

NEWSLETTER

SUMMER 1992

# THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES



National Registered Charity No. 287034

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This newsletter is published quarterly and distributed free of charge to sufferers 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

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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”**

**The annual general meeting of the Society for Mucopolysaccharide Diseases will be held at the Bristol Hotel, Old Market, Lower Castle St. Bristol on Sunday 27th of September at 10.30am.**

By order of the Committee - A.G. King (chairman)



# Contents

Christine Lavery speaks at the House of Commons tea party .....	3
Milestones. ....	4
Fer Pidden speaks at the House of Commons tea party .....	5
Northern Ireland Visit (Ron and Linda Snack) .....	6
June's Day in June .....	8
East Anglia Picnic (Jane Reid) .....	9
Child of Achievement (Emma Briggs) .....	10
Martin Elmer's story. ....	11
Summer celebrations. ....	12
Anniversary pictures .....	13
Sarah Burgess goes to Florida. ....	18
Visit to Czechoslovakia and Poland .....	19
Pictures from Poland .....	21
London Marathon (Mike Willoughby). ....	22
We are going democratic (committee elections) .....	23
Travel costs to hospital (Action for sick children) .....	24
"With you our hope gets stronger" .....	25
Summer Recipes. ....	26
Fundraising Events .....	27
Raffle notice .....	28

## Deadline for Autumn Newsletter

**Saturday 3rd of October.**

On page three is a brief extract from Christine Lavery's speech at the tea party at the House of Commons on the 28th of June. Our thanks to Dafydd Wigley MP and to our sponsors who made this event possible.

# House of Commons

30th of June 1992

## An urgent message

Daily we are reminded of the need for the MPS Society. Only last week on returning home from work, I found the following message.

*Urgent. Jackie, a nurse in \*\*\*\*town rang. She has a mother whose six year old daughter and three year old son have just been diagnosed Sanfilippo. This is a very tragic family. Father died in January. Mother must now face the news that both her children have SF. If you can phone Jackie at home tonight she would be most grateful."*



Christine Lavery and Dafydd Wigley, MP

## So what have we got to celebrate?

Progress was slow at first. We had to establish not only the trust of the British medical profession, but also of a great number of MPS parents caring in isolation. Ten year on many of these same professionals are very much part of an extended MPS family. For those of us who have travelled to European and American MPS meetings will conclude that in the UK we

are very fortunate to have so many caring medical practitioners and researchers.

The Society's funding of two consultant Paediatrician and a Biochemist has helped create a centre of excellence in MPS Diseases at the Royal Manchester Children's Hospital.

## All MPS Genes now identified

The genes of all MPS diseases have now been identified. Although there remains no cure, there are exciting prospects on the horizon. In the last few weeks we have agreed the first year's funding for research into gene therapy at the Christie Hospital in Manchester. This is a three year project, for which we will be raising money.

## A Southern Co-ordinator?

Six months experience with Mary Gardiner's post as Northern Family Co-ordinator, tells us how much we need a similar post to cover Southern England.

The Society's projects are aimed at valuing the life of the MPS child, supporting worried and overstretched parents, and looking to the needs of siblings and extended family.

The Society has many supporters, including members of Parliament. So it is fitting that we have been graciously permitted to hold our anniversary celebration in the mother of Parliaments.

## "An MPs Party!"

Sometimes we are closer to MPs than we think. At our last Christmas party in Newcastle, a passer by who saw the notice (and heard the noise!) went away grumbling, "Those b\*\*\*\*dy MPs are having a party again!"

## Milestones

### New families

**Sharon and Darren Allen** from Birmingham whose son, Daniel Allen, aged three, has Sanfilippo Disease.

**Karen Agett and Paul Crook** from Bridgend, Mid Glamorgan, whose daughter, Carissa, aged one, has Hurler Disease.

**William and Sue Chapple**, from Oldbury, Birmingham, whose son, Luke, aged two, has Sanfilippo Disease.

**Gail Kandel** from Barnsley whose seven year old daughter Ilia has Sanfilippo Disease.

**John and Evelyn Kennedy** from Stockport whose son Andrew aged three has Hurler Disease.

**Hilary and John Kermode** from Ellesmere Port whose daughter Rachel aged eight has Sanfilippo Disease.

**Ann and John Newman** from Tunbridge Wells whose son has Sanfilippo Disease.

**Tracey and Pete Osment** from Portishead whose son Sean aged six has Sanfilippo Disease.

**Parveen Akhtar and Mohammed Latif Saleem** whose son Shahid has Sanfilippo Disease.

**Angela and Andy Seymour** from Ashby, Scunthorpe, whose son David, aged six has Sanfilippo Disease.

**Donna Lowther** from Deckham, Gateshead, whose six year old daughter Siobhan and four year old son Shaun have Sanfilippo Disease.

**Mrs Deirdre Coles** from Stoke de Abernon in Surrey, whose grandson, born in May has Sialic Acid Disease.

### Deaths

We are very sorry to hear of the death of **Nicole Law** from Australia on the 9th of May, only two months after the death of her sister **Katie**. Both suffered from Sanfilippo Disease. Our thoughts are with their parents Denise and Ron and their brother Robert at this sad time.

Our thoughts are with the family of **Caroline Murphy** from Kettering. Caroline suffered from Sanfilippo Disease and died on the 30th of May, aged eleven years.

Our thoughts are with the family of **Bouke Temmink**, of Grimbergen in Belgium. Bouke died on the 22nd of May aged four years and nine months. He and his family came to the conference in Manchester two years ago.

## Why we are celebrating:

● By Fer Pidden

It is now eight years since our daughter Natalie was diagnosed as having Sanfilippo Disease. The unpronounceable word Mucopolysaccharide meant little at the time, but the diagnosis and the prognosis completely shattered our lives.



Fer and Bill Pidden speaking at the House of Commons

### Suicidal thoughts were running wild in my head.

Stunned and shocked; feeling very alone and isolated; suicidal thoughts were running wild in my head. About ten days after the diagnosis the Health Visitor called and said she had details of an MPS Society if I wished to or felt ready to contact them.

Suddenly I felt as if someone had thrown me a lifeline. It had never occurred to me that I would be able to meet another family having a child like our daughter.

### My whole approach changed

From the first moment I contacted the MPS Society my whole approach changed from one of hopelessness to one of eagerness to learn. When we went off to our first conference it was as if we were greeted by a family of ours that we didn't know existed.

