

NEWSLETTER

WINTER 1989

**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 of MPS disorders in Great Britain and, where they are children, to their immediate families. It is also distributed around the world on subscription. Copies are 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 £5 in Great Britain and £10 Sterling elsewhere.

First of all I would like to thank the families and friends of the Society, too numerous to mention individually for their good wishes this festive season and to wish all our members a peaceful new year.

In early December the Management Committee met for the last time under the Chairmanship of Mary O'Toole. Although relinquishing this important role Mary has reassured us all that she will continue to work equally as hard for the Society in the coming years and will be remaining on the committee. On behalf of all the families and personally I would like to say thank you to Mary for taking the Society forward in these important formative years. At the same time I would like to welcome Alf King as the new chairman of the Management Committee.

We are also very sorry to have to accept the resignations of David Watt, and Pat Isaac our fundraising co-ordinator. Without Pat's drive and artistic skills the Society, would not be where it is today. We wish Pat well in her new full time career as an Educational adviser for Somerset, and feel some what comforted that she has offered her continued help in one off tasks in the publicity field. Pat's act is a tough one to follow but the Society should feel confident in the choice of her successor, Ron Snack. Many of you will best remember Ron and his wife Linda for their organising of the very successful MPS Christmas Raffle. Please give Ron a warm welcome and from now on all fundraising enquiries to Ron.

It was lovely to see so many of you at the MPS Christmas Party. Our thanks should go to Sue and Dan Butler, Ann Neal, Mary Gardiner, Andy and Jenny Hardy and of course Father Christmas for making the day such a success. You may feel it is a bit soon to be thinking about next Christmas but if you feel your area could organise our party in 1989 please do let me know.

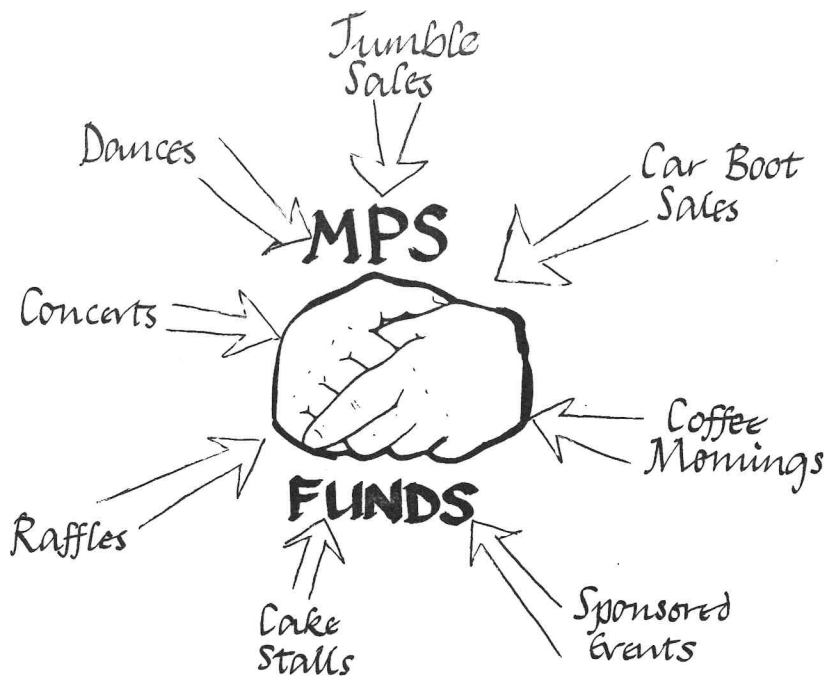
We enter 1989 with plans to consolidate the Society's rapid growth by providing increased support through the Area Family network, publishing the first of a series of leaflets on the individual diseases and facilitating new initiatives in clinical medicine and research to bring us closer to a better understanding of our children's problems and a cure for our children.

We hope that you will continue to benefit from the Society's activities in the coming year and support the Society in achieving its aims.

Christine Lavery

Absolute Deadline for items for Spring Newsletter will be **Friday 3rd March.**

Please note up to date addresses and phone numbers for committee members. Apologies for previous errors: Editor.

