

NEWSLETTER

WINTER 1985

**THE SOCIETY FOR
MUCOPOLYSACCHARIDE
DISEASES**



National Registered Charity No. 287034

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 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

WINTER 1985

The last 3 months have seen the greatest growth in the three year history of the Society. 28 new families have requested contact and as you will see from our 'New Family' list quite a number have already become integrated into the Society. Indeed, eight families joined us at Ron and Linda Snack's Christmas Party at Milton Keynes. We offer a warm welcome to you all and look forward to getting to know you.

Those of you there will know what a success the 3rd Parent Conference was at the Post House Hotel, Heathrow. Over 70 families including 4 from Europe and 1 from South Africa attended. For many the Conference provided another opportunity to meet up with old friends; it was also very pleasing to see that nearly a third of the families were attending their first MPS Family Weekend.

I am sure you will agree that the Post House Hotel, Heathrow was most welcoming and that once again nothing was too much trouble. We appreciate that a number of families had a considerable distance to travel and we have given this every consideration, when deciding the 1986 venue. Nevertheless because of the size of the hotel now required, the enormous number of volunteers we have to call upon, (about 200) and can more easily mobilise locally, we have decided to return to The Post House Hotel, Heathrow, 26-28 September, 1986 for our Fourth Parent Conference. We anticipate a big response so when you receive the booking form early in 1986 please do return it promptly.

3 weeks after the Conference Mary O'Toole was back in action again having initiated and organised the Seminar at which Dr. Kopits, from Baltimore, USA spoke firstly to parents and then to the Medical Profession on Morquio Disease. It was an amazing day culminating in Dr. Kopits running a 'clinic' for Morquio children at The Hospital for Sick Children, Great Ormond Street late into the night.

Following Dr. Kopits' visit the Society decided to take him up on his offer to operate on one of our Morquio children and at the same time provide a learning experience for a handful of British Orthopaedic Consultants. Dr. Kopits has kindly offered to come to England over Christmas to operate and we sincerely hope that by the time we publish our next newsletter we will have some good news to share with you.

Diana Fudge and Robin Lavery, with the support of the Trustees, have been putting the 1984/1985 Annual report together. We hope you will find it informative and helpful. At financial year's end we were in credit and even though September - October are major spending months with payments of up to £16,500 (mainly the Conference and the Research programme) we remain comfortably solvent, thanks to the hard fund raising efforts of many.

Continued over

DEADLINE FOR NEXT NEWSLETTER 24th FEBRUARY, 1986

THE HOLIDAY HOME FUND

Nevertheless 1986 is going to place more demands on the Society, in raising funds for general support, our research programme with Dr Martin Bax, the launching of the Holiday Home project, and of course our annual conference. So please keep the hard work up, taking guidance from Pat Isaac and tips from the Newsletter on others' fund raising successes and on funding events for the future.

Most of the items I touch upon are covered in detail in this Christmas Newsletter. It's been a hectic year and we wish everyone connected with the Society a relaxing and happy Christmas, and a 1986 which will treat all our children and families kindly.

We have a fellowship, not just here in the UK: we think fondly of our new and not so new friends in Australia, Austria, Canada, West Germany, Japan, New Zealand, South Africa and the USA and we all wish them a joyful New Year.

Christine, for the MPS Committee

 * MOBILITY ALLOWANCE *
 * * * * *
 * Call to extend Mobility Allowance *
 * * * * *
 * At its Annual General Meeting the Association of Community *
 * Health Councils for England and Wales agreed that it should *
 * Campaign for a change in the qualifying criteria for *
 * Mobility Allowance so it would recognise and acknowledge the *
 * substantial mobility problems faced by children who are *
 * mentally handicapped. *
 * * * * *
 * If you are having difficulty obtaining Mobility Allowance or *
 * Attendance Allowance, please do let us know as we are trying *
 * to put together a portfolio of MPS cases and present this to *
 * the Minister of Health and interested Members of Parliament. *
 * * * * *

PROBLEMS WITH COMMUNICATION?

Once again, the Parent Conference provided a valuable arena for informal discussion between Members of the Society, Professionals and those of us on the Management Committee.

It is becoming increasingly apparent that, for a multitude of reasons, a number of our families are finding it difficult to "negociate" the complex system of benefits, allowances and community health care.

Dr. Bryn Neal, Medical Advisor to the Society, has offered to discuss any specific problems you may be encountering, and perhaps suggest a course of action.

If you would like to contact Dr Neal, please write to me at :- 'Roselawn', 43 Woodside Close, Amersham, Bucks HP6 5EF. If possible please enclose a telephone number at which Dr. Neal can reach you.

