

**NEWSLETTER**

**SUMMER 1988**

**THE SOCIETY FOR  
MUCOPOLYSACCHARIDE  
DISEASES**



National Registered Charity No. 287034

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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 the Honourary Director at the above address. Annual subscription charges are £5.00 in Great Britain and £10 Sterling elsewhere.

## GRAND EDITORIAL PIECE

Thank you for your many articles and photos. If your piece isn't in it is almost certainly through lack of space, though **Catherine Gardiner** is banned because she is trying to steal my readers. Some notices of events do not appear as they took place before going to print. Keep the material flowing in please. New information --- **COLOUR PHOTOS ARE FINE**, so keep sending them.

While we are on about pictures, a message from Robin Lavery. If you bring a videocassette to the conference it may be possible to get a record of your child on the outing using the Society's video camera.

## AREA FAMILIES

**Christine and Robin Lavery** have always been the Area Family for a large slice of South East England. They have felt for some time that they cannot any longer fulfil the Area Family role in view of the ever growing task of running the national organisation. The last Committee meeting was pleased to accept the offer of Ron and Linda Snack from Milton Keynes to be the Area Family for Herts, Bucks, Berks, Beds, and Oxfordshire. Their son Colin age six has Hunter disease.

London and Essex families are not linked at the moment to any one Area. We are working on this and in the meantime families should feel free to contact their nearest Area Family if they wish to join in any activities.

## North West

**Micheline and Brian Johnson** are not able to continue in an active role, at least for the time being, as their daughter Victoria is often unwell. Our thanks to them for their help and welcome to **Bill and Sylvia Blackburn** from Nantwich who have agreed to share the North West Area with Mary and Colin Gardiner. Matthew Blackburn aged eleven has Hunter disease.

## Northern Ireland

For the first time we have an Area Family for Northern Ireland. **Margaret Kearney** a Health Visitor from Co. Antrim took on this task last April. Margaret has a daughter Joanne aged thirteen and a son Aidan aged ten. Aidan has Morquio disease.

## Births

**Matthew Dore**, born 18th February 1988 to Gerald and Alison Dore of Oakworth, Keighley, West Yorkshire.

To Mary and Robin **Gooch**, Sussex, a son **Adam Robert** born 29th May 1988, a brother for James and Nicholas.

To Kate and Albert **Farminer**, Glos., a son **Joseph Charles** Frederick born 23rd April 1988, a brother for Laura and Beth.

To Stella and Steve **Hale**, a daughter **Katie** born on 22nd of June 1988, a sister for Thomas.

## Marriage

Trevor and Barbara Rollinson of Scunthorpe Humberside, on 16th April 1988. Their daughter Gemma has Hurler disease.

## Deaths

**Paul Love** from Caerphilly, died 19th March, aged eight years. He suffered from Hurler disease. Our sympathies to his parents Clive and Shirley and to his sister Ann.

**Darren Man** from Ashford, Middlesex who had Hunter disease died on 3rd of May aged eleven. Our thoughts are with his parents Dena and Kim and his grandparents June and Den Evans.

## New Families

Mrs Rene Jackson from Oldham whose son Neil Buckley died on 2nd of June 1977 aged 12 years. Neil suffered from Sanfilippo disease and his family have recently sought the support of the Society.

Alison and Andrew Pullin from Chippenham whose daughter Abigail aged five suffers from Sanfilippo disease.

Mr and Mrs Puddy from Somerset. Annette aged four has Sanfilippo disease.

Ida Brierley from Manchester whose granddaughter Ronda aged fourteen has ML III disease.

Mr and Mrs Haq from Rochdale whose children Shabnum aged eight and Misbah aged seven have Morquio disease.

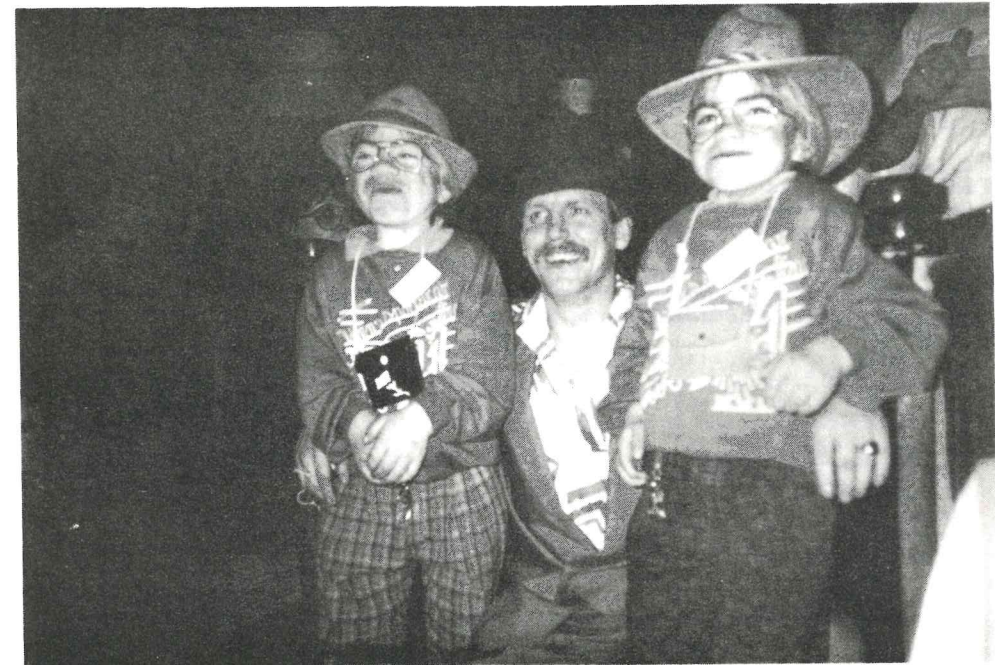
Mr and Mrs Graham from Manchester. Andrew aged six has Sanfilippo disease.

Sue and David Cooper from Surrey whose one year old daughter Amy has Hurler disease.

Mr and Mrs Varsani from Bolton. Rajesh aged six has Morquio disease.

## DATES FOR YOUR DIARY

- August 21st **Family Day** at Pleasurewood Hills American Theme Park, Lowestoft, Suffolk. Everyone welcome. 11.00am to 5.00pm. Meet at entrance at 11.00 am. Bring picnic, or barbecue your own meat on site. Return for light refreshments to **Claire and Richard Mansfield** 5 Corton Rd, Lowestoft. Tel: 0502 515618 for details and map.
- 28th August Informal get together at Alf and Judy King's house  
4 New Park Avenue, Bexhill-on-Sea.  
Tel: 0424 216432  
Open house from 10.00 onwards. Please let them know if you are coming.
- 23rd to 25th September Sixth Annual Conference, Post House Hotel Heathrow. **The conference is now fully booked.**
- 10th December Christmas Party.



Two Hunter boys at the Austrian/German Conference

Christine Lavery who has borne the brunt of the organisation of the Society from the time she founded it has the title of Honorary Secretary. (Honorary means no pay!) The Committee has felt for some time that her role corresponds more to that of Director. It was decided at the last committee meeting that the title of Honorary Director (still no pay) was more appropriate. This brings us into line with many other charities, although most of their directors receive a salary. Linda Golding, who works part time at the "office" (also doubling as the Lavery's spare bedroom) is much more than a typist so we can now refer to her as the Society's Secretary. (Sorry Linda, ---you guessed it, there isn't a pay rise to go with the title.)

#### The (Honorary) Committee

#### Junior MPS Newsletter

AnserBak is a newsletter for the younger generation of the MPS Society.

AnserBak will be published, along with the parent's newsletter, four times a year. For parents who's children are too young or need help with articles, please feel free to help.

Articles are needed about yourself, family, friends, school etc., with plenty of jokes, photos and anything else which you think may be of interest.

For my part, I will do my best to make sure everything possible is published.

A little about AnserBak. It started this June with me as self-appointed Editor and I was quickly joined by the publishers, Andrew and Ben Lavery. They have been extremely busy churning out the first edition of AnserBak on a photocopier in the MPS Office ( Upstairs bedroom, Lavery household ).

Our success will depend on you. Please send your contributions to me for the next issue. The deadline is September 30th.1988.

