

NEWSLETTER

SPRING 1992

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES



National Registered Charity No. 287034

Chairman of the
Management Committee

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

Hon. Director

CHRISTINE LAVERY
7 Chessfield Park
Little Chalfont,
Bucks. HP6 6RU
Tel: 0494 762789

Hon. Deputy Director

MARY O'TOOLE
8 Elmhurst Ave
London N2 0LT
Tel: 081 444 8461

Hon. Treasurer

PAULINE MAHON
41 Stumperlowe Cres. Rd.
Sheffield 10
South Yorkshire
Tel: 0742 304069

Fund Raising
Co-Ordinator

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

Sales Organiser

SUE BUTLER
Spriggs Holly House,
Spriggs Holly Lane,
Chinnor Hill, Oxon.
Tel: 0494 483185

Welfare Rights Officer

WILMA ROBINS
77 Hillview Avenue
Hornchurch,
Essex RM11 2DN
Tel: 040 24 43157

Northern Co-ordinator

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

Newsletter Editor

CHARLES O'TOOLE
(as above)

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



The Society for Mucopolysaccharide Diseases

7 Chessfield Park, Little Chalfont, Buckinghamshire HP6 6RU
Telephone/Fax: 0494 762789

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

- To act as a parent support group
- To bring about more public awareness of MPS
- To promote and support research into MPS

The Society operates a network of Area Families throughout the UK and Northern Ireland, who offer support and links to families in their areas. It provides an information service for families and professionals. At the present time it funds two Consultant Paediatric Posts and a biochemist at Manchester Children's Hospital. It encourages and assists contact and co-operation between parents and professionals and maintains links with sister societies in Europe and throughout the world.

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

“Care Today, Hope Tomorrow”

Contents

A decade with MPS.....	3
Milestones.....	4
Dates for your anniversary diary.....	5
Ingrid Schmalzl.....	7
Fundraising: Ron Snack.....	8
Symmetri Kit Chair: John Peter Hodgetts.....	9
Feature; working with Matthew (Hardy).....	10
Christiana Charalambous: Peter Benbow.....	12
Feature: A tribute to Shelley (Scarr).....	13
Matthew Blackburn: Tube Feeding.....	17
Home Improvement Grant experience (Grandidge).....	18
Experience with the "Sleep belt" (Gooch).....	19
Northern Co-ordinator's report.....	20
Child of Achievement (Edward Nowell).....	21
Area Family Training Weekend.....	22
Children's Hospice Scotland.....	23
London Marathon.....	23
Letter from New Zealand (Diane Bayliss).....	24
North West Family Day.....	25
Northern Ireland report.....	26
New cash help for people with learning disabilities.....	27
Fundraising Events.....	28

Deadline for Summer Newsletter

Friday 3rd of July.

Christine Lavery this does mean you!

A decade with the MPS Society

It is now sixteen years since Robin and I first heard that unpronounceable word "Mucopolysaccharide". That was at the time our first son, Simon, was diagnosed as having Hunter Disease in 1976. With little idea what would lie ahead for us as a family, or more importantly for Simon, we set off to live for four years in Tokyo, Japan. With little medical backup but a determination to live life to the full, for us ignorance was bliss.

We returned to the UK in 1980 to pressures of education and hospital visits and the shocking recognition that Simon was losing ground. He wasn't holding his own with his friends and he stood out in his primary class.

Simon's death lead to the birth of the Society.

Special Education became inevitable. Simon loved his term at Heritage House in Chesham. Simon died in 1982. His death lead to the birth of a new baby, the MPS Society. Since those early days we have been witness to the growth of what is now a highly respected organisation.

An MPS child born every ten days.

Many of you have shared the determination to achieve better things for MPS/ML children and their families. Recently Robin and I were analysing the society's data. We discovered that an MPS/ML child is born every ten days in the UK. Perhaps our children's problems are not so rare after all.

Key Achievements.

If you ask what are the Society's key achievements over the past ten years they must be:

- The production of booklets for each of the Diseases.
- The introduction to the UK of the management of the cervical spine in children with Morquio disease.
- Providing the samples of blood that led to the discovery of the Hunter gene.
- The Society has raised a quarter of a million pounds for research and treatment of MPS diseases. This includes the funding of Dr Ed Wraith's and Dr John Walter's posts at Manchester.
- The setting up of the post of Northern co-ordinator, funded by BBC Children in Need.

Little advance for Sanfilippo

One of the greatest disappointments is that in the past ten years there has been little advance in the treatment of children with Sanfilippo disease and that in some areas it is still not being diagnosed early enough to prevent the risk of further affected pregnancies.

Christine Lavery

Milestones

Births

To **Nora and Tom Corcoran**, the birth of a baby daughter Amanda, on 31st January 1992. Amanda has been diagnosed as suffering from Hurler disease, as are her brother William and sister Marian.

New Families

Julie and Trevor Thacker, from Harleston, Norfolk, whose son Thomas aged 3 has been diagnosed as suffering from Sanfilippo disease.

Ranwear, Savita, Rajesh and Pritika Silhi from Gillingham in Kent. Both Rajesh and Pritika suffer from Scheie disease.

Susan and Vince Hayward from Crawley, Winchester. Susan and Vince's one year old daughter Emily has Hurler disease.

Michelle Brennan, from Dalton, Huddesfield. Michelle's 2 year old daughter, Kellie, has I-cell disease.

Ann and Ron Thompson, from Darlington, Co. Durham. Their four year old son, Michael has Hunter Disease.

Manzoor Akhtar and Ilyas Hussain whose son Zain Ilyas has Sanfilippo Disease. Manzoor and Ilyas live in Tyslea, Birmingham.

Sharon and John Hattle, from Billingham, whose twelve year old daughter Debra has Sanfilippo disease.

Deaths

We were very sorry to learn of the death of **Adrian Twigger**, on 10th February 1992. Adrian suffered from Sanfilippo disease and would have been 15 on the 21st March. Our thoughts are with Shirley, Keith, Charlotte and Paul at this sad time.

We were also very sorry to learn that **James Stenings** died on the 17th December 1991. James suffered from Hurler disease and was aged 20 months. Our thoughts are with his mother Caroline and her family.

We are very sorry to hear of the death of **Timothy Norsworthy** on the 13th of April. Timothy suffered from Morquio disease and was aged 22 years. Our thoughts are with his sorrowing parents Clive and Jenny and his brother Christopher.

We wish to remember the death of **Moustakin Ali**, of Bristol, who died in 1989, aged ten years. Moustakin had Hunter disease. Our sympathies to his parents and family.

Dr Richard Lindenbaum

Many MPS families, especially in the Oxford Area, will be grieved to hear of the death of Dr Richard Lindenbaum, who was consultant geneticist for the Oxford Group of Hospitals. He advised and counselled many MPS families. He was a most accomplished man, a gifted linguist, with a great interest in botany and poetry. He was a pacemaker for Roger Bannister at the time of the breaking of the four minute mile.

Dates for your Anniversary Diary

The North West

- June 7th "Come to June's in June". Fund raising Garden Party. Gilford's Dairy, Eastern Rd. Willaston, Nantwich, 1.00 to 5.00pm. Contact Bill Blackburn.
- June 28th "Family Picnic" celebrating 10th anniversary. Haigh Hall Country Park, Haigh, Near Wigan. 12.00 onwards. Contact Mary Gardiner.
- Dec 6th "Christmas Party" The Haydock Thistle Hotel, Penny Lane, Haydock, St Helen's, Merseyside. 1.00 to 5.00pm. Lunch and children's entertainer.

The North East

- June 28th "Family Picnic" celebrating 10th anniversary. Washington Wild Fowl Park, Newcastle upon Tyne. 12.00 onwards. Contact Barbara Arrowsmith.
- Dec 6th "Christmas Party" Washington Forte Post House Hotel, Washington, Newcastle upon Tyne. 1.00 to 5.00pm. Lunch and children's entertainer.