Catherine Grant

The Holiday Home Fund Steering Committee has to date held two very successful meetings since its formation at the family weekend. The Committee is very enthusiastic about this project, and feel it will have a wide appeal to all families in the Society.

A more structured concept of location, type of building and costs involved in purchasing and running this unit has now evolved. the Committee will be formally launching their Fundraising Appeal in early 1986. Any monies raised prior to this launch will be gratefully received; a boost to the account which already stands at around £12,000.

Please contact Mr Gary Grant
Trustee to the Society
'Roselawn'
43 Woodside Close
Amersham
Bucks HP6 5EF

with your ideas, donations and comments.

INTRODUCING OUR NEWSLETTER EDITORS FOR 1986

At the Management Committee Meeting back in October, Peter and Maggie Archard kindly volunteered to take on the role of Newsletter Editors from the first issue in 1986. The Committee wholeheartedly accepted Maggie and Peter's offer.

Contributions for the Spring 1986 Newsletter should therefore go to: Maggie and Peter Archard
48 Lawrence Avenue
Letchworth
Herts.
Tel: 04626 73830

Please do give them every assistance by getting your articles in by the deadline of 24th February. Personal histories relating to MPS, fund raising activities, useful hints etc articles urgently needed.

Christine

The photographs in this Newsletter depicting the Parent Conference were kindly provided by: Erich Kraft, David Brooks-Daw and Mike Taylor

Dr. KOPITS' SEMINAR

As many of you will know my second daughter Helen, now aged 8, has Morquio's syndrome. Children with this condition often have a problem with the cervical spine, the bones of which are not formed properly leaving the spinal cord at risk of damage. Eighteen months ago after a fall Helen felt she could not move her legs or arms for a short while. Our Orthopaedic Consultant was on holiday and we were told by a doctor from another hospital that Helen would almost certainly need surgery but that there was no one in this country able to perform the operation successfully. She told me about Dr. Kopits, an orthopaedic surgeon from Baltimore, USA who had perfected a technique for fusing the cervical spines of children with Morquio's syndrome. We contemplated trying to raise funds to go to Baltimore but this seemed wrong. How much better it would be if Dr. Kopits could somehow impart his knowledge to Consultants here in Britain.

Our Consultant returned and told us he could carry out the necessary surgery. We had high hopes of the operation and were dismayed to learn that the bone taken from Helen's hip had not fused with the bones of her cervical spine. I remembered Dr. Kopits and with Christine Lavery's support I wrote to him asking if he planned to come to England at anytime and whether he would be prepared to speak at a seminar for Consultants and other professionals. I received a most encouraging reply and so the seminar at the Institute of Child Health was arranged and notices sent to surgeons and paediatricians in all parts of the British Isles.

Dr. Kopits kindly agreed to talk to parents in the morning and about a dozen arranged to come. To my surprise, when I collected him from the airport the morning before, he also offered to see any children who could be brought to London. Frantic phone calls and hectic last minute arrangements meant that all those parents who were coming to the talk could also bring their children at some point. Dr. Kopits has suggested that he might see other children next year if we can arrange a "clinic" for him.

I am sure I speak for all the parents when I say that I could have listened to Dr. Kopits for hours. He has devoted his life and skills to patients with MPS and similar conditions. He has for example about fifty patients with Morquio's syndrome and has performed fusions of the cervical spine on 28. The first three operations failed and he set himself to develop a technique which has meant that the following 25 fusions have worked. He feels it is vital for this knowledge to be shared and is keen to involve a Consultant in this country if one could be found interested in this rather narrow specialisation.

The seminar for professionals was a disappointment as it was not as well attended as I had hoped but we plan to print an account of the proceedings which will share the information with those unable to come.

The talking over, Dr. Kopits began an exhausting programme of examining children both that evening and in spare hours during the following two days of his stay. We are very grateful to Dr. Stephens and other staff at Great Ormond Street Hospital who provided accommodation and gave generously of their time so that this might happen. The shock for us personally was to learn that Dr. Kopits feels that an operation on Helen's cervical spine is most urgent. He indicated that he would be willing to return to England to operate on Helen and another child and our Consultant is willing for this to happen. We are now waiting to see if something can be organised so that a hospital in this country can learn to use Dr. Kopit's technique to benefit the other children whose cervical spines will need fusing in the future.

