

NEWSLETTER

AUTUMN 1985

**THE SOCIETY FOR
MUCOPOLYSACCHARIDE
DISEASES**



National Registered Charity No. 287034

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 'Mossville' Cokes Lane,
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GENERAL MEMBERS

Peter Archard, Sue Butler,
 Catherine Grant, Robin Lavery

AREA SUPPORT FAMILIES:**SOUTH EAST ENGLAND**

Robin and Christine Lavery,
 30 Westwood Drive, Little Chalfont, Buckinghamshire.

EAST CENTRAL ENGLAND

Neil and Jane Reid,
 'Meadowlark', 9 Huddleston Way, Sawston, Cambridgeshire.

NORTH CENTRAL ENGLAND

Alan and Deidre Beavan,
 'Tumbleweed', West Gate Lane, Lubenham, Market Harborough, Leics.

SOUTH WEST ENGLAND

Peter and Marlene Sanderson,
 'Ashley Cottage', 6 Northfield Road, Tetbury, Gloucestershire.

NORTH WEST ENGLAND

Colin and Mary Gardiner,
 35 Church Road, Banks, Southport, Merseyside.

WALES

Mike and Pat Skidmore,
 5 Chapel Close, Wyesham, Monmouth, Gwent.

AIMS

To act as a parent support group.
 To bring about more public awareness of MPS Disease.
 To raise funds in order to further research into MPS



The Society for Mucopolysaccharide Diseases

AUTUMN 1985

This introduction to the Newsletter comes with Congratulations to all Australian MPS Families on the occasion of their 'First Parent Conference', 27 - 29 September, 1985. Some of you will remember from last year the visit to England of Helen Coppock and Ros Smith from the Australian Society. Armed with all the knowledge gained at the Harrogate Conference and subsequent visits to British families and Medical Centres, they left for home even more determined than when they arrived to consolidate their recently founded MPS Society down under. A year later, and for the first time, MPS Families from all over Australia will be coming together for their First Parent Weekend. Best Wishes for its undoubted success and we look forward to hearing all about it.

How quickly the Newsletter comes round, or at least that is how it feels when one is responsible for seeing its prompt publication. Thank you to everyone who prepared articles, it is lovely to see new names coming forward. Don't be shy, do write and tell us any news of interest or comment on any controversial matters. We are always pleased to hear from families who have recently joined us. The Society will always put you in touch with others in similar circumstances but if you write a few paragraphs about your family for the Newsletter, it would give us an opportunity to get to know you and members recognising similarities in their children would be able to make contact. The next Newsletter is due out before Christmas so do let us have your news and views.

For many of us the MPS Third Parent Conference is here, but for those unable to make it on this occasion we shall fully document the weekend's activities and produce a report in due course. We are already thinking about 1986. If you have any views on where the 'Fourth Parent Conference' might be held or the programme content, please do let me know. Each year it seems that we have to decide earlier and earlier the venue and as the number of families wishing to come grows so the task gets more difficult. For 1985 we have been most fortunate that Mary O'Toole has kindly arranged the professional side of the Conference, a full time job in itself, and I am sure you would like to join the Committee in thanking Mary for a job very well done.

With a distinct lack of Summer and the evenings closing in our minds turn to Christmas, and for the Society, our very own Christmas Cards and Christmas Draw. Please do try and support us in what are our two major National Fundraising events. With the Christmas Draw in mind how about marking the 1st December in your diary and coming to a really **Bumper MPS Christmas Party**, when the Christmas Draw will take place. There will be a buffet lunch and magic show, not to mention our visiting celebrity Father Christmas. We hope to see as many of you as possible there, and don't forget Grandparents welcome too!

Christine for The MPS Committee

THE MARTIN BAX RESEARCH PROJECT

A little late, but by now you should have received your letter and questionnaire from Dr. Martin Bax. If you haven't already done so please do complete and return the questionnaire to Dr. Bax as soon as possible.

Several families have commented on the complexity of the questionnaire. If you are having difficulty in deciding your answers please do take the opportunity to discuss this with Martin Bax and Irene Sclare at the conference. If you are not coming to the Conference please do write or phone if I can be of any help.

Christine.

MPS CHRISTMAS DRAW

This year the MPS Christmas Draw will take place on Sunday 1st December, 1985, at The Crawford Arms Public House, 59, Stratford Street, Wolverton, Milton Keynes, Bucks.

For the first time we are combining the MPS Christmas party and Draw which will be performed by The Mayor of Milton Keynes. We do hope that you will sell as many tickets as possible and that you will bring the family to the MPS Christmas Party. Just think, if you're the lucky winner you will be able to take your prize away with you!!!

1st Prize Toshiba Microwave Oven

2nd Prize Home Computer

3rd Prize Food Processor

any many other excellent prizes

Tickets will be available from the Conference onwards and we should be grateful if you would support this event by selling as many books as possible. If you are unable to attend the Conference I will automatically send you 20 books and should be grateful if you would sell as many as possible. Tickets are 10p.

