

NEWSLETTER

SUMMER 1996

**THE SOCIETY FOR  
MUCOPOLYSACCHARIDE DISEASES**



National Registered Charity No 287034



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| <b>Management Committee</b> |
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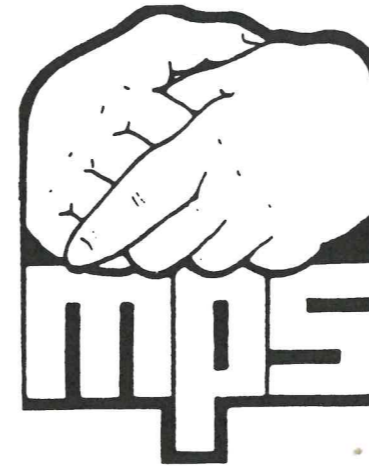
|  |                    |
|--|--------------------|
| <b>Alf King (Chairman)</b><br>4 New Park Ave, Bexhill-on-Sea, East Sussex TN40 1QR                           | Tel: 01424 216432  |
| <b>Lynne Grandidge (Vice Chairman)</b><br>41 The Boulevard, Broughton, Chester CH4 0SN                       | Tel: 01244 531163  |
| <b>Dr Bryn Neal (Vice Chairman co-opted)</b><br>"Hawthorn", Weedon Hill, Hyde Heath, Amersham, Bucks HP6 5RW | Tel: 01494 774421  |
| <b>Pauline Mahon (Treasurer)</b><br>41 Stumperlowe Crescent Rd, Sheffield, South Yorks S10 3PR               | Tel: 01142 304069  |
| <b>Paul Leonard</b><br>15 Langthorne Street, Fulham, London SW6 6JT  | Tel: 0171 386 9285 |
| <b>Kieran Houston (Chairman, Northern Ireland Committee)</b><br>15 Barrack St, Strabane, Co. Tyrone BT82 8HD | Tel: 01504 884168  |
| <b>Tony Eyre</b><br>7 Elmer Close, Malmesbury, Wilts SN16 9UE  | Tel: 01666 825215  |
| <b>John Brennan</b><br>105 Barley Cop Lane, Lancaster, Lancs LA1 2PP   | Tel: 01524 382164  |
| <b>Alan Beavan</b><br>Quarter House, 12 Nithsdale Ave, Market Harborough LE16 9PE                            | Tel: 01858 463757  |
| <b>Wilma Robins (Welfare Rights, Co-opted)</b><br>77 Hillview Avenue, Hornchurch, Essex RM11 2DN             | Tel: 01708 443157  |
| <b>Peter Stuart</b><br>31 Stevenage Crescent, Borehamwood, Herts WD6 4NS                                     | Tel: 0181 9532095  |
| <b>Jon Lawrie</b><br>36 Dressay Grove, Spring Cottage Estate, Humberside HU8 9JJ                             | Tel: 01482 786902  |

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|---|
| <b>MPS OFFICE : 55 Hill Avenue, Amersham, Bucks HP6 5BX</b> |
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|                                    |                        |
|------------------------------------|------------------------|
| <b>Christine Lavery (Director)</b> | Tel: 01494 434156      |
| <b>Sue Balmforth</b>               | Fax: 01494 434252      |
| <b>Joan Evans</b>                  | E MAIL 101716,2774.com |
| <b>Sheila Duffy</b>                | (CompuServe)           |

|   |
|---|
| <b>NORTHERN MPS OFFICE : 168 Hesketh Lane, Tarleton, Lancs PR46AT</b> |
|---|

|  |                        |
|--|------------------------|
| <b>Mary Gardiner (Director of Support Services North)</b>                  | Tel: 01772 815516      |
| <b>Pam Thomas</b>  | E Mail 106025,3374.com |
|  | (CompuServe)           |
| <b>Sue Butler (Sales)</b>  | Tel: 01494 483185      |
| <b>Spriggs Holly House, Spriggs Holly Lane, Chinnor Hill, Oxon OX9 4BY</b> |                        |



## The Society for Mucopolysaccharide Diseases

55 Hill Avenue, Amersham, Buckinghamshire HP6 5BX  
Telephone: 01494 434156 Fax: 01494 434252

The MPS Society is a voluntary support group, founded in 1982, which represents over 800 families in the UK with children or adults suffering from Mucopolysaccharide and related diseases. It is a registered charity, entirely supported by voluntary donations and fund-raising by members, and run by the members themselves. Its aims are as follows:-

1. To act as a parent support group
2. To bring about more public awareness of MPS
3. To promote and support research into MPS

The Society operates a network of Area Families throughout Great Britain 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 supports two specialist MPS clinics at the Royal Manchester Children's Hospital and at the Hospital for Sick Children, Great Ormond Street, London. The Society also funds a biochemist at the Christie Hospital, Manchester. 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 disease, but much can be done to improve the treatment and care of sufferers. The slogan of the Society is:-

**"CARE TODAY, HOPE TOMORROW"**

*Front Cover: The lucky boy on the front cover is Daniel Croghan aged 9 years who suffers from Hunter Disease. He is pictured with his favourite Gladiator, Jet.*



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**Deadline for the Autumn Newsletter  
25th of September 1996**

## DIRECTOR'S REPORT

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It is difficult to know where to start. There have been many high points to the work of the MPS Society over this last three months. Mary and I set forth for Australia on the 19th of May not knowing quite what was in store. We need not have worried! The conference venue was superb and the welcome warm and generous. Families and Professionals were fully integrated both in the Scientific Programme and social events. On our arrival in Woolongong we met up with, Paul, Jean and Christopher Leonard and Keiran and Bernie Houston and family. Paul and Keiran are both Trustees of the British MPS Society. They had chosen to have a holiday coinciding with the International MPS Symposium and we appreciated the time they gave us in Woolongong. We did our best to involve them fully in the International Working Party Meeting and discussions on Enzyme Replacement Therapy.

Due to the lack of space I will write fully about the Symposium for the Autumn Newsletter. In the meantime I would like to thank our sponsors Genzyme, Mangar International and the Guardian Jerwood Award without whose support this visit may not have been possible.

Jeans for Genes Day, March 1st, came and went. It was difficult to comprehend how hard and long one can or should work towards just one period of 24 hours. Well all the questions were answered when in June I collected a cheque for £100,000.00, the Society's interim payment of the funds raised. We expect to receive a further £30,000 in the near future. This money is restricted funds and can only be used towards genetic research for Mucopolysaccharide and Related Diseases.

The Trustees have set up a Peer Review committee that includes Dr Bryan Winchester, Dr Ed Wraith, Dr Brian Fowler (Switzerland), Dr Bryn Neal and Paul Leonard. Further on in the Newsletter we are inviting grant applications and expect the peer Review Committee to meet in early Autumn.

I would like to take this opportunity to thank those families and teenage siblings who kindly completed the questionnaire 'Genetic Testing for Siblings'. I was able to use the findings to present a paper at the British Medical Association. This also coincided with my formal appointment to the Government Advisory Committee on Genetic Testing. I feel very honoured to accept this position and will do everything I can to represent the interests of everyone at risk of Genetic Disease.

Mary tells me the MPS Activity Holiday to Bendrigg Lodge in the Lake District was a huge success with 15 MPS teenagers and young adults participating. There were new challenges for the youngsters including a visit underground - yes real caving!

We have also been considerably heartened to learn of the various fundraising activities being organised in aid of MPS. Large or small everyone's help is greatly appreciated. We need to sustain this effort long term to secure the financial stability of the Society and to feel confident that our support and services will be there for the next generation of MPS children and their families.

## DIRECTOR'S REPORT

You will all have your personal memories of the months gone by - some sad some happy and rewarding. As a family we have had much to be grateful for these past few weeks. First of all Robin and I celebrated our Silver Wedding anniversary the day I returned from Australia, and 3 weeks later our son Andrew reached 18 years. In between times Robin was awarded the OBE in the Queen's Birthday Honours. This was a most unexpected tribute that we shall always treasure.



Mary Paget in Australia with Ros Smith who is the founder of the Australian MPS Society.

*Thank you to all the Families who sent stories  
and photographs for the Newsletter.  
Please carry on the good work  
and keep sending your own stories.*



## CHAIRMAN'S REPORT

### Is there a Treasurer out there?

Pauline Mahon helped by her husband Sean has been the Society's Treasurer for some six years but sadly is relinquishing this important post at the end of our current financial year which ends on 31 October. A full appreciation of both Pauline and Sean's efforts on the Society's behalf will appear in a later edition of the Newsletter so on behalf of the Society I shall now just simply say thank you to them for what they have achieved. Their professionalism and support to me as Chairman have been very much appreciated over the years.

