

NEWSLETTER

WINTER 1991

**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. A Northern Co-ordinator is funded by "Children in Need". 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"

Dates for your diary

Sunday 28th June 1992

National MPS Picnic Day

Fri 25 - Sun 27th Sept

10th Anniversary Conference, Bristol

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Deadline for Spring Newsletter

Saturday 4th April

Births

We were delighted to learn that a healthy baby boy, **Gary**, was born to **Kelly and Carolyn Rocket** from Weymouth on the 19th February 1991. A brother for **Mark**.

New Families

Julia and Mark Wright, from Weymouth, whose four year old son **Matthew** has been diagnosed as suffering from Hunter Disease.

Sue and Peter Stuart, from Borehamwood, Hertfordshire, whose baby daughter, **Jessica**, has recently been diagnosed as suffering from Hurler disease.

Deaths

We are sorry to learn of the sudden death of **Greg Flint** in the early hours of Friday 13th of December. Greg suffered from Hurler disease and was three years old when he died. Our thoughts are with his parents **Brian and Angela**, his sister **Fiona** and their families.

Ayesha Ahmed from Strathclyde, Glasgow, died on the 19th of December 1991. Ayesha is the sister of **Waseem** who suffers from Maroteaux-Lamy Disease. Our thoughts are with her grieving parents and family.

We were very sorry to learn of the death of **Shelley Scarr** from Washington, Tyne and Wear, on the 1st November. Shelley suffered from Sanfilippo Disease. Our thoughts are with **Pat, Trevor, Kimberley and Liam** at this sad time.

Our thoughts are also with **Jill, Eddie, Thomas and Elizabeth Farwell**, from North Devon who lost their much loved daughter and sister, **Katie** on the 4th November 1991. Katie suffered from Sanfilippo Disease.

Doctor Peter Dagnall

So many times in the past in my involvement with Cystic Fibrosis I have met people who have been touched by the disorder in some way or other: rich and poor who have wanted to help.

I have known people who lived on nothing but DSS wanting to give money that they just could not afford, and despite my saying that they could not afford, they still insist on giving you the money, but the family suffer in consequence and so the price is too great.

The best way of raising money for any charity is to do something you thoroughly enjoy, have a really good time and help the charity at the same time. But alas even doing this, the price can sometimes be too great.

The first time I met Dr Peter Dagnall he took me to his Rotary Club to tell them about Cystic Fibrosis. It was the first time I had ever done such a thing and he put me at my ease and helped me through it. Peter liked helping people.

Peter not only liked helping people and causes, he enjoyed it!

His involvement with the his church and the people of his church was deep, sincere and greater than many knew. Indeed, whether it was Church, Rotary or a good cause, if he was involved he was thoroughly involved, but mostly in a quiet way, so that most

people did not realize the extent of his involvement.

Dr Peter Dagnall was killed by a fall, while walking in Snowdonia on the 20th of July 1991. He was forty three.

Peter was well liked and respected in the general practice in which he was a partner. He leaves a wife, Jenny, and four children, one of which has Downs Syndrome and one Mucopolysaccharide Disease.

When I was told of Peter's accident, and the circumstances of his death, I was shocked and terribly upset. I had no idea he was raising money for Cystic Fibrosis, but then as secretary of the Bolton CF Branch, I was the last one he would tell until he brought in the money! But he was doing what he liked doing most, helping other people and enjoying himself walking in the hills which he loved.

But the price. He could not afford it. And neither could his family, nor the people who knew him. That price was too great.

John Taylor (Bolton)

Reproduced with permission of the Cystic Fibrosis Trust

National MPS Christmas Party

Meeting new and old friends

The High Heaton Tenants Club in Newcastle-on-Tyne hosted a most successful Christmas Party on the 7th of December. Congratulations to the Arrowsmith family who catered for everyone in a most welcoming fashion. The meeting was very well attended and provided an opportunity for many families to take part in an MPS event for the first time. Christine Lavery, Ed Wraith and Mary Gardiner had the opportunity to meet many families whom they had not met before.

The Magician was great!

Robin Lavery says the Magician was great, but the greatest magic of all was the price of the beer! Our thanks to the Lord Mayor of Newcastle who opened the proceedings, and to Barbara and John for a very friendly and agreeable afternoon with an excellent meal and rivetting entertainment. David Briggs also performed his magic with the annual raffle. The list of prizewinners is shown elsewhere in this newsletter. What happened in the back seat of the coach going back to Sheffield, Pauline Mahon? I think we should be told.

Northern Co-ordinator A new Beginning

On January 1st Mary Gardiner took up her post as Northern Co-ordinator. She will be working from her home address and her telephone number will continue to be the same. She will work with Area Families north of Birmingham, in Scotland and in Northern Ireland. She hopes to visit new families when they contact the Society.

Families in these Areas who need help, support or advice should contact Mary in the first instance. You can leave a message on her answerphone if she is not in.. (The main MPS office can still be contacted in the usual way, and will work very closely with Mary).

Best wishes to Mary in her new post. We hope it will prove to be a great success both for the Society and for her.

Thanks to Children in Need!

The Society owes an enormous debt of gratitude to the Children in Need Appeal for funding this post, which will enable us to greatly extend links and support to families and children with MPS diseases.

Busy time in Milton Keynes

We had two very busy weekends in Milton Keynes with our flag day on the 30th of November, the Christmas Party on the 1st of December and our giant tombola on the 7th of December. (See the party report).

All the bell-ringers turned out!

We are very lucky here as our shopping centre lends itself to quite a comfortable Flag Day. All the bell-ringers turned out once again in the morning, along with a workmate of Linda's. Christmas Tree hats got us into the spirit. Come lunchtime the second shift arrived, including Linda's mum and dad, Lil and Nobby, Geoff and Ellen Robinson and David and Monica Briggs with Emma and Kristina.

We were all happy to see 5.15 arrive! We rode back to the house in the new Briggs-mobile for hot soup and bread. Counting the money took us a long time. We ended up with a wonderful total of £918.05. Next year's flag day is booked for the 19th of December.

Linda and Monica made the sandwiches

We were reluctant to let the Briggs travel home late after their hard work, so we kept them overnight and then worked them some more on the Sunday. David and I took the girls bell-ringing in the morning, while Linda and Monica had the job of making sandwiches for the party in the afternoon.

Giant Tombola

Linda and I went back to work on Monday to rest and prepare ourselves for the fray on the following Saturday. We had booked the Community Kiosk in the Shopping Centre for the day. Months had been spent collecting prizes for the "Giant Tombola". With the help of Geoff and Ellen Robinson and Linda's parents, everything went very well.

Six-o'clock came and off we went home again. This time there was £375.23 in the pot. Another good day.

And so to bed....

Oh, I almost forgot, Linda and I then went out to a Dinner and Dance. Nothing to do with MPS, but very enjoyable. Why is Christmas time so busy?

