

NEWSLETTER

SUMMER 1985

# THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES



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<b>ACCOUNT</b>	MPS, Barclays Bank Ltd Chalfont Station Road Little Chalfont, Amersham, Bucks
<b>AREA SUPPORT FAMILIES</b>	
<i>Northern England</i>	Colin and Mary Gardiner; 35 Church Road, Banks, Southport, Merseyside.
<i>East Central England</i>	Neil and Jane Reid; "Meadowbank", 9 Huddleston Way, Sawston, Cambs.
<i>South East England</i>	Robin and Christine Lavery; 30 Westwood Drive, Little Chalfont, Bucks.
<i>South West England</i>	Peter and Marlene Sanderson; "Ashley Cottage", 6 Northfield Road, Tetbury, Glos. GL8 8HB.
<i>Wales</i>	Michael and Patricia Skidmore; 'Horizons', 5 Chapel Close, Wyesham, Monmouth, Gwent.

**WHAT ARE THE AIMS OF THE SOCIETY?**

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



**The Society for  
Mucopolysaccharide Diseases**

SUMMER 1985

What a busy few months we've had and what a busy few months we are going to have. The Newsletter is crammed with tales and prophecies. Read it cover to cover: in and between the lines there are pearls of wisdom and practical tips. Pride of place must go to Scott and his family. He is the kind of Ambassador who so rightly represents all our children and we are sure all of us must have thrilled at the news and taken a lot of pride in his achievement.

News from the North, Wales, South and the South West of happy days and fund raising events - with lots of advice for the future. Planning ahead. Who's going to organise Regional Christmas Parties? It's Harry and Georgina's year off! Think about it and get your adverts and plans in to the next Newsletter. Remember the Society can help with funding Family Days. Not everybody has a house big enough so we can pay rental on suitable premises, like the school Pat Skidmore used for her event. Do let us know if you want to host any such event but are concerned about the funding.

News too from our Medical Family. This magazine is for their use too - updates on research and requests for assistance. You will notice the advert for the Steven Kopits Lecture sponsored by the Society. We hope to hold an informal morning session with Steven Kopits, for parents of children with relevant problems, on the day of the lecture. Do remember to draw your paediatricians attention to this advert.

The Conference is still some months off but the arrangements are well in hand and we are thrilled that already 60 families have booked. If you haven't booked but wish to change your mind please do contact Christine as soon as possible. We have room for about 5 more families.

The first few months of the year are traditionally quieter ones for fundraising, but this year has been an exception and families and friends have excelled themselves. Well done and thank you to you all. The month of May must have broken all records with a bumper £9,000 banked for our MPS Conference and Research Projects. Beat that!

Hoping to see as many of you as possible at Dr Garrow's Garden Fayre on Sunday July 7th.

The MPS Committee

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DEADLINE FOR NEXT NEWSLETTER 24th AUGUST, 1985

YOUNG SCOT'S

COURAGE WINS

TOP AWARD

by Bryan Christie

An 11 year-old boy who is terminally ill gave his mother her proudest day yesterday when he was honoured for his courage in coping with disability.

Scott McCarthy, of Jackson Street, Inverurie, Aberdeenshire, could not wait to get back to the town last night to show his friends the scroll he was awarded as Junior Disabled Scot of the Year.

But for his mother, Sheena, the pride in seeing Scott's bravery acknowledged at a ceremony in Edinburgh was tinged with sadness. "This is the only time I will ever see Scott getting an award because he will not be going to university or anything like that. I am proud but quite sad in a way as well," she said.

Scott suffers from Hurler/Scheie disease, a genetic fault which prevents him breaking down the poisons which are naturally created in the body. It affects about 250 children in the UK and results in early death. Scott's walking, eyesight and hearing have all suffered though his brain is unaffected and he attends a normal school. He swims, goes horse riding but enjoys most of all watching television.

Christine Lavery, the Secretary of a Parent Support Group, The Society for Mucopolysaccharide Diseases nominated Scott for the award. She said: "When I first met Scott three years ago, I couldn't help but be amazed at the shining personality of this brave boy."

"Two years ago he underwent experimental enzyme treatment, knowing that this offered little hope for himself, but could pave the way for the future of the next generation of affected children. Sadly it failed. Not long after, his father was killed, still Scott emulated such courage in making the very best of life and supported his mother and younger sister through such a personal tragedy. It seems fitting that this award should be made to such a special child - an inspiration to know."

The presentation was made by the Scots-born disc jockey, Stuart Henry, who in 1979 was diagnosed as suffering from multiple sclerosis and is now confined to a wheelchair. He flew to Edinburgh from his Luxembourg home for the ceremony at the Sheraton Hotel.

Our sincere thanks to "The Scotsman" for permitting reproduction of this article and photograph that appeared in "The Scotsman" on 16th April, 1985.

SCOTT McCARTHY RECEIVING THE 1985  
JUNIOR DISABLED SCOT OF THE YEAR AWARD  
FROM STUART HENRY



GOING TO LUNCH IN EDINBURGH

Housework went to pot the morning that I received the letter from the Scottish Council on Disability announcing the results of the JUNIOR DISABLED SCOT OF THE YEAR AWARD. We could hardly believe our eyes our own 'Scot McCarthy'. Apart from recognising Scot's very special qualities it was a proud day for all other MPS children.

When the excitement settled down I got round to reading the remainder of the letter inviting two of us to the presentation on the 15th April at 11.00am.

Shock, horror, how were we to get to Edinburgh for lunch? All possible routes and modes of transport were considered including using Persil Tickets so one travelled free, only problem was that no train left London early enough to get to Edinburgh in time. Our problems were soon solved after Sue Butler's husband Dan described our plight to British Midland Airways who kindly gave two free tickets for their shuttle flight. At the same time the Scottish Council on Disability gave us some money towards our expenses and all we had to do was try and contain the excitement until the day arrived.