A quick replacement is a must for the Society to continue to flourish. If any one reading this Newsletter fancies the job or knows someone who would like to fill this post please let Christine Lavery or myself know as quickly as possible. If you want to know more of what is involved in being Treasurer I suggest you telephone either Pauline, Christine or myself who will be able to give you more details. Both Pauline and Sean will be delighted to help their successor in any way possible.

### Nominations Required!

The A.G.M. is scheduled for 22 September and it is time once more to cast your vote for the Management Committee. By rotation three peoples terms of office have come to an end but they may of course be re-elected for a further three years - these three are Alan Beavan, Tony Eyre and Lynne Grandidge. At the time of writing this it seems possible that not all these three will be seeking re-election. In addition Pauline Mahon is not continuing and possibly one other member of the current Committee. This means that we shall be voting for as many as five members, three of whom could be complete newcomers to the Committee. If you feel that you can add something to take the Society into the next Century please do put your name forward to me. It is imperative that we have a broad based Committee with vision for the future. To date I have had one nomination so more are urgently required. If you want to know what serving on the Management Committee entails I suggest you speak to either Christine or myself.

### Praise and Criticism.

I suspect that like most people I am more accustomed to the latter than to the former and in my capacity as Chairman I receive comments which fall under both headings. Recently I received a letter full of praise for one of our members and I should like to share this with you all. Although she will not thank me for it I will mention her by name - Mary Paget. The letter mentioned other people but the author felt in particular that Mary had "acted above and beyond the call of duty" - knowing Mary as I do I am sure that this does not understate the situation and I join with the writer in extending the Society's thanks to Mary for what she does for so many people on the Society's behalf.

Alf G. King  
Chairman

The Annual General Meeting of the Society for Mucopolysaccharide Diseases will be held at the Stakis Country Court Hotel, Northampton, on Sunday the 22nd of September 1996 at 9.40 am.

By order of the Committee

A. G. King (Chairman)



## MILESTONES

### Births

Congratulations to Anita and Dave Little who became the parents of Lorna and Lorraine on the 1st of May 1996 at High Wycombe, Buckinghamshire.

### New Families

Claire and James Garthwaite and their sons, Thomas who was born on the 27th of November 1993 and Louis who was born on the 1st of November 1995. Both boys have recently been diagnosed with Hunter Disease.

Moira and Ian Bray's daughter, Amy who was born on the 3rd of May 1991 has been diagnosed as suffering from ML III.

Faiza Shaikh was diagnosed as suffering from Sanfilippo Disease in May. Faiza from Essex is 7 years old.

Lynn and Philip Dawson's son, Nicholas has recently been diagnosed with Scheie. Nicholas from County Durham is 12 years old.

### Deaths

Paul Bean from Middlesbrough died on 4th May 1996 aged fourteen years. Paul suffered from Sanfilippo Disease

Andrew Butler from Chesterfield died on the 23rd of May 1996. Andrew aged 29 years suffered from Hunter Disease.

Miss Vanda Vanni, who lived with her sister at Bookham in Surrey, died on 1st April, 1996. Vanda suffered from Morquio Disease.

Pauline and Peter Headland's daughter Katie died on the 14 June 1996 aged 20 years old and is remembered along with her sister, Victoria, who also died from Sanfilippo Disease.

Alan and Fiona Byrne's daughter Louise died on the 20 June 1996. Louise aged 14 years old suffered from Sanfilippo Disease.

### Congratulations

Congratulations to Christine and Robin Lavery who celebrated their 25th Wedding anniversary on the 29th May 1996. Congratulations also to Robin on his being awarded the OBE.

Congratulations to Tanya Denyer who married Peter Stringhaven on the 1st of June 1996. Tanya is the Mum of five year old Beau who suffers from I Cell Disease.



## AREA FAMILY SUPPORT



### 1996 Dates for your Diary

|                           |                       |                                                 |
|---------------------------|-----------------------|-------------------------------------------------|
| 22-24th September 1996    | MPS Annual Conference | Northampton                                     |
| Sunday 6th October 1996   | Chester Zoo           | Family Day (Blackburn and Brennan - North West) |
| Sunday 24th November 1996 | Christmas Party       | North West                                      |

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### FAMILY NEWS

James Stuart from Londonderry, Northern Ireland celebrating his 25th birthday with his Mum, Dad, two nieces, brothers and sisters and friends.



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**The Gift** A play by Nicola Baldwin being shown throughout the UK in 1996.

|            |              |                                                                                                           |
|------------|--------------|-----------------------------------------------------------------------------------------------------------|
| Edinburgh  | 19-31 August | Information on Tickets can be obtained from The Wellcome Centre for Medical Science.<br>Tel 0171 611 8636 |
| Winchester | 26 September |                                                                                                           |
| Leeds      | 2-4 October  |                                                                                                           |
| Bristol    | 9 October    |                                                                                                           |
| Darlington | 15 October   |                                                                                                           |
| London     | 21 October   |                                                                                                           |
| Cardiff    | 2 November   |                                                                                                           |

This powerful play tells the story of the Kay family. It raises lots of issues relating to genetic disorders. The question the play asks is "Where do you stand?".



AREA FAMILY SUPPORT



*Eleanor Gee aged 7 years (Sanfilippo) pictured with her parents aboard the train ride.*

The Family Day organised by the Fisher family from Essex was held at the Suffolk Wildlife Park. The day was attended by 5 families who met up at 11 am. After walking round the park looking at the animals, in an environment suitable for wheelchairs, the families had lunch in a closed in barn. When the children had had their fill of the play area and the bouncy castle the families went on a train ride round the park followed by some time spent at pets corner handling the animals. The day ended at 4.15.

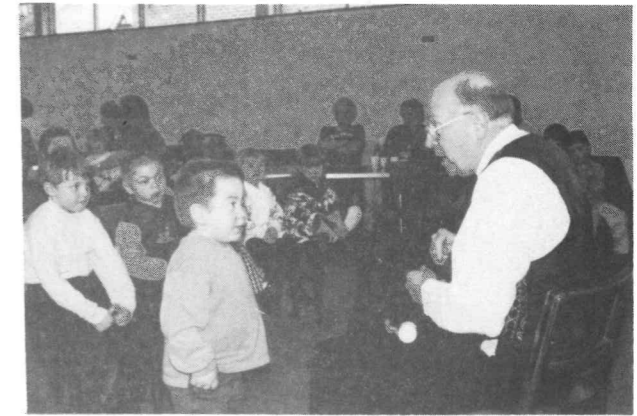


*Pictured above are Justin Robinson, brother of Jade aged 6 years (Hurler) with Adam and Francesca Fisher, brother and sister of James aged 9 years (Hunter) and Jade Thacker, sister of Thomas aged 8 years (Sanfilippo)*

AREA FAMILY SUPPORT

NORTH WEST FAMILY DAY MARCH 1996

*Pictured opposite is Ben Lemon aged 4 years (Hunter)*



Families from the North West Area enjoyed a Buffet Luncheon and Social afternoon at the Crowsfoot Centre in Nantwich on Sunday the 24th March.

A double dose of entertainment was provided - Magic Mister B was a hard act to follow with his puppets, Punch & Judy and magic but David Oulton aged 8 years (Hunter) made the day with his own magic show. He certainly had everyone 'spell-bound' with his magic tricks and balloon shaping and deserves his reward as a junior member of the Magic Circle. Bill and Sylvia Blackburn



*Pictured opposite is David Oulton performing his magic and pictured below are the rest of the children enjoying the Magician except for Harry who is taking this opportunity to have forty winks.*





## FAMILY SUPPORT



### Little Bridge House

I am writing this having recently returned from our third weekend visit to 'Little Bridge House' the Children's Hospice for the South West of England.

When we were first invited to visit L.B.H., last September, our daughter, Hannah, now 3, had been diagnosed with Sanfilippo Disease 6 months earlier, and this was our first get together with other newly diagnosed families. This in itself was a big step for us, but to meet at a new Hospice which we would probably need to use, filled us with absolute dread. However, once we had met the care team, been shown around what is a beautifully designed house and seen Hannah obviously in her element in the huge, boat-shaped sand pit, our fears subsided.

Everybody has pre-conceived ideas about Hospices, particularly those of us who have had adult relatives or friends who have passed away in one. The idea of a children's hospice conjures up such sadness because nobody likes to think of a child dying. But these children, whilst suffering from life limiting conditions, deserve to live their lives to the full, and places like L.B.H. strive to provide this, and do so successfully. Perhaps it would help parents more to think of L.B.H. as a respite centre, rather than a Hospice, and leave the word 'Hospice' for the general public, whose own pre-conceived ideas lead them to be very generous when it comes to fund-raising.

Traditionally, the word 'Hospice' means a place of rest and peace while on a long journey, and this is just what L.B.H. is. The whole family benefits from the care the children receive. We actually get to sleep together, by ourselves, without Hannah trotting in every 3 hours and we can sit in the Conservatory drinking coffee on tap and chatting, while somebody else keeps a constant eye on her. It is such a joy to see the children racing down the long corridor, or outside, knowing they cannot come to any harm, and watching them play with every kind of toy imaginable. They can make as much mess, and get as dirty and sandy as they like - and somebody else will clean up behind them!

