

**NEWSLETTER**

**SPRING 1989**

**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 of MPS disorders in Great Britain and, where they are children, to their immediate families. It is also distributed around the world on subscription. Copies are 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 £5 in Great Britain and £10 Sterling elsewhere.



## The Society for Mucopolysaccharide Diseases

30 Westwood Drive, Little Chalfont, Buckinghamshire.  
Telephone: (024 04) 2789

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 the mucopolysaccharide and related diseases. It is a registered charity, which is entirely supported by voluntary 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. The Society 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, the United States, Canada, South Africa and Australia.

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".**

THOUGHTS OF CHAIRMAN ALF

In the last newsletter Christine welcomed me as the new Chairman of the Management Committee. For those who do not know us, we are what you might call original members of the Society and have been at all the conferences starting with Birmingham 1983. "Us" includes Judy my wife and our daughter Susan, and used to include our son Michael who had Hunter disease. He was at both the Birmingham and the Harrogate conferences but died in 1985 shortly before the first conference at Heathrow.

At this moment I just want to emphasise one thing, and that is that this is **Your Society**. If you have any views or ideas on what directions the Society should take please let the Committee know. Among our members we have people with many different skills - again if you feel your particular expertise can be of use to the Society please do let us know. Drop me a line or give me a call!

**Alf G. King**

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**DATES FOR YOUR DIARY**

- 23rd April 1989 London Marathon. 4 MPS Runners. Who are you sponsoring?
- 1st June 1989 Deadline for Summer Newsletter.
- 3rd June 1989 Northern Ireland Family Day. (contact Margaret Kearney)
- 16th July 1989 Dr Garrow's Garden Party (see notice)
- 5th August 1989 MPS Group Holiday (see notice)
- 22nd September 1989 Annual Conference: Stoke on Trent.
- 31st August 1990 Second International MPS Conference. Manchester

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**BIRTH**

**Raymond and Jacqueline Baird**, of Halifax, Yorkshire, a son **Stephen Charles** born 31st January 1989, weighing 6lbs 9oz. A brother for **Jonathan**.

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**NEW FAMILY**

**Danny and Jackie Reade** from Cheshunt, Hertfordshire, whose son **Christopher** is suffering from Hunter disease.

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**DEATHS**

**Anthony Bayliss** aged 3 from Fazakerley, Liverpool, who had Morquio disease, died unexpectedly on the 27th February 1989 after an operation. Our sympathies to Julie his mother, Diane and Bill his grandparents and to the rest of the Bayliss family.

**Gareth Carden-Edwards** from Colchester, Essex, who suffered from Hunter disease, died on the 10th of March, aged 7 years. Our sympathies to his mother Hilary and to all his family.

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**Toni Bramford**, who died on the 13th of December 1988 was eleven years and ten months and not as stated in the Winter Newsletter. She suffered from Sanfilippo disease. Our apologies to her family for the error.

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**FAMILY CONFERENCE AND INTERNATIONAL SYMPOSIUM  
ON MUCOPOLYSACCHARIDOSES AND MUCOLIPIDOSES**

**31 AUGUST - 3 SEPTEMBER 1990**

**UNIVERSITY OF MANCHESTER, INSTITUTE OF SCIENCE AND TECHNOLOGY**

As some of you will know the Society is in the early stages of making arrangements for our 1990 Conference at UMIST. We are hoping that this event will put the Society firmly on the map by bringing together MPS families and interested professionals from all over the world. Nevertheless in the tradition of past MPS Family Conferences we intend to make this event as family orientated as possible whilst at the same time hosting a major Symposium for interested professionals.

The Conference and catering facilities are booked and we will be offering two grades of accommodation ie. Family Units within the University or Family Rooms at the Chandos and Britannia Hotels located very nearby. Parents are invited to join the professionals on the Saturday at their meeting to hear presentations on the Clinical Management of these diseases including coping on a day to day level. We are hoping that new initiatives will come from these papers and I know it will be interesting to learn how attitudes to the management of our children varies from country to country.

On the Sunday we are organising a Parent Conference whilst the scientists are left to unscramble the genetical and biochemical aspects of MPS and ML.

The Conference will close at midday on Monday following discussions on the treatment of MPS children. We anticipate the papers will include Bone Marrow Transplant, Enzyme Replacement and Orthopaedic Procedures. Parents will be welcome to observe during this session.

Throughout special attention will be given to our children, MPS, ML and brothers and sisters, and a full programme of activities and creche will be organised under the careful eye of our trained volunteers.

The evening activities will provide families and professionals alike with ample opportunity to meet in an informal and relaxed atmosphere whilst safe in the knowledge that their children are being safely cared for.