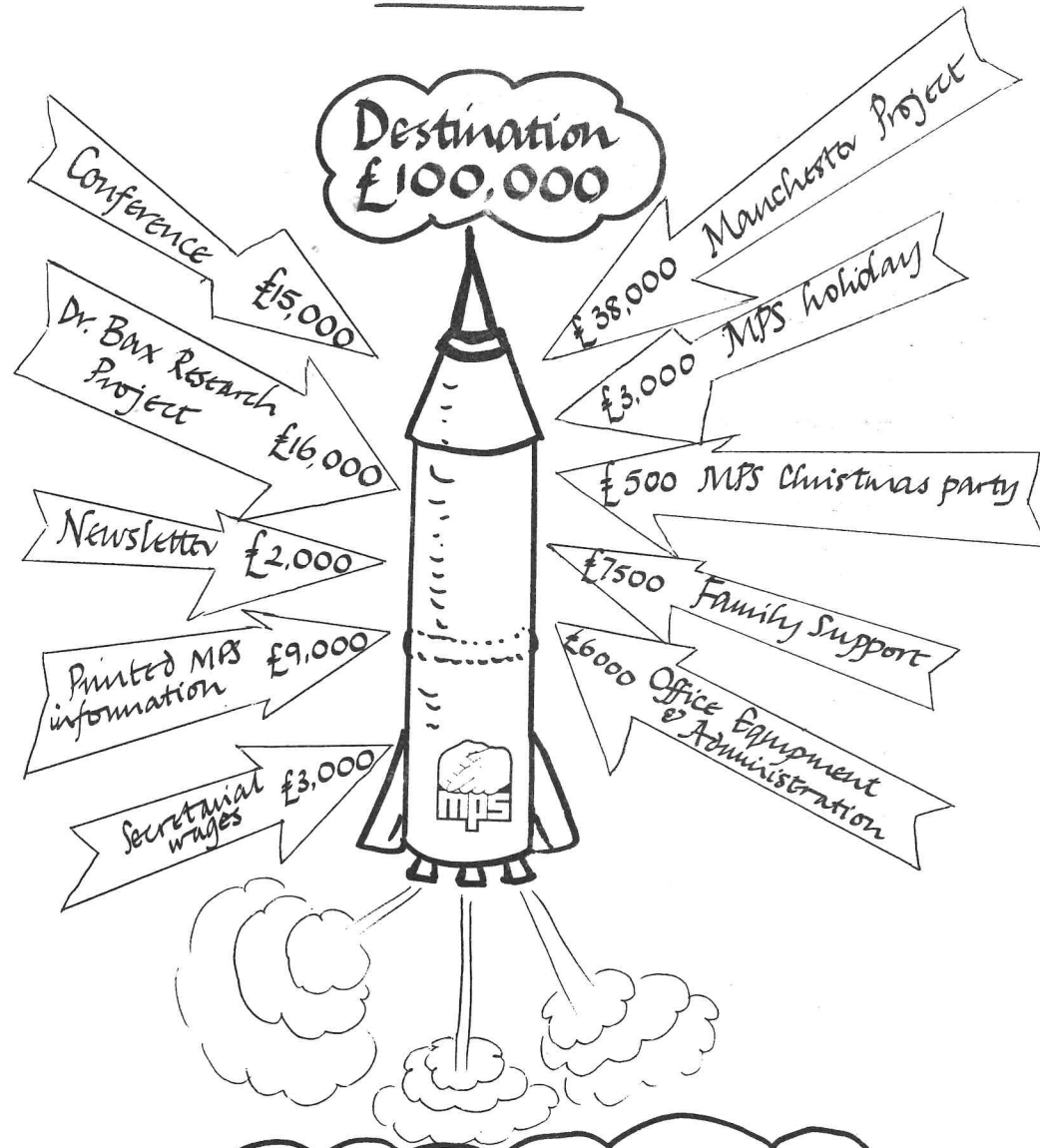


All of the above events are regularly held by MPS families all over the country to boost our funds. Families say they don't know what they would do if the Society didn't exist. Different members of the MPS Society would put our activities in a different order of priority. Which is the most important to you? Newsletter? Conference? a phone call from Christine when your child was first diagnosed? Research an MPS holiday? or just knowing the Society's there when you need it? Less than 7 years ago the Society didn't exist. Perhaps its very existence is the most important 'activity' to you. The Society has been successful; MPS families are part of its success. In order to exist at its present level the Society needs to raise £100,000 this financial year.

What would you do if the MPS Society didn't exist?

Pat Isaac

THE MPS SPACE ROCKET



DO WE HAVE LIFT OFF?
Will you help launch it?

Pat Isaac



The Society for
Mucopolysaccharide Diseases
A SPONSORED EVENT

LONDON MARATHON

Date APRIL 23RD 1989
Name ROGER BENNETT
No. of Miles Completed 26

The money raised will help children and young adults suffering from these rare incurable diseases. Your sponsorship will be much appreciated.

NAME	ADDRESS	AMOUNT PER <u>MILE</u>	TOTAL PAID
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THE LONDON MARATHON 1989

APRIL 23rd

ROGER BENNETT KEN GOSS GLYNN BUSH

Please can you get some sponsors for this event? We have three runners willing to run for MPS this year. Enclosed with the newsletter is a sponsor form. Please fill in the details as shown on the top of this page. If you know of anyone else who is being sponsored please let me have details for the next newsletter, with photos if possible.

Roger Bennett

Roger lives near Bridgewater and works at Hinkley Point power Station. He is thirty seven years old and is married with two children. He knows about MPS because one of his children goes to school with Christopher Isaac. Roger also works with Dave Isaac. This will be the first (and last, he says!) time he will have run a marathon. He ran the Taunton marathon two years ago, but at the end of the run they were told it didn't qualify as a Marathon because the course was twenty yards short!

Ken Goss

Ken is aged 54 and lives at Eastcote near Ruislip in Middlesex. He is married with three children, and works as a civil servant. He ran in the first London Marathon where he did his best time of three hours fifteen minutes. He has been Marathon running ever since. His wife Valerie sometimes feels she is a Marathon widow! He met an MPS parent on the Sunday Times fun run and he is very keen to find sponsors on behalf of the Society.

(Overleaf is a letter from Glynn Bush)

Ms Christine Lavery
Hon. Director
The Society for Mucopolysaccharide Diseases
30 Westwood Drive
Little Chalfont
Buckinghamshire.

37 Factory Road
Watleys End
Winterbourne
Bristol
BS17 1QL

23 December 1988

Dear Christine,

Thank you for your letter dated 19 December, together with Sponsor Sheets and information on MPS, which will greatly assist in our efforts to raise some Sponsorship donations for your very worthy organisation.

I am a married man, a self employed plasterer by trade, with 2 young daughters aged 4 and 7 years.

My interests have always been centred around all Sport, when at Comprehensive School I played both Rugby and Football. Since that time I have played football for many local clubs, but as goal-keeper I received so many injuries that I was obliged to give up playing regularly because of my work. I now play only occasionally for a young team based at the local 'pub' "The Masons", who have always supported me most generously in my running to raise money for charity.

I support Bristol City Football Club and attend most of their Home and some of their Away matches.

I only started long distance running some 4 years ago, as a means of keeping my weight down when I gave up smoking. I have completed several local half and full marathons, including Bristol (3 years), Weston-Super-Mare, Taunton, Kingswood, and Stroud, plus several small 10-mile runs.

I ran in the London Marathon in 1986 and my position was 3,153 out of 27,000 runners and I am enclosing a photograph taken at that time. I tried to enter again in 1987 but was not accepted. I am pleased that in April next year I will be one of the 31,000 runners in the 1989 event.

The name of your charity was brought to my notice at the beginning of last year by a friend who worked with a young man whose child or children were afflicted with one of the diseases mentioned in your pamphlet. He was at that time trying to find a Marathon runner who would assist him in his endeavour to raise funds for your organisation. I did promise him that if I was accepted last year I would be pleased to help, but unfortunately due to the bad luck of the draw I was unable to do so. My friend has temporarily lost touch with her work-mate, hence my letter to you, but as soon as I can find out his name I will let you know. He may possibly also be contacting you for literature for me.

I look forward to running in 1989 and will do all I can to assist your very worthy cause.

Yours sincerely

GLYNN BUSH.



ANGELA at the Disco with boyfriend Jimmy!

I couldn't believe it when my mum told me I was going to Disney World. I always wanted to go there. I went from 14th to 22nd of November on a Dreamflight with British Airways. There were 84 of us altogether and we were treated like royalty. We were given loads of presents including a personal stereo, a camera and twenty dollars a day to spend. The night before we went we had a Disco which Jimmy Tarbuck came to. We went to Disney World twice, the Epcot Centre, Sea World, the Kennedy Space Centre, River Country, and a local shopping centre. We also met Curly Neal, a famous American basket-ball player. The only bad thing about it was coming home. I didn't want to come home because it was the best thing that ever happened to me.

Angela Paton



ROGER BENNETT running for MPS
Get running with your sponsorship form!

CONFERENCE 1989

STAKIS GRAND HOTEL, STOKE ON TRENT

FRIDAY 22ND TO SUNDAY 24TH SEPTEMBER

Those of you who were at last year's Conference will have been sent a small questionnaire seeking your views on the format for this year's event. Many thanks to all those who returned their forms. Incidentally, please note the revised date - the weekend before the one given on the form.

