

**NEWSLETTER**

**AUTUMN 1992**

**THE SOCIETY FOR  
MUCOPOLYSACCHARIDE  
DISEASES**



National Registered Charity No. 287034

## Management Committee

Alf King (Chairman).....	0424 216432
4 New Park Ave, Bexhill-on-Sea, East Sussex TN40 1QR	
Dr Bryn Neal (Vice Chairman).....	0494 774421
"Hawthorn" Weedon Hill, Hyde Heath, Amersham, Bucks.	
Mary O'Toole (Vice Chairman).....	081 444 8461
8 Elmhurst Ave, London N2 OLT	
Pauline Mahon (Treasurer) (see back cover) .....	0742 304069
Susan Butler (Sales) .....	0494 483185
Spriggs Holly House, Spriggs Holly Lane, Chinnor Hill, Oxon..	
Wilma Robins (Welfare Rights) .....	0708 443157
77 Hillview Ave, Hornchurch, Essex RM11 2DN	
Kieran Houston (Chairman, Northern Ireland Comm.) .....	0508 884168
(see back cover)	
Robin Lavery (see below).....	0494 762789
Jenny Broome .....	0734 342436
30 Chaseside Ave, Twyford, Nr Reading, Berkshire, RG10 9BT.	
Martin Sutcliffe.....	0629 824478
The Cedars, Summer Lane, Wirksworth, Derbyshire	
Alan Beavan.....	0858 462182
"Tumbleweed" West Gate Lane, Lubenham, Market Harborough, Leics LE16 9TS.	

### ● Office Holders

Christine Lavery (Hon. Director) .....	0494 762789
7 Chessfield Park, Little Chalfont, Bucks. HP6 6RU	
Mary Gardiner (Northern Co-ordinator).....	0772 815516
15 Sidney Avenue, Hesketh Bank, Near Preston, Lancs	
Ron Snack (Fundraising Co ordinator) .....	0908 666819
16 Wandsworth Place, Bradwell Common, Milton Keynes, Bucks MK 13	
Charles O'Toole (Newsletter Editor).....	081 444 8461
8 Elmhurst Ave, London N2 OLT	
Linda Golding (Office Administrator).....	0494 762789
Ann Neal (Conference Organiser) (office).....	0494 762789
David Briggs (Annual Raffle) .....	0777 700046
7 Humber Street, Retford, Notts. DN22 6LZ	



## 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 500 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"**

**Special message to all members and supporters of the Society.**

**We need to raise more funds! (see page 3)**

## Contents

Society finances.....	3
Milestones .....	4
Tenth Parent Conference.....	5
Conference Photos.....	7
Annual General Meeting .....	8
Song, "People who are handicapped" .....	9
Lisa Nurse .....	10
Garden Fayre.....	11
Fund-raising, Tendring, Essex.....	12
Primrose Valley (Lawrie) .....	13
Summer Holiday (Hayward).....	14
David Criddle .....	17
Lynn Thompson .....	19
David Seymour.....	20
Sherwood Forest of Remembrance.....	21
Midland Area Events .....	22
Abigail Pullin .....	23
Letter from Japan.....	24
Fundraising Ideas.....	25
Sales.....	26
Anniversary Draw .....	27
Fundraising Events .....	28

**Deadline for Winter Newsletter**

**24th of December 1992**

## The financial situation of the Society

### Short of funds

As those who came to the conference are aware, for the first time this year the Society has not raised nearly as much money as we have had to spend. Fund-raising is down about £50,000. This is out of a total budget of about £200,000. A quarter of our annual budget.

### Not broke!

This does not mean that the Society is broke. As a charity we have to raise our money a year in advance. So there is quite a lot in the bank that we have raised for next year.

### Where does the money go?

A lot of the money we are spending this year is on commitments we made a few years ago, for example the salaries of Dr Ed Wraith and Dr John Walters, paediatricians at the Royal Manchester Children's Hospital, and the salary of the Biochemist working on the gene therapy programme. The rest of the money goes on family support, the conference, Christmas Party, administration and publicity, and grants to individuals.

### Don't panic!

Some of these major commitments will come to an end within the next year or so. So we are not in a situation where costs will always keep rising, whether we like it or not. The problem can be managed. We have top class advice and support from our treasurer.

### Other charities also.

The committee is looking very carefully at what savings can be made at the present time. They have an incentive to do this. If the Society cannot pay its way each of them is personally liable. Many charities are facing similar problems because of the general economic situation.

### An urgent appeal.

This is an appeal to all families to make an extra effort at fund-raising. Many have been very effective in raising money. Some have not. To raise the kind of money we need, most families would have to get very actively involved in fund-raising. We accept that for some families their circumstances make this very difficult. We have seen marvellous examples over the years of what can be done when people put their mind to it.

### We mean to go forward.

The Society has gone ahead from the time it started. It has never stood still. It does not intend standing still now. We don't want to cut down on support to families. We don't want to cut down on research, particularly when there is a slight gleam of hope over the horizon through gene therapy.

### Ron Snack will back you up.

Please make a new effort at fund-raising. Ron Snack will be available as always to advise and assist, as will your Area Family.

## Milestones

### New Families

Welcome to **Janice Jennings** from Ruislip, Middlesex. Janice's one year old son Aaron has recently been diagnosed as suffering from Hurler Disease.

Welcome to **Gary and Glynis Marshall** from West Denton near Newcastle. Their son David aged four has been diagnosed as suffering from ML 111 disease.

Welcome to **Mohammed Ishmael** from Leeds. Mohammed's daughter Rozeena aged four has been diagnosed as suffering from Maroteaux Lamy disease.

### Births

Congratulations to **Julia and Mark Wright** on the safe arrival of Amy Rebecca on 23rd of June. A sister for Matthew.

Congratulations to **Kelly and Carolyn Rocket** on the safe arrival of Vicky on the 22nd of July.

### Deaths

**Theresa Davis** who suffered from Sanfilippo Disease passed away on the 18th of September 1992 aged thirteen years. Our thoughts are with her grieving parents Lily and Robert who have now lost a son and daughter to MPS, and with her family.

**Martin Elmer** passed away on the 29th of July aged 29 years. Martin suffered from Hunter Disease. Our thoughts are with his fiancée and his family at this sad time. There is an article about Martin in the Summer Newsletter, written by his mother Beryl Bird.

**Victoria Headland** passed away on the 15th of September, aged twenty one years. She suffered from Sanfilippo Disease. Our thoughts are with grieving parents, Pauline and Peter and their family.

**David Lee** passed away on the 18th of May aged seventeen years. David suffered from Sanfilippo Disease. Our thoughts are with his grieving parents and family.