We now try to stay at L.B.H. every 3 months or so, and are really looking forward to our next visit in July. We feel that just knowing a visit is coming up helps us to cope day to day.

*Jackie Chisling*  
(Hannah's Mum)

## FAMILY SUPPORT

**Teenage Activity Holiday** *Thank you for getting me on a great holiday. I had a lovely time. Ronda aged 21years.*



*Thank you for letting me come on the Bendrigg Trust holiday. I feel that there was a lot more to do at Bendrigg and the activities were a lot more organised. Every year I think that the adventure holiday gets better. When we went caving I was glad that I had done it as it was really scary and cold but I still enjoyed it.. Christopher aged 15 years.*



**MPS Adventure Week 7-13 April 1996 Bendrigg Lodge, Cumbria.**

Fifteen young people plus our army volunteers from 9th Supply Hullavington, myself and Martine and John Brennan all took part in what turned out to be a wonderful week of adventure, thrills, laughter, aching bones, sore feet and a special kind of closeness that only comes from being with "special friends"

The zip wire was a favourite and certainly gave everyone a sense of achievement, flying through the air 200 ft above ground on a wire definitely clears the cobwebs! After that the rock climbing and abseiling were a piece of cake, even for those in a wheelchair. We had a surprise in store for Sarah Burgess the day we went caving - 15 birthday candles lit up the cavern, with Helen O'Toole leading the singing. It was also a tremendous sight to see so many young people crawling through small, damp and watery passages - especially when we heard cries of "let's do it again!"

The emphasis at Bendrigg was to encourage everyone to take part, not only in the activities but in the day to day running of the centre. Each group had certain tasks to perform each day, from hoovering the lounge carpet and corridors, setting and clearing the table stacking the dishwasher, to serving at tables and preparing the packed lunches each evening. Each group had several turns at each task and it was a real pleasure to watch Chris Isaac carry several bowls of soup with the aid of his new whiz-kid wheelchair. Helen O'Toole announced that she had found her vocation in life as a sandwich packer, apparently she has always wanted to have a go at sealing plastic bags with a tape dispenser (a simple thing for us but extremely difficult when your hands don't work properly). Mark Simpson was definitely dangerous with the hoover as was Myles Broughton when it came to wiping tables with a dishcloth and a squirry bottle of disinfectant.

I think the evenings were my special time, not only could I rest my aching feet but it was a time of telling stories, sharing confidences and making friendships.

Mary Pagett.



FAMILY SUPPORT

Hello, my name is Sarah Burgess and I have just come home from a brilliant adventure holiday in Kendall with the MPS Society. On Sunday the 7th April my parents dropped me off at Milton Keynes train station and on the train I met Helen O' Toole and her dad.



We got off at Oxenholme station, where we met Sue and Mel. It took a couple of minutes to get to Bendrigg Lodge. When everyone got there we were told what would go on throughout the week. That night we had an Easter egg hunt; they said there were 190 little eggs some-where outside. So we went out looking and together we all found 196, I don't know how we did that one!

Monday morning Myles, Samantha, Colin and myself went into our group and went canoeing on a very misty reservoir. In the afternoon we went for a local walk and our army volunteers were moaning because it was all uphill. Jason was pushing Myles until his buggie wheel snapped off! That night we went to the pub!

Tuesday morning we did abseiling and went on the zip wire, I went really fast down the zip wire.

Tuesday afternoon we did archery and tube sliding, tube sliding is like a water chute without the water.

We all went down together and it was really fast. Wednesday we went on a steamboat across Lake Windermere. We could not see much because it was raining. In the afternoon we went to the



Lake District National Park where we watched a video on the Lake District. It was very dark and had relaxing music on so by the end of it most of us including myself had fallen asleep even Mary Paget!

On Thursday it was my birthday and we went caving. Everyone had lights on the top of their helmets. Terry our instructor asked me to come to the front, they also had to turn there lights out. Mel came around the corner with a birthday cake and everyone was singing Happy Birthday. In the cave there was a waterfall and a cold muddy crawl which I went through.

On Friday in the morning we went shopping in Kendal and in the afternoon I went on the rope course, tube slide and the zip wire. Friday night we had a party. Saturday morning we had to say bye to everyone. I would like to say thanks to everybody for giving me such a lovely holiday. Thanks very much!

Miss Sarah Burgess, Luton

Teenage Activities

FAMILY NEWS

Dear Mary

Well it's finished and bigger than we visualised.

Martin's room and bathroom are large and has built in wardrobes and large patio doors. It is really bright, especially when the sun shines. What can we say, thank you again for all your help in pushing the council.

Karen Stevenson.

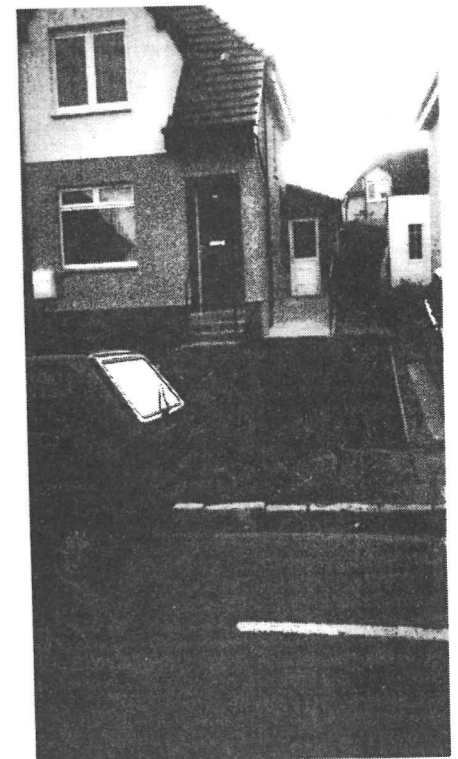


Above are pictured Martin with Ross and Rebekah.

Martin Stevenson, from Lancashire is 8 years old and suffers from Sanfilippo Disease.

The front of the house with direct access to Martin's room.

At the back of the house. Martin enjoys the view from his patio doors.



## FAMILY NEWS

### Keegan's Progress

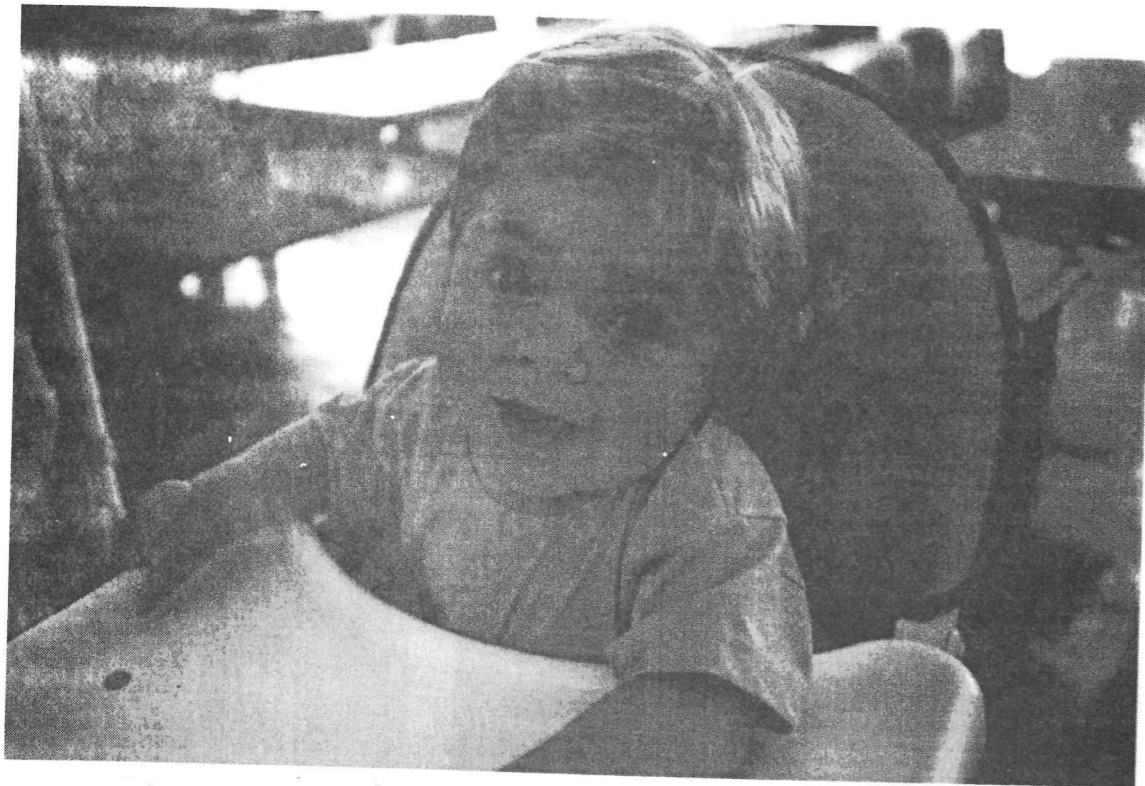
Keegan is 17 months old and was diagnosed with Hurler Syndrome in July 1995. He was eight months old and although we did not suspect anything was wrong he was having a lot of chest infections and the doctor said that his neck was very short. He underwent investigations which proved he had a Mucopolysaccharide Disease.