It was decided that Sue Butler and I would represent the Society and we felt we would like to take this opportunity to put MPS on the map in Scotland. Our flight arrived at 8.20 and we made our way to meet Catriona Ogilvie a friend of the Society since its inception. Catriona became a friend of Sarah Ridley who suffered from Hurler Disease and whom she met in a Leicestershire supermarket whilst living in the locality. At 9 o'clock we were arriving for our first appointment, a visit to the genetic dept of Edinburgh Children's Hospital to meet with Dr. Guy Besley.

By 10.30 our friendly taxi driver, Catriona was waiting to whisk us off to the highlight of the day, the Junior Disabled Scot Award. We arrived just as Scott was stepping out of the taxi and the grin on his face said it all. Helped by sister Vicki, Scott handled his press calls like an expert and we were all left awe inspired as Scott made his own thank you speech having just received his award from Stuart Henry. Lunch followed and all too quickly his big day was over and we were all waving our farewells to Scott and his family.

For Sue and I there was just time to get a quick glimpse of Edinburgh Castle before Catriona arrived to take us back to the airport. All too soon we were back home finding it hard to believe we'd been to Edinburgh for lunch!!!!

Christine

INVALID CARE ALLOWANCE

(DHSS Leaflet NI 212)

This non contributory allowance is paid to people of working age who give up work to look after someone who is getting attendance or constant care allowance. You can't get it if you are a married woman or living as a married woman. You don't need to be a relative of the disabled person. You get £21-50 a week; plus £12-85 for a wife or dependant housekeeper and £7-65 for each child.

Having read the above you are probably wondering why put something which appears totally irrelevant to mothers caring for an MPS child or children in the Newsletter. But this allowance may become applicable to hard working MPS mums, it already applies to hard working Dad's who have given up a job to stay at home, even if your wife goes out to work, although men receiving the Invalid Care Allowance may not claim unemployment benefit.

The reason that this allowance may be paid to mothers caring for their handicapped child/ children in the future is that The Chief Social Security Commissioner has recently referred the case of Mrs Jacqueline Drake to the European Court of Justice to decide whether Council Directive 79/7EEC (on progressive implementation of the principle of equal treatment for men and women in matters of Social Security) applies to Invalid Care Allowance.

The circumstances of many mothers of MPS children are very similar to that of Mrs Drake and therefore it is in the interest of all families to apply for this allowance pending a decision from the adjudication officer following a judgement in the European Court later this year.

If the decision is in favour of allowing married women this allowance all payments should be back dated to date of claim.

Form NI 212 are available from Social Security Offices and some Post Offices.

Christine



### THE MARTIN BAX RESEARCH PROJECT

By now those of you who indicated that you would like to take part in this project which the Society is funding over the next few years will have received a letter and questionnaire on behaviour relating to your MPS child/children from Dr. Martin Bax. I am sure that you will give every consideration to the questions and return the questionnaire as soon as possible.

In case some families forgot to return the form indicating that they would like to be involved I am sending the questionnaire to everyone. If you want to take part after all please return the questionnaire to Dr. Bax. If you do not wish to participate then please forgive me for sending the questionnaire and you will not be contacted again in connection with this project.

Families may be interested to know that Martin Bax has been gathering a lot of very valuable information from various sources and has already visited several of our MPS families. This very important work would not be possible without your help and I am sure that all the information gathered and any conclusions reached will be of enormous help to future MPS families and of course the medical profession.

Any of our new families who have not had an opportunity to meet Dr Bax will do so at our Conference in September.

Christine

### THE PRINCE PHILIP RESEARCH LAB - GUY'S HOSPITAL HUNTER CARRIER TESTING

We've had a delightful letter from Prof. Matteo Adinolfi, whom many of the Hunter families will know as well as his associate Dr. Diana Chase. Recently the Trustees agreed a grant of a further £1,000 as contribution to PRL's Hunter carrier testing. Prof Adinolfi has offered Families a tour of the Prince Philip Research Laboratories with particular emphasis on the work that he and his team have been carrying out into Hunter carriers.

Personally, I feel a bit jealous when Christine pops down to Guy's from time to time, when I'm at work, to see Prof Adinolfi and Dr. Chase. I'd really like to take up their offer and if any Families feel the same would you care to let me know at 30, Westwood Drive, Little Chalfont. I believe Matteo and Diana will be attending the Family Conference in September and I think the best idea is for me to approach them then, knowing which of us is interested, and to fix a time and a date. I am not sure that this is of interest only to Hunter Families - there maybe others interested in the quiet and methodical way the Professionals go about their ways to learn more about MPS Diseases. I won't make any promises, much will depend on response, but if people from far-aparts are keen to come but are worried about the distance, etc., we may try to sort something out. Just let me know your interest in the first place.

Robin Lavery

### HAIR SAMPLES

You may remember my request some time ago for hair samples from MPS children. There was a super response and I am very grateful for all your help. Incidentally, it does show in a small way how valuable the Newsletter is in providing a link between families and the research groups who are investigating MPS disorders.

You will be interested to know that Dr. Lubec, working in Vienna, analysed the hair by infra-red spectroscopy and found a difference between the spectra of normal specimens and those from patients with Sanfilippo A disease. These results were recently published in the Lancet. Dr. Lubec postulates that the difference is due to the major storage product ( heparan sulphate ) in Sanfilippo Disease. However, this substance is also stored in other MPS types which failed to show the hair abnormality.

Thus it appears that infra-red spectroscopic analysis of hair cannot be used as a general screening test for MPS. It would fail to detect most cases other than Sanfilippo disease. The urine tests currently employed are capable of accurate detection of all known types and will continue to be used with confidence in diagnostic laboratories.

Jean Mossman  
Enzyme Laboratory  
Institute of Child Health  
London.

