

NEWSLETTER

SPRING 1986

**THE SOCIETY FOR
MUCOPOLYSACCHARIDE
DISEASES**



National Registered Charity No. 287034

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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 NEWSLETTER

When the need for someone to take over the Newsletter production came up in October last year, we felt that we should offer to 'have a go', although we did so with some trepidation in case we found ourselves unable to cope with the additional commitment. Not least, our combined typing skills and previous relevant experience could be comprehensively detailed on the back of an MPS lapel badge! Our circumstances have changed - our trepidation has not. Well, here we are, our first production. We hope that it doesn't have too many obvious faults and that we will be forgiven for those that there are - this time at least.

The Newsletter itself is now dispatched to a growing number of people around the world and there has been a very large increase in the number of new families in this country over the last two years. The print run now involves several hundred copies. We know that not all of us wish to be associated with the Society in the same way: some, for example, find that the newsletter is upsetting and prefer not to receive it. That is their choice and it will be respected. Others, on the other hand, look forward to receiving it with great enthusiasm: often it is bereaved families who are the most enthusiastic.

Having taken over the production and distribution of the Newsletter, we have regarded this, our first edition, as the opportunity to bring records accurately up to date, to clarify distribution matters and to tackle the matter of subscriptions.

We have sent this edition to every family on our lists (which are held in complete confidence). We have done so in order to give everyone the opportunity of receiving the Newsletter on a regular basis **unless you indicate to us that you do not wish to** do so. To those few who may have given that indication in the past, we apologise but hope that you will understand the need for us to establish a clear understanding and that it is more practical to ask who does not wish to receive it than who does. If you wish us not to send future editions, please will you 'drop us a line' or telephone so that we can note our records accordingly. Thank you.

This brings us to the form of the Newsletter. Above all else, it is a link between and for MPS families. We are developing a few ideas for future editions, but it is **your** ideas, criticisms and contributions that are important. So don't just sit back and expect to receive the Newsletter in the future without also thinking of how you might make a contribution. Make a promise to yourself to make a positive contribution by letting us have details of what you or others in your part of the world have been up to or are planning; let us know what you think of the Newsletter, what should be in it, what shouldn't, what you would like to see in it - better still, show everyone by making a contribution. Make it as long or as short as you like or if it's a date for a future event, for example, give us a telephone call, we can always use snippets of news or general interest items. Don't excuse yourselves with "I can't write" or "people won't be interested". You can scribble a few lines and leave it to us to decipher and/or put into 'shape' if you wish and, of course, people **will** be interested!

Well, there you are. We look forward to receiving a flood of ideas, criticisms and contributions in the next few weeks and on a continuous basis. We'll let you know next time, just how much of a 'flood' you produce. Oh, by the way, the deadline dates are the **last** dates for the normal acceptance of articles. They aren't targets - if everything arrives in the last few days, our four typing fingers (between us, not each!) will become very sore indeed.

Peter & Maggie Archard
48 Lawrence Avenue,
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Hertfordshire SG6 2EY TEL:-0462-673830

FAMILY CONFERENCE 1986

Following on the success of the 1985 conference, arrangements are well in hand for us to return to London Heathrow this year. "Why there again?" is a reasonable question, particularly as earlier years have seen us in other parts of the country. The reasons are basically two-fold: (a) the overwhelming advantages of the hotel being close to those involved in the organisation and, (b) the difficulty of finding any alternative accommodation that could cope with our needs and/or which could compete on price.

This year the Society has been obliged to increase the families' contribution to the costs of the weekend. Increases are never welcome but while the contributions have not changed for the past two years, the cost to the Society have risen considerably. This year the budget is likely to be some £12,000 and although the majority of that will be raised by direct sponsorship, a substantial sum must come from the Society's General Fund. It would be irresponsible and inappropriate to look to those funds to make up all of the increase, however, and a modest increase in the contribution by adults is unavoidable. The contribution for children is again unchanged and, of course, there is no charge at all for those with one of the MPS disorders.

