacy support to over 149 member families. A further 74 MPS individuals and MPS families have received family support through the Northern Ireland MPS Conference, regional and tertiary clinics, family days and the remembrance day in the Childhood Wood. The Society's Development Team have attended Educational Reviews, Disability Benefit Tribunals and multi-disciplinary meetings and met with families in their own homes as necessary throughout the United Kingdom. The principle aim of the Society is to offer flexible family support and advocacy enabling all those affected by MPS to make informed decisions in achieving the help they need.

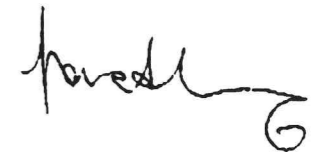
The services the Society offers those affected by Mucopolysaccharide and Related Diseases continue to enjoy the whole hearted support of both Dr Ed Wraith and the Royal Manchester Children's Hospital and Dr Ashok Vellodi at the Hospital for Sick Children and the Institute of Child Health, London.

You may be aware of the emergence of a group calling itself 'friends of MPS'. The Trustees wish to place on record that this is a separate group not associated or supported by the Society for Mucopolysaccharide Diseases (the MPS Society).

Information held by the MPS Society in respect of its members including names and addresses is subject to the confidentiality of the Data Protection Act. No current employee or Trustee who has access to this personal and sensitive information has disclosed this information to any other group. We have learned from some of our members that they have been targeted and mailed by this group. If you have been contacted and are worried about this please contact the MPS office or make your concerns known directly to the Investigations Dept, Office of the Data Protection Commissioner, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF requesting an assessment of any possible breach under the Act.



Wilma Robins  
Chairman



Sarah Long  
Chairperson

## NEWS FROM THE MANAGEMENT COMMITTEE

Again due to the considerable amount of work to address, the Management Committee met twice, in April and May.

At the April Management Committee Meeting the Society's legal advisor provided advice to Trustees on their legal responsibilities and aspects of the Society's constitution.

### STAFFING

Trustees agreed that the Director recruit a temporary member of staff to help cover a void when two members of staff undergo major surgery. (Alex Roberts joined the team at the beginning of June). A number of Trustees met with staff to review issues of Health and Safety. It was agreed following employment advice and an annual appraisal that Ellie Gunary in her post as Senior Development Officer, incorporate the role of Deputy Director.

### FINANCIAL MANAGEMENT

The Treasurer reported on the very good news that the Society has been awarded a grant by BBC Children in Need to fund the sibling workshops at the MPS Conference in Northampton and run regional family days.

The response by donors to requests to complete the Gift Aid certificates has been excellent and will allow the Society to claim an additional 28p in the pound when the donor is a tax payer.

### FAMILY SUPPORT

The Director reported that 8 new families had joined the MPS Society. Five families had suffered the loss of a child or young adult from MPS. Trustees were also saddened to learn of the death of two parents of MPS children.

It was agreed to consult with members on the appropriateness of the family support offered through a user survey.

### REGIONAL EVENTS

Due to only one application for the adult activity weekend at the Share Centre being received it was with regret that the Trustees agreed to cancel this event. With only one participant the aim of promoting

independence and social interaction in this peer group could not be met.

It was agreed that the Family Activity Weekend at the Share Centre, although not fully subscribed should go ahead as planned.

### MPS CONFERENCES

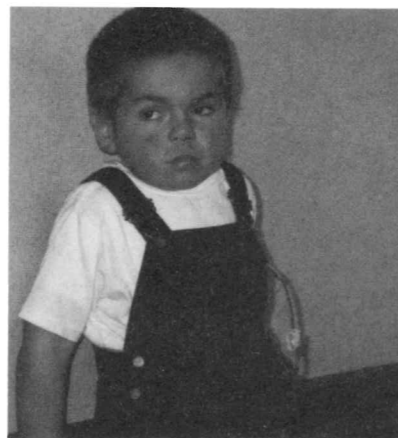
The Trustees asked the Director to invite Dr Emil Kakkis and Dr Shunji Tomatsu to give updates on Enzyme Replacement Therapy at the MPS Conference in Northampton. It was also agreed to invite Prof. John Hopwood to speak at the MPS gala dinner to celebrate the Society's 18th Birthday.

### MPS RESEARCH

Trustees were informed by the Director that clinical trials for MPS 1 are now unlikely to commence in the UK before November 2000. Trustees received an update on Enzyme Replacement Therapy (ERT) following meetings with Dr Ed Wraith and Dr Ashok Vellodi and representatives from Biomarin, Genzyme and TKT. Safety trials for MPS II have not as yet started.

### JEANS FOR GENES 2000 (J4G)

General discussion took place over the J4G campaign. Acting on advice the Trustees didn't feel able to support the proposal from Professor Latchman that MPS join some of the other J4G partners to jointly fund a gene therapy laboratory at the Institute for Child Health, London. It was agreed that the MPS Society should proactively promote J4G elsewhere in the United Kingdom and look to identify regional projects in clinical management and family support that may benefit MPS individuals and families.



Angela Brown  
Vice Chairman's son – Aiden (Hurler Disease BMT)

## NEWS FROM THE MPS OFFICE

### THE MPS STAFF TEAM : WHO WE ARE AND WHAT WE DO ?

#### Christine Lavery – Director

I have been working for MPS for 7 years. My Voluntary sector background is mostly in the area of rare diseases at Contact a Family and with grants from the Mental Health Foundation. My current role includes legal and financial and policy management responsible to the Board of Trustees, as well as family support, fundraising and support to Staff and Volunteers.



Left to Right

Front row: Ellie Gunary, Christine Lavery, Second Row: Angela Ratcliffe, Hannah Crown, Gina Page, Kate Crown  
Back row: Sacha Taylor, Alex Roberts, Sue Taylor

#### Ellie Gunary – Senior Development Officer

Prior to joining the MPS Society in 1999, I spent twelve years working with children and adults with physical and learning disabilities in both residential and fieldwork settings, in the voluntary, statutory and private sectors. It is proving a wonderful opportunity to further my career, build on my training and qualifications in social work and policy whilst putting to good use my own experience of being a carer. I offer family support and advocacy working with families in the north of England, Scotland and Northern Ireland. I have also recently taken on some areas of responsibility in the organisation of the charity and policy work.

## NEWS FROM THE MPS OFFICE

### Angela Ratcliffe – Development Officer

I have been with the MPS Society for 2½ years. I am the Development Officer Responsible for Research and International Collaboration working with MPS Societies, families and professionals world wide. My primary role is the updating and maintaining of the new UK MPS families database and extending this to Europe and beyond. My post and all related expenses is funded jointly by Biomarin and TKT. I am able to use the skills I gained in my previous role within the Society as I work closely with individuals and families affected by MPS who have specific questions or support needs in relation to research and new therapies. I am finding this work very exciting with many individual families and countries joining together with a common goal.

### Hannah Crown – Development Officer (Family Support)

I have worked for the Society for two and a half years. I work with MPS individuals, families and their professionals in the South of England and Wales supporting them from the point of diagnosis through issues such as Disability Benefits, Housing and Education. I work very closely with Dr Vellodi at the Hospital for Sick Children, Great Ormond Street and see patients there on a regular basis as well as facilitating clinics in Birmingham, Bristol, Cardiff and Norwich. I spend a lot of my time away from the office supporting families in their own locality and attending meetings to support a family's needs. In the office I carry out tasks including grant applications and care plans. The Society holds a valuable information resource for families and professionals alike and I am involved in collecting information for this with an aim to educate as many people as possible about Mucopolysaccharide and related diseases. I have a remit for working with individuals and families from ethnic minority groups and the professionals working with them. I also manage the Childhood Wood in Sherwood Pines, Nottinghamshire, where the Society organises a remembrance day and planting day each year. I also support a group of 6 volunteers who care for the wood on a day to day basis.

### Alex Roberts

I joined the MPS Society at the beginning of June as a temporary member of Staff covering for Staff absences. During my employment I am using my computer skills to produce the Annual report, answer the phone to families and plan the regional family support events for 2001.

## NEWS FROM THE MPS OFFICE

### Sasha Taylor – Development Assistant

As a relatively new member of the MPS team I would like to say an official 'hello'. I actually started work in February and have very much enjoyed being here and speaking to lots of you on the phone. I am looking forward to putting some faces to names when I meet you at the Annual Conference in September. My job includes typing family support correspondence and other necessary documents, supporting the Development team, answering the phone and making calls to families to offer support and communicating with MPS families by e-mail. I am also happy to water the plants and make the tea! Unfortunately I have been away from work for the past few weeks having a long standing neck problem sorted out by having a disc removed from my neck and a bone graft inserted. It's great being back at work and part of the team.

### Kate Crown – Project & Information Officer

I have been with the Society over a number of years as a volunteer and employed on a short term contract in 1998 responsible for single handedly organising the Downing Street party. On the 1st February 2000 I was appointed on an 8 month contract to organise and manage the Scottish, Northern Ireland and National MPS Conferences, Share Weekend as well as produce and edit the MPS quarterly Newsletter. My duties also include answering the phone, which, I enjoy doing very much as it gives me an opportunity to talk with you all.

### Gina Page – Administration Officer – Finance

I have been with the Society since November of last year. Under the supervision of the Treasurer and Director I manage all the Society's finances including individual budgets on a day to day basis. We use Sage Accounts and Payroll System and I become very popular at the end of each month on pay day! I also keep a check on the stock levels of MPS promotional goods – these are always available from the MPS office and are frequently taken to events including the conference.

### Sue Taylor – Administration Assistant (Finance)

I joined the Society in November 1998. The Society has recently changed to a computerised accounts system and I have concentrated on learning the system under the guidance of Gina. I continue to respond to fundraisers and acknowledge all donations etc. Don't forget that MPS can reclaim tax on your donations by asking us for a Gift Aid form. I am also currently supporting volunteers working on the annual raffle and MPS Christmas cards as well as organising sales of MPS promotional goods.

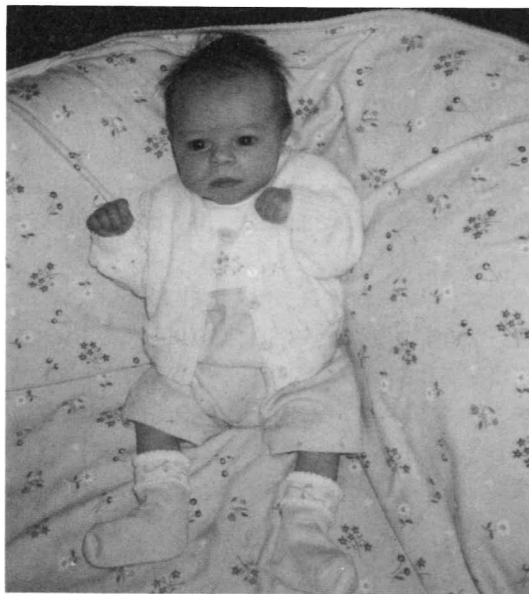
## FAMILY NEWS

### BIRTHS

Debi and Mark McAfee are proud to announce the safe arrival of their son Jake on 17 May 2000. He is a welcome little brother for Jade.