Helen House  
37 Leopold Street  
Oxford OX4 1QT  
Tel: Oxford (0865) 728251  
11th April 1985

 **HELEN HOUSE**  
a hospice for children

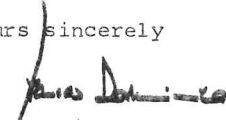
Dear Mrs Lavery & Friends in the M.P.S. Society,

Thank you very much indeed for the present of a special computer and its attendant equipment. Quite a large proportion of our children suffer from the M.P.S. diseases, and I really have no need to tell you how useful this equipment is.

Our children and their parents, together with our staff join me in sending you our heartfelt thanks for your generosity and concern by providing this equipment.

With good wishes to you all, and many many thanks,

Yours sincerely

  
Mother Frances Dominica



# The Society for Mucopolysaccharide Diseases



Hi There, (or should I say G'day)

Thank you for giving me the opportunity to write a few words concerning the Australian Society and our growth since returning from the UK.

As you are aware, Helen and I gained a tremendous amount from our visit and came back enthused and ready to begin in earnest the task of getting the MPS Society recognised in Australia and making people aware of MPS.

This has proved difficult but we have been equal to the task and at this point in time can honestly say that the Medical Profession are beginning to take us seriously. We are now in contact with 40 families. The response from these 'isolated' people has been overwhelming. Their isolation is two-fold, distance and understanding. I am sure we can all sympathize with this.

We have recently written to all major newspapers and TV stations in each state and are now beginning to reap some benefit from this PR exercise. Perhaps of greater interest is the fact that we have recently been notified that a major hotel chain has accepted us as their 'charity' for 1985.

Another plus has been the establishment of a Medical Advisory Board. Although not finalised, this Board will be well-endowed with highly qualified medical personnel.

At present we are hard at work planning our First Parent Conference which is to be held in Albury N.S.W. from 27th to 29th September (the week after yours) and one of our guest speakers is none other than Dr. Ed. Wraith! We feel confident that this Conference will put us 'on the map' so to speak, as far as the medical profession is concerned.

We still have a long way to go, but by degrees things are coming together for us here in the Antipodes! Our umbrella has been enlarged to cover I-Cell, Gaucher's and other storage diseases.. a need too great to be ignored.

To you all, our best wishes for a successful 1985 Conference - our thoughts are with you. Wouldn't it be marvellous if we could have an odd 'wingeing pom' or two at our Conference!!! YOU BEAUT

Ros Smith  
President

## MPS PEN PALS

We have always tried to make our overseas families welcome and provide them with all the up to date information that the UK families enjoy. Recently Pat Skidmore our Overseas Secretary came up with the idea of a Pen Pal Service for Overseas Families. Pat remains in regular communication with many Overseas Families and as the overseas membership grows it not so easy for Pat, herself as a wife and mother of two children to keep up a regular correspondence.

Part of the success of MPS in Britain is the very special personal contact the Society provides and we have now decided to extend this theme to MPS families worldwide. Many British MPS Families have expressed an interest in corresponding with an Overseas MPS family so we are inviting Overseas Families to write to the 'Pen Pal' column that will appear in subsequent newsletters giving a brief description of the family and interests. Don't forget to enclose name and address so that families may respond direct.

If you would like contact with a British Family but for any reason don't wish to have your name and address published in the Newsletter please write to:

Pat Skidmore  
5 Chapel Close  
Wyesham  
Monmouth  
Gwent

If you wish to place an article in our forthcoming 'Pen Pal' column please send details to:

The Newsletter Editor  
Marlene Sanderson  
6 Northfield Road  
Tetbury  
Gloucestershire

Deadline for next newsletter 24th August, 1985

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\*  
\* 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 \*  
\*  
\* Remember to leave a ½" of paper around \*  
\* the stamps. Recently we received a cheque \*  
\* for £20 for stamps saved by MPS families \*  
\* So do get all your friends and relatives \*  
\* to collect them too. \*  
\*  
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## AN INSPIRED RUN

An experience full of emotions; that is the only way I can really describe the London Marathon; the events that led up to my involvement, the exhilaration of the day, and the feelings that I have afterwards.

For some five years I have been a fun runner and a jogger enjoying the benefits of regular exercise, and a yearning ambition to do the "big one". A programme of training starting at Christmas would, I am sure, provide the necessary discipline to ensure completion of the arduous run of 26 miles, 365 yards.

An additional element was my desire to complete the run in memory of Gethin Robins of Hornchurch who died on December 30th at five years of age.

Only after participating can I now understand the lyrical expressions that hardened joggers unceasingly express. I was there, one of 18,000 runners and probably 80,000 entrants. April 21st was my day.

An early morning drive from home in Reading, the 7.10 a.m. train from Charing Cross to Greenwich and a 20 minute walk to Greenwich Park now put me amongst the other competitors at the Red Start - the event I applied for in early October, and had completed about 450 miles since Christmas.

The gun for off - with everyone passing the television cameras and raising their arms so that they could be seen by families at home. Round the Cutty Sark and all is well, settling into a regular pace that would vary by merely a few seconds for each mile. Over Tower Bridge and the realisation that it would be a further 10 miles before I would see the sight again.

The crowds were everywhere, edging us on with tremendous support street parties and a carnival spirit giving a feeling of friendship.

Reaching 18 miles was a real landmark, but hurting quite a lot. Determination was needed to complete each mile, so that at 22 miles there was the beginning of a confidence that I could now sprint to the finish to complete the goal in 3hours, 41 minutes, and as soon as the medal is around my neck a yearning to just curl up and rest.

I derived tremendous enjoyment from the experience and will continue to run to maintain acquired fitness.

A personal thanks to all those who sponsored me and contributed to the funds of MPS, but most of all a special thought for Gethin in whose memory the effort was made.