**Mark Rocket** passed away on the 19th of August aged seven years. Our thoughts are with his grieving parents Kelly and Caroline and their family. Four weeks before Mark's death Carolyn gave birth to a healthy baby daughter, Vicky.

**Sean Russell** passed away on the 31st of July aged four years. Sean suffered from ML11. Our thoughts are with his grieving parents Alison and Ian and their family.

**Rajesh Silhi** passed away on the 5th of September. Rajesh suffered from Scheie Disease and was aged nineteen years. Our thoughts are with his grieving parents Savita and Ranweer and his sister Pritika.

**Christopher Taylor** from Stoke-on-Trent passed away on the 27th of September 1992. Christopher suffered from Hunter disease and was aged thirteen years.

## Tenth Parent Conference

The annual parent conference at the Marriott Hotel, Bristol was a great success. Over eighty families attended. Dr Charles Pennock gave us a warm welcome to his home town. It was a relaxed weekend in pleasant surroundings. Most families were pleased with the hotel services, though some said they still preferred Stoke-on-Trent.

### Outing to Spooky Wookey.

There were a variety of outings to cater for different tastes, to Wookey Hole, to the zoo and to a local park. Organiser in chief **Ann Neal** was a little apprehensive that we did not have an outing on the scale of Alton Towers. She need not have worried. The children said they were very pleased with the witch at Spooky Wookey. Afterwards they made paper at the mill and had lots of exciting games.

### Those wonderful volunteers again.

We are now perhaps starting to take for granted that the skilled and experienced volunteers, mainly from Amersham Baptist Church will turn up and skilfully care for and entertain the children for the outings, the creche and the baby sitting patrol. What a marvellous service this is! Part of the pleasure of the conference is to see them again. Our very special vote of appreciation and thanks.

### Heart treatments

**Dr Philip Rees** from Great Ormond Street Hospital gave a very full account of possible heart problems. His clear slides made complicated problems easy to understand.



Those wonderful volunteers again



Martine Brennan at the Remembrance Service

### Dancing the night away

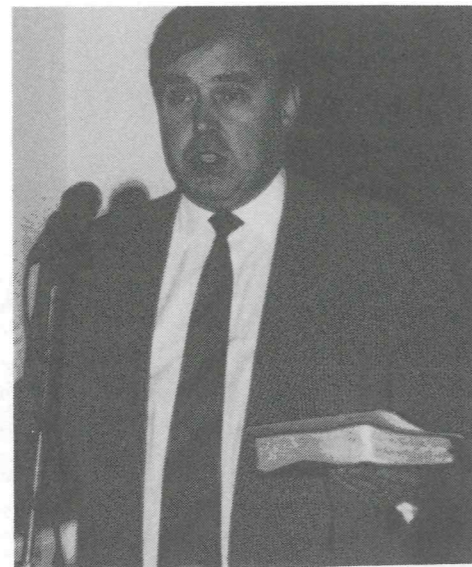
This year the dinner dance was very lively. Dancing went on until one am. The music was excellent. The draw for the annual raffle took place, organised by David Briggs.

### Service of remembrance

A special feature this year was a service in St. Philip and James' church in remembrance of all the children who have died and in celebration of their lives. This was shared by people of all religious beliefs and of none.

### Thanks to all.

Our thanks to the management and staff of the Bristol Marriot Hotel who helped make it an agreeable and relaxed weekend, to the volunteers and organisers and to all who made this tenth anniversary conference a success.



Dr Bryn Neal at the Remembrance Service

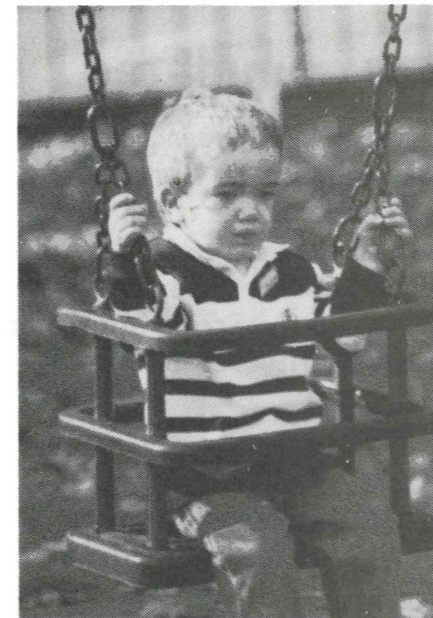
### Enzyme Therapy and Gene Therapy - perhaps.

Dr Ed Wraith explained about new developments in genetic research. These have led to much better carrier testing, information which will be of crucial interest to some families. He described the possible routes to future treatment. Great advances in knowledge are being made. The way forward continues to be complicated and uncertain. Parents sat very still as they hung onto his words of hope for the future. Their feelings were tinged with grief that it may not be soon enough to benefit their children.

### Conference report

As usual there were lively group discussions. The conference report giving a full account of the talks, will appear in the next few months. Have you got any nice photos to go in the report? Please send them to me.

### Caught at the conference



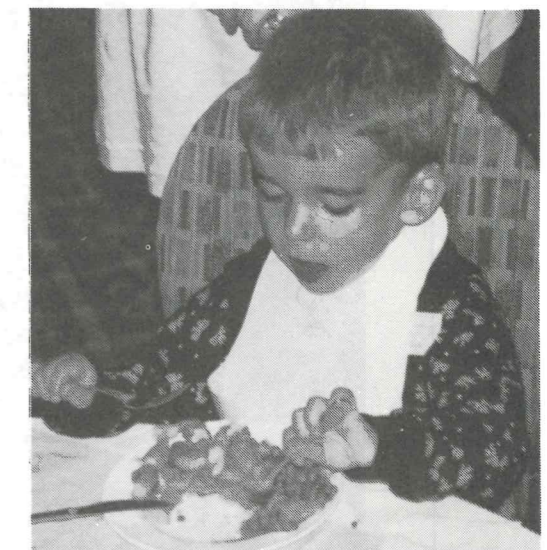
Some people take a while to warm up.....



While others get off to a flying start.



Watch very carefully and I will show you how it's done. How to hold your fork when eating sausage and chips.



I think you should do it my way. I use a knife, fork and spoon.

## Annual general meeting

### Changes in the air

This kind of meeting is not much fun unless there is a good row. There was no row. It was reported that the committee had decided against establishing the Society as a company limited by guarantee. Mary Gardiner is now an employee, busy and blossoming in her new role. A similar post is being considered for the south of the country, subject to finding the funds. The question of seeking a part time paid director was aired, as was the need for office space.