### I expected tears and wallowing in grief.

Although attending an MPS conference is always a daunting experience everyone was friendly and everything was done so professionally. There was an atmosphere of determined optimism and dedication. I expected tears and wallowing in grief. I found light-heartedness and cheerfulness. It felt as if we were there celebrating a joyous occasion; and it has always become one ever since.

### I now know other people have been there before me

Because of the Society, I know that I am not alone and isolated. I know other people have been there before me. I know that they are there when I need them.

Above all the rest the Society has supplied us with vital information about MPS Diseases and early pregnancy tests. No other agency did this. Because of this we are now proud parents of a healthy five year old son.

Happy anniversary MPS Society and thank you.

**Fer Pidden**

5 Westbury Leigh Westbury, Wilts BA13 3SB

An edited version of Fer's speech at the tea party at the house of Commons on the 30th of June.



## Northern Ireland Visit



William Todd and his parents from near Bushmills present a cheque for £1,094 to Ron Snack. The money was raised by a sponsored walk.

### Golf Tournament at Strabane

When I heard that Kieran and Bernie Houston were arranging the MPS Golf tournament again this year my first thought was that I would like to play. My second thought was that it would be better not to make a fool of myself. So when Kieran asked if Linda and I would go over for the prize-giving and collect the cheque, we were delighted to accept.

### Brightening in the west

We arrived at Luton at 5.45am on Friday morning. At this stage the trip did not seem such a good idea. However when we found Kieran waiting for us at Belfast things began to brighten up. Even the weather improved as we drove westwards.

As we were staying with Kieran and Bernie we had time for a good long chat on Friday afternoon before taking a walk around Stra-

bane. Kieran even forced me into his local to sample the Liffey water.

### A 25th Wedding anniversary present.

On Saturday we visited Mr. and Mrs. Davis and family, on their farm just outside Strabane. Their daughter Elizabeth is 21 years old and suffers from Sanfilippo Disease. We were given a great welcome there, as we were everywhere in Ireland. Mr. and Mrs. Davis presented us with a cheque for £300. This had been given to them by family and friends instead of 25th wedding anniversary presents - a lovely thought.

### Brothers with cervical fusions.

After a couple of pleasant hours we dashed off to visit the Devlin family near Omagh, where more food and drink awaited. Dermot and Niall Devlin suffer from Morquio disease and both

have recently had cervical fusions. This has been a great success for both of them and they are a couple of live wires.

### Everything happens later in Ireland!

After a meal at Omagh we were due at Strabane golf club. Kieran and I rushed off to sort out the prizes for the competition and for the raffle to be held later in the evening. Everything seemed to happen later in Ireland. My body was telling me it was ten o'clock at night and I was nearly ready for bed, and there we were just getting ready for an evening out.

### Dancing night and morning!

We were made very welcome at the Golf Club. The prize-giving and my little chat about the Society went off very well. There was dancing for the rest of the evening and for some of the next morning. The total raised from the Golf Tournament came to over £1600. From the comments I heard about the way it was organised, I think Kieran and Bernie can be rightly proud of themselves.

### Bell-ringing in Derry

Sunday morning came all too soon, and it was time for yours truly to go bell-ringing in Derry. When we came back to Strabane we were treated to about twenty marching bands going past the Houston residence on their way to a competition in the town - quite a sight.

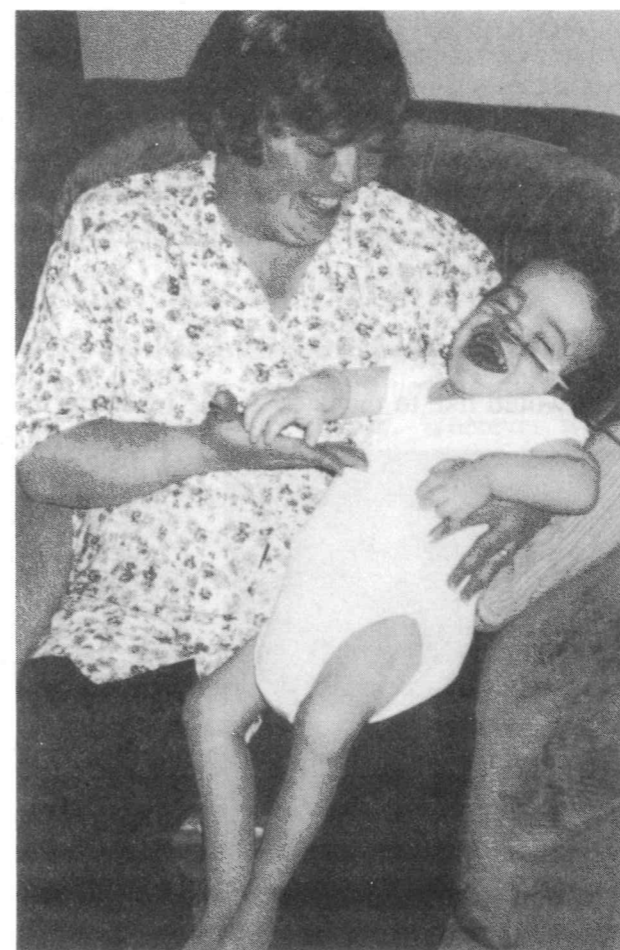
Off again, this time towards the Giant's Causeway, where we met Rachel Todd and her family. We were late arriving of course, but this seemed normal by now. I was presented with a cheque for £1094 which Rachel and her friends had raised by holding a sponsored walk.

The final lap now. We were whisked off to drop in on the Kirkpatricks at Muckamore. Ann had said she would have something ready to eat, but I do not think that any of us were prepared for the spread she had laid out for us.

### A wonderful weekend.

The weekend left us tired, but happy. Thank you to everyone we met in Ireland for the wonderful welcome. Thanks to Kieran and Bernie and their family who put themselves out so much for us. Thanks also to Strabane Golf Club and to all the sponsors, without whom the golf tournament would not have taken place.