Ron Snack



Christmas Party in Milton Keynes

Forget the Eiffel Tower, the Leaning Tower of Pisa and even the Blackpool Tower. Once again party goers at Milton Keynes built a giant Duplo Tower which stood above them all. This year the demolition contract was placed with Kristina Briggs, a good choice.

Some great tricks were performed by John Eaton, the magician. He also does some marvellous things with balloons. Family games such as "Pin the Nose on Rudolf" were organised with spirit by Andy and Jenny Hardy. The best trick was the arrival of the big man himself, (no, not Ron) but Father Christmas.



Everybody thoroughly enjoyed themselves, and as usual, ate and ate and ate, particularly Lil's wonderful Scotch Eggs.

The families would like to thank Linda and Ron for once again organising a most enjoyable afternoon.

Geoff and Ellen Robinson

In Memory

Many thanks to those who sent donations to the Society in memory of Stephen Harvey, David Criddle, Gareth Makepeace, the grandmother of Sarah Lowry and a relation of Mr and Mrs Hayward of Gwent.

Also don't forget about collecting at Sainsburys. Some of the larger stores get an awful lot of customers through their doors on a Saturday and we could be relieving many of them of some of their cash.

Collections

This is the last chance to get your name down for the Mental Health Flag Day. Just drop me a line to let me know where you would like to collect and I will get the permissions sorted out.

Charity Dinner Party

Congratulations and thanks to Pauline and Sean Mahon who organised a charity dinner and raised £2000 for the Society. As well as making an excellent job of being treasurer, Pauline also has time to raise money for us. Well done to you both.

Short Trip to Guernsey

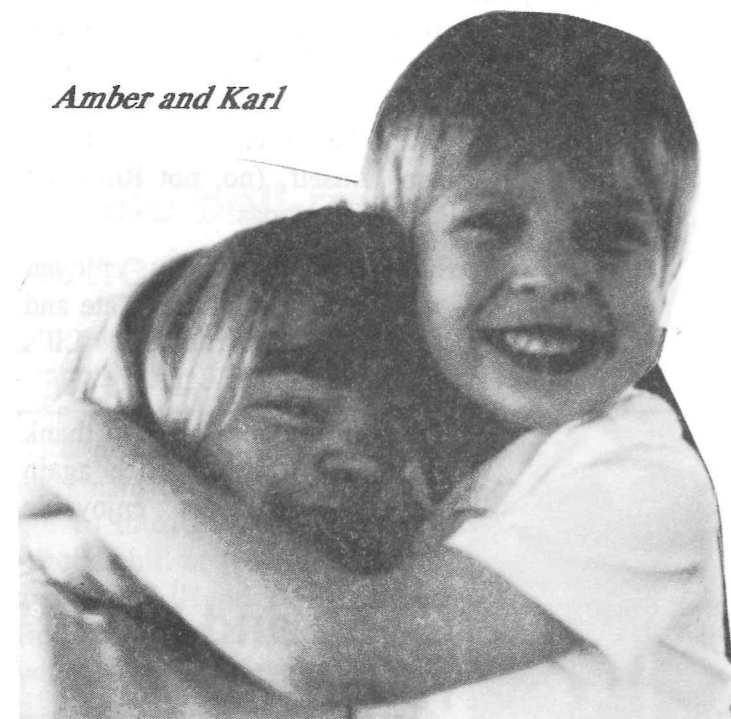
Being an Area Family can sometimes be a traumatic and demanding occupation, but it also has its rewarding and pleasurable moments. When visiting families in our part of the world it's surprising how many of them live in wonderful scenic localities.

Amber and Karl were wonderful

Meeting someone who you have only spoken to on the phone is always a strange experience, but Teresa was very kind and made us very welcome. Her two children, Amber and Karl were wonderful. Amber has Hurler Syndrome but is very active and enthralling, with lots of infectious giggles and smiles. Karl is an energetic five year old and keeps everyone on their toes.

The two days passed quickly and soon it was departure time. Hopefully they can visit us in Bristol soon. We hope we were of some help and look

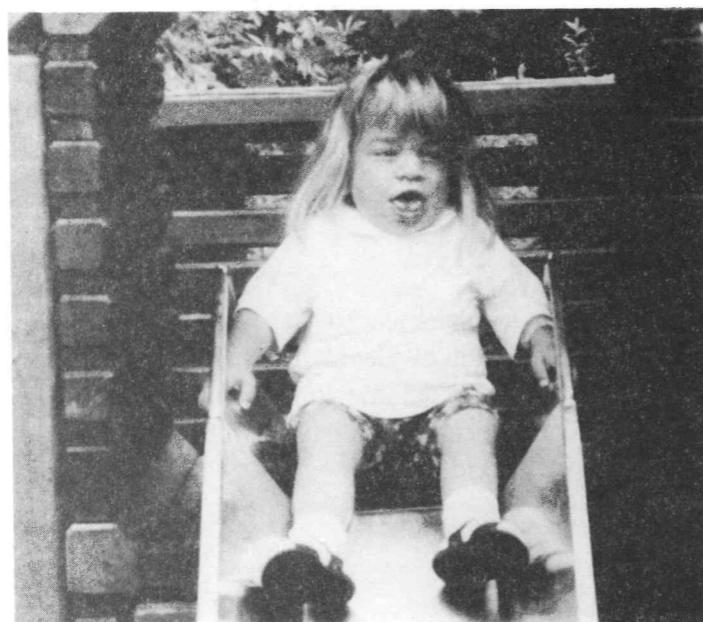
forward to seeing them again before long.



Amber and Karl

Little contact with other MPS families

Teresa Le Page and her two children are such a family, living in the beautiful island of Guernsey. Apart from the occasional phone call and the newsletter Teresa has little contact with other MPS families. So with our two children safely in the keeping of our parents we embarked on a short visit to Guernsey.



Report from

Tony and Shirley Eyre

That first year

We always had good weather that first year,
The barbecue, the outing, the holiday, the conference,

It did a lot to ease the stress

The sun, good weather,

It makes the memories warmer.

And in the sun,

While the children enjoyed being themselves,

We talked

Of fears and griefs and good times.

We laughed and we cried

With new friends

With whom we shared

A lifetime.

Kathy Lawrie,

36 Dressay Grove, Hull, HU8 9JJ

This poem is by way of a thank you to all in the Society who work to make it such a valuable lifeline and also to all the new friends that we have made. The last year has been a crucial one for us. In July 1990, Stuart, then aged five and a half was diagnosed with Sanfilippo. In August Tim was born. Thankfully, both he and David, aged four, were pronounced clear of Sanfilippo Disease. Shortly after that we moved home from Essex to Hull and Jon took on a new job. Not an easy time!

Through it all we have received a lot of support from many people in the Society. We have made many friends with those who shared their experiences with us and listened to ours.