Mary O'Toole

WELCOME AMERICA

About 15 families spread over the length and breadth of the USA wrote to the Society since September asking to subscribe to our Newsletter and publications. We think they were encouraged to approach us by a 1985 visit to the USA by our friends in the Research Trust for Metabolic Diseases and following the visit to the UK of Dr. Steven Kopits. In November Mrs Marie Copobianco the newly elected President of The MPS Society Inc., USA, wrote to us seeking continuing links. We very much welcome this new contact and we are sure that all our overseas friends will look forward to the day when MPS fellowship will girdle the world.

Robin & Christine



VICTORIA and KATIE HEADLAND WITH BARBARA KRAFT

VIDEO CAMERA FOR THE SOCIETY

It was a pleasant surprise when I was asked to give a talk to the Independent Order of Foresters from Blackpool. They wanted to make a donation to the Society in response to the Samantha Walker story. Samantha has Scheie's disease and is a very pretty and intelligent 7 year old.

Following my talk to the Foresters they decided to buy a video camera for us, this was one of the many things I mentioned the Society needed.

For all those who were at the Conference the tall 'John Cleese' act alike, who kept peering down the lens at the children was Colin, needless to say we have many budding stars in our midst. All those happy faces is evidence of what a really wonderful time our children had.

The Society is going to have a great deal of use from the Video Camera and all our thanks must go to the Independent Order of Foresters for their generosity and to Margaret and Tony Walker for stimulating such a great response.

Mary & Colin Gardiner
Area Support Family
North West England

*
* There are several copies of the Video Colin made on the *
* Childrens Outings at the Conference. If you would like to *
* borrow a copy to view yourself or to show to others for *
* awareness or fund raising purposes, please contact Mary & *
* Colin Gardiner, 35 Church Road, Banks, Southport, PR9 8ET *
* Tel: 0704 213438 *
*



FAMILY CONFERENCE, A PHOTO BY MIKE TAYLOR,
CHILDREN'S OUTING, THORPE PARK, COACH No.2.

CALLING ALL CAMERA BUFFS

A lot of talent is being wasted - or so I am told, and now here is your chance to show what you can really do!

I am referring to photography!!

Robin Lavery recently rang me up to say he had a brain wave. So many of you send in really great pictures of your children from time to time that its obvious there is a lot of artistic talent around, but nobody ever gets to see them apart from the few published in the newsletter.

So now we are having a competition. I've made the rules as basic as possible.

1. All prints must be a minimum of postcard size.
2. The subject matter is "MPS Children and Families".
3. All prints to reach me by 31st August 1986.
4. On the back of each print write your full name & Address.
5. If you wish, include a title or caption.

Send your prints to me at:

27, Newbarn Park Road,
Galmington,
Taunton,
Somerset, TA1 4NA

David Brooks-Daw



PAGE 3 GIRLS
ALEVIQUE and DOMINIQUE BROOKS-DAW

THE LONDON MARATHON 1986

This will be our national MPS fundraising activity for the first half of 1986. We know several of you have found sponsorship for London Marathon Runners in the past, but this year we are giving you plenty of notice, so that we hope nearly everyone will be able to find at least a few sponsors for our MPS runner.

Last year £1175 was collected in sponsorship money, but we hope to do miles better in 1986 with so many new families in our Society.

With this newsletter you will receive a sponsorship form so you will be able to start collecting sponsors when you see your friends and relations at Christmas. That's the easy bit..... collecting up the promised money is the difficult part! Still - it can't be as difficult as running 26 miles! If people want to give you a set amount when you ask them to sponsor us, take it and write the amount in the Total Paid column, then and there. You know what they say about a bird in hand!

Our runner this year is MALCOLM HECTOR. He is a teacher in the same school as me and will probably be reading this newsletter so I will have to be careful what I write! Malcolm trains with Bridgwater Athletic Club and this will be the fourth time that he has run the London Marathon and has managed to better his time every year so far. Last year he ran it in 2 hours 34 mins. and he hopes to beat that in 1986. Malcolm is 32 years old and is married with one daughter aged 3 years and another child expected any time now. This is the first time that Malcolm has been sponsored for the London Marathon, so let's see how much we can raise.

If you know someone else who is running in the London Marathon and you would prefer to get sponsors for them, that will be quite in order. Simply cover over Malcolm's name with a sticky label and print your runner's name in capital letters over it.

There is no need to have the form verified - unless you hear differently, you may assume that Malcolm has completed the 26 miles and you can start collecting the money as soon as the race is over. (or earlier, if people want to give you money beforehand.)

To get more money you may think of asking several friends to have a sponsorship form and collect from their places of work etc. I have several extra forms- just write and ask for the number you want. You can also photocopy them if you wish.

