

NEWSLETTER

WINTER 1986/87

# THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES



National Registered Charity No. 287034

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## BITS AND PIECES

### Sorry!

Believe it or not, this is your Christmas edition of the Newsletter. Unfortunately life got in the way of best intentions and we were unable to get copy to the printer in time for pre-Christmas publication. Whilst we are to late to wish you all a happy Christmas, we do wish you a peaceful and happy new year. Also, the delay does make it possible for us to explain that the slip in schedule has been partly due to Maggie contracting a severe case of pregnancy. In its early stages this is (I am told) not compatible with slaving over a hot word processor - or hot cooker; but that is another story!

I'll not bore you with the details, but merely say that in the middle of December Maggie had a Chorion Biopsy and that things have been just a little less straightforward than one might have hoped, with the result that Christmas and the new year has been a period of some uncertainty, unfortunately not yet totally resolved.

While we are in apologetic mood, may I pass on apologies to Rosemary Nurse and friends, who handed over money raised at a jumble sale in December 1985 but did not receive the formal letter of acknowledgement. The money was certainly paid into the account but it has taken some time to track down the particular credit.

Continuing with the apologies, I know that many families sent in photographs of their children for possible inclusion in the Annual Report for the year ended June 1986. Many factors (some are mentioned here) have resulted in the publication of that document being delayed for longer than was expected. It is anticipated that it will be with the printer at about the time you read this and Robin Lavery has asked me to assure all those concerned that the photographs will be returned just as soon as possible.

### MPS Treasurer

For personal reasons, after 3 years very hard work Diana Fudge has been forced to give up her role as Treasurer to the Society.

From the early days of the Society, when finances were modest and more than two noughts in the balance sheet pointed to a typing error, things have grown to the point that our turnover exceeds that of many small businesses. Our commitment to research, annual conference and family support, is now measured in tens of thousands of pounds each year and the individual transactions recorded by the thousand.

That this has been achieved in so short a time and with the minimum of difficulty, is in great measure due to Diana's abilities, selflessness and her exceptional support for the Society. We shall much miss her involvement but send her and her husband Nick, our very best wishes

Fortunately for the Society, continuity (and relative sanity) has been assured, because Stella Hale has dusted off her business skills and with the aid of husband Steve and baby Thomas, has volunteered to take over from Diana. You will find Stella's address inside the front cover of this Newsletter.



### Telephone answering machine

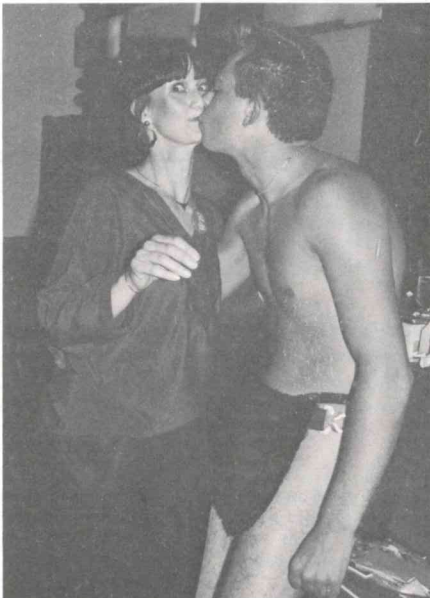
One of the advantages of the MPS telephone answering machine is that it does enable you to leave a message for attention later, if the 'office' is unmanned (or unwomaned) when you call. If you merely wish to have some documents sent to you or wish to convey some information, please try to ensure that whenever possible you leave an appropriate message for subsequent action. Quite frequently, messages are left to "please call back" when it is not strictly necessary. The point, of course, is that unnecessary calls take time that would be perhaps better spent on the multitude of other things that need doing, and adds to the Society's telephone costs. Personally I always try to speak to Christine's answering machine anyway - it doesn't answer back!

### Lucy rules, okay?

Christine and Robin Lavery have asked me to convey a very big thank you to all those who were kind enough to send them Christmas greetings and best wishes on the birth of baby Lucy. Lucy has had one or two problems because she arrived a little earlier than expected. Christine too has been 'in the wars'. Although both are now well, replying to all of the good wishes has had to give way to putting the house back together after the builders had finished knocking it about to squeeze Lucy's bedroom in (in addition to the MPS 'office') and to dealing with the mountain of MPS correspondence that has built up.

### Well I never!

It came to the attention of certain members of the Management Committee that the Hon. Fund Raising Officer, one Pat Isaac, had made arrangements to celebrate the attainment of a certain age, by throwing a party in the village hall of her Somerset retreat. Arrangements were made, courtesy of Yellow Pages, for a locally based "Tarzan-gram" to be delivered to the lady on the evening of her celebration in the village hall.



Share with us this one brief moment captured on film, and the mischievous pleasure that comes from the knowledge that Pat spent the next couple of days quizzing all her local friends and neighbours before 'the penny dropped'. Good taste (this is a family newsletter!) precludes us giving details or publishing photographs known to exist of Pat carrying out her own investigations of her Tarzan-gram man's 'credentials'!

### MPS RESEARCH AT THE KENNEDY INSTITUTE OF RHEUMATOLOGY

The Mucopolysaccharidoses are a group of related metabolic diseases resulting from the inherited deficiency of specific biological catalysts called lysosomal enzymes. Their absence prevents the normal breakdown of very large molecules called mucopolysaccharides, and these consequently accumulate in many tissues of the body.

A number of attempts have been made to treat these disorders by replacing the missing enzyme, and transplantation with normal bone marrow cells as enzyme donors has sometimes been of clinical benefit. However, little is known about how the enzyme(s) from bone marrow cells enters the recipient cells of the patient and corrects their defect. Research in this area is limited, partly because there are only very few animal models of these diseases, and they cannot be considered practicable for experimental purposes.

In the Kennedy Institute we are concerned with the Mucopolysaccharidoses particularly since they are rheumatological disorders, affecting primarily the normal function of connective tissue. The aim of research in the Cell Enzymology Unit is to understand the process of lysosomal enzyme transfer at the molecular level, using patient's cells which are maintained under "test-tube" conditions in the laboratory. In our studies, which are carried out in collaboration with the Director of the Institute, Prof. Helen Muir, CBE.,FRS. and with other research scientists, both in the UK and abroad, we use normal lymphocytes, a main type of white blood cell which arises in the bone marrow and which produces antibodies to protect against infection. We have discovered that they also attach to enzyme-deficient mucopolysaccharidosis cells and transfer to them some missing lysosomal enzymes. We subsequently showed that the transferred lymphocyte enzyme is transported to a site inside the recipient cells of the patient where it is, most importantly, functionally active.

These new findings, that enzyme is transferred by cell-to-cell contact and that it can correct the metabolic defect, suggests that, under the right conditions, enzyme replacement by cell transplantation might be highly effective in the clinical treatment of these diseases.