Catherine Gardiner  
AnserBak Editor  
35 Church Road  
Banks  
Southport  
Merseyside PR9 8ET

#### MPS OVERSEAS

#### AUSTRIA

The joint Austrian/West German conference was held in May beside a lake in the Austrian Tyrol - decidedly one up on the Post House Hotel! Christine and Robin Lavery and Mary O'Toole represented the British MPS Society. They were joined by Charles O'Toole, Bill and Fer Pidden and the Bryans family with their six youngest children including their adopted son Timothy who has I Cell disease. The Austrians were amazed by the size of the Bryans family and rumours spread. "Some say there are ten children, some say there are twenty, no one knows how many there are."

We made some valuable contacts in Austria. Doctors came from East Germany, Hungary and Poland and all hoped to see MPS Societies starting in their countries before long.

We participated unwittingly in a piece of research. Having, we thought, been asked to help round up families to give blood for tests we found ourselves rolling up our sleeves. Dr Adrian Sewell, a British biochemist based in Germany, is working on carrier tests for MPS diseases. His team is fairly confident that they can succeed in detecting carriers of Sanfilippo A disease and they hope to make progress on the other conditions.

While in Austria we discussed plans for a possible European MPS conference. Sadly it is necessary to postpone this event as both the German and Austrian Societies have difficulties within their organisations and are not in a position to take on such a major project at present.

#### MINNEAPOLIS

The First International Congress on Mucopolysaccharidosis was held in Minneapolis at the end of May and attracted doctors and researchers from all over the world. The Medical Congress was held on the same weekend as the Canadian/American parent conference, so that parents could observe the medical congress as well as attend their own one day meeting.

Funds were raised to send Mary O'Toole and Christine Lavery to represent the British Society. There were enough funds to make a contribution towards Dr Martin Bax's fare, and to send Dr Adrian Sewell, the British biochemist from Mainz in Germany who has close links with our society. Dr Ed Wraith from Manchester also attended, funded by his District Health Authority.

It was fascinating to meet some of the doctors whose names dominate our lives - Dr Scheie, Dr Sanfilippo, Dr Sly, and Dr Leroy. Dr Scheie who is now retired was a consultant ophthalmologist who wrote about a group of patients with eye problems who were found to have a mild form of Hurler disease.

Dr Sanfilippo is no longer working with sufferers from the disease named after him, but came to speak at the parents conference.

Dr Kopits and Dr Amato who came to our conference two years ago were both speakers at the congress and both said publicly how much they had learned from seeing the British families who came to their "clinics" at the Post House Hotel. Dr Amato told us that his reports might actually be ready soon but we have long since abandoned hope of seeing the outstanding reports from Dr Kopits.

The International Congress provided an excellent opportunity for researchers to meet each other and to establish ways of working together. It is hoped that there will be a second International Congress in the near future, possibly in England. The British delegates felt that the contacts made and renewed and the information gained about developments in research made this a fruitful if exhausting trip.

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#### PHYSIOTHERAPY

Dr Kopits spoke at some length about physiotherapy at the parents conference in Minneapolis. He said that it is a very valuable resource which should not be misspent. In his view many physicians do not properly appreciate what can be achieved by properly prescribed physiotherapy treatment. It is necessary to ask whether the programme of physiotherapy is justified by what it can achieve or whether it may be a waste of the parents time. Dr Kopits acknowledged the pressure on parents who have many commitments and who are asked to take their child for treatment.

Specific goals must be set for the therapy, such as learning to walk again after surgery, or chest physiotherapy to help drain secretions from the lungs. Dr Kopits made a distinction between **active therapy** where the patient performs the activity with encouragement, and **passive therapy** where the therapist bends or stretches the limbs and joints. He considers that for MPS patients passive therapy may do more harm than good. The joint problems of MPS patients are very different from those of many other diseases, for example, cerebral palsy. In MPS diseases there is thickening and scarring of the capsule between the joints. Bending and stretching the joints may further thicken the capsule and be counter productive. The therapy should not be painful and should not stretch the muscles.

Dr Kopits found warmth and gentle massage more effective in easing stiff or painful joints. He has also achieved good results by splinting limbs at night in a functional position.

He advises that the shape of the splints will need to be changed as the limb alters its alignment.

Mary O'Toole

## Non-means-tested benefits

<b>ATTENDANCE ALLOWANCE</b>		
higher rate		£ 32.95
lower rate		£ 22.00
<b>CHILD BENEFIT</b>		£ 7.25
<b>CHILD'S SPECIAL ALLOWANCE</b>		£ 8.40
<b>GUARDIAN'S ALLOWANCE</b>		£ 8.40
<b>INVALID CARE ALLOWANCE</b>		£ 24.75
<b>INVALIDITY ALLOWANCE (paid with Invalidity Pension)</b>		
where incapacity began		
before age of 40		£ 8.30
50		£ 5.30
60 or 55 (women)		£ 2.65
<b>INVALIDITY PENSION</b>		£ 41.15
dependency addition		£ 24.75
increase for child		£ 8.40
<b>MATERNITY ALLOWANCE</b>		£ 31.30
partner		£ 19.40
<b>MOBILITY ALLOWANCE</b>		£ 23.05
<b>ONE PARENT BENEFIT</b>		£ 4.90
<b>RETIREMENT PENSION</b>		£ 41.15
partner		£ 24.75
Age addition (over 80)		£ 0.25
<b>SEVERE DISABLEMENT ALLOWANCE</b>		£ 24.75
partner		£ 19.40
<b>SICKNESS BENEFIT</b>		£ 32.75
partner		£ 19.40
<b>SOCIAL FUND - Maternity Payment</b>		£ 85.00
<b>STATUTORY MATERNITY PAY</b>		
higher rate	90% of weekly earnings	
lower rate		£ 34.25
<b>STATUORY SICK PAY</b>		
earning £79.50 or more		£ 49.20
£39.00 to £79.49		£ 34.25
<b>UNEMPLOYMENT BENEFIT</b>		
claimant		£ 32.75
partner		£ 20.20
<b>WIDOWS BENEFIT</b>		
Widows Payment		£ 1,000
Widows Allowance		£ 57.65
Child		£ 8.05
Widowed Mothers Allowance		£ 41.15
Child		£ 8.40
Widows Pension - 55 and over		£ 41.15
45 to 54	£12.35 -	£ 38.28
Child		£ 8.40

## TWO MEETINGS IN IRELAND

Two historic meetings took place in Ireland recently.

On Saturday 28th of May ten MPS families met for the afternoon at the Town House Hotel in Naas. This was the very first time that families had been brought together in the Republic. Most of the families had had no previous contact with anyone else suffering from MPS Disease, though the Mc Gaurans and the Bowens had met two years ago in London. There were in all three children and one young man with Hunter Disease, three with Morquio disease, including **Elena Mc Gauran** looking very fetching in her halo, two with Hurler-Scheie, one with Scheie and one bereaved Hurler family. Some people had a very difficult journey to get there. One family with three Hunter boys under five had been on the road since 8.00 am!

This new experience after long isolation brought uncertain feelings, and there was the natural awkwardness of meeting people for the first time. The barriers started to melt away for the young people when they got a card school going at a corner table. Some of them had come reluctantly. They were worried that the adults would be talking about them. They didn't want to be pushed together with strangers just because they had similar medical conditions. But all this was forgotten over the card table.

After introductions and informal chatting the parents gathered round. The group discussed ways of linking Irish MPS families. People felt very keen to make links with each other. They felt that the contact would benefit the young people and the parents and would help in lobbying for improvements in medical services and in promoting research. They felt families could offer support and advice to each other.

The warmth of feeling and the enthusiasm at this meeting is a very good omen for the development of future links between MPS families in the Republic. Go neiri an bothar libh !

**The next milestone in Irish MPS history** was an Area Family Meeting for Northern Ireland on Saturday 5th of June. This was organised by **Margaret Kearney**, who had recently agreed to act as Area Family Organiser for N.I. She was ably and enthusiastically helped by **Ann Fitzpatrick** and friends. Ann organised an excellent venue at Loan Ends Church Hall, between Belfast and Antrim Town. Ann also did trojan work in preparing food. A surprise treat was a birthday cake provided by Winnie Larkin to celebrate the first year of MPS Society in N.I.

The group were delighted to welcome **Professor and Mrs Nevin**. Professor Nevin is Professor of Genetics at Belfast City Hospital. He spoke individually to the families, most of whom were already known to him. Talking to the group as a whole he said that he was a keen supporter of parents groups and felt they could be of great benefit in giving mutual support and in encouraging improvements in services and in promoting research.