Vyvyan James

## FAMILY TRIP TO BURFORD WILDLIFE PARK

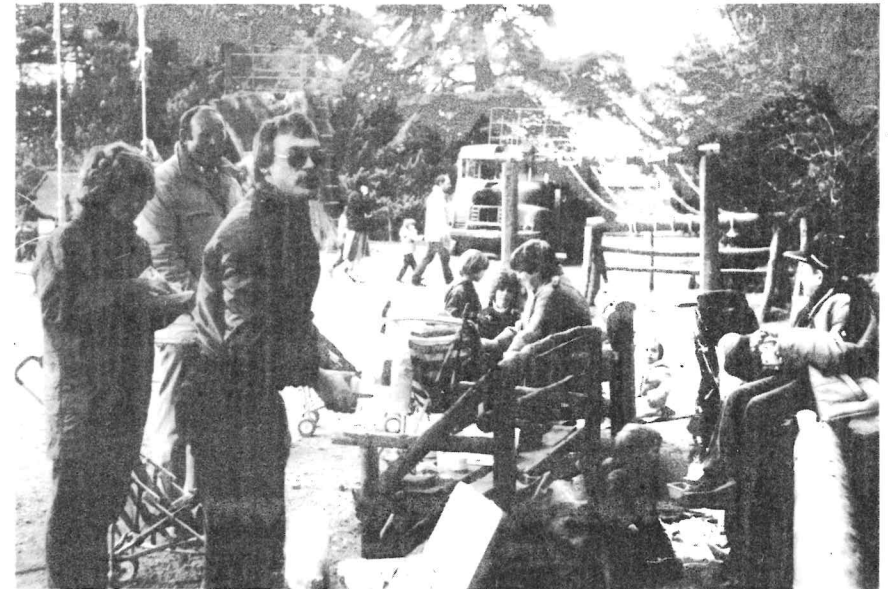
SUNDAY 14th APRIL

Saturday the 13th April weatherwise was a dreadful day, it snowed, so it was with great intrepidation that on Sunday 14th April the Volvo, soon to become the Volvo with the elastic sides was duly loaded with picnic, arctic weather gear, the Laverys and the Butlers and it wound its way from Buckinghamshire to the borders of Gloucestershire. It was with great relief when we arrived to see Pat Isaacs, Ronald and Linda Snack with their families waiting for us. We all set off around the park collecting the Grants, on the way. The Sandersons duly arrived and we all had lunch. The children got to know each other and made new friends and we all caught up with what we had been doing for MPS.

Soon it was a trip on the railway, we practically took over the train; as our party had now been joined by the O'Tooles en route from Cornwall. Pony rides were next on the agenda for the children followed by a marvellous cup of tea for the Mums and Dads. After seeing snakes, frogs, crocodiles, various birds not forgetting the feeding of the penguins it was time to load up once again and make our way home. The weather had been kind, we didn't need wellies and brollies. The company excellent and we all look forward to the next day or weekend. Did somebody mention tents and camping!!!!!!

Best wishes to everyone, Hope to see you soon.

Sue Butler



Feeding the Oops, MPS Families at Burford

## THE PIDDEN OPEN HOUSE DAY

May the 12th it was to be!

The invites to our open day were sent to all those MPS families listed by the Society throughout the South West, those able to attend were asked to bring a sweet or savoury dish, the local press invited and a few words uttered to see if the weather could be favourable for the day.

Some apologies were received from those families unable to attend and when the day dawned, six families arrived together with mountains of food; the weather was dry but cold.

That day the garden became the Apache hunting grounds as about a dozen energetic kids flew around climbing trees, tarzan acts on the swing and generally had a good time.

The parents by contrast, found the splendid food too much for Sunday aerobics and seemed happy enough to sway gently on ground level cushions in the lounge, clutching a glass of wine!

We both enjoyed the day immensely, it was a good opportunity to sit and really begin to know other parents, exchange experiences and to socialise with others who knew the facts about MPS.

Our local Wiltshire Times paper was represented by Carol Billingham who, although about 23 months pregnant, was clearly impressed by the work done by the Society and was keen to make a story for the womans page of the local rag.

Conclusions: we enjoyed ourselves and would like to thank all those who drove many, many miles to make the day worthwhile. We offer our profound apologies that the local council saw fit to close the main road to Westbury on that particular day which made a nonsense of the map we had sent out on how-to-find-us and resulted in most families seeing more of Wiltshire including the White Horse, than they had intended!!

Lastly, although we were a day or so late, David Criddle was still able to celebrate his birthday complete with cake, candles and 'happy birthday to you'. Good on you David.

Looking forward to seeing again our friends at this Summer's Conference at London Heathrow Post House.

Bill & Fer & Natalie



## THANK YOU BILL AND FER

Open House at William and Fer Pidden's in Wesbury, or as Robin put it 'the Mafia at the Pidden's'.

I travelled down to Westbury with my daughter, Sarah for my first open house meeting since I joined the Society three years ago. We got as far as Bath when we were told we had to wait 1hr 40 minutes for the bus to leave. I rang William and Fer to tell them we would be late but William very kindly offered to pick us up at Bath Station

We were the first to arrive and meet Fer and Natalie who is 4½ years. The likeness between her and Toni was unbelievable. It was like home from home for Sarah. Soon after Robin and Christine arrived. A reporter came to interview William and Christine then we were joined by the other guests each armed with sweets and savoury food. We all had coffee and took the opportunity to chat and get to know one another.

Lunchtime arrived : the children were served first ; I fed Natalie while Fer saw to her guests. The children went out to play whilst we adults had our meal with a glass of wine.

It was David Criddle's birthday a couple of days previously so he had a Mr. T Birthday Cake.

Sadly all good things have to come to an end, and it was time to go. Natalie cried, she didn't want us to leave. The feelings were mutual but as I had left Pete looking after Toni, Shelley and Emma plus two other children I just had to go and rescue him.

Thank you William and Fer for a wonderful day filled with lots of memories, love and laughter.