Research funds provided by the Wellcome Trust, Action Research for the Crippled Child, the Muscular Dystrophy Group and the Arthritis and Rheumatism Council, have been of crucial importance in carrying out our investigations. Moreover, the generous support of the MPS Society has enabled us to replace a laborious manual procedure for measuring enzymes with a fully automated system. It will thereby be possible to obtain far more information about the characteristics of the specific molecules which are involved in attachment of lymphocytes to mucopolysaccharidosis cells and also those which help to transfer the missing enzyme from one cell to another. This information will be vital in understanding the role of lymphocytes in MPS diseases and perhaps also in eventually realizing the full potential of their therapy by gene/DNA replacement.

IRWIN OLSEN, PhD. Head of Cell Enzymology Unit.



## SUPPORT FROM THE DHSS?

We first applied for Mobility Allowance for Lisa in November 1984, at that time she was very difficult to take out and she had to wear a built-up shoe. A doctor from DHSS came to visit Lisa but decided that she did not qualify. We decided to appeal.

It took 9 months before we were seen by a Medical Assessment Board. During that time we submitted letters from Lisa's GP and Consultant, as well as from her school, which testified to the difficulties we had when taking Lisa out. The Medical Board decided that Lisa did qualify for Mobility Allowance but the DHSS disagreed and they were then allowed to appeal against the Board's decision.

This meant we had to go to a Medical Appeal Tribunal. We submitted further evidence from Lisa's new Consultant, because we had learned in the meantime that Lisa was suffering from Sanfilippo Syndrome. It was a long drawn-out process, as we were advised by the chair of the Medical Appeal Tribunal to await the outcome of another similar case.

Mobility Allowance is awarded to people who are:-

- (1) unable to walk
- (2) virtually unable to walk

There have been a number of cases which have tried to decide what is meant by "to walk" and what is meant by "virtually unable to walk". Does the word "walk" include walking with guidance, supervision or support. Lambeth Welfare Rights Unit and our social worker looked at the various cases and we were pleased to hear that the case that we had been advised to wait for, had been decided in favour of the claimant.

However, after several trips to the Appeals Centre and a long wait for a decision, we were told that "even though Lisa was aggressive and that she struck out at Rosemary whilst walking, this, the Tribunal decided, did not create any difficulty. The Tribunal said that Lisa "is approaching the point where it may be said that she is virtually unable to walk, but in our judgement that point has not yet been reached."

We feel that, to a great extent, our medical evidence was defeated by Lisa's consultant who said: "I do not consider her virtually unable to walk... I think that within a year or two we will be in the state that she will be virtually unable to walk but this time has not yet arrived." This was used in the Tribunal's argument against Lisa's claim for benefit. We are not medical practitioners, but Lisa is very difficult to take out; she tires easily and needs a great deal of help getting up and down steps. Lisa won her case with the first Medical Board; the DHSS, by being allowed to appeal, was allowed to assess her twice.

We believe that we should have won this case, not only on medical grounds but also on legal grounds. The DHSS should not be the arbitrator by paying for the services of the Tribunal as - "he who pays the piper calls the tune."

Harry & Rosemary Nurse

## OVERDUE FOR CHANGE

As if families like the Nurses did not have enough to cope with, the DHSS. are bound by rules and regulations that can submerge the purpose of benefits like mobility allowance, beneath an avalanche of bureaucracy. The inadequacies of the system are not exclusive to MPS families of course and neither are they limited to Mobility Allowance. It is a sad fact, however, that many, perhaps most, of our families have experienced difficulty in obtaining benefits that one would have anticipated should have been theirs for the asking.

The arguments turning on the ability to walk, or otherwise, doubtless make their contribution to the national economy through the employment of solicitors, barristers and DHSS civil servants. The finer points are, however, understandably not best appreciated by those with children who are blind, deaf or severely mentally handicapped, when they are denied benefit because physically their child is not yet "virtually unable to walk", (and may, perhaps never reach that state) but they nevertheless cannot travel unaided or unrestrained.

The M.P. Jack Ashley M.P. is to present what is known as an Early Day Motion to the House of Commons in January 1987. This will call for a change to the DHSS 'rules', so that those who suffer handicaps which make it impossible for them to travel unaided, will be eligible for Mobility Allowance.

To achieve its purpose the Early Day Motion must gain substantial support from M.Ps. The Society is writing to M.Ps. urging them to support the motion. To ensure that the matter will be taken further, however, 300 or more M.Ps. should sign the document. That is where you come in. Even if you are receiving Mobility Allowance now, or used to do so, other families need your support now as do families yet unknown and unknowing. If EVERY family were to write to their M.P.; to contact those with other handicap problems and urge them to do likewise - your special school is an important place of contact and may even be able to help directly - and to enlist the help of family, friends and contacts to do the same, a powerful lobby would result.

Peter Archard.

**DON'T DELAY, DO IT STRAIGHT AWAY.**

WRITE TO YOUR OWN M.P.  
URGING THEM TO SIGN THE EARLY DAY MOTION  
PRESENTED BY MR. JACK ASHLEY  
IN ORDER TO GET THIS INEQUITABLE RULE CHANGED.

**ASK FRIENDS TO DO THE SAME**



#### WHITBREAD COMMUNITY AWARD.

Earlier in the year, while scanning through our local newspaper, I came across an article inviting people to nominate a person or group of people who had given their time free for the benefit of the community.

A swift telephone call brought an application form in the post. My only problem was, how was I going to say, "in not more than 150 words", why I thought they deserved the award.

This was not an easy task when you consider the person I intended to nominate. She could provide material to fill a book and several volumes. Eventually it came together, the main points were covered but there was so much more I could have written, given the chance.

For example, the first time I met this lady was, by arrangement, at a motorway service centre. She and I had something in common, we had both just lost our children. I can remember pouring out all my feelings of despair; when I finally stopped she told me of this wonderful idea of hers. Wouldn't it be something if there was someone else who had been, or was in, the same situation as yourself; who you could share all the good and bad times with; if when you told someone your child suffered from Mucopolysaccharidosis they would recognise the name and know about it; if those in the medical profession would come together and pool their ideas and help our children have a better life even if it is a short one.

All these things and many more were talked about that day. I know I went home a better person but wondering how on earth was this ordinary mother going to start, let alone achieve all that.

Well, the Society for MPS. Diseases is recognised throughout Europe and is now stretching its way across the world. I think that the lady in question has achieved much more than anyone ever imagined back in 1982.

Needless to say **CHRISTINE** won the award - the first of many Christine - but I know her real reward is the knowledge that no MPS family need ever feel alone again. How can you say everything "in not more than 150 words"?

Congratulations Christine on winning the award and congratulations and welcome to baby Lucy Lavery.

Mary Gardiner

Christine's award is one of four such recognitions given on a regional basis, hers being for the South East. In addition to the framed certificate (shown opposite) she was presented with a cheque for £1,000 - £500 for the Society and £500 for herself. In fact, the whole of the prize money is being used towards the costs of improving the MPS 'office' facilities in order to meet the ever growing workload and accommodate the mountains of paper. I understand that there is no truth in the rumour that some of the money has been put aside for typing lessons for baby Lucy in 1987! Congratulations Christine, thank you Whitbread, nice one Mary. (Editor)

#### MARY'S 150 WORDS - See opposite

"In early 1982, Christine Lavery suffered the loss of her eldest son, Simon. Simon was seven years old and had suffered from a rare progressive genetic disease, Mucopolysaccharidosis.