Its all been said before of course, but that doesn't lessen its value - especially for newcomers like us.



Dominic Hall and Family

Two bone marrow transplants

I am Dominic Hall's dad. Dominic has Sanfilippo. Although he is only three years old he has had two bone marrow transplants. The first was in 1989. Just before Christmas 1990 he rejected the transplant. We decided to go ahead with a second transplant that had been offered. The marrow was taken from Dominic's elder brother Nathan. Nathan has also had an operation on both his Achilles tendons this year. So at one time or another we had a special son in hospital.

A difficult two years

Add to this the death of my mother, which also happened this year and you will

understand the pressure worry and stress that my wife Bernie and I have been through in the last year.

A Poem that helped us

A friend sent us a little card with the enclosed poem on it. As it helped us when times got tough I thought it would be nice to share it with other families who might be going through the same tunnel that we have been through.

Eddie Hall

16 Printer Fold, Hollingsworth,
Via Hyde, Cheshire, SK13 8HX

Don't you quit!

*When things go wrong as they sometimes will,
When the road you are trudging seems all uphill,
When funds are low and the debt is high,
And you want to smile but you have to sigh,
When care is pressing you down a bit,
Rest if you must, but don't you quit!*

*Life is queer with it's twists and turns,
As every one of us sometime learns,
And many a failure turns about
When he might have won and stuck it out.
And you never can tell how close you are
It may be near when it seems so far
So stick to the fight when you're hardest hit
It's when things seem worst that you mustn't quit.*

Alexander Butler's 18th Birthday

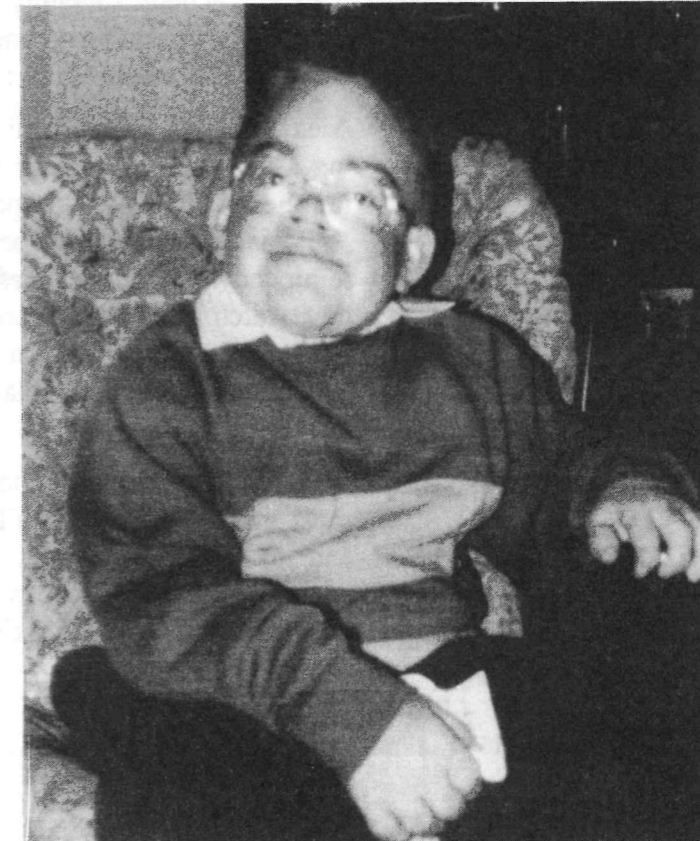
Our son Alexander has mild Hunter's Syndrome. Alex reached his eighteenth birthday on the 6th of October. Twelve years ago we didn't dare think about it. We were determined to make a great celebration for him. We arranged the celebrations for the following Sunday, the thirteenth, which was just as well. The weekend of the 6th was not as it turned out a disaster, but it could quite easily have been. It must have been fate that Dan's brother Paul couldn't do the disco that weekend. We had arranged to take Alex and three friends out to dinner on the Saturday, but Alex had the most horrendous ear infection. We cancelled the 'night out' and hurriedly arranged a night in.

Sunday was the big day, with his favourite aunt and uncle coming for lunch. Neighbours came to wish him happy birthday. Lots of lovely presents and money (which Alex loves). I disappeared to our local GP and got him another anti-biotic.

"Secret phone calls and little white lies"

The next week was full of secret phone calls and little white lies. Everyone was getting into the spirit of what was to be Alex's surprise party.

Alex's god-mother and family were coming from Lancashire, complete with banner. (They were supposedly popping in on their way to a holiday, which they sometimes do.) We had to agree a cover story about where they were going



to - we had to get our stories straight.

The weekend arrived. Gary and Sue (my goddaughter) took Alex to see Wycombe Wanderers - they won 6 - 1. With Alex out of the way we rushed to the Village Hall and arranged the food and drink and put up the decorations and the banners.

Gary was under strict instructions not to be back before five o'clock. It was a close run thing! There was a chain of people whisking food out the front door just as Alex came in

the back. I've never seen Scotch eggs made so quickly.

A big problem was how to get everyone to the Village Hall without arousing his suspicions. This is how we did it. Dan went off,

The birthday cake was fantastic! It was in the shape of a racing car and was made by my good family friends. Robin Lavery made a super speech thanking everyone for their support and for coming to Alex's celeb-

"Words cannot express how we feel"

ostensibly to take Lucinda and a friend to the cinema. Later, I went to pick Lucinda and friend up, telling Alex we would all meet up at a restaurant for a meal. Alex's grandmother left in another car.

Alex was taken completely unawares!

Alex's godmother then asked him to come with her to search for a friend she had in the area. The search took her to the Village Hall, surprise, surprise, Alex all the time completely unawares.

Here Alex was met by Paul. There was a highly charged few minutes while Paul explained to Alex about the party. There were a few tears shed and Alex looked rather bewildered, but then took it all in his stride as he usually does.

ration. It was like "This is your life!" Alex's teachers suddenly appeared, Akela and scouts, friends who had been so supportive over the years. Many thanks, Robin.

Alex received some lovely presents, including a very special present from all the MPS families who came - a portable television. Alex is thrilled. He doesn't need to be reminded to go to bed these days, as he can now watch his favourite programmes in bed! He thought the party was a fantastic idea and is already making plans with his uncle Paul for his 21st.

Words cannot express how we feel. Our most grateful thanks to all who contributed and to those who sent cards and good wishes. A special thanks to everyone for keeping the secret of Alex's Surprise Party.

Sue and Dan Butler

Tony and Mary Lockyer

Tony and Mary have regretfully decided that they are unable to continue as Area Family because of other commitments. What friendly, warm, cheerful and energetic support they offered to families in South Wales during their four years as Area Family! Many families, not only in Wales, have found great encouragement and courage from their example and their help. Best wishes in the work with Ty-Hafon and a very sincere thank you on behalf of the Society.

Help needed!