Pat Isaac
'Beckdell'
Church Road
Fiddington, Nr. Bridgwater
Somerset
Tel:- 0278 732800

Lisa was diagnosed as having Sanfilippo 'A' in November 1984. She was 13 years old then so you can see that this was an unusually late diagnosis. Prior to diagnosis, doctors had told us that Lisa was one of those unique cases, where you will never know what is wrong or why.

Lisa was a perfectly normal baby to us - until at 3 years of age we became worried at her lack of speech. She was clean by day and night at 16 months old, and she walked at 11 months.

At five years she was referred to an Assessment Centre for speech therapy, but we were told not to worry, Lisa was just lazy. She attended our local infant school but by 6 years it was thought she would be helped by attending an ESN(M) school. She was very overactive and hard to control. The Assessment Centre treated her with a mixture of mild and major tranquilisers including 3 Mogadon tablets every night. After a year at ESN (M) school, the teachers decided they could no longer cope with Lisa and she was transferred to an ESN (S) school. It was only then that we discovered that Lisa had spent most of her school day at the ESN (M) school literally tied to the chair.

At home Lisa seemed uncontrollable, she hardly slept, and nor did we. She would empty cupboards, and the fridge with one sweep of her hand. The hardest part to cope with was her behaviour towards her mum. She would hit her with out warning, and for no apparent reason. Her mother could not cope, and didn't know where to get help. The school was worried and a psychologist worked with Lisa for a year, trying to stop her hitting out, but without success. Everyone - doctors, the school, and the social worker - were trying to persuade us to let Lisa go into care.

We wanted to know why Lisa was like she was. We could see that she was gradually deteriorating, and yet no-one seemed to believe us. When we told the doctors that Lisa had been a normal baby they simply ignored us. After constant badgering from us the consultant at the Assessment Centre decided to do some more tests. An EEG showed that Lisa was having petit mals and finally Lisa was diagnosed after her urine had been tested at Guy's Hospital, London. Lisa has been subjected to many, many tests over the years, including skin culture tests. We were never told what they were looking for.

We both feel now that even if we could not have been given a definite diagnosis, it would have helped enormously to have been able to share the doctors' thoughts instead of being disbelieved, or thought of as unable to accept Lisa as she was.

We got in touch with the Society, and Christine Lavery visited us. We attended our first Parent Conference this year. It was very helpful and very distressing at the same time. It is hard for us to think about what the future holds, but meeting other parents has given us lots of support.

Harry & Rosemary Nurse

THE MPS POPULATION AND THE SOCIETY'S COMPUTER

Often when we meet new families we are asked how many children are there of such and such MPS type in the UK? The answer is, we don't know. A rough guesstimate is about 350 which is a figure which has become a bit of folklore for the Society, based on a calculation I did before the first parent conference taking such factors into account as the ratio of MPS to normal births (1:25,000), the UK population, (56 million), the birth statistics of the UK population and the crude assumption of an average "life span" of an MPS sufferer. So it is all a bit hit and miss and I am not even sure about the accuracy of 1:25,000 although it is quite often used in American and British medical papers.

Not that knowing the total is very important anyway, although parents do like to have a rule of thumb to go by. I have recently been updating the information on the Society's BBC micro database and I thought I should share some of the basic statistics which can be taken from it.

There are 231 British MPS and related disorder cases on the Society's register. They include 171 live sufferers and 60 deceased cases of which 12 died before 1982, the year the Society was formed.

Of the 231 families, 45 joined the Society during the course of 1985.

The breakdown of the 231 by type is as follows:

TYPE	TOTAL	LIVE CASES	
MPS 1H	Hurler	49	25
MPS 1H/S	Hurler /Scheie	7	6
MPS 1S	Scheie	3	3
MPS 11	Hunter	56	43
MPS 111	Sanfilippo	74	57
MPS 1V	Morquio	21	21
MPS V1	Maroteaux Lamy	6	6
MPS V11	Sly	1	0
	Not specified	7	6

Related Mucoepididiosis type diseases, ML1, ML11 and ML111 make up theremainder of the cases.

I am inclined to think that there are a lot less than 350 live cases overall. the main hospitals round the UK experienced in MPS are more ready to refer new families to us as the Society's reputation has grown. From such centresChristine has been made vaguely aware of about 40-50 other cases but quite properly the hospitals preserve personal confidentiality and we do not have details. On the otherhand there will be undiagnosed cases; for example the database shows that Sanfilippo are rarely diagnosed before 3 years old; often much later. the same may be the case for the milder forms of the other disorders.