Kieran and Bernie Houston are very pleased to announce the safe arrival of baby Mark on 2nd June 2000. Congratulations to all the Houston's.

Millicent Olivia Bailey was born on 3rd May at 12.35pm weighing 6lb 11oz. Proud parents John and Claire are delighted with their new arrival.



**Millicent (Milly)  
Olivia Bailey  
(3 weeks)**

### NEW FAMILIES

Eight new families have sought the support of the MPS Society since the last Newsletter following diagnosis of MPS on one or more of their children. This includes the two families below who have given written permission for their details to be published.

Karen and Patrick Otway's daughter Emily has recently been diagnosed with Sanfilippo disease. Emily is four years old in July. The family live in the north of England.

John and Sarah Huntley's son Christian has recently been diagnosed with Morquio Disease. Christian is one year old. The family live in the Home Counties.

## FAMILY NEWS

### A POEM ABOUT CRAIG

A little boy was born on March the twelfth,  
He weighed 6lbs 12oz and was bursting with health.  
A few cries were heard of joy and of love,  
He looks just perfect he will fit in like a glove.

A few months pass and not all was right,  
For a few trips to hospital we made at night.  
This did not seem right it did not seem real,  
The infections you had were so hard to heal.

The weeks turned to months and the months  
into years,  
More trips to the Hospital and rivers of tears.  
Something was wrong of that we did know,  
What is it called? What is Sanfilippo?

How could this happen? From where did it  
come?  
Was it my Dad? Or was it my Mum?  
Who passed down this defective Gene,?  
With it's storage disorder that is so cruel and mean.

We went to see the staff at your school,  
And they made you an exception to the rule.  
You have your own carer, who hold's onto your  
hand,  
Her name is Amanda and we think she is grand.

You could not be left on your own at all,  
This was found out as you ran down the hall.  
Where ever you go Amanda is not far away,  
She is always so happy and willing to play.

We know you are lovely, we know you are  
grand,  
As you sing out a song you hold onto our hand.  
You march and you bang, you chew and you eat,  
You watch TV and you laugh yourself off your  
feet.

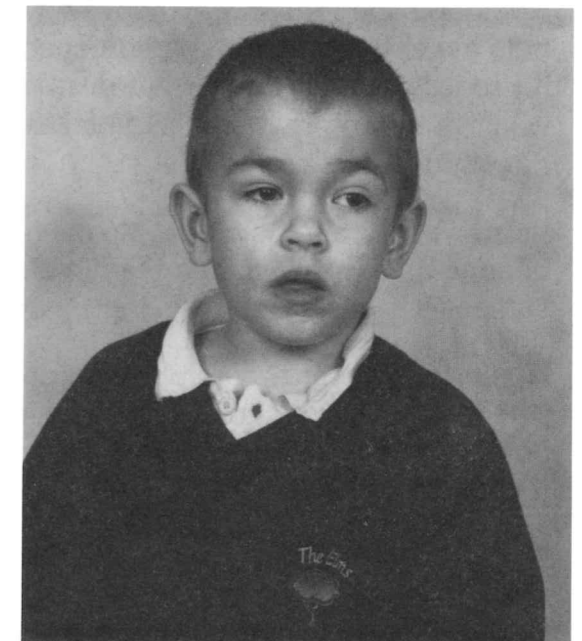
You shout and you bang, you knock and destroy,  
We are so very proud of our MPS boy.  
To keep us awake at night is so much fun,  
When the noise is too loud we put a video on.

We are tired, we are drained, we curse and we  
moan,  
We must look like Zombies at night in our  
home.  
So how can we stop this? What can we do?  
There is only one answer, to keep loving you.

For you are so special and as each day draws  
near,  
We want you to know that we will always be  
here.  
Watching you laugh and giggle and play,  
Knowing for you that time ticks away.

We just live our lives as best as can be,  
You, your Dad, Robert, Kirsty and me.  
We all have our ups we all have our downs,  
We all have our smiles we all have our frowns.

There is no magic potion, no miracle cure,  
I will say it again as I have said it before.  
Come day or come night we want you to know,  
We will always love you Craig and never let  
go.



*Thank you Karen and Rob for this lovely poem  
about Craig.*

## FAMILY NEWS

### 'I've got Hunters' by Claire Garthwaite

*This article was written for a child with Hunter disease who was beginning to question his disability. It was intended to explain in a simple way how Hunter disease affected him so he, his school friends and his siblings could understand. (age guideline 5 to 8 years)*

Everybody is different. Some people are tall, some people are small. Some people have brown eyes and some have blue eyes. People have different coloured skin and hair. The world would be very boring if we were all the same.

I've had Hunters since I was a tiny baby in my mummy's tummy before I was ever born. It is nobody's fault that I have Hunters, its just the way I was made. I have a brother who also has Hunters and a sister who doesn't. Have you got Hunters or your brother? Or do you know someone else with Hunters?

Hunters is the reason why I find it hard to run fast. My legs and arms are a bit stiff and my tummy sticks out so I need a little help to get myself dressed and washed.

Hunters is the reason why my fingers can't straighten out properly. It makes undoing buttons, tying laces and writing more difficult for me. The good news is that I have a computer to write with at school. I had an operation on my hands (carpal tunnel release) when I was younger to stop a fizzy feeling in my fingers.

Hunters is the reason why I have tiny tubes in my ears called grommets. They help me to hear better. I had an operation in hospital to put in the grommets and my tonsils and adenoids were taken out at the same time. Some other children who haven't got Hunters have had their adenoids and tonsils removed and some have grommets too.

I also wear hearing aids to help my hearing. (The good thing about wearing hearing aids is that you can turn them off if you really don't want to hear what someone is saying- only joking!)

Hunters is why I need help when I go to the toilet. Sometimes I have accidents when I don't make it to the toilet in time. I do find it annoying but I know that it is not my fault. At school I have a helper who gives me a hand when I go to the toilet.

If you have Hunters, you may find some of these things difficult and maybe there are other things too. Everything was much easier when I found out about Hunters because I knew why I couldn't run fast or write very well. In my class at school my teacher and my friends know about Hunters so they understand when I can't do something easily and can help me.

## FAMILY NEWS

Hunters is nothing to do with Huntsmen or Hunting. The reason it is called Hunters is that a long time ago a very clever doctor called Charles Hunter discovered there were many boys who all found the same things that I do difficult. Because his surname was Hunter he decided to call it Hunters.

I go to see a doctor at the hospital every so often to check how all the different parts of my body are working like my hands, the grommets in my ears, my heart and my chest. Sometimes I have x-ray photographs taken. Once a year a special camera takes pictures of my heart while I lie still. It's called an echocardiogram.

I also have my hands checked with a machine that makes a funny tingling feeling in my fingers. (nerve conduction studies to look for carpal tunnel)

I have stayed in hospital for a sleep study before. One of my parents stayed too and there was a video camera and other machines that watched my breathing and my heart beating while I was asleep. I hope I didn't snore too loudly!

You can't catch Hunters like you catch a cough or cold. It is just the way I was made. It is nobody's fault and if I didn't have it, I wouldn't be me. I will always have Hunters and will need a little more help than most other people.

Hunter's doesn't stop me having fun at school and at home with my friends and my family. I have many hobbies and lots of plans for what I want to be when I grow up.

There are other boys with hunters too and sometimes we all get together. (The MPS Society is a group set up to help people with Hunters and other similar problems.) While our parents talk we often go on trips to theme parks and have a great time.

### PLEASE NOTE

The views ideas and suggestions published in this Newsletter are those of individuals expressed in their own words.

The articles published in this Newsletter may not be produced or electronically copied without the permission of the MPS Society.

## FAMILY NEWS

*At the Northern Ireland Conference in May 2000, Rosemary Dawson, who is the mother of Michael and Lucia ( Hurler) and Una and Bridget, very kindly wrote about her experiences as a mother of these two special children. Her sister in law, Teresa, read the articles at the conference and as everyone present found them so interesting and informative we thought you would all like the opportunity to share the family's experience.*

### Michael's Transplant

I remember when Michael was born and was diagnosed with Hurlers, I thought that the doctor's were making it all up and that it was just a big joke! I'll never forget that day. We were offered a bone marrow transplant. As most parents would, we jumped at the chance to give Michael a full life. The doctor's had first to find a donor and it had to be a match. They tried all his Aunts and Uncles and my daughter. The closest match was my sister in law Teresa. She was only too glad to help.

So we all went to London for the Transplant. But before they could do the Transplant they had to destroy Michael's immune system and kill off his own Bone Marrow. This was to help Michael's body accept the donor's marrow better. To cut down on infections anyone who was in contact with Michael during this time had to wear gowns, face masks, rubber gloves and plastic shoes. They took Michael down to theatre so they could put two lines for drips into his chest. When Michael came back from the theatre he pulled one of the lines out and had to go back. They had to measure all of Michael's joints and I remember Michael crying in pain because the doctor's were pulling his arms and legs out straight, when they were naturally bent. All I wanted to do was to pick him up and tell them to forget the whole thing but I knew I could not as Michael had no immune system. His hair had started to fall out so we decided to cut the rest off ourselves. Everything that went into Michael's room had to be sterilised.

All the nurses and doctors were very supportive and helped us through. When they told us that his transplant had not worked they offered us another chance to try it again. We were so happy to get Michael home alive and safe, as we could have lost him at any stage during the transplant, I still feel that we made the right decision at the time and have no regrets.

*(Michael Dawson – 1983 – 1986)*

## FAMILY NEWS

### Life with Lucia

When Lucia was born I knew that she had Hurlers. I saw it in her face, she was Michael's double. She was diagnosed as having Hurlers at two weeks old. We were offered another try at a transplant but we turned it down as we could not put her through what Michael went through unless it was 100% guaranteed to work.

It was not as hard to accept that Lucia had Hurlers, as we already had three years of experience. Lucia is a very good sleeper and would sleep from about 9pm until 2pm the next day, if I let her.