Love to everyone who was there.

Sue and Sarah Bramford



Sue Bramford  
and  
Natalie Pidden  
staring wistfully  
at the end of the  
trifle.



### THE FIRST MPS WELSH DAY

It's not often I find time to sit in the garden but today (the 3rd day of Summer) I feel justified having just organised the first Welsh Family Day, (although a few aliens did creep over the border)! In fact it turned out to be more of a weekend than a day because Mervyn and Ann Canton from Pembroke and Wilma and Peter Robins from Essex stayed in Monmouth for the weekend. Wilma and Peter spend almost as much time in Wales as they do at home in Essex and we were thrilled when they decided to join us.

In case of inclement weather, we decided to hire a local school in order to have plenty of room to move around. In fact we were very glad of the school hall to shelter from the sun rather than rain and cold; the weather could not have been kinder.

Planning one of these events does not come without its problems, and having, as I thought arranged venue, families to attend, maps, food etc. and having made the decision not to organise any entertainment or 'officialdom' of any sort but just let it be a purely social event all my problems were over. Famous last words!

At 4.30pm on Friday afternoon I received a telephone call from a local vicar informing me a double booking had occurred and he would be using our venue for an Anglican Seminar to which some 80 people from near and far, including the Archdeacon of Wales, would be attending. His programme included lectures in the main hall, then small discussion groups in each classroom. Can you imagine the combination? MPS v Anglican Seminar!! It was obvious one of us had to move and during the next hour we explored various options. Being a church deacon myself I was in a position to either use my own church schoolrooms except by location they were impracticable for MPS, or to offer them to the Vicar, but there was a snag:- I am a Baptist. Another human division which seems so ridiculous. Unity is something that is very strong within the Society and I hope that never alters. I am sure it's because of the children and perhaps that is the greatest gift that they give us. Eventually the problem was solved, we still had the use of the school and the panic was over. Ann and Mervyn arrived and in true MPS fashion were immediately commandeered into some work!

We are very grateful to the St John Ambulance Brigade for being in attendance throughout the day, and thankfully we only found them one sprained finger to treat, and that was a parent. Some of the children thoroughly enjoyed a 'fun ride' in the ambulance with flashing lights and sirens in operation, especially David Criddle, who was, as a special privilege allowed to wear the uniform 'hat' and sit in the driving seat.

Shirley Love and I had exchanged many phone calls and as with Ann and Mervyn it was good to put a face to a name and also to meet the rest of Shirley's family including mother-in-law, Margaret who has a tremendous relationship with her grandson Paul, who had only come out of hospital the day before. In fact it was due to pressing social engagements as well as recovering from a recent illness that he was discharged. With the Family Day followed by his 6th birthday on Sunday. Apart from a few

renditions of Happy Birthday by us all, Paul and Margaret had a repertoire of their own including the National Anthem, and with all the gusto of a Welsh choir; what more entertainment could we ask for with Monmouth accommodating two of the largest recording studios in the world, had time allowed, we may have been able to arrange a few recordings!

At the very last minute we managed to borrow a very sophisticated video camera from a friend and I am looking forward to seeing the antics some of the children got up to on the ropes in the gymnasium. Why is it that children always do something amusing just as you put the camera away? Our special thanks to Jane Criddle for endlessly supporting Paul and David during their tarzan games.

Like all 'first attempts' we have learnt by our mistakes, one being on the catering side. With a bulging fridge before Saturday and a slightly bulging fridge after Saturday quite a lot of food was wasted! It is very difficult to ascertain exactly how many people are going to attend and maybe it's only by practice we will improve because there are always last minute unavoidable hitches which occur, as was the case with quite a few of our expected families, that make these meetings an impossible goal. If it is left for everyone to bring a contribution one can end up with 14 trifles and nothing else! Has anyone any suggestions, or is it such a minor point compared to the satisfaction gained from the event itself, it is not worth worrying about?

The feed-back I have received from those who did attend was a super day, a lot learnt and when is the next? These must surely be the only important reasons for holding more Regional Family Days. My thanks to you all for coming and to Pam and Robert Hayward for looking after Helen for the previous night and another friend for having Richard, it certainly made life easier.

Pat Skidmore

### OUR FAMILY DAY at WILTSHIRE & MONMOUTH

We just wanted to say how much we enjoyed our "Family Days" at Bill & Fer's and Mike & Pat, who were kind enough to put up with us on each occasion. It was lovely to meet all the families and to put faces to names and just chat about good and bad moments we all have with our children, also to exchange ideas. All the children on both days had a great time and played happily together, they seemed to laugh all day and certainly tucked into the lovely buffets both families had organised. They must have spent hours arranging such feasts and a great deal of effort by our hosts went into these Family Days, to make sure everyone had a good time. I think therefore that it's very important that if for some reason families invited are unable to come, please do let the hosts concerned know because catering on such a scale can be a problem and it's such a pity to see super buffets being wasted.

Thank you very much Bill, Fer, Mike and Pat for your warm hospitality.

Graham, Pat, Jane and David Criddle

THE FIRST NORTH WEST NETBALL TOURNAMENT

by Micheline Johnson

Held on 23rd March, 1985; I think it is another first in fund-raising.

Having taken part in so many netball tournaments over the years it seemed to me that it would be a new sort of fundraising event.

Brian's firm, S.E.S. Shopfitting, donated the trophy, that is I chose it and they paid for it, not really sure what netball is all about!

I then set to work inviting all the ladies teams that play in the Northgate League, in which my own team play. With it being a business league many teams found that one or more players were working on Saturdays so I ended up with 8 teams competing, although 2 other teams paid their entry fee as a donation.

I sent out letters to the larger stores in Chester and all the sports shops, inviting them to make a donation. Many replied with either shop vouchers or cheques, although I was surprised at the lack of interest from Sports Shops. I then wrote to our "local Duke". He had met Victoria last year in Heswall and like all our children - once met never forgotten! He sent a cheque for the fund which surprised Christine as he was not forthcoming when she had written. Maybe he is a secret netball fan!