### Ron Snack



Linda Snack relaxes with Liam Houston

# June's Day in June

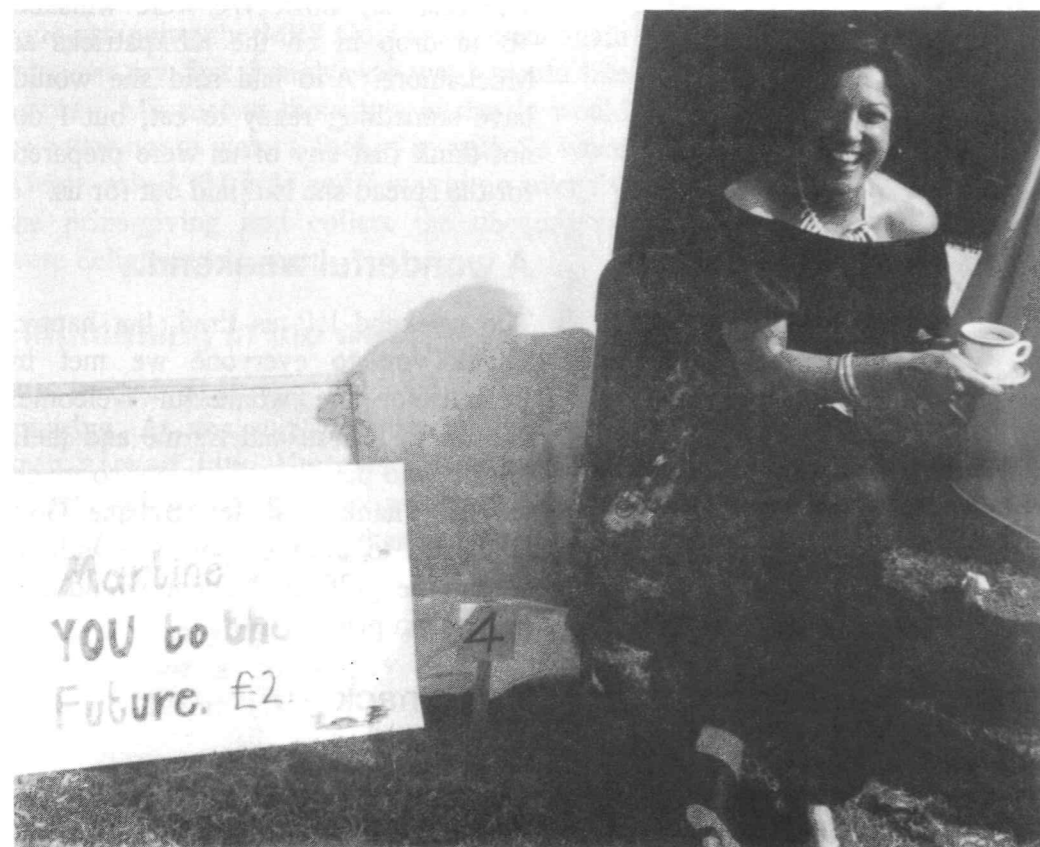
## No party - no milk!

All the customers of Gilford's Dairy were faced with this message recently!

The fun started on Friday evening when the Gardiners, Arrowsmiths and grandparents, the Snacks and Lee, arrived at Willaston to find caravans and tents already set up for them. So we spent the evening settling in, and some of us in sampling the local brew.

## All fell into bed around midnight

The work started in earnest on the Saturday with John Arrowsmith and Ron Snack trying to erect tents under Bill Blackburn's guidance. I don't think any of us had seen a tent put up inside out before. We were glad the marquee came with it's own crew! In the evening we had a sort of extended barbecue and all fell into bed about midnight.



## John Brennan brought a gypsy.

Around 27 MPS families arrived during the morning bringing all sorts of things to sell and games to play. John Brennan brought along a fortune telling gypsy - who quickly disappeared into a tent and was not seen again all afternoon.

## Linda scored a hit!

The whole afternoon seemed to fly, with masses of people around all the time. The Ducking Stool was very popular. Linda scored a hit on John Arrowsmith and sent him flying into the water. The video of that is up for auction at the conference.

## Twenty seven families had a wonderful day.

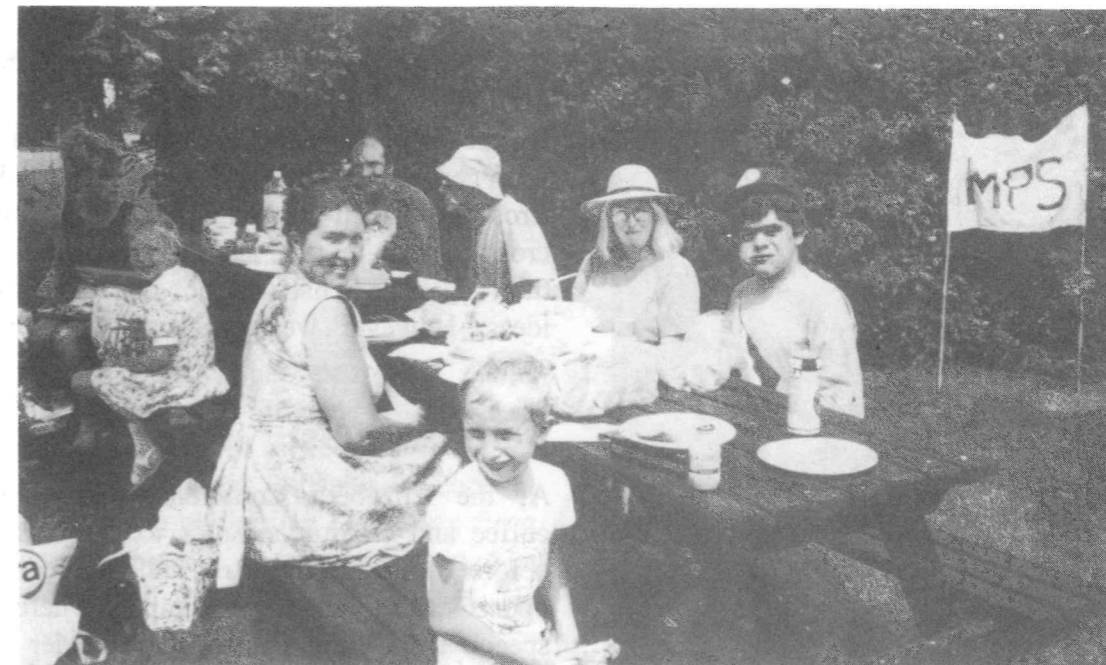
At the end of the day around £1000 was raised. A great effort by all concerned! Even more importantly all the families who came along had a great day out. It was such a success that we are trying to persuade June and her family to make it an annual event.

## Thanks to June and David.

I would like to thank everyone who was involved in the day in whatever way. A special thanks to June and her husband David, who opened their home and garden to us all, and who put such a lot of hard work into making the day what it was - Magic!