If you find you can sell more books or that Grandparents or Friends are willing to help sell tickets, please write or telephone me.

Ron Snack
16 Wandsworth Place
Bradwell Common
Milton Keynes, Bucks.
Tel:- Milton Keynes 666819



The Society for
Mucopolysaccharide Diseases

ORTHOPAEDIC PROBLEMS IN THE MUCOPOLYSACCHARIDOSES

you are cordially invited to a presentation by

STEVEN KOPITS M.D.

Associate Professor of Orthopaedic Surgery in Paediatrics
John Hopkins University School of Medicine,
Baltimore, U.S.A.

on

Tuesday 15th October 1985, 2.00 – 5.00 p.m.

The Kennedy Lecture Theatre
Institute of Child Health
30 Guildford Street, London WC1N 1EH

Talk and questions, followed by tea and case discussions.

(A nominal charge of £1 for afternoon refreshments is payable at the door)

Reply required by 1st October 1985 **ONLY** if you would like to bring Case History X-Rays for discussion.

To: The Society for Mucopolysaccharide Diseases.

Seminar Organiser: Mary O Toole, 8 Elmhurst Avenue, London N2 0LT. Telephone: 01-444 8461

Name

Address

Telephone

I shall be attending the Seminar and bringing X-Rays for discussion. YES/NO

NEW STYLE INFORMATION SHEETS

It has been felt for some time that we need to update our MPS information sheets. We need something simple and easy to read for the general public; also for companies and charitable institutions, whom we approach for donations. Most people have never heard of MPS diseases and we need to have an information sheet to foster awareness, which we hope will in turn bring greater understanding of all our children's problems.

So our aims in producing our new information sheets are twofold:
i) to bring about more public awareness and understanding
ii) to be used for raising funds etc.

They are not intended for parents' information, but inevitably they will be read by parents and possibly non-mentally affected children and adults. (We hope to produce some 'fact sheets' on each syndrome for parents in the future). While we have to be sensitive about parents and children's feelings, we have to tell the truth and make the public sit up and take notice of how dreadful these diseases can be. It is very important but very difficult to get the right balance - and so we need your help.

Some of us have been thinking about the layout of this new information sheet and we have a design in mind. It must be fairly cheap to produce so that we are in a position to hand it around freely. It is intended that there will be a general description of the cause and effects of the diseases and then a short account of each type of disease, outlining the problems of that particular syndrome, hopefully with photos. We may decide to highlight certain children, with their parents' permission of course. A final piece would describe how the MPS Society's activities etc. would help families cope.

We would like as many people's viewpoints as possible in order to compile this information sheet, so I am inviting you all to write to me in the next couple of weeks to tell me anything you think ought to be included. I would especially like a description of how you see your own child's problems. It needs to be personal to be effective, and it doesn't matter if you're a newly diagnosed family or have lived with the knowledge for many years. Bereaved parents' comments about their child would also be appreciated. I would also be pleased to receive notes from adult MPS sufferers, grandparents, members of the medical profession and anyone else who feels they have something to contribute.

Remember it will be read by people who may know nothing about MPS and we want them to help us raise funds for the Society too. We must produce this leaflet as soon as possible so please write to me (or phone) SOON! A few sentences will be fine - it doesn't have to be long. My address is on the front cover.

Thanks

Pat Isaac - Tel. 0278 732800

RIDING FOR THE DISABLED

To witness the massive grin and delighted laughter as they join in all the fun of games on horseback must be proof enough that riding is one of the very best kind of therapies for handicapped children.

Each week thousands of mentally and physically handicapped adults and children go along to Riding for the Disabled groups throughout the country.

For almost everyone it is an exciting adventure. Something different that lifts them out of the confines of their disability and opens out a whole new world.

What else could take a severely physically and mentally handicapped child out of its wheelchair and carry it, three or more feet in the air, through leafy summer woods, or over "jumps" (perhaps a pole on the ground) just like Harvey Smith?

Some sceptics doubt the benefit of riding for the handicapped, but those involved with R.D.A. - the riders, their families, teachers, doctors, physiotherapists, and the many volunteers who make riding possible know different.

As with everything in life, it does not suit everyone. But there are few who don't enjoy their weekly ride.

Just as important as the riding is making friends with the horses and ponies and - disabilities allowing - learning to look after their basic needs and the different aspects of riding, such as tacking up, grooming, and that all important "thank you" pat.

It's generally accepted that many severely mentally handicapped people have a natural empathy with animals: horses don't answer back, or ask awkward questions, and many a usually silent child or adult is heard "talking" to their mount.

Riding also provides a marvellous stimulation to learn and can provide extra teaching material for the classroom. It can also show children normally reliant on people doing things for them that another creature is relying on them: that they are in charge and have to tell the pony where they want to it to go.