Christine had witnessed the disease take Simon from a lively, bouncing youngster to a mentally and physically handicapped boy. Throughout Simon's short life, Christine had been determined that some kind of support group should be set up to help families like hers.

Gripped with the grief of Simon's death and the knowledge of other families in the same situation, she found the strength, courage and determination to approach other families, the medical profession and beyond. By the winter of 1982 the first quarterly newsletter for MPS was printed and the Society was born.

To date, Christine has set up six Area Support Families, bringing help, support and reassurance, but most of all an end to the isolation which is so often felt by those families. September 1986 will see the fourth parent conference/family weekend, the year's main event, which Christine knows is well worth all her hard work. The hands on the MPS logo are those of Simon Lavery; they have not only stretched across Britain, but to Australia, Canada, New Zealand, South Africa and the United States. But it is Simon's mum who has worked and slaved against so many obstacles in the belief that the children and families should have the best the world can offer.

Christine Lavery is a remarkable woman, she has proven that when a heart is touched with love it can move mountains. For all of her work on behalf of all the MPS children and families, I would like to nominate her for your award."



Christine (with Lucy) receives her award



## PUB CRAWL FOR GARETH

Christine Lavery telephoned Paul and me to ask us if we would mind doing a trip to The Prince of Wales P.H., Colchester where there was to be a 'pub crawl' to raise money to send Gareth Carden-Edwards and his family to Disney Land. Paul and I went along to represent the Society on the appointed day and we were met by the landlord, Mr. Bruce Paton. He was dashing around organising the amazing number of people who had willingly volunteered to take part. I suppose that once everyone knew that the event was to raise money to send Gareth to Disney Land - Gareth is now 5 years old and suffers from Hunter's Syndrome - nobody could refuse to help.

As things were being prepared and all the lads were being dressed up, the atmosphere was electric with their enthusiasm. They really did 'look the part' in black stockings and suspenders! The race was a tremendous event and attracted the local newspaper's interest. Paul and I spoke to a couple of reporters and put them in the picture about MPS. Paul and I had to make our return journey without knowing what the final amount raised was going to be, because there was to be a disco and Bar-B-Q at 7pm. that evening. I understand that all of the food had been donated by a local shop so that all the proceeds of the evening would go to Gareth's fund. I must say that the landlord and everybody involved with all the preparations had a lot of hard work on their hands. It really does warm the heart to think that there are such a lot of grand people about. I should like to thank everyone concerned for their efforts in making the event such a big success.

On the following day, the landlord's wife telephoned me to say that well over £2,000 had been raised, with still more to come. The principal purpose of the fund was to pay for Gareth and his family's trip to Disney Land but the balance was to be donated to the Society. Subsequently Paul and I were invited back to receive a cheque for the Society and I should like to give a special thank you to Mr. Paton for making us so welcome.

Carol Hubbard.



Gareth and Hilary,  
his mum. I wonder  
who the others are????

## NEW FAMILIES

We are pleased to welcome the following new families to the Society :-

Mr. & Mrs. Harvey from Oxford. Their three sons, Stephen aged 6 years and twins Mark and Ian aged 5 years, have been diagnosed as suffering from Sanfilippo Syndrome

Mr. Julian Warren from York. He is 28 years old, and suffers from Morquio Syndrome.

Drew and Evelyn Millar from Fife in Scotland. Their son Andrew, aged 16 years, suffers from Sanfilippo Syndrome

Mr. & Mrs. Norsworthy from Devon. Their son Timothy is aged 17 and suffers from Morquio Syndrome

Ian and Anne Bean from Cleveland. Their son Paul, aged 4 years, has just been diagnosed as suffering from Sanfilippo Syndrome

## THE UNCERTAIN CHOICE

The following two articles have been submitted by parents of children who have successfully received bone marrow transplants. The Society has striven to avoid giving medical advice and regardless of personal views on such controversial subjects as bone marrow transplants, it has sought to give full support to all families - if they have decided to proceed with a transplant and if they have not. That position of impartiality is unchanged and the comments here are mine, as Newsletter Editor, and not necessarily those of the Society.

The benefit of B.M.T. is not proven and there is considerable doubt within the medical profession whether or not a successful transplant (or any other largely experimental "replacement" technique) can transmit any benefit across the so-called blood/brain barrier. The truth of the matter is that nobody knows the answer to this and there is no evidence to support any assertion that B.M.T. effects a cure for MPS, albeit that its efficacy is well demonstrated in the case of many other life-threatening disorders such as Leukaemia.

The medical profession lacks a comprehensive knowledge of the natural progression of the MPS Disorders. Awareness of their nature has only recently been acquired and the more knowledge that is gathered, the greater is our ignorance shown to be. Does every case follow a similar pattern? Are the so-called severe and mild Hunter's Syndromes different disorders or merely two levels on a continuous 'sliding scale of severity', i.e. the same condition? Is every case of a particular disorder the result of a similar defect or are there several potential problems each giving rise to similar symptoms, and, thus, each calling for fundamentally different treatment?

Continued overleaf



These and many other questions are unanswered at present and that is why the Society concluded that it was right at this time for it to sponsor Dr. Martin Bax to undertake research into the natural progression of MPS in order to provide a comparative basis for determining whether or not any claimed treatment actually could be said to have secured improvement in any particular case, or, rather, if the "progression" in that case was within the known natural history range of the disorder in any event.

Bone Marrow Transplant is a treatment of last resort and it is a sad fact that many of our children have not survived the treatment. For those that have we are thankful. That these two families and others, have come through the trauma with greater hope for the future, can only be a matter for happiness and we are delighted for them. In reading their stories however, may I ask you to please bear in mind that their experiences and feelings, valid though they may be, are regretfully the exceptions rather than the rule.

Peter Archard.

#### Colin Griffin

On the 4th December 1979, I gave birth to a 9lb 6oz baby boy at King's College Hospital. My husband and I could not believe the size of him, he was much bigger than the other babies on the ward. We named him Colin Peter.



Since Colin was three weeks old he was catching colds and chest infections frequently. At six months he had quite a bad chest infection and was admitted to the Belgrave Hospital. At first the doctors suspected meningitis and we were both relieved when the tests for this were negative, little knowing at the time that he had a far more serious disease.

After a series of tests the doctors diagnosed Hurler's Syndrome.

The name of the disease didn't mean anything to us as we hadn't heard it before, but after the doctor explained we were devastated. We were told there was no cure.

Colin pulled through that chest infection and we took him home with heavy hearts, now knowing what the future held, or so we thought at the time.

For the next six months he visited the outpatients department at the hospital and, bit by bit we learned more about this horrifying disease. Just before Christmas, when Colin was one, a doctor spoke to us about the possibility of a bone marrow transplant. For the first time in six months, after the tears and feeling of hopelessness, we felt there was some hope for Colin.