Now that Tony and Mary have resigned, the committee would like to hear from any families in **South Wales or Border Counties** who might be willing to help organise two events this year, a picnic on the 28th June and a Christmas Party. (We will of course be looking for an Area Family, but the most urgent need is start planning the two events). If you would like to discuss further, please leave a message at the office and Christine will get in contact.



Mrs Mary Whitehouse presents Ron and Linda with a cheque on behalf of Tom and Maureen Fryer and friends at the Tendring Tavern.

MPS Fun Day in Essex

In the cold depths of winter it is difficult to bring back to mind those lovely hot days of Summer 1991. One thing that is very memorable is the weekend of inter pub competition that was organised in Essex by Maureen Fryer and her husband Tom. Not one for doing things in a small way, Maureen arranged and "Its a knockout" competition, with loads of other things happening as well. Everyone had a great time, apart, perhaps, from those who got thrown into the stocks!

Mary Whitehouse officially set the proceedings in motion, and was also present at the formal presentation of the cheque to Ron and Linda Snack. A total of £1,400 was raised during the weekend.

We would like to express our warmest thanks to Maureen and Tom for all their hard work and ingenuity in organising the weekend. This looks set to become an annual event in the MPS year.

Ron and Linda Snack

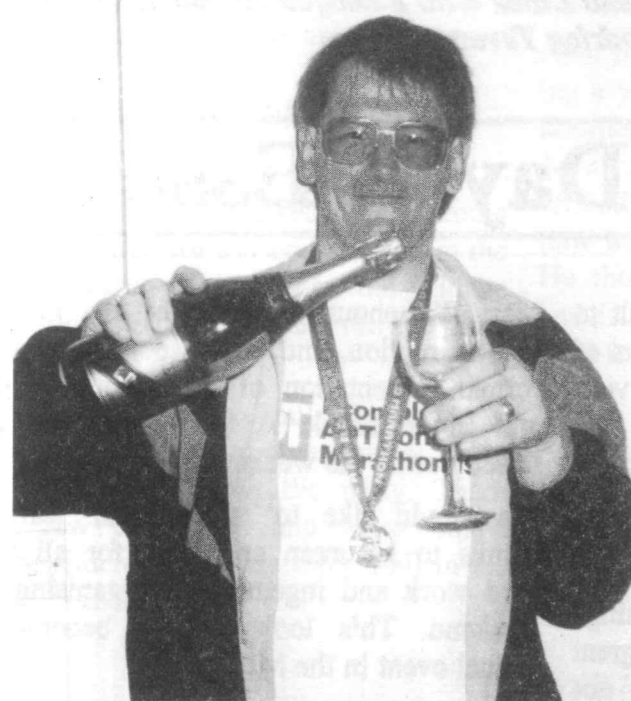


*Thorpe Social Savages show their muscles as they battle to raise money for MPS
No more jokes about Essex, please!*

Running the Marathon for

MPS

As I arrived at work one day in September 1990, I announced to my startled colleagues, "Today is the last day for entering the 1991 London Marathon, I think I may have a go!"



At £50 per mile, Keith has earned his champagne!

Their response was unanimous. "You", they said, "You couldn't run up the stairs." It was this massive support that kept me going through the long months of training that lay ahead. I put in my application.

No running since 1984

I hadn't done any running since my previous (and only) Marathon in 1984. Brushing the cobwebs off my prehistoric running attire, I

set off on my first outing round the village. It was not long before I had the familiar feelings of fresh air filled lungs, pounding heartbeat and sweated brow. Passing the local pub at the 150 yard mark, I began to

feel that my colleagues were right after all. Arriving back home exhausted, gasping for breath and sweating profusely I was greeted by my family. "How far did you go? Five miles or ten?" "About half a mile (puff, pant) and I only stopped to catch my breath four times."

Accepted!

In November a letter dropped through my door. Amazingly, I had been accepted for the Marathon at my first attempt. Included within the package was a detailed training programme designed to build me up for the big day. The suggestion for day one was a run, or walk, of about half a mile. No problems! I was already way ahead of schedule. I could run all around the village and still

come back feeling almost human.

Weeks, months and miles passed so quickly. I was soon running thirty to forty miles a week and I began to feel confident that I could at least complete the Marathon.

Aimed to raise £1000

My friends, family and colleagues agreed to my subtle approaches for sponsorship. I

secured my first £100 backing in less than a day. I had set myself a goal of raising £1000 for my designated charities, the main one being the MPS Society, with donations also going to our local church and school PTA. The support I received from everybody was tremendous. By the day of the Marathon I was ahead of my target and running to raise almost £1200.

Snow and hail

Arriving in London on Saturday the 20th of April, we were greeted by snow and hailstorms. Perhaps it wasn't going to be ideal running weather after all. I am grateful to Christine Collins who put me and my family up for the weekend.

The Adrenalin started pumping

The long awaited day arrived. We were greeted by blue skies and sunshine. The feeling of anticipation was wonderful. I left Kensington at 7.00 am and made my way to Blackheath. The adrenalin really started pumping as we waited for the starting gun. With the huge crush of competitors it was eight minutes later before I passed the starting point and was on my way.

The camaraderie and support was tremendous for the first few miles. I was able to savour the occasion and enjoy the banter of my fellow runners. As I passed the balloons at two miles I thought to myself, "There goes my first £100!"

I saw my daughters cheering!

The course weaved its way through London's East End, past the Cutty Sark, London Bridge, Docklands and out onto the embankment. Weary legs now carried me on. My family were waiting for me at the 24 mile point by Cleopatra's needle. When I saw my daughters cheering and waving flags this

gave me the push I needed to plod the last few miles.

It was an emotional finish!

I had done it!!

The enormity of what I had done began to hit me. The personal achievement of completing the marathon left me stunned. Raising over £1000 for charities left me breathless and flushed with relief.

A proud day

The occasion will always fill my memory. The atmosphere all through the event was tremendous. After collecting in my sponsorship money I was able to hand over a cheque for £900 to Pauline Mahon, MPS Treasurer, with a further £300 going to the local church and school.

Many thanks to everybody who supported my efforts. It was a proud day. Here's to 1992!

Keith L. German

26 Retford Road, Mattersley
Near Doncaster, South Yorkshire,

Do you know any 1992 Marathon Runner who might be interested in raising money for MPS? Contact Ron Snack please.

Snack Bar!

Collecting boxes

If, heaven forbid, there are any collecting boxes lying around in your house not being used for their proper purpose, could you please send them back to me. I can find them a good home.

Ron Snack

Sponsored Head Shave

Denis Baker and his wife from Milton Keynes knew our Colin very well from our visits to the local Working Men's Club and Dennis decided that he wanted to raise some money for the Society. He chose to have his head shaved! Although he suffered cruelly from the comments of his friends, he managed to collect a goodly sum for us. His local, the Crauford Arms in Wolverton also held raffles. The total reached £759.09. The money was ceremonially handed over to Linda and me recently at the pub.