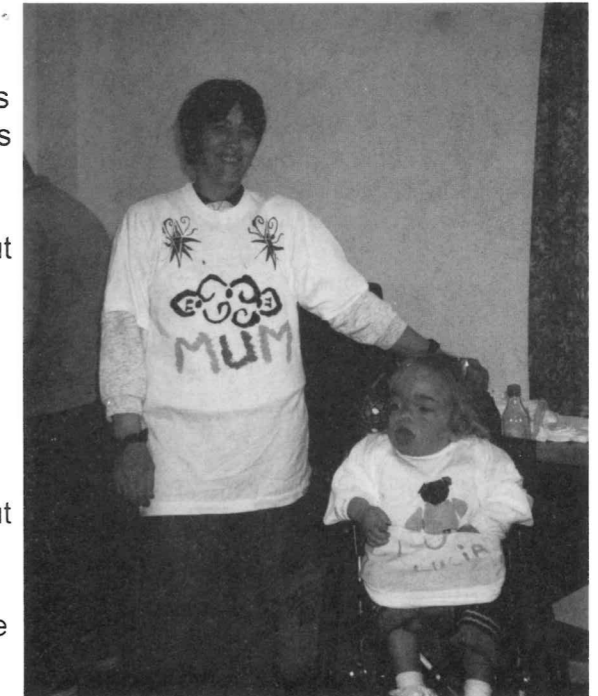
Lucia is not treated any different from the other two girls but she is spoilt to a certain extent.

Lucia's treatment is different from Michael's as she gets nebulised four times a day, where as Michael was always in and out of hospital with chest infections. Lucia is only ever in hospital to get grommets put in. She has had a tracheostomy for five years and needs suction around seven times a day. She has very few bad days.

She used to play with the other kids but now she sits and watches them. Her hands and feet are always ice cold which is caused by her body making extra tissues and it takes a long time to get them warmed up. She sometimes wines a lot and points to her fingers they must be very sore because of the cold and sometimes numb from being cold.

Lucia goes to school five days a week from 9am until 1pm, she cannot manage any longer than this and some days she will go to sleep after school. Sometimes her legs buckle from beneath her and cause her to fall, sometimes she hits her head but most of the time we catch her. Also at night she will wake me and cry for no reason and I still don't know why this is as she can't tell me.

Lucia understands a lot more than most people give her credit for. It is hard sometimes to look at the other kids and see them doing things for themselves and see how much Lucia has slowed down over the last few years. She does not have the same grip that she used to have as her fingers are stiff. **Cont...**





## FAMILY NEWS

Lucia is now coming up to 10 years old and loves going swimming with the school and us, she also loves the summer scheme at school and likes going to the disco's. I do not regret giving Michael the transplant nor do I regret not giving it to Lucia. I feel that we have made the right decision in both children.

*Editor's note:*

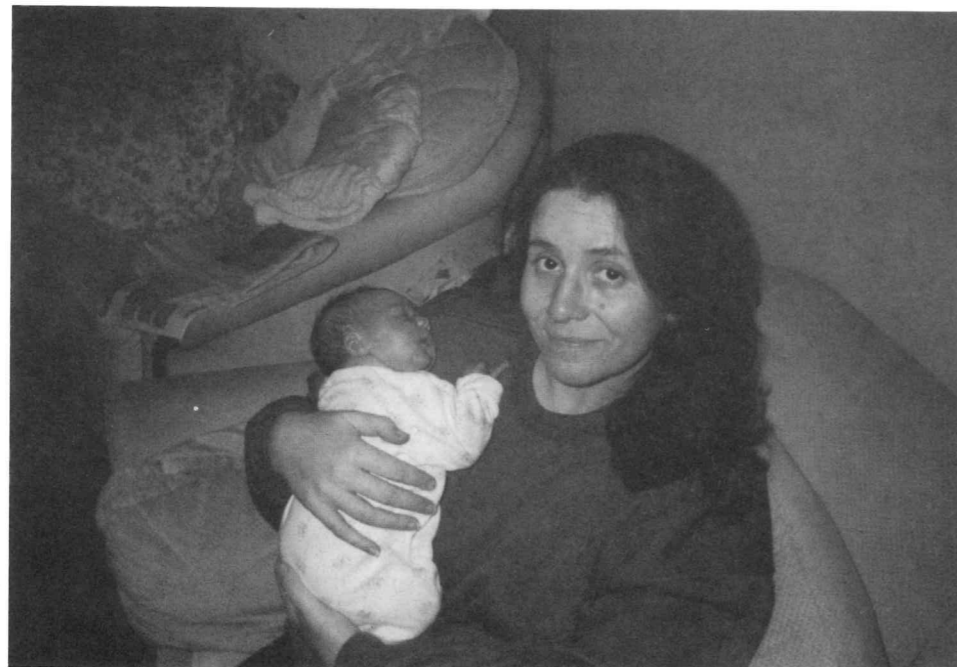
Thank you Rosemary *(photo on page 11 shows Rosemary & Lucia T-Shirt painting, Share Centre Family Weekend- June 2000)*

## NEWS

In the Spring 2000 edition of the Newsletter we announced the safe arrival of April Louise – a much longed for addition to the family of Jackie and Loz. Here is a picture of April and her proud Mum – April is 4–5 days old in this photo and Jackie has written to say “ I hope that all the other mums who have had a hard time and a lot of heart ache trying to conceive a healthy baby will take heart and know that miracles do happen – I do still think of James every day!”

*(James died in 1997– he had Hunter disease)*

**Jackie and  
April  
(January 2000)**



*Please send your family news and photo's for the Family News pages – we would be very happy to include them.*

## REGIONAL EVENTS

### SHARE WEEKEND IN NORTHERN IRELAND

When we were asked if we would like to join the group to go to Ireland we had no idea what was in store for us (except to expect from Sharon)!!

After a 2 hour delay at the airport, sitting on the plane with nothing to do, we took off and had a nice flight over. Arriving at Belfast the bus took us on a very scenic route of mountains, sheep, goats, cows, horses, fields and small villages eventually arriving at the Share Centre at around 5.20pm where we met up with other MPS families who had travelled on the Seacat from Scotland and by road from other parts of Northern Ireland and also by staff members of the centre. These greetings were extremely welcoming and all the staff were very helpful, carrying cases. Nothing was too much trouble to any of them.

Our co-ordinator for the weekend was Margaret who seemed never to sleep as she was there first thing in the morning until last thing at night. She took a genuine interest in our children and was a very caring person who asked about the conditions and what MPS was all about. It was nice to have someone who took such an interest.

The activities arranged for us were great fun. The children loved every minute of it. Going on the barge trip was certainly an experience we won't forget in a hurry. Thomas wrapped in a towel and Linda with a pair of Tom's trousers on her head with the legs wrapped round like a scarf to keep the wind out of her ears. It was freezing!! But... We enjoyed it and just hope that next time we go the weather will be warm and sunny so we can have the longer cruise around the lake.

Saturday evening was good fun with the surprise party for Sharon (who never gets embarrassed ha ha) for her birthday and for Graham and Judith Evans 20th Wedding Anniversary. The Barbecue was really good and the disco was welcomed by all. The children had a great time. Over to the bar later in the evening for a few much needed drinks which ended in quite a late night. Poor Margaret was still around at 2.30am!!

Sunday morning and time to start re-packing for the journey home. The sun had decided to come out for a while so some of the group went swimming and others chanced their luck once again on the Lake taking a Speedboat ride. (Must have been mad, I say) but with wet bottoms at the end of it, they all came back after having a great time.

The centre provided us with a huge amount of food to take with us on the bus back to the airport and we set off after saying our goodbyes to everyone at the Centre.

We feel that the weekend was a great success and would really love to go again, perhaps for a longer stay.

Thanks to Ellie, Kate and our volunteer Clair for organising such a fun few days and for all the help they gave us while we were there. Also thanks to you all from Sharon for her Birthday Party.

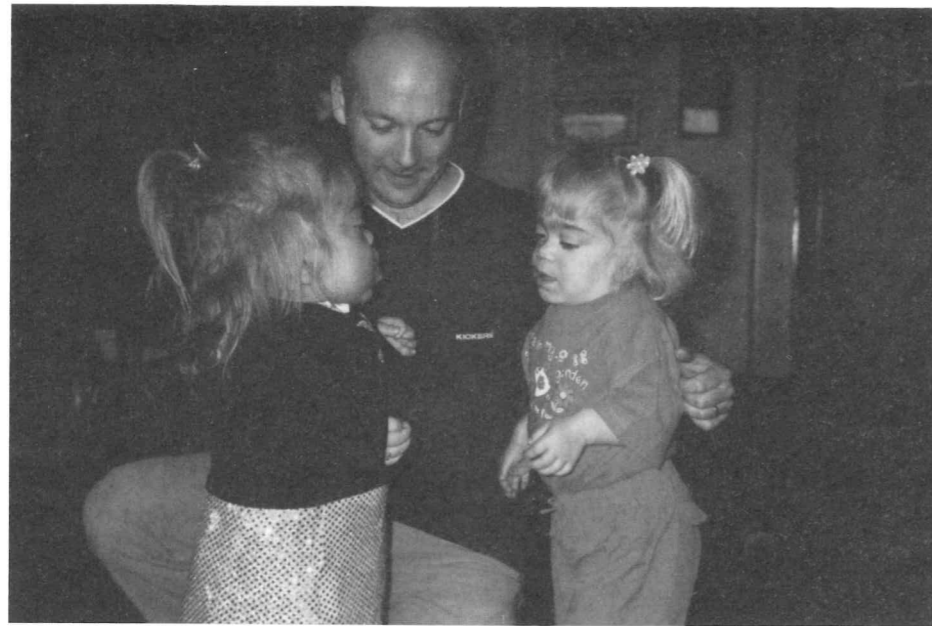
We would like to take this opportunity of thanking everyone at the office for all the hard work and support you give to all the MPS Families. We are all grateful that you are there for us. You are all greatly appreciated.