Ctd.

The doctors explained the risks involved and that this treatment was in its early stages. It had only been performed on one child with Hurler's Syndrome before Colin, and had been successful. We discussed it with our families over Christmas and had already made up our minds to give Colin this chance when we met Professor Hobbs and Dr. Hugh-Jones at the Westminster Children's Hospital in January.

So on the 13th May 1981, Colin received his Uncle Thomas's bone marrow. I was pregnant with my second child by this time and underwent two amniocentesis tests (the first one failed) to see if my baby was affected. Thankfully he was not.

Colin's transplant was successful and after only nine weeks in hospital, he came home with us. We were all amazed at his quick recovery.

We named our second child after Thomas, Colin's bone marrow donor.

We are happy to say that Colin improved all the time and is now 7 and leading a normal life. He attends a normal school and is learning to read and write. He might not be as agile as the other children, and he will come last in races for some years to come, but he's got a lot of spirit and is a very bright child.

What more could we ask for?

Annie Griffin.

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#### Ross Lockyer

For those of you who do not already know us, we are Tony and Mary Lockyer from South Wales. We have a daughter, Sally, born in 1977 and in 1980 we thought our family was complete with the gift of a son, Ross. We lived in peaceful ignorance for two and a half years as Mr. & Mrs. Average with our two children before our world was shattered in September 1983 with the news that Ross had Hunter's Syndrome. Like many of you we had never heard of the disease or the long name Mucopolysaccharidosis, and all of you will know the feelings of disbelief, shock, horror and anger we went through in those first few weeks.

Initially we were told that there was no treatment or cure available, but, fortunately for us, this was at the time when Womans Own magazine was running its appeal, in conjunction with the Save the Children Fund, for a Bone Marrow Transplant Unit at Westminster Childrens' Hospital.

We immediately asked our local Paediatrician to be referred to the WCH, and in February 1984 we made what was to be the first of many visits to the 'big smoke'. Dr. Kenneth Hugh-Jones, the senior consultant in charge of BMTs did not mince words with us and gave us no guarantees, no promises of success or of survival, but he did give us the only chance Ross had of beating this 'monster', provided we could find a donor. It wasn't to prove so easy!!

Ctd.



All our immediate family members were tested for compatability, which seemed to take an age, but unfortunately the results in the laboratory were so 'horrendous' that there was no way Ross could be given a transplant. We had previously mentioned the Anthony Nolan Bone Marrow Appeal to the doctors, but we had been told that related donors were preferred to unrelated ones as there was a better chance of the tissue types matching. However, as we had drawn a blank with all our relatives, in sheer desperation enquiries were made to see if there was a good match on the Anthony Nolan list of donors.

Then began a six month wait as the original list of 50 'possibles' were whittled down to 20, then 10 and then 2 probables. Bad weather hindered the search making travel to London for us and the donors impossible, but eventually the wonderful news came that a donor had been found and what was even more wonderful was, that on paper at least, it was a 'perfect' match. We could not believe our good fortune, and for a few days we were riding on a cloud, but then the doubts set in.



While searching for a donor, we had, through contacts made with the MPS Society, explored other avenues of treatment for Hunter's Syndrome. We saw Prof. Adinolfi and Dr. Diana Chase at Guy's Hospital, Dr. Rosemary Stephens at Great Ormond St. and Dr. Ian

Young at Leicester Infirmary, all experts in these MPS Diseases and each with their own valid arguments for and against BMT. We spoke on the 'phone to parents of children who had had BMT; some who had survived and some who sadly had not. (By this time we had a file an inch thick!) After much soul searching, praying, sleepless nights and many tears we decided that Ross should be given the chance of fighting this disease. Having made this enormous decision (this was now February 1985) we now had to wait until June for the new BMT unit to be opened. As Ross's donor was unrelated he would be a 'high risk' case, and Dr. Hugh-Jones wanted to wait for the new unit to reduce the risks.

Eventually, in August 1985, Ross was admitted to the Gomer Berry Ward at the WCH, and on September 11th he was transfused with the bone marrow of his donor, Valerie Gledhill, a nurse from Hampshire I think the doctors were amazed at how smoothly the ensuing weeks went (for them that is, not for us - seeing Ross pumped with toxic drugs, losing his hair and bloated with steroids). After 6 weeks we returned home, with Ross looking none the worse for wear except for some 'battle scars' and a bald head!

We met his home-coming with some trepidation - it's easy to cope when there are doctors and nurses always on hand in case something goes wrong. Our local G.P. would be helpful, we knew that, but how much would he know about the ins and outs of a BMT and its after-effects? The first week went smoothly enough, but then during the second week Ross contracted a viral infection and rejection set in and unfortunately we had to return to London. For the next six weeks Ross was desperately ill but thanks to the expertise of the doctors and nurses, he pulled through and by mid-January he was well enough to come home again, and, touch wood, he has stayed home.

It is now over one year post-transplant and already we can see signs that the transplant is working. Briefly, Ross's present condition is as follows:-

#### HAIR.

No longer coarse but this may be due in part to the Cyclosporin drug he takes daily.

#### JOINTS.

An assessment by the physiotherapist at WCH 6 months post-transplant showed that nearly every joint had some improvement.

#### LIVER and SPLEEN.

These have now returned to normal size. Ross is still incontinent but no longer has 'Hunter's diarrhoea' and his bowel movements are normal.

#### MENTAL STATE.

When Ross was desperately ill just before Christmas 1985, he regressed substantially and has yet to make up lost ground, although he is making slow but steady progress.

Putting Ross forward for a Bone Marrow Transplant was not an easy decision to make, and we cannot pretend that life has been easy since he came home in view of his regression, but we are confident that he will progress; how far remains to be seen - not even the medical experts know the answer to that - but at least this way we have hope for the future.

Tony and Mary Lockyer



## DEATHS

It was with very great sadness that we learned of the death of the following :-

**Alexandra Wright** of Chelmsford in Essex, who died on July 24th aged 13 years. She had been suffering from Sanfilippo Syndrome.

**Alyn Scullion Wilson** from Glasgow, who died on 22nd. September. Alyn suffered from Sanfilippo Syndrome and was aged 13 years.

**Anthony Bennett** from Blackpool. Anthony was 12 years old and had Sanfilippo Syndrome. He died on 1st October.

**Alevique Brooks-Daw** from Taunton in Somerset aged 9 years. Alevique died on October 9th after a brave struggle against Hurler's Syndrome.

**Linda Gannon** from Dagenham in Essex. Linda had suffered from Maroteaux-Lamy Syndrome. She failed to recover from major heart surgery and died on 15th. December. She was aged 31 years.

Our thoughts are with their families and friends during this very sad time.

## BIRTHS

Congratulations to Sarah and Mick Corbett on the safe arrival of **Elizabeth Sarah** on 6th October 1986. Elizabeth weighed in at 8lb 10ozs and is a sister for Gemma (who suffers from Hurler's Syndrome)

**Lucy Martha Rosemary Lavery** arrived a little earlier than expected on the 18th November, weighing 4lb 12ozs. Well done Christine and Robin! Congratulations too to Andrew and Benjamin for helping to care for their new sister - it won't be too long before she is playing football with you!  
(Editor's note:- The name Martha means "ruler of the house"!)