Apart from wishing to keep everyone informed of our plans I would like to ask your help in raising the funds needed to subsidise the family accommodation and board, and the childrens' activities. As we have in the past, we intend to subsidise the costs so as to enable as many families as possible to afford to come. Because we are expecting many more families than usual to attend we need to double our conference budget for 1990 and hope that much of this money will come from Companies and industry. We have already made some approaches in this direction and £7,000 has already been pledged. Nevertheless to be able to proceed with comfort we need another £20,000. I would be very grateful if at least 20 mums or dads who work for companies who make charitable donations (most do) would let me know for whom they work so that supported by the employee, the Society can make the appropriate approach. If 20 companies each gave £1,000 we would be home and dry.

Just send your supporting letter stating the benefits and importance to you as a family that this event should take place and we will do the rest. If you would like to know more please contact me on 02404 2789 or leave a message with Linda or the answer machine and I will call you back.

Looking forward to hearing from you.

Christine

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#### RESPIRE CARE PROJECT

On behalf of Pauline Pruce, who is coordinating this research, I would like to thank all the families who so kindly took the time to sit down and complete what undoubtedly was a time consuming questionnaire. I am sure that you will be pleased to learn that 77 families have responded and we are hoping that those of you who haven't as yet will as soon as possible. It maybe that you felt some of the sections of the questionnaire were not relevant. We appreciate this but collectively your answers, or non answers as the case may be will prove most useful.

Already the preliminary data is showing strong trends, not least the need for respite care comparable to the standards set by Helen House, Martin House and Acorns, at a more local level. Many families have stated that they do not use respite care locally because it does not suit the needs of their MPS child/children. Many of your answers could have been predicted but the value of this study is that it provides the Society with data and evidence that many local authorities may not be giving sufficient thought to the needs not just of MPS families but those of thousands of others families where a child is suffering from an often rare and degenerative condition.

It isn't too late to return the questionnaire. If you need a replacement or failed to receive the original please do let me know. COPIES OF THE FINISHED REPORT WILL BE AVAILABLE TO PARTICIPATING FAMILIES and the findings published in a future newsletter.

Christine Lavery, 30 Westwood Drive, Little Chalfont, Bucks HP6 6RJ  
Tel: 02404 2789

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#### FAMOUS MUG

We have two limited edition plates and one mug commemorating one million tons of coal being extracted from Bevercotes Colliery. If anyone knows someone who would like to make an offer for one or all of these items please call me.

Ron Snack

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MANCHESTER PROJECT  
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Last August, Dr Ed Wraith took up his post as a Consultant Paediatrician at the Willink Biochemical and Genetics Unit at the Royal Manchester Children's Hospital. This post is funded entirely by the Society for the first year and will be partially funded for the following two years until it is finally taken over by the District Health Authority. We have received generous donations from trusts totalling around £10,000 to date. Many families are working very hard to raise funds for the project but two in particular deserve a special mention.

Gemma Rollinson's parents are organising a sponsored cycle ride in June from St. Peter's Square in Rome to Scunthorpe. They are hoping eventually to present the Society with a cheque for £10,000. Wayne and Karen Hoather from Manchester, whose two small sons suffer from Hunter disease, have handed over substantial sums to the Society, including a number of Covenants. Keep up the good work, everyone; we may be not far off this year's total but we would all, including Dr. Wraith, feel more confident if we had next year's amount in hand!

Although this is called the Manchester Project, Dr. Wraith is very happy to see families from any part of the country whose GP or paediatrician wishes to refer them. Dr. Wraith tries to see MPS families in a special Friday clinic which gives them a chance to meet each other. Mary Gardiner aims to be there when she can to offer her support and to provide the sandwiches.

#### Note from Mary Gardiner

There have been a steady stream of new and familiar faces over the past few months at the Friday MPS clinic. For my part, it has been a pleasure to meet and chat with so many of you. For those who attended the clinic when I was not there, I'll catch you next time!

I know from these meetings how those of you who have seen Dr Wraith, especially those who came for the first time; benefitted from seeing him. Dr. Wraith is naturally charming and understanding, but what really matters is that he knows MPS and is committed to improving the care of our children.

Families have travelled from as far away as Norfolk, Somerset, Yorkshire and Ireland. I am beginning to understand the geography of Britain, something that has evaded me for the past thirty years! The things we learn through the MPS Society!

Mary Gardiner

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**AREA FAMILY PROFILE**  
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**Sean and Pauline Mahon.**

**(Yorkshire, Lincolnshire, Humberside and Nottinghamshire)**

We are **Sean and Pauline Mahon** and we live in Sheffield which is fairly central to the area we cover. Sean is a chartered accountant for a national and worldwide firm of accountants. I keep myself busy with the house, children, some voluntary work at a special school, MPS and various other activities.

We have three children. **Sean** is seventeen years old and doing A levels, **Victoria** is sixteen and doing GCSE and **Siobhan** is thirteen and a half. Our fourth child **Anne-Marie** had Hurler disease and died aged two years two months following a bone marrow transplant.

We learnt a lot about the Society from around the time of Anne-Marie's diagnosis in 1984 but didn't meet anyone until the 1985 September conference just three months before she died. We all know what a tremendous shock it is to find that your much loved child has MPS but we found that being with people who understood and experienced the feeling we were going through was a great comfort and support, even though it didn't lessen the pain and the grief.