Many who came to last year's conference were, I suspect, a little surprised by the London hotel prices and the cost of a family meal. This year we have negotiated a buffet meal on the Friday evening as part of the inclusive deal with the hotel. This will, we hope, not only make your individual arrangements more convenient but will provide a more satisfactory basis for a relaxed, informal get together at the start of the weekend.

The hotel is a large one and if you are not familiar with it, it can be a little confusing, although with more time to plan than last year, we hope that most activities will be reasonably close together. Those of you who may be thinking of coming this year, who were not with us last year, may wish to note that all rooms are air-conditioned, have colour television and an en-suite bathroom. With the hotel's help, we will do our best to meet your particular requirements for sleeping etc. All MPS families will be accommodated on two complete floors, we hope.

Please send your form back to me as soon as possible. If you have any particular worries, don't hesitate to get in touch, by telephone or in writing. All problems will be dealt with entirely in confidence, of course, and we'll do our best to help, whatever the difficulty. In previous years, for example, several families have mentioned the daunting cost of travelling which, together with the cost of the weekend itself, made it impossible for them to come, much as they would have wanted to. Although we cannot offer direct financial assistance, in many instances we were able to achieve local sponsorship through the Lions, Round Tables etc. and thereby enable families to make the trip - we can't help if we haven't been asked!

The booking form this year is a little more complicated than last time. It includes a provisional programme and an explanation of the discussion groups. It is important that you make your choices now, so that we may assess the demand and make arrangements accordingly. The main part of the form is self explanatory I think, but I would emphasise two points in order to avoid misunderstanding. Firstly, the Friday evening buffet will be available to ticket holders only and will start at 7.00pm. - late arrivals take their chances! The second point concerns the dinner-dance on Saturday evening. Primarily this is for the **parents** to relax and enjoy themselves and one rule applies to all - the evening is not open to sons or daughters, regardless of age. We realise that some may feel this to be unfair, but it is only by such a restriction that we can avoid being asked to make the judgement of Solomon.

We very much look forward to seeing many old and new faces at the Conference.

Peter Archard, for the Management Committee.

HELEN'S OPERATION

Those who read my account in the last Newsletter of Dr. Kopits' visit in October will know that I was in a state of suspense, wondering whether it would be possible for him to return to England to operate on Helen. I am very happy to be able to write now that he did and that, as far as we know at this stage, the operation was successful.

The only way Dr. Kopits could find time to come was by giving up his holiday and leaving Baltimore on Christmas Day. This presented problems as hospitals are obviously short-staffed at that time. Great Ormond Street Hospital could not help and so we turned to our own hospital, University College (UCH). Our consultant, Mr. Andrew Ransford, has always been very open to learning from others about this rare condition and had participated in Dr. Kopits' seminar. He was very willing to make it possible for Dr. Kopits to operate with him at UCH but we ran into almost insoluble difficulties as the hospital was partly closed to save money and admitting only emergencies.

I would hate to live through those weeks again; in fact the surgery and hospitalisation seemed nothing in comparison. Christine and Robin Lavery, with the help of Sue and Dan Butler, worked tirelessly, badgering administrators and organising the practical details of the trip as well as supporting us. With only ten days to go the final permission for the operation was granted and then I started to worry that Helen would get flu or worse - visitors needed a freedom from infection certificate before crossing the threshold! When I heard from Helen Sigwald, the nurse who accompanied Dr. Kopits, that she was worried the airline would lose the box containing the 'halo' I was relieved I had not thought of that one!

Dr. Kopits and Helen Sigwald arrived in England on Boxing Day morning courtesy of Trans World Airlines who gave free return tickets. Trust House Forte helped us again, this time by providing accommodation at an hotel.

We were admitted to hospital on the Friday and the metal 'halo' was screwed to Helen's skull under a local anaesthetic and secured by a plaster cast round her body. This was done in the operating theatre, but as she was awake, I was able to be with her suitably attired in gown, mask and hat. Saturday's operation lasted over seven hours. Bone was taken from three places in Helen's legs and grafted to her cervical spine.