## GERMAN CONFERENCE

At the conference at Heathrow last year, several families asked our German guests about the date of their proposed conference in 1987. We have now been advised that it has been necessary for a new date to be arranged and you are asked to note that it will now be held at Bodensee, West Germany on 20th.- 22nd. March 1987. Details are available from Christine Lavery.

## PHOTOGRAPHIC COMPETITION

There were a large number of entries for the photographic competition held at the Conference this year, and they made a lovely display for the whole weekend. Unfortunately Camilla Jessel was unable to judge the competition due to sudden illness, and we are very grateful to the team of 'professionals' led by Dr. Charles Pennock, who gallantly stepped in at the last minute. They had a very difficult task - the standard of photography was very high and of course, the subject matter so appealing.

The winner was Mollie Griggs with this beautiful photograph of her two grand-daughters Natasha and Kirsten Macintyre.



We are very grateful to David and Michele Brooks-Daw, for their hard work in organising the competition and their artistic display of all the photographs.

Unfortunately, a few photos went astray at the end of the weekend, so please look to see if you have picked up a few extras by mistake.



Mollie Griggs - winning photographer



## REFLECTIONS ON THE CONFERENCE

Our first introduction to the MPS Society was through Micheline Johnson, who, after attending the 1985 conference at Heathrow, came back to us full of ideas and enthusiasm. Curiosity well and truly roused, we asked for more information, and the result of that was that Millie Sartain and myself attended your conference in September.

We are classed under your heading as 'professionals' but we are known to many of you through Micheline as Victoria's "second family" on U.ward at Alder Hey, Liverpool.

After a very easy but noisy journey, classed grandly as a "sky-hopper" by the air-line, known locally as the "flying bedstead", we arrived at the Post House and introduced ourselves to Maggie Archard.

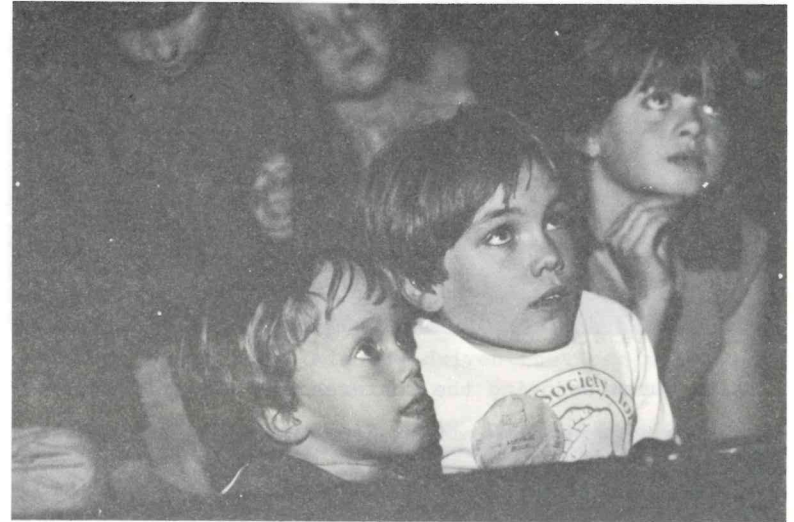


Bundle of fun - Victoria Oldaker

Armed with our files of information we made our way into a room which appeared full of Vicky look-alikes, but nearly all blondes! There were children charging in all directions and the general hubbub of people greeting each other, many friends made since the advent of the Society's first meeting. The photographs gendared a great deal of interest, what delightful little people - all in various poses, how difficult to choose a winner!

We were interested in the toys provided for the children and have subsequently decided to purchase some of those we saw displayed. Talking to parents was very easy, we found them willing to discuss their problems and meeting their children was an experience we both enjoyed. Our overall admiration for the parents increased each day - we look after Vicky for eight hour shifts, how do you all cope for twenty-four hours? The stories you told us we could visualise, we have also experienced the frantic behaviour, the

diarrhea plastered everywhere, the constant chewing of fingers and clothing, days and days when you literally need eyes in the back of your head! Behind the stories you laughingly told us was the evidence of heartbreak; it may be funny in the telling but not at three in the morning when you are surrounded by broken articles, dirty beds and a child that doesn't want to sleep.



Magic at the conference - Lorraine Rock & Christopher Issac

Millie and I learned a great deal, not only from the lectures that we both enjoyed, but the information from you as parents was invaluable. What we have learned from you all we will pass on to the other members of staff and perhaps be able to look after Vicky with a little more awareness of how the disease affects the children and the different stages of deterioration they all seem to pass through. These stages we could see for ourselves in the children present, from the hyperactive to those confined to wheel chairs and being totally tube-fed. The appalling fact remains that these children are often diagnosed very late so that some of you have two children affected.

Your Society has expanded and with it the knowledge and awareness of MPS. We were very impressed with the organisation and the way everything just seemed to run on oiled wheels, evidence of a great deal of hard work being done by you all.

We had to go all the way to the Post House to meet a local family, Colette and Joe Lee with their son David who also suffers with Sanfilippo. Hopefully they will visit us, we look forward to meeting them again.

Out of the conference also came a new understanding with Micheline and Brian, they found it easier to talk to us in a more informal setting without Vicky's presence.





Lisa Nurse enjoying the Conference - also see page 4



Simon Mansfield - looking after dad!

Thank you for making us so welcome, many of you expressing delight that we were interested enough to come. I certainly hope that we will be able to fund further attendance at your annual conference. You told us that you have very special children - may I also have the temerity to tell you, that you are very special parents.

Julia Martin (Ward Sister)

#### OUR SPONSORED WALK

On 14th June the 2nd Hawarden Guides did a sponsored walk from Harwarden to Chester to raise money for MPS Diseases. At 2 o'clock we gathered at Moor Lane, Harwarden. It was a blazing hot day and we came laden with bottles and flasks to help us survive our 8 mile walk.

We started down Moor Lane, walking neatly in twos like animals approaching the Ark. We had decided to walk along the banks of the River Dee, through Saltney, as this seemed the easiest route. We joined the river at Sandycroft and were thankful to be able to take off our shoes and walk along barefoot. There were 21 of us walking and we were all high-spirited ( mind you after about 7 miles we began to get a bit downhearted when we could not see our destination).

It was very peaceful walking along. We hardly saw a soul. About three miles along the river we stopped for a rest as some people seemed to be suffering from dehydration by this stage. After 10 minutes we started up again, fully refreshed and were soon approaching Saltney Bridge. We saw some children swimming in the river and I, for one, felt like joining them. We were nearing the end now, and apart from Nia Salt, who had twisted her ankle, we were still in one piece ( Nia was driven the last mile as she was unable to walk).

At last our destination was in sight. The younger Guides ran to play on the swings at the playing fields: I was content to flop on the grass in the shade, as the last of our party tramped in. We had raised £120 for MPS and most of us had also acquired a mild sunburn after walking for two and a half hours.