Sharon, Linda, Ann-Marie, Gordon  
Thomas, Zara and Christopher

*(It is with much sadness that we report the untimely and sudden death, at the end of June, of Gordon who accompanied the Birch family as a carer for Thomas and Christopher)*

REGIONAL EVENTS

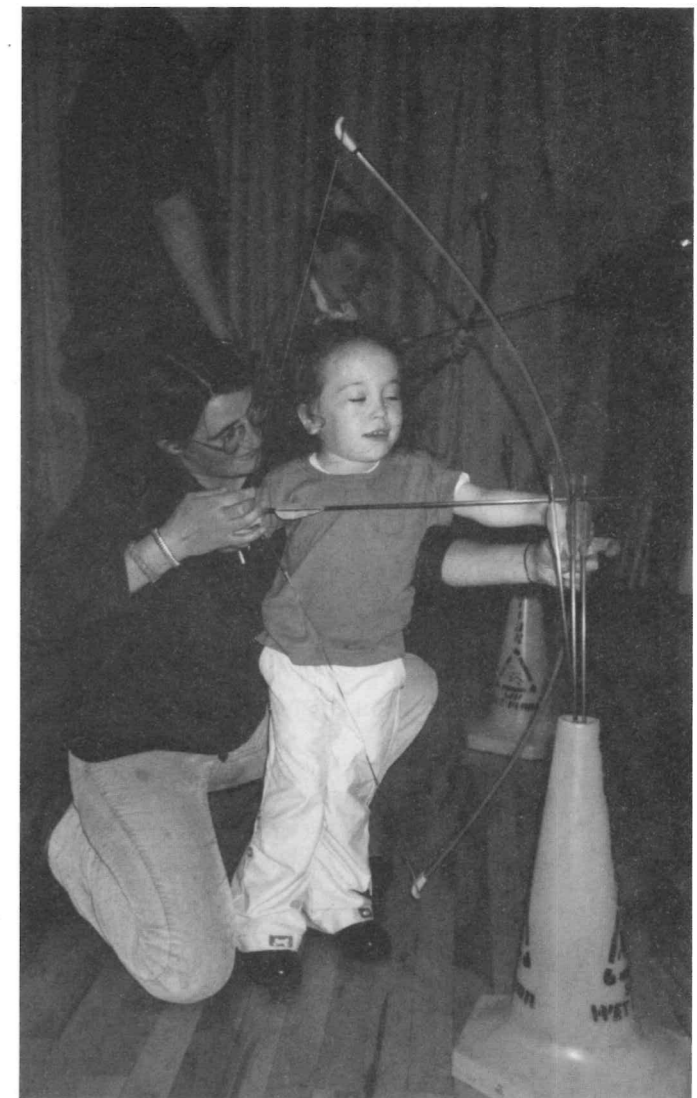
SHARE WEEKEND - GALLERY



Top: Gilbert Watterson introduces his daughter Robyn to Lucia Dawson  
Bottom left: Joanne Evans in party mood Bottom right: Amy Pain painting a T-Shirt

REGIONAL EVENTS

SHARE WEEKEND - GALLERY



Top left: Angela Brown and Aiden going sailing

Bottom left: Linda, Zara and Thomas get some fresh air

Right: Roma Drayne in competition with Robin Hood

**REGIONAL EVENTS – LEGOLAND**



*Hannah and Angela with friend !*

On Sunday 14th May the MPS Society organised a day out at Legoland.

Four families came along to enjoy this super day, bringing their children and extended family members.

The weather was lovely (probably the first – *and last* – good weekend this year) and everyone met up to have lunch together, followed by a very welcome ice cream!

The day was a great success and enjoyed by all – little ones and not so little ones alike.



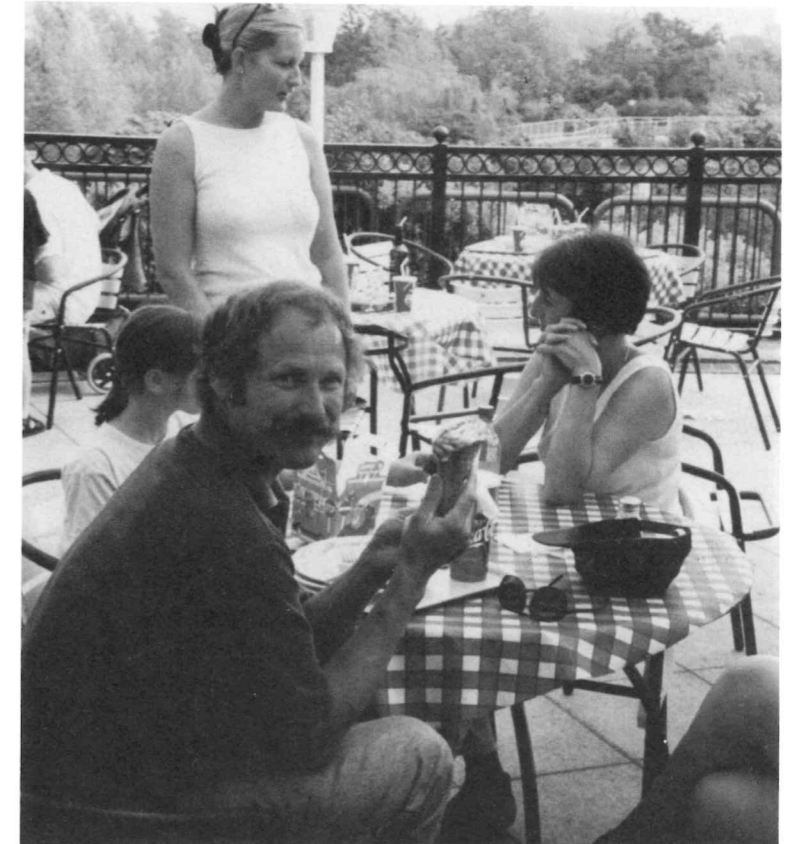
*MPS families enjoying the sunshine*

**REGIONAL EVENTS– LEGOLAND**



*Paul Leonard and Christopher enjoy an ice cream!*

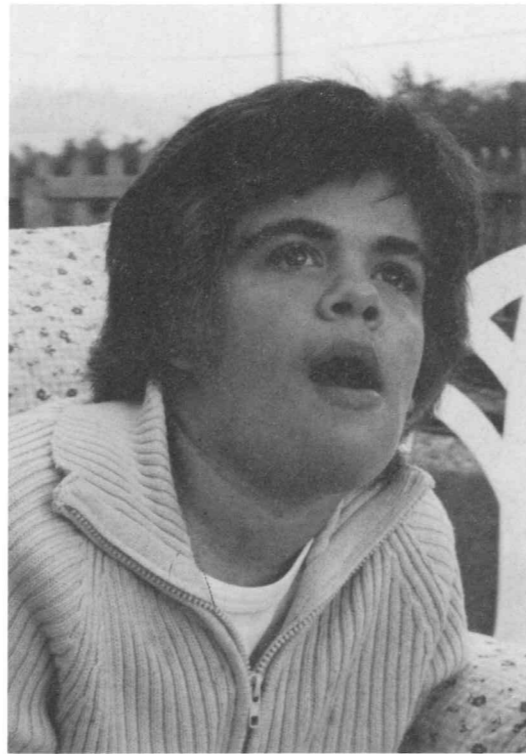
*Should you be eating that Gordon ?*



**REGIONAL EVENTS**

**SOUTH WEST AREA  
FAMILY BARBEQUE**

*Louise Hill age 21 (Sanfilippo)*



On the 7th May Gordon and Anne Hill very kindly hosted the annual barbeque for MPS families living in South West England.

As you will see from the photographs the weather was on their side and 22 adults and children enjoyed a lovely afternoon in the warm Devon sunshine.

*Everyone enjoying the wonderful Devon hospitality!*



**REGIONAL EVENTS**



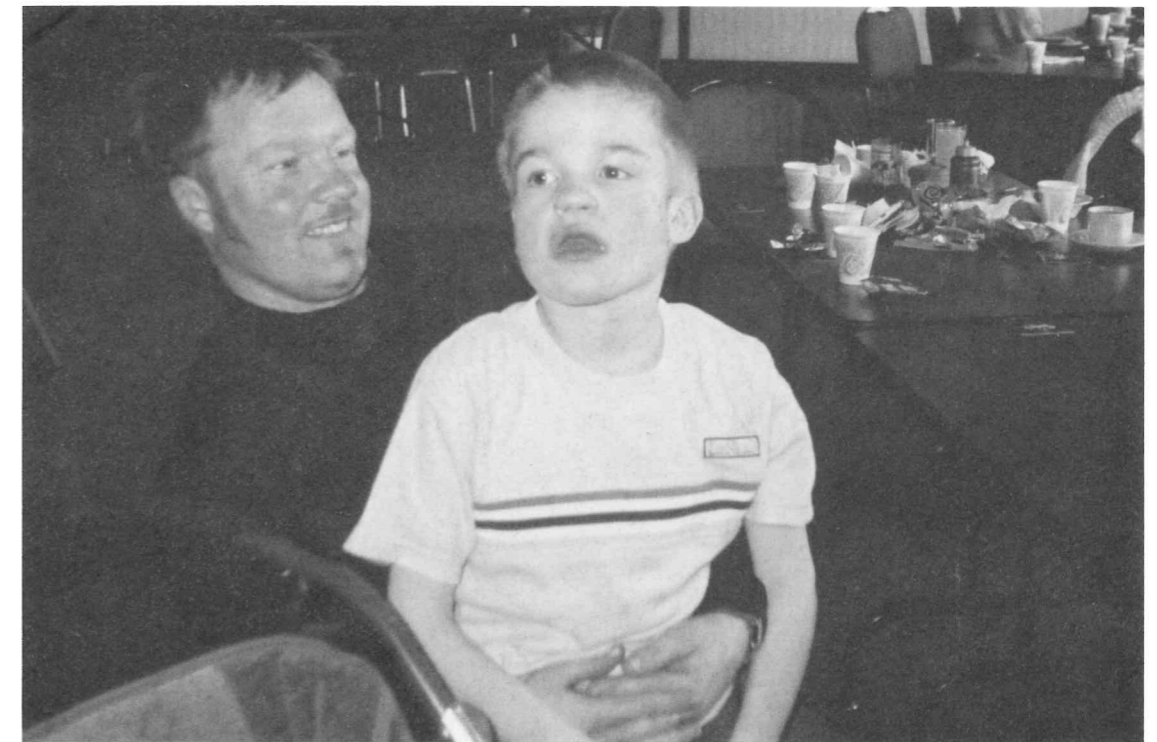
**A GREAT RESULT FROM  
BRAMALL LANE**

The Easter Eggstravaganza at Sheffield United FC was a great day and seemed to be enjoyed by all. We had a great raffle with some excellent donated prizes, just to give him a mention Andy Seymour walked away with the crate of beer, to help him get over Scunthorpe United's relegation!

The Easter bonnet competition was a close one; everybody put lots of effort into their hats. And Lynne was the winner, and Jamie Moxon with his balloon hat came a close second! Zoot the juggler kept the kids entertained with his acts, unfortunately the only two children that didn't seem to approve was our two Jordane & Brooke Robjohns.

The ball pool was a success; Jamie Moxon was the (Sheriff) anyone not doing as they were told in the ball pool got escorted to jail by him. Thanks to Amy Rollinson for entertaining the kids with pass the parcel and making sure everyone was a winner.