Ron Snack

# East Anglia Picnic



Jinks, Mansfield and Reid Families enjoying sun , food and music at Wimpole Hall Farm

## Brass Bands in the Paddock

When we went to Wimpole Hall on the 28th of June we didn't know they were hosting the first National Music Day in Britain. Wherever we went we had a musical accompaniment. Brass bands in the paddocks, orchestra's on the lawns, children's choir and recorder groups in the chapel and corridors. In the stable yard my personal favourite was the Steel Band. You could close your eyes and imagine you were on some tropical island.

## Simon did the full tour!

The Fishers, Mansfields, Jinks, and Birds all had a relaxed and pleasant afternoon, enjoying the exquisite gardens, the sumptuous hall and pala-

tial rooms. We strolled on the shady lawns and later took the stage-coach to the Home Farm to see a craft fair and sample the home made ice creams. We managed to lose Simon Mansfield, and all the men rushed off in different directions to look for him. After ten minutes Simon emerged nonchalantly from the back door of the Hall - no doubt he had done the full tour - upstairs and downstairs!

We left for home, foot weary, hot and tired after a wonderful day celebrating ten years of the MPS Society.

## Jane Reid

Sawston, Cambs



# Child of Achievement



**Emma Briggs and Bob Holness**

## A mysterious brown envelope

A few weeks before the day of the awards Emma received a large brown envelope when she arrived home from school.

“What’s this?” said Emma.

“Don’t know”, said dad, looking innocent.

“Don’t know”, said mum, trying to look innocent.

Rip, tear..... puzzled silence ..... frown.

Broad smile as she found the letter in the pack and read it. “I’ve won an award”, she yelled.

“Wow”, said dad. “Wow”, said mum. Both still trying to look innocent.

After a few seconds light dawned.

“You knew!” she exclaimed, “and didn’t tell me”. “Sorry, but we were not allowed to”, explained mum.

At this point Kristina arrived home from school and everything reverted to it’s normal state of chaos.

On the morning of the awards she was having her hair done by one of her cousins at 6 am. By the time we caught the seven am train she was getting excited and nervous. At Kings Cross I decided it would be just as easy to cross London by tube as to try and get a taxi in the rush hour. That was not one of my better ideas. However we got there with time to spare.

## Surprise guest

At the Elizabeth Conference Hall we had coffee and children’s bands to calm us down before going into the main hall. The ceremony opened with a fanfare of trumpets. There was a speech from Julie Fisher, the founder of the Awards. The surprise guest turned out to be John Major, the Prime Minister, who in his speech praised the efforts of all the children.

## Emma captures Andy Crane

The awards were presented by TV personalities, including Andy Crane, Bill Oddie, Tracy Childs, and Bob Holdness. One hundred and fifty children had been chosen out of nine thousand entries. Each child got a certificate and trophy with a holdall, cap and cake to commemorate the 10th anniversary of the awards. After lunch Emma sped around getting her picture taken with the celebrities. She was finally happy when she managed to corner Andy Crane, while he was practising for the TV recording.

## Another MPS award winner

Another surprise came when we found that we were not the only MPS family at the Awards. I was so busy clapping when Edward Nowell received his award that I forgot to take a picture. (See Spring Newsletter: Ed) Well done Edward, see you at the conference.

**.David Briggs**

7 Humber Street Retford, Notts.

# Martin Elmer

It was in 1983 when I last wrote an article for the Newsletter about my son Martin Elmer who suffers from Hunter Disease. The disease has been in my side of the family for at least four generations.

## Living at the Papworth Community

Martin has been resident at Papworth, a community for handicapped people in Cambridgeshire for the last thirteen years. He is very happy there. Martin is now deteriorating so much that he finds it difficult to cope at home. Papworth is only half an hour away from home so we can see him frequently and take him out for a pub lunch which he enjoys. He can only walk now with assistance and when he is away from Papworth he is in a wheelchair. He does come home for an occasional day, usually for a visit to the barber.

## In 1988 he was given two years to live.

His problems are that all his heart valves are faulty and his ankles swell. He is living on diuretics which control his whole life. He puts up with it very well, but lately he appears very fed up, which is very understandable. In November 1988 we were told about his heart problems. The doctors said there was absolutely nothing they could do and they gave him a maximum of two years to live. It will be four years this November. In all honesty his life really is terrible and very difficult for him to cope with.

## He suddenly announced his engagement.

Having said all this we had a very pleasant and unexpected surprise this April when Martin suddenly announced that he was going to be engaged on the 30th of May to a young lady called Paula. We think it is wonderful that they should have found each other. We feel that they deserve love and happiness.

Paula is a spina bifida sufferer and like Martin she has been at Papworth for many years. Prior to going to Papworth she lived in a Barnardo’s home until she was twenty, having been abandoned at birth. She is very sweet and they seem happy together. It was her 28th birthday on the 30th of May.

Papworth put on a lovely party for them and lots of our friends and family were invited. We had a lovely video of the whole evening, with lots of photographs.

## I never imagined it in my wildest dreams.

Paula seems to have given Martin something to live for, although there are times when he is very down. No other Hunter sufferer in my family has ever got engaged before, although the last one before Martin did live until a week before his 30th birthday. I never in my wildest dreams imagined Martin would ever have a girlfriend, let alone become engaged.

I tend now to live each day as it comes. My only hope is that he does not suffer too much. I do feel he is suffering all the time to a certain degree.

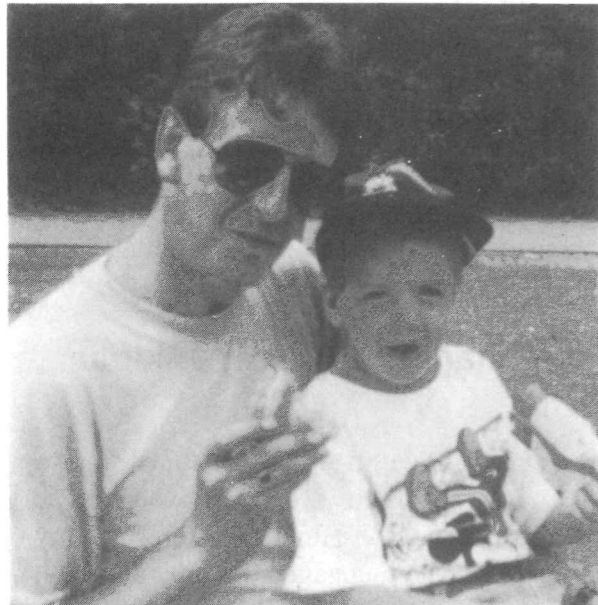
**Beryl Bird.**

## Martin and Paula at their engagement party





## Summer celebrations



Ron and Michael Thompson did it in Washington

### Like minded folks in fields

Even as I write reports are still coming in of an outbreak of picnics all over the British Isles. From Edinburgh to Exeter, from Newcastle to Bexhill strange events have been taking place. People gathered together enormous amount of food, furniture and children, packed them all carefully into cars, abandoned their comfortable homes, tore through the peaceful countryside for hundreds of miles, met up with other like minded folks in fields, unpacked everything, nibbled little bits, lost a few children, had a row, packed up everything again and then went home.

