

**NEWSLETTER**

**AUTUMN 1991**

**THE SOCIETY FOR  
MUCOPOLYSACCHARIDE  
DISEASES**



National Registered Charity No. 287034

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(as above)

This newsletter is published quarterly and distributed free of charge to sufferers from MPS disorders in Great Britain and to their immediate families. It is distributed around the world on subscription. Copies are also sent to those members of the medical profession who are directly concerned with MPS, many of whom make a donation towards our costs, for which we are most grateful. If you wish to be added to the circulation list, please contact **Christine Lavery** at the above address. Annual subscription charges are £7.50 in Great Britain and £15 Sterling elsewhere.



## The Society for Mucopolysaccharide Diseases

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The MPS Society is a voluntary support group, founded in 1982, which represents over 300 families in the UK with children or adults suffering from mucopolysaccharide and related diseases. It is a registered charity, which is entirely supported by contributions raised by its members and it is run by the members themselves. Its aims are:

To act as a parent support group

To bring about more public awareness of MPS

To promote and support research into MPS

The Society operates a network of Area Families throughout the UK and Northern Ireland who offer support and links to families in their areas. It provides an information service for families and professionals. At the present time it funds a Consultant Paediatric Post at the Manchester Children's Hospital. It maintains links with sister societies in Europe, North America, South Africa, Australia, New Zealand and Japan.

In most cases there is at present little treatment for MPS diseases but much can be done to improve the care of sufferers. The slogan of the Society is:

**"Care Today, Hope Tomorrow"**

### A Constitution for the Society

The biggest changes are often the least dramatic. Before the conference all MPS families and other members of the Society were sent copies of a draft constitution and were advised that this would be put to the vote at the annual conference. On Sunday morning 22nd of September this document was duly presented to the meeting and after brief discussion it received unanimous approval. When this is sent back to the Charity Commission with the minutes of the meeting where it was adopted it becomes the legally binding constitution of the Society.

A major change for us is that in future the committee must be elected by the members. Something that will not change is that sufferers from MPS diseases and all families with an MPS sufferer will belong to the Society by right. That includes families who have been bereaved. From the beginning bereaved families have played a key part in the work of the Society and it is doubtful if the organisation would be able to function without them.

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Is the Newsletter ready yet? I need something to read.

Jim Bryans from Borehamwood  
at the outing to the Cotswold Wild Life Park in the Summer.

B i r t h s

Congratulations to **Andrew and Sandra Hunt**, from Banbury, Oxon on the arrival of **Sophie Caroline** on 5th August 1991 weighing in at 7lb 6oz, sister for **Nicholas**.

Congratulations to **Ali and Pernia Arshad** on the birth of a son, **Ebrahim Hassan**, born 16th September weighing in at 6lb 10oz. A brother for **Jibreel**.

Congratulation to **Kieran and Bernadette Houston** from Northern Ireland, on the birth of your baby daughter. A sister for **Liam**.

Congratulations to **Mr and Mrs Mc Donagh**, who live in East Acton, London, on the birth of a son **John**, a brother for **Martin and Kathleen**.

N e w F a m i l i e s

**Elaine and Stuart Pragnel-White** from Selby, North Yorkshire, whose one year old son **Liam**, has been diagnosed as suffering from Hurler Syndrome.

**Angela Craig** from Bristol, whose brother **Morgan Healey**, died from Hurler disease in 1976.

**Lynn and Chris Grandidge**, from Chester, whose son **Steven**, has been diagnosed as suffering from Sanfilippo disease.

**Sue and Anthony Woodhouse**, from Linthripe, Middlesborough. Sue and Anthony's son three year old son **Daniel**, has been diagnosed as suffering from Morquio disease.

**Beverley and Shaun Yates**, from Cheshire. Beverley and Shaun's six year old daughter **Sarah** and one year old son **Christopher**, have both recently been diagnosed as suffering from Sanfilippo Disease.

**Mrs Gay Hosking**, from Tregar, Dyfed. Gay and her husband, who is away working in the Middle East, have recently learnt that their four year old daughter **Bethan**, is suffering from Sanfilippo Disease.

**Marjorie, Ken and Karen Naish**, from Brislington, Bristol. Karen is aged twenty one and was diagnosed at the age of thirteen as suffering from Sanfilippo disease. The family have only just heard of the Society.

D e a t h s

**Gareth Makepeace**, from West Bromwich, died on 5th August 1991, aged 22. Gareth suffered from Hunter disease. Our sympathies to his parents, family and friends.

### C h r i s t m a s P a r t y

The National Christmas Party will take place this year on Saturday 7th of December from 1.00 to 5.00, in Newcastle-on-Tyne.

The venue is

H i g h H e a t o n T e n a n t s C l u b  
B e h i n d N e w t o n R o a d ,  
H i g h H e a t o n  
N e w c a s t l e - o n - T y n e

The party is being organised by the Arrowsmith and Mahon families. It will be opened by the Lord Mayor and there will be an extremely popular Magician. You will receive a reply slip with this newsletter with full details. Please reply right away!

### D a t e s f o r y o u r D i a r y

7th December	National Christmas Party	Newcastle
14th December	Christmas Party	Retford
25-27th Sept 1992	Annual Conference	Bristol
May 1993	International Conference	Essen, Germany

### A V e r y S p e c i a l O c c a s i o n

The tenth anniversary of the Society will be celebrated at the next conference which will take place at the Holiday Inn Hotel in Bristol from Friday 25th to Sunday 27th September 1992. During the conference we will remember and celebrate the lives of the children we have lost during this time. Mark the date in your diary now! Further information and booking forms will be sent with the Winter newsletter.

### M P S P u b l i c a t i o n s

At the last conference there was a considerable demand for back numbers of conference reports and newsletters. We have decided to make these available on special offer of the cost of postage only until the end of the year. Please contact Linda Golding at the MPS office for details. The next newsletter will contain a contents list of the reports that are still available.

### 1991 CHRISTMAS DRAW

By now you will have received your Draw tickets. Could you please read the information sheet enclosed with the draw tickets! If it does not answer all your questions, do not hesitate to contact me.

Please, Please, Please try to sell as many tickets as possible. Even if you are only able to sell one or two books it will make a difference to the profitability of the draw. One or two tickets sold will at least cover the cost of the postage and printing.

The list of winning numbers will be published in the winter newsletter. If you wish a list to be sent to you personally,

please enclose a stamped addressed envelope, so that I can send the list to you quickly after the draw.

I am now waiting for all those lovely (large) cheques and postal orders to come rolling in. I have new batteries in my calculator, I have sharpened my pencils. I have scrounged hundreds of elastic bands and cash bags. I have cleared my desk and wound up the elastic band on the computer. My family and I are doing finger exercises to get us ready to fold up all those counterfoils. I am ready.

**Now make my day !!!!!**

**David Briggs**  
Christmas Draw Co-ordinator  
7 Humber Street, Retford, Notts. DN22 6LZ  
Phone 0777 700046

### C H R I S T M A S P A R T Y

We will be holding a Christmas Party in Retford again this year. It will take place on Saturday 14th of December, from 1.00pm.

at

St Joseph's Church Hall,  
Babworth Road,  
Retford

All are welcome. However it would be nice to know how many will be coming. Then we can ensure that all are fed and watered! If you wish to come please drop a line to David Briggs or Pauline Mahon and we will send you maps and full details. All families in this area will be sent maps and details. If you don't make up your mind until the last minute, please come anyway.

**David Briggs**  
(Address above)

### G O L D E N W O N D E R P O T N O O D L E

Has David Briggs finally flipped his lid? He is collecting "Golden Wonder Pot Noodle" foil lids. No, don't ask me why. That's a confidential matter between him and his psychiatrist. Humour the poor man --- send him any you have got.