Helen was in intensive care for several days afterwards with tubes and machinery all around her. In spite of this she was rarely distressed and enjoyed being read to and listening to tapes. I plodded through one "Secret Seven" book a day! To our relief there was almost no pain involved in Dr. Kopits' technique, presumably because the neck was immobile. Last time Helen suffered agonies every time she was moved or the dressing was changed. Dr. Kopits and Helen Sigwald were in London for five days and supervised the post-operative care, enabling the staff to benefit from their experience. Dr. Kopits and Helen Sigwald were a great support to us and we were sad to see them leave. The staff at UCH were marvellous, however, and we met nothing but enthusiasm and help throughout.

Once on the children's ward, Helen was able to join in the ward classroom activities, including cake-making. She came home at the end of two weeks and will have to remain virtually immobile until the end of April when we hope the bones will have fused. She spends the time on the settee or a reclining wheelchair and is amazingly cheerful. We are fortunate to have an enthusiastic and imaginative home tutor for six hours a week and I have no fears that she will get behind with work. Her friends come round to play and I take her to school for the percussion club and the choir.

contd. overleaf.

Caring for Helen is physically hard work and it is teaching us what it must be like for those of you whose children are more severely handicapped. When I long for an unbroken night's sleep, I remind myself that our problem is only temporary. I have been busy taking photos and keeping notes so that I can help prepare other families who will go through the same procedure. We feel we have been very privileged to have Dr. Kopits operate on our daughter and it is good to feel we can make some small contribution in this way. Finally a big thank you to all the Society members who have been fund raising on behalf of this project or even just keeping us in their thoughts - your support has meant a great deal.

Mary O'Toole.



Helen in her 'halo'

POSTSCRIPT

Originally Dr. Kopits offered to return to England to operate on Helen provided the Society was able to meet travelling and accommodation costs. As you will see from Mary's article, Dan and Sue Butler were able to secure two free airline tickets from TWA and I was able to call upon acquaintances at THF to provide hotel accommodation. Dr. Kopits left John Hopkins University Hospital in early December to set up the International Centre for Skeletal Dysplasias, a venture dedicated to 'little people' and substantially funded by him personally. Therefore, in gratitude the MPS Society donated £2,500 towards Dr. Kopits' new clinic. This was a small token in relation to the amount of help he has given two British Orthopaedic Consultants, not to mention Helen personally. Already another of our Morquio children has been medically assessed and will probably be operated on by one of these consultants in the coming months.

You may be interested to know that Helen's story featured in the Sunday Times 'review' of the 16th. February. Anyone wishing to see a copy can write to me or to Peter Archard. As a direct result of that article, hundreds of donations have been sent to the Society and as we go to print, nearly £4,000 has been received.

Christine Lavery.

DR. KOPITS AT THE MPS CONFERENCE

Dr. Kopits is to speak at our conference in September and he has generously agreed to make time to see families and children. As you know he has a wealth of experience with MPS patients, not just those needing cervical fusions and may be able to offer you and your consultant fresh views on what can be done to help.

Dr. Kopits will be available at the hotel on the Friday before the Conference (September 26th.) and the Sunday afternoon (September 28th.). He will also be able to see any families not coming to the Conference at a hospital in central London on Thursday September 25th.

If you would like to see Dr. Kopits, please write or phone me as soon as possible so that I can arrange a time. If the demand is great we may have to use a first booked, first on the list, system. Any family wishing Dr. Kopits to examine their child, should discuss this with their GP or consultant and bring with them a letter of referral. Dr. Kopits will then be able to write back with his assessment and suggestions.

Mary O'Toole,
8 Elmhurst Avenue,
LONDON N2 0LT.
Tel. 01-444-8461

MPS IN CANADA

I am sorry I don't write something for your newsletter more often, but keeping the Canadian Society operating keeps me more than busy. It seems that all I ever do is write, since we publish a monthly newsletter in Canada.

We are planning our first national parent conference to be held on May 23rd. to 26th. 1986. We have rented a resort and we have Doctors from across Canada as well as Dr. Kopits from Baltimore, U.S.A. as speakers. The resort has individual rooms for the families and speakers, a dining hall, a conference room and an indoor heated pool. We also have volunteers to keep the children busy while the parents are listening to the speakers.

We have put together a slide presentation. I showed it to a service club and the women were filled with tears and the men were very quiet. They all told me that it was very effective to get the message across about what life is like for MPS families. They are going to be holding a fund raising event for the Society.