### A special investigation

The Society for the study of the paranormal (Them that's interested in corn circles) has set up a special branch to

look into this outbreak. I have conducted my own investigation. When I asked the participants about what happened, they all said the same things -- "We went there..we ate.. the sun shone..we enjoyed ourselves.. we went home".

### At Westminster too

Not content with doing it in the country some people did in the very heart of our capital city - in the very mother of parliaments. This is a very interesting variation of the disease. People bought new clothes, dressed themselves up to the nines, travelled hundreds of miles, crowded into a hot room in the centre of London, sweated profusely, had a cup a tea and a cake, couldn't hear each other above the din and then went home in the rush hour.

### Every picnic tells a story

You may not believe all this happened. The camera does not lie. See for yourself in the following pages. Then talk to your medical adviser.

### Eeyore the Editor



Gemma Thompson and Claire Arrowsmith rave on. Barbara has taken to her wheelchair while her friend looks out of it completely.

## Anniversary Events in pictures



Jackie Piromalli with Robert and Vivienne Culley at the South West and South Wales Picnic at Bickleigh Mill Devon. "The hottest party of the year"



Wynford and Christopher Rees from Clydach, Swansea, enjoying themselves in the playground.

Families came from far and near. We all relaxed with children's games and lots of conversation into the cool of the evening. "A perfect anniversary celebration", says Tony Eyre.



### Anniversary Pictures



The Rt Hon Nicholas Scott, Minister of State for Social Security and Disabled People joins with Sarah Kilvert to cut the cake at the House of Commons Tea Party on the 28th of June.

Trevor and Barbara Rollinson, Sean Mahon and David Briggs. Behind is one of the giant display boards showing different aspects of the Society's work. This one has a map showing the distribution of the Area Families.



### Anniversary Pictures



William Holroyd with guest, Natalie Pidden, at his 18th birthday party on the 5th July at Chew Stoke near Bristol. Both suffer from Sanfilippo Disease.



Roger and Elaine Britton from Downend, Bristol, with Christopher and Natalie.

Shirley Eyre, with Stacey and Sam.

Drinking a toast to William on his birthday.



### Anniversary Pictures



Scottish Families after their picnic at Edinburgh Zoo on the 28th of June. Some of the children in the picture are **Graham Johnston, Marc Dickson, Kerry and Laura Graham, Robert Murray and Louise Byrne.** Ed Wraith came for the pork pies. **Emma MacLean and Stephen Chalmers** did a display on the trampoline and Emma also tackled the assault course. Afterwards they all had an excellent buffet meal at the Post House Hotel. Talk about doing things in style!



**Kelly and Carol Jinks** enjoying the food at the East Anglia Picnic

### Anniversary Pictures



**Billy Burlison and friends** meet **Ken Dodd** at turf cutting for **Derian House Children's Hospice,** to be built at **Chorley, Lancs.**



**Christine Lavery**



**Alexander Butler**



**Ann Neal**

Now which garden party was that?



## Sarah goes to Florida



Sarah Burgess. "I liked all of it best!"

Dear Christine,

We would like to thank you very much for nominating our daughter Sarah for the holiday with the National Holiday Fund. When we received the phone call to say that Sarah was going to Disney World in Florida it came as a complete surprise. When I first told her she was very excited. As it came nearer she did become a little apprehensive, not knowing what to expect.

We had to take Sarah to the Gatwick Hilton Hotel on the Friday afternoon. There was a nice get together with the other children, six boys

and six girls aged between seven and eighteen all with different disabilities. We stayed for about three hours, giving Sarah plenty of time to mix with everyone. We talked to her doctor and her helper about everything Sarah can or can't do, her likes and dislikes etc.

They stayed at the Gatwick Hotel overnight. They flew out in the morning and arrived in Orlando in the late afternoon, receiving VIP treatment on the way. During their stay they visited Sea World, Disney World, the Epcot Centre, Busch Gardens, NASA, MGM and Universal Studios, and Cypress Gardens. Not only do we have a lot of photos we also have a wonderful three hour video which was filmed throughout the holiday by the NHF.

We asked Sarah which part of the holiday she liked best, but all she can say is "All of it". Thank you again and a special big thank you from Sarah.

Mrs. L Burgess

72 Bosmore Rd. Luton, Beds

## MPS Sales Items

Many families purchasing sales items are sending the money to the MPS Office, to Ron Snack or to Pauline Mahon. If you get goods from me please send the money direct to me, otherwise I don't have a record of what has been paid for. If you do this it will save me the embarrassment of contacting you about a payment that has already been made.

Susan Butler

Sales Co-ordinator

## A CZECH SPRING AND AN EARLY POLISH SUMMER FOR MPS

### Dzien dobry. Jak sie pan miewa? (G'day. How are you?)

I think that is as far as I shall ever get in Polish. It is just as well that MPS families are the same all over the world, and sometimes language is not important.

### First Polish Conference May '92

I am delighted to report that the first Polish Parent Conference, arranged by Marek and Joanne Popek was all that a first MPS conference should be. The Lavery Family are very privileged to have been there and to have shared in the Popeks' marvellous achievements. The venue was Jaworse, a small village in Southern Poland, at the edge of the foothills of the Tatry Mountains, and about 25 miles from the Czechoslovak border. Poland is a big country and if I say that families travelled all the way from Gdansk in the North (famous for its port, and steelworks of "Solidarnosc" fame) you will understand that a big MPS movement is beginning in Poland, with all the fervour and need for knowledge and personal contact which we have all enjoyed in the UK and elsewhere for some years.

### Thirty five families

35 Polish families with siblings and a number of exciting, troublesome, happy, personality-full, parent-destructive MPS children, attended. A brilliant turnout for a first. How the Popeks did it I do not know - not so many families have 'phones in Poland, so most of the arrangements had to be by letter. At first, Chris and I were disappointed (actually, rather angry) that so few Polish doctors had bothered to attend.