It can help physical disabilities, too: co-ordination and posture are improved, and "butterfly" minds concentrate for just a little longer than usual!

But above all it is fun: a relaxing and healthy exercise in the fresh air for people who through force of circumstance, tend to live most of their lives indoors.

There is probably an R.D.A. group near you. If you have difficulty contacting them, write to: **The Riding for the Disabled Association, Avenue R, N.A.C., Kenilworth. CV8 2LY.** or telephone Coventry (0203) 56107.

Helen Holt
South Bucks Riding for the Disabled.

CARRY ON CAMPING

On Friday 28th June the Laverys, Lockyers, Isaacs, O'Tooles and Blackburns, invaded the Braceland camping site in the Forest of Dean with an assortment of caravans and tents. Having staked our claim to a parcel of land we all pitched camp and settled down for a quiet evening.

The children ensured we were up bright and early on Saturday morning and for the more energetic one of the highlights of the Weekend was a hike through the forest down to the River Wye. At first we thought we would not be able to join in the hike because Matthew only walks short distances and we thought it would be impossible to take a wheelchair along the forest trail. However, we decided to 'tackle it' - so off we set with Matthew in the wheelchair, Helen and Christopher in their buggies and all the baggage etc. We did not have to worry for long, if we came to any obstacles such as branches/ logs across the path, stiles etc. Matthew and wheelchair were lifted over them (he thought it was good fun) by the menfolk. At last we came down to the river and the sun was shining. We enjoyed a leisurely walk by the river, the children were all happy, some were running, climbing and laughing - others were quietly enjoying themselves being pushed along. After having walked some distance we came to the wire suspension bridge over the Wye - how did we get across this with a wheelchair? Buggies were easy enough to cope with as they are so light but once again the men came to the rescue - Matthew was helped up the steps and then pushed across in his wheelchair (he did not care for the bridge as it was unsteady). Once over to the otherside we had a good walk by the side of the river - the undergrowth was quite thick in part - I think Bill thought he was back in the Malayan jungle for a while!! By this time we were all getting rather hungry and thirsty and the Pub was back across the other side of the River Wye, so we walked until we came to the ferry - we all piled on to this flat bottomed boat, not unlike a rowing boat and across we went. We were all feeling a little exhausted but totally relaxed and having found a nice grassy spot in the sun a picnic lunch was enjoyed by all followed by a nice refresher from the pub.



'We decided to tackle it' - Matthew encouraging the others.

I think we walked about 4 miles. After Lunch and a rest some of the families made their way back to camp on foot, but as it was all up-hill and heavy going we opted for a lift in Robin's car (he first kindly "running" back for the car whilst we waited).

Bill and I had not done any walking like that for years and would not have dreamed of doing so but we really enjoyed ourselves and so did Matthew, but it would not have been possible if we had not all pulled together and helped each other like one big happy family. We look forward to doing something similar next year - in fact we have bought a ruck sack so I think we must invest in walking boots for next time!!!!

Intermittent rain slightly marred the evening barbeque, but not to be outdone 3 barbeques were set up under the canopy of the O'Tooles tent and an eating area was accommodated under my awning. I got the impression Robin had some misgivings about some of our barbequing abilities as he kept a fire extinguisher close at hand. Cooking in such a confined space meant that the atmosphere was very smokey and large quantities of wine were essential to sustain those operating the barbeques! The food did eventually get cooked with a little help from our friends. At a vital moment Pat and Mike Skidmore arrived and soon their car boot was filled with jacket potatoes destined for the microwave and salad that would benefit from the wonders of running water. The children sat down to the first sitting and soon we were joined by the Skidmores with the freshly dressed salad and hot jacket potatoes.

After the parents had eaten and the children had gone to bed we rounded the evening off with a quiet chat and a drink under the awning.

The weather was much kinder on Sunday morning and whilst the majority of us spent the morning lazing about the children were thoroughly enjoying themselves playing and exploring the uncharted depths of the Forest of Dean.



The Wye Valley Wanderers

Continued

DR GARROW'S GARDEN FAYRE

For Sunday Lunch 25 of us descended on the Old Ferrie Boat Inn for a barbeque dinner on the banks of the River Wye in Symonds Yat. After lunch it was back to the camp site to pack up and say our farewells.

The weekend break was a great success and the atmosphere generated was that of one big happy family.

Here's to the next one.

Tony & Mary Lockyer
Bill & Sylvia Blackburn

+++++
+
+ Ross Lockyer was admitted to Westminster Childrens Hospital+
+ recently for a Bone Marrow Transplant. I am sure you would +
+ like to join with all of us in wishing Ross our very best +
+ wishes. +
+
+++++

BOOK REVIEW

'BLESSINGS'

by Mary Craig

I have just finished reading this book and wondered whether anyone else has read it? The book is an autobiography by a woman who had four sons. One of them had Hurler's Syndrome (spelt Hohler's in the book) and another had Down's Syndrome. To appease her own suffering she took on board the sufferings of Survivors of Concentration Camps through the Sue Ryder Foundation.