### A new committee

Warm thanks were extended to outgoing committee members Dr Donald Garrow, Pat Isaac and Ron Snack. (Ron is going to continue doing the work - he just can't stand the meetings). A new committee was elected by ballot to run the Society for the coming year. (See inside front cover).

### A time to show appreciation

The work of Christine and Robin Lavery in founding the Society and running it for the first ten years was warmly acknowledged by the meeting.



Helen O' Toole wrote the song and Elspeth Crilly prepared the music. Here they are performing it at the Service of Remembrance at the conference. There have been many requests to put it in the newsletter. "People who are handicapped" - on next page.

## People who are handicapped

People who are handicapped,  
For them we can adapt,

Going to hospital all the time,  
Having operations - some of them don't mind.

Wearing a hearing aid when they go out,  
Talk to them slowly there's no need to shout.

Struggling to walk going up the stairs,  
Dancing round in wheelchairs everywhere.

Some are short and very small,  
Don't you "coochy-coo" them, it drives them up the wall.

People who are handicapped,  
For them we can adapt,

They like to be treated like everyone else,  
Treat them how you would be treated yourself.

Helen O'Toole and Elspeth Crilly



**Harry, Rosemary and Lisa Nurse on her birthday**

## Twenty first birthday.

Lisa celebrated her twenty first on July 29th. It seems only yesterday that we were celebrating her 18th. It was only seven years ago that she was diagnosed as having Sanfilippo Disease. We did not dare to think about her twenty first birthday then. So when it came we were determined to make it a great celebration.

Harry's birthday was on the 18th July so we had

a wonderful party for both of them. Lots of cards and flowers arrived and my cousin made a lovely cake. Family and friends helped with the cooking and preparations. Everyone enjoyed themselves and danced the night away to a great disco. It was nice to see Lisa's teachers and her headmistress from her old school.

Our thanks to all those who sent cards and good wishes to make Lisa's birthday a day to remember.

### Rosemary Nurse

2 Russell Grove Brixton, London SW9 4HU

## MPS Garden Fayre

Another enjoyable day was spent by MPS families in the garden of Dr Donald and Mrs Garrow at Little Chalfont on the 19th of July. The event was ably organised by Christine, Anne and Linda.

The milling hordes were entertained by Morris Dancers and by members of the Misbourne Orchestra and very pleasant it all was.

All the families who came along helped to run the various stalls. Over £700 was raised for the Society. Look out for this event next year.

### Sick as a parrot

The Fancy Dress Parade was a great success - I went as a pirate. Faye Rowe, dressed as a princess was the winner. All I got was the bird - perched on my shoulder.

### Ron Snack

## Morris dancers aid disease research



## Fun in the Tendring sun.



### Tender sights for sore eyes on Saturday night in Tendring

#### It's a Knockout

Sunday 23rd October saw Linda and I trekking across country to see Maureen and Tom Fryer and their "It's a Knockout" competition near Clacton. This seems to be becoming an annual event for the Society - and a good day it is.

#### After the crawl was over.

On arrival we were met by quite a few bleary individuals - there had been a fancy dress pub crawl the night before. No opportunity is lost to raise money!

Although the weather looked very doubtful everyone got stuck into the preparations. By the time the gates were opened to the public all was ready.

#### Pubs fight it out.

The main event of the afternoon was the "It's a Knockout" competition between about six local pubs, all very keen to carry away the lovely trophy. As well as the competition there were loads of stalls and rides for the kids - a really good afternoon's entertainment.

#### Maureen and Tom Fryer - Super fundraisers.

Prior to the fundraising day Maureen had held a dance locally. Altogether they managed to raise £2,000. Well done to both of you.

Ron Snack

## Primrose Valley 1992

### I want to go on holiday.

The first thing I said when I got back home from Primrose Valley was "I want to go on holiday". Mum and Dad looked at each other, put on a "Fireman Sam" video and went to unpack the car.

### We had a terrific week.

We've had a terrific week. We took Grandma and Grandad with us. Mum says that a ratio of four adults to three kids is the only sane way. So we had lots of grown-ups to play with. I like to keep them on their toes; off I run to see who will chase after me. Emma Briggs is a bit too good at catching me - she has been trained by her sister Kristina.

We stayed in a chalet - well, I didn't do too much staying. I liked the three am walks around the camps and running after people on those big family bikes. We had a couple of rides on those bikes. The parents kept gasping about headwinds and hills. There was also a big adventure playground that David and Tim and I loved. The helpers took me out one evening to see if they could wear me out. I won that one. They took me and David swimming too. Ron taught me how to bat a ball so I taught him how to throw the bats around.

### A ride in Dave's blue van.

We had a brilliant barbecue on Sunday afternoon. How those grown ups talk! I kept trotting off to investigate the motor cars and eventually wangled a ride in Dave's blue van. Bliss.

### Lots of new friends.

I made lots of new friends. There were mainly children like me with Sanfilippo providing a sort of continuous cabaret and our less boister-

ous Hurler chums who really know how to smile.

### Elephants - grey and pink.

On Tuesday one coach party went to York to look at trains and Vikings and shops while the rest of us went to Whitby for ice-cream and fish and chips. We saw three elephants on the way. (Dad said he saw the elephants too, but shut up quickly when someone asked him if they were pink).

### The old drink eat and talk routine.

On Wednesday night the parents went out to dinner without us, which must have been the old eat drink and talk routine, though they seemed to enjoy it.

### Fish and chips and ice-cream.

On Thursday we did our own thing and went to Bridlington for more ice-cream and fish and chips. We had a lovely day on the beach though Dad stopped me jumping on everyone else's sandcastles.

### Birthday for Alex.

We had a farewell tea party on Friday afternoon with a birthday cake for Alex who was seven and my brother Tim who was two. Tim slept through it all so David and I blew out his candles and opened his cards and presents.

### What mum told Mary.

Then it was time for us to leave. We sat in the car for about half an hour while mum and dad went round everyone at least twice saying goodbye and doing more talking. I overheard mum telling Mary that without the MPS Society she would have neither the energy courage or money to talk to us all on holiday. So thanks everyone.

Lots of love,

**Stuart Lawrie (aged 7). 36 Dressay Grove Hull, HU 9JJ**



## Summer Holiday Filey 92

"Mummeeee! Are we half way yet?". Amelia's question, repeated every ten miles in a journey, reminded Susan and I of the distance we had driven from Winchester. The motor way was packed, shoulder to shoulder, the sky was cloudy, the day cool and the prospect, according to the weather forecast, was rain. It was August, after all, and this was England. Sally, an old school friend of Susan's, was persuaded to come with us as a helper. We were both grateful for the chance to lighten the strain at bedtimes, the worst end of the day. We have twins, Amelia and Sarah (six years) plus twins Emily and Thomas (eighteen months).