We are still having a hard time trying to locate more MPS families. It is very hard to get media coverage in Canada. I think that our biggest problem is that Canada is so large and families are very spread out. We now have a Public Relations Officer who is trying to get our story into magazines and newspapers. The Society has around 32 MPS families as members, as well as another 30 made up of professionals.

We have a medical advisory board consisting of five doctors from across Canada. These doctors are full of encouragement to push on with the Society. One doctor even stated that the formation of the Society is the most important thing that has happened for MPS families in the past ten years. The main aim of the Society at this point, is to bring about more public awareness of MPS diseases in order to locate more MPS families. Strength is in numbers.

I really enjoy your newsletters and family stories. I would like to wish your Society growth and strength in 1986.

Sheila Lee, President - Canadian Society for Mucopolysaccharide Diseases

JUST SIX SHORT YEARS

On 8th. September 1979, Christopher Thomas came into our lives, at what appeared to be a healthy 9lb.14oz! He spent a few days in special care (precautionary only) where he was dubbed "Incredible Hulk". He was, in comparison with the little mites that shared his accommodation - he filled his incubator.

A few days later he was home and the joys of parenthood were all ours - colic, no sleep, and a kitchen full of bottles, in four varieties - being sterilized, to be sterilized, just been sterilized and Scotch (daddy's!).

At seven months Chrissy was seen by our 'new' consultant paediatrician during a routine clinic. It was his first day. Two weeks later we received the news that Chrissy had a genetic disorder at the time described only as Hunter/Hurler syndrome.

What a black picture was painted: a very short life, dwarf, deaf, perhaps blind, heart problems etc. etc. More was said than we heard but even so we were crushed by the news, just as the majority of you reading this have been at some time.

In retrospect, we are grateful that the initial prognosis was so black because the reality has been that much easier. Chrissy developed all the classic severe Hunter characteristics, but through it all shone a personality and character that melted the hearts of all who met him. He never did develop language but he communicated with us and we with him. He brought to us, and shared, a love that many do not ever experience, and we are the better for that. We are doubly lucky to now also have James, aged 3, who's first word was Mucopolysaccharidosis (almost)!

On 8th. December 1985 Chrissy died at home in his dad's arms, with the taste of his favourite chocolate ice cream on his lips. He left us so gently after a few weeks of struggle and uncertainty. How he wanted to stay: how we wanted not to have to say goodbye, although we knew that we had no choice.

MPS. lives are very, very special, no matter how long or short they may be and all of us should regularly put the world into perspective by reminding ourselves just how lucky we are to be close to such individuals.

We have been luckier than many. The support and assistance that Chrissy and we have been fortunate to receive have been outstanding and the friendships that we have made through him have been as sustaining and are as valued as we hope they will be long.

Many families have deep religious convictions, we know. We have the greatest respect for those convictions although we do not ourselves share in them. It has occurred to us that some who read this Newsletter may be similarly minded and, even if only as a result of these few words, may wish to consider the alternatives to a religious ceremony. Such things are very much a matter of personal conviction and faith but it is as well to develop a clear mind on those matters before grief, confusion and the pressures of convention make it impossible.

We are profoundly grateful to have found the British Humanist Association and to have had one of their officiants say goodbye to Chrissy in a way that was dignified, avoided hypocrisy and, most important of all, respected and honoured a mischievous, happy little man whose smile will be with us for ever.

continued on next page.

DEADLINE FOR THE SUMMER NEWSLETTER 26th. MAY 1986

The Association is non-religious but it is **not** anti-religious. Should you feel that their organisation may be able to help you at some time in the future, as they have helped us, they may be contacted at 13, Prince of Wales Terrace, London W.8. Their telephone number is 01 937 2341. Initially you may wish merely to have a greater insight into the nature of the Association and the service they provide through their voluntary officiants. If so, they do produce a simple booklet, priced £2.00, which although designed as guidance for their own people, we found moving and helpful. It is there that we first found some of the words that we asked to be spoken when we said goodbye to Chrissy:-