### Mark Simpson

Here is a photo of Mark which was taken in St James' Hospital. He had his operation on August the sixth and was in hospital for two weeks. After three weeks at home he went back to school. He has been doing very well. He didn't eat while he was in hospital but he is putting on weight now. We go back for a check up on 30th of September. Sorry we couldn't get to the conference this year. We thought it would be too much for Mark.

With love from,

**Ruth, Barry, Clare and Mark Simpson**

14 Oaktree Lane  
Haxby, York, YO3 3YL



### Congratulations!

Many of you will know that **Mary Gardiner** has been appointed as **Northern Co-Ordinator** for the Society and will take up this full time post early in the New Year. It's a new departure for the Society to employ a professional worker and a measure of how it's work has expanded. An adventurous move also for Mary, after a long career in the NHS, but she has never been one to shirk a challenge. Here she is, looking radiant, at the MPS Summer Holiday in Primrose Valley. Our very best wishes, Mary, in your new job.



### Annual Conference 1990

#### The Stakis Grand Hotel at Stoke on Trent

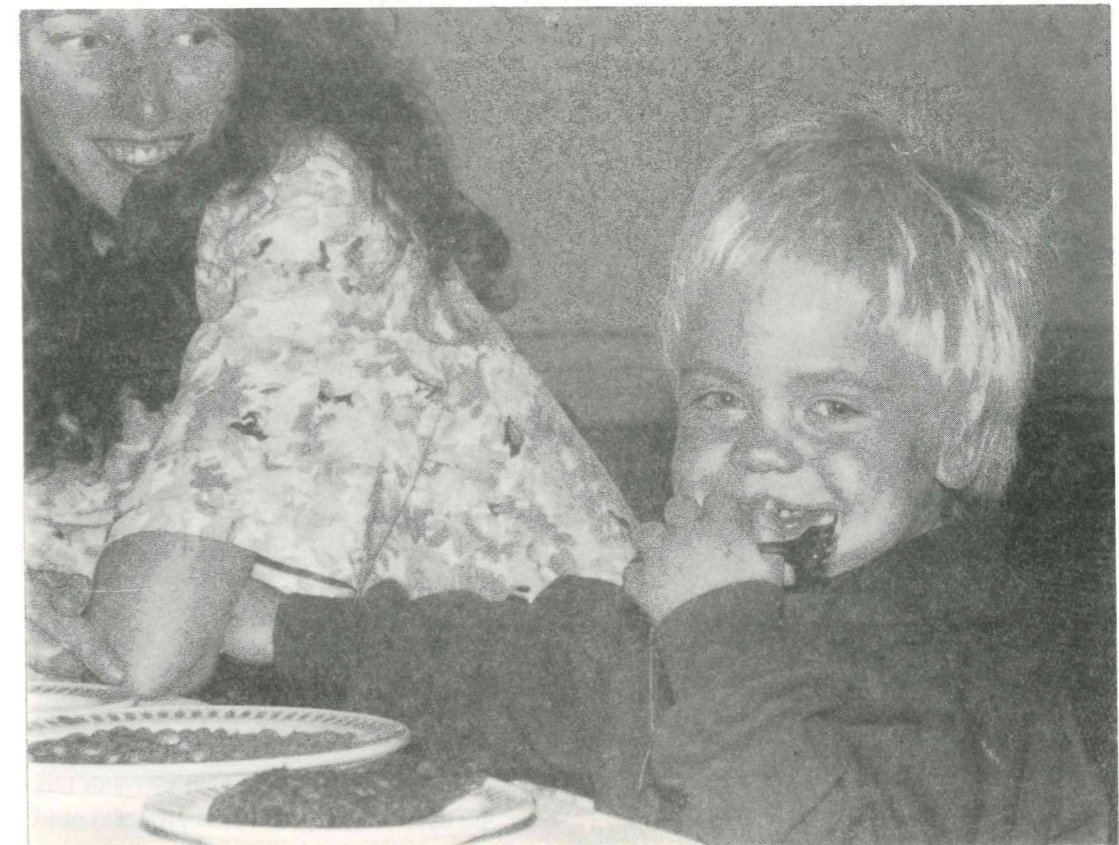
hosted our annual gathering again this year. They catered for over ninety families with the efficient ease which we now take for granted from them. Excellent meals were served on time and the atmosphere was comfortable and relaxed. The conference talks this year were focussed on the practical needs of the children. Families appreciated the hours left free for chatting and relaxing and many people remarked how much they had enjoyed this more informal atmosphere. The weather favoured us again and the outings were a great success.

Our thanks to the remarkable contingent of volunteers who came again in their charabancs from Amersham, and cared for the children at the outings, in the creche and during the babysitting, with great skill and sensitivity. A measure of their commitment is that over twenty of them have now applied to join the Society.

Pat Isaac developed a new technique for presenting the annual report. Instead of talking heads galloping through dry pages of facts and figures she had dressed up characters galloping across the stage dramatically re-living the years activities and achievements.

Many families expressed their appreciation of the expertise and hard work that the organisers had put in to make the conference run so smoothly. The contact with other families and the friendships made and renewed helped people go away with a sense of courage and comfort in the sharing of their difficulties.

As usual a full report of the talks given will be provided in the conference report at a later date.



**Daniel Croghan** (Hunter, aged 5) keeps close to his mum as he tucks into his beans at Stoke-on-Trent.

## The Volunteer's Story

It was great looking after Billy. What can I say. I'm wasn't worried about it. I've done four years now. It's was just slightly embarrassing at the beginning when I was thinking I've got to get to know a child, whom I don't know at all at the start of the morning. I'm not saying I know him very well now, but during one day you start getting to know their character, for instance -- what makes them laugh. The way I set about getting to know him was by just waiting. The first bit of the morning I just held myself back. He was looking at me as if to say -- "Who is this woman? We spent the morning quietly, wandering around, with me talking to him. By lunchtime he started talking -- getting up to mischief. We had lunch and I took him out of his buggy so that he could wander around.

I think the children are so well behaved, in a way this is good, but also quite sad, because they are so compliant. So I thought I would let him out, to see what he gets up to. And he was off! He played peek-a-boo round the trees and that made him laugh. When you know you have made a child laugh you know you are partly there. After that he started talking. When I went into the toilet, I said "I'm just going in here for a wee, Billy, I won't be a minute." Well, I thought, I can't leave the door wide open, he may be a little anxious on his own but he can't run away, he's in his buggy. So I went in and after thirty seconds a little voice piped up. "You finished?" I thought, "Is that Billy?", because up to then I hadn't heard him speak properly. It made me laugh!"



Amanda Sanbers  
with  
Billy Burlison

Christine Reid  
with  
Colin Arrowsmith

We didn't really go on any of the rides. We tried to go on "Round the world in eighty days," but it was too dark. That was the only time he cried. I took him away to look at the horses, to calm him down, and later we came back to look for Colin. He was quite agitated and I think he was worried for Colin. He and Colin are really good friends. I think he was worried because Colin was still in there.

When Colin came out of the ride, Billy shouted at him, "Get in the buggy!", as if to say, "I want you safe, I don't want you going in there any more!" That was really good.

You just don't know what level the children are going to be at each year when you see them. One year you can have a child who has no vocabulary at all. You get another child the next year who as far as you can see doesn't look any different. You don't want to be rude, by asking what he can or can't do -- you have got to find out slowly.

When he was upset about the dark ride he said "I want to go home. I want Mummy." That was the only time he asked. The rest of the time he seemed quite relaxed and secure with me.

The best bit, which I think is wonderful for the MPS children, is "Adventure Land". It's like a ball pool. It's got lots of things to touch and feel. Billy loved it in there. He was laughing and throwing the balls around. It wasn't very crowded because most of the children were on the big rides. Billy liked the gentle things. It was good fun for both of us!