There was a lovely spread put on by Sheffield United and Barbara & Trevor brought the necessities crisps, chocolate, pop etc for the kids. The day came to a close as Amy and Lexie Rollinson dressed up as Easter bunnies and gave all the children Easter Eggs! Thank you to everyone who turned up on the day.



*Daniel Ellis with Dad Stephen enjoying their afternoon together*

**REGIONAL EVENTS**

David Seymour with Mum & Dad, Angela and Andy tucking into the lovely food.



Thank you once again to everyone who generously donated items to make this event such a success, we had a great raffle and the money raised went to the MPS Society where it will be put to very good use.

By Paula & Steve Robjohns (a list of donors can be found on page 39)

**Beatitudes for Friends of the Handicapped**

Blessed are you who take the time  
To listen to difficult speech,  
For you help me know that if I persevere  
I can be understood

Blessed are you who never bid me to "hurry up"  
And take my tasks from me  
And do them for me,  
For often I need time rather than help

Blessed are you who stand beside me  
As I enter new untried ventures,  
For my failures will be outweighed  
By the times I surprise myself and you

Blessed are you who asked for my help,  
For my greatest need is to be needed

Blessed are you who understand that  
It is difficult for me  
To put my thoughts into words

Blessed are you who, with a smile,  
Encourage me to try once more  
Blessed are you who never remind me  
That today I asked the same question twice

Blessed are you who respect me  
And love me as I am...  
Just as I am  
And not like you wish I were

Anonymous

**MPS CLINICS AND CONFERENCES**

**NORTHERN IRELAND**

This was my first clinic and conference. I arrived in Belfast on Thursday 11th May and with Ellie and Hannah visited the Share Centre near Enniskillen to ensure that everything was OK for the MPS family Activity Weekend, being held in June.

**MPS CLINIC – FRIDAY 12 MAY**

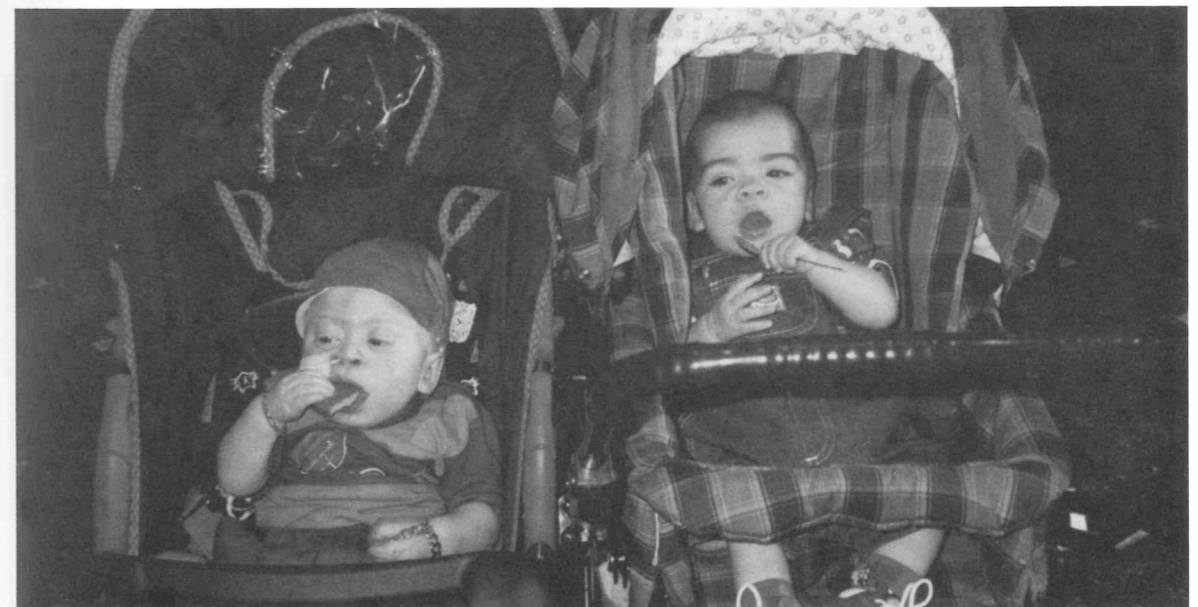
The hotel were very aware of the MPS families and professionals needs and had arranged the clinic rooms exactly to our requests. Dr Ed Wraith's flight, at 7am from Manchester was cancelled, delaying his arrival at the hotel by 2 hours. Dr Fiona Stewart, from Belfast, had a somewhat easier journey!

The families arrived at their designated times and were able to spend as long as they needed with the Doctors. There were two new families who were very grateful for the information, support and help offered by the medical professionals and the MPS Development team.

Refreshments were served all day, as requested and sandwiches were provided at lunch time.

I was impressed with the informality and friendliness of the clinic. It was very clear that the families enjoyed meeting Dr Wraith and Dr Stewart as well as the staff from the MPS Office and that they all went away with questions asked and answered and plans being made for the future.

Kate Crown – Project & Information Officer



On the left is John McDonagh 2yrs (ML II) & on the right is his cousin Brian McDonagh 6 months (ML II) - it was lovely to see both boys and their parents at the clinic – they were great fun!

## MPS CLINICS AND CONFERENCES

### NORTHERN IRELAND GET-TOGETHER!

On the Friday evening between the Clinic and the Conference the MPS Society held a 'Get-Together' for professionals, MPS staff and families who were staying at the hotel or lived nearby. The evening was a huge success with adults and children sitting down at one long table to enjoy a lovely meal in each others company. A birthday cake, adorned with candles, was produced at the end of the meal to mark the 18th birthday of the Society and as you will see from the photo below Dr Stewart made a good job of blowing out the candles!



*Dr Fiona Stewart and Dr Ed Wraith with the MPS birthday cake!*

*Alison & Andrew Shields*



## MPS CLINICS AND CONFERENCES

### NORTHERN IRELAND CONFERENCE

The Northern Ireland Conference was held on Saturday 13th May 2000. It was the first conference that I had organised and with lots of help and guidance from everyone in the MPS office the day was a success. The conference was due to start at 10am with Dr Fiona Stewart, our Chairman for the day, making the introductions. However, before Dr Stewart could start the proceedings it was my role to give out the housekeeping notices which included the tone of the fire alarm bell. I had asked a member of staff who had overseen the setting up of the conference facilities, to describe the noise of the fire bell to me, he apologised for not being able to activate it so that I could hear for myself.

At 5 minutes to 10 everyone was starting to take their seats in the conference room, I had my notices ready and the description of the fire bell in my mind, when all of a sudden and to my complete amazement it was no longer just in my mind but actually ringing – it took me quite a few seconds to realise that I was not imagining it. We all left the building and made our way to the meeting point where everyone's name was being called out over a loud hailer – this caused great amusement especially when 'Mr & Mrs Smith' were mentioned and where were the honeymoon couple!

We were eventually let back into the hotel and the conference got underway. The speakers were all exceptionally interesting and the subjects covered were varied and informative. The feedback from everyone was very positive. Dr Stewart did a wonderful job as Chairman and everything ran smoothly.

We finished on time and the MPS staff made a dash to the airport to catch the only flight to London on a Saturday evening, that's when things started to go wrong – the flight before ours had a technical fault and was grounded. An aircraft which had not yet left London was going to take us all (both flights) home. After a couple of hours of hanging around Belfast International and only having a small Guinness or similar each, we eventually boarded a very full plane -standing room only! We took off and became aware of the aroma of hot food and our much needed 'in flight' meal only to be informed that due to the fast turn around of the aircraft they had not had time to load enough meals for everyone, so Business Class were eating and the rest of us could just sit there and enjoy the ambience – we were not amused!!!

We eventually arrived home after a very long winded and winding taxi journey (we think he was trying to increase his fare – in which he was completely unsuccessful) we were tired and hungry but also very happy that the Clinic, Get-Together and Conference had been a unanimous success.

Our thanks go to everyone we met in Northern Ireland, to the families, the speakers, the professionals and the staff of the Hilton who looked after us all so well.

Kate Crown  
Project & Information Officer

## MPS CLINICS AND CONFERENCES

### NORTHERN IRELAND CONFERENCE – TRIBUTE

The following tribute was made by Christine Lavery at the Northern Ireland MPS Conference – 13 May 2000, to mark the retirements of Professor Norman Nevin, Consultant Clinical Geneticist and Wendy Johnston, Genetic Health Visitor.

“Professor Norman Nevin has for over three decades headed the only genetic service for the whole of Northern Ireland. We are very privileged to have had such an authoritative speaker today on Gene Therapy, as Professor Nevin is Chairman of the Department of Health Advisory Committee on Gene Therapy – GTAC. Our sources tell us that Professor Nevin will soon be celebrating his sixty-fifth birthday. On the mainland that special birthday would lead to the ‘R’ word We don’t know Professor Nevin’s plans for the future but we do want to thank you for all you have accomplished for people suffering from or at risk of genetic disease, particularly the MPS and related disorders in the Province.

Since 1972 until very recently Wendy Johnston has been the only genetic health visitor for the whole of Northern Ireland. Some MPS families will have been visited by Wendy, following an MPS diagnosis on their child. Wendy has been an enthusiastic supporter of the services and activities the MPS Society offers MPS families in Northern Ireland and has regularly attended our MPS Conferences. What you probably don’t know is that for 3 years Wendy and I served on a Department of Health Advisory Committee on Genetic Testing, and it was through these meetings that Wendy took on the behind the scenes role in helping to establish the Annual Northern Ireland MPS clinic. At the end of this month Wendy takes well earned retirement”.