The printed programme and booking form is enclosed with this newsletter. Be warned - we will almost certainly not be able to accommodate all those who want to attend so please send back your form quickly to obtain a place. If you have difficulty raising the money, send your form in and let us know. It may be possible to contact a local trust which would help with your expenses.

Ninety families attended last year's Conference and we had to turn a few latecomers away. This year we have a problem with the budget and at present have only enough funds to subsidise places for sixty families. If the financial position improves, we will ask the Trustees to increase the budget so that more families can come.

Although it will be more complicated organising a meeting further away, we all feel pleased to have a change from the concrete and motorway wilderness at Heathrow. After analysing the replies to the questionnaire, we have changed the format of the Conference slightly. There will be no workshops this year and we will have talks on Saturday afternoon, leaving plenty of time to chat over tea and to slip off for a dip in the hotel pool. Sunday morning will be more relaxed with a brief session on the Society's activities and plans for the future followed by coffee, the mini market and a chance to wander round and chat to friends.

The children will be going to Alton Towers on Saturday but the rest of the programme is yet to be decided. We will be bringing a party of our faithful volunteers from Amersham and will also be recruiting local help.

Mary O'Toole

Births

To Natalie Wells, granddaughter of June Evans of Ashford, Middlesex, twins Holly Louise and Aaron Michael, born on the 15th of December. Congratulations and best wishes.

NEW FAMILIES

Mr and Mrs Vigus from Hayle, Cornwall, have a seven year old daughter, Emma who suffers from Sanfilippo Disease.

Mr Richard Bilson from Warwick, aged twenty eight suffers from Morquio Disease.

Mr and Mrs Ullah from Forest Gate London. Forhan is suffering from Sanfilippo Disease.

Iris and Henry Whiteside from Hartlepool. Jeanette and Andrew both suffer from MLlll.

Betty and Tom Sweeney from Airdrie in Scotland. Their son Christopher is ten years old and suffers from Sanfilippo Disease.

Mike and Ann Kilvert from Newtown, Powys, whose fifteen year old daughter Sarah suffers from Morquio Disease.

Ray and Andrea Richardson from Kent and their daughter Carrie. Carrie is aged seven and has recently been diagnosed as suffering from Sanfilippo Disease.

Kieran and Bernadette Houston from Strabane in Co Tyrone. Their year old son Liam is suffering from Hurler Disease.

Barry and Michelle Watkinson from Clwyd whose two year old son Michael suffers from Hunter Disease. Michelle gave birth to a daughter, Hayley Marie on the third of September, weight 7lbs 4oz. Our congratulations and best wishes.

Mohammed Younis and Jan Begum from Bradford have two sons both suffering from Morquio Disease. Sharaz Hussein is aged five and Shazad Hussein is aged three.

Mr and Mrs Richardson from Bungay in Suffolk. Their ten year old son Derek suffers from MLlll.

DEATHS

Lisa Alam from Bethnal Green in London who suffered from Sanfilippo Disease died on the 24th of November aged ten years and four months. Our sympathies to her family and friends.

Toni Branford from Swindon Wilts died on the 17th of December aged ten years and ten months. Our sympathies to her family and to her friends at Tadworth Hospital.

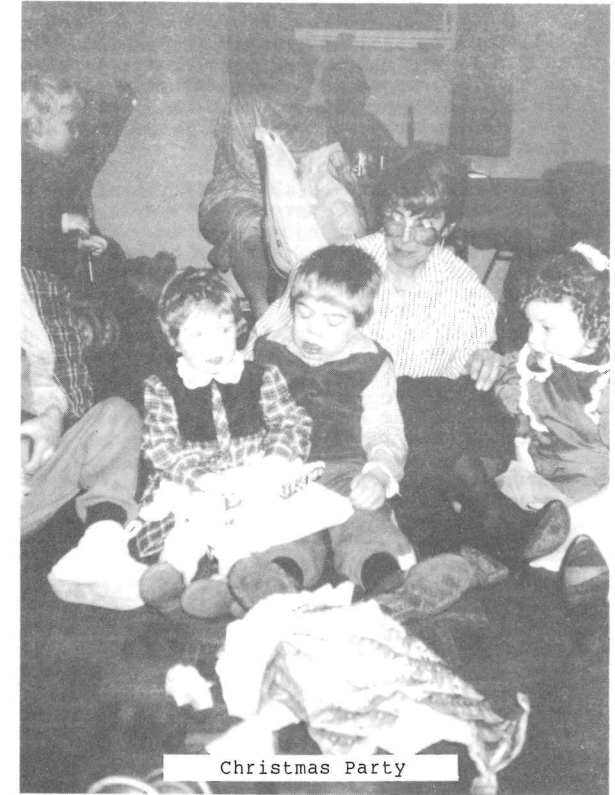
CHRISTMAS PARTY

The village hall in Radnage was the scene of the Christmas party on the 10th of December. Radnage is set, or it would be more accurate to say scattered, near the wooded ridges of the Chilterns in deepest Oxfordshire. It is so well scattered, that despite the map several people had difficulty finding the hall.

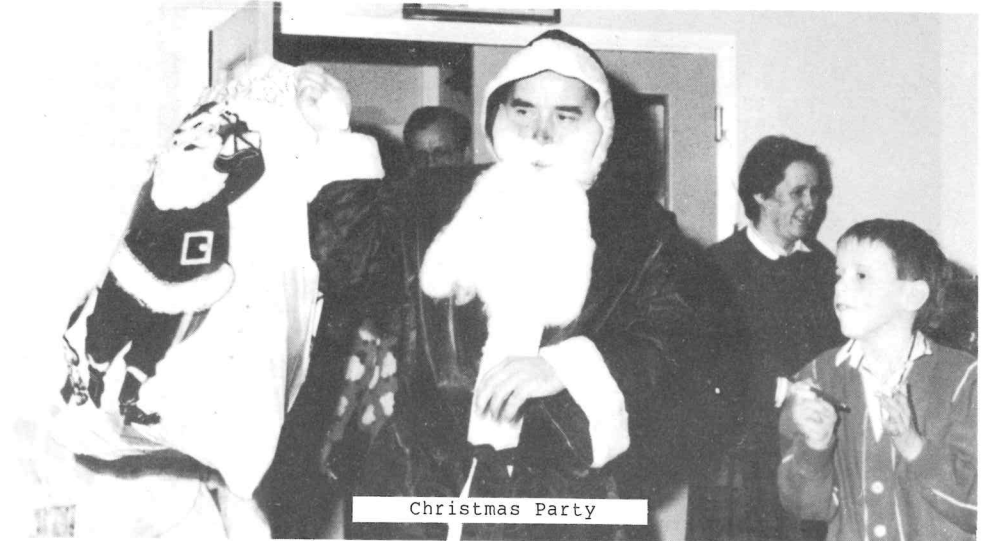
Sue Butler and friends with the help of Christine Lavery and Ann Neale provided an excellent hot meal. Andy Hardy

organised a series of highly original games which got both children and parents climbing all over the furniture looking for hidden pictures of Kylie Minogue and Steve Mc Queen.