Once the money started coming in I got "fund-fever" and decided that my team could find sponsors for every goal they scored, it was a great success.

My sixth form at school, all being wealthy youngsters, were extremely generous and money is still coming in. So far we have topped the £300 mark and for our first fundraising event both Brian and I think that is a good start.

Now for the day itself. Perhaps if I quote one of my team it will give everyone an idea of the conditions "Please hold the tournament in May or June next year!!" Yes it was freezing cold and pouring with rain! No wonder we had so few spectators. Macdonalds came to sell orange juice but I think perhaps Nescafe would have been better! The players competitive spirit kept them chasing the ball and scoring the goals despite the blackening sky. We had no formal presentation, I just handed the winning team, Beafeater, the trophy and we all dashed inside for a warm drink!

Brian and a pregnant member of my team, Blacon Ladies, sat for nearly 4 hours underneath a large umbrella keeping time and score. Needless to say as soon as we arrived home it was a "wee one" to re-circulate the blood! Our only regret was that our daughter, Victoria was not able to be there but beside it being far too cold and wet for her she needs such alot of attention and entertaining that it would have been impractical.

I would like to thank all the teams who took part, the companies that made donations, all the goal sponsors and all the youngsters who came to help prepare courts and sell refreshments, especially as they put up with Charlotte organising them!

1985 Winners of the North West MPS Netball Tournament - Beefeater



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FREE ORANGE BOWL  
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Macdonalds provide a free orange bowl and staff to sell the  
juice and all monies made go to the event, so if anyone else  
has a Macdonalds nearby they are worth approaching. In the  
Summer months you must book early.  
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\*  
\* DEADLINE FOR NEXT NEWSLETTER - 24th AUGUST, 1985 \*  
\*  
\* DATE FOR PUBLICATION - 19th SEPTEMBER, 1985 \*  
\*  
\* Remember the Newsletter is as interesting as you make it so \*  
\* please do keep your articles coming in. Food for thought; \*  
\* Has anyone got any views or ideas on the MPS Holiday Home \*  
\* Project? With a vision for the future should we be aiming \*  
\* higher, maybe a MPS Holiday Centre, multipurpose enabling \*  
\* several families to come together, a venue for Area Family \*  
\* Meetings, who knows! Perhaps you feel there are already \*  
\* adequate holiday homes for the disabled? Please do let us \*  
\* know your views. \*  
\*  
\*\*\*\*\*

## TYPING, RECORD KEEPING AND ALL THAT BUREAUCRATIC NONSENSE

Sadly, running any kind of organisation, an amateur tennis club or a multinational trading company means a certain amount of essential bureaucracy to keep the wheels oiled. For a voluntary organisation trying to do a worthwhile and efficient job, it can be a killer even though essential. Faced with choices of bathing/feeding/fetching the children, talking to a new family, or updating the membership address lists or the details of bookings for the Family Conference by the umpteenth re-type, what takes priority? Well of course the children first, the new families second. But what about the paperwork? If it's not done the MPS wheels don't turn. Typing, yards of it, is essential. Worst of all the retypes: over and over again. If as one example you could see just how complex is the changing detail; rooms, beds, menus, special diets, outing arrangements, specialist speakers creche requirements, volunteer helpers etc for the family conferences, you'd know what I mean.

However BRITISH OLIVETTI and the Department of Health and Social Security have come to the rescue. In the last newsletter we reported the grant approved by DHSS for a micro-computer system. More of this in a moment. Early in the year, and almost out of the blue British Olivetti offered the Society an Olivetti 351 electronic typewriter with dual disc drive memory, for a ridiculous knock down price (£200). It has been a boon, is easy to use (even by me) and seems to be still full of great potential. We've used it for 'round robin letters', conference arrangements (saving all the time and energy of retypes for additions and amendments), draft Society policy papers and medical articles. In future we will be using it for preparing and editing Annual reports. Everything of potential future use is stored on disc memory for quick retrieval and amendment; so no laborious retypes.

By early May, now growing familiar with the Olivetti word processing system, we had taken delivery, via Peter Archard, of the DHSS funded micro-computer system. For the technical this is a BBC Acorn B, 32K, with DFS interface, ROM wordprocessing ("View") and database ("Starbase"), plus twin double drive/double density Mitsubishi disc drive, Juki 6100 daisy wheel printer and Philip's "Green Screen" VDU. since we are already efficiently using the Olivetti word processing facilities I am concentrating on the database package in the BBC based system. Although I am a novice it seems to me that the database facilities hold great promise. I'll try to master this first, before exploring the advantages/disadvantages of the Olivetti wordpro system against the BBC. The BBC offers full screen editing which should be useful for large text documents against the "thin" screen Olivetti. On the other hand the Olivetti is a dedicated word processor of business scale and very flexible.

Privately and by other means, and as we are talking about advanced technology, Christine and I have acquired/purchased a telephone charge monitoring machine and a number memory phone. These should both, and are in fact, creating economies; especially the charge monitor.

Undoubtedly all this advanced information technology is already making us more efficient and saving time (especially typing) for other useful purposes. The question is, will it last? At the last resort all it will mean is that even more work will be done. In two years time, and nervous wrecks, I'll report that we've bought a quill pen, some parchment paper, and two cocoa tins with a long piece of string!

Robin

## BOOK REVIEW

'Your Child in Hospital : A Parent's Handbook'

by Priscilla Alderson and Mary O'Toole

Published by The National Association for the Welfare of Children in Hospital (NAWCH), available from Christine Lavery, 30 Westwood drive, Little Chalfont, Bucks. priced 75p

The National Association for the Welfare of Children in Hospital was started in 1961. NAWCH works for all Children in Hospital to be cared for in Children's Wards with Trained Children's Staff, Unrestricted Visiting for parents and Accommodation for parents who want to stay. NAWCH aims to persuade hospitals that parents have a necessary and practical part to play in the care of their sick child.