*Professor Nevin and Wendy Johnston were each presented with an Acer tree in appreciation of their work and support for the MPS Society and wished every happiness in their retirement.*



*Professor Nevin and Wendy Johnston being presented with Acer trees by Alison Shields and Debi McAfee*

## MPS CLINICS AND CONFERENCES

### SCOTTISH CLINIC AND CONFERENCE

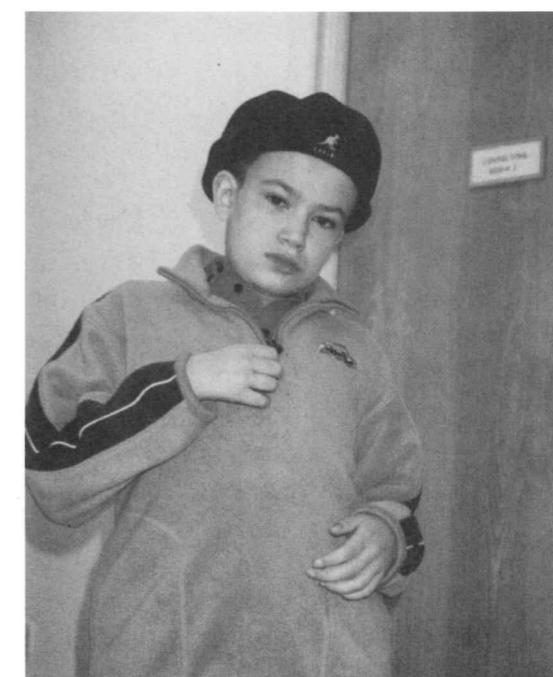
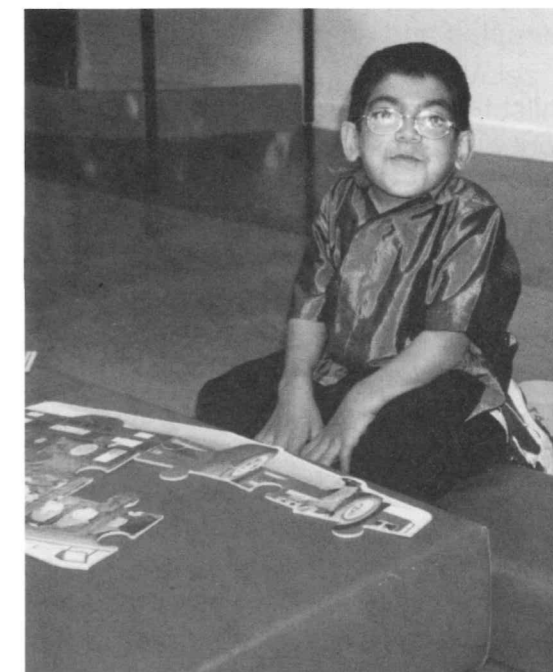
The Scottish Conference that never was! Just before leaving for the MPS International Symposium in Minneapolis we received a phone call from the Hilton Hotel, Edinburgh Airport to inform us that due to flooding they could no longer hold the MPS Society's Conference and clinic.

The quest began over the Atlantic Ocean to try and relocate this event. Angela Brown, Trustee, stepped in, visiting many alternative hotels. Unfortunately none of those available had wheelchair access and we had to accept that the weather had beaten us!. All was not lost though. The Hilton Hotel Group have, as compensation, funded the flights and extra costs incurred to enable those families disappointed by this cancellation to attend the main Northampton Conference.

We are very grateful to Angela Brown, who not only stepped in to help out with the Conference but found an alternative location for the Scottish clinic. MPS patients were seen by Dr Ed Wraith, Dr Maureen Cleary and Dr Peter Robinson from the Royal Hospital for Sick Children, Yorkhill. They were able to use the Child Development Centre, Boathe School Campus, Livingstone. The facilities included a large waiting area with ball pool, which kept the children entertained, giving Angela Ratcliffe and I an opportunity to talk with the parents and adults. We are very grateful to the staff of the Child Development Centre who helped us out at short notice and were so welcoming and helpful on the day.

Ellie Gunary  
Senior Development Officer

*Rahman Ali (top)  
Christopher Scott (bottom)  
At the Scottish MPS Clinic*



## OVERSEAS

### NEWS FROM THE 6<sup>TH</sup> INTERNATIONAL SYMPOSIUM ON MUCOPOLYSACCHARIDOSIS AND RELATED DISEASES May 19-21 2000 Minneapolis, Minnesota, USA

This meeting was run jointly with the International Symposium on Innovative Therapies and attracted delegates from all corners of the world.

Whilst the scientific and clinical conferences were interesting and we learnt about a newly identified MPS disease the most useful aspects of the symposium were the workshops on education, new-born screening and FDA (Food and Drug Administration) regulatory policy.

We also took part in several face to face meetings with representatives of the pharmaceutical companies involved in developing enzyme replacement therapy. The International Working Party of MPS support groups met and discussed in depth the role of the voluntary sector (not for profit organisations) in supporting their members through the clinical trial and the licensing of new therapies.

A major disappointment from the meeting was Dr Joseph Muenzer who is pioneering enzyme replacement therapy for MPS II (Hunter) not making it. Unfortunately severe storms and some local tornado's hit the East Coast of the USA as many people were travelling to Minneapolis. For those who persevered like Dr Ashok Vellodi who had an unscheduled night in Chicago and reached Minneapolis some 48 hours after leaving London we were very grateful.

*On behalf of Ellie, Angela, Hannah and I thank you to our anonymous donor, Genzyme, BioMarin and TKT for their financial support enabling us to participate in the International Symposium.*

#### NEWBORN SCREENING FOR MPS DISORDERS WORKSHOP

Newborn screening for genetic disorders has been available for 30 years. Many of you will have had experienced of the heel prick test in new-born babies to diagnose PKU (phenylketonuria). Specific criteria have been developed under which all new conditions being considered for newborn screening are compared. Although newborn screening for MPS diseases may become technically available, this raises many dilemmas for families.

As part of the discussion several families presented their own perspectives.

*We are grateful to Ernest & Debbie Dumann for allowing us to publish their views.*

## OVERSEAS

### FDA REGULATION AND MPS CLINICAL TRIALS WORKSHOP

Karen Weiss MD, Director of the Division of Clinical Trial Design and Analysis in the Centre for Biologics Evaluation and Research, US Food and Drug Administration spoke about the FDA's role as a regulatory agency to evaluate the safety and effectiveness of drugs, devices and biological products, including the assessment of clinical trials and evaluation of the trial data. Karen Weiss provided general answers to questions relating to clinical trials of enzyme replacement therapies for rare diseases. This included policies and procedures already available or in development in regards to standards for product approval for serious/life threatening diseases and procedures for patient access.

Stephen Smith, father of Ian Michael Smith who has Morquio disease type A gave an overview of his recent dialogue between MPS parents, the FDA and with members of the US congress. This dialogue has been necessary to express concern about the efficacy of the FDA supervision of clinical trials for enzyme replacement therapies for the MPS community, and the impact this has on the speed with which all MPS children and adults might have access to these treatments. Steve also thanked the MPS Society's around the world for responding to his recent e-mails and offering support for his efforts on behalf of us all.



*Carlos Pittol (Clubb Captial) Theresa Llewellyn Evans (President Australian MPS Society) and Hannah Crown at the Sixth International Symposium*



## OVERSEAS

A young lady, Molly Sue, with Morquio disease type A, who lives in Minneapolis USA would like contact with another adult with Morquio type A disease. If you would like to make contact with Molly Sue please contact Ellie at the MPS office.



### NEXT INTERNATIONAL SYMPOSIUM

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

This International Symposium which is being jointly organised by the British MPS Society and the French support network 'Vainacre les Maladies' is planned for May 2001 in Paris.

By placing this meeting on the mainland of Europe we hope that it will be as accessible as possible, both financially and geographically to as many, scientists, doctors, individuals and families affected by MPS and Related Diseases. We also expect that with nearly two years until May 2001 there will be significant new developments to be presented in areas at clinical management and new therapies.

Angela Ratcliffe

## OVERSEAS

### THE POWER OF DIAGNOSIS

Hello - I am Debbie Dummann, and this is my husband, Ernie Dummann. We are the proud parents of 2 young men, Trent who just turned 22 and finished his 4<sup>th</sup> year of college, and Sean, our 20 year old SanFilippo A son. We travelled from Alaska to attend this symposium.

We have been asked to speak on the positive aspects, had our son Sean participated in newborn screening, with a successful diagnosis. you see, we are the unusual ones, as our Sean was not diagnosed until the age of 16.

Face it, Alaska is somewhat remote when it comes to medicine. A lot of folks feel that the poorest of Dr's come to Alaska as they can't make it in the 'lower 48'. Others believe we get the doctors who are escaping the HMO's of the world, with all their rules. I'm hoping, our practising Dr's come to the "Last Frontier" because they truly want to make a difference in the vast, rural communities we have.

Our son's paediatrician certainly falls in the latter category. Dr. Kiehl has seen our family through thick and thin for 19 years, and I can't help but wonder how much easier it would have been for her to have been able to pick up the phone and call any of the practising universities, or medical centres. To think, she could have been in touch with the Mayo Clinic, John Hopkins, heck even the University of Minnesota. Maybe we could have found medications that would have helped with the years of diarrhoea. Even better, maybe Sean and his parents would not have lost 11 years of sleep! We certainly would not have actively searched for a diagnosis for 10 years !!!

When it comes to Sean's schooling, perhaps his teachers would have had more compassion and understanding knowing this illness is devastating and that he just can't perform to 'their' standards. And think of the education Sean could have given his classmates, along with the many students from other classes that volunteered time, in the many special ed. classes Sean has attended.

These are just some of the questions that were in our minds for years before Sean's diagnosis:

- Is Sean like this because of a head injury ? (A shelf had fallen on Sean when he was about 3 years old).
- We were outside one afternoon, Sean was swinging, when our neighbour started spraying Cygon 2E, the aphid bug killer. Sean got very ill that night. Is that why Sean is like he is, or was that just a coincidence?
- Sean had many high fevers with his years of ear infections, respiratory Infections, mononucleosis, etc... Could these high fevers have caused all of Sean's problems?
- And then you go to church and hear a sermon on the devil, while our Sean is truly acting up. So, is Sean the devil?

These questions and thousands more we had until Sean was diagnosed at the age of 16.

Sean attended public day care, and then later attended a day care for special needs children. Just think of the information we could have shared with these workers about Sean's hyperactivity, short or no attention span, etc... In retrospect, these day care businesses probably would have charged us more !

continued.....