Bethan Hooson  
2nd Hawarden Guides

#### MPS GROUP HOLIDAY

We have had a good response to the group holiday and have now confirmed the booking for May '87. Those of you who have already sent back your forms will be receiving the brochure in the New Year.

If the response continues I shall arrange another self-catering holiday for 1987. I have several in mind eg. Cottages in Wales and Forestry Commission cabins in Yorkshire and the Lake District.

For those families who have not yet sent back their forms or may have mislaid them, please do write and let me know if you would like to participate in the group holiday. I know there will be some of you who will want to take a break without your MPS child and those of you who no longer have your child, please do not let this stop you from taking advantage of the holiday.

Mary Gardiner,  
35 Church Road,  
Banks,  
Southport,  
Merseyside PR9 8ET



## THE YOUTH OF TODAY ARE UNCARING??

It is often reported by our older generations, that young people today are uncaring; that they are mostly all 'TAKERS' and very few are the 'GIVERS' to society. I'm sure that most of our readers can think of exceptions to this statement - may I take this opportunity to thank one young man for his efforts towards our Society. His name is Andrew Hastie, he is 18 and hails from Glasgow and his only connection with the Society is that his mother is a friend of my wife. Andrew is just like any other young lad; he has just left school and is working in a bank. He has won the Silver Duke of Edinburgh Award, is a keen footballer and is a Staff Sergeant in the Boys Brigade.

Last year, when Andrew was still at school and one of the 'boys' in the BB, he took up the banner on behalf of MPS. He took part, along with the other boys in his company, in a 24-hour sponsored Games Marathon. The boys raised £1,000 - half of which was to go towards paying the company's annual fees to BB Headquarters and other commitments. The other half was to be donated to charity. The officers allowed the boys to choose which charity and five boys each spoke for five minutes in front of the whole company of 56, to state a case for the charity of their choice. Andrew spoke to an attentive company about a little girl who stayed round the corner from him who had just been diagnosed as suffering from Sanfilippo syndrome. He couldn't even pronounce Mucopolysaccharide at the time ( could you when you first heard of it?) I heard later that Andrew's story was so convincing that he carried the overwhelming vote in his favour.

A cheque for £500 was duly dispatched. ( May I record a hearty vote of thanks to the staff and boys of the 131 Glasgow Boys Brigade Company - Well done lads! ) Fortunately for Andrew and his company, Christine and Robin contacted London HQ, who, in turn, contacted Glasgow HQ., and Andrew and his company gained some excellent publicity, unexpected but most well deserved.

This was only the start for Andrew. His next assignment was to take on the Glasgow Marathon. I'm sure that Andrew will forgive me when I say that although enjoying his sport, he will never be a Daley Thomson or Kenny Dalglish. To attempt the Marathon when he had never done any form of competitive or non-competitive running was a hazardous commitment. Andrew worked very hard at his training, suffered a few set-backs through injury, took part in a few 10km. races and when his big day arrived in October, produced a very creditable time of 4 hrs.15 mins. He says the most enjoyable time was stocking up on carbohydrates during the week preceeding the race! Andrew's effort in collecting sponsors was equal to his effort in training, and as a result he collected around £240 for MPS.

On behalf of MPS may I say "A great big thank you" to Andrew and all the other youngsters throughout Britain for their efforts in trying to secure a better future for those youngsters less fortunate than themselves. Four others also ran in the Glasgow Marathon for MPS: teachers Jim Brownlie and George Potter, Robert McFadzen, a doctor, and Owen Reid a lab. technician. The total amount raised will be over £700. Many thanks to them all.

Alan Byrne.

## SKIPPING FOR MPS

Last July we held a very successful coffee morning for MPS. Many people in Haddenham know Matthew, who has Hunter's Syndrome, and support from the village was tremendous.

A lovely sunny Saturday meant everyone could sit in the garden. The children had great fun on Matthew's trampoline and slide, Granny and Grandpa sold masses of cakes and plants, friends and neighbours made endless cups of coffee, sold raffle tickets and all sorts of bits and pieces on the Bring and Buy tables. Alexandra Butler and his family popped in to help and we were delighted to raise £280 in one and a half hours!

Just as we were enjoying a fish and chip lunch, two teenage friends from the village, 13 year old Honor White and 12 year old Rachel Race, came to see us with the following idea: Honor writes:

"This is how I found out about the MPS Diseases. Mum came home from a coffee morning in aid of MPS. She told me about it and I decided that I would like to do a sponsored skip to help them. So I told my friend Rachel about it and we decided to do it.

Rachel did 55 skips in one minute and got £17.80, I did 92 skips and got £27. Three of our friends joined us and altogether we have raised £74."

A very big thankyou girls.

Andy and Jenny Hardy

## GUESS THE WEIGHT OF THE BABY!

At the conference we had a competition to guess the weight of the Lavery's new baby. Congratulations to Lucy Lavery, who even before her birth had raised £23 for MPS!

She weighed in at 4lbs 12ozs and the winner was Maggie Archard by pure chance! Maggie has nobly not claimed her prize from the fund.

Any other pregnant mums may like to try this novel way of raising a few pounds for MPS - charge 20p a guess and make a list of weights going up in half-ounces (or metric if you prefer)

[ Okay Pat, hint taken, I shall make my list out soon - Maggie.]

## FIT 'N' FAMOUS COOKBOOKS

There are still plenty left for sale, even though Julie Macintyre and her family have managed to sell over 2,000!!!!

Please send your orders to :- Mrs. Pat Isaac,  
'Beckdell', Church Road,  
Fiddington,  
Nr. Bridgwater,  
Somerset.

Cost - £3.40 per book  
(£2.95 + 45p p&p)



## HEALTH INFORMATION SERVICE

Much has been written on the provision of health information, from both within the medical profession and without. During my 23 years in the library profession I became increasingly aware that although a wealth of written information is available about medicine, the information (for whatever reason) was not reaching out as far as it could. One of the first precepts we learn at library school is that it is the librarian's task to get the right book to the right reader at the right time.

Early in the 1970's I compiled a small booklet called "Help! I need somebody", which listed self-help groups. I did it simply because I was being increasingly asked whether a group existed for this or that and I was frustrated because I couldn't find such a list. Much to my surprise it was a sellout. Since then others have produced similar publications and I have been commissioned to compile a fourth edition. Coupled with this I was being increasingly asked via my public librarian colleagues if I could recommend various up-to-date medical articles for their readers. Those appearing in academic journals were not suitable so I started publishing an index of medical articles from journals like Good Housekeeping, New Scientist, Women's Realm etc. all of which have accredited medical authorities on their editorial staff.

I also began assembling folders of information in the library at Lister Hospital on various topics for which it was sometimes difficult to find information in normal published sources. This has grown now to 3,000 folders which are compiled at two levels. One for the layman and one for the professional. I also have on file, details of many self-help groups to complement these folders, plus bibliographies of books currently in print on most of these topics. I also keep a small collection of paperback books for immediate supply in response to demand.