He considered that the Faculty of Genetics has a key role in relation to rare diseases in Northern Ireland. They deal with all diagnoses in the province and so can be of great service in working for the co-ordination of knowledge and of services to sufferers and their families.

**Wilma Robins, Welfare Rights Officer** for the Society came over specially for the meeting and spoke individually with families. It would seem that obtaining benefits such as attendance and mobility allowance is more difficult in Northern Ireland and work will need to be done with the Area Office of the DHSS.

The terms of the British MPS Society's constitution do not allow it to operate outside the United Kingdom. It is hoped that the Republic will be able to start up its own Society and develop close links with the Area Group in the North.

Charles O'Toole

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"AFTER SIMON"

THE MPS SOCIETY WILL BE FEATURED IN A 45 MINUTE DOCUMENTARY ON RADIO 4 ON WEDNESDAY 10TH AUGUST AT 11.02 AM.  
ALSO ON SUNDAY 14TH AUGUST AT 10.15 PM.

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Diane Bayliss  
27 Edna Avenue  
Fazakerley  
Liverpool 10 OAN  
Tel: 051 525 3205

Hello to all Grandparents,

I am Diane your grandparent contact. I would like to tell you a little about myself.

I am a \*\* year old State Enrolled Nurse. I work three nights per week at the Womens Hospital Liverpool. I have been married for thirty years to Bill. We have three children, all girls. Julie is aged twenty seven and is a hairdresser.

Helen is twenty three and is an office administrator. Elizabeth is twenty two and she also is a hairdresser and beauty consultant. None are married and they all live at home. Julie is the mother of our grandson Anthony, aged two years who has Morquio disease. I look after Anthony daily so Julie can continue working.

Now a little but only a little about Bill. He is fifty three years old and is a technical clerk at Fords Motor Company, Halewood. He has worked there for twenty five years. Bill has only one hobby and that is to slip to the corner pub for a quiet pint -- if we let him.

My hobby is knitting. I now have a knitting circle formed. We make toys and sell and raffle them and all monies go to help MPS children.

I will finish up now. Enough is enough about me. I want to hear from you. If you need someone to talk to or someone to just listen give me a call or drop me a line. I will answer all letters personally and in strictest confidence.

Regards,

Diane Bayliss

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### SOUTHERN GRANDPARENT CONTACT

If Liverpool seems too far away for grandparents south of Watford, Pam Macintyre, grandmother of Natasha who has Sanfilippo disease has offered to be a contact. Her address is:

Hart Cottage  
West Langdon  
Nr Dover, Kent CT15 58N  
Tel: 0304 852624

# Trapped inside a tiny body



Tragic toddler Anthony Bayliss with his grandma Diane

LITTLE Anthony Bayliss is destined to develop the mind of a man trapped inside the body of a boy.

For the two-year-old Liverpool toddler suffers from an extremely rare disease which will prevent him from growing more than a foot from his original height at birth.

But all of Anthony's internal organs will grow and he is expected to have above-normal intelligence.

Doctors broke the news about his bone condition to devastated relatives after they realised that he was not walking properly at 18 months.

They were told there was no cure for the potentially fatal illness which is brought about by a million-to-one combination of his parents' genes.

Anthony may live well into his 20s or even longer.

#### Heartache

Heartbroken mum Julie, 27, is now dedicating her own life to making that of her only child as happy and full as possible.

But the heartache was too much for her to speak about Anthony and the rare Morquio Syndrome he suffers.

Her mother Diane Bayliss, 50, said: "He is her world. She has said she will never have another child. She wants to devote everything to him."

Anthony's grandmother, who is a nurse, told how the family of Edna Avenue, Fazakerley, is now caring for the toddler, with the help of medical advice from a specialist centre at Manchester.

#### Wonder

She said: "He is going to wonder why he is a man trapped inside a child's body. How do you explain that?"

He is going to have to accept the stares and the finger-pointing. You can't hide him from the world.

"And no way would we want to. To me, Anthony, whether he is small or not, is going to walk tall."

Anthony was 24 inches tall when he was born - the average being 19 to 21. He is now just 29 inches.

Support has come from friends and neighbours. Staff at the local Birds Eye store have helped organise a charity night at the Dockers Club in Townsend Lane next month.

There is also the National Society for

## Tragic Anthony can never grow up

Diseases, of which Anthony's Morquio Syndrome is one of, five different strains.

Mrs Bayliss, who has three daughters, believes there are other parents on Merseyside whose children suffer from one of these rare conditions and she wants them to form a self-help group.

There are less than 100 Morquio syndrome sufferers nationally. Parents can contact her on 525 3205 or the society on 02404 2789.

### HOLIDAYS

Threshold Travel's 1988 brochure demonstrates that holidays for people with disabilities can be exciting and interesting. The company specialises in holidays for people with disabilities and its staff personally inspect all hotels and resorts for wheelchair access. They also make arrangements for personalised service at airports, both at home and abroad, with special airport/hotel transfers. For a brochure write to Threshold Travel Ltd, PO Box 25, Wythenshawe, Manchester M23 9JB. ☎ 061-905 1144.

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12 St John Street  
Wirksworth  
Derbyshire

To Pat Isaac

Dear Pat,

How do you do! We've never met but I've heard a great deal about you - I'm Jill Sutcliffe and my little boy Henry was diagnosed to have **Morquio Syndrome** in February.

I'm very pleased to enclose three cheques for MPS with this letter.

The largest cheque was raised by the Gatehouse Well Dressing group and other well dressers. Every year Wirksworth has a well dressing weekend over the Spring bank holiday. The custom dates back to 1851 when the local landed gentry subscribed together to have piped water brought down from the moors. As a thank you the people of Wirksworth began to decorate the taps with floral pictures based on a religious theme. From simple beginnings this has now grown to a grand scale and fourteen well dressings are done every year. The pictures are on a wooden frame plastered in clay. Only natural materials such as flower petals, seeds, alder cones maize, moss, bark and reeds are used. The box is approximately eight feet high.

For a number of years we've helped with the Gatehouse Well and Martin designed this year's well dressing. When he was approached we were feeling rather low having just discovered what Morquio Syndrome was. The initial reaction was to say no, we have enough to cope with, and then came the grim determination that life must go on. Martin designed the well on a theme requested by the Florence Nightingale Trust, on the understanding that some of the collection went to MPS.

Henry's sister **Hannah** age six made her own little well with a notice asking for donations to MPS. £200 was collected by the Gatehouse Group, £30 was raised by Hannah, and £70 was donated by the Church of England Infant School. A few people said "Why do MP's need money, they earn enough"!

Our friends and neighbours were pleased to be able to do something to help. Although it sounds a bit corny the well dressing really became dedicated to the skills of the medical profession who help our children.

Is this a fundraising first? I enclose a photograph for the newsletter. Henry has had numerous tests in the past months - his neck is causing quite a lot of concern. It gives us hope when we see the courage of other Morquio families and MPS sufferers.

Best wishes

Jill Sutcliffe

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### Diets and Diarrhoea

**Natasha Macintyre has Sanfilippo disease.** Her mother Julie writes:

'For Natasha we keep her on a low fibre diet, i.e., white bread, no beans, corn, fruit etc., plenty of lean meat and low fat. She also has mineral water and blackcurrant to drink. Any fibre that she may accidentally consume shoots straight through in no time!

I smiled when I heard about the **BRAT DIET**. That would send Natasha to a hospital spell within days!

### **Judy King's son Michael's diarrhoea had a different cause:**

'As a baby Michael who had Hunters disease, often used to have attacks of very runny stools for no apparent reason. These normally cleared up after one day. We were abroad for a period in Zambia and he regularly had diarrhoea which was caused by minor infections and cleared up by antibiotics. He had not been diagnosed at this time.

On our return we continued to have the same problem, but neither antibiotics or binding type medicines did any good. The Paediatrician then said he considered Michael was suffering from constipation with diarrhoea overflow and advised me to put him on bran. The appropriate amount had to be worked out by trial and error. It took a week or so for the bowels to settle down. On occasions the bran came out undigested, but Michael was on this for several years and it certainly solved the problem.

Natural unprocessed bran is available from chemists and is very cheap. Be sure to consult your Doctor before following this suggestion.