## OVERSEAS

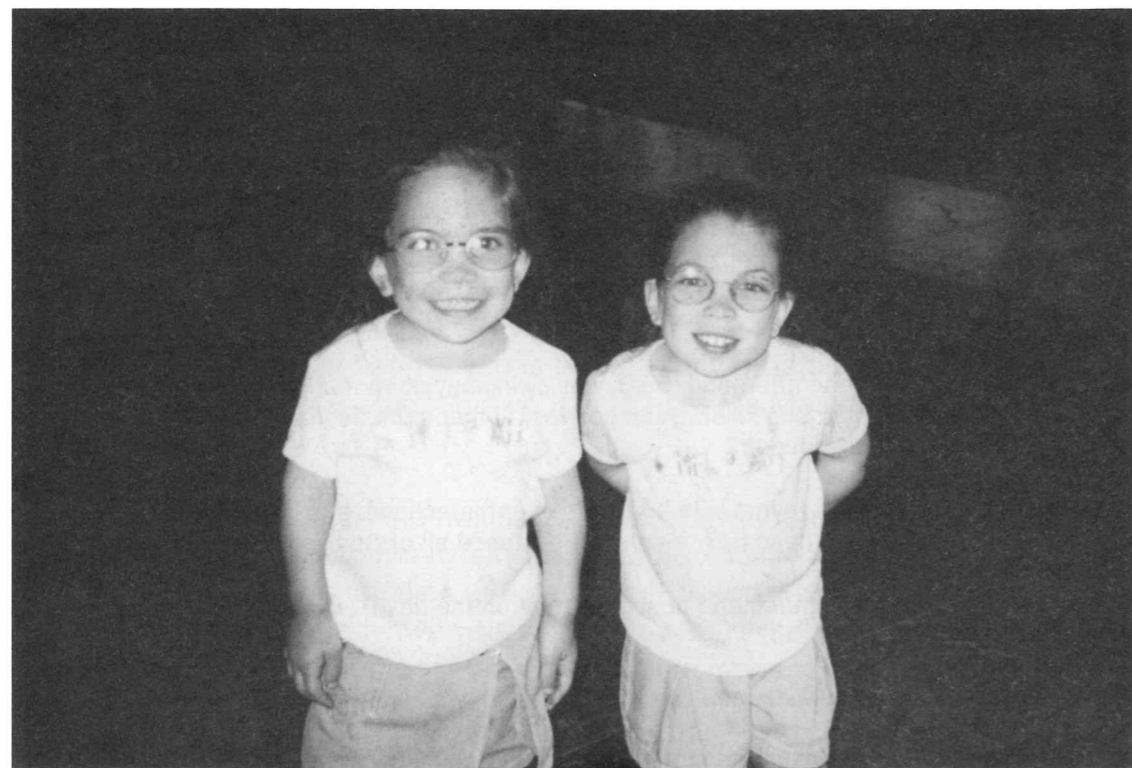
Something, which could have drastically affected our lives for the positive, would have been some in-home supports. As it was, Sean started receiving services at the age of 14, by that time, our family was in a crisis. It actually took us 2 years of contemplating before we asked for help. Then it was another 4 years before Sean received services. Had we had this diagnosis, maybe, just maybe, we could have received services before the age of 14.

And then there's Trent, the 'biggest brother', as Sean used to call him. This young man had no choice but to grown up quickly. How would Trent be different today with a diagnosis. Perhaps Trent would not be the shy, quiet one of the family. Would Trent's friends have accepted Sean's illness, instead of being somewhat scare of him.

In 1979, when Sean was born, there were no cures or treatments for SanFilippo Syndrome. Unfortunately, that still holds true today. However, there would have been a certain 'peace of mind' that maybe we should of had. We have always felt that knowledge is empowering. The San-Filippo brochure would have been a valuable tool for which we could have gauged Sean's every move. And, it all boils down to the fact that we as Sean's parent's would have been better prepared for Sean's future, and feel that Sean's quality of life, would certainly have improved had we had

"The Power of a Diagnosis".

By Debbie and Ernie Dumann.



Two sisters with Morquio Disease attending the Sixth International Conference

## IN REMEMBRANCE

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

*Brian Ward who suffered from I Cell (MLII) 05/09/97 – 01/03/00*

*Stuart Lawrie who suffered from Sanfilippo 10/04/85 – 12/05/00*

*Daryl McLachlan who suffered from Hurler 12/10/89 – 28/05/00*

*We walk through life with those we love, but sometimes we must part..  
So for a while they pass from sight... but never from the heart.*

### CHILDHOOD WOOD REMEMBRANCE DAY 2nd JULY 2000

*Gemma & Rebecca Russell, remembering  
their brother & sister, Katherine & Matthew*

On a very wet day eleven families gathered in the wood to remember children and adults who have lost their lives to MPS. A small ceremony took place with the names of those remembered read out.

The Society's Chairman, Wilma Robins read the poem 'Remember' by Christina Rossetti.

All the families then met at the Clumber Park Hotel for a buffet lunch and the opportunity to talk and share experiences. It was good to catch up with so many old friends.

Ellie Gunary



## IN REMEMBRANCE

### Grieving – What It's Like

*Written by: Joanne Chekryb Reimer & Betty Davis, 1996*

The physical and emotional hurt you feel is part of the process of grieving over the loss of your beloved child. Although it is excruciatingly painful, experiencing the hurt helps you adjust to this massive, almost overwhelming change in yourself and your family. Parents who have lived through this terrible experience have learned that grieving, as complex and difficult as it is, is necessary to survive such a loss. However, grieving does not undo the death or take away the void. The loss will never be forgotten, but with time you will find ways to remember your beloved child and live with your loss.

You will experience powerful reactions and feelings you are not accustomed to. You need not be afraid of the reactions or physical symptoms you experience. These reactions, although intense and complicated, do not mean something is wrong if you do not feel or behave a certain way at a certain time. Individuals handle grief in their own way, according to their own schedule.

Reactions to death are very personal and vary immensely. For some people, the initial reaction is one of extreme pain: they feel as they are being stabbed in the heart. Others are physically and emotionally numb. This numbness is the way the brain protects itself and refuses to take in what has happened. Initially, parents may find they can only recall the image of their child at the time of death, perhaps in pain or suffering. In time, this image fades and they are able to visualise the more familiar features of their child again.

When death occurs suddenly, the bewilderment and numbness are more intense. The news is overwhelming. As a result, families often remember little of the funeral or surrounding events. Some say photographs of the funeral and surrounding events later helped them to remember what happened.

When the initial shock has worn off, parents face a highly emotional time as they confront day after day without their child's physical presence and begin to understand their child will never come back. You experience extremes of emotion as you remember the hopes, expectations and dreams you held for your child. The

longing you feel for your child can be extremely intense. It may take the form of a gut-wrenching, gnawing emptiness or pain. You imagine your heart is somehow breaking.

You glance at a baby carriage, attend a school concert, drive past the playground, or walk past a video arcade and memories come flooding back. Time and again, you catch yourself looking for your child, talking to her footsteps. Sometimes you fear you are losing your mind. You are not: these reactions are common and related to a natural wish to undo the loss. It is important to allow room for your feelings and find your own way to express them by talking with others, writing a journal or hitting a punch-bag.

Gradually, almost imperceptibly, parents say they notice changes in the way they feel. Your energy begins to return and you take part in the events of everyday life with greater ease. The changes do not mean the pain will ever go away completely. Indeed, agonising moments and bad days return but parents say that slowly, over time, they are better able to tolerate them. Gradually, you begin to be able to recognise you will survive. You also know you will never be the same.

You find ways to remember your child and carry on living as a changed person and a different family. To say when these changes may occur or to give them a time frame is difficult because all parents grieve in their own way.

*Taken from: Finding Your Way: Grieving the Death of Your Child.*

*Pub: Canuck Place – A Hospice for Children*

*Yesterday is experience –  
tomorrow is hope – today  
is getting from one to the  
other as best we can*

*Taken from Ginger Snaps – Fun Thoughts on Life compiled by Dian Ritter*

## MPS NOTICE BOARD

### RESPONSE

#### NASO GASTRIC TUBE AND FEEDING GROUPS ?

We have had a response to the request, featured in the Spring edition of the Newsletter, for help with replacing Naso Gastric Tubes.

Linda Partridge from Contact a Family has very kindly contacted the office and suggested asking the following groups:

Action for Sick Children (020 8542 4848 - [www.actionforsickchildren.org.uk](http://www.actionforsickchildren.org.uk)) or the paediatric division of your local hospital .

Linda also suggests contacting an organisation called Pints (adults) 01202 481625 -[www.actionforsickchildren.org.uk](http://www.actionforsickchildren.org.uk) OR Half Pints (children) 01777 710723 these are feeding groups. Carolyn Wheatley from Pints explained that a monthly rota is in operation and details are given when you phone.

We would be very interested to hear how you get on!

Thanks to Linda and Diane at CaF for your advice.



#### **Spare or Old - McLaren Buggy Needed!**

The MPS Society is responsible for training its volunteers in Moving and Handling skills– to that end we have a training day coming up before the next Conference.

If we had a buggy to work with it would make the demonstrations a lot clearer.

It doesn't matter if the buggy is broken and we can arrange for collection.

Please contact Kate at the office if you can help.

## MPS NOTICE BOARD

STOP PRESS !

LETS MAKE IT WORK !

### 'BRING & BUY'

ALL FAMILIES ATTENDING THE  
MPS 18TH ANNUAL CONFERENCE  
IN NORTHAMPTON

Please bring any unwanted gifts etc.  
For bring and buy stall being run by Sue Lowry  
All proceeds to MPS



**ORDER YOUR CHRISTMAS CARDS  
NOW!**

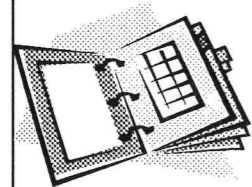
SEE THE FLYER ENCLOSED WITH YOUR NEWSLETTER

### CLOTHES FOR SMALL PEOPLE

Judith Evans – mother of Joanne, who has Morquio disease, has asked me to let you know that the French catalogue – La Redoute – has some lovely, fashionable clothes in small sizes.

Joanne always looks very fashionable and trendy – so what better advert could you have!

Phone MPS office for more details.



**2001**

**ORDER YOUR 2001 MPS DIARY NOW!**

**SEE FLYER ENCLOSED WITH YOUR  
NEWSLETTER**

## INFORMATION

### AN INTRODUCTION TO EMPLOYING AND MANAGING PERSONAL ASSISTANTS

As I'm sure you will all appreciate this is a vast subject, but I hope the following information will be a useful starting point when considering employing Personal Assistants.

Many people with MPS will sometime in their lives consider living independently. To do this successfully many of us will need to examine the option of using Personal Assistance services.

There are two main sources of funding for personal assistance, Social Services departments, and the Independent Living (1993) Fund.

The first thing to do is to contact your local Social Services and request an assessment of your needs for personal assistance.

The Government has advised Social Services departments to assess people's needs in the following six main categories:

- Personal/social care,
- Health care
- Accommodation,
- Finance,
- Education/employment/leisure,
- Transport/access

The assessment should take into account your whole life and what is required to live independently – make sure that you get a 'needs-led' and not a 'service-led' assessment.

When your needs have been assessed, a Care Manager, in consultation with you, will decide how your needs will be met. It is important for you to decide if you want to manage your own care package, control the funding of it, and be responsible for the recruitment of your own Personal Assistants.

Employing and managing Personal assistants may give you more control over your own life, but it also involves added responsibilities that need to be considered.

You need to know what your personal assistance needs are before you employ a PA. Compile a detailed list, which includes everything. You then need to estimate how many hours per day and days per week personal assistance will be required and how much this is likely to cost.

You should now be in a position to write a job description to ensure that your PA knows exactly what his/her duties will be.

When advertising for a PA don't display your address in the ad, only telephone or PO Box number. Some people might want to make arrangements for a friend or their local disability organisation to receive applications on their behalf.