### We made contact immediately.

Emily's diagnosis of MPS 1 (Hurler's) was in February '92. We knew very little about the MPS Society, just a page in a journal that Emily's paediatrician gave us. Straightaway we made contact with Christine Lavery, feeling the urgent need to talk to someone and find out what we could about this disease that had changed our life.

### Too soon for a holiday?

Amongst the information we received was a single sheet that promoted a holiday in Filey, Yorkshire. The idea of a holiday immediately appealed to me but Susan was unsure, it was early days yet with enough to cope with. As the months went by, however, we decided to find out more and contacted Mary Gardiner, whom we had met briefly at Pendlebury where she had given us cherished support at our first meeting with Ed Wraith. Mary is a great listener and the phone call, ostensibly to enquire of the holiday, became an essential therapy. We were eventually found a chalet and we looked forward to the first day of August.

### Eyes as wide as saucers

The Primrose Valley sign appeared and we drove slowly into the entrance. The slides, bouncy castles and adventure playground produced eyes as wide as saucers in the rear seat. It was all I could do to keep the children inside the car. We picked up the key and found 114 Lakehill Chalets that was to be our address for the next six days. It was Saturday night and after a much needed *cuppa* we relaxed.

### Hard to prise them away

Sunday morning was for exploring. The acres of caravans were a new sphere for Amelia and Sarah, who became more excited as the day went by. The free adventure playground was *the tops* for them and it was difficult at times to prise them away. In the afternoon Ron Snack with a host of helpers kept the barbecue going and fed (and watered) the multitude. The children played on the swings or occupied centre stage. Everyone renewed friendships or met families for the first time, as we did, who felt and shared our feelings.

### Outings.

Tuesday morning and a horde of parents, children and the odd wheelchair or two waited patiently for the coaches to Whitby and York. The coaches arrived late, due to a breakdown, and together with the road works on the A64 we arrived in York at lunch-time. The green around the Minster was a good spot for a picnic lunch. After a visit to the building itself I took the girls on an open topped bus for a tour of that beautiful city. I later heard that Mary Gardiner and some youngsters were jumping

### Parents evening.

The MPS minibus and a car convoyed into Filey on Wednesday for a memorable (children less) evening. Good food and better company made it all too fleeting, but nevertheless an occasion not to be missed. Thanks to the efforts of tireless volunteers looking after the little ones and not so little ones back at Primrose Valley.

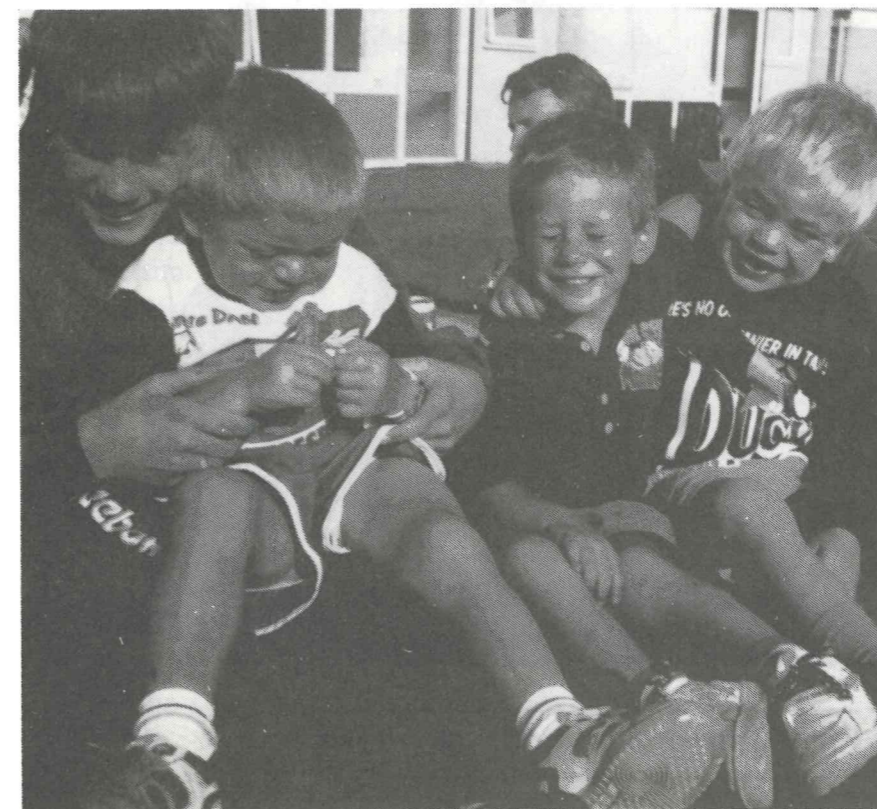
### Goodbye time

On Friday we all got together for tea, the same location, on the green. This was goodbye time till another year. Addresses were swapped among the youngsters who had become firm friends for the week. We said farewell till the conference, which would be our first, and regretfully returned to the chalet to pack. Each day that passed had absorbed a little more of the pain. Now we are still slowly feeling our way, but now with others to help us. We won't forget Filey in a hurry!

Vince Hayward,  
Winchester, Hants.  
0962 776416



Enjoying the sun at Primrose Valley



## More Holiday Pictures from Primrose Valley.



Jenny Dagnall with her daughter Rebecca, aged five and a half, and Emily Hayward.



The Tailford Family from Stockfield- on -Tyne

## David Criddle



of my GP, I started to administer this medicine. After a day or two David seemed happier and now calmer, but he still enjoyed TV and played for short spells with his tray.

### Running down

By now it was Christmas. It was very sad because David was now getting very weak. All the things he used to enjoy were now a thing of the past. The caretaker of the junior school, David Wood, came dressed up as Father Christmas. (He's been doing it since David was three years old). David did smile, but he was really very tired, we had to help him unwrap his presents. I was very glad when it was over, because usually he would be laughing and shouting, saying "Merry Christmas" and kissing everyone. He was a real poser, he liked having his picture taken.

### We would cuddle up

After Christmas David now asked to spend more time in bed. I would carry him upstairs and we would both lie on the bed. We would cuddle up to each other, me telling him that I loved him very much. He would smile and kiss me and then fall asleep. I had been sleeping in the same bed with him for about six months - it made David feel more secure, especially at night, because he was losing his sight.

### Precious times

Some days I used to cradle him in my arms and just walk about the house, looking out of the windows. He would snuggle up and hold me tightly. These times were very precious. The medicine made him happy and gave him peace. His cat, David called him Robert, would follow us around. When we lay on the bed he would sleep at David's feet.