### **Editors Note:**

It is an impression that the diarrhoea in MPS children is not usually caused by severe constipation and 'overflow'. I understand that a simple abdominal X ray may resolve whether constipation is in fact the problem.

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## HEIDERS WALLBURG

I met Heideros (Heidi) at the Austrian/German conference which was held at Pertisau on the last week in April.

She told me she was born in a small village in 1945, and grew up there with her parents and her younger sister. When she was young she developed a "pigeon chest" and the medical opinion was that she had rickets (not uncommon in Europe after the war). When she was four her left leg became bent and she stopped growing. She was treated with hormones and Vitamin D. From the age of four she was made to wear splints on her legs and a body cast at night. She even spent six months in hospital in a cast to try and correct her orthopaedic problems.

When she started at the village school she rode there on a small bike.

Heidi showed me photographs of herself as a toddler with her parents and her baby sister. The later photographs show her sister catching up with her and getting much bigger, until at thirteen her sister is towering over her.

At sixteen Heidi had had enough of splints and casts. "That's it" she said, "No more. This is doing me no good."

On leaving school she was trained in an institution and obtained a qualification as a seamstress. She made good use of this skill for several years by making her own clothes. Later on increasing problems with her hands and fingers forced her to give this up. She also worked for a period in a factory.

She has had quite a lot of medical problems, chest infections and respiratory problems, arthritis and pains in her limbs, ear infections and hearing difficulties. She suffers from allergic asthma.

It was not until 1975 when she was thirty five that a diagnosis of **Morquio's Syndrome** was suggested. This was only confirmed in 1984.

Heidi's mother died some years ago. Heidi now lives in a specially adapted flat in her home village. Her father lives in a flat upstairs, and her sister and family are in regular contact. She is almost entirely independent, cooking and shopping for herself. A cleaner comes in once a week. She gets around the village in her electric wheelchair. "How do you manage?" I asked her. "I have to manage, so I do," Heidi told me. Once her cleaner jokingly told her to eat up her food so she would grow big. "Never fear," said Heidi, "If I grow big I will have to clean the windows myself, I think I will stay the way I am thank you." A spirited sense of humour seems to be common among people with Morquio Disease.

Heidi has many friends and helpers in the village. Two of them came with her to the conference. Heidi had never met another Morquio until she came to the conference. She was delighted to meet a young man and a family with a Morquio child. She was especially pleased to hear about English Morquio members and to see their photographs.

## NorthWest Bar-B-Q

Thirteen families and friends came along to the Bar-B-Q, held at our home on Sunday June 12th.

I had spent the previous week praying the weather would improve, as I did not relish the thought of fifty or so people jostling for space in the house. Thankfully, it turned out to be a glorious summer's day.

Unfortunately, our chief cook, Colin, had been called away by his company to participate in a management development course, aimed at improving his skills in management. The course had him, amongst other activities, abseiling down a mountain at 2 a.m. in the morning. Anyone who knows Colin will be aware of his strong aversion to outdoor pursuits.

Meanwhile, back at the Barbie, Bill Blackburn was on hand to take charge of the cooking and what a marvelous job he did! Thanks Bill.

The families who arrived early, were immediately put to work so by the time everyone else arrived we appeared well organised and competent.

It was a pleasure to see both old and new friends come together and we had the opportunity to welcome Renee and Barry Jackson and their daughter. Renee had contacted the Society following a television programme, featuring Billy Burlison and Darren Horsley. Although they had lost their son Neil, some ten years ago, with Sanfillipo Syndrome, it was lovely to meet them and share with them part of Neil's life.

Happy memories are made on days such as this, one memory of mine, is watching Michael Watkinson, nearly two years old and suffering with Hunter Syndrome, climbing up the ladder of the slide. Michael was determined to do it on his own, without our interference. He made it up to the fourth step, before we stepped in to help. A tremendous achievement, considering he had only just mastered walking.

Poor Margaret Leask hobbled in due to an accident the previous month. Our sympathies were not just for her injuries but also for the embarrassment she suffered because of husband, David, who turned up ready for Wimbledon, complete with thin, white, hairy legs.

We have a short video of the day, capturing all of our children, laughing and playing happily together. Even the teenagers found plenty to talk about.

Mary Gardiner

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SPECIAL CARE \* 9th October 1986

Today a very special little girl died. She was born with a incurable genetic condition and lived nine years with increasing deformity and pain. This little girl's struggle has taught those around her a lot about patience understanding and love. She like thousands of others severely handicapped throughout the world was lucky to find in humanity such selfless love. The parents are heartbroken. No parents can wish their child, however ill, to die. They grieve for the life she might have had, and the life that will never be. They grieve for her and for themselves. I wish to pay tribute to all those who have these children in their care, their special care.

Your little one she is dead.  
 You rang me and you said.  
 Then I wanted so to share,  
 Felt you needed my care  
 If I came would I help you  
 If I spoke would I tell you  
 If I touched would I show you  
 Let me be by your side,  
 Understanding as you cried.  
 For what else could I do  
 For you.

Liz Harker

#####

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##### PAYING FOR TREATMENT #####

IS THERE AN ALTERNATIVE TO THE NHS?

In the light of the current debate about Health Services finance we wondered if private health care schemes had anything to offer our MPS children and adults. We wrote to two of the largest private health schemes, **BUPA**, and **Private Patient Plan**.

BUPA replied. "We are not able to accept an application from a known MPS sufferer. If a child is already registered before an MPS condition is diagnosed it might be possible to receive cover for operations or acute illness, but any long term nursing care would not be covered."

Private Patients Plan did not specify what would happen if a child was registered before diagnosis but stated that, "The children you mention ----fall into the area of existing medical conditions which are not covered."

American MPS families give a horrifying account of their financial problems when faced with expensive medical procedures. One father had given up work to become a full time fundraiser to get together enough money to cover the search for a bone marrow donor. Another family who have to pay 20% of their daughter's bone marrow transplant face a charge of **£100 per month for the next ten years**. They ran into financial difficulties and were unable to make payments for a while. The first transplant failed. While the child was in hospital for a second transplant, the same hospital was suing them for the money they already owed!

Although the Government says it does not want to see the American model of health care for this country it seems in the interests of MPS families to support the NHS in whatever way we can.

One specific way would be to ask for a quotation for private health insurance and to send the result to your MP asking for their comments.

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Ann Fitzpatrick and Wilma Robins at the Northern Ireland Area Family Day.

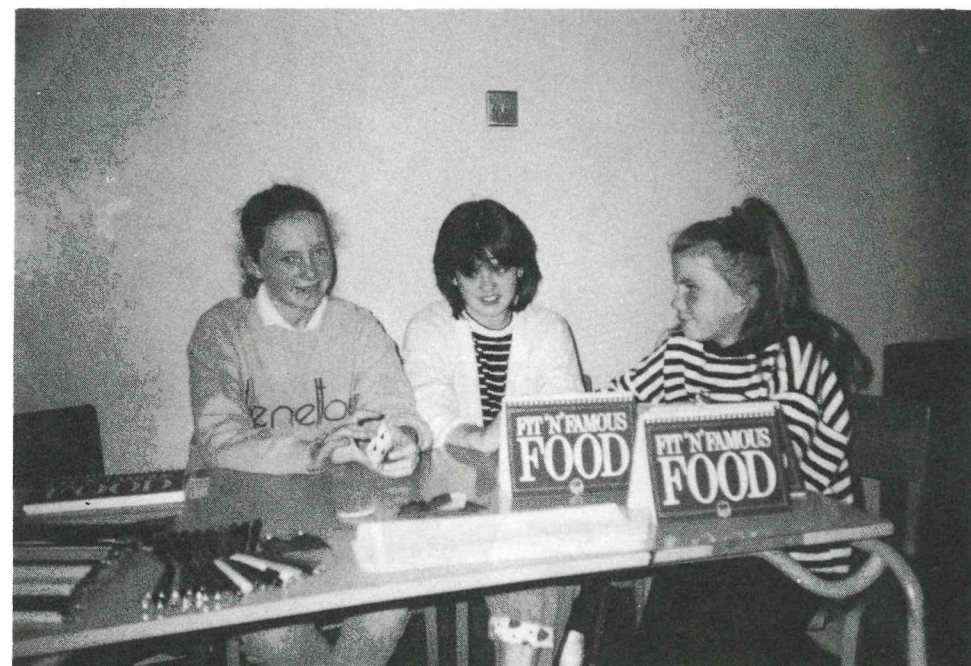


Birthday time for MPS in Northern Ireland and also for Martina Larkin. Professor Nevin helps her cut the cake.