The interview stage can be stressful for all concerned but if you prepare well with set questions you'll be sure to gain as much information as possible about the candidate. But as pointed out by CI's who have gone through the process, in the end it can all boil down to 'gut feeling'.

## INFORMATION

If your PA is to work more than 16 hours per week then you are legally obliged to provide them with a contract of employment. Help with writing contracts can be gained from Citizens Advice Bureau also, by contacting a local disability organisation or Social Services department you could find out if there is an Independent Living Support Scheme in your area.

A pay-roll scheme, such as the 'Simplified Deduction Scheme' (SDS) will ensure that your PA's income tax and National Insurance is calculated correctly. Ask for the 'P4Q Starter Pack' from your local Inland Revenue Office.

As an employer you will have a legal duty to insure against accidents or injury to your PA, or accidents or injury caused by them while they are in your employ. You will need to take out 'Employers Liability Insurance' can be included in a comprehensive household policy. Remember to take the cost of insurance into account when estimating how much personal assistance will cost you.

It is a good idea to devise a rota and work sheet that sets out exactly what needs doing and when.

Agreeing a set of ground rules between yourself and your PA can help in avoiding conflict and help to establish and maintain professional boundaries.

We have merely scratched the surface here but there is a growing amount of information to tap in to.

Some Useful Contact Numbers: -

**BCODP**  
**BRITISH COUNCIL OF DISABLED**  
**PEOPLE**  
01332 295551

**DISABILITY ALLIANCE**  
020 7247 8776

**DISABLED INCOME GROUP**  
020 7263 8776

**DISABLED LIVING FOUNDATION**  
020 7289 6111

**INDEPENDENT LIVING**  
**ALTERNATIVES**  
020 8902 8998 EXT. 228

A list of useful publications: -

'Guidelines for Self Operated Care Scheme Users', Greenwich Centre for Independent Living, Christchurch Forum, Trafalgar Road, Greenwich, London, SE10 9EQ  
Tel. 020 8305 2221

'The Personal Assistance Users Newsletter' BCOBP, Litchurch Plaza, Litchurch Lane, Derby, DE24 8AA  
Tel. 01332 295551

'User Control and Employing Personal Assistants for Independent Living' Disability Advocacy Network, 20-50 Southern grove, London E3 4PX.  
Tel. 020 8980 2200

### NOTICE OF AGM

Notice is hereby given that the Annual General Meeting for 2000 will take place at the Hilton, Northampton on 8 September 2000 at 7.30pm

## FUNDRAISING

### SPONSORED WALK BY CHRIS AND SOPHIE LONGLEY

Over the Easter Break, my eldest daughter Sophie (aged 12) and I completed a walk of The Cotswold Way. This is a way-marked footpath stretching the length of the Cotswold hills from Chipping Campden to Bath, a distance of 104 miles.

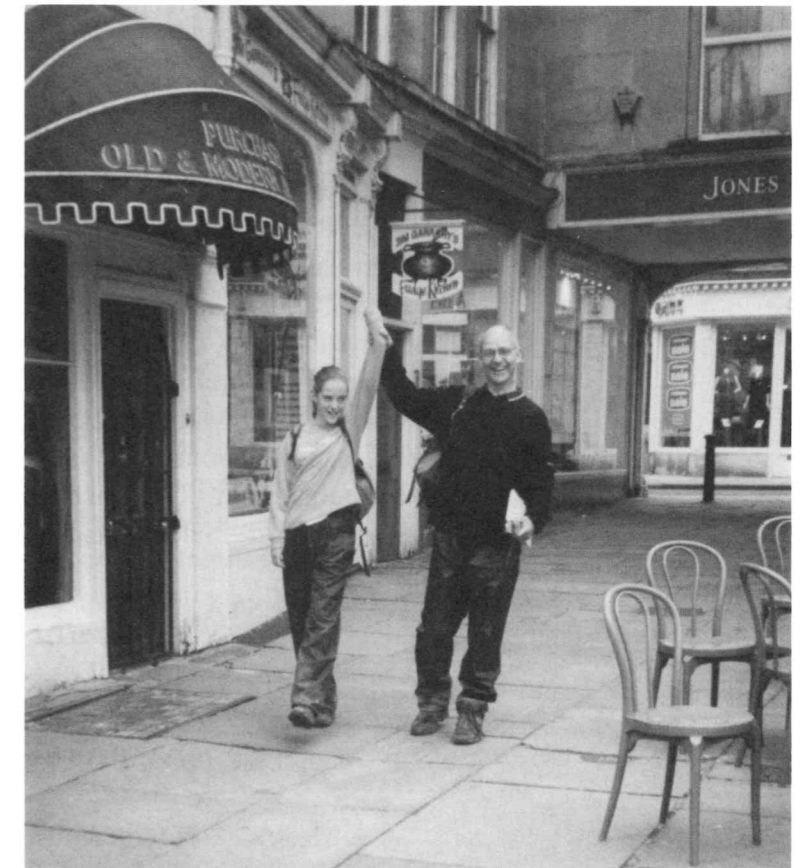
It has been a long time ambition of mine to complete this walk and as I saw it as quite an challenge, I decided to make it a charity walk in aid of the MPS Society and Whizz Kidz who supplied Faye's electric wheelchair. Our younger daughter, Faye, suffers from Morquio Syndrome.

I am very happy to tell you that I managed to raise £1405.20 of which we are passing on half (£702.60) to the MPS Society.

Sophie and I completed the walk over 6 days, averaging around 17 miles per day, most of which was either up or down hills! Sophie did particularly well as I set out with the expectation that she would do two or three days with me. To stick out the entire 104 miles was a brilliant achievement for a 12 year old.

You may remember that Easter this year followed a week of record rainfall in Britain and so the ground was extremely muddy which made for a very slow progress at times. We also received a good few soakings along the way too!

However, with sore legs and feet, we eventually completed our walk in the centre of Bath, very tired and relieved that we had completed our challenge.



*Chris &  
Sophie Longley  
'crossing the finishing line'  
in Bath*

## FUNDRAISING

### FUNDRAISING EVENTS

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

Chris Savage - Motorcycle Beach Race  
 Marina and Dave - Car Boot sale  
 Mad Eli - Car Boot sale  
 Jackie Chisling - Raffle  
 Spiffing Stationery - Sale of Greetings Cards etc.  
 Dr Challoners Grammar School - Talent Show  
 William Durrant School - Mufty Day  
 Plymothian & Old Mannameadian Club - Draw/Raffle  
 Steve Bithell, BNFL - Sponsored Run  
 Mr W Stock - Easter Sale  
 Hilary Lawrence - Ski Marathon, Switzerland  
 Barbara Rollinson - Raffle at Easter Event, Sheffield  
 Mrs Jean Cockman - Sale of Bags and Cans  
 The Elms Special School, Liverpool - Sponsored Bounce  
 Carol Westland - Woodley Extravaganza  
 Charity Flower- Commission  
 Marianne Stimpson - Webb Ivory Catalogue  
 Abbey National, Sheffield - "Dress Down" Day  
 Charity Raffle at Ladies Festival, Hampden Lodge  
 Ysgol y Lawnt - Collection at School  
 Tony Trevor - Reading Half Marathon  
 Abbey National, Sheffield  
 Thelma Pidden - Copper coin collection  
 Marina and Dave - Car Boot Sales  
 Diane and Rose - Raffle at The Sandringham  
 Heather Rice - Not drinking for one month  
 Northgate Information Solutions - Sale of Obsolete Furniture  
 Mr Hawkins - Weightwatchers Breakaway Group  
 Chris and Sophie Longley - Sponsored Walk - The Cotswold Way  
 Gryffe High School - Guidance Department  
 Pam Ballard - Sale of Tennis Balls

### STAMPS

Stacey Taylor  
 Ernest Butler

### COLLECTION BOXES

A A Mellor - F R Monkhouse Ltd  
 Patricia Lomas

## DONATIONS

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

Wilkinson  
 Cadogan Charity  
 Challenger Children's Fund  
 Laxdale  
 Booker Cash & Carry  
 Stanshawes Service Station Ltd  
 St Peters Toddlers Group, St Albans  
 G Jones  
 The Adamson Trust  
 The Gerald Micklem Charity Trust  
 Ken & Pam Ballard  
 Research Machines Plc  
 Adam Sutcliffe  
 International Motors Ltd, West Bromwich  
 Mrs Lazenby  
 Mr & Mrs Rowan  
 Hartwell Plc  
 Bertrams Books  
 The Baltic Exchange  
 TDG plc, London  
 Hampden Freemasons Lodge, Aylesbury  
 Rutherglen Congregational Church  
 The Dorothy Askew Trust  
 Riverstone Management Ltd  
 Mr S Blanch  
 Mr S A Brown  
 The William Leech Charity  
 Mrs J Thacker  
 The Clover Trust  
 Mrs S Altaf, Aylesbury  
 Doreen Iles  
 Dr Bansal  
 Rhian McKnight  
 Dawn Brennan  
 Andy Pack  
 Woolworth, Sheffield Town Centre, Hillsborough & Rotherham  
 Makro Wholesales, Sheffield  
 John Smiths Ltd, Newark  
 Debenham, Meadowhall  
**IN MEMORY**  
 Olivia Bailey  
 Mrs Susan Cox

## **WACKY FUNDRAISING TIPS FROM THE MPS TRUSTEES !!**

The Society for Mucopolysaccharide Diseases depends upon its members, friends and the general public for their generosity in raising funds to provide family support to over 1,000 individuals affected by these diseases their families and carers.

- ⇒ Ask your Teacher if you can sell cakes in your school break-time
- ⇒ Hold a dinner party– perhaps a “Murder” or theme party – and ask people to pay to come
- ⇒ Sponsored Pub Crawl (wonder who suggested this one!) - fill a potty (or similar receptacle) with Gold coins only
- ⇒ Bingo Nights
- ⇒ Have a Banana eating contest, the first to 100 is either very hairy and lives in a jungle or they make us lots of money ( no prizes for who suggested this !)
- ⇒ Take part in a local Fun Run , Marathon or Half Marathon – thus getting fit by taking exercise whilst making lots of money through sponsorship for MPS.
- ⇒ Baked bean eating competition — How many baked beans can your family and friends eat using a toothpick ?
- ⇒ Coin trail, get permission from your local council to lay a coin trail in your local town, chalk the route and encourage the local shoppers to donate.



**PLEASE SHARE  
ANY WACKY IDEAS**

**PLUS NEWS OF  
SUCCESSSES**

**The Society for  
Mucopolysaccharide Diseases**

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Registered Charity No. 287034