Yorkshire and Borders

- May 31st "Family Barbeque" Sean and Pauline Mahon, 41 Stumperlowe Crescent Rd, Sheffield, South Yorkshire. 1.00 to 5.00pm.
- June 28th "Family Picnic" celebrating 10th anniversary. Castle Howard, Near York, Yorkshire. 12.00 onwards.
- Dec 6th "Christmas Party" Venue to be confirmed.

The Midlands

- June 28th "Family Barbeque" celebrating 10th anniversary. Sharrats, School Lane, Hopwas, Near Tamworth, Staffs. 11.30 am to 5.00pm. Contact Jeff Hodgets
- August 9th "Boat Trip" Abbey Park, Staffordshire. 10.00 to 5.30pm. Lunch at 1.00. Limited numbers.
- Dec 6th "Christmas Party" Grand Hotel, Stoke on Trent. 1.00 to 5.00pm. Lunch and children's entertainer.

East Anglia

- June 28th "Family Picnic" celebrating 10th anniversary. Wimpole Hall Park and Farm, Arrington, Near Royston, Herts. Meet at 11.15 am by stable block near car park. Contact Jane and Neil Reid.

Dates for your diary (cont'd)

Home Counties

28th June "Area Picnic" for 10th anniversary. Sue and Mike Blaney, Littlewood Corner, Wood Lane, South Heath, Great Missenden, Bucks.
11.00am to 4.00pm

South East

28th June "Family Outing to Bentley Priory, Sussex. Details from Alf King.

South West

28th June "Family Outing" to Devonshire Centre, Bickleigh Mill. Meet at 12.30pm.
Details from Tony Eyre.

Scotland

28th June "Family Outing" to Edinburgh Zoo followed by tea in the Post House Hotel
Details from Alan Byrne.

Northern Ireland

20th May Mixed foursome golf at Strabane, followed by prizegiving on Sat. 24th of May attended by Ron and Linda Snack.. Details: Kieran Houston.

7th June Co-ordinating committee meeting at Strabane.

28 June "Family Picnic" at Port Ballintrae. Organiser Rachel Todd. 02657 32042

Wales

We hope to organise an event in Wales for the 28th June. More local help is needed. If you can help please contact Christine Lavery as soon as possible.

National

30th June Afternoon tea at House of Commons, hosted by Dafydd Wigley MP.
Guests will include Area Families and Committee members. Contact Christine Lavery.

25 - 27th Sept "Annual Conference" Holiday Inn Hotel, Bristol.



Auf Wiedersehen

With great sadness I am leaving my post as Ward Sister of Ashby Ward, Royal Manchester Children's Hospital on February 7th.

Twenty three years of service.

After nearly 23 years service to the hospital, its' Salford patients who have been nursed on my ward, and many families from all parts of Britain, I would like to say that it has been a privilege to get to know you and to be allowed to look after your children.

My extended family.

I have always regarded you as my extended family and I have done my best to make a stay on the ward as comfortable as possible. I know we have won a place in the hearts of many of you and you can be assured that you occupy a place in mine.

A privilege.

The need to remain a well informed, practical, children's nurse has been my motto. By example and endless teaching I have tried to

hand on my knowledge and skills to generations of trainee nurses. It has been a privileged to have been a valued member in a multi-disciplinary network of professionals involved in caring for your children. As always, with love and affection,

Sister Ingrid.

- (with acknowledgements to the Manchester Evening News)

Dear Christine,

Only today have I enough peace of mind to write to say thank you so very much for the lovely present, book tokens and dinner out. I was quite overwhelmed by it all and your generosity - it looks as if you have also spoken to the reporter from the Manchester Evening News about me - by what I read in the paper on Saturday. For it all, and your friendship most of all, a plain "thank you" does not seem sufficient. Perhaps I can repay it in some other way in the future.

Kind regards

Ingrid Schmalzl

Another bellringer found

I'm sure that you know that one of my main interests, apart from the MPS Society is bellringing. Ever since we joined the Society I have been looking out for other bell-ringing members, but to no avail. What a shock then to find that two of the people I used to ring with in Leeds have now joined the Society. The Grandidges, from Cheshire, have a three year old son with Sanfilippo.

A very creditable quarter peal!

This was too good a chance to pass up, so when Mary Gardiner was holding a little family day I arranged some ringing near Nantwich. Although Chris (Stephen's dad), has not rung for more years than he cares to remember, we rang a very creditable quarter peal - that's about three quarter of an hour's ringing - with help from Stephen Marchbank and three local ringers.

Now that there are two of us I am seriously thinking about arranging some ringing to coincide with our tenth anniversary conference - so keep your ears open in Bristol in September.

Ron Snack

Events calendar

The Charities Aid Foundation produces an events calendar to publicize fundraising events anywhere in the country. If you have an event you would like to go on the CAF calendar please let me know the details.

The calendar is updated every three months and lists events in date order for the coming year. There is no charge for entries.

Ron Snack

Looking forward

Garage sale

With the better weather of Summer just round the corner how about sorting out the garage or the shed and arranging to have a stall at the local car boot sale. Always a way of raising a few pounds and meeting new people as well.

Kiddies fashion show.

If you don't fancy that, how about organising a kiddies' fashion show? Let the children decide what they will wear. Suggest they mix and match their clothes with some of their friends. Then charge people to see the results. A cup of coffee and a cake at the interval will also boost the takings.

Stage your own catastrophe!

For all you First-Aiders, why not arrange a First Aid display with a difference. Stage a mock disaster and show the paying public what a brilliant job you would make of coping.

I'm sure you can think of other things to raise money. Every little helps. Whether it's a fiver or five hundred pounds it's all worth doing.

Ron Snack

Thanks for the stamps

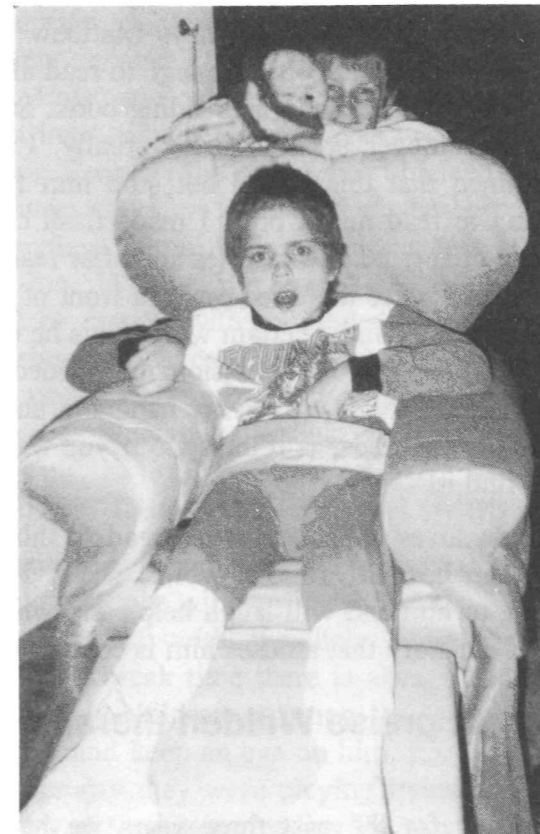
Thanks to everyone who passed on postage stamps to me. I will send them to Paul Hubbard who arranges for them to be sorted and sold.

In memory

Our thanks to those who have donated money to the Society in memory of **Gethin Robins** and **Harry Butler**, Alex Butler's grandfather.

Ron Snack

John-Peter's Chair



His Royal Highness on his Throne

Our son John-Peter suffers from Sanfilippo and is aged eleven and a half years.

We experienced a lot of trouble finding a chair that was comfortable and secure for him. After finding John-Peter on the floor again after falling continually out of his bean bag, we decided enough was enough.