I am still very much a novice in using the computer database but am learning all the time. I have now constructed two other 'files', one for "international MPS families" who are in direct contact with the Society and a third for "rare types" comprising British and overseas families. Until recently our alphabetical card index for British and overseas families was quite adequate (and in any case Christine has a fantastic memory) but expansion over the year means that more sophisticated information retrieval is necessary. The purpose of the databases is not just statistical sorting. I am sure the "international" and "rare types" will be most useful in future to help match like families with like for correspondence links, especially rare cases.

Robin Lavery



CHRISTOPHER and LORRAINE ROCK
by ERICH KRAFT



MPS CHRISTMAS DRAW

PRIZE WINNERS

Microwave Oven	18315	Richard Earl	Milton Keynes
Home Computer	12611	de Mathos	Fordingbridge
Food Processor	33938	Starling	Westbury
Electric Hotplate	28084	Crawford	Blacon, Chester
Electric Razor	277	Ealing	Birmingham
Rainbowbrite Doll	10989	Clarke	Heysham
Camera	15642	Miles	Leeds
Beefeater Voucher	4020	Malfitt	Romford
Camera	38319	Moore	Maidenhead
Desk Set	18224	Pretty	Milton Keynes
Royal Doulton Vase	17584	Byrne	Glasgow
24 Cans of Pale Ale	15396	Evans	Cardiff
Cool Box	23924	Boswell	Penn, Bucks
Writing Case	23653	Macky	Bridgwater
Lego Set	603	McKenna	Taunton
Road Atlas	15554	Olekrik	Newcastle/Tyne
Road Atlas	2566	Wallace	Birmingham
Case of Coca Cola	33134	Reid	Aberdeen
Case of Coca Cola	23578	McCabe	Burnham / Sea
Boots Voucher	6594	Collins	High Wycombe
Smiths Voucher	27263	Limes	Rotherham
Model Set	39712	Smith	Bristol
Model Set	24645	Canham	London
Parker Pen	10149	Chalston	Caenarfon
Wallet	34881	Brunty	Saffron Walden
Wallet	28819	Jones	Corringham
Hand Towels	4686	Penman	Glenrothes
Teddy Bear	13865	Brimble	Bristol
Wurzel Gummidge	31985	Burgin	Salford
Tin of Biscuits	8564	Massey	Reading
Childrens Book	16172	Munro	Worthing
Bottle of Sherry	36841	Blagborough	Glasgow
Childrens Book	21398	Warman	London
Childrens Book	7600	Goulden	Widnes
Childrens Book	37266	Male	Hitchen
Cuff Links	36872	McGowen	Blantyre
Key Case	32399	Foster	Saffron Walden
Lace Bookmark	36110	Bennett	Portsmouth
Cuddly Squirrel	14810	Hale	Sheffield
Stilton Cheese	3808	George	London
Childrens Game	2718	Salter	Ickleford
Stilton Cheese	18305	Sullivan	Milton Keynes

We are most grateful to the following individuals and companies who kindly donated prizes for the Raffle.

Toshiba Ltd., Mr&Mrs Ballard, B.Scurr, Mattel Toys, Kodak, Beefeater Ltd., Menowell Ltd., Mr&Mrs Griggs, Mr&Mrs Harris, Manns Brewery, Sarah Corbett, Mr&Mrs Lowry, Lego Ltd., Goodyear Tyre Company, Coca Cola Ltd., Boots the Chemist, W.H.Smith, Galt Toys, Audi VW, Mr&Mrs Westlake, Linda & Colin Snack, A One Stores, C.Lavery, Stantonbury WMC, Ladybird Books, Aston Martin Ltd., Ros Tyrell, Telephone Rentals plc., Acorn Exal Ltd., Gordon Fraser Galleries, St.Ivel Dairies.



THE CHRISTMAS PARTY



Our warmest congratulations must go to Ron and Linda Snack for their superb arrangements not only in arranging the Christmas Party on Sunday 1st December but in managing our Christmas Raffle so successfully. Our hosts at the Crauford Arms, Milton Keynes, Colin and Val Bell, worked so hard to make us welcome and the Society does really appreciate their kindness and interest. We do hope we did not let you down in anyway and that you did actually feel that you were appreciated.

In some ways I am the worst and best person to write about the party. I was so looking forward to it, remembering Harry and Georgina Taylor's efforts last year in Stoke on Trent. But on the day I was a misery and not just up to it, suffering as I was with an access above a tooth. I felt such a wally "more than usual," you say?). For most of the time I tucked myself away in a corner trying not to attract attention to my misery. Everyone was genuinely very kind to me and I felt very touched, since my temporary swollen cheek was not an important consideration given many of our children's continuing troubles.