Since then he has had two Inguinal Hernias repaired and a trigger finger released and he is now awaiting grommets. But despite everything Keegan is a very happy and energetic little boy. Everyone who knows him loves him very much. He is very special, just like every other MPS child.

He is walking now and can say 'Mumma' and 'Dadda' and he says "EE-yalt" which means:- where's that, what's that and who's that? Keegan is always making us laugh even at 3am in the morning. He is a right little comedian.

Just because he has 'Hurler Syndrome' does not mean he can't have a happy life. We really enjoy him and make the most of him, and so should every MPS family.

Melissa Lovick ( Keegan's Mum)



## FAMILY NEWS



*Have you been watching Blue Peter recently because if you have you will know that I appeared on the show three times. Tim Vincent, pictured opposite presented me with my new wheelchair on the 14th of February.*

*It was great meeting all the presenters live I feel like I am a star now as well. Chris Isaac*

Also pictured opposite are Glyn Williams, Senior Technician and Hayden Williams, Deputy Manager of Mangar International who built Chris's new wheelchair.

## DISNEY WORLD



Here we have Chris Isaac, aged 15 from Somerset (Morquio) and David Marshall aged 10 from Newcastle (MLIII) at Disney World in Florida with the National Holiday Fund.

The boys visited Cypress Gardens, Sea World, MGM Studios, Magic Kingdom, Epcot, Leesburg Police Station and Kennedy Space Centre. They had a wonderful and exciting time.



## FAMILY NEWS



Daniel Croghan - Hunter- Aged 9 years.

On Monday 18th December, Daniel, Alex, Louise, Geoff and I arrived at Stockport station to board a train to Cambridge where Daniel was going to meet the lady of his dreams. We travel infrequently by train, so it was quite a treat, no driving for us and freedom for the children to wander up and down the carriages. Daniel was particularly fond of the refreshment trolley and the ability to have a picnic on the move.

The following afternoon, we arrived at the Cambridge Corn Exchange for the matinee performance of Aladdin, where "Jet," of Gladiators, was appearing as the Slave of the Ring. Daniel was the first person through the doors and could barely contain his excitement. We soon got into the pantomime spirit, lots of shouts of "it's behind you," "boo, hiss" etc. Daniel's highlight was Jet cartwheeling onto the stage in her Gladiator costume which had him jumping up and down in his seat, clapping and cheering.

After the performance we were all escorted backstage to meet "Jet." We had to battle our way through an assortment of props and costumes, which looked far less impressive off stage than on. Daniel had gone very shy by this point and we were beginning to worry that he would become completely tongue tied when we eventually met "Jet". We needn't have worried, she put him at his ease immediately and was very taken with his "I love Jet" tee-shirt. The pair chatted for quite a long time and we got lots of good photos and Daniel got a kiss, his tee-shirt has lipstick on the collar and I have been forbidden to wash it since. "Jet" was a Lovely lady, far prettier than she appears on the television, and she gave Daniel a treat he will remember for a long, long time.

Many thanks to the Round Table Children's Wish for granting Daniel's wish.

## FAMILY NEWS

## ARTICLE PUBLISHED IN SUNDAY PEOPLE'S YES MAGAZINE

*The following letter is from Eddie Hall who is the father of Dominick aged 7 years and Oliver aged 1 year who suffer from Sanfilippo Syndrome.*

I would like to take this opportunity to say how sorry both Bernie and I are at any upset caused by this article.

About five months ago our local paper did an item on our fundraising efforts of holding boot sales etc. so that we could raise enough money to take our boys to Disneyland. We were then approached by Cavendish Press who did a story to be sent to the national papers. We gave both our local paper and Cavendish Press a copy of the MPS booklet on Sanfilippo so that hopefully they would have a better understanding of MPS Disease.

The next we heard of this was a phone call telling us to read the Sunday People. When we read this article we were shocked and angry at the horrid way we, particularly Dominick and Oliver had been labelled.

I would like to make it clear that we have **never** referred to any MPS person as a Gargoyle and **never** would do this as we know how much it would hurt and indeed how in some cases it has hurt deeply.

Bernie's sister, Mrs Lofthouse has been in touch with the editor of the People and demanded a written apology (still waiting). The editor verbally apologised and said it was done in this format to be more sensational (well that certainly worked).

Once again we are sorry to you all and would like to state that it was not our intention to hurt anyone.

Eddie Hall

*The following letter was sent to the MPS office in reply to a letter that Christine sent to the People objecting to their artistic license.*

Dear Mrs Lavery

I am writing to offer you our apologies for any distress you feel was caused by the article "Every minute counts for the gargoyle boys" printed in Yes! magazine on April 21st, 1996.

On a more positive note we feel that the article brought the tragic complaint to the attention of the public and I hope the appeal for our readers to help with cash donations, is a great success.

I am shortly to assume the duties of John Smith, Man of The People, who, as you will know, does a great deal of good work and through his column to help organisations which strive, like yours to help ease the plight and suffering of the less fortunate.

Tom Petrie (Executive Editor)

## SOCIETY NEWS

### FOR SALE

Amstrad PC 2086D, Keyboard and Ricoh RP3200Q Printer

This is an old system in good working order and it comes with a useful as word processing package.

Any reasonable offer to be made to the Amersham office. Proceeds to MPS.

### NEWSLETTER ARTICLES

Thank you to everyone who sent articles for the newsletter. As we received so many we have added four more pages and have decided to hold some articles over until the next edition. Thanks again for all your input and keep those articles coming.

Joan Evans

### CHILDHOOD WOOD

The planting of the Childhood Wood will be held on the 25th of October 1996. Anyone who is interested in attending should inform the Amersham office as soon as possible.

*Neil Whitewick asked that his new address be included in this Newsletter*

2472263S Cpl Whitewick  
Reg't Trg Wing, 27 HQ Sqn2  
Close Support Regiment RLC  
The Princess Royal Bks. BFPO47

### 1996 MPS CONFERENCE

We still have a few places left for this year's conference. So if you would like to come please return your booking form/or ring for a new form as soon as possible.

### GENES FOR JEANS

The Society welcomes applications for grants into research for Mucopolysaccharide and Related Diseases. Applications should follow the Medical Research Council format and must reach the Society no later than the 31st August 1996.

### CHRISTMAS CARDS

Yes it is that time already. We have included an order form for MPS Christmas Cards with this Newsletter.



## OVERSEAS NEWS



### Greetings from Ireland

On Saturday the 18th of May we had our 2nd Annual Family day which was thoroughly enjoyed by all from Grans to babes in arms. The rain clouds cleared by early afternoon and the sun shone on us as we picnicked, chatted and enjoyed the facilities of 'Fort Lucan' Dublin's Outdoor Adventure World.

We welcomed our newest family, Paul Casciani (Hurler), with his Mum, Dad, Gran, Aunts and cousins.

Ned, Clare and Allison Murphy from Cork would have loved to have been with us but they were celebrating the safe arrival on the 14th May of a healthy baby girl, Judy. Congratulations to Ned, Clare and Allison. We are looking forward to the next family day.

Best wishes to all

Mary, Eamonn and Elena

Chairperson

Mary Boushel

101 Hillside

Dalkey Co. Dublin

Secretary

Mary McGauran

Clackbawn

Calry Co. Sligo

Pictured below is Gavin Fitzgerald aged 3 years old (Hurler)



This is a photo of Cillian Bushell aged 6 years (Hurler)





## OVERSEAS NEWS

### First Swedish MPS Parent Conference - 15-18 February 1996

After the first Norwegian MPS Parent Conference in May 1995 there had always been the promise that a similar event would be held in Sweden.

As luck would have it this winter in Sweden was the worst they have had for 20 years. In four days all we saw was white outside and a temperature of minus 20 degrees centigrade.

However the cold outside was more than compensated by the warmth of the welcome Ed Wraith and I were given by the 18 families and many professionals.

The Conference was held on the island of Långholmen in Stockholm Harbour. It was until 1975 a prison holding some of the most notorious Swedish criminals. The cells are now Very Small but comfortable bedrooms.

The Conference lasted 3 days and addressed all area of management for the MPS child. There were small personal parent workshops and the thirst for information from parents was at times overwhelming.