These children have made such an impact on all of our lives and when I'm flagging I only have to think of Anne-Marie and that helps me pick myself up and get on with doing something good and worthwhile to help all the other children who are still suffering with MPS.

So far we've only had one Area get together since we took over as Area Family in 1987 but I hope 1989 will be different. Quite a few people in the Area seem to be doing their own particular fund raising; it would be nice if a few families could get together and find a way of enjoying themselves and raising some money together.

If any family would like us to visit them or would like to chat on the phone, please contact me, I'd be delighted to hear from you.

**Pauline and Sean Mahon**

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In November or December this year we are hoping to hold a giant Tombola in Milton Keynes city centre. If anyone has any items they think would be suitable please bring them to the conference or call in to see Linda and I at Milton Keynes. If you would like to come along and help please call me.

**Ron Snack**

# Brave Chris strikes out for glory

**BONE disease boy Chris Isaac has learnt to swim — an astonishing achievement for the Fiddington youngster who 18 months ago was languishing in a surgeon's steel cage.**

Brave Chris, who suffers from a rare disease which has stopped him growing, swam a length of Burnham pool after receiving special help from dedicated members of Bridgewater Swimming Club.

Club secretary Yvonne Lock said: "We were absolutely amazed when he did so well. It was incredible. A huge cheer went up when he completed the length."

The eight-year-old had to beat a number of hurdles before he could throw away his water wings. The biggest problem was the pressure on his lungs which made breathing very difficult.

Chris was given individual attention by the club for his first 14 weeks with them. "Eventually after many weeks he did a few strokes to the edge of the pool and about three weeks ago he did a width," said Mrs Lock.

Last week he was taken to the deep end, and, with experienced swimmer David Lock at his side, struck out for glory. A weak left shoulder meant Chris in fact swam diagonally across the pool.

adding to the distance — and his achievement.

Proud mum Pat said: "It's the first-time the club has taken on somebody so handicapped, and we are very grateful to them."

Mrs Lock added: "Chris needs to be handled very gently, but he's proved himself. His beaming smile showed how pleased he was with himself. It shows what can be achieved with care and attention."

● The Mercury and Gazette featured Chris in his "cage of hope" in August 1987. He was imprisoned in the device to prevent movement for four months after surgeons performed a delicate bone transplant operation. The surgery was successful, but Chris will never be more than three feet tall.



● Bone disease youngster Chris Isaac is raised aloft by Bridgewater Swimming Club swimmers Louise Spooner and David Lock after striking out for glory at Burnham Swimming Pool. Full story Page 20.



**Sean and**

**Pauline**

**Area Family  
 Training Day  
 1988**

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**PETER BATTLES ON AGAINST THE ODDS**  
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On reflection Peter's problems didn't become obvious until it was time for him to start at the local primary school. In some ways Peter had been a quick learner, knowing his colours and chatting twenty to the dozen. Even so it worried me that I couldn't teach Peter to write his name and that he failed to respond to simple commands. I used to take him to coffee mornings. The other children would stop touching the ornaments when told to. Not Peter, he would just carry on touching and so earned the name of "fingers Benbow".

The time it really dawned on me that all was not well with Peter was when we were trying to cross the road to the cinema. Peter was nearly five and we were going to see "Chitty Chitty Bang Bang" when he threw an uncontrollable tantrum. We had become accustomed to Peter's difficult behaviour but this was quite the worst we had encountered so far. From then on Peter's behaviour continued to deteriorate. By this time our younger son Martin was two and a half years old. Although Peter wanted to help him, if you gave him an instruction to fetch something he was unable to carry it out.

Peter started at ordinary school, but teachers found his unpredictable behaviour and lack of self discipline and concentration difficult to handle. Peter then changed to an assessment centre but escaped on a child's bike when the baker left the gate open. The next morning I was telephoned to come and collect him. Peter was expelled from school at the grand age of six!

Good news comes out of bad and Peter was offered a place at Neston Autistic Unit. There were only two children per teacher and only seven children at the centre and it was secure and safe for Peter.

Still no one had offered any solution to understanding Peter's behaviour. He was repeating the same questions over and over again. He hated a change in routine as much as he hated hospitals. He insisted that our route to the shops never differed and watched Arrowe Park Hospital being built proclaiming "No hospital, no hospital".

By the time Peter was seven years old we were desperate for answers. Peter's balance was deteriorating, but the most worrying problem was his diarrhea. Often nine times a day. At about this time we took Peter to see Dr Vernon Jones at St Catherine's Hospital. Four days after Peter's tenth birthday we were told of Peter's diagnosis. **Sanfillipo Disease.** Initially there was a sense of relief that at last Peter had a label. Shock followed when we were told that children with this condition don't usually live beyond the age of ten years. (This information was inaccurate: Editor). Following the diagnosis Peter went to Woodvale, a unit for autistic children and this meets his needs very well.