Cards, cards and more cards!

Mary and Robin Gooch have loads and loads of all sorts of greeting cards available for sale. These have been donated by a friend of theirs. There are some very ingenious cards among them - cards that pop up as a little parcel when the envelope is opened and others which make up into small houses.

Robin and Mary would be only too pleased

to pass on some of these to people who may be able to sell them for the Society. Please contact them on 0435 883329 for more details.

Fancy seeing you here!

Linda and I were spending a fairly fruitful day at the Newport Pagnell Service Station on the M1 a couple of months back, shaking our collecting boxes - like you do - when who should come along saying, "We know these posters", but Jackie and Ray Baird from Halifax. They were on their way home from the deepest south when they decided to stop off for a cuppa. Talk about coincidence - it really made our day.

Chat from Down Under

I had a lot of correspondence recently from Beryl Cavanagh, who lives in Adelaide, and who is the aunt of Dominic Hall from Cheshire. She has been sending me one or two prizes for our tombola stall, including some smashing Australian calendars which sold like hot cakes.

Easter Bunnies

She has also sent some knitting patterns for Christmas Boots, (small ones) and Baby Bootees, instructions for making decorative ropework and ideas for Easter Bunnies and Colourful Clowns. If anyone would like copies of any of these please contact me.

Ron Snack

Sid's System Thanks to Asda

We try to outdo each other!

My family and I try to collect as much as we can for charity. All my relations have

I take my box down to my union meeting once a month and my fellow members are very generous. I have a boxes in the 'Deli', in two barber's shops, in the shop at the underground station and still more in restaurants and bars all over Merseyside. The cash keeps rolling in. My local ASDA



Sid's sponsored bikers outside the Rover's Return with Percy Sugden, Coronation Street Summer 1991

collecting boxes in their living rooms. They each have different ways of getting them filled. Some put in their loose change at the end of the day. If there is a card school something from each hand goes into the box. We try to outdo each other each month. We enjoy opening the boxes and counting the cash. Gert and Mert, Hilary and Dave, Helen and Harold, Bernice and Alan and all their friends, it's nice to know that people care.

Superstore is very kind in allowing collections on their premises. My thanks to their customer relations manager, Mrs Helen Dykes.

It's hard going, standing for three hours shaking a box. But it is worth it. Thank you to all those anonymous donors!

Sid Shiff

Morquio Disease and Similar Skeletal Disorders

Dr Charles Pennock

The Institute of Child Health Royal Hospital for Sick Children Bristol

Hereditary bone dysplasias

There are a great many disorders primarily involving the skeleton which are noted at birth or during childhood. Some of these occur because of defective genetic material causing a disorder of skeletal growth and they are usually called hereditary bone dysplasias.

- Over one hundred varieties

Clinical and radiographic descriptions now indicate over 100 distinct skeletal dysplasias in which the chemistry is known in but a few. Numerous attempts have been made to classify these diseases, but as most of them are very rare, this has proved difficult and confusing.

- International classification agreed

However an international classification is now available which is helping to unravel some of these problems.

- Five main groups

These bone abnormalities are divided into five main groups. The first of these, called chondrodysplasias, include conditions in which there is an abnormality of cartilage or bone growth affecting the ultimate development of the skeleton.

- Group five - Identified biochemical abnormalities

There are three other groups which need not concern us here, but the fifth group includes all those bone disorders in which an underlying biochemical abnormality has been identified. The MPS Diseases come within this group.

- "SED" - Where does Morquio fit in?

The group of chondrodysplasias are further subdivided. One particular group deserves our attention. This group includes disorders known as spondyloepiphyseal dysplasia (SED), in which the cartilage and growth plates of the bones are principally affected. Some years ago Morquio would have been classified in this category, but we know now that there is a basic biochemical abnormality in this disorder and it is now classified in group five alongside the Mucopolysaccharidoses and other known biochemical disorders.

- Conditions like Morquio

This leaves behind in the SED group a number of other conditions very similar to Morquio but in which the chemistry is totally unknown and which present difficulties in diagnosis for the physicians and radiologists.

How SEDs compare with Morquio

Although Morquio is classified with the other MPS disorders it is very different from them in that the patients usually retain their intellect and the bone changes are very distinct. Morquio is much more like the other SEDs in which the vertebrae are wide and flat and the growth of the long bones is affected in such a way that the individual usually ends up with short stature, usually associated with knock knees and other bony deformities causing difficulties in walking.

- Odontoid peg problems

A special feature of Morquio is seen in the second spinal bone of the neck (the axis), and the failure to develop the small peg (the odontoid peg) which supports and controls the movements of the neck. Some of our members have had the first two vertebrae joined together surgically to protect them from damaging their spinal cord.

- Excretion of Keratan sulphate

When they are young and their bones are developing Morquio patients excrete an MPS called keratan sulphate (KS) in their urine due to their inherited deficiency of one of two enzymes necessary to digest that MPS.

- KS also excreted in SEDs

The same MPS (KS), is excreted in other

SEDs in which we do not yet know the true chemical or genetic abnormality and which are even more rare than Morquio. These are very difficult for the doctor to diagnose although there are some distinctive features on x-rays which may give clues.

- An example - Kniest Syndrome

One such example is the condition described in 1952 by Dr W Kniest and named after him as the Kniest Syndrome. In rare cases this may be recognised at birth because of shortened spine and limbs. However, like Morquio, it usually presents a bit later with short stature, depression of the bridge of the nose, and an unusually rounded facial appearance. Half of these children have a cleft palate and a failure in the formation of the roof of the mouth. Many are shortsighted and deaf. Inheritance is not clearly understood and the biochemical abnormality is not known. Like Morquio children they usually have flattened vertebrae. They don't have abnormalities of the odontoid peg - called odontoid hypoplasia.

- Other SEDs like Morquio

There are at least four other SEDs which result in short stature. They have a lot in common with Morquio, such as knock knees, flattened vertebral bodies, odontoid hypoplasia. They have normal intellect and may excrete keratan sulphate.

- Importance of studying these rare conditions

As KS is an important MPS in developing cartilage, studies of these other rarer SEDs and their biochemistry and genes (alongside Morquio individuals) may one day throw light on how the spine and long bone growth areas function in the development of normal bone and may help us to find out more precisely what goes wrong in SEDs generally.

The Laboratory Diagnosis of the Mucopolysaccharidoses

In the laboratory the analysis of a random sample of urine is the first step in the diagnosis of a mucopolysaccharide disorder. Generally 10 ml of urine is sufficient for our investigations but urine that is very weak or too alkaline will not give a true result. Everyone excretes mucopolysaccharides - chemical name glycosaminoglycans (GAGs) - in their urine but most affected children show elevated levels. However, as we get older we all excrete less GAG so it is essential to compare the amount of GAG in the patient's urine with age-matched controls; e.g. a value which is normal for a 6 month old child could be grossly abnormal for a 6 year old. It is our experience that in a few older children there may be little or no increased excretion. Therefore, we always look at the actual composition of the GAGs excreted in all children aged 8 years or over in addition to those whose urine shows an elevated level.