We went into the shop at the end. Billy had his own money and I wasn't sure how capable he was at choosing for himself. I thought about letting him out of his buggy in the shop, but I wasn't sure that he wasn't going to grab everything. I didn't want to baby him by choosing for him, but I didn't want him to get something that he would chew and choke on -- so we compromised with a football. I took one out, one of those nice squidgy ones and put it in his hand and he said "Ball". I gave him all the three colours and said, "Which colour do you like?" I don't know if he recognised the colours, but when I said, "Do you like the black one or the red one or the blue one," he said the colours after me.

He was busy singing all day --- "The big ship

sails on the Alley Alley O." He was counting his numbers and singing "Happy birthday," to everyone.

When were getting ready to go home at the end of the day he saw one of the big men on our coach and he went up to him and said "Daddy" and went to look in his pockets. I asked him, "Does your Daddy always have something in his pocket for you?"

He was quite happy on the coach, both coming and going. He was very friendly with Colin and Claire Arrowsmith, who know him very well. Claire was quite protective. The message that was coming from her was, "He's my friend and you're a stranger." On the way she didn't at first want me to have much to do with him. She wanted to sit next to him. I thought that was right because she is a familiar face for him. She asked if she could give him a lolly, and I didn't know whether he might jam it in his throat -- I hadn't got to know him yet. At the end of the day it was different -- I'd seen him eat a meal and formed a clearer impression of what he was able to do. Right at the beginning, when you get on the coach, you just don't know. You have to play it by ear. I would rather veer on the cautious side. So I said to Clare, "I don't know, he might just jam it in his throat." So she said, very indignantly, "He's not stupid, you know! He's not dumb!" So I thought fast and I said to her, "Claire, I don't think he is stupid or dumb either. I wouldn't be here if I thought he was stupid or dumb." "But I'm not his mother, and I have to be extra careful. How could I go home to his mum and say, "He's choked on a lolly."

Clare was fine with me on the way home. She's got a brother who is similar, and I think this makes her very protective of MPS children.

Billy sat next to Colin on the way back and had a little sleep. I didn't let him sleep too long. His parents wouldn't thank me if he was up all night as a result!

The Monday before we came to the conference we had a meeting where we were told which children we would have. I said to Ann, "Is it possible to have an address?" I thought the parents would be a bit wary, sending their child off with a stranger. I would have liked to have written to the parents saying, "Hi! My name is Amanda", and perhaps have sent a

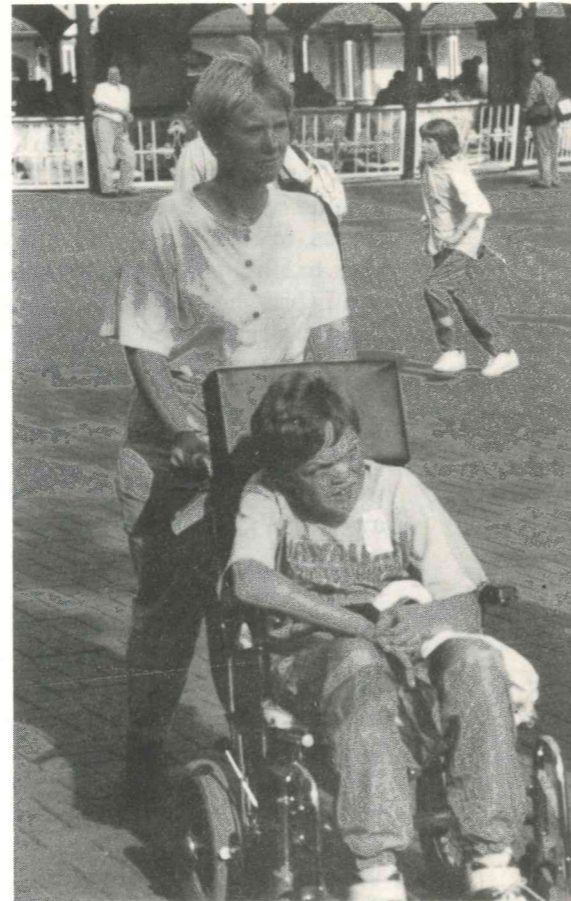
photo, as much for their benefit as for mine.

I think you should try harder to keep the same volunteer with the same child every year. I feel the need to stay in contact with Billy's family -- I don't know whether this is appropriate or not. I've come to the conference for four years and it feels a bit bizarre to have two days of intense contact -- and then, nothing. Yes, I do agree that it may be important to use experienced volunteers for particular children, for example for new families.

We get a sheet which the parents fill in saying what the child can and can't eat and so on.

For example the child may have a special word when they want to go to the toilet, and it would take you all day to find out what it was.

However, in the end, it's the personal contact that is important in getting to know them. I feel sad that the conference is only two days and I don't see the children again. I think it would be nice to keep in contact more. This year Ann was encouraging us to join the Society, partly as a way of raising more funds, but also so we could get the newsletter and read what was happening with people. It might even be nice to take my family to some Society events.



**Linda Golding**  
(MPS Office)  
**Marc Smith**  
from Lancaster,  
take time out  
to see the sights



**Catherine Gardiner, Elizabeth Kirkpatrick and Christopher Isaac** get taken for a ride.

**"A relaxing and carefree conference"**

We would like to say thank you to all involved, for the excellent annual conference. We appreciate the amount of organisation behind giving us a relaxing and carefree weekend. It was lovely to see and chat to folk we haven't seen for some time and to learn how they are coping with life. It was also good to hear about the latest in MPS research.

Please also thank the band of volunteers. Without them the weekend would not have been possible. The venue was of course up to the usual exceptional standards and the staff were very helpful and understanding.

**Doreen and Monty Russell**  
**Gemma and Hannah**  
71 Templemore Drive  
Great Barr,  
Birmingham, B43 5HF



**Stephen Grandige**  
showing just how relaxed you can be!



**Elizabeth Kirkpatrick** with her mother **Ann**, celebrating a surprise Twenty First Birthday Party at Stoke.

## PRIMROSE VALLEY 1991

I feel sure that someone will be writing an official piece about the 1991 MPS Holiday but I thought that I would like to give you my bootleg version.

I think that someone upstairs knows when we are going to Filey because, once again, the weather was wonderful. In the weeks leading up to the big day there were several thoughts in my mind about taking wellies and a plastic mac, but I'm glad I didn't - they would have been a waste of luggage space.

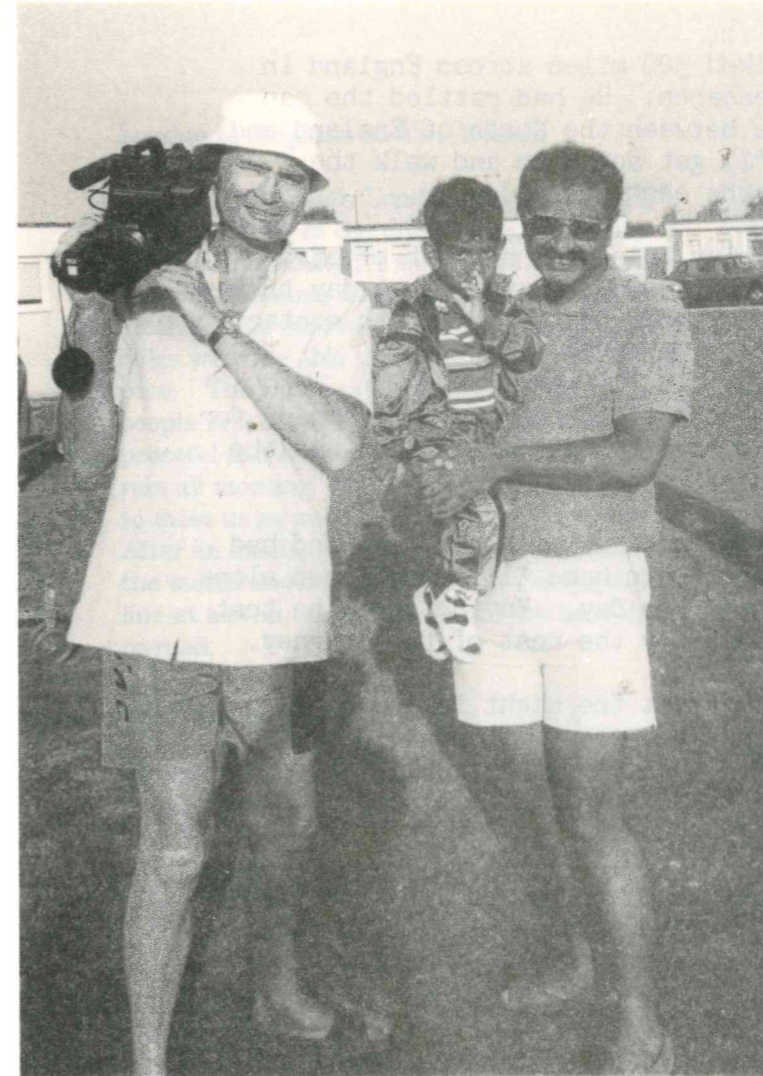
I must admit that Linda and I had some feelings of trepidation about the holiday this year - our first time without Colin - but although the memories did come flooding back when we arrived we soon had lots of new memories to add to them.