### The courage to write

It is now more than eighteen months since David died, but it still feels like yesterday. I have only now plucked up enough courage to tell you my story - or at least some of it.

### His little body was slowing down

About the end of October David was kneeling by the chair. By that time he could not stand. David was crying, which was something he rarely did. The tears were streaming down his little face. Then he became really agitated and bad tempered, which was really out of character for him. I had also noticed that when I changed his 'trachy', the little hole in his throat seemed dead - there was no muscle movement. I felt that his little body was now slowing down and that his little life was coming to an end. I could see that he was now becoming uncomfortable. I picked him up, cuddled and kissed him and said that I would make him better.

### Happier and calmer

I rang Ed Wraith to explain what was happening and he suggested 'Diamorphine'. With the help

## Friends joined us in bed

I made our bedroom very bright, plenty of flowers, toys hanging from the ceiling, everything he loved surrounding him. Friends used to call in. On their way up they would put the kettle on. They would come into the bedroom, take their shoes off and climb onto the bed with us. David liked having his head stroked. Our friends Heather and Margaret used to take it in turns every morning to call. They would care for David while I bathed and dressed and put my make up on, just as if it was a normal day.

## A weak little smile

By now David was having his medicine through a syringe, because it became difficult by mouth. He used to give me a weak little smile. But he was very comfortable and free of pain. By now he had stopped eating. He was now more time asleep than awake.

## “He’s saying goodbye”.

Two days before he died, Margaret and I were sitting on the bed stroking his head, when suddenly he opened lovely eyes and gave me the most beautiful smile and kissed me. Margaret said, “Pat he’s telling you he is happy, he’s saying goodbye”. He never smiled after that. On Saturday at about eleven o’clock the doctor told me to pick him up and cuddle him - he said I would not hurt him - he had given him an injection because his breathing was so irregular. That last hour was the most precious. I held him very close and kissed him and told him Mummy loved him very much.

## I cried and screamed.

At 12.30 David gave a little sigh. That was it. All over. I couldn’t believe it. I cried, shouted and screamed. I was so angry. Just then the doorbell went. It was our local vicar. He had been in the town and just come home. He said he just knew. David’s dad, his sister Jane and her friend were all sitting on the bed. So David had everyone he loved around him. David died on the 16th of February 1991.

## A wicked sense of humour

I must tell you something else that happened amongst all this sadness and anger. About twenty past twelve the District Nurse called to change his syringe. She said “David Criddle you are a little pain in the neck” - She was hurting her fingers breaking all the capsules. She knew how ‘wicked’ David was, and how normally he would have laughed and thought it great fun. When she had finished and placed the syringe in the slot - that’s when David gave a little sigh and died. She said, “You little bugger, David Criddle, you’ve had the last laugh”. He would have enjoyed that.

## We were both free

I cuddled and kissed him for a long time. Then the doctor came and asked if I could set him free and take his ‘trachy’ out of his throat. I took it out and all of a sudden I knew that I too was free. The doctor said I must make sure I use that freedom. - By the way, that tracheostomy did help David to die without struggling for breath. There is a reason for everything.

## To help other parents

Now, ten months after, I have cried the whole time I have been writing this. But, as I have said, among all the grief there was laughter and funny things happening. It was though he was still around. I can still hear him laughing and shouting. Now that I have written it down I do feel better, as though a weight has been lifted from me. I thought perhaps it would help other parents to know that amongst all the sadness of the last eighteen months lovely things have happened because of my little boy David.

## Pat Criddle

88 Bryn Pinwydden,  
Pentwyn, Cardiff, CF2 7DF

# Lynn Thompson

*(Lynn is aged 27 and suffers from Morquio Disease. Her mother has sent this letter).*

## ‘Nothing wrong with her’

From the age of nine months I visited a GP with Lynn. He said that there was nothing wrong with her. When Lynn was four she could hardly walk so I changed my GP. She was then diagnosed as being deformed from head to toe. This went on for four years.

## Paralysed from head to toe.

Then Lynn fell out of bed after losing her balance. She was sent to Sheffield Children’s Hospital, paralysed from head to toe. She was just lying there in pain.

## The surgeon was amazed.

The surgeon came to look at Lynn. He said he was amazed, as he had just read an article about dwarves in America. He said he had never seen a child with this condition. He laid Lynn flat, moved her neck and head together and pulled on them. He called Lynn his miracle child. He said the spine had gone in the neck.

## Spinal fusion - old style.

That was on Christmas Eve. Lynn then had to lie flat in bed until March to have the neck fused. When Lynn had her neck fused there were no cages as there are now. So Lynn was clamped to the bed with weights, but only for six weeks.

## Lucky to be alive.

The surgeon was not sure she would ever walk again. He said Lynn was lucky to be alive as the spine was only hanging on by a thread. Lynn did walk again, not very well, but she lived.

She is still only three feet tall. She has not been able to walk at all since she was sixteen. She is now twenty seven years old.

## My feelings now.

I feel that if the GP had only cared that bit more, then Lynn might have been diagnosed earlier.

## Disappointing services.

I gave up on Social Services long ago. I have had bad experiences in trying to get help for Lynn. I have not been able to get suitable aids because no one had ever come across Lynn’s complaint in Rotherham before. I had to give MPS booklets to my GP and to the social worker and to the paediatrician at the hospital, because they had never come across Lynn’s condition.

## ‘Carry her up the stairs’.

We were turned down for a bungalow because Lynn is so tiny. All I was told was that she could be lifted up and down the stairs. Now I don’t ask for anything anymore.

## Julie Duckmanton

31 Burns Rd, Herring Thorpe  
Rotherham, South Yorks.



### David Seymour

On the 14th of October 1991 our six year old son, David, was diagnosed as having Sanfilippo Disease. We were horrified at the bleak future that lay ahead.

### I was frightened for all of us.

Andy who is in the Royal Navy, had to return to Portsmouth the same day. To face everyone on my own and explain what was to happen to David seemed impossible. I was frightened for Andy who was on his own three hundred miles away, I was frightened for myself, I could hardly let David out of my sight. I was frightened for Christopher, my four year old son. How could I explain why I was crying and why everyone around was crying or was unusually quiet? All parents of MPS children know the uncertainties and sadness that follow such a diagnosis.

### Local fund-raising - how I reacted.

The news of David travelled fast. Before I knew it I was contacted by a local pub to see if I would have any objection to them starting an appeal in David's name, to send us to Disneyworld. My first instinct was to say no. What was the point? What good would it do? Then I realized it was a selfish way to react to such a compassionate offer. After all I had to consider David, Andy and Christopher.