Our next test is to see which GAGs are present in the urine and their relative proportions. Normal urine contains chondroitin sulphate and a small amount of heparan sulphate (HS). The presence of excess dermatan sulphate suggests a diagnosis of MPS I, MPS II or MPS VI whereas excesses of HS and a heparin like component are indicative of MPS III. Keratan sulphate is present in MPS IV but is also found in urine from cases of GM1 gangliosidosis. These abnormal findings, together with the clinical story give us a very good idea as to the actual diagnosis but this has now to be confirmed by assay of the relevant enzymes and demonstration of an enzyme defect.

For the majority of the MPS disorders white blood cells and plasma separated from 10 ml of blood are suitable material in which to assay the enzymes. A skin biopsy is likely to be requested if there is an unusual finding in the blood enzyme result, if a child who is thought to have Sanfillipo disease is not type A, B or C, and if the blood results indicate the diagnosis of a mucopolipidosis or the very rare type VII mucopolysaccharidosis. Once we have shown that a particular enzyme is missing a definitive diagnosis of MPS I or MPS II or Sanfillippo A, or B or C etc. can be made. In cases of MPS II the level of the relevant enzyme should also be measured in the mother and for all the other MPS disorders in both parents. These results give the clinician the information required for genetic counselling of a family with the option of prenatal diagnosis in subsequent pregnancies.

In the not too distant future the laboratory diagnosis of inherited metabolic disorders will not be complete without investigations into the genetic mutation. It is now becoming the accepted policy of laboratories involved in the diagnosis of these disorders to store DNA, extracted from blood or fibroblasts, so that once the tools and techniques are available the genetic mutation can be identified in each family thereby allowing accurate carrier detection of family members and possibly a more accurate prediction of the clinical course in an affected child.

Elisabeth P. Young
Principal Biochemist
Enzyme Unit
Hospital for Sick Children and Institute of Child Health
LONDON WC1N 1EH

An Autumn Tree

An Autumn tree has no green leaves
Because they have turned golden or brown
And drifted slowly, quietly down
An Autumn tree is getting ready for Winter
Instead of growing, closing its engines down
The leaves go slowly into the ground
Changing slowly and quietly into the earth
An Autumn tree is getting ready for the winter wind
So that it cannot be blown down.

Helen O'Toole

Deadline for Spring Newsletter

Saturday 4th April

Attendance Allowance for Under Twos

- Lower age limit should always have been six months.

The MPS Society would like to draw members' attention to the fact that the lower age limit for claiming Attendance Allowance is now 6 months. Families have discovered that those who did not claim until their child was two years old under the old rules may now be entitled to the 18 months back-dated allowance from 6 months to 2 years.

- Backdated claims possible

*Recent Commissioners Decision (CA/380/1990) has established that the age bar on entitlement of Attendance Allowance below the age of two which applied up to April 1990 was "ultra vires" (beyond the power of the decision maker). The 1975 Social Security Act (Section 35) which introduced Attendance Allowance did not give the Secretary of State any powers to limit entitlement by age. If you consider your child qualified for attendance allowance

before the age of two, an application to the Appeals Section should be sent.

- For babies, proving the need is difficult.

It is of course much harder to establish a claim for attendance allowance for babies. There is an extra "test", on top of the ordinary rules. You have to show that a child needs attention and supervision "substantially in excess of that usually required by a child of the same age and sex." As babies need so much looking after anyway, there has to be some extra special reason for claiming. This might be, for example, severe feeding difficulties, a need for frequent physiotherapy, or a great deal of extra stimulation to develop simple skills.

- Contact Wilma for advice

For further information and advice about making an application for a backdated allowance please contact **Wilma Robins**, Welfare Rights Officer, (address and phone number inside front cover).

MPS National Picnic Day Sunday 28th June

In our 10th Anniversary Year we thought it would be a striking idea for all the Areas to hold a picnic on the same day. We are asking all Area Families if they can organise a picnic on Sunday 28th June. Details of all the events will be in the Spring newsletter. Members will sent an invitation to the event in their Area. But why wait to be invited? If you can offer to help, why not contact your Area Family now!

The European MPS Movement

- MPS Maastricht Summit soon?

Is the time ripe to start talking about a European Organisation for MPS? The contacts we have had this year make us very hopeful for the future. We reported back in the summer newsletter on our stimulating trip to Italy and the events of the Italian conference. In June the conference for rare metabolic diseases in the Irish Republic was well attended by Irish MPS families from North and South of the border. The Wraith and Laverys were there, with Ed and Christine presenting papers and leading two of the workshops. There is a very articulate family movement in the Republic. Their inspired organisers are winning the confidence and trust of enlightened doctors.

- Newly formed French Group

In September we had a bonus when three representatives of "Vaincre les Maladies Lysosomales" (VML), the recently formed French group, stopped overnight at the Laverys while attending a conference in Birmingham. VML has a strong MPS and ML contingent and their three representatives showed every sign of being a professional team.

- Need to co-ordinate major events.

Other people are also thinking of the need for European links. Marion Kraft of the Austrian Society and Dr Susanne Fang-Kircher spoke to us at the Italian conference. Their view at present is that at least an informal co-ordinating group of the national

societies would be helpful, for example, to decide on the host country and the timing of major family conferences. This would ensure that conferences were spaced effectively and could be given maximum support and publicity. Now that MPS is becoming known throughout Europe we also think it is important to seek agreement on what Societies who use the name or the logo should aim to offer to their members. I think this is important.

- Will Brussels help us?

With MPS and associated groups now established in the UK, Ireland, Germany, Italy and France and with strong family and professional links with Belgium, Holland and Spain, and non EC countries, Austria, Poland and Switzerland it seems to me that it might be worthwhile approaching the EC in Brussels for support. I do not suggest that help from the EC would be forthcoming in the short term. It seems to me that the EC's Social Directorate is a fairly cumbersome machine and what it has to offer at present is fairly limited. But the time may come soon to start influencing future policy thinking. With the groups in Europe we have the potential for a strong lobbying force.

Here's looking forward to an exciting era of co-operation in Europe!

Robin Lavery

YOUR SOCIETY NEEDS YOU!

(Or your Relation, or your Friend, or your Relation's or Friend's Friend). I hope you agree that the MPS Society is going very well for everyone concerned. I like to think it is. But none of us can be complaisant. It does worry the Management Committee that the charity is run mainly by families who have been with the Society from its outset in 1982.

New blood needed.

We need new blood to take up voluntary executive positions nationally or within the support areas. Longstanding Committee Members and Area Families may worry at times that they are not generating new ideas, or that we may in due course become detached from the needs of younger MPS families.