There are statements in the book which we can all relate to - perhaps with sympathy or hostility. The basic question it makes us think about is - what do we do with our own suffering because of our children?

If you have read the book or manage to read it (available from libraries) before the next newsletter, why don't you pass on your comments or a book review for inclusion in the next news letter? I, for one, would be very interested in reading other people's reactions after reading the book.

Pat Isaac

'Blessings' by Mary Craig published 1979 by Hodder and Stoughton
ISBN 0 340 23561 6

Paul and I decided when we saw this coming event, what a lovely day out this would make. We even took our swim wear to sit and laze by the swimming pool after we had finished strolling around. Maybe I would even get up some courage to put my big toe in the water. Did I say sit by the swimming pool!

On arrival we were passed by Christine and Robin in the driveway. "Just off to get some more tables" Christine shouted, "do go and introduce yourselves to the others that are there". As we walked into the huge gardens everybody there was busy setting up their stalls, we offered our help and soon had a job to do - we were informed Christine will not be long, she has just gone to get some more tables for your stall. I looked at Paul, was I hearing right, our stall! Surely they were never going to trust us with a stall. My hearing was perfectly alright as two tables were set up for us. Two tea urns emerged from Dr. Garrow's house. I was beginning to get quite worried. On making enquiries as to what we were going to be doing, "Refreshments" came the reply. By this time Paul was looking quite concerned. He said we will never manage, it will be an absolute disaster.

Everybody else seemed to trust us, so it was "CARRY ON CREAM TEAS"!

Paul took charge of the urns and I looked after the scones, cream and jam. I thought if we were going to have hundreds of people there, we needed to get a system going. All the cups were set out ready for our mad rush. We also prepared jugs of orange squash, but where were our customers! The first ones arrived and before we knew it we had a queue. A cry come from Paul "I am running out of milk". This was my first of many dashes to the house to restore the milk. Before the afternoon was out we had sold lots of cream teas and childrens drinks, and before we had time to breathe it was time to finish up. What a shame I was beginning to enjoy myself. We did not even have time to observe how busy and hardworking everybody else must have been to make it such a successful day as it was. We enjoyed every minute of it.

Was I saying something about sitting by the swimming pool!

Carol & Paul Hubbard

* STAMPS *
* Do please keep sending your used postage *
* stamps, British and Foreign to: *
* Carol and Paul Hubbard, 71 Preston Road *
* Harold Hill, Romford, Essex RM3 7YU *
* *
* With Christmas fast approaching please *
* ask all your friends and relations to save *
* them for us. How about asking your local *
* schools to collect as well. *

AN MPS JULY

Hello all you MPS kids, it's me again, Christopher Archard. Sorry I've not been in touch recently but I've been a bit busy keeping the old folks on their toes and reinforcing my position as head of the household. That takes some doing mind you and it wasn't until I'd been forced to adopt my 'can't breathe and going blue' routine a couple of times earlier this year, that I felt that I could relax a bit and do a little more of the old fund raising.

The thing is you see, the old folks had been looking ahead a bit (that's the trouble with grown-ups isn't it? Why can't they take each day as it comes I really don't know) and last year they decided that we should put an extension on the house to give me a downstairs bedroom and toilet. Actually, while I wouldn't dream of admitting it to them, it's quite a good idea, although I do miss dad puffing and panting when he carried me up the stairs. As usual though, nobody asked me for my opinion and I had to find out what it was all about by going through the plans and papers when the folks weren't looking. Very complicated it looked; Planning permission, Building Regulations, Improvement Grants etc. Still dad's involved in all that so it wasn't too bad. If any of you have got parents who are thinking about that sort of thing, tell them that my dad might be able to help with general advice, plans and applications if they care to get in touch.

Anyway, back to what I was telling you about. The extension costs lots of money of course and mum decided that dad should do the decorating, tiling and fitting-out of the (gutted) kitchen in order to be able to afford it. Poor old dad is still at it, but I must say that he's made a decent job of my bedroom and bathroom and I did the right thing a couple of weeks ago and moved into it without my usual fuss and bother. Mind you, having had a few weeks to get used to it did help and having my old bed and toys move with me was reassuring.

Things had been put back a bit in March by something called burglars and I guess that the broken window frame and patio doors and the footprints all across the nice smooth concrete floor were something to do with that. Dad managed to use that as an excuse for not finishing the tiling for quite some time, but two weeks ago the window and doors were replaced so he had to get on with it. I helped, of course!

Well, what with this DIY going on every weekend and every spare evening, my social life went out of the window but I reckoned that with a little care I could organise things so that I would get out and about a bit and see some of my old friends.

continued over

DEADLINE FOR NEXT NEWSLETTER 24th NOVEMBER,1985

Do you remember the summer this year - each of the three days? I certainly do because each of those days was marked by an MPS event that could have been a disaster had the weather been any less kind.