When it was time for Peter to go to Adult Training Centre he had calmed down considerably and the worry of him escaping and coming to harm subsided. Now, at twenty four, Peter still goes daily to the ATC where he is in special care. It was only fourteen months ago that we surrendered to incontinence pads and even so we still take him to the toilet regularly; sometimes we catch him especially if we give him a magesine with lots of smiling faces. Peter likes this and if he laughs we seem to have more success! We have recently had a disabled toilet and walk in shower installed which certainly makes life easier. Peter can only manage the stairs if two adults lift him and he can only get down using two cushions under his bottom while furiously hitting me! Despite Peter's limitations he gets a lot of pleasure from the television, especially "Pippin Fort", and "Soldier Boys". He can still manage to feed himself his cornflakes with a spoon.

When Peter was eighteen he suffered two strokes down the left side but has since completely recovered from these. One thing we put down to Peter's longer than usual life expectancy is that he has never had a convulsion (fit) and generally keeps well.

We have now come a long way from those early days. Peter's brother Martin is 21 now, a sales executive for Nissan and engaged to be married. From time to time we get to go out as a couple. Besides Martin and his fiance we are able to depend on Wirral Crossroads Scheme to help with caring for Peter in our own home. They are marvellous with him.

There have been very bad times, like the occasion when the Consultant wanted Peter admitted to Greaves Hall (a psychiatric hospital) but that was a red rag to a bull and made us more determined to care for Peter within the family.

Peter has brought us an awful lot of joy and we don't know what we would have done without him. Even our friends think the world of him. If there are regrets, perhaps it is the wish that we had more time to spend with Martin when he was younger when perhaps we concentrated too hard on getting through the day with Peter.

**Sheila and Ken Benbow, as told to Christine Lavery.**

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**ADVANCE NOTICE!!!**

The Society has secured a slot for a radio appeal.  
Sunday 17th September, Radio 4, 8.50am  
"This week's good cause".

## THE RED-HAIRED PRINCESS AND THE GENTLE GIANT

Have you noticed how fairy tales always end, "... and they lived happily ever after." Of course as a child I believed and expected such an ending, without question. But as a cynical 45 year old I think this kind of story ending is a cop-out. If there are no worries and concerns to mar domestic bliss, how can you measure the happy times and moments?

Whether in a fairy tale or in real life a red-head and a gentle giant sound a very powerful combination and you might expect that anywhere they went the effects would be immediately obvious, and noisy. Dan does of course have a booming laugh. (Yes, if you are a regular attendee of MPS events you will know immediately that I am writing about Sue and Dan Butler). There the similarity ends. It has puzzled me for the last six years how the Butlers can do so much for the Society in such an unassuming way. I can't think of many important Society milestones where their contribution has not only been significant but often essential to the successful outcome to a major problem or project. Yet their touch has always been light and discreet. They surface when needed and then merge into the background.

Sue has been a member of the Management Committee from the earliest days. You will know her for a variety of roles, including Sales Coordinator and Overseas Liaison. Sue has also arranged at least one major fundraising event each year, including some very good fun themed-fancy dress parties/dances in their local village in Chinnor, Buckinghamshire.

Dan is the proprietor of BBW Transport, a small (at present) go anywhere, do anything freight company. We have used BBW often, to go anywhere and do anything, and although the Society offers Dan payment we are not very successful. It is not that we wish to exploit him for free (after all he has a business to run). Just that Dan and his staff really know about MPS. His compassion, and humour and his reliability are so reassuring. We want the best for our families. Dan and Sue deliver.

The Butlers and their specialist business experience have got us quickly out of difficulty, eg taking care of import documentation for special halos (Morquio treatment) from the United States, a large consignment of Jersey carnations for Lady Mountbatten's event in Tenterden. Our conferences over the last four years have been much improved by Dan and his brother Paul, who have engineered the audio-visual and discotheque.

Sue and Dan did once have a starring role when they represented the Society at the first Canadian Conference in Winnipeg in 1986. There are other stories, some of them sad, others happy and a few hair raising, that I am unable to write about because the details are confidential to one or two people on the Management Committee, to the Butlers and to the families concerned.

Above all the Butlers are important to The Society for themselves as an MPS family. Alexander, his Mum and Dad and Lucinda and Grand Mum are a particular inspiration to Hunter families and the rest of us as well. At 15 Alex is challenging the world and confounding the usual run of Hunter prognosis. Yet Alex and his family seem to find so much

time to shoulder and solve others' problems, and in a very cheerful way.

Grey clouds come and go so I do hope Sue and Dan are having their fair share of happiness-ever-after too. They deserve it, and more.

Robin Lavery

## Incontinence supplies inadequate

Parents of children who are incontinent are being denied adequate provision, according to the Association of Continence Advisers.

"Parents are often left uninformed of what facilities they are entitled to, and the Government has been very woolly about the regulations," said Helen White, a continence adviser in north east England.

On average, 70 children per health area are incontinent, but standards of provision for them differ wildly between regions.