Of course being tucked away, I was in a great position to observe.

Never in the course of human history was so much done, by so many in such a crowded space. From my position it was organised chaos. But happy organised chaos. And once again I felt very proud of my MPS friends and thought about how far we've come in 3 years. Apart from the three family conferences there has never been an occasion when so many families have got together at the same time. Colin and Val, Linda and Ron looked after 44 families. I am sure this will be good news to Toc H who handsomely sponsored the party.

Most everyone knew everyone and few people sat alone for long. Having joined several organisations in my time I was deeply concerned that the 8 newcomer families would not feel left out. Being new does not mean being inexperienced and everyone has a contribution to make. It was really quite a responsibility and a tribute to Linda and Ron that so many people should travel so far, for an afternoon party, and I hope particularly that one newcomer, Ann Marie McCormick from Port Glasgow, Scotland was like everyone else not disappointed (sh. don't tell the Aussies they might want to drop in next year as well).

The buffet was superb but in my condition I could not eat my share. Normally no problem; Peter Archard would have done it for me. I know many regretted and understood Chris, Jamie, Maggie and Peter's absence.

Pip, Jane and Julie did marvels entertaining the children in the confined space. Had there been more time I imagine "sardines", and "murder in the dark" could have been included for the adults, but of course there was violence a plenty with baby, wife, police bashing, and husband harrassment tempered by Prof Cornelius and Josie, his partner, with her winning ways. Personally Father Christmas was a disappointment since I did not get a present. Every child did though and wasn't he amazing, for the presents were matched pretty well to each child (something to do with the generosity of "The Entertainer" and some thoughtful hard work by Cath and Gary Grant).

Some mayors and mayoresses turn up to events out of duty. In my position it was quite clear that Their Worships Mr and Mrs Cowley were warmly in tune with the party. They could not stay away from the children or the parents either. Having given up the whole of their Sunday afternoon and officiated with the draw of the major prizes I do hope they felt we were worth supporting.

Of course there was the Chester and Stoke on Trent mafia who came by coach. we were delighted you made it. I was told there was brown ale at the back but when I smuggled myself aboard for the return journey my sons came and fetched me out. Thanks Margaret for all your hard efforts and for facing adversity (I hope you got your tachograph sorted out, or are you care of Watford Gap M1 Service Station?)

Reporting on last year's party I invited others to take up the challenge from Harry and Georgina for 1985. No need to do so for 1986. For the present the 1986 host must remain nameless especially as the offer was made rashly to escape "murder in the dark", but eather is spelt with an 'H' and roughthon with a 'B' and you should never leave the 'Sh' off you know where in Yorkshire, for this is a family magazine..

Happy Christmas and New Year 1986.

Robin



CHRISTMAS CARDS

Our MPS Christmas Cards are going well - there are still a few packets left if you want to order some more. If you received a packet of cards in your last newsletter and don't wish to order any more will you please send either the 70p payment or send the cards back to Pat Isaac (address on front cover), if you haven't already done so.

We have heard that one packet has been damaged in the post and the contents lost. I hope that this has not happened to anyone else. If you have ordered cards and not received them, please can you let me know. I usually send the cards within 2 days of receiving the order, so if you have been waiting a long time they might have gone astray in the post.

Congratulations to Peter and Wilma Robins and family who have sold over 700 packets of Welsh Cards plus a considerable number of English packets as well.

Congratulations too, to Doreen and Monty Russell from Birmingham who have managed to sell 240 packets of Christmas Cards.

Can you beat that!

Pat Isaac

SPECIAL SCHOOL

For some parents, the beginning of a new school term brings very special worries and problems. Jill Maynard, former Chairman of Westminster PPA Branch, was invited by the Editor of the Inner London PPA News to write something about what it was like to have a child at a special school. She agreed, and the following is taken from the PPA Magazine "Contact".

What can I say? That my bowels turn to water at the thought of our girl's future; that my heart aches each morning as I wave her off on her 'special school bus' in the company of her schoolmates; that 'special school' means a handicap and that a handicap calls into question why we had children? Can I say that 'handicapped' child means 'handicapped' family, that I should take even more care over my 'normal' child, and that what I really want to do is to take off my clothes in Tesco's and scream? That I have so far failed to take such brave, evasive action and instead, a coward, become aggressive, obsessive, unpredictable and desperately inclined to tilt at windmills. That I keep frenetically busy, too intense over life in general, and turn into a female ancient mariner, grabbing passing sleeves and bending ears. Small things get out of control because I cannot allow the big thing to get out of hand. Can I say that it hurts to see my child so obviously at home in a 'special' school, and that I hurt for all her schoolfriends too, and their families; that I can see the effect on my fellow-parents: we talk too much, perhaps, or smoke too much, or argue too much, or eat too much, or drink too much, or over-dress or under-dress or don't eat or are 'on pills'; that in each one I know there is such a grief that cannot be 'got over' because there is no end to the sadness until death for some children brings an end to grieving..... and then grief and guilt begin a new cycle.