In reviewing this informative and well written booklet, I realised just how inadequately informed I was in dealing with the routine and emergency admissions we encountered in Simon's short life. We frequently relinquished our rights as parents to stay with our child on admission to hospital for fear of upsetting the staff. Mary O'Toole the co-author of this booklet and perhaps better known to many of us as Helen's mother describes in her story 'The Blue Dress' just how untraumatic the sick child's stay in hospital can be with the mutual co-operation of hospital staff and parents. It is not always possible to plan so carefully in advance your child's admission and stay in hospital as Mary has done with Helen, but there are many useful ideas for dealing with each individual situation and I would highly recommend all parents making themselves familiar with its contents particularly those parents whose children are more likely than most to spend spells in hospital.

Christine

#### NEW FAMILIES

Mr a Mrs Colvin from Kent. Their 10 year old son Dean suffers from Hunter Disease.

Mr a Mrs Hale from Hertfordshire. Their 8 Month old daughter, Joanne was recently diagnosed as suffering from an MPS type Disease.

Mr a Mrs Lewis of Hull wrote to the Society after seeing an article on MPS in her local paper. 19 years ago their son, Philip was born with Hunter Disease. Sadly he has since died but Mrs Lewis is keen to keep in touch of developments in MPS as she has a daughter and niece who may be carriers.

Mr a Mrs Love, whose son, Paul is suffering from Hurler Disease. Paul is 6 yrs old and lives in South Wales. Paul's twin brother Clive died from Hurler Disease in January.

Katie and John Bottom from West Yorkshire. Their 5 month old son Paul has just recently been diagnosed as suffering from Hurler Disease.

#### BIRTHS

Lisa and Keith Huxted are proud to announce the arrival of Matthew Thomas born on 8th May, 1985. A brother for Vicki and Daniel.

#### DEATHS

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

Clive Love aged 5yrs of Caerphilly, Mid Glamorgan died peacefully at home on January 12th. Clive was suffering from Hurler Disease.

Our thoughts are with Clive's parents, sister Ann, and brother Paul, during this sad time.



## 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



MPS CHRISTMAS CARDS

I am sure you will be delighted to know that after the enormous success of our first Christmas card last year we are all set to publish a brand new design this year. Several artists submitted ideas and we had hoped to have two designs printed, but due to printing costs and minimum runs we have had to opt for just one type this year. It was a difficult choice and a number of MPS families were consulted and a robin design by Nigel Hubbard, a friend of Gethin Robin's was chosen. We are very grateful to the other artists for their help and support.

The cards, in packets of 5 priced 70p, will be available from Pat Isaac, 'Beckdell', Church Road, Fiddington, Nr. Bridgewater, Somerset. from 1st September. Order forms and a sample packet will be enclosed with each September Newsletter and of course families will be able to take packets away from the Conference.

Please do tell your friends and relatives about the MPS cards and gather as many orders as possible.

Christine



Black and White?  
This could be a  
label for Scotch  
Whisky! How True.  
Just wait 'til  
Hogmanay - lots  
of little robins  
round the fire.  
All in glorious  
MPS COLOUR.

FUNDRAISING

First of all we must offer our sincerest thanks to Lorraine Stenson who took over Fundraising from Susan Heath. Unfortunately Lorraine will be going into hospital for major surgery in July and will need a long period of convalescence. Sadly in the circumstances Lorraine is having to step down as Fundraising Officer. I know you would all like to join with us in wishing Lorraine a speedy recovery.

We are most fortunate that Pat Isaac has kindly agreed to take over the position and will be a great asset to the Society. Pat and Dave's, youngest son, Christopher was recently diagnosed as suffering from Morquio Disease. Pat is a school teacher and since joining the Society in 1984 has raised in excess of £6,000 for MPS. We know you will be hearing soon from Pat concerning her fund raising plans for 1985/86.

MPS CHRISTMAS RAFFLE

Although our Christmas Draw which last year netted in excess of £2,300 is a major fund raising event, previous experience has proved it sensible for one family, with no other MPS jobs demanding their time, to organise and see the event through.- it is a major task. We are most grateful to Ron and Linda Snack for so kindly offering to 'beg' for prizes, distribute and fold tickets and arrange the draw.

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. The draw will take place in early December.

It has occurred to us that some Dads or perhaps Mums work for Companies and firms who might be willing to donate a prize. We always aim to have about 40 prizes so if anyone is able to help by getting a prize or voucher donated please tell :

Ron Snack

Christmas Draw Organiser  
16 Wandsworth Place  
Bradwell Common  
Milton Keynes  
Bucks  
Milton Keynes 666819

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+  
+ LATE        Congratulations to Peter and Lesley Greene of the        +  
+                Research Trust for Metabolic Diseases in Children        +  
+ NEWS        on the safe arrival of baby Rebecca Anne, born 12th        +  
+                June. A very special sister for Jennifer.        +  
+  
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## FUN WITH FUNDRAISING

When our little son, Christopher, was first diagnosed as suffering from MPS, the feeling of emptiness and hopelessness was gradually replaced by desperation - there MUST be SOMETHING we could do to help. So I threw myself into organising a coffee morning at the playgroup where Chris goes to raise funds for the Bone Marrow Unit. I wrote what seemed like hundreds of letters asking for help. In the beginning I thought I would be lucky to raise £500 through the coffee morning and by asking friends from further afield for cash donations. I was amazed and overwhelmed by the support everyone gave and what started off as being a "one off" event has snowballed and I'm still getting more ideas for fundraising 11 months later! I didn't realise so many people knew us - after I started with the Playgroup Coffee Morning (which incidentally raised £555 in one and a half hours!) every one wanted to help further and organised more events to raise funds.