I've had such a nice summer and I would like to say thank you to all those lovely people who made that possible by their organisation, efforts and concern. I think that I should also say thank you to Mother Nature who's efforts this year, whilst not outstanding, have been kind on those days that really mattered to me.

On Sunday 7th July, the social event of the Buckinghamshire year was arranged to take place at the home of Dr Donald Garrow. He again made his gardens available to MPS for a fun-day. He's a Paediatrician you know, but even so, he's not a bad chap really and it really is very kind of him.

I knew that the folks wouldn't want to miss the event and for several days beforehand the newly fitted (but uncompleted) kitchen was destruction tested by the mass production of tons of jam and hundreds (literally) of scones.

You wouldn't believe all the hard work that was put in by so many people but, as a strictly outdoor event, everyone's thoughts must have been on the weather which had been definitely awful for some time. In the event, the day was just right, sunny but with just enough cloud to make sure I didn't get burnt -just how I like it in fact. Just to emphasise just how lucky we had been to have been able to enjoy cream teas on the lawn accompanied by the delights of an open air orchestra, it poured with rain the next day.

The day really started for me when we confidently set-off for Chalfont St. Giles and found that, according to dad, someone had moved the road that he had intended to take! Anyway, we arrived in good time as everyone was unloading and setting-up stalls etc. It wasn't obvious then, but I overheard someone talking about the 'layout plan' and guessed that there was some organisation somewhere. That became a little clearer later when the chaos turned into a Garden Fayre including several stalls, pony and train rides, raffles and, oh yes, did I mention cream teas to an orchestra on the lawn?



Carol Hubbard serving cream teas

Carol Hubbard and her husband 'volunteered' to do the cream teas and I'm sure they'll want to tell you about that themselves. I must say though, that I was very impressed by the service they gave and by the fact that they were still smiling gallons of tea and zillions of jam scones later.

It was nice to see Robin Lavery briefly between his eighteen trips home to pick-up things that he (or others?) had forgotten and his drive around Buckinghamshire putting up, in obscure locations, little signs announcing the Fayre.

Dr. Garrow spent the greater part of the morning getting the MPS banner 'level' (nearly!) and I didn't have much chance to chat to him while he was up and down the ladder. Later he was doing his thing (a Flute I think it was) in the orchestra - versatile these Paediatricians!



Dr Garrow going up (or coming down?) for very nearly the last time.

With so many having been involved it would be wrong for me to pick-out any individuals wouldn't it? However, being 'special', I can get away with things like that and on behalf of all my MPS brothers and sisters, siblings, and their Mums and Dads I would like to say a big TA! not only to **Donald and Ros Garrow** but to Cathy and Gary Grant, who will protest that they did nothing, but I know better. Quite apart from the fun had by everyone, MPS funds were better off by nearly £400.

On Saturday 13th July, the Amersham Carnival was to be held and a 'pitch' had been arranged for MPS via the Round Table. Christine Lavery was already tied up with the Carnival and it only needed me to be even more 'helpful' than normal for mum and dad to volunteer to help out. So it was that the car found its way to Buckinghamshire once again.

I had a smashing time, although I guess that it was so many 'special requests' for sun that caused it to be so hot. There were huge crowds in the afternoon and so I sat in my wheelchair in the shade of an adjoining tent. Sue Butler and her mum were

there, Pat Isaac and Robin Lavery and my folks all of whom dashed around like mad things on the MPS 'Can-Can', Tombola and bric-a-brac stalls. Everyone had a super time but because they were 'crackered'; I think that's right, the Laverys Isaacs and Archards revived themselves in a local public house garden where we kids (down to six by then) had pub nosh alfresco - great! By then though, all the 'special requests' must have worn off because to emphasise how lucky we had been with the weather all day, it started to rain and poured all the way home.



MPS Corner - Maggie Archard & Pat Isaac on Duty

I suspect that my scheming to improve my social life had perhaps been overdone, because from the weeks of social deprivation in the Spring I now found out that for the third time in as many weeks I was going to another MPS event. This one I particularly didn't mind, because it was a return to Sue & Dan Butlers house for a family day. The last time the BBC had come along and filmed us all having fun and I'd been on TV. My little brother James, can never quite get over seeing the video tape of that - I'm sure he's just jealous.

What a smashing day it was and do you know that once again it didn't rain all day despite some threatening clouds. It was great to see so many friends, to introduce new ones and to meet families who had travelled over quite long distances.



Some of the eight MPS families at Sue & Dan's Family Day

Arrangements were made, it seems, for individuals to each bring a dish of something or other. This ensured that there was both an assortment and quantity of food verging on the spectacular. Somebody had also highjacked two lorries on route to Macdonalds and Kentucky Fried Chicken, the spoils of which did not quite give way to the combined and sustained efforts at incineration by Dan Butler, Robin Lavery, Paul Hubbard and Andy Hardy. Have you ever noticed how it is at barbeques that it is usually the dads who 'know how it should be done'? Have you noticed too that they always serve chicken and sausages contained in an outer shell of charcoal that, we are assured, gives it more flavour! At least they match the beefburgers and are just as crunchy.