Memories of little Amy Cooper with the cheeky face and the ever present smile, of Colin Arrowsmith and his football, of Leanne Woods under her sunshade and of Shyam Chandegra on his little trike. Memories of Billy Burlison and his new train, of Stuart Lawrie slowly coming out of his shell, of Emma Briggs eating anything she could find, and of Elizabeth Murphy trying to turn a cafe table over - with her feet! Memories, in fact, of everyone who was on the holiday and who made it such a marvellous week.

Thank you all.  
Linda and Ron Snack



**Daniel Croghan with mum, auntie and friends.**  
This kid gets everywhere!



**Ian Russell**  
with Camera

**Mr Chandegra**  
with his son, **Shyam**,  
at Primrose Valley.  
Shyam suffers from  
Winchester Disease.



Sunshine, good food and good company.



## THE PENNINE WAY WALK

A colleague at work, Clive, had walked 300 miles across England in 1989 to raise money for Leukemia Research. He had rattled the can through numerous towns and villages between the North of England and London. The next time, he said, I'll get sponsors and walk the Pennine Way to save having to bank the cash every day.

He chose the MPS Society as his charity this time and set off from Edale with his son Gavin on July 14th (1990). On the first day they fell into a peat bog and got lost on Kinder Scout, having to contact another colleague in Manchester to pick them up.

A quick bath, a few beers, a good nights sleep and they were ready for more problems the next day. As it turned out that first day was the worst and they made good progress Northwards.

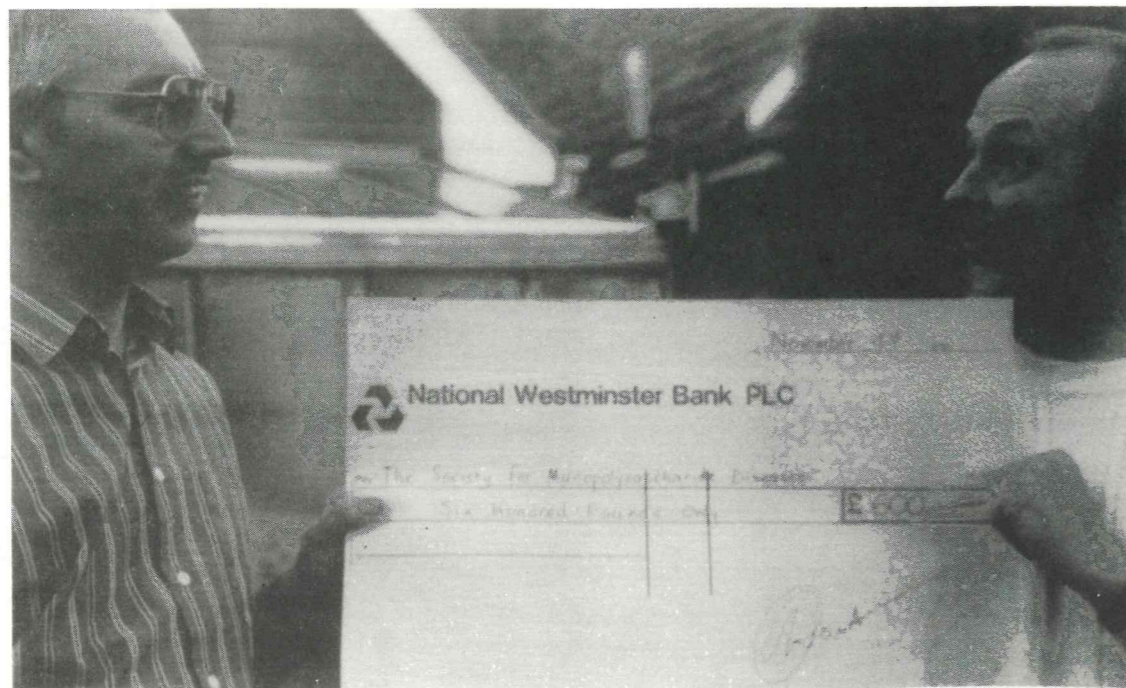
After about five days Gavin developed problems with his knee and had to drop out. After seeing him onto a train home Clive continued alone at a very good pace averaging 20 miles per day. Having sent the tent back with Gavin he chose Youth Hostels for the rest of the journey.

On the 12th day he covered 37 miles, spent the night in a mountain hut, and covered the final seven miles between 4.30 and 5.30 the next morning. Whilst waiting for a bus to the nearest Railway Station Clive rang us at the office to say he had completed the walk, and was back in the Midlands by midday.

We collected £600 from colleagues at work, and Doreen and I collected a further £600 from family, friends, and anyone else we could nab. This year Clive is running the Berlin Marathon, this time for the fun of it.

The photo shows Clive presenting me with the cheque for the MPS Society.

Monty Russell



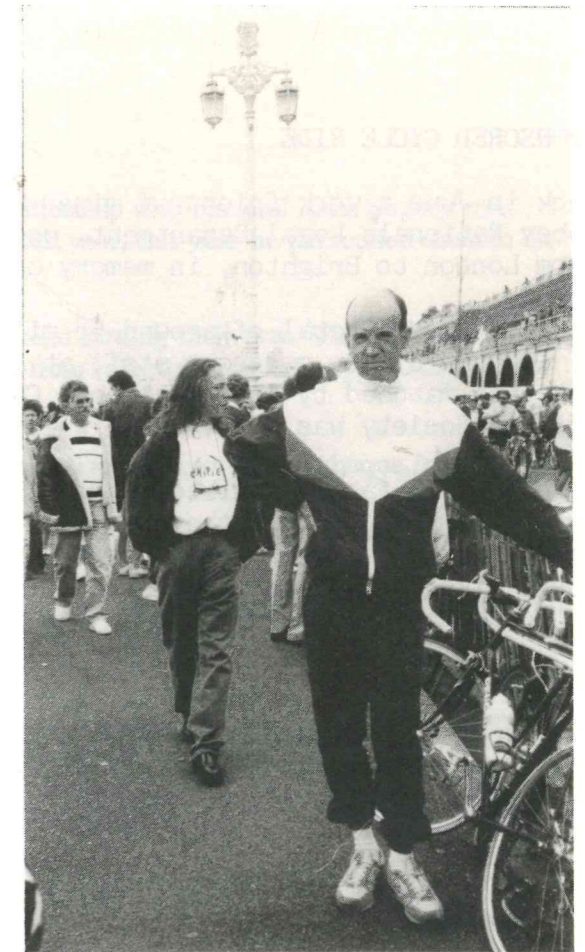
Monty Russell with Clive Evans from Cannock, Staffs.  
in classic "Grip and Grin" pose.