After a lot of research and costing we found out about the "Symmetri Kit Chair".

The Symmetri Kit Chair

This chair is designed to be fully adjustable, in order to adapt to position required for comfort, whatever the deformity. The chair covers are all fully washable and made of velour, so that it

looks like any ordinary armchair.

The arms adjust in height and tilt to the front or the back. The seat can be adjusted. The overall seat height can be changed. The seat rake has two positions, the lower one is obtained by lifting the back up and dropping the seat down into a second slot. To change the angle of the back-rest a pedal at the back of the chair is depressed and the back rest adjusted as necessary. This leaves your hands free to support the occupier. The wings are also fully adjustable for full head support.

Price Guide:

Small £610 Large £630

It is always advisable to consult the Occupational Therapist from your local Social Services Department before buying an aid. They may be able to prescribe it free of charge, or at a reduced charge.

The Family Fund, or React, 73 Whitehall Park Rd., London W4 3NB, may also be able to help with the cost. Do not be afraid to contact them.

Sue and Jeff Hodgetts

6 Godolphin, Riverside, Tamworth, Staffs. B79 7UF 0827 56363

For further information, contact:
Symmetrikit Ltd.
The Sharratts, School Lane,
Hopwas, TAMWORTH.
Staffs. B78 3AD.
Tel: 0827 69992/67414
Fax: 0827 67414

Working with Matthew

Just over four years ago I was working with special needs children in a mainstream first school. Out of the blue I was approached by the school's child psychologist who asked if I would be prepared to transfer to Stoke Leys, a special school, to work on a one to one basis with Matthew Hardy, a six year old boy with Hunter Syndrome, who would be starting there in the autumn. I had never heard of MPS, let alone Hunter Syndrome, but when it was all explained to me I had no hesitation in accepting.



Matthew working on his logic box
with Val

I felt it was important for Matthew to meet me and for me to get to know him before starting at his new school. I visited Matthew at his home and was surprised to find how active he was. When we first started working together at Stoke Leys I had to sit next to him with my left leg over his legs and my left arm around him, just to keep him in one place. This left my right hand free to work with. It did not take long before he could sit quite happily on his own and

I could stop the contortionist act.

If you want it - you find it!

In his early days at Stoke Leys Matthew was still able to talk and could manage to read aloud the few simple words in his reading book. Sadly he can no longer communicate verbally. I was determined that this would not stop him from learning to read new words. I made flash cards of the words from news stories and after reading the stories I place the three cards in front of him and ask him to find a certain word. This he does most of the time but occasionally he decides that it is my turn. He grabs my hand and pushes it towards the cards, as if to say, "If you want it - you find it!"

Matthew loves to have stories read to him. I find that he will follow words when I am reading to him and will laugh helplessly when a part of the story that amuses him is coming up.

I cannot praise Walden therapy enough

Every day for the past three years we have a session of "Walden Therapy." This certainly stimulates Matthew and he is now doing such things again as building with bricks, pushing toy cars and fitting shapes into the logic box. I have been told that he dips his biscuit into his mum's drink and will reach out for things across the table at meal times. Prior to starting the Walden Therapy Matthew had not been doing these things. I cannot praise this therapy enough. It certainly has helped Matthew.

Swimming

Swimming is another favourite with Matthew. He goes to the hydrotherapy pool once a week and also to the ordinary pool with the rest of the school and I go in the water with him. He is so relaxed in the water now. To start with I had bruises on my legs where he used to cling to me and try to climb up me because he was unsure

of himself in the water. Wearing armbands he will now float quite happily on his back without being held. Matthew also enjoys movement and PE with the rest of his class.

Lots of excited little noises

I have managed to continue number work with Matthew by using pictures and numbers on cards. I also use coloured cotton reels threaded on strings which incorporates finding the colours. Recently the school has obtained some computers and I am able to help Matthew with the numbers game, which I must admit I find great fun. In "weekly news" he will hold a pencil or crayon with me and will do a little colouring on his own. When he has finished there are lots of excited noises as I read what we have written and talk about his picture.

Matthew has a go at most things

Matthew is able to have a go at most things at school, not only with my help and that of my colleagues but with the help of his many friends. At break time there is always a surfeit of willing children wanting to play with Matthew and keep an eye on him. For instance, the other day they were playing trains and had Matthew as the engine leading the way.

The most rewarding job I have done

I have been working with children now for thirty eight years, in nurseries, schools, hospitals and also fostering. I can honestly say that working with Matthew has been the most rewarding job that I have done.

I cannot begin to understand what it would be like to have an MPS child of my own.

Finally I would like to say that in no way can I begin to understand what it would be like to have an MPS child of my own. Having worked with Matthew for the past four years I naturally feel very close to him and I am sure that everybody who works with these special chil-

dren must share a little of the sadness that their parents have to bear.

Val Merry Welfare Assistant

Stoke Leys School

Aylesbury, Bucks.

Thanks to Ann Kirkpatrick and Martha Rea

After several busy years of fundraising and publicity on behalf of the Society the MPS shop in Antrim town, Northern Ireland, has closed on the 4th of April. We hope to give you the final figures raised by the shop in the next newsletter. A special thanks to Ann Kirkpatrick and to her friend Martha Rea, who continue to be very active in the NI group.

Petrol Vouchers

BP have a scheme where charities can exchange vouchers for cash. Other vouchers can be used to get prizes for raffles etc. Why not ask your local garage if you can put a shoebox decorated with MPS publicity on their counter for unwanted vouchers? All vouchers to Ron Snack or the MPS office please.

Conference 1992 - Bristol

There are still some bookings for the conference, but hurry, they are going fast. We have a new payments scheme where families can make monthly payments over six months and this is proving very helpful. If you would like to come to the conference but are worried about the cost do not hesitate to contact the office who may be able to find ways to help. (This is dealt with in confidence).

Christiana



Christiana with her brother Thalís
Summer 1991

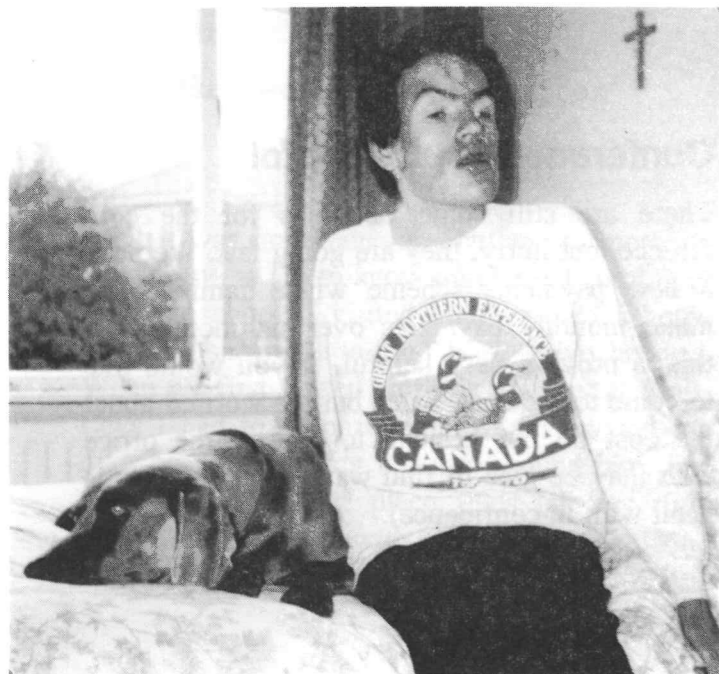
As many of you know the first evening of any MPS conference can be a little overwhelming, especially when it is your first. The Manchester conference two years ago was like that, but an introduction to a little Hurler girl and her father made it a very special occasion for us. Her broad smile melted into an infectious giggle and we were totally won over.

Christiana and her father Andreas had travelled from their home in Cyprus and looked a little bewildered. However it was not long before they made friends. As the weekend progressed more and more of us fell for Christiana's smile.