"We grieve most for the death of a child. When people die in old age, we recognise a natural event, as when the sunset dissolves into the dusk and the night. But the death of youth shocks as though the sun were blotted out by an unexpected eclipse. Our very grief, however, is a token of the strength of love, which is the greatest of all human treasures. And if love is so strong as to grieve, it can also use that strength to grasp the joy of memory. And of all memories, memories of the young have the sweetest poignancy. They come to us like the springtime, renewing our feelings of tenderness and softening our judgement of humankind. There will be strength for you in knowing that for the whole short lifetime of this beloved child he knew nothing but the love of those about him; he knew nothing of life's burdens or the desolation of loneliness. Child-life is a pure blessing that cannot be sustained in adult-hood."

Just six short years, but the most important in our lives. Through the MPS Society we all can gain strength from the experience of others, courage in the support of our large 'family'. That is why it exists, why it will continue to go from strength to strength and why September 26th.-28th. is **THE** most important weekend in our calendar for 1986.

With our very sincere thanks to all of our many MPS friends for their letters of sympathy, their support and their donations to MPS in memory of Christopher.

Peter, Maggie and James Archard.

CHRISTMAS CARDS

1985 There are just a few families who have forgotten to send me money for card that they ordered last Christmas. If this note jogs your memory, please send the money for those you have sold straightaway please - it saves the expense and time of sending reminders to individuals. Thank you.

1986 We are already beginning to think about cards for next Christmas. We have had some offers of designs already, but if anyone else would like to submit a design or designs, we would be very happy to consider them. All designs should be sent to me for consideration by the end of April, when the Committee will choose the most suitable one. We are limited to a few colours because of the cost of printing. "Four colour" is the trade description (ie. no shades).

Pat Isaac
"Beckdell"
Church Road,
Fiddington,
Nr. Bridgwater,
Somerset.

THE SOUND OF MUSIC? by Natasha Macintyre's "Nan".

Following my letter, "It all started with fishing nets" (Autumn 1985), regarding the amazingly varied ways of raising money for MPS, I thought you might be interested in more - and then I'll shut up as I expect lots of you have different ways too. You will be pleased to hear that even Father Christmas has given to the Society after attending a playgroup party - my husband accepted the donation on behalf of Santa.

We had a late shopping evening in our little town of Hythe in the week before Christmas and a brass ensemble (including Natasha's uncle) raised money for MPS by playing carols and Christmas music in the High Street.

Bagshot School (Natasha's first) gave all the proceeds of their Christmas concert to MPS and very generously let Julie (Natasha's mum) have a 'Chocolate stall' in their Christmas Bazaar, solely for MPS. A sponsored slim for Julie raised yet more, although I think that Christmas has put her back to 'square one!' (she's not alone! - Editor)

I have written a Christmas musical which has been produced five times in our area - the last production by Tonbridge Road Methodist Church in Maidstone raised £100 for MPS. And now I have another idea..... Is there anyone reading this who is connected with a church group or an amateur dramatics group who would be interested in putting this on? I would ask no royalties or performing rights whatsoever, as long as all proceeds went to MPS.

Briefly, it is an updated - very updated - version of the Prodigal Son. Bearing in mind the unemployment and housing situation in our country today, it is very topical. It has had very good receptions from audiences wherever it has been played and so if anybody is interested, I will send you a copy and a cassette to give you some idea of what is involved, if you get in touch with me at the following address:-

Mrs.Molly Griggs,
"Mollison",
25,Napier Gardens,
Hythe,
KENT.

THE SCOUT HOLIDAY HOME TRUST

For families with a handicapped member, finding holiday accommodation to suit their needs can be frustrating and expensive. To answer that need, the Scout Holiday Homes Trust was created in 1969. It is a voluntary charity supported by the Scout Association which provides low cost holiday accommodation, for families such as these. **Any** family with a handicapped person may apply (you don't have to have any connection with Scouting).

The units are all self-catering and comprise of chalets or caravans at 13 different established Holiday Camp sites around the country. Each 6-berthed unit is self-contained and has its own flush toilet and bath or shower and colour television. The units are fully furnished and the standards of fittings and equipment are very high. They also have widened doors and entrance ramps to accommodate wheelchairs. As a non-profit making organisation, accommodation rents are kept to a minimum, and the price rates appear quite reasonable.