## London to Brighton on Two Wheels

I set off from South London just before eight in the morning in the midst of 28,000 or more riders. Immediately I was forced to dismount and walk because the mass of cyclists was too much for the narrow road. After a couple of miles we were able to continue at a reasonable pace. The ride was made colourful by many people in fancy dress. We had a pleasant, peaceful and friendly ride. The sky threatened rain all morning. An angry sky dipped down to meet us as we crossed the South Downs. After an exhilarating spin downhill we raced the storm clouds into the town. I crossed the line at eleven thirty, just before the heavens opened.

A most enjoyable ride!

Mike Willoughby



## LONDON MARATHON

The final figure for money raised from this years London Marathon was almost £3,000.00 - another fantastic effort by all concerned.

I must make mention of Keith German of Mathersey, Nottinghamshire, who raised £900.00 for us and Rob Burgess, one of our own dads.

While we are on the subject, if anyone knows anyone who is hoping to run in the 1992 Marathon, then please try to persuade them to run for us. Running vests with the MPS logo on are available, as of course are sponsor forms.

Ron Snack

## MENTAL HEALTH FLAG DAY 1992

The dates for the Mental Health Flag Day for 1991 have now been fixed and they are:-

NATIONAL 25 APRIL 1992

LONDON 28 APRIL 1992

If anyone would like to take part, and they did not take a form from the Conference, then please get in touch with me as soon as possible.

Ron Snack

## SPONSORED CYCLE RIDE

Back in June a work friend of mine, Mike Willoughby, who works in Abbey National's Legal Department, undertook a sponsored Cycle Ride from London to Brighton, in memory of Colin.

Mike covered a total of around 58 miles and was sponsored to the tune of £470.88 by the generous staff at Abbey National's Head Office. This was then matched by Abbey National Charitable Trust so the final total for the Society was £941.76 - a great effort by everyone concerned.

Mike had, in fact, promised to do a sponsored ride for the Society before we lost Colin but events overtook us all. I think, however, that this was a fitting tribute to Colin's memory, and I would like to thank Mike for all the time he spent on this event and for his promise to do another sponsored ride in the future.

Ron Snack



Ron Snack receiving a cheque for the total amount from Tim Canniffe of Abbey National Charitable Trust (right) and Mike Willoughby.

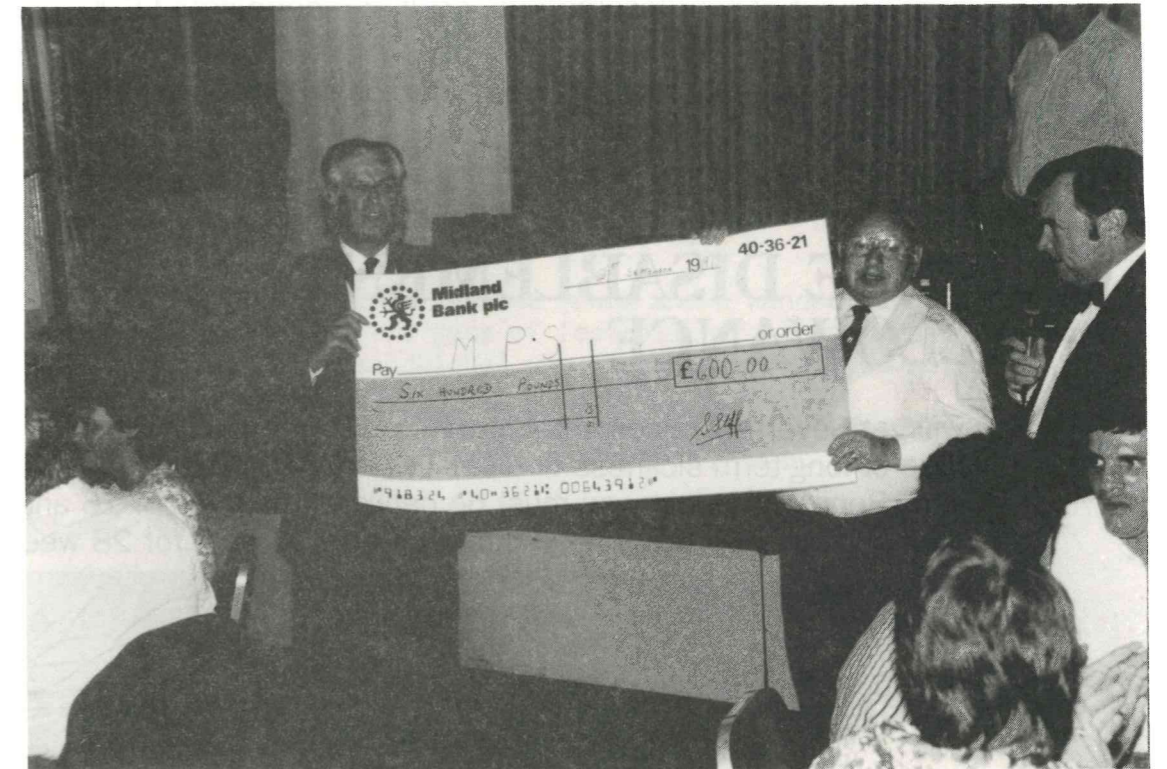
## It ASDA be Sid!

I feel sure that Sid Shiff has some sort of special relationship with his local Asda Superstores! Not content with arranging his "Trolley Dash" there last year, this year he persuaded them to let him hold a "Flag Weekend" at the store.

Sid and friends spent the August Bank Holiday weekend rattling their tins. They managed to collect £476.00. When they added this to the money from collecting tins kept by his family and friends they had a wonderful total of £600.00.

Here you see Mr Stan Beate, former Mayor of Stoke-on-Trent, receiving the cheque from Sid on behalf of the Society. Well done Sid!

Ron Snack



## COPPER COLLECTION

Thank you to whoever it was who left £2.60 in coppers in a bag of stamps at the Garden Party. This wasn't found until Peter Robins started to find two pence pieces rolling around his garage. Thank you.

Ron Snack

## INVALID CARE ALLOWANCE

Your carer may be able to get Invalid Care Allowance (ICA) if you are getting Attendance Allowance.

- Your carer must be aged between 16 and 65.
- They must be looking after you for at least 35 hours a week.
- They must not be left with more than £20 a week, after expenses, from a full time or part-time job.
- ICA is £28.20 weekly. It is not tax free and will affect the amount of Income Support, Housing Benefit and/or Community Charge Benefit your carer gets.
- From October 1990, a carers premium of £10.00 will be introduced for people who get I.C.A. and get Income Support. This means that some carers who get I.C.A. will also qualify for Income Support for the first time.
- If you live on your own and your carer wants to claim I.C.A., seek further advice, as you will lose the severe disability premium of £28.20 out of your Income Support if someone gets I.C.A. for looking after you.

To claim, get leaflet NI.212 from your local DSS, your neighbourhood office or local advice agency.

## SEVERE DISABLEMENT ALLOWANCE

You will get Severe Disablement Allowance (SDA) if you cannot work because of long-term sickness or disability, and you do not get Sickness or Invalidity Benefit. To claim you must be between the ages of 16 and 65.

You will get SDA if you have not been able to work for 28 weeks and:

- you are under 20;
  - you are getting Attendance or Mobility Allowance;
  - you are registered blind or partially sighted;
- or
- you are 80% disabled. This will be decided by a doctor; but it may be best to get advice before claiming.

SDA is £28.20 weekly. It is tax free and will affect the amount of Income Support, Housing Benefit and/or Poll Tax Benefit you get.

To claim, get leaflet NI.252 from your local DSS office, neighbourhood office or local advice agency.

From December 1990 you will get an extra amount, depending how old you were when you first became unable to work:

- £3.10 if you were aged 50-59;
- £6.20 if you were aged 40-49;
- £10.00 if you were aged under 40.