Jennie Hardy led Christmas Carols on the piano and the younger children were entranced by the magician. The list of winners of the very successful Christmas draw is given at back of the newsletter. Thanks to Sue Butler and all the organisers and helpers for a very successful party.



Christmas Party



Christmas Party

12 Hour 'Bop until you Drop'.

Over £800 was raised for our Society on Saturday 25 June by two Rock and Rollers bopping till they dropped in Milton Keynes.

Bill Guntrip, 19, and Mick Wilson, 24, danced for 12 hours, with only a five minute break each hour, to raise money for research into MPS Diseases. Their marathon started at 9am at Wolverton Central Workmens Club and did not finish until 12 hours later when the rafters were raised by the crowd cheering the lads final fling.

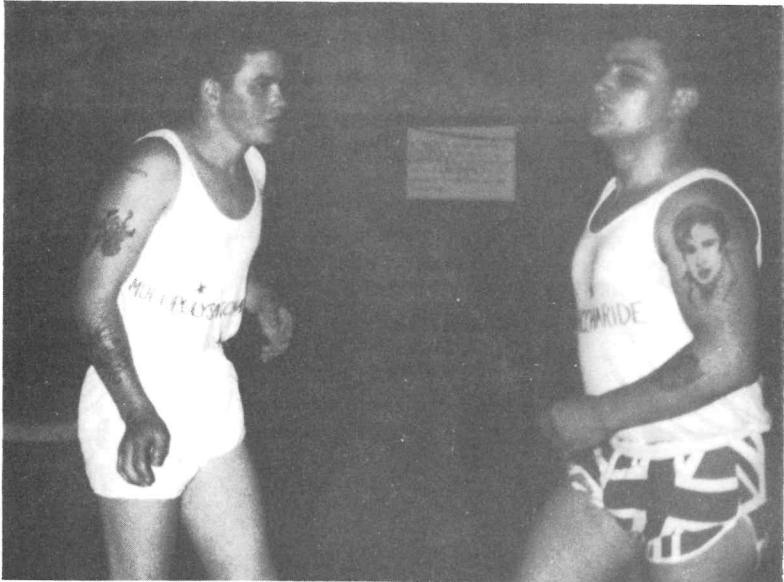
Although exhausted by their efforts at the end of their epic stint Bill and Mick were delighted to have completed the full 12 hours which they set out to do. The worst time for the lads seemed to be between 2 and 6pm but their girlfriends Donna and Sharon helped them through this period with coaxing and applications of Deep Heat.

During the last two hours the Club started to fill up and by 9 o'clock it was standing room only as everyone joined in the last ten minutes of dancing. The fund raising was boosted by 'roll a 10p' for a bottle of Whiskey and 'roll a 2p' for a bottle of Coke for the kids. A very good raffle was organised by Fred Foote and Ted Freer and this also added to the grand total.

Thanks are obviously due to Bill and Mick for the tremendous amount of hard work that they put in, but we must also thank Donna and Sharon, Mark Wyatt who played the records all day, and Shaun who was in attendance for most of the time. Final thanks must go to the Club Committee for allowing the event to take place.

WELL DONE LADS

Ron Snack



Bill Guntrip and Mick Wilson
Rocking in Milton Keynes

NEWS FROM NORTHERN IRELAND

Five families came to a meeting on the 15th of October at Loanends Church Hall to discuss the future of the MPS support group in Northern Ireland, and there were apologies from three other families. The Larkin family brought photos of the Family Day we held in the Summer and Ann Kirkpatrick had photos of the conference so we decided to keep a photo album and a scrapbook.

We got to know each other a lot better that afternoon and we felt we would commit ourselves to establishing a strong relationship with each other. We discussed again the difficulties families have in Northern Ireland (as compared to the rest of the UK) in obtaining Attendance and Mobility Allowances. We decided to lobby our MPs on this subject.

We talked about fundraising and Ann told us about progress on her Nearly New Shop in Antrim. Ann also reported back to us about the conference and we decided that each year a family from NI will go to the conference.

We set a date for a Family Day on Saturday 3rd June 1989. We decided to extend the invitation to relatives, friends and people working with MPS. Times and programmes will be given later. We would welcome anyone who would like to come over from Britain.

The afternoon was a great success and we set out for home refreshed and encouraged, and clutching bundles of tickets for the Christmas draw.

Margaret Kearney
Ballycastle, Co Antrim
Ph 02657 62073

DAY OUT AT MARGAM PARK

On the 30th of July the Welsh families met at Margam Park. Tony and I came a quarter of an hour early to welcome everybody but we were the last to arrive! The weather was windy and showery so we were thankful that we had booked lunch at a local hostelry. After much chatting and laughing over lunch we were encouraged by a hint of sun to brave the elements. We tried unsuccessfully to lose the kids in the maze, which is said to be the longest in Europe. The rain eventually came down again and we retired for coffee and icecream. In the true MPS tradition we had a very enjoyable day, despite the mixed weather.

Mary Lockyer

RALLY IN THE VALLEYS

An event we had locally on July 14th may prove of interest to other fund raisers as it delivered a lot of money with little effort. A friend organised a car rally/treasure hunt. Tony helped plan the route and sponsorship money and prizes were obtained from local businesses. The local sports centre was booked for the evening with a buffet and cabaret act. There was no charge on the hall and the buffet was given at cost price as the club made their money on the bar. The comedian donated half his fee.

I had MPS items for sale at the hall and when the chairman spoke about the diseases I was inundated with customers and sold out within half an hour!

Some sixty cars and 170 people took part in the rally. With tickets at £3.50 a head that raised over £800 and also made a lot of people aware of MPS, which can only be good. Indeed I received further donations from people who had heard about MPS though the rally.

If anyone wants to organise a similar event and wants a copy of a typical rally programme or any other advice please ring me on 0443 203845.

Mary Lockyer



Mary and Tony Lockyer
 looking very debonair
 at Area Family Training Day 1988

WALKING SLOWLY IN WALES

When our local paper the Western Mail sent me details of their "Walk for Wales" I thought that this was something all the local MPS families could get involved with to raise money for MPS. I duly sent out details to all the Welsh families and to the Area Families bordering Wales.