Then I wrote to friends and relations all over the Country (who normally only get a letter at Christmas!) telling them our sad news about Christopher, enclosing an MPS information sheet and suggesting that if they wanted to help, they could send a donation for MPS. They did better than that - most of them organised something to raise more money: coffee mornings, luncheon parties, collections at work, jumble sales, donations from companies or the Lions, Round Table etc., auctions, suppers, raffles, sponsored slims, sponsored swims, bring and buy stalls, Tupperware parties and book parties. I've also done a lot myself locally and have a willing band of helpers who are always ready to assist with serving coffees, selling tickets, etc. and without whose support I couldn't have raised nearly so much money - not to mention my long suffering husband!

Most of the events have been very successful but on a few occasions I have spent a lot of time for little return. I always set myself a modest target and then I am usually pleased when the event raises more. The most enterprising event I organised was a "Charity Musical Evening" in our Village Hall. Our next door neighbour plays in a small local brass band and he agreed to a concert, together with a folk guitarist and a group of Madrigal Singers. We drew up a programme, found a local Master of Ceremonies and had tickets, posters and programmes printed for £5. The Village Hall agreed to let me have the hall rent free. Sainsbury's gave me a voucher to buy coffee etc. and a bottle of wine for the raffle, milk was provided by the local dairy, and other raffle prizes were donated - I even managed to get free beer for the band from Whitbreads! We sold 130 tickets at £1 each, hoping that they wouldn't all turn up, as the hall only seated 100. The concert was thoroughly enjoyed, and encouraged by the M.C., further donations were put in the jar and altogether we made a profit of £200. In addition to this the Madrigal Singers later went carol singing and presented me with a further £60 and one of the band raised £110 on a sponsored parachute jump recently.

As well as fund raising I've also tried to spread awareness of MPS by talking to local groups of people. This usually brings in more money and normally has a "knock on" effect. For example

I talked about MPS at an area playgroup meeting (P.P.A.). At the time I had donations for coffee (one person wrote a cheque for £100!) and later at least 7 different playgroups held events to raise money for MPS. I've also received a good deal of money from schools. I wrote to all the schools where I knew someone on the teaching staff asking them to donate their Christmas Concert collection to MPS. It was very pleasing to get such a good response as so much attention was being given to the Ethiopia appeal at the time. The worst ordeal was going to talk to the boys at a weekly boarding school. The boys usually donated half of their annual whist drive money to a nominated charity and half to the school. However when I returned home the Headmaster phoned to say the boys had unanimously decided to donate the whole amount (£525) after listening to my talk on MPS.

Well - I am just about running out of people to ask for money for MPS so I have been very pleased that after generating the initial interest in our area, I have received offers of help from various places - for example, the local college gave £400 from their Rag Week and a local pub ran a disco and raised £250. I have always avoided any newspaper publicity as the headlines can be so cruel - not only for Christopher's sake but also his brother and sister.

I've now raised £7,600 since I started last July - the first £2,600 for the Bone Marrow Unit at the Westminster Children's Hospital and the remaining £5,000 for the MPS Research Project. I know I can't possibly go on raising money at this rate but I hope to keep raising a small amount for the MPS Society. I wouldn't have dreamed it possible for me to raise so much a year ago. I know everyone is not in a position to give so much time for MPS but if you are able to do anything on a small scale, you will be surprised at the way it grows. Perhaps reading this article has given somebody the incentive to try - I hope so. I have found that being so involved with fundraising for the Society has helped me cope with the news of Christopher's illness and I hope it will benefit us all in some small way.

Pat Isaac

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+
+ GARDEN FUN DAY +
+
+ 30th July +
+
+ 2.30 - 5.00pm +
+
+ Bring Swim Suits-Cancelled if Wet+
+
+ Further details from: +
+ Pat Isaac +
+ 'Beckdell', Church Road +
+ Fiddington +
+ Nr Bridgewater, Somerset +
+ Tel.Nether Stowey 732800 +
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We thank the following Companies and Associations for their contributions to the Research and General Funds

Colgate Palmolive Coupon Redemption                      Harrison and Clough  
Nelson Clearing House Coupon Redemption  
Winsford Constitutional a Conservative Club  
Brixton Contact a Family held a Jumble sale  
Inverurie Ladies Circle  
The Amersham Inner Wheel held a Fashion Show which quite a few  
Committee Members Attended and thoroughly enjoyed.

WE would also like to thank

British Olivetti, Mr. Wynne Davies, for the Olivetti 351 word-processor, and Vicky who spent a half day at Little Chalfont, courtesy of British Olivetti, to provide training.

The DHSS for the grant to purchase the BBC micro-computer system, and to Ian Brown and Peter Archard, who defined and procured the system on our behalf.

We send our grateful thanks to all Companies, Associations and Private Individuals for their donations towards the cost of this years Conference to be held at The Post House Hotel, Heathrow in September. Without these contributions the Conference and Childrens Outing to Thorpe Park would be impossible.

The Eva Reckitt Trust                                      Weetabix  
Black and Decker      Marks a Spencer              Hewlett Packard  
Nabisco                      Amersham International  
Hallmark Cards              Paul a Carol Hubbard              Marian Astbury  
Electrolux                      National Westminster Bank Plc  
Mr Norris                      Nationwide Building Society  
Alliance Building Society  
Collection Boxes at a Judo competition in Milton Keynes  
Fox and Hounds Public House, Rickmansworth

Sue Butler - Donations Secretary  
Spriggs Holly House  
Spriggs Holly Lane  
Chinnor Hill, Oxon.

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o
o          BBC CHILDREN IN NEED APPEAL          o
o
o We have just heard that the Committee         o
o responsible for the distribution of the         o
o the money raised in 1984/5 have decided       o
o to donate £1,000 towards the forthcoming      o
o Family Weekend and Conference.                o
o
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