James Stewart aged 18 from Derry who has Hunters Disease, enjoying a game of snooker with Mr Larkin.

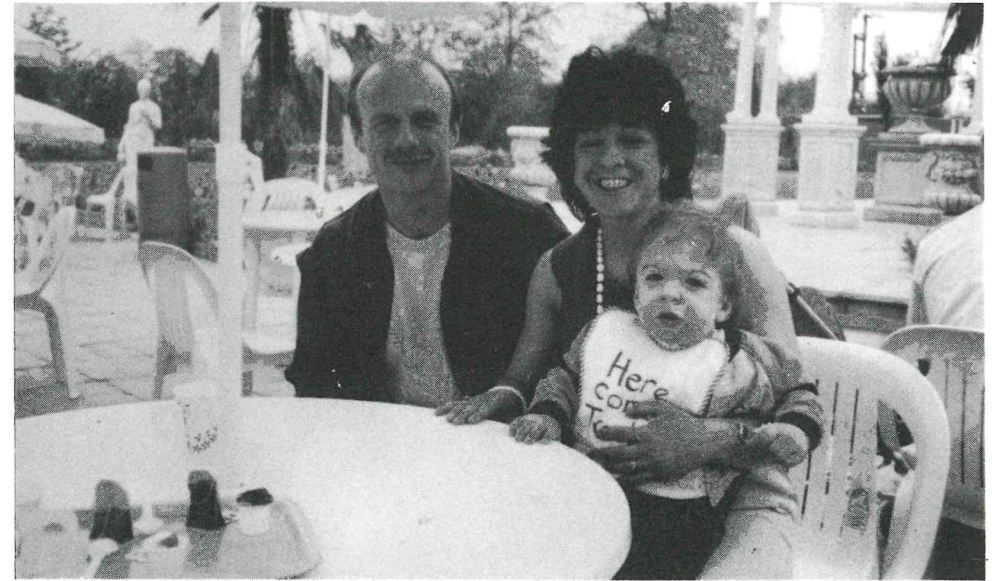


Sisters of MPS young people get in on the act. Joanne, Kate, and Martina.





**Heideros Wallburg** enjoying the air at the Austrian/German Conference. Heidi is aged 43 and has Morquio disease.



**Harry Brennan** with Mum and Dad at the Stapeley Water Gardens outing on the 6th May. Harry has Sanfilippo disease.



No this isn't Transylvania! **Christine** is enjoying giving a blood sample. I can't speak for **Professor Pontz** from Mainz.



**Bill Blackburn, Alec Brown, Harry Meadows & David Leask** testing the punch at the Barbie on 12th June.

NORTHERN IRELAND AREA FAMILY DAY



Fiona and Bernadette Larkin and Aidan Kearney. All are mildly affected by Morquio disease.

FIRST IRISH MPS MEETING



The three Grimes brothers from Mayo suffer from Hunters disease.



Post House Hotel, eat your heart out!  
The Austrian/German Conference at Pertisau.



Dr Anna Tylski-Szymanska from Warsaw  
pretending the Editor is not stepping on her toes.

AREA FAMILY DAY IN WALES



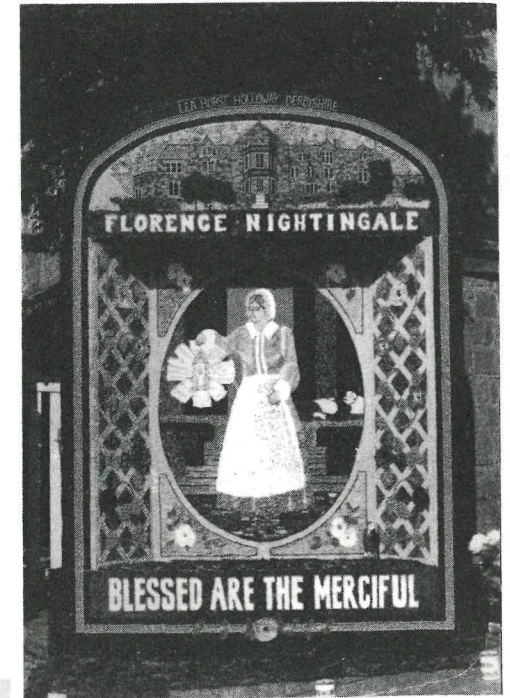
Helen Skidmore, David Criddle, and Caroline Sweeney.



Ross Lockyer aged 7 (Hunters disease) enjoying his party.

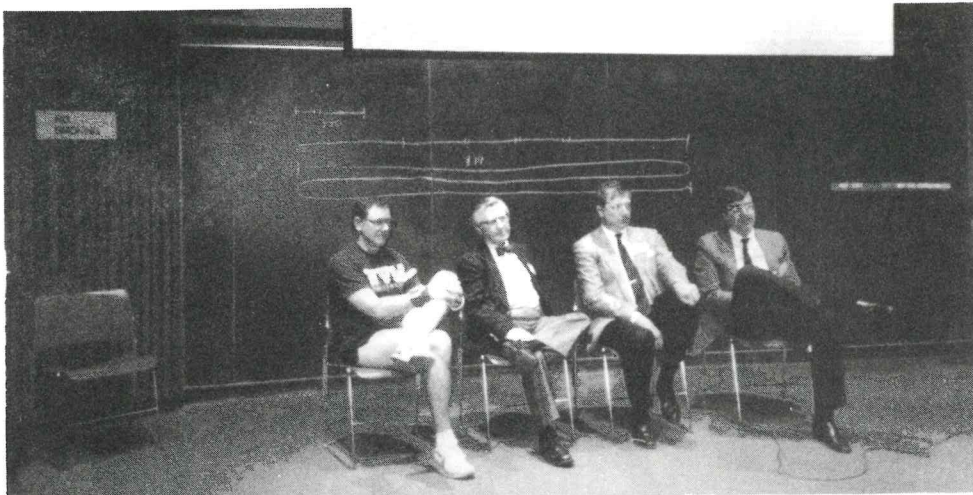
The Gatehouse Well 1988, designed by Martin Sutcliffe, father of Henry who has Morquio disease.

The design celebrates Florence Nightingale's childhood home. It is now a Nursing Home run by the Royal College of Surgeons for ex-nurses.



Michael Watkinson aged two (Hunter's disease)

Climbing high with Alexandra Gardiner.



Doctors **Amato, Sanfilippo, Kopits & Muenzer**  
at the Minneapolis Conference.



**Sarah, Emma, and Toni Bramford**  
at Tadworth Children's Hospital

## CHILDHOOD BEREAVEMENT

I recently attended a talk on childhood bereavement given by **Dr Dora Black**, a Consultant Psychiatrist from the Royal Free Hospital in London. The talk was aimed primarily at workers with under fives. Some of the points made seemed very relevant to MPS families who know that their MPS child may die while brothers and sisters are very young.

Dr Black emphasised the importance of grieving. Grief and love are like two sides of a coin. We won't feel grief unless we have loved, and **unless we grieve our capacity to love again will be impaired.** In order to grieve we must understand that the loved one will not return. Young children find it hard to grasp the concept that death is final much before the age of eight. Hence the little girl who said, "I know Daddy is gone to heaven but when is he coming back? When he went to Manchester he was home in time for tea. Heaven must be very far away."

Children can however be helped to understand what death means. For those who will have to face it at an early age preparation will be vital and can help them to cope much better when a brother or sister dies. Pets can be useful, especially the short lived variety --- Dr Black recommended goldfish, particularly those which died almost before arriving home from the fair! She says they should not be flushed down the loo but buried with a little ceremony in the garden, or other convenient spot of earth.

Children can begin to understand the concept of a body being outgrown like an old shirt or dress which is no longer needed and is given to the jumble sale. If you have firm religious beliefs, share them with your children, but if you don't believe yourself don't pretend to --- just say that you don't know. **Heaven is a very hard concept to explain to small children.** I remember my daughter asking the address so that she could write to her granny, and also wanting a long ladder so that she could climb up and visit her. Young children can be frightened by the idea of a spirit as it is linked in their minds with ghosts. They easily misunderstand what is said, like the child who thought angels cut off the dead people's feet and took them up to heaven. (How else would the soles get there?) It is hard to know what to say - I talk about the thinking part of the person but Charlie claims that that is theologically incorrect!