You may be wondering why we are reminiscing about an event which happened two years ago. Sadly, we have heard that Christiana died in December. She lives on in our memories and that wonderful warm Mediterranean smile radiates still for all who met her. Our hearts go out to Andreas and his wife Olya. We hope they will have a happy future with their son Thalís and their new baby expected in the Summer.

Tony and Shirley Eyre 6 Westway Park, Yatton, Avon.

Peter Benbow in his room with his faithful friend. Peter is aged 27 and lives with his mum and dad in Greasby, Wirral. He suffers from Sanfilippo disease.



A Tribute to Shelley

She has captured the spirit of MPS children.

When Shelley passed away I thought my world had ended. I asked her teacher to say a few words at the funeral. I would like to share what she said with other families because I feel she has captured the spirit of many MPS children, not just Shelley. Every time I feel down or have a bad day I read it and I can almost get to the end without crying. This is what she said.

Sharing some of the happy memories.

I feel very privileged to have been asked to say a few words about Shelley. I would like to share just a few of the happy memories that I have of her with you.

Tears turn to laughter.

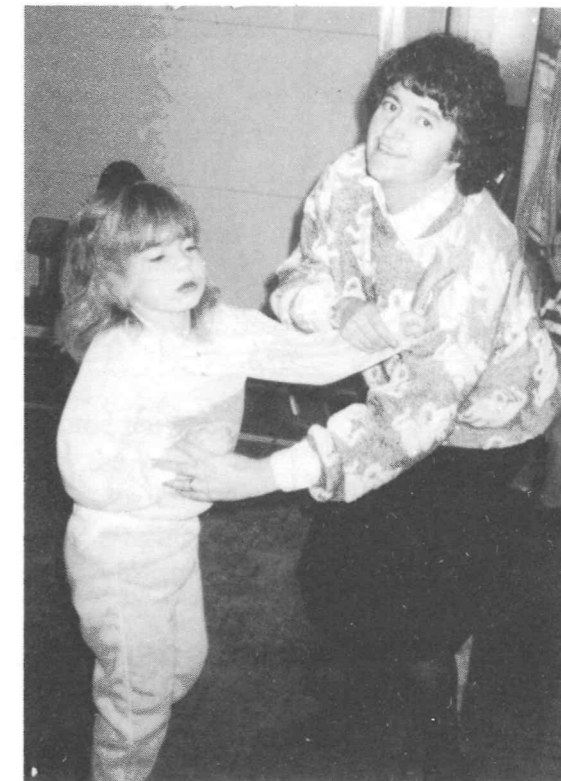
When I have tried to put my thoughts down on paper the sadness of losing her fades into the background momentarily and the tears turn to laughter when I think of the many situations where in a matter of seconds a perfectly normal and calm situation could be turned into sheer chaos and devastation by just the briefest appearance of Shelley.

Fun, laughter and mischief oozing out of her.

When I first met Shelley she was an active lively six year old with what I can only describe as fun, laughter and mischief oozing out of her. She chattered non-stop. Her big brown eyes weighed you up and took everything in. She was one of a group of six 'Special Care' children who were designated to my care.

Then I met Shelley..

Now, I never thought for a moment that it was going to be an easy class - but at the back of my mind was a comment that had been made to me during my teacher's training course - "As long as you are always one step ahead of the children you will be all right". That had always worked for me in the past. Then I met Shelley.



Shelley with her teacher Mrs Andrews

During the course of that first morning I discovered that she could run faster than me, she could eat faster than me, she could actually talk faster than me -- and she could certainly spot an open door faster than me.

I turned and ran away from her as fast as I could.

So I had this idea - it seemed quite a good one at the time - that I would play Shelley at her own game. I would start by curing this running off habit she had. Off we went, hand in hand, holding tightly, over the road to the playing fields opposite. Shelley always loved music, so I would sing the first half of a song or rhyme and she would finish it off. We reached the field and walked right into the middle of it, looked at each other and sang a few bars of one of her favourites, "If you're happy and you know it". Then I turned away from her and ran as



fast as I could. I came to a stop, turned to look at Shelley and there she stood, absolutely amazed, eyes disbelieving. After a few seconds she ran straight over to me and took hold of my hand.

Cracked it in one lesson!

Well, this was it! I had cracked it in just one lesson. We went back to school, with me telling Shelley what a good girl she was and Shelley telling me what a good girl she was.

She fled in the opposite direction.

The next day it was exactly the same procedure - hand in hand over the road and into the middle of the field. We sang the song and off I went twice as fast and twice as far and full of confidence. I looked back at Shelley, she looked in my direction, burst out laughing, turned on her heels and fled in completely the opposite direction.

The thing was with Shelley, when you eventually caught up with her, breathless and panting, to tell her off, she would be laughing so much that all you could do was to laugh with her.

Important school documents retrieved.

It didn't matter how careful we were, in or out of school, Shelley always managed to acquire something she shouldn't. The assortment of items that were retrieved from her mouth over the years is never ending - buttons, safety pins, crayons, Remembrance Day poppies, and not least, important school documents.

Shelley Scarr ate my dinner money!

Then there were the things we didn't retrieve - like the day she ate someone's dinner money. One of the taxi drivers had brought two pound coins and left them on



the table. On his way out, some ten seconds later, he went to hand over the coins, but could not find them. There was only one answer. Waiting by the door, singing more sweetly than Boy George, with a big smile on her face, was Shelley.

Still no change from Shelley.

We had to keep a careful eye on 'proceedings' - if you know what I mean - over the next few days. In between we would receive notes from her Mum like, "Still no change from Shelley". After two days she delivered the goods, slightly tarnished, but still legal tender.

Remember the time that Shelley did...

I could of course go on with Shelley stories. I'm sure there are many people who could

do the same. They all start with, "Remember the time that Shelley did..." - The day she managed to take a whole serving of mashed potato from an unsuspecting customer in the Sava Centre cafe - the time she tried to take a Macdonald's hamburger from a chap - he wasn't prepared to let go and in his efforts to hang on he spilt his cup of tea right down his front.

"Shelley Scarr's ate an Elephant."

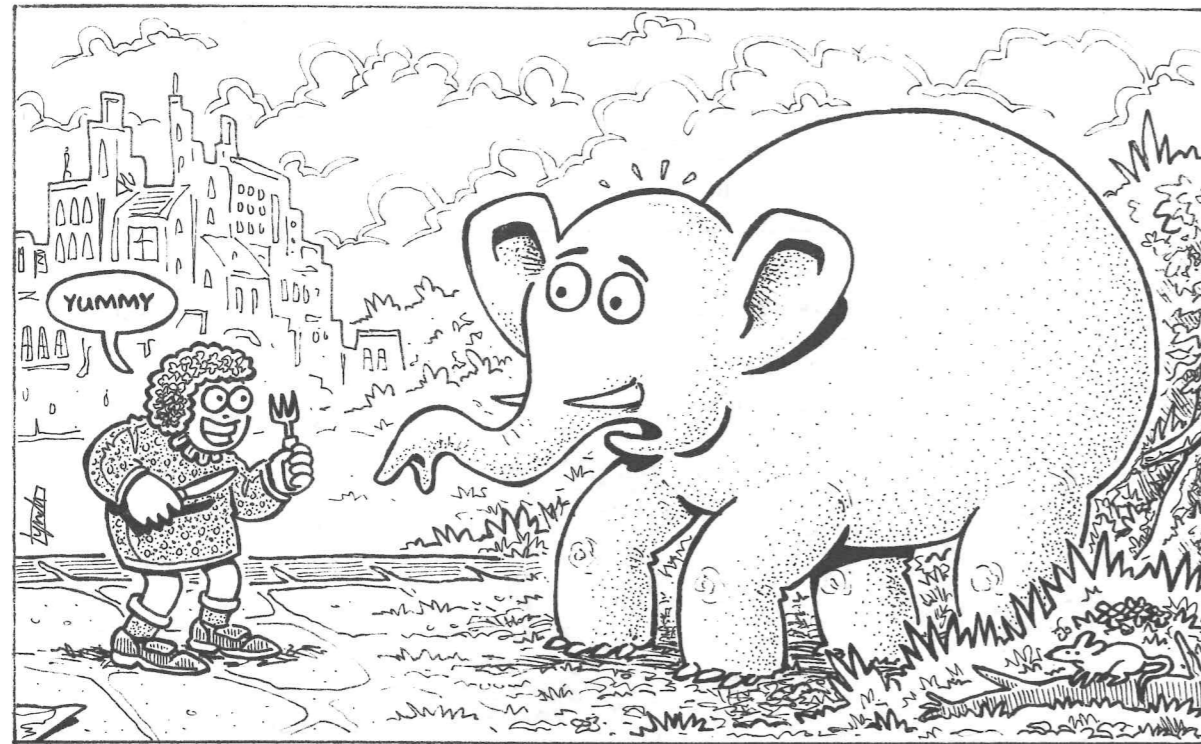
But my last tale belongs to Pat. The day Shelley ate an elephant. I can't tell it as well as she can but I will have a go.