### Two excellent doctors

But sometimes it is quality and not quantity that counts. Professor Ewa Pronicka, Consultant Paediatrician and Dr Joanna Daniel, Cardiologist, at the Monument Hospital Child Health Centre, Warsaw Children's Hospital, are an MPS family's dream. They had travelled all the way from Warsaw too. They both played a major part in the formal conference proceedings. Marion Kraft (Austria) had star billing on the opening Friday evening.

### A painful film of a state run home

On Saturday morning we travelled in convoy by car to the nearest town to see a film at a real cinema - about a home in Poland for mentally disabled. It was brutal, but at the same time compassionate. It was probably no different than the UK. It moved me deeply, and made me very sad; well, tearful. I thought it was wholly inappropriate for MPS, but then I had been shown this possibility 11 years ago, and all my grief for Simon came flooding back. A state run home, in England or Poland, is not a respite home such as Helen and Martin House. I hope Richard and Elizabeth Volk (our greetings, and warm memories of the beautiful weekend we spent with you at Sinzig) are reading this in Germany - press ahead. So, the Polish doctors from Warsaw had to lift the parent conference from a very sad Saturday lunchtime.

### Telling them like it is...

Then it was Christine's turn. Michael, a young and urbane lawyer, who had studied jurisprudence in England, translated for Chris. We had brought some MPS slides with us, showing the various types of MPS, and the management of



MPS. The questioning was deep and searching, and the answers had to be responsible, but at the same time compassionate, but not guarded, nor economic with the truth. That is not what the MPS Society is about. However, we are only "professional parents", not medical nor research professionals. These were tense moments, until Chris held eye contact with the doctors from Warsaw. Polish people like straight answers, and this is what we were able to give.

### Ingrid Schmalz tells about Manchester

A pleasure of the performance was a double act by Sister Ingrid Schmatzl and Chris. Ingrid gave a very fine, and loyal, presentation about the facilities at Manchester and the Willink. It was as if Ingrid had not left RMCH. I hope RMCH will note.

### After the work, sightseeing.

There is so much to write, but I think I have already captured the vital story from Poland. Typical of any MPS conference, the hard-pressed organisers on the closing Sunday afternoon had to wind-down from an adrenalin-high. For relaxation, Joanne and Marek, Kamilla (SF) and Magda, with some of the remaining families, took Ingrid and the Laverys on a gentle sightseeing tour of the local countryside.

### Renewing contact in Czechoslovakia

A bonus of the visit for MPS was that the Laverys journeyed to Poland via Prague in Czechoslovakia, to meet Family Pfauser for the first time, and Dr Martin Hrebiceck (who came to UMIST). We discussed the creation of an MPS Society in Czechoslovakia. Accidentally, our arrival in Prague could not have been better - the Czechoslovak laws had only just changed to permit a group like the MPS Society. Our MPS friends in Prague might have been directed along the path of linking MPS with an umbrella group, under the old Czech laws. Martin invited us to his laboratory in Prague,

and we were all very impressed by his diagnostic facilities - even though he claimed they were not the most modern.

### A meal in old Prague - with old friends

Separately, Chris met the equivalent of Contact a Family in Prague. Much of our serious discussion on organisation of an MPS Society in Czechoslovakia took place over a meal at an old fashioned tavern in the old part of Prague, as guests of Milota and Catherina Pfauser and Martin Hrebicek. We very much appreciated their kindness and hospitality.

So thank you Milota, Catherina, Martin, Joanna and Marek. We are sure the Czechoslovak and Polish MPS Groups will be a great success.

Dekuji/Dziekuje bardzo .....

### Robin Lavery

### 1991 Raffle

Thanks again to David and Monica Briggs for the excellent organisation of the MPS Christmas Draw. A final total of £6,182.60 was raised. This was slightly down on 1990, mainly due to less support from companies. If anyone can get hold of raffle prizes David would be only too pleased to hear from you.

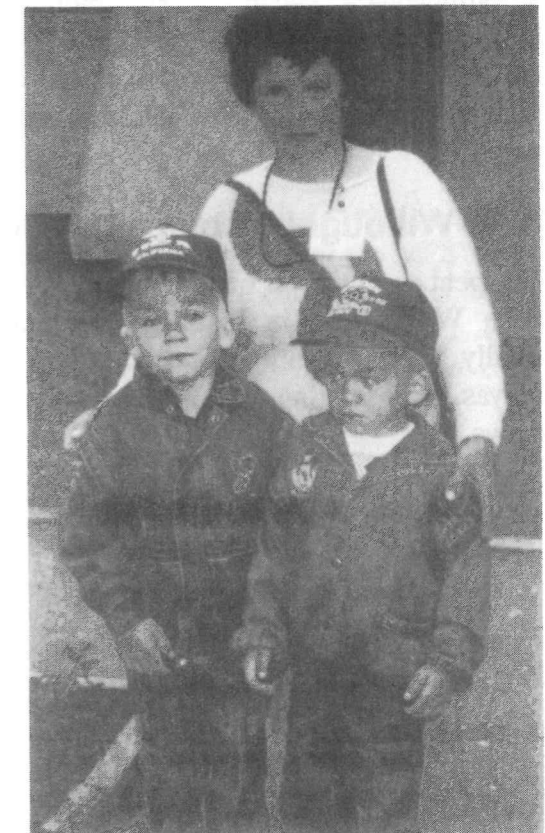
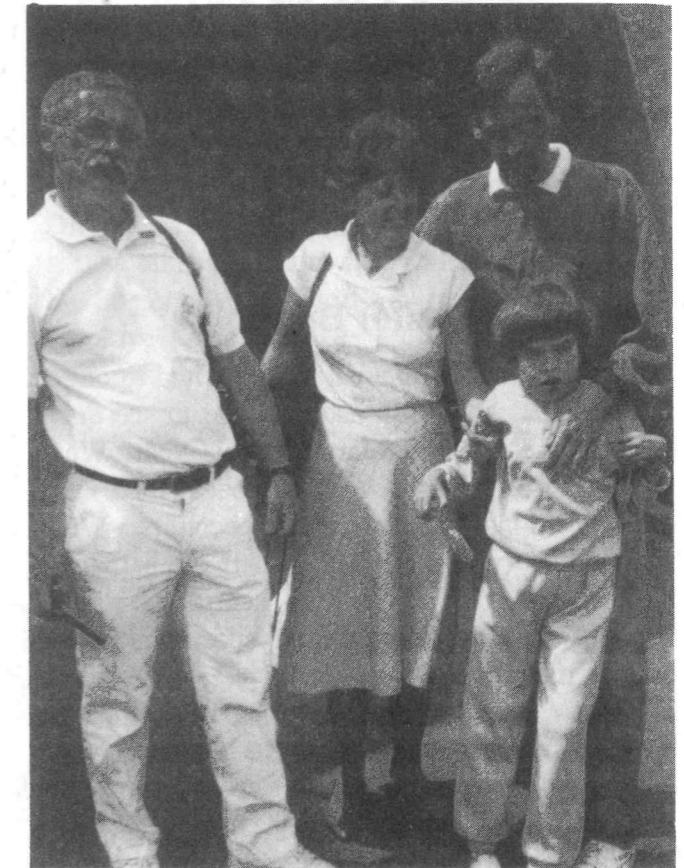
### Ron Snack