In Bloomsbury, North London, there are four continence advisers running clinics and assessments for children.

In neighbouring Hampstead, however, there is only one adviser who sees no patients and deals mainly with stores and supplies.

The Department of Health maintains that children who are registered disabled and are in full-time education are entitled to an adequate supply of equipment from their local health service.

But Helen White stresses that this supply is infrequent and inadequate.

"There has been confusion between the health authority's power to provide equipment, and parents' entitlement to it."

"It's often a matter of budget," said Dorothy Mandelstam, chairman of the Association, "and some health authorities give incontinence a different priority."



## HOUSE OF COMMONS

### Extending Mobility Allowance

An amendment submitted by the Mobility Allowance Campaign (a group of voluntary organisations) was moved by John Battle (Lab) at the committee stage of the Social Security Bill on 19 January.

It aimed to extend mobility allowance to people with a mental handicap whose behaviour is unpredictable and to people who are both deaf and blind.

Peter Thurnham (Con), supporting the amendment, said that in the light of cases produced by MENCAP and The Spastics Society, extra provision should be found to help people who have real problems in qualifying for the allowance.

Minister for Social Security Nicholas Scott was sympathetic to the cause, but said it was complex. It would be best to "await the results of the OPCS survey and consider the matter comprehensively against the background of other changes to benefits that we might make at that stage".

The amendment was withdrawn.

If any families are having difficulties obtaining adequate and suitable supplies of nappies please let us know.

If your child is mentally handicapped due to MPS disease and you are having difficulty in getting Mobility Allowance, please let us know.

*Children with Special Educational Needs* is the first detailed explanation of the new legislation for children with learning difficulties in Northern Ireland. Published by the Northern Ireland Council on Disability, the 72-page book has a clear style and explains the legal changes, assessment procedures, statement contents and appeals advice, plus questions and answers for parents and sample letters. £1.50 + 52p p&p from NICD, 2 Annadale Avenue, Belfast BT7 3JR.



A quilt to grace any child's bedroom. From left Dominique Brooks-Daw, Mrs Pat Tozer, Mrs Irene Beech, Mrs Margaret Sunter, Mrs Judy Brooks-Daw, Mrs Jenny Wheaton, Mrs Michelle Brooks-Daw with baby Antoinette on her lap.

# FUND-RAISING QUILT

SOUTH Devon's Moor to Shore Patchwork and Quilting Group has made a fine applique quilt to raise funds for research into degenerative diseases.

The quilt is to be donated to the Society for Mucopolysaccharide Diseases who will put it in a national raffle.

Last week it was presented to Mr and Mrs David Brooks-Daw, of Taunton, and will be taken to the MPS Parent Conference in London.

Mr and Mrs David Brooks-Daw's daughter, Alevique, died in October 1986, aged ten, of Hurlers Syndrome, and the quilt is in her memory.

It is intended it will travel round England, Scotland and Wales to area support families, to

aid the sale of raffle tickets. Moor to Shore hopes it will be possible for the quilt to return to Newton Abbot where it can be shown in an exhibition of quilts by members of the

Quilters' Guild. About 300 hours went into the making of the quilt which began in May this year. It was made by Mesdames Judy Brooks-Saw, Mary Pearson, Mil-

dred Marchington, Irene Beech, Pat Tozer, Elizabeth Hawkins, Ceciley Coates, Margaret Sunter, Sue Edmunds, Jenny Wheaton and Barbara Paul.

Any one wishing to make a donation to the Society for Mucopolysaccharide Diseases should send it to the society at 30 Westwood Drive, Little Chalfont, Bucks.

The patchwork quilt which was displayed at the annual conference in September is to be raffled in aid of MPS. The draw will take place in September 1989 at the next conference. The quilt has been presented to the Society by the "Moor to Shore Patchwork Quilting Group" of South Devon.

Anyone can help promote the draw by arranging with local stores to sell tickets on their premises. (Sainsbury's can be very profitable on a Saturday!) If you would like to display the quilt please let me know the dates you have in mind and I can have the quilt forwarded to you. Please write or phone me if you think you can sell some tickets.

David Brooks-Daw, St Mary's Lodge, Wellington Rd. Taunton, Somerset TA1 5AS Ph 0823 74661