Four families from Wales donned their walking shoes, the Sweeneys, Lanes and Lockyers set out from Cardiff and the Skidmores walked in Gwent. The rest of the Welsh families sponsored those who were brave enough to walk. As it happened July 9th was one of the rare good days of the summer, though it started to rain shortly after we finished! We thoroughly enjoyed our two and a half hours together walking the five mile stretch (OK, we weren't out to break any records). This may become an annual event so look out for Welsh Walkers!

PC David Rowlands (Matthew Blackburn's uncle Dave), walked fifteen miles from Flint to Chester along with his spotty dog Freckles and members of the Bravo I Outward Bound Group. They raised £160 for MPS. Well done everyone!

From Mary Lockyer and Sylvia Blackburn.



Welcome to Alf King
 as Chair of the Management Committee!
 With **Judy** and their daughter **Susan**.

CERVICAL FUSIONS

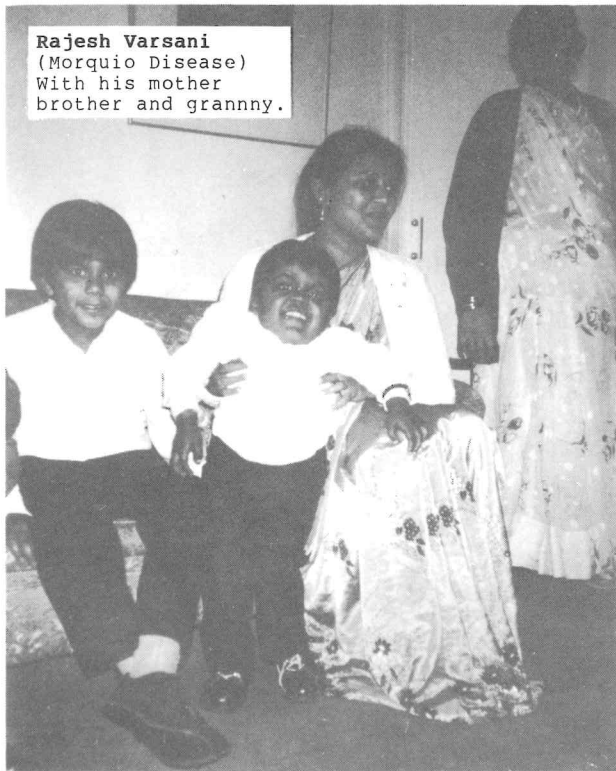
Mr Ransford, the Consultant Orthopaedic surgeon and his team at University College Hospital, London, have been busy in the last few months. All three of the Society's halo frames are now in use on three little boys with Morquio disease from the North of England.

Surgeons in the North have chosen to refer their patients to Mr. Ransford. It makes sense for one hospital to develop expertise in this kind of surgery, but it is hard on the families who have to spend several weeks far from home.

Three year old **Suqlain Shah** had his operation in September and may have his halo off by the time this newsletter is sent out. Suqlain's operation was more complicated than most and there have been many worries for his parents since.

Rajesh Varsani is six and has not been walking for some time following a fall. While I was visiting him in hospital I was amazed to see another three year old with Morquio disease, **Shazad Hussein**, who had recently fallen and lost the use of his legs. It was encouraging to know that a patient had finally found his way to London without the Society's involvement. Shazad made a very rapid recovery from his operation and his family have now joined the Society.

We wish all the boys well and will have fingers crossed that they do not have to spend too long in their halos.



SCOTTISH CONTACT FAMILY

Alan and Fiona Byrne

We are Alan and Fiona Byrne. I am thirty eight and Fiona is thirty five. Our children are **Derek aged nine and Louise aged six, who has Sanfillipo Syndrome.** I am head PE teacher in a local comprehensive school with approximately 1100 pupils. Fiona is a housewife who apart from organising the parent support group at Louise's school spends most of her time (like most MPS mums) looking after Louise as she is more often off school than at it.

I am currently involved with the major changes facing Scottish Education at the moment, but I enjoy playing golf now that my football days are over. Fiona (enjoys?) swimming and jogging, plus total freedom on a Saturday afternoon, allowing a jaunt around the shops.

Derek is just like any other normal nine year old. He has his ups and downs, but to him Louise is not handicapped, just a "special girl" who sometimes pulls his hair or stands in front of the television during his favourite programme.

We joined the Society three years ago, being rather fortunate to have heard of the MPS Society straight away. There has never been an Area Family in Scotland and so Christine asked us if we would become a contact family for MPS in Scotland. We were rather embarrassed at not being able to take on the task of Area Support family but my work gives me little time, even in the evenings, and Fiona has her hands full with Louise.

We have only thirteen families registered in Scotland and they can be anything from ten to one hundred and fifty miles apart.

There must be many more MPS children in Scotland undiagnosed and we have been trying to spread the gospel via the major hospitals and the local health centres but this has proved a difficult task. Most Scots families, mainly because of their isolation from other MPS families are more content to care for their children on their own. Perhaps it is also because we are a stubborn race (as if you didn't already know) and find it difficult to share a problem.

It would be most helpful if a family were able to act as Area Support Family. However until this happens we are delighted to be part of the Society and help as much as we can, albeit in a rather limited fashion.

Best wishes to all and remember, **Scots families**, we may be miles apart but **we are only a phone call away.**

ANSABAK, the newsletter for Junior members has been delayed and will appear with the next issue. Sent your items to Catherine Gardiner.

LEAFLETS

We are delighted to be able to enclose copies of the Society's first two leaflets with this newsletter. The blue information leaflet is primarily intended for new families who have just received a diagnosis and it will be given out by paediatricians and biochemists. Families who contact the Society will then be sent a copy of the green leaflet on the pattern of inheritance and, if they wish, a leaflet on their child's disease.

Three of the individual disease leaflets on Hunter, Morquio and Hurler (including Scheie and Hurler/Scheie) diseases are nearing completion and I have started work on the one about Sanfilippo disease. I am very grateful to the doctors and biochemists who have patiently corrected my drafts and given me generous support and encouragement in this project. As they become available, these leaflets will be sent to the adult sufferers and to families with children affected by the disease.

We have obtained grants to pay for the design and printing of the leaflets, but will have to find money for reprinting when stocks are depleted. Families and subscribers are welcome to photocopy the leaflets, but the Society will have to make a small charge for any extra leaflets ordered.

Charges will be as follows:-

Introduction to MPS diseases) 25p
Pattern of Inheritance) each
Individual Disease leaflets 50p

Any number of copies of the fundraising and Manchester project leaflets continue to be available free of charge.

WHAT ON EARTH IS ASPARTYLGLUCOSAMINURIA?