### Jewellery boxes

We have quite a lot of children's ear rings, bracelets and necklaces that we can sell at fetes, but we are short of small boxes to put them in - they look so much better in a proper box. Any small jewellery boxes to me please!

### Ron Snack

## Pictures from Poland





# London Marathon 1992

## Upon Westminster Bridge

Linda and I were privileged to be invited to one of the stands on Westminster Bridge to see the finish of the London Marathon this year. We left home very early with a coach load of Abbey National runners and spectators. We dropped the runners in Blackheath at 8.15am and then made our way into central London dropping off the unprivileged spectators just south of the river.

## The atmosphere became very emotional

We had not been in the stand long before the wheelchair athletes started coming through and the atmosphere became very emotional. To think that people with the physical handicaps that were evident could manage to get round a 26 mile course in their wheelchairs was quite incredible.

## Mike Willoughby comes through!

We spent an awful lot of time trying to pick out Mike Willoughby in his MPS running vest. Finally after just four hours ten minutes, there he was - still looking quite fresh - as the picture shows.

After collecting Mike we walked along to the Uniysys boat moored near Lambeth Palace where food and drink were available. Later we made our way slowly back to Milton Keynes. A highly successful day for everyone.

## Next year 120 families getting sponsors?

We raised about £3,200 from this year's marathon, but that included £1000 from Abbey National. Thanks to the thirty families who collected sponsors! Just think what we could have raised if we had sixty families with sponsors, or even better 120 families. Perhaps next year we will.

## Ron Snack



**Mike Willoughby:** All bright and glittering upon Westminster Bridge. Dull would he be of soul who could pass by a sight so touching in it's Majesty! Apologies to Wordsworth.

# We are going democratic!

## Annual General Meeting

On the first page of this newsletter you will find the formal notification of our Annual General Meeting, which will be held in Bristol on Sunday 27th of September.

## Opening up the Committee

In the past membership of the committee has in general been by invitation. However things are changing, the Society is growing and we want to open up membership of the Committee to everyone. I and others in the past have asked for new talent to join the Committee. New blood is essential to any progressive society. The cliché of hidden lights under bushels has been echoed before and I make no apologies for asking you all to ask yourselves again whether you feel you have something to give the Society by becoming one of the Management Committee

## Anyone can serve

Under the rules sanctioned at an Extraordinary General Meeting of the Society held at the annual conference last September, any member of the Society over eighteen is eligible to serve on the management committee. The committee now has a maximum of ten members.

The present members of the committee are:-

Jenny Broome	Sue Butler
Donald Garrow	Kieran Houston
Pat Isaac	Alf King
Robin Lavery	Pauline Mahon
Bryn Neal	Mary O'Toole
Wilma Robins	Ron Snack

You will see that the present committee has more than ten members and there are some notable absentees. **Christine Lavery**, as Hon. Director is not actually on the committee but of course takes the major role in the running of the Society. **Mary Gardiner** is now a paid employee, so cannot be on the committee, although she of course also still continues to play a major role in the conduct of the Society.

## Co-opted members

As to the numbers on the Committee, under the rules up to three people can be co-opted and in particular we look to people like our medical advisers, Dr Bryn Neal and Dr Donald Garrow to fill these posts.

## Send your nominations now!

With this newsletter is a nomination form on which you can nominate up to ten people, including yourself if you wish, to the committee. We must have nominations, otherwise there will be no committee. Do please return the nomination papers quickly.

## Ring me to discuss

If you want to know more about what is involved, do please phone me or the MPS office. I cannot emphasise enough the need for you to make nominations, preferably after checking that the person is willing to serve on the committee.

## Alf King - Chairman MPS Society

4 New Park Ave. Bexhill-on-Sea East Sussex, TN40 1QR

Tel: 0424 216432

## Travel costs for visiting a child in hospital

**"Visiting is not a luxury - It is fundamental to the care of the child" says DoH.**

As all parents know, it is very important for the well being of children to have frequent contact with parents while in hospital. Very often it is best for the child if a parent can stay with them, although because of circumstances this is not always possible. The Department of Health has recognised this in its recent guidance, which says. "This is not a luxury. It is now generally accepted that the care and comfort of parents for a child is fundamental to the care and treatment of children in hospital". (The Welfare of Children in Hospital, HMSO 1991).

**A significant number go into debt over visiting costs.**

Unfortunately some parents are prevented from from being with their child as often as they would wish because of the financial cost. Action for Sick Children has recently conducted research which shows that a significant number of families go into debt over visiting costs. It also shows that many more families are unable to visit as often as they would like.

**Few were helped by the Social Fund**

We found the difficulties affected families at all levels of income. Families on Income support often failed to receive the discretionary help that is available from the Social Fund, either because their application was turned down, or because they found the application process too complicated and unhelpful. Families not on Income Support had to 'make do' or rely on charities or friends. When a child was in

hospital for some time parents found themselves unable to pay essential bills or they got into debt. Some parents lost their jobs because their child was in hospital for a long time.

**Many families could not afford costs.**

Overall we found that 18% of families could not afford visiting costs from their normal income.

**An Autumn Campaign!**

Armed with this research Action for Sick Children plan to run a campaign in the autumn. We will be calling on the Government to create a special visiting costs fund for families that have difficulties. We want it to cover all families who experience such hardship, not just those on benefits.

**Please support us.**

Organisations or individuals who would like to support the campaign should contact:

**Pauline Shelley,**

Action for Sick Children,

Argyle House

Euston Rd. London NW1 2SD

071 833 2041.