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MARK SIMPSON

Dear Friends,

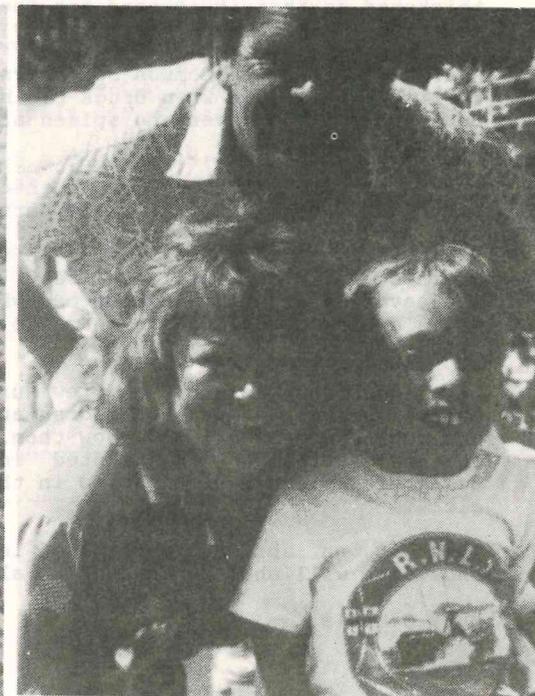
Mark will be nine years old in July. He suffers from **Morquio** disease. He attends a special school, Northfield, which provides transport to and from school. Mark loves playing football but soon gets tired. He hates school holidays as he never sees any of his friends because they live all over York.

He spends all day and most of the night playing with his Lego and he would love to go to Legoland. He also loves playing on the computer and also very much enjoys doing DIY with his Dad. Mark has an older sister Clare who is fifteen years old and is studying to be a nursery nurse for disabled children. As a back up she is doing a computer studies course. In her free time (when she gets it!) Clare sings in the local Church Choir and is a member of a Christian Youth Group.

I work part time in a local supermarket. I haven't much time for any hobbies but I enjoy gardening and helping Mark with his Lego.

With best wishes from **Barry, Clare, Mark and Ruth Simpson.**  
14 Oak Tree Lane, Haxby, Yorks.

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JEMMA'S DIARY (Part 6)  
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7th November 1986

Annabel Edwards (Speech Therapist) who is expecting a baby in January came for the last time today and was delighted with Jemma's progress. I fall about every time Jemma answers "All right", when asked to do something, and when I listen to her giving Colin a verbal clip round the ear while playing in the Wendy house. "Naughty boy!" and "Stop it!", who does she take after? Its now the place names that need to be understood, "Next to", or "Beside", "Under", "On", "Behind", "In front". It is a bit hit and miss at the moment, even when stress is put on the vowels, but it is coming. She is also matching colours well but when asked to choose a named colour sometimes gets it right, sometimes wrong. I don't usually teach colours but she and Ashley seemed so close that for the next week we shall be working on RED. Any spare red items do send in. I'll send them back again later. Sorry about the dirty skirt but Jemma had a session of trying out various potties and little toilets and en route did a poo and sat on her skirt. She is very good now and tells us each time.

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12th November 1986

Sarah to Julia.

Jemma has been very good over the past few weeks using the toilet at home. In the mornings she sits on the loo seat before getting dressed. I usually ask her to poo and wee and on Monday she replied "I'll try", and did! I had to leave the bathroom it was so funny. I didn't want to upset her by laughing at her, she was so serious.

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28th November 1986

The dentist looked at Jemma's teeth and said they were fine. She has all her baby ones and may be ready to lose her front ones soon. Jemma has been marvellous this week, all her social skills are just fine. She's been given an impressive list of jobs because she is so capable. Her self help skills are coming along fine too, its just her little shape that gets in the way sometimes.

\*\*\*\*\*  
FUNDRAISING  
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Flag Days

We have held a flag day in Milton Keynes for the last three years and in 1988 we collected over £550, a good deal of money for very little work. All you need is permission from the local council by way of a license, a few helpful friends and some collecting tins. If anyone is interested in organising a flag day please get in touch and I will try to help in any way I can. Linda and I have found that MPS posters are a great help for flag days.

Ron Snack

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JEMMA'S DIARY (Part 7)  
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January 22nd 1987

Our first week back to routine and everyone breathes a sigh of relief. Could write a book about Jemma this week. She has been marking the register. She sits with a pencil in her hand and asks where is .....? Then she asks them if they want dinner. She gets the names in the same order as the register, hows that for memory? Then she writes a squiggle in the square I point out beside each child's name. As she is getting a bit precious about HER jobs I have asked each child to take a turn returning the register to Pat Wheeler. Jemma has learned to part with it but always give her own instructions. When it was her turn I hope you noticed Pat gave Jemma her own wage slip. I've also tested Jemma's comprehension and listening skills with a lot of dollies, teddies, a cup, bed, spoon, dolls clothes etc. Without me signing Jemma picks up the right things and performed the correct tasks without me having to accentuate any part of my sentence. Today we had PE and a real increase in confidence. She needed no coaxing, watched others and tried it out for herself. She asked me to hold her hand as she walked along an upside down form along a piece of wood no wider than one of her little feet. A good test of balance. She tried swinging from a ladder and lifted her feet an inch from the ground. She was highly amused with crawling through a tunnel.

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February 10th 1987

Life is all one 'allright' or 'ok' from Jemma. Everyone wishes she was in their class and to be quite honest she is so good at keeping everyone on their toes in our class. I shall soon be out of a job.