Should young children be taken to funerals? Dr Black does not suggest that parents do this if they feel very uncomfortable about it themselves. **On the other hand she believes it is helpful for children to go.** It would be better however if their first experience of the ceremonies surrounding a death were not at the funeral of someone very close.

Children can be prepared by ceremonies for pets, by walking in graveyards and talking about the inscriptions on the gravestones, and by going to the funeral of someone who is not so important to them. If a young child is to be at the funeral of a brother or sister where all the adults who care for him will be very upset, it would be helpful for someone else who he knows to be there to look after him and explain why people are crying.

Children often feel they are responsible for the death of someone close to them, as they still believe in the magic power of their wishes. Many brothers and sisters, however loving and caring they are towards an MPS sibling must have moments of jealousy and anger, particularly if the MPS child takes up a lot of the parents attention. **When the MPS child dies the brothers or sisters may feel it was their anger that killed him.** We can help our children by talking to them about angry feelings; how everyone has them, and how feelings cannot physically hurt another person.

**Young children may also worry that they too are in danger of death.** I think it also helps even quite young children to talk to them about MPS and reassure them that they have not got it. They can be told that their brother or sister may die because their heart is worn out or their chest is very poorly, but that theirs is strong and they will grow up to be adults. The trick I find most useful when talking with children is to ask them why they think something has happened - children who have had to leave their family or whose foster placement has broken down almost always say that it was their fault. For example one child said, "I was naughty and I kept getting out of bed, that's why I had to go away from home." Asking children why they think their brother or sister is ill or has died may help to discover a clue to their fears.

The illness and death of a young child is devastating for us as adults to cope with and too often we are afraid to talk to children about death for fear of upsetting them, or because we are too distressed ourselves. This leaves children struggling alone with their fears and fantasies. We may think that children do not hear or understand. Then we find out years later how well aware they were of what was going on, even if their interpretation was totally muddled and incorrect. **Talking honestly to all our children is the best remedy.** They may not be able to take in everything but they will sense when they are being told the truth. They will know that we are prepared to talk and answer their questions. We can't always say the right thing but for a child talking is always better than silence.

There is a book for young children which you may find helps you to talk about death. It is called, "I'll always love you", by Hans Wilhelm, published by Hodder and Stoughton in 1985. He tells the story of a little boy whose beloved dog gets old and fat and eventually dies and is buried. The boy takes comfort from the fact that he told the dog every night that he loved him.

Mary O'Toole

BOOKS ABOUT DEATH FOR ADULTS AND CHILDREN

BOOKS FOR PARENTS AND WORKERS

Helping children cope with separation and loss by Cladia Jewett  
Batsford Academic, 1984. £8.95.

PICTURE BOOKS

Goodbye, Max by Holly Keller  
Julia MacRae, 1987. £5.95.

Granpa by John Burningham  
Cape, 1984. £5.95.

I'll always love you by Hans Wilhelm  
Hodder & Stoughton, 1985. £2.50.

Mary and her grandmother by Bettina Egger  
Viking Kestrel, 1987. £6.95.

Nana upstairs and Nana downstairs by Tomie de Paola  
Methuen, 1983. £4.95.

Remembering Grandad: Facing up to death by Gianni Padoan  
Child's Play, 1987. £3.95.

When Uncle BoB died by Althea  
Dinosaur, 1982.

Why did Grandma die? by Trudy Madler  
Blackwell Raintree, 1981. £4.95.

BOOKS FOR OLDER CHILDREN

How it feels when a parent dies by Jill Kremantz  
Gollancz, 1983. £6.95.

When people die by Guinevere Williams & Julia Ross  
Macdonald 1983.

Does anyone have any unwanted new or nearly new toys that they are prepared to part with to help swell the funds of the Society? If so can I suggest to those of you attending the Conference in September to bring them along to sell at the Mini Market on the Friday evening. In addition to raising money for the Society I am sure many parents would welcome a few bargains.

Tony Lockyer





Institute of Medical Genetics  
Heath Park, Cardiff, CF4 4XN  
Tel. 0222 (direct line)  
0222-755944 Ext.

Dear Mrs. Lavery,

Over the past two years we have been analysing DNA from blood of patients and families with MPS II (Hunter's syndrome) in order to localise and in time isolate the gene involved on the X chromosome. Our family studies and the careful analysis of chromosomes from an affected girl with a rearrangement of the X chromosome have localised the gene accurately near the end of the long arm of the X chromosome. (I enclose reports).

We are now studying DNA probes in detail from this region to detect the gene itself; this will be of practical importance in improving carrier detection. We are particularly looking for 'gene deletions' (loss of small portions of genetic material) that can be detected by new techniques. To achieve this we need to study as many as possible unrelated patients, since only a few are likely to show the critical change that will help us to identify the gene.

Until now we have requested help mainly from families with several affected children; now we need a single blood sample from isolated cases as well. The help of your members would be greatly appreciated in achieving this and any family willing to help can contact me by letter or telephone.

Our research has been supported by the Research Trust for Metabolic Diseases in Childhood and Action Research, who also generously contributed to our newly opened Institute of Medical Genetics.

PETER S. HARPER  
Professor & Consultant in Medical Genetics

Uxbridge, Middlesex UB8 3PH  
United Kingdom  
Telephone Uxbridge (0895) 74000 Ext 2504  
Telex 261173 G

Health and Disability Research Group  
Department of Human Sciences

A REQUEST FOR YOUR HELP

LEARNING THE DIAGNOSIS

I am writing a book to be published in early 1989 on the process of giving medical diagnoses to people and their families. The object is to review present knowledge about this often difficult time, and to offer information to doctors, nurses and other health-care workers on how diagnoses might best be communicated. I am anxious to draw on the experience of as many people as possible who have been through such a situation - particularly where the diagnosis has considerable implications for the person concerned, their families and friends. I would therefore like to invite you to write about your experiences to me.

I am particularly interested in a number of issues such as: Who communicated the diagnosis to you, or how did you learn it? Where was it given to you? What were the circumstances leading up to the communication of the diagnosis, and your feelings about them? Did anyone else know about the diagnosis before, or at the same time as you? Did you suspect the diagnosis before it was formally given to you? Was the diagnosis a shock, a surprise - or a relief that you knew something definite? What was your immediate response? Why was that? What sort of support were you offered at the time the diagnosis was communicated - from doctors, nurses, or other health-care staff, or family and friends? Were there any particular problems for you in relation to your family and friends? Looking back what are your feelings now about the experience? Finally, what sort of way would have been best to learn the diagnosis? Who should have given it? In what circumstances, and in what ways? What sort of support or help would you have liked after being given the diagnosis?

I realise that looking at some of these questions may be difficult or painful, so write as much or as little as you like. Anything you say will be helpful. All the information I obtain will be treated as strictly confidential. Please write to:-

Ian Robinson  
Health and Disability Research Group  
Department of Human Sciences  
Brunel,  
The University of West London,  
Uxbridge,  
Middlesex UB8 3PH

The Children's Hospice Trust Appeal was formally launched in January 1986 with a remit to raise sufficient money to develop and manage a Home Support Service for families of children with a limited life expectancy and to build, equip and endow a children's hospice to provide respite care for these young people. The Trust's service is intended to support families within an approximate twenty five miles of the Home. For practical purposes the catchment area may be regarded as covering the same geographical area as the West Midlands Regional Health Authority, but this will not preclude support, particularly for respite care, being given to families outside this area.

The service we are planning to provide is support - practical, emotional and above all caring, to families who have children diagnosed as having a condition or disease which makes it unlikely that the child, or young person, will attain the age of 20 years. So - this is support over months or years for those youngsters who may be regarded as being chronically terminally ill. The entire service will be provided free to the family.

The Home Support Service is now being developed and links made with health, education and social services. Liaison with other voluntary organisations and parents' self-support groups is also a major priority.

It is anticipated that the initial service given by the Home Support Teams will be one of visiting families giving practical advice, help and counselling and developing links between families and services available in their own area. The Trust's staff will always work in close liaison with statutory and other voluntary organisations to ensure that "our" families receive all the assistance which is accessible to them.