Part way through the conference, parents and professionals went by bus to Huddinge University Hospital where we saw round the transplant unit which includes BMT for MPS.

A visit to the Ronald MacDonald House in the grounds of the hospital was next on the agenda. Getting through the snow with me in my high heeled shoes I began to think I was more likely to end up in the Accident and Emergency Department.

The Conference culminated with a small working party of parents agreeing to set up an MPS Society.

I would like to thank Dr Gunilla Malm for the wonderful Swedish hospitality.

Christine Lavery



## OVERSEAS NEWS

### VKS Verenigen voor Kinderen met Stofwisselingszlekten

#### Support of MPS Families in the Netherlands - 11 May 1996

VKS is a parent support group for families whose children have a Metabolic Disease. Within the umbrella VKS supports a significant number of MPS families.

Their parent meeting on the 11th of May concentrated on the problems facing MPS families and I was invited to talk on how the British MPS families are supported.

The meeting started at the 'Het Land Van Ooit' (The Land of Ever). This is an amusement park with Earls, Princes, Princesses, Fairies and Ooit money. As the Dutch put it 'the Children are in charge there'! Parents left their children with volunteers and made for a nearby venue where the conference was to be held.

I was joined in Drunen by Ceri and Andrew Coleman from Cardiff. Their eldest son, Joseph is the only child in the UK with Aspartylglycosaminuria (AGU). The co-ordinators of VKS, Arjan and Hanka Meutgeert also have a son with AGU and know of 2 more families in the Netherlands with similarly affected families.

During the conference I met with two families, one of whom had just had a Hurler diagnosis of their son and the other whose young daughter had died from Hurler Disease at Christmas. Although there is only a few miles of water separating our two countries the lack of knowledge by parents and the reluctance of professionals to inform parents was most concerning.

I hope I will have further opportunities to help MPS families in the Netherlands in the future.

I would like to thank my hosts and particularly Arjan and Hanka for their kind hospitality.

Christine Lavery

**Life with Aspartylglycosaminuria (AGU)**  
**Department of Child Neurology**  
**University of Helsinki**  
**Finland**

This book by Maria Arvio is a series of thesis (in English) studying every aspect of AGU from the enzyme deficiency through to the behavioural and development problems of those affected by AGU.

## INFORMATION

### NAESC

#### National Association for the Education of Sick Children

18 Victoria Park Square, Bethnal Green., London E2 9PF Tel 0181 980 8523 *Working for every child's right to education when they are sick*

#### PUPIL'S AND PARENT'S VOICE PROJECT

#### AS THE PARENT OF A SERIOUSLY ILL OR LIFE THREATENED CHILD DO YOU HAVE VIEWS ABOUT:

#### THE IMPORTANCE OF EDUCATION IN HOSPITAL AND AT HOME? WHAT KIND OF EDUCATION, WHO SHOULD DECIDE?

In 1996 the NAESC is carrying out the Pupil's and Parent's Voice Project. gathering evidence on:

- your view of good educational provision
- the role of education in your child's life
- the quality of the educational provision you have received
- your needs and concerns

If your child has a life-threatening or terminal condition we would like to include your views in the research. As a parent of a seriously ill child there are many things to take up your time but anything that you have to say would be an important contribution to this valuable project.

The National Association for the Education of Sick Children was founded in 1993 to work for equal access and entitlement to a good education for all sick children throughout the country. By sick children we mean: children who are seriously or chronically ill, who have been injured in accidents, children with Special Educational Needs when they are ill, children with mental health problems, and children with psychological conditions when they are physically ill. We work to ensure that sick children do not face the double burden of educational disadvantage. Contact with parents increases our understanding and ability to recommend change and promote good practise rice.

We would like to hear about your experience or views on education for your child; as it has been and as you would like it to be.

YOU can write an open letter to me or request a questionnaire to provide more detailed information.

Angela Bolton Project Officer

## INFORMATION

### BEREAVEMENT

*(The following is an extract from the MPS Canadian Newsletter)*

#### HOW DO YOU MEASURE YOUR GRIEF?

For years, I have gauged my grief by the measure of a single, tall, oak tree that towered over the other trees in the nearby woods at the side of our yard. Actually, three oaks stretched skyward beyond the green-topped pines, but the center oak loomed at least thirty feet taller than the other two. The winds of each season bent its top in a bowing motion over the flanking trees, and the March wind lashed it as if to snap it in two, but still it dominated the dense woods---just as my grief ruled my life and governed my restless sleep at night.

Several months after my daughter died, I was just beginning to discover I would awaken without instantly being thrust back into her hospital room to re-experience her death. Now, as soon as I woke, I began to focus intently on the sky and these majestic trees as they were framed in my upstairs bedroom window. This blind-staring stage is familiar to many

bereaved parents, and it immobilized me until I could force my enervated body out of bed to drag through the tasks of the day.

The Tree, reaching toward Heaven and speaking its lonely thoughts to God, came to represent my grief, my aching disorientation, my agony. As The Tree commanded the forest, so my grief mandated the path of my life. My eyes were drawn to it each morning when I wakened or whenever I came into the room for any reason through the day. It was still there in winter, fall, spring and summer; still tall, still master of the landscape.

In the rain and sunshine that followed winter, its buds burst into spring leaves. I watched it stand quietly in the summer heat, keeping its distance from the other trees. In fall, its greenness changed to orange yellow, and it was an even more beautiful master of the sky and woods. In the grey

gloom of winter, its bare limbs were silhouetted against the stark winter sky, pronged out like the many facets of my own naked grief.

Though I did not name its limbs, I instinctively knew every branch in that giant, stately tree. The trees around it couldn't touch its height and dominance. As each part of my life shifted with new values and new assessments, this tree became the yardstick for my grief.

How many seasons my eyes were drawn to that tree! How many bleak mornings I stared at it. One morning last fall, twelve years after Tricia's death had devastated me, I woke with a headache. Almost automatically, my eyes turned to the window, to the woods, to The Tree. Hadn't it always illustrated my pain?

Without knowing exactly when or how it had happened, I realized my grief tree was no longer thirty feet above the others.



## INFORMATION

Time and growth had gradually altered the woods and the landscape. When the wind blew, my tree nodded no more than a few feet above the others. Their supporting branches caught it when it swayed, kept its top from bending down too far, joined it in its once-lonely vigil with the sky.

Like many aspects of my life, they reached Heavenward, joining

my grief tree, dwarfing its starkness. The dark green pines, now tall themselves, and stronger, also nudged toward it.

Startled, I knew nature had grown a symbol for me. While I had worked at living my changed life, my grief (like my tree) no longer dominated my horizon. Grief is still there, but other "trees" have grown tall to fill the gaps around it and bring it more in

proportion with its surroundings. It may always be a little taller than the others. Or, (who knows?) in a few years, one of the other trees may outdistance it.

But for now, I look out my bedroom window - thankful for the changes in nature and in me.

Reprinted from the Bereavement Magazine

### HELPFUL HINTS

Due to diet changes or the ability to swallow and chew or to get the pills or tablets down, we use this recipe to help. It is my own version of "Wobble" you can buy in the dairy section which is jello and yogurt mixed together. This is quite a bit cheaper than brand name.

Jello-ORurt    1 box jello  
                   1 cup low fat plain or flavoured yogurt  
                   1 cup boiling water  
                   1 2 cup container

Boil water in microwave for 2 minutes on high. Add jello powder and stir to dissolve. Pour yogurt into 2 cup container. Let jello cool for 15 minutes then add to yogurt and mix thoroughly. Chill.

\*\*When set this can be used to help medications go down smoothly or as a snack or dessert.

\*\* While jell-ogurt is still a liquid, I pour over wafers, tea biscuits, banana bread etc., so that it softens and moistens the food and then can be used as a snack, dessert etc.

### THICK 'n EASY

Many families find that drinking is a major problem for their sons and daughters in the late stages of MPS particularly Sanfilippo Disease. Thick 'n Easy can be purchased at the chemist and added to milk and fruit based drinks.

This can prevent a child feeling that they are drowning when drinking.

## INFORMATION

### Do you look after a friend or relative who is disabled, frail or ill?

There may be local services to help you. You can get your free carer's assessment guide by calling Boots Carers Hotline on 0115 959 2282 or obtaining a form from your local Boots.

**A carer is someone who looks after a friend, relative or neighbour who cannot manage without help because of illness, old age or disability.**

If this applies to you, then you may be entitled to help from Social Services"

From April 1st 1996, there is a new Act of Parliament to help carers - the Carers (Recognition and Services) Act. Under this Act, if you are providing care for someone or will be doing so in the near future, you will be able to ask your local Social Services\* to carry out an assessment of your needs, as well as for the person you are caring for. This assessment will help them decide what help they can offer you and your family.