None of us were experienced when we started.

You might be shy or reserved. No one may have asked you to help. You feel you do not have experience in executive charity work? Or you are not an affected family? Not to

worry. Hidden lights under bushels (I am not quite sure what bushels are) are our business. This is how the MPS Society began. We can give you the training and help you gain experience.

The kind of support we need is from people who "can do", who given responsibility can get on with a self-contained job, which may require planning, organisation or management. You might have an expertise in parent advice or support (following MPS training), or in planning, organisation, management, fund raising (including approaches to companies).

Translation or interpretation (especially in German, Italian and French) or accounting and book-keeping skills are important. We would like a tame expert in PC information technology and in Desk Top Publishing.

Pick up your phone now!

Do pick up the 'phone to "HQ", and speak to Linda or Ann, or to Christine or me in the evenings. Or have a word with any member of the Management Committee shown on the inside cover of the Newsletter. Bounce ideas around with us.

Video of 1991 Conference Stoke on Trent

I am pleased to report that a video was made of the children and their volunteers during the 1991 Parent Conference. It includes the following:

- **Outing to Alton Towers**
- **Children's Tea Party**
- **Older Children and Volunteers having tea**
- **Outing to Trentham Gardens**

The video lasts for fifty minutes. If you would like a copy please send a blank VHS Video Tape plus a postal order for 85p to cover postage and packing to :The MPS Society,

Aid, Equipment & Benefits

Councils: you can run but you can't hide

Councils are expecting a rise in legal challenges from disabled people dissatisfied with their services after a Hereford man won his legal fight for a full-time carer.

The man, in his thirties and cared for at home by his mother, alleged that Hereford and Worcester County Council were acting illegally by refusing to provide him with a full-time carer on the grounds that the authority could not afford one.

The man, who does not wish to be named, was granted leave to mount a High Court challenge by Mr. Justice Brooks in September. But the case was settled out of court last month when the council agreed to provide the man with the care he needs.

The man's solicitor, Luke Clements, alleged that the council had failed to meet its statutory obligations under the Chronically Sick and Disabled Persons Act 1970 to provide adequate services for disabled people.

He also claimed the authority's actions were in breach of the provision requiring "adequate staff" set out in the Local Authority Social Services Act 1970.

Mr. Clements said: "If a council has assessed someone and are satisfied they need a service, it can't escape its statutory duties by pleading poverty. Hereford and Worcester Council was in breach of its duties because it has been massively and illegally understaffed."

Laurie Gregory, the council's assistant director of social services, said the authority had agreed to provide the man with the carer, plus compensation and costs.

He said: "We never disputed the man's need for a carer, it was just a question of resources."

"We have accepted for several years that we don't have enough staff but the council last month agreed to employ an extra 41 staff in the department."

He said that the council had also agreed to increase the department's budget by £2.6 million over the next three years to help it cope with the new obligations placed on local authorities under community care legislation and the Children Act.

Mary Holland, assistant director of RADAR, said: "We are very glad to see that this man has been given the support he needs to live in the community and hope other disabled people who are not receiving the services they need will also take legal advice."

"We also hope this case will make councils realise that they cannot fail to provide a service on the grounds of poverty."

Rick Lewis, the chairman of the ADSS disability committee, said more challenges from disabled people were "inevitable".

He said: "Directors of social services department directors want to provide the best services for disabled people but are often in a difficult position if they do not have the money to provide them."

Our thanks to "Disability Now", November 1991 issue, for the reproduction of this article

Disabled children 'trapped at home'

The majority of disabled children are not having short-term spells away from home to give them a change and their parents a break from the constant burden of care, the National Children's Home says in a report out today.

The breaks, known as respite care, are being received by only one in 20 children with disabilities and by one in four with the most profound disabilities.

Yet under the Children Act, which becomes law on 14th October, handicapped young people will have an automatic right to respite care in a residential home or with a family to give their parents the chance of a holiday.

The report says that respite care provides a short-term break for parents from the constant care and attention disabled children often need, while for the child it is an enjoyable break from home.

But many families only discover respite care services by accident or when they reach breaking point.

Family doctors, hospitals and social workers often do not tell families about respite care, and more than half of all families of children with disabilities have no idea that it exists.

Mr. Tom White, chief executive of NCH, said it was shocking that the vast majority of families with disabled children were receiving so little practical support.

"Many children with the most severe disabilities need almost 24-hour care and yet their families are expected to cope alone," he said.

"This is not only exhausting and stressful for the parents; it also means they often have little time to spend with their other children."

He said that, once the Children Act became law, parents could expect respite care as a right.

"We believe that there should be an immediate increase in respite care provision, with health and local authorities working together with voluntary organisations to develop new schemes."

He called on local authorities not only to inform parents of disabled children that they had a right to respite care but to draw up accurate registers of children so that the services could correctly reflect the need.

A Department of Health spokesman said that the Children Act included respite care as part of a planned range of support services for children and their families.

Guidance issued under the Act indicated that respite care should be planned and flexible, not just an emergency service.

By David Fletcher
Daily Telegraph - 16.9.91

Alvema have produced a new range of pushchairs and accessories - see the following article.

ALVEMA 200 - The pushchair for young teenagers on the move

The families and carers of young teenagers with disabilities are constantly at pains to find them a means of good personal transport. They are also right to demand the same exacting standards of technical quality and design as they would from any other consumer product. Alvema has listened closely to the problems, ideas and suggestions of parents, medical staff, carers and children alike in developing their range, and the new Alvema 200 reflects this in a product which, for ease of use, durability, flexibility, comfort and style, is second to none.

Easy to use, fold and carry

Carers will find the Alvema 200 has an ideal push-handle position and balance, resulting in easy movement and excellent control. The back wheels are fitted with foot-operated drum breaks. The stable chassis can withstand heavy loading. Alvema 200 has a safety device to prevent unintentional folding - yet it can be folded down for transportation and storage using only one hand.

Comfortable to sit and ride in

Both carers and - most importantly - the teenagers themselves want the most comfortable ride possible. Alvema has made this a priority in the design of the 200. It has a firm seat and back with a comfortable protective cushion; the seat back can be reclined totally; the footrest is adjustable in length and has complete vertical adjustment; and a comprehensive range of accessories provides maximum opportunities for good positioning and support.

All the wheels have pneumatic tyres carefully proportioned to give a comfy ride over any surface. Additionally, the 'live' frame provides protection over bumpy ground.

Stylish and flexible

Alvema has not forgotten that looks are important, and the smart livery of the 200 is stylish and contemporary. It also offers the teenager an active role in his or her ride where possible, with a front-mounted grip rail.

Built on experience

Alvema 200 is the pushchair with which your views have been incorporated in to top quality design and technology. It reflects Alvema's continual commitment to building well-designed equipment of the highest durability.