The new information leaflet lists the diseases which come under the MPS Society's umbrella. In time every family joining the Society should be able to have a leaflet describing their child's condition. That will still leave them wondering about the rest. Those who are really keen could buy themselves a set of leaflets on all the conditions, but perhaps it would be simpler to read a shortened version in the newsletter. Mary has rashly promised to work on this by condensing each disease leaflet as it is produced.

We have been spurred on by the following article on Fucosidosis (one of the rarer diseases covered by the Society), contributed by Dr. Bryan Winchester. Many of you will know Victoria Oldacre who has a very mild variant of the disease.

Mary O'Toole

FUCOSIDOSIS

Fucosidosis is a rare lysosomal storage disease resulting from a genetic defect in the enzyme α -L-fucosidase, from which the disease takes its name. It was first described in two brothers in Italy in 1966 as a "new mucopolysaccharide lipid storage disease" because the two boys showed many of the features of Hurler disease. However, fucosidosis is not a mucopolysaccharidosis because there is not excessive excretion in the urine and accumulation in the tissues of mucopolysaccharides. In fucosidosis the defective enzyme is involved in the breakdown of carbohydrate chains attached to proteins and complex lipids. Fucosidosis is therefore most closely related to other storage disorders such as mannosidosis and aspartylglucosaminuria.

To date about 100 cases of fucosidosis have been reported worldwide. Approximately one third of the patients are of Italian origin and several of these can be traced to two large pedigrees arising from neighbouring villages in Calabria in Southern Italy. Cases have been detected in several other European countries, North America, Japan, Hong Kong, Algeria and Turkey. Interestingly many of the families have Italian ancestry. As far as I know this is not so for the three documented British patients.

Clinically, two forms of the disease are recognised; Type 1, a very severe infantile form and Type 2, a less severe juvenile or adult form. Patients with the infantile form are normal at birth and during the first few months of life but symptoms such as repeated respiratory infections, feeding difficulties and failure to thrive appear within the first year. From then on physical and mental development are retarded and there is progressive deterioration of nervous functions and health. Patients usually die between 4 and 6 years from pneumonia.

The onset of clinical signs occurs later in the Type 2 form of the disease but may be apparent as early as the second year of life. The symptoms are similar to those in the more severe form but develop more slowly and patients survive into adulthood. A common early symptom is difficulty in walking due to weakness of the legs and unsteadiness. The facial features become more coarse as the disease progresses and characteristic clusters of purple pinhead-sized spots appear on the body. Growth is retarded and skeletal abnormalities develop. Not all symptoms have been observed in all patients and there is considerable variation between patients in the severity of a particular symptom.

Recent researchers in the United States have developed by genetic engineering a 'gene probe' that can be used to investigate the genetic defect or mutation in fucosidosis. Using this probe research groups in Italy and the United States have shown that there is more than one mutation causing fucosidosis. This may well explain some of the differences in severity of symptoms observed between patients. Surprisingly the same mutation has been found in some Type 1 and Type 2 patients, almost certainly confirming that other genetic factors affect the disease process.

Our research group is using this technique to develop a procedure for the detection of carriers and to study the defect in the British patients, all of whom are unrelated and

very different clinically. We also have preliminary results indicating that yet another mutation, different from that found in the Italian and American patients, is present in a Chinese family with fucosidosis.

There is no cure for fucosidosis but the research described is revealing the molecular basis of the disease. This will help us to understand the disease process better, to recognise the different forms of the disease more clearly and earlier and it will make detection of carriers more reliable. All this will enhance the genetic counselling and support available to families at risk for fucosidosis.

Dr Bryan Winchester
 Enzyme Section
 Department of Clinical Biochemistry
 Institute of Child Health
 University of London

IT WAS FUN ALL THE WAY, SAYS PAT, FORTY!

Ex Hon Fundraiser, mother of three from Somerset tells her own heartwarming story.

"I've been raising funds for the MPS Society for the past four and a half years. I can't give up now, it's in the blood. During this time I've had to receive cheques on behalf of MPS in many strange places including perched inside a supermarket trolley and standing behind a bar. Once I was staggered to be confronted with a semi-naked man who claimed he was Tarzan.

HE SAID HE HAD BEEN PAID BY A TRUSTEE TO KISS ME!

I've been featured in the "Star" and the "News of the World". My only regret is that I never made it to "Sport on Sunday".

The buxom teacher concluded with a giggle, "I'd like to be remembered for adding some FUN to Fundraising!"

Her husband Dave, (40+), declined to comment.



Helping Chris

WHEN regulars at the Cottage Inn, Keenthorne, heard of the plight of little Chris Isaacs who suffers from a rare life threatening enzyme disorder, they decided to do something for him and others who suffer from the disease.

They organised a flower and vegetable show and let it be known the produce was for auction. Other regulars chipped in with knitwear and cakes, a regular auctioned everything and all told they raised £245 for the Society for Mucopolysaccharide Diseases. Chris, of nearby Fiddington, is pictured here saying cheers to Roger Oldridge, one of the regulars who helped with the auction.

INCIDENCE OF MPS/ML DISEASES IN BRITAIN AND NORTHERN IRELAND

Christine Lavery is preparing a paper on MPS/ML statistics. Here are some of her preliminary figures.

Number of MPS/ML Births per Year Known to the Society

Year of Birth	Boys	Girls	Sex Unknown	Total
1944	-	-	1	1
1945	-	1	-	1
1946	-	1	-	1
1947	-	1	-	1
1948	-	1	-	1
1949	-	-	1	1
1950	-	1	-	1
1951	-	1	1	2
1952	-	-	-	-
1953	1	-	-	1
1954	1	-	-	1
1955	-	1	-	1
1956	1	1	-	2
1957	-	1	-	1
1958	2	-	-	2
1959	1	2	-	3
1960	1	1	-	2
1961	3	-	-	3
1962	3	4	-	7
1963	3	3	-	6
1964	2	1	-	3
1965	2	3	-	5
1966	5	1	1	7
1967	3	4	1	8
1968	2	4	-	6
1969	9	4	-	13
1970	10	6	2	18
1971	2	9	2	13
1972	7	7	1	15
1973	12	7	3	22
1974	18	7	1	26
1975	7	5	4	16
1976	6	4	3	13
1977	9	10	5	24
1978	18	6	2	26
1979	19	15	3	37
1980	14	7	4	25
1981	18	10	3	31
1982	12	11	3	26
1983	7	5	2	14
1984	9	4	-	13
1985	10	3	6	19
1986	7	2	3	12
1987	7	8	1	16
1988	2	1	-	3

Total at December 88: 449

There are in fact quite a few cases not known to the Society, but we are working closely with the regional diagnostic centres to ascertain a true picture of incidence.