### FAMILY DAY TO DRAYTON MANOR PARK

Linda and Ron had planned a day out at Drayton Manor Park so a couple of families from the Birmingham area decided to gatecrash and join the Snacks for the get-together. We arranged to meet at the entrance and by 10 o'clock we were forming our own queue. Before we knew it a long queue had formed behind us - they must have heard how good MPS outings are.

However, we were soon in the grounds and looking for our first ride. Most went their own ways so we arranged to meet up for dinner. We first boarded the "Golden Gallopers" on a horse called Liz. Not being very adventurous we didn't choose the sickly rides, but opted for a lazy time on the lake.

The weather was fantastic so what better than a rowing boat. Doreen stayed with baby Hannah so Gemma and I gingerly stepped on board. Not knowing much about boats I had to be reminded that it's sharp end first (sorry "bows") but we managed without falling in and Gemma even had a go at rowing - and did very well too.

At lunch time we had a picnic - it was too hot by the cars so we sat in a little copse and munched merrily away. Ron was kept busy with his camera and Doreen was kept busy dodging him.

Back to the Show and the "Pirates Adventure" was well worth the wait. We sailed in an eight seater boat through a winding passageway past skeletons, mock battles, flying cannons, gun fire, treasure trove and even saw a man walking the plank. Past the usual water sprays, galleons and gaols it was a display to be remembered.

After this it was time for an ice cream and a wander back to the cars. We all met up again for a game of football but it was really too hot. What was left of the sandwiches was finished off and we all made our way home - weary but happy.

Many thanks to Ron and Linda for a lovely day out.

Doreen, Monty and Gemma Russell



**Doreen  
Monty  
Gemma  
Russell  
with baby  
Hannah**

A Day in the life of  
Sarah Kilvert

Tuesday 24th September 1991.

My dad leaves at six to work in Telford. My mum leaves at eight-thirty to work in school which is just up the hill from where we live in Newtown. I get up about ten. When I wake up I shout to my nanny who helps me get up. (Because I have had a spinal fusion operation I can do very little for myself).

My nanny passes me my hearing aids and then she puts her hand under my plaster jacket and slides me to the side of the bed. Dad has made me a wooden box to step onto to save nanny lifting me, as I am rather heavy in the "halo" at the moment. Then she pushes me to the loo. While we are in the bathroom I have a wash and I clean my teeth with my electric toothbrush.

After that it's into the kitchen where we have a TV, which I watch most of the day. After breakfast my friend Ivy comes to visit. She stays until lunchtime and tells me all her news.

In the afternoon I write a letter to my friend Jane in London and watch some more TV. Mum comes home at four fifteen. Today tea is staggered, first me, then the rest, and then dad when he comes home at about seven.

I go to bed at about ten thirty. Mum lifts me into bed and I am propped up with pillows in the same position all night. Thank goodness I am having my halo and plaster cast removed this weekend!

Last weekend I did enjoy the conference at Stoke. Thank everyone for a wonderful time.



Sarah and her parents dining in style at Stoke.

A Day in the life of  
Kristina Briggs

When I arrived home from work at 6.25am on Monday, Kristina was still asleep. Usually she is up by this time. Tired from the conference weekend, no doubt. (Make note in diary: go to more conferences). After covering her with her quilt I dive into bed and warm my feet on Monica.

Later Monica wakes Kristina for her first bath of the day. Kristina has two bowls of cornflakes, but half a bowl goes on the floor. After a wash and cleanup and a battle with the hairbrush Kristina is ready for school. As usual the bus is late.

Staff encourage Kristina to step down from the bus using handrails and holding hands. With help she can hang her coat up. (At home she hangs it on the floor). For her own safety she sits in a chair with a built in table.

Today, at registration she does not respond to her name. She is leaning forward badly and showing little interest. (Still tired?) When we start singing Kristina perks up a little and joins in the vocalization.

During P.E Kristina is encouraged to stay on her feet and explore the room, avoiding equipment, stepping over mats, etc. Once on the floor Kristina gets on her hands and knees and shuffles to a piece of equipment to pull herself up.

Normally Kristina then joins the special needs class for swimming or physiotherapy. Today she had a drink, using a straw, and a biscuit - very

messy. Then she has a session with a fitter to have some plastic leg splints made. Kristina later plays in the sand alongside the other children - with a close eye kept to stop her eating the sand. More physiotherapy and then toileting before lunch.

After the break, spent outside with the other children, we listen to a tape and do some rain printing on cloud shaped paper. At the work table Kristina shows interest in the activity board, mainly to chew it.

Monica is suffering from a cold, so I collect Kristina from the bus, and get a nice smile. Kristina goes straight into the kitchen to see what she can get, while I hang up her bag and holding reins.

She stands at the sink making sucking noises, which is usually a sign that she wants a drink. While drinking she often tries to inspect the bottom of the cup. Each time she does this I take it from her. She grunts in disgust, takes back the cup, and drinks up.

Off into the kitchen, where she finds an apple and bites into it. We have a short battle while I take the apple and peel it. (She tends to choke on the peel).

The dogs come in to see if there is anything for them. Thomas, the rough collie, retreats when he gets Kristina's fingers up his nose. Sweep, (Heinz 57), goes to inspect Emma who has just come in from school.

Kristina tires of the apple and throws it at Monica, who decides that this is a good time to go to make the tea! I switch on the TV. Good! It's "Fireman Sam", which she likes.

Engrossed as I am in trying to balance the bank account, I don't notice that "Sam" is finished - that is until Kristina starts eating the bank statement!

Tea's ready, and Kristina has her sleeves rolled up and her large wrap round bib on and is put in her tray chair. Thirty minutes of peace as she eats her tea. I nip upstairs and get ready for work.

Kristina complains loudly because she knows that after tea it's time for bath number two.

Recently we have been retraining Kristina to climb the stairs, which she does on all fours. A few weeks ago she suddenly stopped climbing. We had to show her how to move her arms and legs and in what order. Now if she stops we lift her left leg onto the next step and off she goes. We have to lift her over the last few steps.

#### DRESSING PROBLEMS?

Damart, the mail order company best known for thermal clothing, has produced a Special Supplement, in association with the Disabled Living Foundation, to guide and advise those who have dressing problems. This catalogue contains advice that users can apply for all their clothing, whatever the particular problem, and covers sizing, fabric choice, advice for wheelchair users, and those with specific problems such as weak fingers. Available from Damart, Bowling Green Mills, Bingley BD16 4BH (Tel: 0274 568234). Ask for the Special Supplement.

It's time for me to go to work (for a rest). Kristina then has a long soak and a read (or chew) of her bath books. Then downstairs for a drink and more havoc until eight o'clock.

Some nights she will sit on Emma's knee and give her a cuddle for ten minutes. She will rest briefly or wander round. Thomas licks her hand, but she tries to catch his tongue. She gets bored or he backs off, deciding he doesn't want to be pulled inside out by his tongue.

Eight o'clock and time for bed. Sometimes she will go to the stairs earlier, and wait to be taken up. She does a round of all the rooms upstairs before allowing herself to be guided into her room. She settles down to play with her toys and listens to a nursery rhyme tape.

At nine o'clock Monica goes up for her bath and there is an ominous smell emanating from Kristina's room. Time for bath number three! At about ten she settles to sleep.

**SURPRISE**, she sleeps right through the night. Marvellous things these conferences!

#### David and Monica Briggs

#### SEAT AND BACK SUPPORTS FOR WHEELCHAIRS

Innovention Products Ltd produce these items for both adult and children's wheelchairs, and they are often available through and for NHS chairs. The company are willing to advise, assess and give a demonstration.

They can be contacted at: The Business Centre, Colne Way, Watford, Herts WD2 4ND. Tel: 0923 245050

There is also a Freephone number: 0800 181709.