Shelley had managed to get hold of one of the ornamental elephants they had at home and swallowed it. Just a small one. But to be on the safe side her Mum, Pat, phoned the doctor. When she got through to the receptionist

she said. "It's Mrs Scarr here, it's about our Shelley, she's swallowed an elephant". Silence at the end of the phone. "It was just a small one, about the size of a pickled onion". The receptionist recovered sufficiently to squeak, "Just a minute, I'll tell the doctor." Pat could hear the confused conversation. "It's that Mrs Scarr, she's just told me that Shelley has swallowed a pickled onion the size of an elephant."

A shining example of happiness.

If I had to choose one word to describe Shelley, it would be 'happiness'. In her short life she made more people laugh than we could begin to count. She laughed more in one day than other children laugh in a week. She was a shining example of happiness, a ray of sunshine and a joy to work with.



Shelley Scarr's Ate an elephant!

I was her teacher but I learned from her.

I was her teacher but I learned from her. She had already acquired the important qualities in life: courage, determination, perseverance and not least, a sense of humour.

Her memory will be treasured, - her story will be told.

There is a space left in our classroom and also in our school. The memories of Shelley will be treasured by all of us who were

lucky enough to know her. Her stories will continue to be told.

If you're happy and you know it, and you really want to show it, your name is Shelley Scarr.

From : Pat Scarr

84 Raby Rd

Oxclose

Washington, NE38 OLX

Stop Press!

Bob, Caroline, James and Francesca Fisher are pleased to announce the arrival of Adam Howard, born on 2nd of April, weight 7lbs. 5oz

Matthew Blackburn - Tube feeding



Bill, Matthew and Sylvia Blackburn at the North West Area Family Day

Matthew is now fifteen and a half.

Many of you will have read our article about our son Matthew (who has Hunter Syndrome and tube feeding in the summer newsletter 1990. I expect some of you may be wondering how he is getting along. Matthew is now fifteen and a half years of age and has been tube fed for just over two years because of deterioration in his swallowing reflex. His tube feeding is really working.

We get a lovely smile - when he is in the mood.

Matthew has gained weight and looks really well. He is not so vulnerable to infection. If he does get a cold or a chest infection he is so much stronger to fight it off. Although Matthew is physically fragile and need gentle handling he appears still to have some understanding of language. He communicates by eye contact and when he is in the mood we get a lovely smile. His hearing and vision are not affected in any way and are very good. He enjoys watching TV and shows an interest in his surroundings.

Matthew still attends special school which is four miles from home. His school day begins at about 9.45am. He participates with assistance in all sensory play, play dough, water, sand, finger paints etc. Also, with assistance, he works a touch pad to operate toys.

"He seemed to be sinking before our eyes".

Although these may not seem great achievements they are a great boost to us. Two and a half years ago Matthew was interested in nothing at all - he seemed to be sinking before our eyes.

Aromatherapy

Matthew also has and enjoys gentle physiotherapy on his hands and feet, which are massaged daily with a body toner. He also enjoys aromatherapy sessions.

We would not have hesitated so long...

I do wonder whether some families may have

Matthew Blackburn- Tube Feeding (cont'd)

thought about tube feeding their MPS children but are holding back because they think it is a last resort. In a way it is. We all try to struggle along with normal feeding as long as we can. Believe me, if we had known the difference it would make to Matthew's quality of life we would not have hesitated so long. Now I am beginning to feel that if many children could speak for themselves they would say. "I'm hungry, feed me."

**Sylvia and Bill Blackburn 11 Beatty Rd.
Nantwich, Cheshire. 0270 626809**

One Family's big mistake

Home improvement grant.

We are writing in the hope that our experience will stop other families making the same mistake. On the advice of our Occupational Therapist we applied for a home improvement grant to help build a downstairs bedroom, bathroom etc., for our son Stephen. The grant is means tested. The OT felt we might not qualify but that it was worth a try and she produced the application form. This we duly completed, confessing all savings, insurance policies, attendance allowance, everything.

No grant, no explanation, no nothing.

We received a reply from the council a few weeks later. No grant, no explanation, no

nothing. We were annoyed at the lack of explanation. We were furious when the OT told us that we would not get a grant or help for any equipment either.

Not one family has succeeded.

We then rang Christine Lavery, explained what had happened, and enquired whether any other form of grant might be available. Christine told us that, in her experience, not one family had succeeded in obtaining this grant since it had become means tested. She felt it would have been useful to contact her for advice before filling in the form.

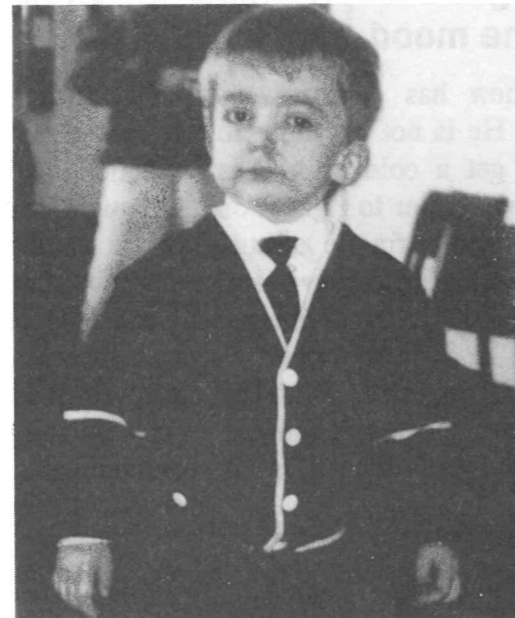
We have since written to the council to ask for reasons why we were turned down. When we get a reply we intend to take it up with the help of the Society and our local MP.

Get advice before you apply!

So please, if you are applying for means tested grants for major items, we suggest you contact the MPS office for advice about what to put on the form. The grant we applied for is a "once only" application. There is no appeal and no second chance - and we got it wrong. We are still fighting for the equipment, as we are unable to finance the extension and the equipment. Don't make our mistake. Get expert help before you apply!

Lynn and Chris Grandidge

41 The Boulevard, Broughton, Chester,
CH40SN 0532 637296



Experience with the "sleep belt"

Our son James is aged eight and suffers from Hunter Disease.

We would like to let you know our experience with the "sleep belt".

Endless sleepless nights.

We were introduced to the belt at the family conference at Stoke in 1989. Although we could see a lot of good aspects in using the belt, we both felt that we could not tie James down. During the following two years we experienced endless sleepless nights, with James spending most nights in our bed.

Things came to a head.