There is much evidence in the literature that however much a doctor explains matters to his patient, there is still a great desire on the part of many patients to follow up this information. Many are very resourceful in obtaining information: better they receive it responsibly handled than finding it in places like Black's Medical Dictionary. All this collection of resources has had to be housed in a cubby hole because of lack of space but work is in hand for extensions to the library and when the work is complete it is hoped the service will expand. Two recent evaluative studies of the service recommended that:-

- (1) The public should have access by 'phone or by personal visit to locally based health information service.
- (2) Such services should be backed up by national servicing agency to ensure that the supply of medical information is accurate.
- (3) Services of this kind should be provided by the Health Service.

It is hoped this service will flourish and grow in Hertfordshire.

Any enquiries about the service or for information please contact:  
Mrs. Sally Knight, District Medical Librarian,  
Lister Hospital,  
Corey's Mill Lane,  
Stevenage,  
Hertfordshire SG1 4AB

## MIDLAND AREA SUPPORT FAMILY - AUTUMN 1986 REPORT

We really enjoyed the Conference again this year and it was good to see so many old friends and many new families from all over the U.K. and overseas. We are sure that all would agree that one of the main advantages of an annual conference is that it not only draws us together to benefit from exchanging ideas and experiences but reminds us of what the Society is all about. It perhaps also reminds us that although we may have MPS in common, our own personal circumstances may be very different and our needs and expectations will vary from one to another.

As Midland Area Support Family we hope to offer the opportunity on a more local level for families to meet and benefit from shared experiences and arrange activities that anyone can enjoy. This may also involve fund raising which will help the Society in a variety of ways.

Since the Conference we have had two events. A street collection was held in Market Harborough on November 1st. and despite appalling weather £132.93 was collected. A very big thank you to Ron and Linda Snack, who came to help at the eleventh hour, and to the others who took part.

David and Sue Peach from Rugby kindly hosted a Cheese and Wine Party at their home on the 29th. November, which was a great success. A very special thank you to them for their hard work and to those who collected raffle prizes - a most enjoyable evening, in which a total of almost £100 was raised.

The next event planned is a coffee morning :-

January 22nd. 10.30am. at 'Tumbleweed'

Further dates for your diary:-

May 9th. - Midday at Weston Park

June 27th. - 12.30pm. at Twycross Zoo

August 1st. - Family picnic at a venue yet to be arranged - East Carlton Park perhaps?

Any suggestions for area venues or activities would be welcome.

We look forward to seeing you during 1987.

Alan and Deirdre Beavan

## NEWSLETTER

The next Newsletter is to be published at the end of March (we hope). Please let us have your articles by the beginning of March if at all possible.

Area Families, what about advertising your plans like the Beavans and letting us have brief details of what you've been up to (remembering that it is a family newsletter!).



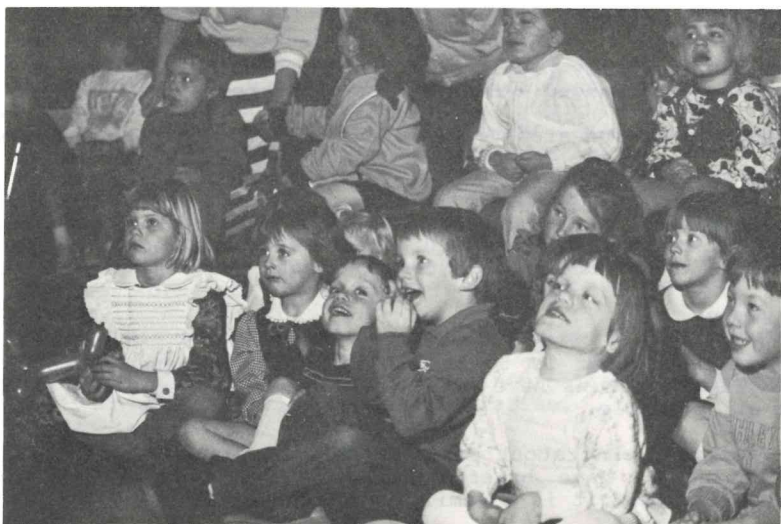
## PARTY PARTY

On Saturday 13th. December, the centre of the most intense MPS activity this side of the 1986 Conference was to be found in the hitherto little known Newton Hall, Sheffield. From early morning, assorted foods had been assembled, innumerable raffle tickets had been folded and organisers had mentally steeled themselves for the onslaught of dozens of MPS kids and their brothers and sisters. Yes, it was time for the MPS Christmas Party once again.



Leigh Bottom on her third bottle!

"That's the way to do it!"



Families came from the four points of the compass and more than 100 people turned up. It was particularly pleasing to see several families who haven't previously been involved with MPS activities, and to see more than a few grandparents

How does one measure the success of such an event? I suggest that the kids are the real judges, and from their antics there's no doubt that it was a smash! Did anyone notice that the Mayor didn't turn up to draw the raffle? I don't think so - we were all far too busy enjoying ourselves by chatting or watching the kids have a whale of a time.

Contrary to earlier predictions, Heather Broughton didn't appear as Santa because he turned up in person and distributed gifts to all the children. Very "Ho!Ho!Ho!" he was too, particularly bearing in mind how hot Sean Mahon said it had been inside the red 'bell tent'. What a smashing day it was and how much everyone appreciated the hard work that had been put in to make it a success from every point of view. Thank you to Heather Broughton, to Sean and Pauline Mahon, to the Punch and Judy man (and woman) and to all the many others who put themselves out to make a memorable day - not least the families and the children.

Peter Archard.

## WHEELCHAIR TRANSPORT

One of the eternal problems faced by families with a member who is wheelchair bound, is that of transportation. Some MPS families have, we know, already discovered the virtues of the Nissan Prairie, but even that versatile vehicle can be improved. The added attraction is that in doing so you can actually save money.

Mr. Gordon Langford took the ideas of a local man, the father of a handicapped daughter, and put them into practice. His design incorporates folding, alloy ramps that can be longer than a single piece design. They fold onto the floor rather than standing vertically inside the rear door. The wheelchair is held securely by approved quick-release clamps that instantly unhitch to clear the floor for easier manoeuvring of the chair.

Because the installation is permanent and approved by the Inland Revenue, cars fitted with it for bona fide use by handicapped persons or the disabled, are not liable to car tax or to V.A.T. Together with an additional discount, this cuts the cost of a converted Prairie 1.5SGL to about £5,700 from the normal list price in excess of £6,700. The conversion costs in the order of £300 and can accommodate the wheelchair in a forward facing position or sideways, when the rear seat may then also be used to carry three additional passengers.

Mr. Langford may be contacted at Motor City, Billacombe Road, Plymouth. Tel. Plymouth 46064. and is willing to travel to assist in the conversion or purchase of the Nissan Prairie.

The Society is extremely grateful to Dr. Charles Pennock, Consultant Paediatric Chemical Pathologist at Bristol Maternity Hospital, for drawing this information to our attention. We are sorry that it has not appeared earlier.