Alvema 200 - a pushchair to be proud of.

For more information:

Rainbow Rehab
Unit 15
7 Airfield Road
Christchurch
Bournemouth BH23 3TQ
Tel: 0202 481818

Photo
Album

Acknowledgements
Bucks Examiner



Front: Matthew Hardy, 10, Simone Piromalli, who does not have MPS, and his bother Jamie who died aged eight. Back: volunteer Fran Knapton, now landlady of The Squirrel, Penn Street, Angela Piromalli and Wendy McGinn.



Raw Steel making music for Mucopolysaccharide in the name of their brother Timothy. Their concert at the Polish Club raised £306.



The Society for
Mucopolysaccharide Diseases

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

1991 XMAS DRAW WINNERS

1	CANNON 8mm CAM-CORDER KIT	06657	MARGARET CASSON. NOTTS
2	P & O FERRY TICKETS for 2 PEOPLE AND CAR +£100 CASH.	02841	BEV KNIGHT. STOKE-ON-TRENT SANDRA.
3	ANSWERING MACHINE & CORDLESS PHONE	17040	S. WILLIAMSON. NEWCASTLE
4	RADIO CASSETTE/PERS CASSETTE/TAPE	21174	J. FARMER. BIRMINGHAM
5	BRITVIC ATLAS	46865	FREDA BOOCOCK. RETFORD
6	£25 WH. SMITH VOUCHER	06747	N. BROAD.
7	BELLS 1.5lt WHISKY	01922	C. MOSS. TAUNTON
8	BOOK, FACTS & FALLACIES	30104	J. RIDGEON. BUCKS
9	SET OF 12 NOVELS	22320	P. LAWRENCE. NAILSEA
10	LEGO BRICKS SET	29702	M. BURR. COLCHESTER
11	BOTTLE OF DUBONNET	46206	DAVID. LEIGHTON BUZZARD
12	£20 M & S VOUCHERS	49119	M. DALZIEL. GLASGOW
13	TEDDY BEAR	28995	J. FOSTER. HULL
14	READERS DIGEST COOK BOOK + RECIPE BOOK	01053	N. COOPER. HADDENHAM
15	4 x 4hr BLANK VIDEO TAPES	48509	E. BENJAMIN. EDMONTON
16	BOTTLE OF WHISKEY	47899	CLARE. SOUTHPORT
17	2 x UMBERELLAS	18853	K. EASON. FIFE
18	2 x CHILDS JIGSAW	37344	J. BRENNAN. LANCASTER
19	BOX OF MARIGOLD GLOVES	14048	D. SLEIGH. WHITNELL
20	HOUSE BOOK BY LAURA ASLEY	12198	K. SANDERSON. BRISTOL
21	4 x 4hr BLANK VIDEO TAPES	09996	ALAN REED, LONDON
22	TEDDY BEAR FROM RADIO TRENT	38908	RUTH, ROTHERHAM
23	24, CANS OF LAGER	00682	HALLIDAY, BIRMINGHAM
24	TOOL KIT IN CARRYCASE	35015	SARA EBORN, SWANSEA
25	FAMILY VISIT TO DENBY POTTERY	19194	MR. KERR BRECHIN
26	2 x UMBERELLAS	36066	H. ALLISON. EDINBURGH
27	2 x CHILDS JIGSAWS	27723	IRIS BYATT. RETFORD
28	£10 WH. SMITHS VOUCHERS	06667	J. RALEELTS. NEWTOWN
29	TOASTER	11528	G. AMOS. PEMBROKE DOCK
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31	SCARF & HERB PILLOW	02404	R. THOMAS. POWYS
32	BOX OF MARIGOLD GLOVES	11806	T. ROLLINSON. HULL
33	SIX ASSORT PAPERBACK NOVELS	22560	T. MELVIN. GOLDEN WONDER?
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36	PAPERMATE PEN	22752	S. BARNES. KINGS LYNN
37	HOZELOCK HOSEPIPE	20713	F. EYRE. SUTTON BRIDGE
38	BOTTLE OF WHITE WINE	15274	EVE. PORTESBERY
39	£10 WINE VOUCHER	30799	

PROMOTER: D. BRIGGS, 7, HUMBER STREET, RETFORD, NOTTS, DN22 6LZ.

DATE OF DRAW: 7th December 1991.

Registered under Section 5 of the Lotteries & Amusements Act, 1976.

FUNDRAISING EVENTS

I see you have all been "at it" again, raising money by holding dinner parties, running marathons, shaving heads and doing all those daft things you think will raise money for our Society. Well - it works, thanks to all of you who have helped in whatever way to raise funds for us.

Linda and Ron Snack, MK	Flag Day at Newport Pagnell Services
Doreen and Monty Russell	Proceeds from office dinner
The Gooches, Kent	Collection
J & K Lawrie, Hull	Great North Run
B Smith, Tendring	12 Hour Darts Marathon
Shell 498 Club	Fundraised
A Hastie, Glasgow	Glasgow Half Marathon
Alan and Amy Bottrell, Glasgow	Saving 20ps
Kirkhill Golf Club, Glasgow	Auction Evening
Boots and RDC, Broughton	Collecting Boxes
Dennis Baker, Milton Keynes	Sponsored Head Shave
Billy Ingham, N Ireland	Collecting Box
Ladybridge Residents Club	Collecting Box
Monkhouse Sports, Cheshire	Collecting Box
Wilma Robins	Collection at work
Jon and Kathy Lawrie, Hull	Collecting Box
Linda and Ron Snack	Flag Day at Milton Keynes
Ben and Gabrielle Robinson	Sale of Sweets
Lucy and Sarah Taylor	Sale of Sweets
Mrs Finch, Somerset	Tupperware Party
Mrs Price, Rochdale	Car Boot Sale
Paul Hubbard, Essex	Sale of Stamps
Linda and Ron Snack	Tombola and Sale of Goods
Sid Shiff and Family, Liverpool	Collecting Boxes
Southport Firemen, Lancs	Fundraised
Christine Butt	Coffee Morning
Pauline and Sean Mahon	Charity Dinner
Fer Pidden	Coffee Morning
Craven Arms Country Music Club	Raised
Kings Church Slimmers, Amersham	Raised
Kieran and Bernadette Houston	MPS Golf Tournament
Crendon Morris Men	Raised
Andy and Jenny Hardy, Bucks	Garden Party
Rachel Todd	Collecting Box
J Broome, J Reed & D Lambert	Sale of Rag Dolls
P Ballard	Sale of Stamps
S Gregory	Sale of Baby Clothes
Mrs Lamb and Class	Raised
Mike Reeves	Fun Run
Mary O'Toole	Collecting Box
F Mummery and C Howley	Tombola

Area Support Families

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

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

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

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

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

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

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

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

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

Contact for Scottish Families:-

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

Northern Ireland Co-ordinating Committee:-

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

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