FUNDRAISING EVENTS

We have received many donations from individuals and companies which have been acknowledged separately. In addition the following clubs, groups and individuals have been working hard to organise fundraising events. We hope the following list of events will spur you into action to try and raise some funds for MPS!

Christine Collins, London.....Sunday Times Fun Run - ran and collected sponsors
 Colerne Rugby Club, Wilts.....Sponsored 24 hour marathon - darts snooker etc.
 The Kershaw family,Merseyside..Friends at Barclays bank, Kirby -sponsored walk
 Anita Allen,Bristol Rock and Roll Danvce
 Wayfarer's Pantomime, Taunton..Donated some of the proceeds
 The Watt family, Yorks..... David's father designed and made a pulpit drop -donation given to MPS
 Tony and Shirley Eyre,Bristol..Guy Fawkes party
 Alison Glassford, Bridgwater...Christmas Sale
 Carol Smith, Bridgwater.....Commission for perfume sales
 Downend Baptist Church Bristol..Family Gift Church Proceeds
 Gill Sutcliffe's friends,Derbs..Mammoth cake stall
 Pat Isaac, Bridgwater.....Toy Sale
 K. Pullin, Wilts ran and collected sponsors - Marshfield Fun Run
 G. Finch, Bridgwater Tupperware Party Commission
 J. Rimmer, Glasgow Donated a day's pay
 Ambulance Station, E. Sussex...Raised in various events
 Trevor Rollinson,Scunthorpe Relay Marathon Blackpool- and friends Cleethorpes and other events
 The Cottage Inn, Bridgwater... Grand Auction of produce
 Gaye Finch, Bridgwater Weekly staff weigh - in
 Ladies Enterprise, Bristol.... Coffee evenings
 I Brierley, Manchester Made cushion covers
 J. Gilbert..... Sponsored swim
 E. M. Hill..... Sponsorship of London Marathon
 Mrs Jean Townsend Sponsored bike ride
 K & W Hetherington Marathon in memory of Adele
 A & C Martin Pub collection
 S. & V. Harrison..... Sponsored run
 Pauline Mahon, Sheffield..... Charity Dinner
 Ken Ballard, Bucks Sale of foreign coins
 Carol Hubbard Sale of used postage stamps
 B.B.C. Donation for Radio 4 programme
 RF & JFS Parker Sponsored go-cart push
 DW & MM Briggs Fundraising event
 MJ & EM Reeves..... Wycombe half marathon
 EM Lamb Wycombe half marathon
 P. Mclean..... Methodist Church Carol Singing
 C A Hyde..... Sponsored bounce by Richard,James and Katie
 Stirling University Donation from Rag Week Appeal
 Wolverton WMC Fundraising Events
 MJ Sutcliffe..... Sponsored walk
 J. Sweeney..... Car boot sale
 Sponsored "Walk Wales"
 P & J Dagnell..... Sale of dried flowers
 B. Card..... Sponsored bike ride
 Hythe Methodist School..... Concert

FUNDRAISING EVENTS (CTD)

The Brennan family,Lancs.....Charity Evening Show
 The Blackburn family,Cheshire..Sponsored swim
 Maggie Archard,Herts.....Hot Potato Lunches & Open House
 The Brooks-Daw family Taunton..Sale of 2nd hand ballet clothes and raffle for ballet ticket
 Jane Reid.....Sponsored fast and clothes sale
 Midlands T.V.....Telethon donation

NOTICE TO ALL FUNDRAISERS

The Little Chalfont Bank Account has changed. Two banks have merged. The new bank details are as follows:

BARCLAYS BANK PLC
 AMERSHAM- ON-THE-HILL BRANCH
 SORTCODE: 20-02-06
 ACCOUNT NUMBER: 11423223

If you have a paying in book for the Little Chalfont Account, you may continue to use it. If you pay MPS money directly into the bank don't forget to let us have the details and the bank counterfoil. We cannot send a receipt or write the event in the newsletter without the details being sent by you!

PUBLIC LIABILITY INSURANCE

Our Insurance policy with Sun Alliance covers individual members running small events to raise money for the MPS Society. This covers events such as jumble sales, car boot sales, garage sales and fete stalls etc. Any activities which are dramatically different to the above mentioned have to be notified to our insurers before the event. Please let us know of any events which you will be holding to raise money for the Society prior to the event taking place so that we are properly insured.

COLLECTIONS FOR MPS OUTSIDE SAINSBURY'S STORES

The Society for Mucopolysaccharide Diseases has been included on Sainsbury's list of 'authorised' charities. This means that we will be looked on favourably when applying to hold charity collections on the forecourts outside their stores. If you think you could organise a 'flag day' outside a Sainsbury's store near you, please let us know your chosen date and store address and we will apply on your behalf.

Pat Isaac

Jemma's Diary will be continued in the next issue.

MPS RAFFLE 1988
PRIZE WINNERS

1	Video Recorder	39664	Mrs Large	Dartford, Kent
2	Microwave Oven	17940	Mrs L Smith	Loughton, Milton Keynes
3	Deep Fat Frier	52669	A McDonnell	London
4	Wall Clock	52541	D Criddle	Cardiff
5	Weekend Break	66623	J Slade	Kent
6	Weekend Break	55510	M V	London
7	Oil Painting	56095	Terry	Scunthorpe
8	Umbrellas	57565	Mrs Bailey	Amersham, Bucks
9	R D Book	50347	Mr Mauld.	Hull
10	Bottle Whisky	36464	A Dunsire	Pife, Scotland
11	Tool Set	67712	D Joyce	Romford, Essex
12	Bottle Whisky	65879	Salteñ	London
13	Sports Holdall	66543	K Obeney	Essex
14	Magazine Subscription	55979	Halladay	Romford, Essex
15	Blowlamp	65744	M Wood	Saffron Walden
16	Magazine Sub	39202	Wheatley	Erith, Kent
17	Ferry Trip	39105	Rahman	Kent
18	Linen Basket	72099	Kirkpatrick	N Ireland
19	Cuddly Toy	10160	Black	Glasgow
20	Fountain Pen Set	39912	Sandford	Kent
21	Jigsaw	48124	McIntyre	N Ireland
22	Bottle Port	41695	McLean	Magor, Wales
23	£5 Voucher	55509	M V	London
24	£5 Voucher	74648	D Lee	Milton Keynes
25	£5 Voucher	24699	Mr Ireland	Perth, Scotland
26	£5 Voucher	67785	Davis	Dagenham
27	Lager Glasses	4007	Murphy	Kirkby, Liverpool
28	Lager Glasses	9495	Carter	Roxwell, Cambs
29	Suit Holder	4230	Prendergast	Liverpool
30	Bottle Sherry	54312	Butcher	Rotherham
31	Daytime Animals	43815	Evans	Lincoln
32	Nighttime Animals	55613	Barrett	Essex
33	Wedgewood Dish	55007	Wheeler	Plymouth
34	Tin Biscuits	8020	Rigby	Isle of Wight
35	Tin Biscuits	26164	Parkin	Doncaster
36	Cheese Slicer	26321	Garfitt	South Yorks
37	Chopping Board	26967	Cozens	Notwich
38	Jigsaw	36119	Evans	Norfolk
39	Stationary Set	47765	Mrs Wakefield	Milton Keynes
40	Childrens Books	27630	Hicks	Barnet, London

DONATIONS

Our thanks to all of the following for their generous contributions.