Things came to a head in the Autumn of 1991. James was becoming even more active at night and all of us were getting even less sleep. On medical advice we decided to try to quieten him down a bit with sedation. Although there was a slight improvement this proved to be short lived. Within a matter of days his activity increased at an alarming rate for no apparent reason.

No alternative.

After much thought and consideration we decided we had no alternative but to try the belt, even if it was only for one night. Our previous thoughts and worries had now dissolved amid endless days and nights of being on constant vigil. Even when the belt arrived we wondered if we were doing the right thing. However in the end we decided to give it a go.

"What an amazing success!"

All we can say is, "What an amazing success it has been". The first night James was obviously a bit wary but was not unduly depressed in any way. The most startling thing was that he slept nearly the whole night! Before then he would

be up and down all night. Now even though he couldn't get out of bed he was actually contented to lie in bed. As time went on, when we came to put him in bed he actually made motions with his hands to help us put the belt round him. We came to the conclusion that being in the belt made him feel secure in bed. Furthermore, as he was getting more sleep, his behaviour during the day has improved.

A dramatic improvement.

James has now used the belt for about two months. Although he does not now sleep as well as when we first used it, it is still a dramatic improvement. We would encourage anyone who has similar problems to at least give it a try.

Robin and Mary Gooch

High Bank House Swifehill, Broadoak, Near Heathfield, East Sussex. 0435 883329

Note: Please contact the MPS office if you wish to borrow the "sleep belt" to try it out. You can also order the sleep belt via the MPS office.

Look to today

Look to this day

Yesterday is but a dream

Tomorrow is only a vision

But today, well lived,

Makes every yesterday a dream of happiness

And every tomorrow a vision of hope.

Look well therefore to this day.

Sanskrit proverb

Northern Co-ordinator

I am happy to report that I have now settled into my office and new job. It still feels a little strange after twenty something years in the Health Service, not to be running round a hospital unit.

Many families need a lot of help

Even though I have been around the Society since the beginning, I was a little uncertain about the volume of work I would be taking on. After three months in the job I have been left in no doubt that there is a great need among many families for help in a whole range of areas, from schooling, housing and respite care to general guidance on the care of MPS children.

Support your support families!

Since January I have visited several area support families with a view to a programme of events for the 10th anniversary. A message of thanks is in order for the hard work and commitment of the Area Support families who have been busy organising events to celebrate. I know they will be looking to you to support the events in your area. If you can lend a hand do contact your Area Support Family.

Mary Gardiner

Northern Co-ordinator

Help wanted

Is there anyone in the North West Area who is good at painting and decorating and who has a few hours to spare?

The Society now has a room on Stancliffe ward at the Royal Manchester Children's Hospital. Stancliffe ward has been closed for some time so our room is in need of a few coats of paint. Anyone willing and energetic, please we need you!

The room will have lots of uses. It will be available for use by families when they visit the hospital or when a child is admitted. MPS information will be kept there.

Once we have decorated the room then we can set about making it as comfortable as possible. Offers of help to:-

Mary Gardiner. 0772 815516.

Coin collection

It's holiday time again and a gentle reminder to all friends and supporters that we raise money from the small change in coins and notes left over when you come back from abroad.

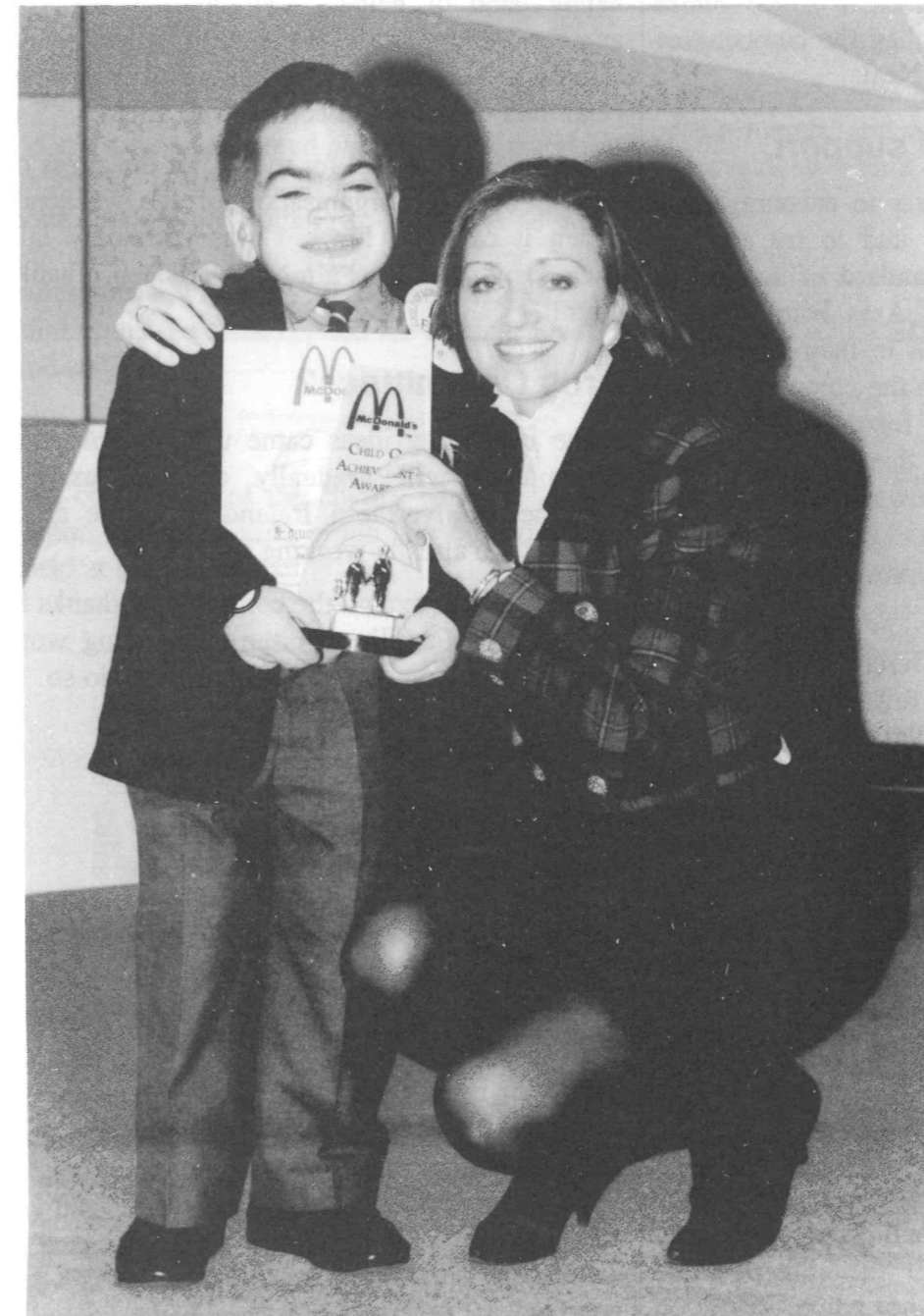
English currency of any age is also wanted. Please keep it rolling in. Send your change direct to me or pass it on via Area Families or Committee members at any Society events. Thanks to everyone who has already contributed.

Ken Ballard (Christine Lavery's dad) 15 Bengeworth Rd. Harrow, Middx. HA1 3SF. 081 904 9876

Child of Achievement Award for Edward

On the 5th of February, Edward Nowell, aged eleven, of Wells in Somerset was the proud recipient of a Child of Achievement Award.

Edward travelled to London where he was presented with the award by beautiful BBC Newsreader, Anna Ford, on behalf of McDonalds. Edward goes to Wells Cathedral Junior School. His teacher was so impressed by his positive attitude and constant good spirits that he nominated him for the award.



He has a go at everything!

Edward loves maths and computers and wants to be an American stockbroker. He has a go at everything, from swimming and fishing to bike riding and roller skating. Edward has Hunter disease, but remains cheerful and caring despite frequent pains and much frustration.