## CHRISTMAS RAFFLE PRIZES

Video Recorder	51856	M.Marjorana	Grays, Essex.
Microwave Oven	18432	H.Vanston	Bingley, Yorks.
Electric Drill	25600	J.Brookes	Sheffield.
Electric Kettle	10102	W.Fear	Bath, Avon.
Disc Camera	29605	C.Hubbard	Romford, Essex.
Large Holdall	57419	S.Lewis	Shrewsbury.
Twin Dolls	979	J.Crowland	Wirral, Cheshire.
Metal Hammer	3777	B.Hible	Sheffield.
Small Holdall	26530	B.Voss	Southport.
Whiskey	10821	K.Williams	Trowbridge, Wilts.
Hamper	48180	M. Pullin	London.
Whiskey	29558	M.Hemock	Romford, Essex.
Large Teddy	3216	C.Cosbridge	Portsmouth.
24 Cans Beer	27676	M.Jones	Lutterworth, Leics.
Monopoly Set	48013	H.Scott	Milton Keynes.
Chocolates	21634	S.Turner	Reading, Berks.
Sports Book	13213	N. Cooper	Caerphilly.
Kitchen Set	23843	A.Jackson	Doncaster.
Bath Towel	43909	A.Craven	Sheffield.
Lego Set	34434	L.Barbe	BFPO 825
Bathroom Set	13350	N.Willets	Caerphilly.
24 Cans Coke	21572	S.Heath	Maidenhead, Berks.
3M Gift Pack	31434	G.Dymond	Harlow, Essex.
Model Car Kit	6067	A.Corrin	St.Oswald's School.
Silk Scarf	30423	D.Farthing	Chigwell, Essex.
Cheque Bk. Cover	51124	C.Gosling	London.
Set of Glasses	9885	W.Pidden	Westbury, Wilts.
Chocolates	5034	Mr.Foers	Sheffield.
Lace Bookmark	41356	D.Beattie	Carlisle.
Tin of Biscuits	48227	P.Kesic	Waltham Abbey, Essex
Stationery Set	40356	H.Sistig	Sawston, Cambs.
Lace Bookmark	6002	B.Rennie	Rutherglen, Glasgow
Painting Set	43207	S.Wallace	Newcastle.
Scarf	30206	Mr.Lea	Cottenham, Cambs.
Pop Quiz Game	49790	M. Evans	Abercarn, Gwent.
Wooden Puzzle	59501	J.Tolman	Gt.Yarmouth.
Golf Balls	57482	M.Roberts	Shrewsbury.
Doll & Cottage	689	Blanchard	Barnet, Herts.
Child's Book	35660	B.Smith	Liverpool.
Small Teddy	44831	J.Knight	Widnes, Cheshire.
Cuff Links	51083	C.Coxon	London.
Pens & Crayons	29133	S.Towne	Hockley, Essex.
Book	25008	L.Dawson	Twyford, Berks.
Pens & Crayons	27841	A.Butcher	Andover, Hants.

### Congratulations to all the prize winners.

This year the raffle has been a great success and has raised £3,834. The cost of prizes, printing and postage etc. was £734 - a nett profit for the Society of £3,100.

We are most grateful to all the companies and individuals who kindly donated prizes for the raffle and our special thanks also go to Ron and Linda Snack whose hard work in organising, securing donations and promoting the raffle, ensured its success.

**Most of all, our thanks to all those who bought & sold tickets!**

## DONATIONS

We thank the following families, friends, associations and companies for their donations and fund raising efforts:-

Donations continue to be received from around the world following the Sunday Times articles about Helen O'Toole and her operation for cervical fusion. We are most grateful for the continued interest and support, not least for that from Helen's school. A.E.U. Shop Stewards Committee at Rolls Royce, Bristol; Mrs.Lear; Anne Chamberlain; Milton Keynes Renzoku Judo Club; J.Cockell; 154th.Edinburgh Waverley B.P. Scout Guild; Bagillt Brownies(Clwyd) 2nd.Hawarden Guides; C.A.Danes; P.Isaac; Dr.& Mrs.Moulding; Mr.Geering; Mr.Cooper; Mrs.Blatch; Mr.& Mrs.Hooper; Dr.& Mrs.Hall; Mrs.Higgins; Mrs.Archard; Mr.& Mrs.Wall; W.H.Smith; Conservative Central Office; National Association of Tangent Clubs; Mr. Walker Bushey & Dist.Club - U.K.Federation of Business & Prof. Women Paul Kossoff Fund, Hatfield; Beaufort Women's Club,Downend,Bristol Mrs.M.Saunders; Nutmeg Club,Talbot Inn,Keynsham; P.& Mrs.W. Robins Mr.& Mrs.Boyle; Mr.& Mrs.Y.Motomura,Tokyo; Potterspurty Lodge School,Towcester; Downe House School,Newbury; Prince of Wales P.H. Colchester; West Midlands Travel Ltd.,B'ham; Mr.& Mrs. Obeney; N.H.D.C.'slimmers'; Cliff & Joy Loft; Melanie Gore; Maria Bondi; John & Janet Melleney; Miss Rawlinson.

### Charity Boxes

Tipputs Inn, Nailsworth; Kiln Farm Club; Cyncoed Post Off. Cardiff Hewletts Greengrocers, Bristol; Heysham Central Post Office Conference Weekend, Post House Hotel, Heathrow.

### In Memory

We are very grateful for donations sent in lieu of flowers and in memory of MPS victims - Alevique Brooks-Daw and Anthony Bennett.

### Fund Raising and Sponsored Events

Jill Carless held a pottery party.  
Ann Barnet, Rosemary & Harry Nurse, Anne Hill and Mr.& Mrs. P.G.Harvey each held a car boot sale.  
Hamp Infants School, Bridgewater, sold Harvest Festival produce.  
Alan & Deirdre Beavan held a Flag day.  
Clydebridge Steel Works, Glasgow gave their bottle fund.  
Margaret Leask, B.M.Oldridge, Sheila Benbow, Mrs.Lily Strong and Marlene Sanderson each held a coffee morning.  
Mrs. Diane Morris contributed proceeds from a sponsored 'slim'.  
Maggie Archard held an MPS 'open house'.  
Marjorie Eaton ran a raffle.  
N.J.London took a collection box to a football match.  
St.Leonard's Church, Hythe, gave a concert by Molly Griggs.  
Mr.& Mrs.Bishop, St. Clears, West Wales, held a disco for MPS.  
Mr. Jarrett & his granddaughter held street collections in Yeovil.  
Tipputs Inn, Nailsworth, held a raffle.  
High Wycombe C.of E.School contributed the collection from the end of term service and Angela Bunsell, Victoria Knibbs, Tanya Bunsell and Katie Fenton from the school also held a mini-fair.  
Little Chalfont Methodist Church held a Summer Fair.  
Dr.Garrow's garden party generated a sponsored swim.  
Honor White, Rachel Race, Amanda Harland, Claire Gilham and Gail Shardlow, all of Haddenham, held a sponsored skip.  
Robert MacFadyen ran in the Glasgow Marathon.  
Denise Jaggard held a book party.