### Five of the most commonly asked questions by carers

#### 1. How do I ask for help?

Simply ask your Social Services Department" for an assessment of both you and the person you care for. The assessment will take the form of an interview and will focus both on your needs and the needs of your friend, partner or relative. The assessment should be put in writing along with a 'care plan' detailing the services that are provided.

**2. Can I get any financial help with caring?** If you are aged between 16 and 65 and look after someone for at least 35 hours a week then you may be able to claim Invalid Care Allowance (ICA). The person you care for must be in receipt of Attendance Allowance or Disability Living Allowance Care Component at the middle or higher rate. There is a limit on how much you can earn to qualify for ICA.

#### 3. What about Council Tax?

It is sometimes possible for carers to get extra help with their council tax regardless of their financial circumstances, through the system of discounts and disability reduction.

Additionally, council tax benefit may be available for those financially eligible and is more generous for those entitled to Invalid Care Allowance

**4. I could really do with a break from caring to recharge my batteries but I can't leave them alone. Who can help me?** Social Services\* must assess your needs as a carer. If you need a break from caring, they may be able to help with respite care or a short break so that you can go out during the day, or for a longer period. Respite care may be offered at home or in some form of residential care.

## INFORMATION

**5. How can I get support as a carer?** Many parts of the country have a carers' project, centre or support group where you can meet other carers and get information and support. Carers National Association can tell you what is available in your area.

If you would like more details or advice on benefits call CNA's 'Carers Line' on 0171490 8898  
(open weekdays between 1- 4pm)

\* Social Services is referred to as the Social Work Department in Scotland and the Health and Social Services Trust in Northern Ireland.

### Spotlight on Northern Ireland New Legislation

The new Children's Order comes into force in the Autumn. Equivalent to the Children Act in England and Wales

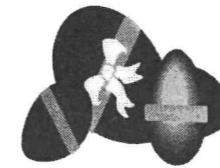
The Order is the first time children with disabilities, together with their families, have featured in legislation. The voluntary sector is seizing this opportunity to come together in a coalition and speak with one voice. For example it is vital to ensure that resources do not get too directed towards child safety at the expense of health promotion/ disability. Hence the Children with Disabilities Network has been set up. It is co-ordinated by Disability Action and consists of any, and hopefully, all voluntary organisations which have a concern for children with disabilities. The Network hopes that eventually parents and children will also have a voice through the Network. If you need more information contact Sharon Garvey, Disability Action, Tel. (01232) 491011.

The second development is the Education (Northern Ireland) Order 1996. The key measures are:

- to set statutory time limits for completing stages in the procedures for making assessments and statements
- to introduce a Code of Practice on special educational needs, providing detailed guidance for boards, schools and others with an interest
- to introduce new rights of appeals for parents and to create an independent tribunal to hear appeals from parents on aspects of the statementing process.

The new Order requires the Department for Education to issue a Code of Practice giving practical guidance to help parents and professional workers and this will include a five-staged approach to assessments and partnership with parents. The draft Code was circulated for consultation until the end of May and will come into force in September 1997 although schools are expected to work in the spirit of the Code from this September.

## INFORMATION



During the Easter holidays we (Mary and Tony) took Ross who has Hunter Syndrome and his Nanna to a delightful 'holiday home' in Tenby, West Wales called Harriet's House. The 'House' - it is actually a self-contained ground floor flat of a house which is in a lovely location overlooking the harbour. The house is specially adapted for handicapped children and is run by the Harriet Davis Trust, set up by the parents of Harriet Davis who died a few years ago from a rare metabolic disease.

The house is very spacious and can accommodate up to seven people plus a baby. The special bedroom is equipped with a Baltimore Superbed which is hydraulic and fully adjustable and the en-suite bathroom has a Kingcraft rise and fall bath and an adjustable sink for wheelchair users. Other equipment includes floor sitters, wedges and a portable feeding chair. The flat is fully centrally heated and all fuel charges are included in the rental.

The kitchen is fully equipped with dishwasher, microwave, cooker, fridge/freezer and even a food processor. The spacious living room has plenty of room to manoeuvre a wheelchair around and has view across the harbour. There is also a TV, video and a pair of binoculars to view the boats coming in and out of the harbour. There are also spades and buckets supplied for the children.

The Trust also provides a Family Helper for two hours a day, at no extra cost, to do shopping, cleaning or washing and ironing.

The beaches (there is no oil on them, honestly) and the town centre are only a few minutes walk away. The property is usually only available to families with a disabled child under 21 years of age. Weekly charges are reasonable given the spaciousness and fine location and the fact the flat can accommodate up to seven people.

The prices for 1996 are as follows

|           |             |           |      |
|-----------|-------------|-----------|------|
| 6 January | to 23 March | inclusive | £215 |
| 30 March  | to 18 May   | “ “       | £265 |
| 25 May    | to 13 July  | “ “       | £315 |
| 20 July   | to 31 Aug   | “ “       | £365 |
| 7 Sept    | to 28 Sept  | “ “       | £315 |
| 5 Oct     | to 26 Oct   | “ “       | £265 |
| 2 Nov     | to 14 Dec   | “ “       | £215 |
| 21 Dec    | to 26 Dec   | “ “       | £315 |

The flat is likely to be booked for the rest of the summer but we can recommend it for the Autumn break or Summer holiday next year. We will certainly be returning.

For further information and bookings contact Harriet Davis Seaside Holiday Trust for Disabled Children on 01874 - 730500 (Reg. Charity No. 1015096). Or if you want to have a chat about the flat, give us a ring on 01443-217787. *Mary and Tony Lockyer*



## FUNDRAISING

### MPS Mum runs the London Marathon

The Holroyd family of Chew Stoke, near Bristol have been members of the MPS Society since 1985. Our eldest son William who will be 22 this month has Sanfilippo syndrome. Although Will can no longer walk and has problems with eating, he leads as normal a life as possible. He attends an adult day centre during the week where he receives individual care, the quality of which is excellent. We also have great support from our local Community Mental Handicap team and think we are very lucky in this area in the quality and sheer professionalism of the support services we receive.

In April I took part in the London Marathon. I have been running for about 12 years now mainly across the fields with the family dog, but never more than 5 miles at a stretch. I have had a latent ambition to run in the London Marathon and when my application this year was successful I girded my loins and the dog's and we started running with more purpose. Unfortunately the dog befriended a local collie quite early on and found herself pregnant so I had to finish the training on my own.

The day of the Marathon was the hottest of the year so far. I started right at the back with all the rhinos, clowns, bananas, surfboards and ladders, Progress for the first 18 miles was fairly uneventful. After that I found the pace pretty gruelling so it was a great relief to finish in just over 5 hours. However it was an excellent day, full of good spirit and a satisfying sense of achievement on crossing the finishing line.

With wonderful support from family, friends and my husband, Chris's business contacts I managed to raise £1600 for the MPS Society in sponsorship.

In retrospect I don't know which was harder - running in the Marathon or looking after a litter of 10 puppies.

Judy Holroyd- Chew Stoke



This is a Holroyd family photograph taken last year on William's 21st birthday. With William, Mum and Dad and the dog are brothers Tom (20) and Anthony (17) and sister Jilly(15).

## FUNDRAISING



This is Jayne Shrimpton, friend of the Kilvert family who ran in the London Marathon. She is pictured with some friends who were with her. Jayne completed the London Marathon in five and a half hours and she raised £1,353 for the MPS Society.

### The Liversedge Half Marathon

My wife Maureen and I thought it would be nice to let the newsletter know of a recent fundraising activity for the Society. Our two boys Dale, aged 7 and Kyle aged 4 were diagnosed as having mild Hunter Disease about a year ago. Since then we have found family and friends to be very supportive.



From left to right; Kyle, Paul, Pete, Ian, Dale and Clive.

This was demonstrated by our brother in law, Ian who knew fellow drivers at the company we both work for ran marathons to raise money for charities. After approaching all three runners they instantly agreed to do their next run in aid of MPS. The run was the Liversedge half Marathon and took place on a freezing cold Sunday on the 18th of February 1996. All three runners, Clive Wilson, Paul Jeffries and Pete Chapel, completed the gruelling 13 mile course in under 2 hours with very respectable times considering the strong wind and steep hills included in the run. On completion of the marathon each runner was presented with a small plaque and Clive and Paul donated theirs to Dale and Kyle. You would have thought both lads had won the marathon when presented with these.

Finally we would like to say a big **THANK YOU** to Clive, Paul and Pete for not only doing the run but also collecting sponsors, along with other kind family and friends. Thanks to everyone who contributed, and with all the help we are pleased to announce that fantastic sum of £481 was raised for the Society.