Over the Moon!

"He was over the moon when he heard about the award", says his mother, Holly.

Eddie, Holly and Edward Nowell

'Beryl', Wells,

Somerset, BA5 3JP
Tel. 0749 78738

Area Family Training Weekend

Downtown Milton Keynes!

On the weekend of the 14th-15th of March most of the Area families gathered at the Forte Crest Hotel, in downtown Milton Keynes for a training weekend. We also had the company of Dr Ed Wraith and Dr Bryn Neal.

Encouragement and support.

The aim of the weekend was to encourage and support the Area Families and to try and get agreement on minimum standard of support to be provided in each Area. Area Families, like the committee do the work in their own time, without any reward. Unlike the committee, they do not have the support of regular meetings, so this was an attempt to fill that gap. The extent of their enthusiasm was shown by the distances people travelled to be there.

Work - and Play.

We had speakers on different topics. Mary Gardiner organised a very full discussion about the precise tasks to be undertaken by the Area Families and asked each family to specify the minimum they would do. Sue Butler spoke about her marketing, Sean Mahon on book keeping, Wilma Robins on welfare rights and allowances and Ron Snack and David Briggs on Fundraising. The light entertainment was provided by Charles O'Toole with a little bit of role playing.

A happy band of helpers.

While all this was in progress Roger Broome, Ann Neal and Peter Robins with their happy band of helpers took the small group of children on an outing. After supper the elite of these helpers baby sat while the adults went on talking.

Coping with stress

Sunday morning - up bright and early. Did anyone go jogging? Not me that's for sure. The happy band of helpers and children went on another outing while Ed Wraith talked about referral to Manchester Children's Hospital. Bryn Neal then talked about coping with stress.

This was very helpful for me - after the stress of coping with the organisation of the weekend! When it came to lunch I was extremely laid back. Driving home I almost fell asleep. Thanks Bryn!

Area Committees?

Some interesting ideas came up. Perhaps Area Committees will gradually develop, as has happened in Northern Ireland. In some areas families are already working in tandem.

I would like to extend the committee's thanks to all the Area Families for the outstanding work they do, and long may they continue to do so.

Jenny Broome

30 Chaseside Ave Twyford, Near
Reading, Berks 0734 342436

MPS Christmas Cards for 1992

This year three designs have been chosen from a range of cards printed commercially and overprinted with the Society's logo and details. We are very pleased with the new cards and we are sure you will be too! It's nice to send a distinctive card of top quality and it's a very good way of making the Society better known.

CHILDREN'S HOSPICE ASSOCIATION SCOTLAND

1-3 Colme Street, Edinburgh EH3 6AA Tel: 031 220 8211 Fax: 031 225 4108

Dear Christine,

We have started a charity here to set up a children's hospice in Scotland, (CHAS for short). We are modelling it on Martin House in Wetherby. I think it is long overdue to have such a facility in Scotland. At present many families are travelling south to some of the hospices in England.

We are now a registered charity and a company limited by guarantee. Things are beginning to move. People are helping to fundraise as word gets about. It is mostly parents and some professionals who are keeping the office open at Edinburgh. We have applied for funding for full time staff.

Co-founder.

I am co-founder of the charity with my Health Visitor, so I feel quite proud and on top of the world at the moment.

Marc is not keeping too badly although he has had a lot of pain lately. The GP has put him on strong painkillers and this is helping him. He is sporting a smart new pair of specs and looks like a little professor. His eyesight is badly damaged due to MPS (Hunter Disease) and the specs let him see a little.

It is hard to believe he will be fifteen at the end of the month, and also that the Society is ten years old. It seems only yesterday when we joined.

Take care,

Lorraine Dickson

11 Sycamore Terrace,

Corstophine, Edinburgh.

(Please send any contributions towards the hostel to the address at the top).

London Marathon

You will be pleased to know that Mike Willoughby finished the Marathon in four hours ten minutes on behalf of the Society.

Don't forget to return your Marathon sponsorship form to Ron Snack as soon as possible! If we can collect £1000 in sponsorship Abbey National has agreed to match this sum.

Action for Sick Children

The National Association for the Welfare of Children in Hospital (NAWCH) is now called "Action for Sick Children". They produce some excellent leaflets about problems which may be encountered when a child is admitted to hospital. For further details contact: Action for Sick Children, Argyle House, 29-31 Euston Rd. London NW1 2SD. Tel. 071 833 2041.

Diane Bayliss: Letter from New Zealand

225 Marine Parade New Brighton, Christchurch, New Zealand. 23 3 92

Dear Friends,

As you see from the above address I am staying in New Zealand. I have been here six months up to now. After all I have been through since I lost Anthony, then Bill and Liam, I just had to get away to find myself once again or I would have cracked up.

My daughter Julie, Anthony's mother, is expecting a baby this coming June. My other daughter Helen whose baby was due in May underwent an emergency Caesarean on the 14th of February. She gave birth to a beautiful baby boy, Daniel Anthony, who weighed in at two lbs. eight oz., eleven weeks premature. He is now doing well. He is out of intensive care and in the special care baby unit. He has to be five lbs before he is allowed home. He is now feeding from a bottle so he shouldn't be long before gaining his weight. Helen is now doing fine and both are coming along by leaps and bounds. I am in constant touch.

I will be home in time for the birth of Julie's baby at the end of June but I will be returning to New Zealand at the end of July, I hope for good. Yes! I have put in for citizenship! This has shocked a lot of people but Julie, Helen and Elizabeth are delighted that at long last I am back to being their mum again and that I am happy and content.

These last six years have been one nightmare, since I was told of Anthony's disease. It has

been three years since Anthony died. I would not wish that pain on anyone. It still hurts. It has been over two years since I lost Bill. I now feel ready to start a new life afresh. So I am hoping to do just that.

While I have been here I have visited Anne and Andy Swarbrick. They live only walking distance from where I am staying. Their son Glen has Sanfilippo. I enclose a photo I took of Glen and his mum.

Anne is making arrangements for me to meet up with another MPS parent. I still have a great deal of interest in the MPS Society. I could never forget all the kindness shown to Julie and I.

I will end now. I hope you are all keeping well. Give my love to everyone.

Kindest regards,

Diane Bayliss



Glen Swarbrick with his mum.



Family Day in the Northwest

Hi everyone! My task is to give you my impressions of the North West Family Day, held at Mere Brow Institute, near Southport, on the 16th of February.

Mary Gardiner chatting them up

It's an eye-opener to see what goes on before the day. Mary Gardiner is often observed "negotiating" the services of shopkeepers, magicians, landlords, and the like for weeks beforehand. Have you seen Mary in action.... It often looks more like she's chatting them up.

How many baked potatoes?

A few days beforehand a hand picked bunch are given little lists of jobs to do. They are often written on rolls of wallpaper. Anyway, I digress, off we go....to shop, peel, wash, wrap, etc....anything to keep Mary quiet. Have you ever tried counting how many baked potatoes go in your oven...don't bother, just ask me. Have you ever got to church on a Sunday morning and realized after all the work that you have forgotten to turn the oven on. I couldn't work out what would be worse, walking out on

Father Peter's sermon or the wrath of the MPS families as I served up raw potatoes.

Down come the barriers

Most families arrive looking tired and a little shy of us, but as the bar shutters go up, down come the barriers. The children are washed, the teenagers warned, the Karaoke machine set up and off we go!

Minimize the fuss, maximise the care

Food time now and everyone seems happy with the spread. I am always impressed at how organised most families are at looking after their own child's particular needs; the minimum of fuss the maximum of care, would appear to be the motto.

Washing up starts with welcome offers of help and the cutting wit of Mary's sister in law, Christine Farrington. (I always thought she was a WRVS lady, or was it just the way she sits at the drinks trolley!)

I'm glad the rabbit survived..