Well, that was July. Dad was on holiday for the first part of August and so, of course, it has rained virtually every day. I'm looking forward now to September and to the Conference at Heathrow. Quite apart from all of the fun arrangements laid on for us kids, it is possibly the best opportunity of the year to wind up my mum and dad. I've got my fingers crossed (well, nearly) for fine weather again and I shall spend the next week or so practising my 'right little B. routine' for the evenings. Trouble is that I think they're bringing reinforcements this year and will have a minder in tow. Still, if I'm tied up perhaps I can give one or two of you a hand with some useful tips and advice -----? Hope to see you at the hotel where perhaps we can have an orange juice in the bar and discuss the problems we have with our parents?

Love and Kisses

Chrissy Archard

I would like to take this opportunity through our newsletter to thank my friend Lesley Bennett for her sponsored slim she did for the MPS Society. 14lb lighter in weight was Lesley but £32-30p richer was the MPS Society.

Thank you also Lesley for letting us use your house as a store cupboard for the silver foil we have been collecting to raise a little more money. I don't think anyone can even have a bath in Lesley's house as even the bath is always full up with silver paper!

Still it is all for a good cause.

Carol Hubbard

NEW FAMILIES

Carol Newson from Peterborough. Carol's 6yr old daughter Kelly has recently been diagnosed as suffering from Sanfilippo Disease

Christopher and Anne Dymond from Essex. Twins Lorraine and Samantha aged 8yrs are suffering from Morquio Disease.

Doreen and Monty Russell, whose 13 month old son Matthew is suffering from Hurler Disease. They live in the West Midlands.

Richard and Claire Mansfield from Suffolk. Their 9 year old son, Simon is suffering from Sanfilippo Disease.

Alan and Fiona Byrne from Glasgow. Their daughter, Louise, aged 4 years has just been diagnosed as suffering from Sanfilippo Disease.

BIRTHS

John and Rebecca Travers are proud to announce the arrival of Stuart Adam born on 11th July, 1985. A brother for Kerry Ann.

Colin and Mary Gardiner are proud to announce the arrival of Alexandra Elizabeth Jayne born on 5th August, 1985. A sister for Catherine.



Catherine with baby Alexandra

DEATHS

It is with great sadness that we learned of the death of:

Shelley Corfield aged 11yrs of St.Dominick, Cornwall died peacefully at home on July 10th. Shelley was suffering from Sanfilippo Disease.

Kathleen Kearle aged 7yrs of Cardiff, Wales died on July 19th. Kathleen was suffering from Hurler Disease.

Richard Nicholson aged 11 years of Steyning, Sussex died peacefully at home on July 19th. Richard was suffering from Hunter Disease.

Michael King aged 10yrs of Bexhill, Sussex died peacefully at home on August 27th. Michael was suffering from Hunter Disease.

Our thoughts are with the families and friends of these children, during this sad time.

EXEMPTION FROM PAYMENT OF CAR TAX

When your child receives Mobility Allowance at the age of 5 years or older, you are sent a form on which to claim Exemption from Vehicle Excise Duty (Car Tax). It has recently come to light that some parents are not aware that this exemption can be claimed from the child's second birthday if:-

- a) the child is unable to walk
- b) he/she needs to be driven
- c) he/she has a vehicle registered in his/her name
- d) he/she is eligible for Attendance Allowance

The registered vehicle must be suitable for your child's use.

Applications should be made to the DHSS, Block 1, Government Buildings, Warbreck Hill Road, Blackpool, FY2 0UZ. If you are granted exemption you will be sent a form MHS 330 which should be taken to your main post office together with a completed car tax application form and the other necessary documents (MOT Cert., insurance etc.). The MHS 330 will be stamped and returned to you and you will be given a tax disc without charge. If you have any difficulty with the post office, send all the forms to your local Vehicle Licensing Office with a covering letter, and they will deal with it for you.

Once you have Attendance Allowance and an MHS 330 you may be eligible for an Orange Parking Badge from Social Services.

MAKATON

The Makaton Vocabulary comprises of a specially selected Vocabulary considered to be most essential and useful in providing basic communication. It is structured in stages of increasing complexity and follows the normal pattern of language development. The initial stages comprise of the basic vocabulary necessary to express essential needs, the subsequent stages expand them and more complex language concepts are introduced. The aim is to ensure that if limited learning ability and poor retention prevent an individual from progressing beyond the initial stages, then he or she will still have acquired a useful, though limited communicative language.