If you would like further details you should apply to :-

The Scout Holiday Home Trust,
Baden-Powell House,
Queen's Gate,
LONDON SW7 5JS.
TEL.01-584-7030

ACROSS THE 'POND'

The following is the text of a letter addressed to all the individuals with MPS and ML and to their families. It comes from Bill Sellmeyer who lives at 834 Gannon Avenue Madison, Wisconsin 53714, U.S.A.

"Dear all,

First I want to introduce myself. My name is Bill Sellmeyer. I have mild Hunter's and live in the United States of America. I have thought for a long time how I could express my thanks to individuals, families and doctors who have been directly affected with MPS and ML.

I went through a very traumatic experience in 1984. I nearly lost my life from my airway collapsing. When the priest gave me my last rites, I could only think of my wife and two sons. It would have been terrible to think that I could have very easily have died and not come to terms with God. I was in a state of shock, never believing that this could possibly happen to me.

The doctors suspected that I had severe asthma even though they knew I had Hunter's Syndrome. The information I had about Hunter's never mentioned two major areas: the risk of surgery and that an abnormal trachea may be present in some individuals.

A month later I was having more respiratory problems and was sent to a hospital in Denver, Colorado, that specialises in hard-to-solve respiratory cases. It was here that I finally came to know more about mild Hunter's. Now I know the report was written about individuals with severe problems and although I don't project an image of Hunter's Syndrome I have been affected in a major way. I have chronic illness and have been in the hospital six times in a period of three years. I have lost my job teaching hearing impaired children because I am dealing with trying to manage this problem.

The positive message I want to give is to say "thank you". Without the two reports written about the long term implications of Hunter's Syndrome and a report about 31 cases of mild Hunter's in England, my case would never been solved. I wanted to thank Dr. Harper and Dr. Young for publishing the reports.

My major appreciation goes to the individuals who were tested and were put through so much. I know how it feels as sometimes we feel like guinea pigs. I have deep feeling for those and truly have some idea of your emotional feelings. When reading the reports I saw human beings and not medical numbers.

I would also like to express a few thoughts to those parents whose sons died from surgery, heart failure or respiratory causes. Sometimes you may think that you son died in vain and feel very bitter about it. I want to say I can't change the death or loss of a son but the information gained from your experience has helped me and my family make medical decisions. I will forever be grateful to your son and to your family. Now it is my turn to try and manage to live with a life threatening illness. I am trying and I don't want to be a model but I recognise that we are all models in trying to live with this thing.

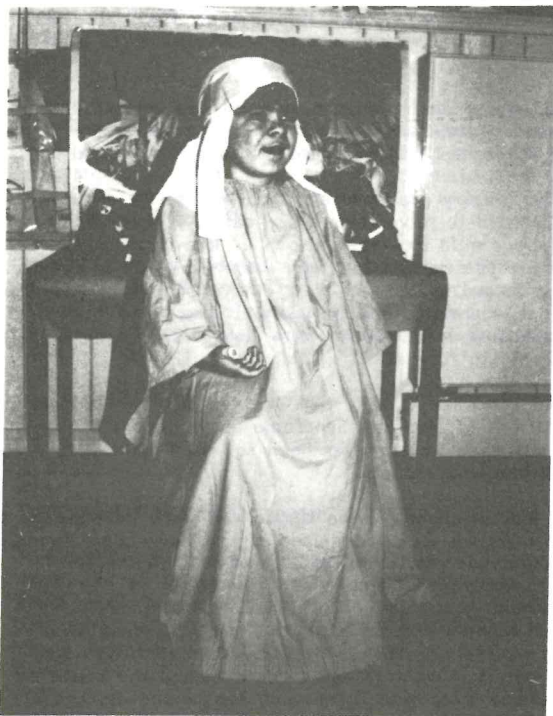
I hope that my thoughts were expressed clearly and that you continue to work for this worthwhile cause. It is an international issue and hopefully one day an international conference can be held to exchange support and information."