Martin and Maureen Taylor

## FUNDRAISING



THE TERRY SCHOOL OF DANCE

Principal ; Mrs. T. Ferguson F.I.S.T.D. 17, Carruth Road, Bridge of Weir, Renfrew. PA11 3HQ Tel; 01505 690757

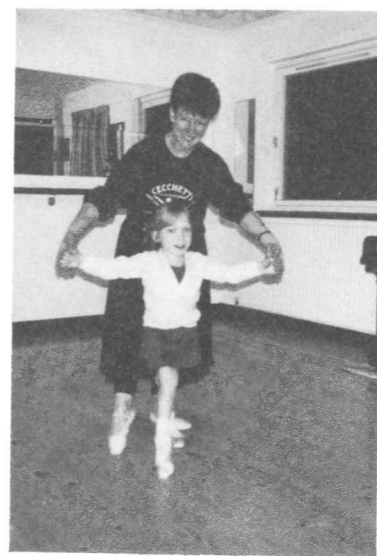
It is with great pleasure that I enclose a cheque for £500 for the Society for Mucopolysaccharide Diseases. This is the proceeds from an 'Evening of Dance' which I put on with my ballet school on 23rd March 1996 at Gryffe High school theatre in Houston .

Joanne Evans from Bridge of Weir is 10 years old. She suffers from Morquio Syndrome and is a great friend of my daughter. When I first moved to Bridge of Weir from Hertfordshire, Joanne was most anxious that I should re-start ballet classes so that she could attend. Naturally I was somewhat apprehensive at taking on Joanne as a pupil, as ballet is hard enough for the most 'able-bodied' child, let alone a Morquio child. However she was so enthusiastic that I could hardly refuse.

Well, 2 years on Joanne is still attending weekly lessons and although there are many of the exercises she really cannot manage to do she nevertheless inspires us all with her determination and the great joy she derives from being able to participate in a ballet class. She never uses her disability as an excuse for not trying her very best and often puts the other class members in their place when they are not doing all they can.

This year I decided to mount a performance with the 71 pupils in the ballet school and naturally Joanne was included. The first half of the programme was 'The Seasons' in which all pupils, from 3 to 16 years danced; Joanne was a snowflake in our Winter scene. The second part of the programme was a ballet of 'Alice in Wonderland' danced by the senior pupils and Joanne appeared as a card she was the Ace of Hearts and performed a lovely mime when the Queen of Hearts discovered her 'painting' the white roses red. Parents of all the pupils bought tickets to watch the show and were most generous with donations for programmes and raffle tickets. We are delighted to think that this small contribution may go towards helping other children like our friend Joanne

*Teresa Ferguson*



Joanne Evans with her dance teacher, Mrs Ferguson.

## FUNDRAISING



### Tesco Collection

Over the Easter week-end, our local Tesco generously allowed us to hold a collection in aid of MPS. Having never done anything like this before, I can now honestly say I will never, ever walk past anyone holding a collection again!

I suppose one in about 20 people actually put money in our tins, but their generosity was overwhelming when we saw 50p pieces and £1 coins dropping in. We decided to give away Jelly Babies to children and this was very successful, these days people seem to expect something in return for their donation. Only a few people refused one because of the gelatine content - obviously they were at great risk from catching BSE from a Jelly Baby!

Obviously, very few people had heard of MPS but quite a lot asked what it was and showed genuine interest. One man was so impressed by my sister-in-law's explanation, he gave her £3! Some of the comments made were amazing from being told we were too unpronounceable- "*You must call it something else dear*", to an absolute grilling on our status as a registered charity!

Anyone thinking of holding a collection must be prepared to be rammed by trolleys and not just the shoppers either - seeing how the 'trolley kings' collect and return them to the pound, it's not surprising that so many trolleys have minds of their own. Also, be prepared for the amount of barking dogs tied to the pillar you are standing by, particularly when they decide to pee up it!

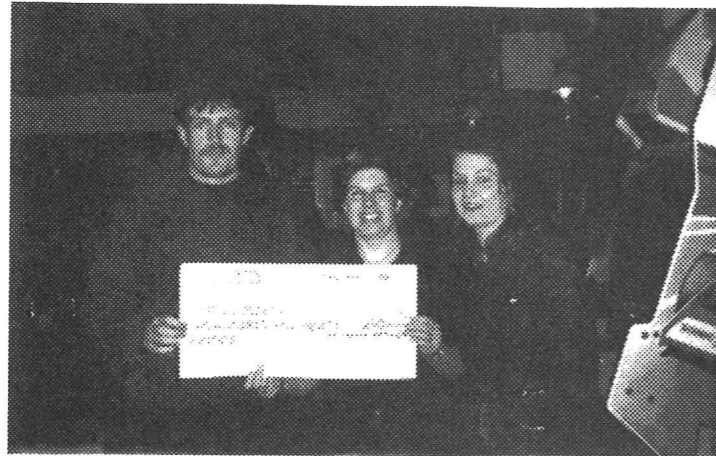
Seriously though, Tesco appears to be a very generous company and I would encourage anyone to approach their local store to hold a collection. We raised nearly £500 over 2 days for which we were very grateful so it was well worth it. Even in April, it was very cold and it was a good idea to rope in friends and family to do 2 hour shifts. Needless to say, we headed straight for the Coffee shop when finished!

We haven't been put off though - we hit Sainsbury's at Chippenham next January!

*Jackie Chisling*



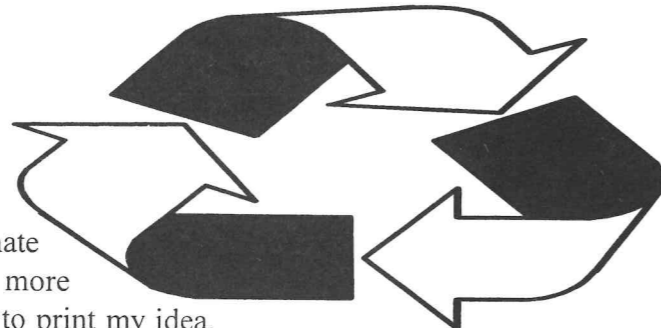
## FUNDRAISING



Christine was invited to accept a cheque for £290.00 which was collected by friends of Tom and Nora Corcoran, London.

Dear Editor

We are all aware that in this present climate funds for the MPS Society are becoming more difficult to raise. I would like to ask you to print my idea.



Over the past eighteen months I have talked many friends and colleagues into saving Alcan cans for me. I then take them to the Alcan Centre and obtain money for them. Over this period I have sent roughly £100 to the MPS Society. When you consider that this is raised by people's waste and does not take too much effort, maybe others would consider doing this.

I never go out without a handy carrier bag to collect any cans I find. My friend walks her dog and collects cans on her way. Another friend has talked her local 'Bingo Hall' into displaying Alcan bags and cartons for the cans to be bought whilst people are playing. She takes them home and I collect them, on average about once a month. Children also collect cans for us.

They all know about my 7 year old grandson, Steven who has Sanfilippo Disease. I have given out leaflets to help spread the word and hopefully to encourage others to become involved.

It takes so little time that I feel maybe people whose time is at a premium, might still be able to take up this idea.

Mrs I Wicks.  
(Steven Grandidge's Grandmother)

## FUNDRAISING

### → Wanted Air Miles →

→ The Society has important links with MPS Societies, affected families, doctors and scientists throughout the world. It is vital in keeping abreast of scientific and medical development as well as the management of MPS children around the world to be able to attend relevant conferences and meet with MPS families overseas. Occasionally we will also be called upon to offer 'know how' to families in countries where the expertise on Mucopolysaccharide is not as developed as in the UK.

Please send your airmiles to the MPS office and help the Society to maintain a high profile internationally. →



### Stamps and Foreign Coins

Please send me your stamps and foreign coins. Every year used stamps, whole stamp collections and foreign coins are sold to raise much needed funds for the Society. Please continue to help the Society by bringing any of these items to family days, conferences, management committee meetings or give the office a ring and they will try to arrange collection from someone in your area.

In 1995 several hundred pounds was raised in this way.

Alternatively you could send them to  
Ken and Pam Ballard  
15 Bengeworth Road  
Harrow Middlesex.



**REACT has range of equipment available**



**REACT has a range of equipment in stock which is available to children and Families**  
It includes an electric wheelchair, snugseat, car seat, symmetrikit chair, Plexiglas tray with trim, portable oxygen cylinder, kirton chair, hand driven trike, inflatable padded playpen with pump and pushchair.