The original version of the Makaton Vocabulary was devised to be used as an aid in the teaching of sign language to mentally handicapped deaf people living in a hospital environment. It has since been revised by Mrs. Margaret Walker M.Sc.,L.C.S.T. to increase its size and scope and is being used successfully in promoting communication with non-communicating SSN hearing children and adults, with some autistic children and with some normal adults presenting specific communication problems following neurological damage as in the case of a 'stroke'.

Only key words are signed, but they should always be accompanied by normal grammatical speech. Signs may be performed with either hand and it is often possible for a physically handicapped person to make the necessary adaptation of a sign without losing its meaning. The signs are a way not only of communicating facts, but of expressing emotions. The signs themselves should, where appropriate, be accompanied by suitable facial expression e.g. pleasure, pain, enquiry, surprise and so on.

The Makaton Vocabulary is being used very successfully at a number of Special Schools around the country and a number of MPS children have achieved the basic signs.

Further information is available from: MAKATON Vocabulary Development Project, 31 Firwood Drive, Camberley, Surrey.

This article was compiled by Mary Hourigan and appeared in the First Edition of the MPS Newsletter, September, 1982.

THANK YOU TO OUR MARATHON RUNNERS

Peter and I wish to convey our deepest gratitude to Vyvyan James who ran in the London Marathon this year accepting sponsorship in memory of our beloved son Gethin, for the benefit of the Society. Readers will recall Vyvyan's stirring account of his feelings that morning in the last Newsletter. He completed the run in a very credible 3 hours 41 minutes and thereby realised £680 for the MPS cause. Our sincere thanks go to those who accepted sponsor forms and went about the unenviable task of collecting donors, in particular our parents (and especially my father who spent two days door knocking and cajoling friends and neighbours at home in West Wales), and other family members and friends. Thankyou too to Vyvyan's friends in Reading, and most of all, to Peter's colleagues in the Stock Exchange and mine in HM Customs and Excise HQ. who I was still hounding for some weeks after the event! The special explanatory leaflet about the Society and its aims which we devised to show people, was particularly useful, and as a special touch it also showed a picture of Gethin.

Peter and I also wish to extend our gratitude to Barry Stearman a neighbour of ours in Hornchurch, who disappointingly was not accepted for the London Marathon but ran in the Havering half marathon some weeks later, and asked to do so in memory of Gethin. A sum of £54 was collected which was very good considering it came so soon after the London Marathon and we could not ask everyone to contribute again!

With thanks to everyone who contributed to the success of these ventures.

Wilma Robins



Barry Stearman who ran in the Havering Half Marathon.

I would also like to offer our gratitude to our other London Marathon runner, David Percival. I am sure you will be thrilled to learn that the total monies raised in the London Marathon were £1175-46. Thank you you for this super effort.

Christine



David Percival our Wheelchair Entry in the London Marathon.

EVERYBODY'S DOING IT.....!!

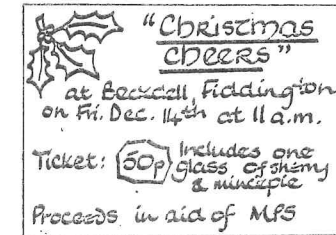
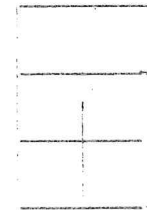
.....Fundraising, that is! Now that you're all freshly inspired after the Conference, perhaps it's time to start thinking about Christmas.

What about planning a Coffee Morning with a difference and call it:

CHRISTMAS CHEERS

Instead of serving coffee - serve sherry and a mince-pie! If you haven't got a large enough house, maybe a friend will hold it for you. I held one last year and this is what I did.

I had some 'tickets' photocopied. (You can get 8 tickets on one sheet of A4 paper like this:)



I sold these about 2 to 3 weeks before the event to friends. It's a good idea to make tickets, no matter how amateurish they are, because people will often buy a ticket to support the event, even if they can't come. I charged 50p for one glass of sherry and a mince pie. If you manage to get these donated then it's all profit. (Of course, if you live in the affluent Home Counties you can double the price of the ticket!) I then charged 30p for extra glasses of sherry and 20p for coffee. It was much more lively than a normal coffee morning! Once you've got everyone there you can then have a stall selling MPS Christmas cards, pens etc. and any handmade goods for gifts with a Christmas theme. You can always raffle a Christmas cake or Xmas hamper or sell books of MPS Raffle tickets.

PLEEEEEEEAAAAAASE keep Christmas card money separate and send it to me. Draw tickets and money to Ron Snack. I know it's a nuisance but we have to account for all the draw tickets and cards sold separately.

How many people are going to try a "Christmas Cheers" morning or Evening then?

Good Luck and success with your endeavours!

Pat Isaac

"IT ALL STARTED WITH FISHING NETS"

When the local Rotary club needed some nets to decorate for a flower festival it was natural that they should contact my husband who is a retired fisherman. He, in turn, borrowed some new nets and "No" said the fisherman, he wouldn't want any payment - any money could go to charity. As our granddaughter, Natasha, has Sanfilippo syndrome, my husband suggested the MPS Society, and a cheque was written. A week later we were delighted to receive another cheque for a substantial amount from the same Rotary Club! They had been moved by our daughter's letter of thanks and enclosed MPS Information sheet.