Thank you for writing Bill. Your thoughts come across loud and clear although I hope that you will forgive me for converting the American into English! The Doctors will get your message of thanks. Our very best wishes to you and to your family.

NATASHA STEALS THE SHOW

Natasha used to be in a special class in a local primary school but left at Christmas to go to a Special School. As a 'goodbye', the collection at the end of the school's Christmas play was donated to MPS. £120 was very generously given by parents. I raised another £18 by selling chocolate 'goodies' from a stall I was allowed to have for the Society at the school's Christmas Fair.

Natasha played Mary in her class's contribution to the concert, which ensured that there was hardly a dry eye in the hall. She behaved herself very well and didn't throw baby Jesus into the audience as I had feared, but sat as good as gold, enjoying the proceedings, one small 'slip' excepted, when she clipped one of the shepherds round the ear with his own lamb!



Natasha plays
Mary in her school's
Christmas play

Does anyone else have problems as we did with 'little fingers' undoing the car safety belt buckles as soon as they are done up? I contacted my local, and very helpful, Occupational Therapist (Joan) and she came up with the name of a firm that sell special harnesses and buckles that are 'little finger' proof. They are Crelling Harnesses, 11 The Crescent, Cleveleys, LANCS. Their telephone no. is 0253-852298. Joan, however, came up with her own excellent solution. She made a cover for the buckles out of Orthoplast, which means that it can be used in both my car and Ian's. It is so simple and works so well that I suggested to Joan that she patent the idea! If anyone would like details of the design and measurements please contact me.

Julie Macintyre, 31 Elizabeth Avenue, Bagshot, Surrey.

WHICH SCHOOL?

Just over a year ago we were stunned to learn that our three and a half year old son, Matthew, was suffering from mild Hunter's Syndrome. Through the initial period we very much valued the support of family and friends, and still do. By the beginning of 1985 we felt that we were able to approach Matthew's immediate future with a more positive attitude.

Hospital appointments seemed never-ending - now hospital means toys to Matthew and the story 'Topsy and Tim go to hospital' proved invaluable! Weekly visits to physio. and speech therapy are something he looks forward to, and since the insertion of grommets in his ears, his language development has improved greatly. We seem to be very lucky in this part of Buckinghamshire as all the doctors and medical staff that Matthew has come into contact with are keen to learn more about Hunter's Syndrome and M.P.S. in general - publication of the Conference Report is eagerly awaited! (Buckinghamshire - isn't that near Westwood Drive?)

The highlights of Matthew's week are his three mornings and one afternoon session at the local playgroup. His confidence has grown so much that we cannot praise the group highly enough for the encouragement they have given him. "Radio Today" became the most frequently used words in our house - by Matthew that is - and nearly drove us mad. Matthew was convinced that each playgroup session would include the radio - he loves music.

With Matthew fast approaching school age we had to make decisions about his education and from the beginning felt it was important for him to attend the local school if at all possible. We had a visit from the Educational Psychologist, who explained the system of assessments and placing of children in schools, whether they be special schools, schools with units attached for children with special needs, or ordinary schools. Then began the series of assessments - medical and psychological, both at home and at playgroup. We approached our village church school and at once were made to feel that Matthew would be very welcome there, with assistance where needed. Both the Governors and the staff were keen to offer him a place. There has been close liaison between the playgroup, the school reception teacher, the Educational Psychologist and ourselves. This liaison has proved invaluable to all concerned.

We are delighted that Matthew will be starting school after Easter - mornings only - with a welfare assistant. He is looking forward to going there and already knows it, having visited it several times. He will be starting with many of the children from his playgroup.

We must emphasise the need for early contact with the school and indeed, with the Education Department of your county council. It has taken us a year to get Matthew into the school of our choice. Go all out for what you believe is right for your child and contact your local Educational Psychologist as soon as possible - keep 'phoning so that they do not forget you. Do not give up: M.P.S. will support you too. After all, you want what is best for your child and you know them and their capabilities better than anyone else.

Andy and Jenny Hardy
Haddenham, Bucks.