"Acorns" itself is a bungalow type building with a flat for parents at first floor level. There are ten bedrooms for children - all of which can accommodate a parent, or other family member, overnight. The staff within "Acorns", and in the Home Support Teams, will be mainly nurses with social workers, teachers, nursery nurses, psychologists and others, including a cook and housekeeper, all being part of the caring team. The care given within "Acorns" will be at a level that could be given in a child's own home with the support of community nurses and General Practitioners. "Acorns" will always be an alternative to the child's home, not hospital, (except where a hospital placement would be an inappropriate alternative).

We shall be very pleased to hear from you, whether you are a local group or family in the West Midlands, who believes that our service could be of benefit to you, or if you have information to give us to enable this Trust to provide the service you would like to use.

Our present address is Monaco House, Bristol Street, Birmingham, B5 7AS, telephone number 021 622 4650, but in August this year we shall move to "Acorns" at 103 Oak Tree Lane, Selly Oak, Birmingham, B29 6HZ.

"Acorns" is scheduled to open at the end of September, but during late August and early September there will be publicised Open Days when you will be very welcome to visit.

#### NEW MOBILE CHILD ALARM

I have been fortunate enough to get Mothercare to donate a Mobile Child Alarm to the Society so that we can try it out before families spend £29.99 on something which does not meet their requirements.

This alarm is different from most others in that it is cordless and only plugs into the mains in your child's room. The receiver is small, portable and operates over a maximum distance of 100 yds. It can be in the same room as you or clipped to your person whilst you are on the move. It would therefore seem to be ideal in that it can be used at home or perhaps for holiday use in caravans, flats etc.

Fiona and I have, however, two major reservations -

- (1) There is a constant buzz from the receiver, albeit quiet, which means that there is no way you could hear your child breathing. However, you can definitely hear your child making noises or crying.
- (2) The noise level from the receiver cannot be increased and therefore you must be reasonably close to it to hear your child.

I have only one alarm, and with around 400 families it would be impossible to allow everyone to try for a week or so. However, one family in each area may wish to borrow it and others could visit and view for themselves. If you wish to do so, please do not hesitate to phone and I will post it on.

ALAN BYRNE (GLASGOW)  
041 643 0034

## NEW BENEFIT RATES

### INCOME SUPPORT / HOUSING BENEFIT

#### PERSONAL ALLOWANCES

Single Claimant:	
under 18	£19.40
18 to 24	£26.05
25+	£33.40
Lone Parent:	
under 18	£19.40
18+	£33.40
Couple:	
both under 18	£38.80
at least one 18+	£51.45
Child or Young Person:	
under 11	£10.75
11 to 15	£16.10
16 to 17	£19.40
18+	£26.05

#### PREMIUMS

Family Premium	£ 6.15
Lone Family Premium:	
Income Support	£ 3.70
Housing Benefit	£ 8.60
Pensioner Premium:	
single	£10.65
couple	£16.25
Higher Pensioner Premium:	
single	£13.05
couple	£18.60
Disability Premium:	
single	£13.05
couple	£18.60
Severe Disability Premium:	
single	£24.75
couple - one qualifies	£24.75
couple - both qualify	£49.50
Disabled Child Premium	£ 6.15

CAPITAL LIMIT £6,000

TARRIFF INCOME £1 for each £250 between  
£3,000 and £6,000

#### EARNINGS DISREGARDS

higher	£15.00
lower	£ 5.00

#### BOARDERS

B+L limit (ordinary/hostels):	
Adult/child 11+	£70.00
Child under 11	£16.15
Meals allowances	
breakfast	£ 1.10
lunch/dinner	£ 1.55
Personal allowances	
claimant/partners (basic)	£10.30
" " " " " (higher)	£11.50
child or young person 18+	£10.30
16 - 17	£ 6.20
11 - 15	£ 5.30
0 - 10	£ 3.45

#### HOUSING BENEFIT CALCULATION

Maximum rent rebate: 100% rent  
Maximum rate rebate: 80% rates  
Income above Applicable Amounts  
Reduce rent rebate by 65% of surplus  
Reduce rate rebate by 20% of income

#### NON-DEPENDANT DEDUCTIONS

Rate rebate	£ 3.00
Rent rebate: higher	£ 8.20
lower	£ 3.00
Income Support (housing costs)	
higher	£ 8.20
lower	£ 3.45

#### FUEL DEDUCTIONS

National charges:	
Heating	£ 6.70
Hot water	£ 0.80
Lighting	£ 0.50
Cooking	£ 0.80
Maximum deductions (1. Support): as above plus £1.50	

#### FAMILY CREDIT

Threshold	£51.45
Maximum Credit	£32.10
Adult Credit	£ 6.05
Child 0 - 10 years	£11.40
11 - 15 years	£14.70
16 - 17 years	£21.35
18 years	£21.35

#### FAMILY CREDIT CALCULATION

Reduce maximum credits by 70%  
of income above Threshold.

## LETTER TO THE EDITOR

I would like to respond to the Abortion Amendment Bill and the lobbying of parents. I was deeply saddened that such an article was placed in your newsletter. The Society claims to take no stand, yet a letter is written to proclaim the right to abortion. I am an MPS sufferer who sees beauty in each person from the very mildly affected to the severely affected.

It is true that I cannot judge, for only on your death will you need to come to terms with your life. I only need to hear the word of God which I believe is truth. "For the least things that you do to the least of my brothers and sisters that you do unto Me." It sends a mixed signal to me to fight to make life experience better for the child with MPS, and for their parents and siblings, only to have people say, "It would be better that we never existed at all." In the future let's see no more articles about this issue and keep it a personal decision that your individual conscience must make. Individuals must also deal with the consequences of what they choose.

**Bill Sellmeyer**

## FROM THE EDITOR

Bill's letter raises painful issues which deserve a response. As Editor I will respond as best I can, making it clear that this is a personal response and that I cannot speak on behalf of the Society. I can however repeat what was said in the last newsletter, namely that there is no Society view on what the law on abortion should be and those who hold positions in the Society in no way wish to interfere with members individuals views.

Secondly, material submitted to the newsletter is not censored and members are invited and encouraged to tell of their experiences and to express their views. This applies whether they are on the Committee or ordinary members. It would be difficult to imagine how people who take a leading part in our Society could avoid issues that are personally and morally painful, uncertain, and difficult. The MPS Society was formed to help sufferers and their families deal with matters that most families can scarcely imagine. Its leaders cannot avoid the issue of abortion because few MPS families can avoid a direct choice for or against abortion.

Members of the Committee felt that they had an obligation to oppose the Bill, so that families could still make this choice for themselves. It is not that they favour the abortion of handicapped children, or that they feel they can speak for other members of the Society. They simply say it is better to have a law that leaves some choice to families.

Does it devalue the lives of sufferers if new sufferers are prevented from being born? If the most devoted and selfless parents that we know decide on abortion do we then decide that they are people with no respect for life?

**Charles O'Toole**

## SHOES

For children with problem feet, Contact a Family, which is a network of support groups for children with special needs has come up with several firms that might be able to help:

Soma Footware,  
John Drew (London) Ltd  
433 Uxbridge Rd  
Ealing, London W5 3NT  
Tel: 01 992 0381

Soma produce 'made to measure shoes for problem feet' and see they can make every shoe to fit individual foot problems providing a combination of comfort and good looks.

Adimed (The Adidas Orthopaedic Range)  
Jane Manning Ltd  
1070/72 London Rd, Thornton Heath,  
Surrey. Tel: 01 684 2364

Adimed is a wide range of track shoes which can be adapted for special feet and ankles. They are available on request from retailers.

## THE MOBILITY INFORMATION SERVICE

This service exists to give advice on all aspects of mobility. If you would like advice or information please to:  
Mobility Information Service

Unit 2a  
Atcham Estate  
Upton Magna  
Shrewsbury SY4 4UG  
Tel: 074 377 489

## Statementing of Children with Special Educational Needs.

Radio 4 has produced a basic but very clear leaflet about procedures for statementing, and the various time limits involved, including appeals etc. The leaflet is available from :

BBC Education  
Villiers House  
London W5 2PA

## Who wants an au-pair ?

Hello,

I have been studying pedagogy of the physically handicapped and speech impaired since 1984. At the moment I am writing my final thesis about my work with a 15-year-old spastic girl. After I finish this part of my exam I would like to come to Britain. I would like to coordinate my interest in working with handicapped children with some work on my English because I need to prepare for my examination. That is the reason why I am searching for a family who is willing to give me a kind of au-pair job. Unfortunately I cannot stay for longer than four months because of my exam. I am aware of the possible problem resulting from the time limitation for both - the family and me. I hope I can prove what people say about my sociability and flexibility.