I run the Methodist Church Choir here in Hythe, and we gave a concert. (Quote from the organiser) "We would like to give a donation to your unpronounceable society".....Thankyou..We're getting recognised...A Coffee Morning then?...Just a small one to start with at home...These things snowball. Everybody I asked came - brought friends and neighbours - We must have served 100 cups of coffee - and made the incredible total of £230!

Another choir borrowed some anthems that I have written - A donation for MPS please? My music is being performed again in September... proceeds to MPS please..... These are yet to come, but it just shows how many and varied are the ways of raising money.

Molly Griggs

CALLING ALL SERVING FAMILIES

My name is Louisa Dawson, I am the Grandmother of Julia and Louise Broome who suffer from Sanfilippo syndrome and who belong to the MPS Society. I too am a member of MPS. I have also been for many years a member of a charitable organisation for serving personnel, The Guild of St. Helena.

The Guild's aim is to help and support financially associations and societies of physically and mentally handicapped children of serving personnel. They have already made a donation of £500 to the MPS Society to help towards their Holiday Home Project and would be willing to help further if they can trace a serving family, either at home or abroad, who have an MPS child or children.

Unless a family with such a child can be found the Guild of St. Helena are unable to make any further donations to the Society.

I, personally, have raised nearly a £1,000 for this very worthwhile cause and can help no further, substantially, without your assistance.

We know you are out there and need your support in this project. We need your permission to use your name so please put pen to paper and write to Christine Lavery at 30 Westwood Drive, Little Chalfont, Bucks., or telephone her on Little Chalfont 2789.

Please come forward, we are waiting to hear from you.

FUNDRAISING AT ORMSKIRK MARKET

July 18th once again saw our charity stall on Ormskirk market. As usual on these occasions my friend Dot (posing for the photo) was there with her army of volunteers.

The stall was given free by West Lancs Council and as everything else from odd cups to Dr. Diana Chase's mother's home made marmalade was also free, the takings of £100 plus was clear profit.

However, at one stage Dot and I were convinced that things were multiplying as the mound seemed to be getting bigger, fortunately, good business sense told us to sell at 10 - 50p an article. We did see daylight and it was home for a bath and good cup of tea. Roll on next year.

Mary Gardiner and Dot Courtney

" Things were multiplying as the mound seemed to be getting bigger."
Quite so. Baby Alexandra arrived 18 days later - Ed.



DATES FOR YOUR DIARY

SEPTEMBER

Friday 20th- Third Parent Conference, Post House Hotel,
Sunday 22nd Heathrow, Middx.

OCTOBER

Saturday 12th Market Stall at Romford Market, Essex
8.00am - 4.00pm
Items to sell and help wanted on the day.
contact: Carol Hubbard
71 Preston Road, Harold Hill, Essex.
Tel:- 040 23 40587

Tuesday 15th Steven Kopits MD will meet informally with
parents of MPS children, prior to presentation
2.00-5.00pm 'Orthopaedic Problems in the
Mucopolysaccharidoses'. Parents welcome to
attend, lecture geared for professionals.
Details from: Mary O'Toole
8 Elmhurst Avenue, London N2 OLT
Tel:- 01 444 8461

Friday 18th Cheese & Wine Party 8.00pm
Everyone welcome!
Further Details : Alan & Deidre Beavan
Tumbleweed
West gate lane
Lubenham, Market Harborough, Leics
Tel:- 0858 62182

NOVEMBER

Thursday 7th Coffee Morning 10.30am
Everyone welcome!
Further Details : Alan & Deirdre Beavan

Sunday 24th DEADLINE FOR ARTICLES FOR NEWSLETTER

DECEMBER

Sunday 1st MPS Christmas Party & Drawing the Lucky Tickets
in the MPS CHRISTMAS DRAW.
12.00-4.00pm , The Crawford Arms, Stratford Rd,
Wolverton, Milton Keynes, Bucks.
Families & Grandparents Welcome!
Further Details: Ron Snack
16 Wandsworth Place, Bradwell
Common, Milton Keynes, Bucks.
Tel: Milton Keynes 666819

PEN PALS

Hi my name is Maggie, my husband's name is Ian, we
have a daughter Natalie aged 4 yrs. Our son, Michael
suffered from Hurlers Syndrome, but he passed away a
year ago aged 14 months.

We are a British family presently living in the States,
formerly from Surrey. We would like to correspond with
families in similar situation to ourselves.

Look forward to hearing from you.

Maggie Westlake
810 Firmona Avenue
Redondo Beach
90278 California
United States of America.

We regret to announce the resignation of Newsletter Editor,
Marlene Sanderson. Until our new Editors take over in
January, please send all articles for publication to
Christine Lavery, Secretary.