### I could not believe what followed.

The aim of the appeal was to raise enough money for the holiday in Florida and that any extra money would go to the MPS Society. The

appeal was started just three weeks after David's diagnosis. I could not believe the events that followed. Raffles, bungee jumps, car lifts, football matches, sponsored walks and sing songs, donations from as little as a few pence to £650 from one local company.

### Over £5,500 raised.

It was hard to believe that after eight months in a recession hit town over £5,500 was raised.

### For research and the annual MPS holiday.

We have now booked our holiday to Disneyworld. David is totally unaware that we are going, as he understands little or nothing these days. Christopher is very excited. Although it seems ironic that any good should come of David's disease, the Society has benefited from a £2,500 donation. The committee who raised the money would like to see it split between research and the MPS annual holiday.

### Some very dear friends.

Although a year has passed since that awful day and although we cannot accept what will happen to David, we can now live with it. The Society has been a great help and I have made some very dear friends. I have read all the MPS newsletters and each time I promise to send something for publication, so finally, here it is!

### Angela Seymour

22 Lindale Gardens, Ashby, Scunthorpe,  
South Humberside DN16 2HW

## Forest of Remembrance

### It started with a seed.

It started with the seed of an idea. How about having a memorial to all the MPS children who have died? The tenth anniversary year seemed a good time to do this. But what sort of memorial? What about a book of remembrance? This seemed attractive at first. But doubts arose. Where would the book be stored? How to make arrangements for families to see the book?

### The seed became a sapling.

Then we saw a plan on Blue Peter. Nottinghamshire were starting to replant Sherwood Forest. Children from all over the country could become involved in developing a special section with raised walkways and access for handicapped people. We wrote to Nottingham County Council asking if we could have a tree in memory of MPS.

### From the sapling came a Forest.

The council were very interested in the idea. They told us that they were setting out a section of the forest with raised walkways to make it accessible to handicapped people. Instead of one tree, why not plant a tree for each MPS child? They even said they would meet the cost of each sapling and pay for its upkeep. The MPS Forest was ready to grow. And what a very special forest!

There can be very few children in the British Isles who do not treasure the idea of Sherwood Forest. Our imaginations and childhood memories are rich with colour and excitement of the tales of Robin Hood, with Maid Marion and his merry men.

### A life remembered - a new life

By planting an oak tree for each MPS child we are creating a new life for every child lost to the

disease. We are also making the country green again. Each young tree will be marked by a plaque designed for the Society where families can have an inscription of their choice. The cost of the plaque will be met from the Society's funds. We are sure, also, that many families, friends and relatives will be delighted to contribute towards such a pleasing memorial.

### Our thoughts will be drawn there

On sad cold days their desolate thoughts will be drawn to that little sapling strong and enduring in the lonely wood. When the sun shines their feelings may lift and fly to the green shoots of new life reaching up through the wood's fragrant warmth, with the birds singing and the voices of children in the distance.

### A place to visit

Sherwood Forest is in a very central location for people to travel to. People can get a welcome and refreshments at the visitors centre. There is space in the forest for people to be alone with their feelings, or to meet together for a picnic or walk or play.

### Like the flight of an arrow

We look forward to many bitter sweet meetings at Sherwood. When we meet with a friend who has lost a child, without words we will share together an image of new growth, frail, vulnerable but sturdy, and our minds will fly like the flight of an arrow to Sherwood.

### Opening in February

Letters have gone to all bereaved families inviting them to apply for a memorial. An opening ceremony is planned for February. There is likely to be publicity on "Blue Peter". There will be further information in the winter newsletter.



## Midlands Area Events - Summer 92

(Left)

Darren and Daniel Allen take to the water on the 7th of August.

(Bottom Left.)

Lorraine and Christopher Rock with parents Helen and Peter getting ready for the barge trip.

(Below)

Carl Hodgetts,  
Luke Chappel  
John Hodgetts  
Daniel Allen

get together for lunch at the Hope and Anchor. We must do this again sometime!



# Abigail Pullin

## Abigail has SF and we suffer from it!

Abigail is nine and a half years old and suffers from Sanfilippo disease - or should I say, Abigail has SF and we suffer from it - but only sometimes.

## Keyworkers fought to have Abi.

In many ways Abi has a charmed existence. She is loved and somewhat spoiled at home and at her respite care home "Derriads". They have recently introduced a keyworker systems at Derriads and two of the staff nearly came to blows about who got to be Abi's keyworker. That made us very secure in the knowledge that she is looked after there almost (because nobody is better at it than us - right?) as well as she is at home.

## That unpronounceable illness.

Abigail was diagnosed at four and a half years old. The minute I saw *MPS?* on her x-ray form I started making enquiries of my own. But what exactly was this unpronounceable illness - surely nothing that couldn't be cured. How wrong we were! Round about that time childhood cancers struck the most fears in us. Never in our wildest dream could we imagine something worse.

## Our worst nightmare.

Bit by bit the information filtered in to us. We then realised we were living our own worst nightmare.

## Garlic cloves and double cream.

At the same time Abi decided to begin the dreaded hyperactive stage. We needed six arms and legs and God knows how many pairs of eyes to keep up with her. The minute you took

your eyes off her she was in the fridge. Her favourite things were whole garlic cloves, butter by the pound and double cream. We caught her one day about to begin a main course of defrosting leg of lamb.

## No gates for Abi.

Mick made a gate to stop her reaching the kitchen but a good kicking from Abi soon put paid to that. The straw that broke the camel's back was when she ate some haemorrhoid ointment (I won't say whose) and we had to explain to a giggling casualty staff. It became obvious that we had to make the house safer.

## What was it to be, sink or swim?

Those first few months after the diagnosis were horrendous but we quickly came to the conclusion that we had two choices. Carry on or throw in the towel, sink or swim.

## I became a bully.

We swam. We investigated respite care, social workers, allowances, aids. I became quite a bully at getting what I was entitled to because nobody seemed to offer. We consider ourselves quite fortunate that we have (at the moment) marvellous respite care and what must be one of the best special schools in the country. It is recently opened, complete with jacuzzis and sensory perception room.

## Abi comes with us everywhere.

Abigail comes with us everywhere we think is suitable. This includes the Rugby club. The Liberal club put the skittle alley at her disposal. They never have any chalk left when she is finished.

## Feeling guilty about respite care.

We have heard of people feeling guilty about

using respite care - the first few times Abi went we put ourselves through hell wondering if she was alright. We lost the benefit of the respite because we worried too much. Then we stopped panicking. We began to realise that that it was sometimes o.k. to be a little selfish. If you don't recharge the batteries when you can I think eventually you will keel over and not be any use to anyone.