## Con te la speranza diventa piu forte. (With you our hope gets stronger)

**Once upon a time, in a local village, there lived a family which was in love with life. One day, from this love, a rose was born.**

**Rose became the aim of their life; they fondled her and she grew up and developed. In their dreams they saw her blossoming.**

**A terrible day came. They noticed their beloved Rose was slowly withering. She stopped learning and began to forget what she had learnt. You could hardly recognise her.**

**A strange disease was destroying their great dream. All their efforts to fight it seemed to be useless.**

**Then they could only cling to a hope, fed by the love of those who are close to her, and who would not be defeated. They wanted to understand this illness which continued to blight many other roses.**

**That's how it was, once upon a time.....But now there is an immense family who also live in hope: it is our association which is slowly but gradually growing, anxiously awaiting the fruits of research.**

**If your heart is still open to fairy tales, share with us the joy your gift can bring. If you are with us, our hope gets stronger.**

**We need you to join us. Do think about it.**

Translated from a poster prepared by the Italian MPS Society



# Recipes

Christine Marchbank produced some delicious home made ice-creams at one of Ron Snack's family days. Not one to miss out on good food, Ron felt that access to Christine's recipes should be one of the benefits of Society membership.



It's clear that Ron Snack enjoyed his tea as he chats to Dr Rosemary Stephens at the House of Commons. Did they have icecream?

## Blackcurrant Ice Cream (Serves 8-10)

150ml (1/4 pint) fresh double cream

125 gram (4 oz.) blackcurrants

50 gram (2 oz.) castor sugar

14 - 16 sponge fingers (boudoir biscuits)

- Cook the blackcurrants with the sugar and two tablespoons of water until tender. Allow to cool.
- Sieve the blackcurrants and juice to make a puree.
- Arrange a flat layer of sponge fingers, sugar side down, in the bottom of a flat picnic box, 10cms x 20cms, lined with cling film.

- Whip the cream with the milk until softly stiff, then swirl in the blackcurrant puree.
- Spread this mixture over the layer of sponge fingers in the box.
- Top with the remaining fingers, sugar side up. Cover and freeze until firm.
- Remove the frozen ice cream from the box, cut into slices and serve.

## Rhubarb ice cream

150 ml fresh double cream.

150 ml fresh single cream.

675 grams (1 & 1/2 lbs) rhubarb.

175 grams (6oz) castor sugar.

Pink colouring (optional).

2 tablespoons lemon juice.

- Cut the rhubarb into small pieces in a saucepan. Cook very slowly without adding any liquid until the juices run, add the sugar and continue to cook to a pulp. Press

the rhubarb through a sieve (or liquidize in a blender) and allow to cool.

- Whisk the creams together (until they are the consistency of a coating sauce) and fold into the cold puree. Taste and add lemon juice or more sugar if necessary. Stir in the pink colouring to give a delicate pink tinge.
- Turn this mixture into a two pint jelly mould or plastic container and freeze until solid. If you use a ring mould it is easy to cut wedges to sandwich between ice cream wafers.

## FUNDRAISING EVENTS

Many thanks to everyone who has raised money for us recently. All sorts of things have been going on and I hope the following list shows the different things that people get up to. Well done all!

Paul Hubbard	Sale of Stamps
Haylie Hotel, Largs	Raffle
British Steel, Glasgow	Walking the West Highland Way
Calderwood Primary School, Glasgow	Car Wash & Games Day
Allan and Amy Bottrell, Glasgow	Collecting 20ps
Alan and Fiona Byrne, Glasgow	Dance
Mr Yunis, Bristol	London Marathon
Rita's Eater, Glasgow	Collection Box
A Copeland, Belfast	Collection Box
Jenny Dagnall, Bolton	London Marathon
Mr and Mrs Maguire, Liverpool	" "
Jon and Kath Lawrie, Hull	" "
Mr and Mrs Hamilton, London	" "
Wilma Robins, Romford	Collection Box
Carol Westland, Reading	Sale of Goods, Books etc
Sid Shiff & Family, Liverpool	Collection Box
Mr and Mrs Woods, Bracknell	London Marathon
Mrs Simpson, York	" "
Mr and Mrs Pack, Cheshire	" "
Mrs Nurse, London	" "
Tony Cast, Milton Keynes	" "
Linda and Ron Snack, Milton Keynes	Flag Day at N P Service Station
Mr and Mrs Blackburn, Nantwich	London Marathon
Pam Croghan, Cheshire	" "
Mr and Mrs Hayward, Newport	" "
Mrs White, Selby	" "
Mr and Mrs Mort, Swansea	" "
Mrs Kershaw, Cheshire	" "
Mrs Johnson, Clwyd	" "
Mr and Mrs Thacker, Norfolk	" "
Mr and Mrs Puddy, Somerset	" "
Heaham Bakery, Leics	Collection Box
Langfield School, Leics	School Project
Clevedon Golf Club, Avon	Collection Boxes
R Varsani, Bolton	London Marathon
Mrs Harris, Kent	" "
Kieran and Bernie Houston	MPS Golf Tournament
Rachel Todd & Friends, Bushmills	Sponsored Walk
Mr and Mrs Davis, Strabane	In lieu of Silver Wedding Gifts
Mrs Naish, Bristol	London Marathon
Mrs Gosgrove, Salford	" "
Ellen & Geoff Robinson, MK	Car Boot Sale
N W Families	F/R Garden Party
Mr and Mrs Eyre, Bristol	London Marathon
A/N Charitable Trust	Matched Funding for Marathon
S Hodgetts, Tamworth	London Marathon
Mrs Todd, Glasgow	Collection Box
Cathkin High School, Glasgow	Raffle
Billy Ingham, Belfast	Collection Box
Ladybridge Residents Club, Cheshire	Change Collection
Carol Westland, Reading	Mental Health Flag Day
Hendon Police Training College	Coin Collection



Debenhams Sports and Social	Fundraised
G & F Knapton	Darts Marathon
P J Hall	Darts Marathon
D J Taylor	Get Out Of That Challenge
Mrs Finch	Staff Weigh-In
C & G Vivier & Groombridge CC	Sponsored Walk
D Brooks-Daw	Collection Box
St Elphins School	Fundraised
J & B Rollinson	Raised
Mr Sander	Sale of Stamps

**IN MEMORY**

Thank you to everyone who has made donations to the Society in memory of Ashley Cooling, Timothy Norsworthy and Gareth Makepeace.

## Raffle 1992

This year,s raffle will take place at the annual conference on the 29th of September in Bristol. You will have recieved raffle tickets by now, so please sell them as fast as you can! So little time - so many tickets!

### 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