Today for cooking she collected all the aprons together and brought the same one each child has for dinner. Then she helped me get the bowls, scales, patty tins and spoons with baking cases, all good fine finger work, and had time to tell Ashley he was naughty because he squashed his. Next she weighed, beat, stirred, and told Ashley to get his fingers out of the mixture. Then she gave instructions to Nazim and had time to tell Ian not to scatter the flour.

Apologies, we all ate rather a lot of raisins waiting for the cake to cook - while Jemma was telling Ian off for pinching her raisins.

Jemma also helped me to wipe up all the bowls and put everything back. She was so good it was tempting to let her do her little woman bit but work has to be shared out so I let her chat while the boys did a bit of tidying up. Women's Lib in the nursery.





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Once again it is time to think of the Summer holidays, and the TV is showing far away places in the sun.

Well, there are still five places left on the MPS Group Holiday at Filey, Near Scarborough, Yorkshire, in August. We cannot guarantee the weather, but if last year is anything to go by, we can guarantee plenty of sunshine of the "human kind".

As you will have seen from the form sent out with the last newsletter, we have chosen one of the Haven holiday parks again. It really offers a great choice in activities yet provides scope for us to organise get-togethers like barbeques and days out etc. The site is mature and the staff are helpful and kind.

The MPS holiday was first thought of in 1983/84. The idea was to bring families together to share each others company for a short time. It provides an opportunity for brothers and sisters of MPS children to make friends with each other and to enjoy being part of a group who understand and care.

The holiday is for everyone regardless of income or whether your MPS child is with you or not. As a bereaved family we have enjoyed being with all the parents and the children on these holidays and in many ways it has given us a lot of help.

If you feel your family would like to join in such a holiday, please return the form to me as soon as possible to secure one of the remaining places. Please note that the holiday is self catering.

Mary Gardiner  
Holiday Organiser

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**DR GARROW'S GARDEN PARTY**

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16th July 1989

12.00 noon for Buffet lunch

Roughwood Farmhouse, Roughwood Lane,

Chalfont St Giles, Buckinghamshire

We do hope that we will see as many families and extended families as possible at our Grand Garden Fayre. We have hired a marquee for the day and there will be plenty for the children to do. The grounds are extensive and on a fine day the swimming pool is a big success, so dont forget your costumes! The Bucks Advertiser is loaning us a giant bouncy castle and there will also be a magic show, donkey rides and sidestalls.

If you plan to bring your own stall, want to help in any way, or just relax to the sound of the Misbourne Orchestra and enjoy a leisurely day out in the countryside, (only two miles from Junction 17 or 18 on the M25), then a warm welcome awaits you.

Do let us know if you plan to come, and a map and programme will be enclosed with the Summer Newsletter.

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**GRANDPARENT CONTACT**

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Diane Bayliss the Society's Northern grandparent contact, has recently suffered the devastating loss of her grandchild Anthony. Anthony who was three years old had Morquio disease and had just undergone surgery to correct a defect in his cervical spine. Although the surgery itself seemed to have gone well something went wrong afterwards and Anthony died three days later in the arms of Diane and his mother Julie. There is to be an inquest and it is hoped that any lessons learned from Anthony's tragic death will be used to make the operation safer for others.

I know that everyone who has got to know Diane and her family since they joined the Society will share their sorrow. I am sure that Diane would appreciate letters from the grandparent contacts and I know you will understand that she may not be able to respond just yet.

Mary O'Toole

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# Brave fight by parents of the doomed toddler

By Heather Bennett

**HEARTBROKEN** parents Alison and Nick Pullin are coming to terms with a terrible wasting disease that is killing their young daughter by raising money for research.

Abigail, aged five, was a normal baby, just a little light, weighing just six pounds.

She was a cute toddler with a shock of unusual coarse bright blonde hair, and chubby face — but these proved to be early symptoms of the disease which will soon claim her life.

## Incurable

A pre-school check revealed a few learning problems, and earlier this year the Pullins, of Poplar Way, Colerne, were told Abigail had the incurable genetic disorder Mucopolysaccharide.

In the last six months Abigail has lost the ability to talk, and eat with knife and fork — she is now incontinent, hyperactive and cannot sleep.

As the disease takes over her brain she will forget how to walk and be unable to breathe or digest her food properly.

# of the doomed toddler

Doctors at Manchester Children's Hospital have reassured Mrs Pullin, aged 34, and her plasterer husband that their daughter is blissfully unaware of her tragedy.

"She is probably quite happy, the sorrow and the guilt comes from us," said Mrs Pullin.

She said: "She went to Middlefield special school in Chippenham a little star, but now she is incapable of learning."

She could die in just three years time, or live a dependent existence until 30, although the average age of victims is 14.

Their young son Tim, two, has a one in three chance of being a carrier of the disease, although tests show he should not develop it himself.

There are 350 children in Great Britain suffering from the

disease and parents are raising cash for research.

It was a chance in a million that the Pullins both had the killer gene, and they had no idea until Abigail was diagnosed.

Mrs Pullin's eldest daughter Katie, 15, by a previous marriage, is perfectly healthy.