### Abi's Rugby booking.

Sometimes we use the time constructively, decorating or giving Tim a day out somewhere not suitable for Abi. Sometimes we just enjoy ourselves. Abi is booked in for every Rugby Union cup final at Twickenham.

### The hardest part is to ask.

Respite care is only part of a whole package aimed at making life more tolerable in an intolerable situation. Although I do not have too much faith in social services I landed myself a gem who helped me through a lot of hard times - emotional and financial. Friends are invaluable - the hardest part is to ask. We have never yet been let down when we needed someone - if you don't ask you don't get.

### Happy and contented.

Abi is fit at the moment and gives the impression of being happy and contented - we certainly are left in no doubt when she is not. However that is a story for another time.

### Alison Pullin.

15 Martin's Croft, Colerne, Near Chippenham  
Wiltshire.

Bungalow for rent. Sleeps five people and is suitable for wheelchairs. £70 per week. Contact Mary Tubb, White Horses, 23 Princes Esplanade, Gunard, Isle of Wight. Tel: 0983 200354. (Mary is an MPS member. She is the mother of Pam Tubb who died in 1986).

## Japanese MPS Annual Meeting

Dear Mrs Lavery,

The fifth Japanese MPS Society meeting was held in Osaka in July. We would like to tell you briefly about it. Your message was greatly appreciated. Despite the language barrier we all feel a wish to keep in touch and to exchange information.

### Professor Orii

Twenty six families attended, some with their affected children. Professor Orii of Gifu University attended with his five assistants. Two doctors from Osaka City University and some school teachers were also present.

### Bone marrow bank.

A talk was given on the bone marrow bank now established in Japan, followed by a talk from Professor Orii and group discussions.

### A silent tribute.

The meeting paid a silent tribute to those patients who had died.

### Lively conversations after bedtime.

The evening was rounded off by dinner and friendly conversation. After the children were in bed the conversation became a bit more lively over the beers.

### A mistake by the volunteers.

We had ten volunteers who looked after the children in the hotel. After they had left the manager called us. The children had scribbled all over the walls while the volunteers backs were turned. After we offered profuse apologies, the children were pardoned. After all, children will be children, we thought.

### Again next year.

Some families were unable to attend because of distance and for health reasons. We felt this years meeting was successful and we plan to meet again next year.

### Masoki Toroko

## Sid's Little Helpers

The intrepid Sid Shiff of Liverpool has got all his friends busily making carrier bag holders (cloth bags to keep those errant carrier bags from wandering around the house).

The bags cost £1.50 each. If you would like one to use, or even a supply to sell, please contact Sid Shiff at 31 Laxton Rd., Hunts Cross, Liverpool, L25 OPG.

## Sherry and Stuff

With Christmas rapidly approaching now is a good time to be thinking of a Sherry and Mince Pie Morning - so much more congenial than a coffee morning.

### Even I can make mince pies.

Most off-licences will let you have bottles of Sherry on sale or return and they will loan you glasses for free. It's not too difficult to make a batch or two of mince pies - even I can manage that.

### As many people as possible.

It's then just a matter of letting as many people as possible know what is happening and where. You could sell MPS goods and have a raffle or just charge for the eats and drinks and have a good chat. Either way you are raising money for the Society. Good luck.

## London Marathon 1993

I heard at the conference that we will hopefully have a man and wife team running in the 1993 London Marathon. They are Dave and Jo Rikalans from Tamworth in Staffordshire. If you think you can get sponsors for Marathon runners please contact me. I look forward to giving more information in the winter newsletter.

### Ron Snack

## Congratulations

To Paul and Sue Hubbard on their wedding on the 25th of July 1992.

Very best wishes for the future.



Henry Sutcliffe with Friend  
at the conference



## MPS Sales

There are still a few **baseball caps** available with the 1982 - 1992 logo. Colour Royal Blue. Price £3.50. These are becoming collectors items so please contact me as soon as possible.

**Fundraising White Cap** in cotton. £1.50. Ideal for wearing on your MPS stalls.

### Childrens Polo Shirts

**Red:** Sizes 22/24, 26/28, 30/32.

**White:** Sizes 22/24, 26/28, 30/32.

**Navy:** Sizes 30/32 (Small)

**Royal Blue:** Sizes 26/28

### Adult Polo Shirts

**Red:** Extra Large, Large and Medium.

**White:** Extra Large, Large, Medium, Small.

**Royal Blue:** Extra Large, Large, Medium, Small.

**Black:** Large.

### MPS ties

Blue or Maroon with Logo in white....£6.50

### Anniversary T-shirts.

Red or blue to fit child age 3 to 6. Free!

### Christmas Cards.

A range of top quality cards still available.

**Sue Butler 0494 483185**

## Grand 10th Anniversary Draw 1992

This year saw a departure from our usual annual Christmas Draw. One of the reasons for this was the number of other raffles taking place around Christmas time. As it turned out some found it easier to sell tickets in the summer and some found it harder.

### Around £6000 profit

The profits from this years draw will be around £6,000. The exact figures will be provided in the next newsletter after I have posted out the remaining prizes and worked out the postage costs.

### They sold £300 worth

Congratulations to one of our new families, Mr. and Mrs. Allen, who should by now be the proud wearers of MPS sweatshirts awarded for selling the most tickets. Those of you with weak hearts please read the next bit sitting down. They sold £300 worth of tickets. However it was a close won race with several families selling almost as many.

### I wish you all could win!

Next year it could be your turn to win a prize. Congratulations to the prizewinners and commiserations to those who were unlucky. I wish you all could win. Thanks you to all who sold tickets. Without you the many hours Monica Emma and I spend on the draw would be wasted.

A happy Christmas and a prosperous new year.