The magician has the adults enthralled, pity about the children. I'm glad the rabbit survived

the trick, or was it a birthday cake....It's so confusing when you only watch bits of it.

Toddlers wander, laughter, giggles, fingers in the trifle...and the washing up goes on and on. Next year the teenagers are doing it.. Everyone wanders off home with baskets and bags, boxes and best wishes.

Waiting for the next wallpaper roll.

We wind our weary way back to Mary's for a thank you cup of tea. Exhausted, exasperated, exhilarated and desperate we reel home-wards...thankful for sharing the day with you and waiting for the next list of jobs from our Northern co-ordinator...Bless her little cotton socks.

Ann Baker

Hesketh Bank

Lowering Kerbs

Don't you get so frustrated when you are out for a walk and you come to a kerb that hasn't been lowered and you can't get up the pavement the other side. I asked the local council to lower the kerbs in East Finchley so I can get around on my own. They did the ones on the High Road and a few more.

I get mad when someone parks their car in front of the kerbs which the council have kindly lowered. I inform the police and give them the car number and make. Unfortunately the car has usually gone by the time the police have got to them. Grrrr!

Helen O'Toole

Northern Ireland Report

The tenth anniversary of the MPS Society will be a double celebration for the families in NI, as it will be the first anniversary of the formation of the NI MPS Committee. We have had some very successful meetings, dealing mainly with the setting up of the group but then getting down to business with great enthusiasm. We are thankful for the help and support of the main group in this new venture.

● Fund raising

We are going to continue the various fund raising activities, like collection boxes, the golf tournament, coffee mornings, race nights and more recently, a charity disco. We are exploring new ideas for fund raising as we expect to be spending more money in the future.

● Coming Events.

The first Christmas Party was held in 1990 and thirty people attended. In 1991 sixty people came! Because of this success it is expected to become an annual event. The family day will be held in the summer. A coach will be organised to the conference at Bristol in September. We feel that travelling as a group has helped to bring the families closer together.

● Holiday in Ireland?

The most adventurous scheme that is being proposed for the future is an MPS holiday in Ireland. Families from the rest of the UK would be welcome to join us

Insurance for events

If you are organising a Family Support or Fund-raising Event in the name of the Society you can be covered by our insurance. It's important to do this. All you have to do is notify the office twenty one days in advance and we will do the rest. We need to know the date, the type of event and where it will be held.

NEW CASH HELP FOR PEOPLE WITH LEARNING DISABILITIES

Many children and adults with learning disabilities will be able to get new cash help as a result of changes in social security benefits for disabled people next April.

We want everyone who works with people with learning disabilities to know about these changes and help us spread the news about them.

What the changes are

From April 1992 there will be a new social security benefit for people who have an illness or disability and have care or mobility needs. Called **Disability Living Allowance** (DLA) it:

is not affected by savings or income

replaces Mobility Allowance and, for people disabled before age 65, Attendance Allowance (Attendance Allowance will continue for people whose care needs first arise after age 65)

covers a wider range of needs than Mobility Allowance and Attendance Allowance and so helps many people who have previously been unable to get benefit.

How People with Learning Disabilities May be Affected

The change from Mobility Allowance to the **mobility component** of DLA is especially important for people with learning disabilities.

- * At present people with learning disabilities are often physically able to walk and if so they cannot get Mobility Allowance under the current rules.
- * Under DLA for the first time some people will be able to get help specifically because they have learning disabilities. This is because the higher rate of the mobility component (equivalent to Mobility Allowance in cash terms, will go to people who are able to walk but are severely mentally impaired and have severe behavioural problems.
- * Only a minority of people have learning disabilities which are severe enough to qualify for them for the higher rate. Many more will be able to benefit from a new **lower rate** which is for people who are able to walk but need someone with them when they are out of doors - for example because otherwise they would get lost or be in danger from traffic. This will be relevant to a wide range of people with learning disabilities - and it does not matter if they have learned to manage a few familiar routes on their own.

The mobility component can be claimed at any time between the ages of 5 and 65. But to get the lower rate children must need more guidance or supervision than another child of the same age.

FUNDRAISING EVENTS

Thanks to all of you who have raised money for the Society in whatever way. Without all of you who spend time raising money for us the Society would not be able to function nearly as well as it does. Keep up the good work.

Friends of Daryll Westland, Reading	Sale of Toys
Billy Ingham, N Ireland	Collecting Box
Charity Trophy Teams, Chipping Sodbury	Disco
Duchess of Kent pub, Erith	Collecting Tin
Mr and Mrs Lee, Tunbridge Wells	Christmas Lunch
PTA Stonelaw High School, Glasgow	Raffle and Sponsored Swim
BSC Ravenscraig	Raffle
131st Glasgow Boys Brigade	Hiking the W Highland Way
Alan and Amy Bottrell, Glasgow	Saving 20ps
Abbey National, Milton Keynes	Matched donation
I Wicks, Leeds	Loose Change collection
Pam Croghan, Cheshire	Car Boot Sale
Pam Croghan's parents, Cheshire	Collecting Tin
Mr and Mrs Chandegra, Birmingham	Raised
Hurst Ladies Golf Club, Reading	Raised
Mr and Mrs White, Lancs	Cabaret Evenings
Mrs Long, York	London Marathon
Billy Ingham, N Ireland	Collecting Tin
Eileen Gillis, Manchester	Collecting Tin
Mr and Mrs Grant, Southport	Bottle Collection loose change
J G Bryans, Herts	Raised at Gig
D and R Todd	Guess the doll's name
c & J Rogers, L Scott & M Wiggins	Sale of Rag Dolls
C Beresford	Carol Singing
J & M Miller	Diet Classes
Crowborough Townswomens Guild	Loose Change Collection
Miss T Lawson	Raised
Staff at Bevercotes Colliery	Canteen Collection
Rachel Todd	Collecting Box
C and M O'Toole	Collecting Tin
C P Copeland	Disco
Little Chalfont Post Office	Collecting Tin

House of Commons Reception June 30th

Dafydd Wigley, MP, will be the host for afternoon tea at the House of Commons on June 30th, to mark the 10th anniversary of the Society. Guests will include committee members and Area Families. We hope this meeting will help MPs and fund-holders to get direct knowledge of the work of the Society.

Area Support Families

Neil and Jane Reid Tel: 0223 834570
19, Hillside, Sawston, Cambs. CB2 4BL

Alan and Deirdre Beavan Tel: 0858 62182
'Tumbleweed' West Gate Lane,
Lubenham, Market Harborough, Leics. LE16 9TS

Alan and Audrey Noble Tel: 0664 77494
1 South View, Burrough on the Hill, Melton Mowbray, Leics.

John and Barbara Arrowsmith Tel: 091 2812062
140 Newton Rd, High Heaton, Newcastle on Tyne NE7 7NH

Sean and Pauline Mahon Tel: 0742 304069
41 Stumperlowe Crescent Rd.
Sheffield 10, South Yorkshire.

Alfred and Judy King Tel: 0424 216432
4 New Park Avenue, Bexhill on Sea, East Sussex, TN40 1QR

Bill and Sylvia Blackburn Tel: 0270 626809
11 Beatty Road, Nantwich, Cheshire.

Ron and Linda Snack Tel: 0908 666819
16 Wandsworth Place, Bradwell Common, Milton Keynes, Bucks.

Tony and Shirley Eyre Tel: 0934 834537
6 Westway Park, Yatton, Near Bristol, Avon.

Contact for Scottish Families:-

Alan and Fiona Byrne Tel: 041 643 0034
3 Jedburgh Ave, Rutherglen, Glasgow, G7 3EN

Northern Ireland Co-ordinating Committee:-

Kieran Houston (Chairman) Tel: 0508 884168
15 Barrack Street, Strabane, Co. Tyrone, BT82 8HB

Margaret Kearney (Secretary) Tel: 026 57 62073
12 Coleraine Road, Ballycastle, Co. Antrim