Can I say all this and say I am glad to hand her over each school day to her splendidly equipped 'special' school, so full of caring people of great skill, kindness and patience? That is a relief to be rid of my irritation, for a while, with a speech-defective child, of my own uncomfortable anxiety with her with her epilepsy, and my own heartbreak at patching and plastering constantly battered knees and arms, and my own anger at having to parade the daughter I love for every single benefit made available by society? Yes I have a Parking Disc; yes, I will soon be receiving Attendance Allowance; yes, the Family Fund has helped me; yes, various charities have also helped. But, ungrateful as I may be, I would rather with all my being that none of them were necessary; that no 'special schools' were necessary; that all those lovely people were working elsewhere. But then, what does one do with our 'special' children? The stake or the bare mountain are no longer acceptable, but neither, really are our 'special' children.

Because we love our handicapped daughter to distraction and because we desperately wish that she, and indeed her school-mates, was not quite so very 'special', you have, dear Editor, your answer - and it's "HELL".

MEMORIAL TRIBUTE - GETHIN ROBINS

When our beloved son Gethin died on 30th December last we stated in the death notice in the paper that we desired family flowers only but donations in lieu would be gratefully accepted for the benefit of the Society for Mucopolysaccharide Diseases to further the cause of medical research. I am delighted to be able to report that the money received amounted to £570 and this sum has subsequently been enhanced by other sums raised through various activities when it was specially requested that the money should go to the Society in Gethin's memory. The total now stands at £977 and we are still expecting to hear how much was raised at the opening night of a pantomime held last week in West Wales when the takings were intended for Gethin's memorial fund.

Peter and I wish to thank all our family, friends and neighbours in West Wales, Peter's colleagues in the Stock Exchange, neighbours in Hornchurch, and other friends up and down the land for their thoughtfulness. We have been deeply moved by the response of people everywhere.

It has been a very difficult year. Having lost our only child the home will never be the same again. There is a feeling of interminable emptiness and loneliness. The existence of the Society has been vital to us and publicising projects concerning Gethin has kept us closely involved with him throughout the year. For example, a friend ran in his memory for the Society in the London marathon; we held a charity stall in Romford market with Paul and Carol Hubbard, and in these last weeks, we have given a talk about the Society and have busied ourselves with selling the Society Christmas card which a friend designed for us in Gethin's memory for the benefit of the Society.

Christine and Robin have been very supportive throughout the year, and Christine has listened patiently and sympathetically to me talking endlessly about the little fellow we miss so much - never giving any indication that she was bored with my hundreds of 'photos!!' She encouraged us to attend the family weekend at Heathrow and it was with some trepidation and anxiety that we anticipated the event. But we are so glad that we did go. It was an emotional time for us but had we stayed at home knowing it was taking place we would, I am sure, have felt worse. Instead we derived great satisfaction from meeting and talking and comparing stories with other families we have become acquainted with, and enjoyed looking after the two children in our charge. I am sure bereaved parents have an important role to play within the framework of the Society. Our experience must be useful and should not be wasted. Equally, for our part, involvement with the Society has been crucial to help us to adjust to our new situation in life.

Wilma Robins

Postscript

With Christmas and the end of the year fast approaching we particularly remember Gethin at this poignant and essentially family time. As we cannot buy presents for him this year we are donating £130 to the Society which we would like to benefit the Holiday Home Fund.

Wilma

ROMFORD MARKET CHARITY STALL

It was well over a year ago now when I first saw published in our local paper an idea of having a Charity Stall in Romford Market. Any Charity wishing to book the space was to contact the local council, which I promptly did as my first thought was for the MPS Society. Unfortunately I received a letter to say the charity stall could not go ahead as the police would not allow it. What a disappointment this was, as it would have been a good way of raising more funds.

The idea of the Charity Stall had completely gone from my mind, when a few months ago a letter arrived from our local council to say the police had had a change of heart and the charity stall will be going ahead. We were invited to write in with a choice of dates. The 12th October was then provisionally booked for us while I applied for a police permit. When all the paper work was done all we had to do was collect lots of goodies for our stall.

Wilma and Peter Robins were to help us on the day so between us all we collected some really lovely things.