**David Briggs**



## The Society for Mucopolysaccharide Diseases

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

### GRAND 10th ANNIVERSARY DRAW, 1992

1	NICAM T. V. & VIDEO RECORDER.	33926	J. CARTWRIGHT	TELFORD
2	WORKMATE & TOOLS ETC.	06824	C. PENNOCK	BRISTOL
3	CASSETTE, CLOCK, TAPES ETC.	29822	H. BROTHERTON	HINGKLEY
4	LGE. TEDDY PRINT & SOFT TOY	42550	H. STANTON	HAMPSHIRE
5	LGE FIRST AID KIT	26131	THOMPSON	LOCHMABEN
6	PETITE CHILDS TYPWRITER	15330	LOCKYER	PONTYPRIDD
7	LEGO SYSTEM SET	19976	B. TILBURY	HIGH WYCOME
8	1992 ROYAL MINT COIN SET	21222	J. WILSON	HADDENHAM
9	READERS DIGEST GARDEN BOOK+GLOVES	47763	WARREN	SALFORD
10	1.5ltr BOTTLE OF WHISKEY	49630	M. LYNCH	DYFED
11	PETITE CHILDS SEWING MACHINE	15175	A. MASTERTON	?
12	TWO SILK SCARVES	00587	J. ROWE	STAMFORD ESSEX
13	FISHER PRICE GARAGE+MATCHBOX TOYS	32693	M. REID	CAMBRIDGE
14	LAURA ASHLEY HOUSE BOOK+DIY GLOVES	47986	S. HALL	? MANCHESTER
15	LIMITED EDITION PLATE	12466	M. CASSON	WORKSOP. NOTTS
16	BEACH(PILLOW)BAG, BEACH TOWEL, TOWEL SET	47854	J. COSGROVE	SALFORD
17	FISHER PRICE WALKIE TALKIE	47704	D. MOTT	?
18	PAIR OF PRIMA UMBERELLAS	05260	D. HOE	DONCASTER
19	BARBIE DOLL + BARBIE WASHER SET	17968	D. ASTLE	CHESTER
20	TICKETS TO DENBY POTTERY+UMBERELLA	18240	M. HAINSWORTH	?
21	BOTTLE OF PERNOD.	18712	J. LOGAN	BROADOAK
22	4x3hr MAXEL VIDEO TAPES	45109	M. BRIDGES	READING
23	DISNEY TOY TELEPHONE	05083	M. CROGHAN	CHESHIRE
24	PAIR OF PRIMA UMBERELLAS	03103	N. PULLIN	WILTSHIRE
25	4x3hr MAXEL VIDEO TAPES	27592	MRS. PUTT	PENZANCE
26	2 x LADYBIRD BOOKS.	20281	K. FARRELL	AYLESBURY
27	£10 GIFT VOUCHER	47463	M. JACKSON	NANTWICH
28	RAVEL UMBERELLA, SUIT/DRESS HOLDER+BAG	40233	YOUNG BOB	COVENT GARDEN
29	COMPENDIUM OF BEATRIX POTTER TALES	29662	J. HARDY	SHEFFIELD
30	TWO SILVER PLATE, DISHES	01871	MOLLY	?
31	FISHER PRICE BAND + EAR PLUGS	08721	MRS. COMBER	WOKING
32	BOTTLE OF CHAMPAGNE	14997	SALLY PREENE	WEMBDON. SOM/SET
33	RADIO TRENT MUG & CAP+	33446	P. DIFFIN	NTH. IRELAND
34	KNIGHTS OF THE SWORD X 2	27319	J. RITCHI	SEAHAM. DURHAM
35	WINES	47998	J. COSGROVE	SALFORD
36	TOY TRAIN SET	39438	DR. PATEL	KENT
37	WINES	13471	M. SLACK	ROTHERHAM
38	MARS WATCH & TSB STOP WATCH+	40537	A. CULLEY	AVON
39	HAND MADE SOFT TOY	26519	A. DOW	BIRMINGHAM

Promotor:- DAVID BRIGGS. 7, HUMBER STREET, RETFORD, NOTTS, DN22 6LZ.  
Registered under Section 5 of the Lotteries & Amusements Act 1976 with Chiltern D.C.  
REG No. 263. Drawn 25th September 1992

**FUNDRAISING EVENTS**

Once again you have all come up trumps with fundraising ideas. Thank you all.

Mr and Mrs Shiff, Liverpool	Collecting tins and sale of goods
Mike Willoughby, Milton Keynes	London Marathon
Sue and Jeff Hodgetts, Tamworth	Raffle at picnic
Quantock Foods, MK	Collecting Tin
Maquires, Liverpool	Raised
John Robson, Hull	Fishing Match
K and J Lawrie, Hull	Collecting Tins
Cedric Gooch, Tunbridge Wells	Mental Health Flag Day
Monkhouse Sports, Cheadle	Collecting Tin
Sid Shiff and Family, Liverpool	Sale of Goods and Collection
Mr and Mrs Lee, Tunbridge Wells	Luncheon Party
Alexandra Hildrew & Friends	Garden Fete and play
Gay Finch, Bridgwater	Staff Weigh-In
Scottish Area Families	Raised at Family Day
Mr and Mrs Benbow, Wirrall	Weekend in Refreshment Bar
Mrs Adams, Ludlow	Car Boot Sale & Tuck Shop
Stratheven Golf Club,	Auction
Mrs Jordan, Tunbridge Wells	Collected
The Gooch Family, Kent	Langton Green Horticultural Show
Mr and Mrs Johnson, Catford	Raised
Sheila Adams, Shropshire	Car Boot Sale and Tuck Shop
Peter & Sue Stuart, Borehamwood	Sale of Knitted Toys
Miss D Coles	Sale of Craycom cookery books
S Kumar	Sponsored Head Shave
Dave and Monica Briggs, Retford	Sale of Webb Ivory
Mr and Mrs Simpson, York	Sponsored Slim
Bonnie, Tesco, MK	Canteen Collecting Tin
Rod Vann	London Marathon
C E M Sports and Social Club	London-Brighton Cylce Race
Comet Hotel	Raised
Christine, Anne and Linda	MPS Garden Fayre
W And F Pidden	Collected

**In Memory**

Many thanks to all those who have given money to the Society in memory of:

**Martin Elmer**

**Rajesh Silhi**

**Victoria Headland**

**Sean Russell**

**Area Support Families**

**Neil and Jane Reid** . . . . . Tel: 0223 834570

19, Hillside, Sawston, Cambs. CB2 4BL

**Robert and Caroline Fisher** . . . . . Tel: 0799 86631

The Horrells, Great Samford, Saffron Walden, Essex

**Alan and Deirdre Beavan** . . . . . Tel: 0858 62182

'Tumbleweed' West Gate Lane,

Lubenham, Market Harborough, Leics. LE16 9TS

**Susanne and Jeffrey Hodgetts** . . . . . Tel: 0827 56363

6, Godolphin, Tamworth, Staffs. B79 7UF

**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. S10 3PR

**Mary and Robin Gooch** . . . . . Tel: 0435 883329

Highbank House, Swifehill, Broadoak, Nr Heathfield,

East Sussex.

**Bill and Sylvia Blackburn.** . . . . . Tel: 0270 626809

11 Beatty Road, Nantwich, Cheshire. CW5 5JP

**Ron and Linda Snack** . . . . . Tel: 0908 666819

16 Wandsworth Place, Bradwell Common, Milton Keynes, Bucks. MK 13

**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