## A day in the life of

### Ian Maguire

I feel a hand on my shoulder. A voice says, "Alright Ian, time to get up. My expression says it all, but up it is. Louise guides me to the bathroom. I'm great at walking but wayward in direction.

I usually don't say much at this time. I just go along with the run of things. There will be plenty of time to get my thoughts across as the day proceeds.

The group room is usually fairly quiet. Peter and Leigh have gone off to school. I like Leigh, but first thing in the morning she can be too much. Chris and Andie are getting sorted out for Daycare.

To be honest I only really associate with people who come up to me and try to catch my eye. When they do this I sometimes have a good laugh, which everybody enjoys, or else I stare into their eyes or look away. Twirling the toast round in my hand, I ponder the day ahead. Will it be daycare, or will it be a more easy-going day when my Mum and Dad come to see me? Whoops, the toast goes on the floor!

I feel quite full of myself by now. Alan tries to clean my teeth; always a great battle. I fight off the flannel and twirl round and round. "No! you can't take my trousers down."

It's lovely to see Kay and Vicky. "What's on today ladies?" "Swimming! Great!" But they do expect me to work my arms and legs hard. At lunch time they both encourage me to help feed myself. "Shadow feeding", they call it. Sometimes I just can't concentrate. Then I want to shout, bang and pick up all sorts of things.

#### NEW AIDS AND EQUIPMENT CATALOGUE

'Ways and Means' is a free mail order catalogue of everyday aids and equipment for disabled people.

The address is Ludlow Hill Road, Nottingham NG2 6ND Tel: Nottingham 452205.

After lunch I get to wander about outside. I really enjoy this, strolling where I want, shouting away. Over comes Angela to take me back to the Red House. The group gets back together for tea. Leigh pinches my toy, but I get it back with some outside assistance.

Our evening meal can sometimes be hysterical. Something is quite likely to happen. The distraction gives me a chance to flip up my plate, or pick things up. Then there is a chorus of "Oh, Ian!"

Tonight, I'm going out for a country drive and a drink at the pub. I love going in the minibus or car. It's exciting to see all those things flying past my eyes. I can't drink Guinness while I am on these sleeping tablets - I miss that creamy head.

When we get back I wander in my corner of the room. I come across that strange face on the wall again. He never has a body, just a face. He makes me laugh, and he laughs too.

I'm in bed now, talking to myself before I drop off. Tonight my mind is still whirling round, I can't lie down just yet. My belt lets me sit up comfortably, but not get out of bed. I'm going to lie down now because I'm ready for sleep.....

#### Note:

Ian is aged 22 and suffers from Sanfilippo C. He comes from Liverpool and lives at Barnardo's Red House, Ripon, Yorks. His parents visit him weekly.

Ian presents very differently from most Sanfilippo sufferers. His condition is not at all typical.

#### SPECIAL AIDS CATALOGUE

CARE STORE MAIL ORDER CATALOGUE of special aids and tools for disabled people, free from Care Store, 14 Wellfield Road, Folkestone, Kent CT20 2PJ. Tel: 0303 220477.

### STACKPOLE CENTRE, STACKPOLE, SOUTH PEMBROKESHIRE

The Society has recently received a letter from Selina Barker of The Stackpole Centre, enclosing details of their purpose built holiday centre for disabled and disadvantaged people, in the hope that, we may be able to nominate someone who is really deserving of a holiday.

Selina has informed us that they have some funds available to them, for the remainder of this year and for 1992, for the purpose of providing such a holiday.

The Stackpole centre has been designed to enable people who have disabilities to share with family, friends or others with similar interests the relaxation or stimulation of a holiday course or study facility.

The Stackpole Centre Offers access to:-

Historic Pembrokeshire  
Beautiful Countryside  
Lakes - Lily Ponds  
Secluded Sandy Bays  
Wildlife - Tranquil Walks  
Fishing  
Abseiling  
Canoeing  
Riding

If you feel this sort of holiday is of interest to you please contact the MPS Office, 7 Chessfield Park, Little Chalfont, Bucks HP6 6RU Tel: 0494 762789 for more information.

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#### CYCLING OVER 60 MILES RAISED £160

Greater Manchester Passenger Transport Executive employee Pete Wraxall cycled from Manchester to Blackpool in Granada Television's Annual Cycle Run in June with the Executive's Sports and Social Club.

Not having his own bike, Pete, aged 31, borrowed his nephew's mountain bike to enter the event.

"It was not easy. My saddle fell off at the start of the cycle run and I struggled somewhat. I was determined to finish though" said Pete. Despite the setback Pete successfully completed the distance in five hours.

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#### CAR SEAT

Mr Chandegra, of 11 Cole Valley Road, Hall Green, Birmingham, has a Britax car seat available for anyone who may be interested. It would be suitable for a child up to about seven years old.

Please contact Mr Chandegra on 021-777-7030 if you would like more details.

Ron Snack

### Fun and Fundraising - £1400

#### Coffee and Doughnuts

The sun shone; (the only Saturday in July when it did!). Willing friends helped. Over 200 people came. Over 200 doughnuts were eaten. Not homemade as Ron Snack expected. Sorry Ron.

You couldn't see the lawn for stalls of cakes, toys, white elephants, grandpa's plants, and MPS goods. We decided we needed a bigger garden. The main attraction was our local Crendon Morris Men. They danced on the pavement in the front of the house, much to the amusement of the passers by. A passing horse was quite startled!

A warm thank you to the Morris men who collected for MPS in previous years. They presented us with a cheque for £200 on the day. We are trying to book them for Dr Garrow's garden party next year. Also a special mention for Matthew's welfare assitant, Val, who did wonders in advertising the MPS goods.

#### A "Souper" Morning

A good money spinner is an MPS Soup Morning. Our friend, Andrea Brock held her second one at her house this month and raised over £200 for the Society. The lure of over five different varieties of home made soup donated by friends and plain rolls donated by a staff member at Macdonalds was too good to miss on an Autumn morning. Another attraction was an "Usborne Books" party lady, who sold a range of attractive children's books. (Like a Tupperware lady, but more highbrow). Andrea charged £1.00 for tickets and ran a raffle as well. Look out Macdonalds! MPS are about to take over the fast food industry!

**Jenny and Andy Hardy**  
**Matthew and Rebecca**  
48 Churchway,  
Haddenham, Bucks.  
HH17 8HA

#### Video Cameras

The Society recently purchased two new video cameras. One is to be held by Kieran Houston to be used by Northern Ireland families. The second is a replacement for the one stolen from the Britannia Hotel during the 1990 conference at Manchester.

As of the 16th of October the cameras are with the following families:

Barnfields, Glos.	On loan from Alf King, East Sussex
Neals, Amersham	On loan from MPS office
Snacks, Milton Keynes	On loan from Tony Lockyer, Wales
Russells, Humberside	On loan from Mary Gardiner, Lancs.

We plan to buy two more video cameras this year, one for the Yorkshire/Humberside area and the second for South West England.

If you would like to borrow one of our cameras, please contact either your Area Support Family or the MPS office in Little Chalfont.

### The Parent's Story

We've been at three conferences before. We didn't go on the outing today, we took some leisure time. It was lovely to take some time by ourselves. We've hardly spoken to anyone. We didn't feel we needed to go to the talks. We've been quite happy to browse around, look at the children, see everybody having a good time. We've had all the hustle and bustle before and it's not what we needed this time.

You need a conference like this -- a chance to relax! The information is there for those who need it -- for those who want to relax that was there as well -- and a chance to meet with people we've seen in previous years. A very agreeable conference.

Other parents have asked us about Chris, so we have exchanged information. That's what we're here for -- to help each other out.

Chris is going through a bad time at the moment -- he keeps having fits. He's been quite poorly -- we were surprised we were able to come. We were debating it up to the middle of the week.