I must add that I think half the stall must have come from my sister Linda's bedroom. Every time I went to visit her I would go into her bedroom and raid it. I assured her that she really did not need all these lovely things, so with her arm twisted up her back she willingly parted with hundreds of records, brand new hair dryer and lady shave, lots of perfumes, bath cubes, body lotions and record cases.

The 12th October arrived and at 5.40am two cars full to the brim headed for Romford Market to set up our stall. By 8.30am Wilma and Peter, Paul and myself were anxiously waiting for our first customers. Meanwhile I thought I would take a photograph of the stall for our newsletter. Alas! I had forgotten my camera with the excitement of everything else. "Never Mind" Wilma said "there is a polaroid camera for sale on the stall, I will buy that, then I can go and buy a film somewhere, we will then have an instant photograph for our newsletter".

Unfortunately Wilma did not get the time to run off and get a film for this camera. With all the mad rushes we kept getting from our customers, we all got very involved in the stall. We even got enquiries asking if we were coming back next week! All I can say is they must have thought we were gluttons for punishment. So Wilma got left with a camera she did not really need. Still it will probably end up at Dr. Garrow's Garden Party next year.

By 5.00pm totally exhausted we loaded our cars back up with the few items left, and headed off in the direction of the nearest fish and chip shop as we were starving.

Back home we got to work counting the money, the most important bit! We arrived at a total of £220-24p. What a day and well worth it. Paul and I held this Charity Stall in memory of Gethin Robins, Peter and Wilma's son who died last Christmas.

Paul & Carol Hubbard

Mr & Mrs Williams from North Wales. Their daughter Lucy aged 5 years died in 1981 from Hurler Disease.

Mr & Mrs Wright from Essex. Their 13 year old daughter Alexandra suffers from Sanfilippo Disease.

All but five of these new families contacted the Society as a result of the Martin Bax Research Project. A number of other families also requested information on the Society but we have yet to hear back from them.

* CHRISTOPHER ARCHARD *
* Chrissie died peacefully on Sunday 8th December at home. *
* Maggie, Peter and Jamie will know that we will all remember *
* him very fondly. *



WAS HABEN SIE HEUTE ABEND VOR?
ANN RIDLEY UND ERICH KRAFT

DEATHS

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

Funda Ahmed aged 9 years of South London died on September 3rd, 1985. Funda was suffering from Hurler Disease.

Paul Bottom aged 9 months of Cleckheaton, West Yorkshire died on October 4th, 1985. Paul was suffering from Hurler Disease.

Duncan Hall aged 10 years of Blaby, Leicestershire died on September 4th, 1985. Duncan was suffering from Sanfilippo Disease.

Make everyday a happy day
Make everyday lots of fun
Make everyday the best we have had
before the rain clouds come.

You will feel so glad with the Fun we had
The laughter and the play
The hurt will go like the falling snow
but our love is here to stay.

by Jean Towing

Lloyd & Jean's youngest son Mark died on Boxing Day 1984. Mark was 11 years 3 months old and suffered from Sanfilippo 'A'.

BIRTHS

Gerald and Alison Dore are proud to announce the arrival of Rachel Louise born on 23rd September, 1985.

Andy and Jenny Hardy are proud to announce the arrival of Rebecca Suzanne born on 25th October, 1985. A sister for Matthew.

WHO SELLS WHAT FOR THE SOCIETY

Badges with Society Logo	15p	Pat Isaac 'Beckdell'
Christmas Cards packet of 5	70p	Church Road Fiddington
Pens with Society name	20p	Nr. Bridgwater Somerset Tel: 0278 732800

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Childrens T Shirts white with blue logo (22" - 32")	£2-95p
Adult T Shirts white with blue logo (Medium & Large)	£3-95p

Available from Sue Butler:-Spriggs Holly House, Spriggs Holly Lane, Chinnor Hill, Oxon.

Please include 30p postage for one T-Shirt; 50p on orders of two or more T Shirts.

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FUND-RAISING 'PUBLICITY' MATERIALS AVAILABLE

please state number required!

1. Posters with centre blank to enter own event
 2. Car Stickers
 3. Information Sheets
 4. Current Newsletters
 5. Business Cards
 6. Annual Reports
 7. Official Sponsor Forms
 8. Covenant Forms
- Christine Lavery
30 Westwood Drive
Little Chalfont
Bucks
Tel: 02404 2789

All items are free but we would appreciate a few stamps to help cover the cost of postage.

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PUBLICATIONS

1983 Parent Conference Report	£2-00
1984 Parent Conference Report	£2-00
1985 Parent Conference Report	£2-00 (Available Spring '86)