**If you know of a child suffering from a potentially terminal illness who may benefit from any of the above please contact:**

**REACT** 73 Whitehall Park Road, Chiswick,  
London W4 3NB  
Tel: 0181 940 2575 

## FUNDRAISING

### DONATIONS

The Society is grateful to the following who made donations.

|                              |                               |
|------------------------------|-------------------------------|
| Mr Belton                    | Mrs Boscombe                  |
| Kalon Decorative Products    | Mrs T B Pidden                |
| J Mather                     | Refuge Assurance plc          |
| Haselmere Estates            | Mr Skene                      |
| Keith and Jackie Jones       | St Anne's Primary School      |
| Mr and Mrs Shaw              | Clydebridge Works             |
| Mr and Mrs Lynch             | Rodborough Tabernacle         |
| Andy and Jenny Hardy         | Genzyme Ltd.                  |
| Mrs A King                   | Mr and Mrs Hayward            |
| Mr and Mrs Short             | Vicky and Samantha Brockie    |
| Mr and Mrs Mayhew            | Clive and Jackie Chisling     |
| Mrs A Nurse                  | Mrs Johnson                   |
| Mrs B Cox                    | P C Brice                     |
| Vic and Sue Lowry            | Eddie and Linda Tailford      |
| Norweb                       | Securicor Charitable Trust    |
| St Machar's Church           | Willow Farm Trust             |
| Mr A Shaikh                  | Pukka Pies Ltd                |
| Lilly Industries             | Mrs L Creevy                  |
| Barclay's Bank (Northampton) | Mr R A Baker                  |
| M Goscombe                   | Marin and Caroline Garthwaite |
| Mangar International         | Mr and Mrs Headicar           |
| Jardine Insurance Services   | Mr and Mrs Clarridge          |
| Joan Adams                   | Rudolf Wolff                  |
| Barclay's Bank (Basingstoke) | Sappi Specialists             |
| Alan Marchbank               | Al Fayed Charitable Trust     |
| Tommi Saukkoriipi            | Scottish Amicable             |

Friends of Bishop Henderson Primary School  
 The Eleanor Hamilton Education Charitable Trust  
 North Avenue Toddler Group  
 Sir James Miller Edinburgh Trust  
 The N. Smith Charitable Settlement  
 Catholic Women's League, Wells

## FUNDRAISING

### FUNDRAISING EVENTS

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

Penryn Junior School - Mufti Day

Keith and Angela Thompson, Birkenhead - Pub Fundraising on behalf of Holly Thompson

Sylvia Blackburn, Nantwich - Easter Raffle

Maureen Lord, Saffron Walden - Lent Lunch

Lansdowne County Middle School, High Wycombe - Mufti Day

Martin and Maureen Taylor, Yorkshire - Leversedge Half Marathon

Mrs Ferguson, Terry School of Dance, Bridge of Weir - "Evening of Dance"

Tracey Long, Bristol - Meet-a Mum- Evening

Kate Richardson, Northampton - Product sales at work

Ushers of Trowbridge - Company Christmas Raffle

Karen Wheeler and Company, Old Woking - Parachute Jump

Wells Cathedral School - "One World Day Lunch"

Jackie Chisling, Trowbridge - Tesco collection

Danetre School, Daventry - Mufti Day

Thelma Barton - Jumble Sale      Fer Pidden, Westbury - Sale of Jewellery

London Heathrow Bristol Bike Ride

Mr and Mrs Armstrong, Malta - Marathon in Malta

St Albans Church, Hull - Musical Concert

Mrs McSherry, Ayrshire - Oriflame Make-up Evening

Malmesbury Primary School - Mufti Day

Mr and Mrs Holden, Haddenham - Maypole Dancing

Aylesbury Vale Guides - Carol Service

Mrs Rush, Tunbridge Wells - Sale of Musical Tapes

Mrs Topping, Wigan - "Guess the weight of my baby?"

Nicola Longdon/Steve and Nicola Gee, Cambridgeshire - Food for Friends Cookbook

Mrs Brooks-Daw, Taunton - Video of Ballet "Nutcracker" sales

St Mary's School, Bideford - Cake Stalls and collections

Peter and Sue Stuart, Borehamwood - Jessica Rabbit Fund

Judy Holroyd, Bristol - London Marathon

St Martins De Porres School, Luton - Mufti Day

Mr and Mrs Westland, Reading - Folk Music Garden Party

Mr Frazer, Cheadle Holme - London Marathon

Jane Shrimpton, Powys - London Marathon

BACCA, Bath - Rag Week

Mr and Mrs Cocoran, Ealing - Pub Night

Alan and Fiona Byrne, Glasgow - Dance and Raffle

E.J. Thompson, Somerset - Auction

Chiltern Trinity School, Somerset - Auction

Mary Tubb, Isle of Wight - Talk & Poem Reading

We would like a special thanks to go to all the people who participated in the  
New Severn Bridge Charity Walk organised by Chris and Julie Kembrey.



## FUNDRAISING

### CHARITY BOXES

|                                    |                              |                            |
|------------------------------------|------------------------------|----------------------------|
| Pat Lomas, Nottinghamshire         | Fox & Hounds, Batley         | Holly Nowell, Wells        |
| Mary and Brian Lovick, Oxfordshire |                              | Dalsetter Rise Post Office |
| T.W. Coulter, Antrim               | Mrs Wicks and Friends, Leeds | Mrs Todd, Glasgow          |

### DONATIONS IN MEMORY

The Society is grateful to the friends and relatives of:

|                                                |                |
|------------------------------------------------|----------------|
| Rhianneth Wheeler                              | Katie Headland |
| Tom Flanagan (Chris Isaac's Grandfather)       | Thomas Fuzzard |
| Miss E Bentley (Dr Bryn Neal's Aunt)           | Irene Fraser   |
| Mrs Gladys Dickson (Shane's Great-Grandmother) | Abigail Pullin |

### SPECIAL OCCASIONS

The Society would like to thank the people who gave donations on the following special occasions.

The 80th Birthday of Mr Mervyn Stroud - Jenny Hardy's Dad.

### STAMPS

|                                      |                     |
|--------------------------------------|---------------------|
| Croyden Vehicle Registration Office  | Mr and Mrs Tiley    |
| Mrs Aylesbury                        | Ken and Pam Ballard |
| Mrs I Wicks (Also Alcan Collections) | Lynne Grandidge     |
|                                      | Patricia Stevens    |

## AREA SUPPORT FAMILIES

|                                                                                                                                                              |                   |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| Robert and Caroline Fisher<br>The Horrells, Great Samford, Saffron Walden, Essex CB10 2 RL                                                                   | Tel: 01799 586631 |
| Mary and Robin Gooch<br>Highbank House, Swifehill, Broadoak, Nr Heathfield, East Sussex TW21 8XG                                                             | Tel: 01435 883329 |
| Bill and Sylvia Blackburn<br>11 Beatty Road, Nantwich, Cheshire CW5 5JP                                                                                      | Tel: 01270 626809 |
| Tony and Shirley Eyre<br>7 Elmer Close, Malmesbury, Wiltshire SN16 9UE                                                                                       | Tel: 01666 825215 |
| Ann and Michael Kilvert<br>Windy Way, Nantoer, Newtown, Powys SY16 1HH                                                                                       | Tel: 01686 624387 |
| <i>Support Families for the West Midlands</i><br>Sue and Jeffrey Hodgetts<br>6 Godolphin, Tamworth, Staffordshire B79 7UF                                    | Tel: 01827 56363  |
| Zerina and Sajjad Shah<br>37 Lowe Street, Wolverhampton, West Midlands                                                                                       | Tel: 01902 656147 |
| <i>Support Families for the Yorkshire and Humberside</i><br>David and Monica Briggs<br>7 Humber Street Retford, Nottinghamshire DN22 6LZ                     | Tel: 01777 700046 |
| Barbara and Trevor Rollinson<br>43 Crosby Avenue, Scunthorpe, Humberside                                                                                     | Tel: 01720 864115 |
| <i>Support Families for the North West of England</i><br>Martine and John Brennan.<br>105 Barley Cop Lane, Lancaster, Lancashire LA1 2PP                     | Tel: 01524 382164 |
| Joanne and Gary Adshead<br>10 Church Lane, West Houghton, Nr. Bolton, Gt Manchester BL5 3PP                                                                  | Tel: 01942 810109 |
| <i>Support Families for the North East of England</i><br>John and Barbara Arrowsmith<br>11 Penfold Close, Fairways Estate, Benton, Newcastle on Tyne NE7 7UQ | Tel: 0191 2921234 |
| Ann and Ron Thompson<br>7 Sunningdale Green, Darlington, County Durham DL1 3SB                                                                               | Tel: 01325 489920 |
| <i>Contact for Scottish Families</i><br>Alan and Fiona Byrne<br>3 Jedburgh Avenue, Rutherglen, Glasgow G7 3EN                                                | Tel: 0141 5695376 |
| Cath and Jim McLean<br>5 Tern Avenue, Inverness, Highland IV2 3YN                                                                                            | Tel: 01463 224615 |
| <i>Northern Ireland Co-ordinating Committee</i><br>Kieran Houston (Chairman)<br>15 Barrack Street, Strabane, County Tyrone BT82 8HB                          | Tel: 01504 884168 |
| Margaret Kearney (Secretary)<br>12 Coleraine Road, Ballycastle, County Antrim BT54 6DU                                                                       | Tel: 0126 5762073 |