We had a really bad night last night. We were quite worried about him. He's had a really bad week. He's been in the creche today. That worked out super. He had his breakfast and then he slept until we collected him to have lunch with us. He slept most of the day because he was awake most of the night. He's become nocturnal! We were all in the one room, so nobody got much sleep. Never mind!

Our other child is very adaptable. He's never known any different, because he's grown up with Christopher from a baby. He's very good with him. He shows the normal sort of jealousy. They both get upset with each other. What can one do? At least we have him at home with us.

It's a struggle, isn't it, lets face it. We are all finding it hard.

We like hearing what is happening with other families. Some children go off their legs sooner, some children sleep better than others. People have different ways of trying to make them sleep.

He didn't react very well to being away from home. We had a week in in a caravan. He was terrible, coughing and choking, as he is now. Whether it was psychological or not I don't know. We had all our own things, his chair and so on. He likes his own environment.

It's difficult at this stage. We don't know what he reacts to. Sometimes we do get a lot of contact and a lot of concentration. At other times he's way, way off track. It's hard to know what his mental state is. Sometimes I think he's very aware. Certainly when he's away from home, there is a big difference in his attitude, in the way he is in himself. He's definitely saying something to us -- that he doesn't like it.

We are very fortunate. We've still got Christopher. He's thirteen now. He's doing very well....

We were pleased that the conference was going to be more relaxed. People have been more available to the families that needed them more. I think it's been the best since the very first one. You always think the first one is the best!

"Some people find the first one a bit difficult....."

I didn't find it difficult, everybody was so friendly. The group of families was smaller then.....We've grown so big.

### German MPS Conference 1990

Mary and Charles O'Toole attended the German MPS conference in the picturesque hamlet of Mauloff in the Taunus hills near Frankfurt on the first weekend in October. The accomodation was in comfortable bungalows and flats in the wooded grounds, with a panoramic view over the little valley and the surrounding wooded hills. It was very agreeable to meet with old friends and to hear news of their families and of the German Society.

They are very busy making preparations for the next International Conference, to take place in Essen in 1993. The reason we were there was to discuss how this was developing so that the British Society could decide whether to run a conference in 1993, and also so we could plan for the support of British families going to Germany.

In this very welcoming setting fruitful discussions took place, which were reported back to the Committee, who will shortly be circulating families about what is planned.

Jurgen and Brigitte Zumbro send their affectionate regards to all families whom they have met. Their daughter Natalie is keeping very well. Our special thanks to Dr Michael Beck who collected us from the airport and delivered us back again. Dr Beck is responsible for the professional symposium in 1993 and he has now set up a committee to plan the speakers.

The indomitable Heidirose Wallburg, (Morquio, aged 45) travelled 200 kilometres by train, on her own, to get there, despite increasing pains and worries about her health. She wishes to be remembered to everyone.

### Acknowledgement

An article on "Chronic Upper Airways Obstruction" in the Spring Newsletter written by Dr JTR Clarke should have been attributed to the Canadian MPS Society, as he is one of their medical advisors. Our apologies. When we copied it from the New Zealand Newsletter we were not aware that it had originated in Canada!

## FUNDRAISING EVENTS FOR THE SOCIETY

Once again many thanks for all your ingenious methods of raising money for our Society.

Mrs McLachlan	Raffle
Aylesbury High School	Sponsored events & pocket money
PCC All Saints Weston Green	Church Fete
Jenny Broome	
S and S Gregory	Sale of Baby Clothes
21st Wycombe/Totteridge Scouts	Raised
GA and JA Renton	Coffee Morning
A J Howard	
P J Croghan	Garden Party
Mrs A Fraser	Collecting Tin
Pinewood School	Sponsored Walk
1/2 Betty Shackman	Sponsored run/cycle ride
Mrs M Miller	Raised - diet correction class
M and A Canton	Tupperware Party
Wendy McGinn	London Marathon
Rand L Snack, Milton Keynes	Mental Health Flag Day
Brenda Lofthouse, London	" " " "
Cedric Gooch, Tunbridge Wells	" " " "
Margaret Horsley, Carlisle	" " " "
S McNee, Renfrew	10 Kilometre Race
Kirkhill Golf Club, Glasgow	June Medal
Mrs Richardson, Sufflok	London Marathon
Bridgewater Lions & Swimming Club	Sponsored Swim
Mr & Mrs Evans, Lymington	London Marathon
Addington & Bothwell Youth Forum	Bottle Stall
J & M Murray, Lanarkshire	Raffle and Bingo
Mary and Robin Gooch, Sussex	Clothes Party
Gillis Newsagent, Bury	Collecting Tin
Clevedon Golf Club, Avon	
T Black, Clevedon	London Marathon
Billy Ingham, N Ireland	Collecting Tin
Mrs Davis, Walsall	London Marathon
Mrs Stenning, Pinner	Nursery Race
T Garwood, Luton	
Mike Willoughby, Milton Keynes	Sponsored Cycle Ride
Abbey National, Milton Keynes	Matched Donation for above
Pam Croghan, Cheshire	Car Boot Sale
Pam Croghan's parents	Collecting Tin
Monkhouse Sports, Cheshire	Collecting Tin
Mr & Mrs Haigh, Huddersfield	Great North Run
Paul Hubbard	Sale of Stamps
Pauline Mahon, Sheffield	Great North Run
Barbara Arrowsmith, Newcastle	Great North Run
Betty Cox, London	Copper Collection
Rosemary Nurse, London	Car Boot Sale
Gill Sutcliffe, Derbyshire	Wirksworth Well Dressing
Sid Shiff, Merseyside	Flag Day and Collecting Tins
Anon	Copper Collection

## AREA SUPPORT FAMILIES

<b>Neil and Jane Reid</b>	<b>Tel: 0223 834570</b>
19, Hillside, Sawston, Cambs, CB2 4BL	
<b>Alan and Deirdre Beavan</b>	<b>Tel: 0858 62182</b>
'Tumbleweed', West Gate Lane, Lubenham, Market Harborough, Leics. LE16 9TS	
<b>Alan and Audrey Noble</b>	<b>Tel: 0664 77494</b>
1 South View, Burrough on the Hill, Melton Mowbray, Leics.	
<b>Mary Gardiner</b>	<b>Tel: 0772 815516</b>
15 Sidney Ave, Hesketh Bank, Near Preston, Lancs.	
<b>John and Barbara Arrowsmith</b>	<b>Tel: 091 2812062</b>
140 Newtown Rd, High Heaton, Newcastle on Tyne NE7 7NH	
<b>Sean and Pauline Mahon</b>	<b>Tel: 0742 304069</b>
41 Stumperlowe Crescent Rd. Sheffield 10, South Yorkshire.	
<b>Alfred and Judy King</b>	<b>Tel: 0424 216432</b>
4 New Park Avenue, Bexxhill on Sea East Sussex, TN40 1QR	
<b>Bill and Sylvia Blackburn</b>	<b>Tel: 0270 626809</b>
11 Beatty Road, Nantwich, Cheshire.	
<b>Ron and Linda Snack</b>	<b>Tel: 0908 666819</b>
16 Wandsworth Place, Bradwell Common, Milton Keynes, Bucks.	
<b>Tony and Mary Lockyer</b>	<b>Tel: 0443 217787</b>
Blaen-y-Wavn, Salem Lane, Church Village, Pontypridd, Mid Glamorgan, CF38 1PT	
<b>Tony and Shirley Eyre,</b>	<b>Tel: 0934 834537</b>
6 Westway Park, Yatton, Near Bristol, Avon.	
<b>Contact for Scottish Families:-</b>	
<b>Alan and Fiona Byrne</b>	<b>Tel: 041 643 0034</b>
3 Jedburgh Ave, Rutherglen, Glasgow, G73 3EN	
<b>Northern Ireland:-</b>	
<b>Margaret Kearney</b>	<b>Tel: 026 57 62073</b>
12 Coleraine Rd, Ballycastle, Co. Antrim	