I am willing to do all kinds of housework and baby-sitting and I would not expect pay, just a bed and board. As I said above I am well experienced in work with handicapped children as well as in managing a household.

My friend, Liz Volk, has two children suffering from MPS so I have some knowledge about the disease. I am willing to tackle the occurring problems.

For me it would be ideal to start work between the beginning of November and the middle of December.

I will gladly supply references, if desired and look forward to hearing from you.

Silke Hano  
Dürener Str. 322  
D- 5000 Köln 41  
Tel. 011049 /221 /434449



## GUIDELINES FOR FUNDRAISING

Sometimes, when people are raising money for the Society, they are not sure what to do with all the cash they are given. The easiest method is to pay the money into the main MPS account at your local bank. Cheques and F.O.s can be sent to the Treasurer or Fundraising Co-ordinator.

If you wish to pay directly into the Society's account, the details are as follows:

**Barclay's Bank, Little Chalfont;**

**Sort code 20-50-48**

**Account number: 31301764.**

**Account name: The Society for Mucopolysaccharide Diseases**

Please send the counterfoil and details for a receipt to the treasurer.

Sometimes people like to open a special bank account for money raised. The Management Committee feels this is unnecessary but if you do so can you please make sure that the account name **doesn't** have **MPS** in it.

The above rule is made for 2 reasons: **Firstly** all the Society's accounts have to be audited and access to the money held in any account must be available to the Treasurer, who cannot be held responsible for accounts which are outside her control. **Secondly** the Society obtains higher interest rates than normal, because of the amount of money held in our account. Also **we do not pay tax** on interest gained. This concession is only possible through the trust deed, so by paying in the money to the MPS account straightaway, you are benefiting the Society with added interest.

I have a complete set of guidelines for fundraising designed to help you with the money side of things. If anyone would like a copy, I will happily send you one. (Your area family also has a copy). I will also issue a letter of authority to fundraise if you request it. Keep up the good work!

Pat Isaacs  
for the Management Committee

\*\*\*\*\*  
TIDDLER JAR!

If you belong to a club of any sort that has regular meetings - why not suggest a 'tiddler jar'? The jar is kept on the chairman's desk and anyone attending the meetings who has loose, small change in their pockets or purses can be invited to get rid of it into the jar for MPS funds! If the jar is taken to every meeting, it soon becomes a habit.

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## FUNDRAISING EVENTS

Sue and Dan Butler held a cheese and wine party

Pat & Ken Mould held a variety of events in memory of their grandson, Simon Fisher

St. Michael's Youth Group, Bucks, went carol singing

Miss A. Day did a sponsored walk

Helen Humphreys and Michelle Watkinson held a Spring Fayre

Talisman telephone exchange held a raffle

Nelson Lodge had a collection

Kelly & Caroline Rocket held a coffee morning

Silver Cross Scottish Come Dancing Group raised money from their funds

2nd Biggleswade Guide Company and M.E. Humphries held a coffee morning

Edward Hodgkins held a concert

Mr. G. Smith, Bristol, held a raffle

Carol & Paul Hubbard held various sales

Katie Bottom held a clothes party

Doreen Russell's Church held coffee mornings and ran a charity shop

Alison Glassford sent Webb Ivory Catalogue Commission

Bridgwater National Union of Teachers raised money from their funds

M.A. Bouch held a coffee morning

Bridgwater College donated the proceeds from their 'Rag week'

1st Rutherglen (Glasgow) Ranger Guides held a fundraising event

Doreen Russell organised a raffle at a skittles evening

G. Simms raised money selling plants

Pat Isaac held a book sale

Gaye Finch organised a weekly staff weigh-in for the Spring Term

Sedgemoor District Scouts, Somerset, donated half their St. George's day Parade Collection

Sarah Lowry, Barry and Joanna Winsley collected 1p pieces

Doreen Johnson held a fashion show

Remy Moynihan did a sponsored goal - kick

Helen Humphreys raised money at Michael Watkinson's Toddler Group

Edgarley Hall School, Somerset held a series of events

Diane Bayliss and friends sold their hand-knitted toys

London Marathon

The following people have so far sent in London Marathon sponsorship money: V. Kaye; Mr & Mrs A Hunt; C. Collins; Val Gerrard; C.J.H.Gooch; Sylvia Maguire; Lesley Harvey

### Charity Boxes

The Society acknowledges with thanks the funds that continue to be regularly received from MPS collection boxes in shops, pubs etc. around the country. The latest one we heard about was in a taxi!

### Donations

The Society appreciates the many donations received from individuals and companies - these are too numerous to mention individually, but each will have received a personal acknowledgement.

### NORTH WEST LEISURE GROUP OUTING.

On Sunday May 8th 40 of us in the North West met at Stapeley Water Gardens for a social afternoon. Although the weather was a little overcast and my family as usual were late arriving we all had a good chance to see all the different things on offer.

There were large ponds with different sizes of what looked to me like gold fish, but I had never seen any before over 12 inches long. There was a shark and an octopus and lots of very brightly coloured fish as well. I was most fascinated by the one that was bright pink at the front and yellow at the back

Then we all piled back into our cars and descended on Bill and Sylvia Blackburn's for tea. I think their house must have elastic sides. Quite a few of the children spent the rest of the afternoon in the garden playing a ball game. They managed to lose two and puncture another one. The rest of us had time for a chat passing backwards and forwards any advice that we could.

### Margaret Leask.

FUNDRAISING EVENTS (continued)

Carol Hubbard \*\*\* raised money on used postage stamps.  
Margaret Horsley \*\*\* held a perfume party and raffle.  
Sainsbury's (Kingswood Branch) \*\*\* held a series of fundraising events.

Milton Keynes Renzoku Judo Club \*\*\* gave a donation  
Cow and Gate (Wilts) Staff charity committee \*\*\* gave a donation.

Westbury Keep Fit Club \*\*\* held a jumble sale.

M.Hudson \*\*\* organised a sponsored walk.

VAT International 3 \*\*\* collected 5p from anyone drinking alcohol in Lent.

PJ & BM Oldridge \*\*\* held a coffee morning.

Una and Dermot Murphy \*\*\* held a dance at Camden Irish Centre.

P Harrison \*\*\* ran and collected sponsors for the Fleet Half Marathon.

D Brooks Daw \*\*\* ran and collected sponsors for Taunton Half Marathon.

Jean Graveney \*\*\* organised a Glitter Ball, Summer Barbeque, and Samarkand Summer Sale. (What's that? Ed.)

Bennet Memorial Girls School Tunbridge Wells \*\*\* held a sponsored spell.

St Oswald's Special School, Glasgow \*\*\* threw coins at a bottle.

Trinity St Pauls Junior Players, Glasgow \*\*\* held a variety show.

Gaye Ward \*\*\* organised a sponsored football match.

Thomas Cook Employees (Cambs) \*\*\* ran a series of events.

Yvonne Hardy \*\*\* collected coppers in a tiddler jar.

The Sutcliffe family and Gatehouse Well Dressing Group (Derbyshire) \*\*\* collected donations at their decorated well.

A & J Price \*\*\* held a car boot sale.

Trevor Rollinson and colleagues \*\*\* ran in a Marathon from Blackpool to Cleethorpes.

Paul Wright and Nick Loach \*\*\* did a sponsored parachute jump.

Anne Hill \*\*\* held a second hand clothing sale.

Donations in lieu of flowers have been received in memory of **Darryl Hughes and Darren Man**

London Marathon

Michael Barnett was at the last minute unable to run in the London Marathon so he was replaced by Bill Buckley aged 72 years. He is an ex British Airways engineer, who took up running 6 years ago and completed the 1988 London Marathon for MPS in 4hrs 3mins.

Frances Toptani completed the London Marathon in 4 hours 44 minutes. She was very thankful when it was over but will have another try next year! Frances works in publishing magesines. She raised £60 for MPS and £418 for Great Ormond St Hospital.

**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

**Colin and Mary Gardiner**

35 Church Rd, Banks, Southport, Merseyside.  
Tel: 0704 213438

**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: 0242 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