Cardiff Wales Airport	Jewson Ltd
Townsend Thorensen Ltd	Dickens and Jones
Chris Stokes	National Magesine Co
John Lewis plc	Gordon Frazer Ltd
Reader's Digest	Nabisco Group Ltd
Belsize Engineering	National Physiotherapy Centre
Ladybird Books	Boats
Anocoil Ltd	C & A
Anglia Building Society	Chiltern Radio
Langlow Products	Carlsberg Brewery
Kellogs	William Yates
Hallmark Cards	Jack Green
Woolworths	Florence Young
Plysu plc	
Wolverton Central Club	
Steve Westcott	

CRUSE - BEREAVEMENT CARE

Dear Friends,

You might like to know that I am a bereavement counsellor for **CRUSE** working for the Hull and District branch. This has come about, I am sure, through interest in loss and grief due to my own loss of a son in 1970 through Hunter Disease.

If you feel I can be of any use to the MPS Society in any way through experience with Cruse please let me know. I was interested to read the article in the newsletter based on a talk by Dora Black, Consultant Child Psychiatrist, who is of course our vice chairman. I helped to start Cruse in Hull and I am Secretary of the Counselling sub-committee.

I would be most happy to be touch by telephone or letter with bereaved families if this should be of help.

Further information about Cruse can be obtained from Cruse House, 126 Sheen RD, Richmond, Surrey TW19 1RU. Phone 01 940 4818.

Yours sincerely,

Ingrid Lewis
1001 Anlaby Rd
Hull HU4 7PN
Ph 0482 52266

**PARKING AT THE HOSPITAL FOR SICK CHILDREN
GREAT ORMOND STREET.**

Mary O'Toole has just started work at the hospital and one of the first things she discovered was that the information about parking in the last MPS newsletter is no longer correct.

It is no longer necessary to write to the police. The task of issuing parking permits has been delegated to the Accommodation Officer at the hospital. If you are staying at the hospital or bringing your child to an outpatient appointment, you should go to the accommodation office in the corridor leading to the Cardiac Unit with details of the clinic or ward your child is on and the registration number of your car. You will then be given a form to display on your windscreen allowing you to park on a single yellow line in certain adjoining streets.

Mary is working part-time as social worker attached to the Cardiac Unit and looks forward to seeing MPS families when they come to the hospital. If your child is admitted let Mary know on extension 5792 and she will come up and see you in her lunch hour.

6.4 TRAVEL TO HOSPITAL

Certain people are entitled to help with the cost of their travelling expenses to hospital where they are attending hospital for treatment. The expenses considered are the cost of travelling by the cheapest form of transport available. A companion's travelling expenses can be paid if it is medically necessary that the person going to hospital is accompanied on their journey.¹

You can get your fares paid in full if:²

- you are getting income support, or a member of your family is getting income support;
- you are getting family credit, or a member of your family is getting family credit;
- if you or a member of your family qualify on low-income grounds (see 6.6 for how low income is calculated).

Even if you are entitled, you have to make your own way to the hospital, but can apply for the full travelling costs from the receptionist once you are there. You will need to show evidence that you get income support or family credit, or, if you know that you are entitled on low-income grounds, your certificate (form AG2) proving this. If you think that you may be entitled on low-income grounds, see 6.7. See 6.7 also for where you have paid the expenses yourself and think that you may be entitled to a refund.

Even if you cannot get your fares paid in full, you may be entitled to part-payment of your fares.³ This is the case where your income resources exceed your requirements (see 6.6 for how this is calculated) by less than one-third of the travelling expenses, and you have less than £6,000 capital. You are entitled to a payment for the difference between the travelling expenses incurred in any one week, and the amount by which your income resources exceed your requirements.

See 6.7 for how to go about applying for partial help, and see 6.7 also for where you have paid the expenses yourself and think that you may be entitled to a refund.

6.6 CALCULATION OF LOW INCOME FOR HEALTH BENEFITS

Low income is determined by comparing your 'requirements' to your 'income resources'.

Note: The terms 'requirements' and 'resources' are not generally used in the new scheme. 'Requirements' has been replaced by the term 'applicable amounts', and 'resources' by the terms 'income' and 'capital'. The old terms are used here because they are used in the regulations dealing with health benefits.

Your requirements are the applicable amounts that you would get under the rules for income support (see 2.4) less any housing benefit received by your family. Your income resources are calculated according to the rules for calculating income under the income support rules, subject to some modifications of the regulations. (These will be explained in a future edition of CPAG's *Welfare Rights Bulletin*.) In calculating both income resources and requirements, the income resources and requirements of the rest of your family are taken into account. You have a 'low income' if your requirements exceed your income resources, and you have less than £6,000 capital.

To assess the 'patient's contribution'² towards the cost of glasses, the DHSS works out the difference between your requirements and your income resources, calculated as above. The difference between the charge for your glasses, and three times the amount by which your income resources exceed your requirements is then calculated. This is the amount of the charge you are entitled to have remitted. The 'patient's contribution' is the difference between that figure and the actual charge for your glasses.

AREA SUPPORT FAMILIES

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

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

Mary Gardiner
15 Sidney Avenue, Hesketh Bank,
Nr Preston, Lancs. (awaiting phone)

John and Barbara Arrowsmith
140 Newtown Rd, High Heaton, Newcastle on Tyne. NE7 7NH

Tel: 091 2812062

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

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

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

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

David and Michelle Brooks-Daw
St. Mary's Lodge, Wellington Rd, Taunton,
Somerset. TA1 5AS Tel: 0823 271661

Tony and Mary Lockyer
29 Llanberis Close, Tonteg, Pontypridd, Mid Glamorgan.
Tel: 0443 2032845

Area Family for Northern Ireland:-

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

Contact for Scottish Families:-

Alan and Fiona Byrne
3 Jedburgh Ave, Rutherglen, Glasgow G73 3EN Tel: 041
643 0034