Abigail has the Sanfilippo Syndrome of the illness which affects the nervous system.

Mr Pullin, 32, and his fellow players in Colerne Rugby Club are raising money for the research in a 24 hour sponsored dark, skittles, cribbage and pool marathon on August 26-27 at the village Liberal Club.

"I wanted to do this fund-raising because it is a positive aspect, I know there is no hope for Abigail but we can still help those yet to be born," said Alison.

Money raised will go to The Society for Mucopolysaccharide Diseases which funds the work of the Manchester hospital.

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## MPS RUNNERS DOMINATE MARATHON !!!!

There will now be four London Marathon runners sponsored by MPS on the 24th April, Roger Bennett, Ken Goss, Glyn Bush, and Charles Pike. There is still plenty of time to get a sponsorship form from Ron Snack. Go to it!

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**FUNDRAISING EVENTS**  
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Our thanks to all those who sent donations. These have all been acknowledged separately. As usual there have been many and various fund raising events held. We need to hold more to keep the money rolling in. Perhaps the following list will give you some ideas; personally I think that sponsored pub crawls are the best thing since sliced bread!

**Ron Snack**

J R Townsend	Sponsored Bike ride
P&JM Dagnell	Sale of dried flowers
A&C Martin	Pub Collection
SR&V Harrison	Sponsored Run
P Mahon	Sponsored Dinner
JA Sweeney	Car Boot Sale and Walk
FA Sandon	Sale of Stamps
B Carol	Sponsored Bike Ride
Hythe Methodist	Sunday School Concert
Brennan family	Charity Evening
W Blackburn and	
E Mc Garry	Sponsored Swim
P&M Archard	Xmas Party
D Brookes Daw	Raffle and Sales
P&M Archard	Sponsored fast and clothes sale
C&R Lavery	Xmas Party
C&M O'Toole	Two collection boxes
M&P Short	Coffee Morning
S&E Wallace	Disco and Raffle
R&J Macintyre	Sponsored Caterpillar Walk.
Mrs Masters	Jewellery Party
J.Towning	Collection Box at Boots Basildon
J&E Broughton	Garden Fayre
Downend Baptist Church	Event.
Crowborough Townswomen' Guild	Copper Collection
W Robins	Collection Boxes
A Byrne	New Year Party and Collection Box
Stonelaw High School	
(Glasgow)	Sponsored Swim
Penny Warner, Newbury	Garden Party
Sue Butler	Luncheon Party
Carol Eastwood	Raffle
British Airways (Heathrow)	Collecting box.
Darkes family	Collection box
Sarah Lowry (Herts)	Carol Singing
Barry Lowry	Coins in a bottle
Colerne Rugby FC	24 hour Marathon Events
W Fawcett (Yorks)	Wetherby half Marathon
J Winsley	Coins in a bottle
A Clamp (Derbys)	Bingo Evening
Wirksworth Rotary Club	Christmas Activities
Harrogate Lions	10k Road Race
CS Smith (Somerset)	Perfume Sales
P Isaac	Valentine Dance
J Eyre (Avon)	Sponsored Cycle Ride

**AREA SUPPORT FAMILIES**

**Neil and Jane Reid**

19 Hillside, Sawston, Cambs. CB2 4BL  
 Tel: 0223 834570

**Alan and Deirdre Beavan**

'Tumbleweed', West Gate Lane, Lubenham,  
 Market Harborough, Leics. Tel: 0858 62182

**Mary Gardiner**

15 Sidney Avenue, Hesketh Bank,  
 Nr. Preston, Lancs. Tel: 0772 815516

**John and Barbara Arrowsmith**

140 Newtown Rd, High Heaton, Newcastle on Tyne. NE7 7NH  
 Tel: 091 2812062

**Sean and Pauline Mahon**

41 Stumperlowe Crescent Road,  
 Sheffield 10, South Yorkshire  
 Tel: 0742 304069

**Alfred and Judy King**

4 New Park Avenue, Bexhill-on-Sea,  
 East Sussex TN40 1QR  
 Tel: 0424 216432

**Bill and Sylvia Blackburn**

11 Beatty Road, Nantwich, Cheshire  
 Tel: 0270 626809

**Ron and Linda Snack**

16 Wandsworth Place, Bradwell Common,  
 Milton Keynes, Bucks.  
 Tel: 0908 666819

**David and Michelle Brooks-Daw**

St.Mary's Lodge, Wellington Rd, Taunton,  
 Somerset. TA1 5AS Tel: 0823 271661

**Tony and Mary Lockyer**

29 Llanberis Close, Tonteg, Pontypridd, Mid Glamorgan.  
 Tel: 0443 2032845

**Area Family for Northern Ireland:-**

**Margaret Kearney**

12 Coleraine Road, Ballycastle, Co. Antrim  
 Tel: 026 57 62073

**Contact for Scottish Families:-**

**Alan and Fiona Byrne**

3 Jedburgh Ave, Rutherglen, Glasgow G73 3EN  
 Tel: 041 643 0034