Editor's note

Under the provisions of the Education Act 1981, which came into force in April 1983 and is based upon the Warnock Report, Education Authorities have statutory duties to ensure that appropriate educational provision is made for all pupils who have special educational needs. They must identify those children, assess their needs and, in the case of those requiring additional resources, draw up a formal statement, in the preparation of which the parents must be involved. Has anyone had or are they having particular difficulties with their education authority? If so let us hear from you.

OPEN HOUSE BIRTHDAY

It was a bright sunny day on Wednesday 5th. February 1986. I was picked up by car at 9 o'clock and taken to Newport hospital to be fitted for an indoor electric wheelchair. I did not want to miss this appointment as it meant waiting a further month if it was cancelled.

Meanwhile, back at our new home, which we had only moved into on January 31st., not quite 10.30, and people were already arriving for an early morning coffee. From that time onwards a steady flow of 200+ people flowed through our doors.

I arrived home about 11.40am and went straight to my room only to find my bed laden with presents and cards. It was a shame I could not have thanked them personally. However, from what I could gather later, Carol Hubbard, my 'double', was getting all the attention of "hello Pam" and presents coming in from all sides. Caused quite a bit of a stir when they realised.....it wasn't me!

When I finally decided to take a deep breath and face the music, so to speak, I was greeted by a great sea of faces singing "Happy Birthday" - I had reached my 40th. birthday. It was so nice to see Christine Lavery and Maggie Archard, each with their children. They met up with Carol and Paul Hubbard who stayed on for two nights.

Finally, the raffle, with 29 prizes. There were many cash donations and goods for sale. Altogether we raised £440.42. The following morning Paul and my aunt were kept busy counting the money and donations. It was not until the Friday that we saw a write-up with a donation sent in by my very dear friend Dr. Elliott Burrows.

It had been quite a day, and it was so nice to have Carol and Paul and to have a good 'jaw' about it afterwards. The next day we woke up to 4" of snow! How lucky we had been to have our 'open day' amongst so many wonderful friends. A big thank you to my mum, who put her heart and soul into making it all so successful.

Pam Tubb.



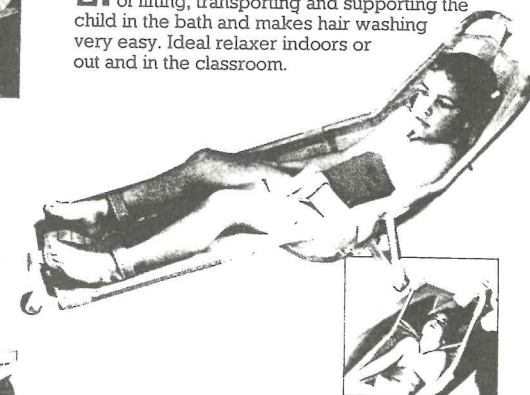
Pam, who, with her 'double', Carol Hubbard, has Maroteaux-Lamy. She lives with Mary, her mum, on the Isle of Wight. Shown here at her party, Pam is on the left.

FOR LOAN TO MPS CHILDREN



1. Travel Chair
The wide range of supportive and positioning accessories enable this chair to be tailor-made to each child's requirements. One adaptive chair becomes a high-chair, push-chair, recliner and car seat.

2. Bath Care Chair This chair does all the work of lifting, transporting and supporting the child in the bath and makes hair washing very easy. Ideal relaxer indoors or out and in the classroom.



The Society have a 'Travel Chair' and two Bath Chairs made by Ortho-Kinetics. The 'Travel Chair' has been kindly donated by Val Corfield and suits children between 5 and 14 years of age. The chair was used by Shelley but has been recently serviced. If you would like further details or would like to borrow it, please contact:-

Val Corfield
Furslow Bungalow
Furslow Farm,
Blunts,
Saltash,
Cornwall.
Tel. Liskeard 20059

If you would like further details of the Bath Chairs or would like to borrow one, please contact:-

Christine Lavery
30 Westwood Drive,
Little Chalfont,
Bucks.
Tel. 02404-2789

NB These items are available without charge but anyone wishing to borrow them would be responsible for collecting them or paying the carriage charges.

CARS - HELP AVAILABLE

Car tax

Have you claimed exemption on vehicle excise duty yet? (See Autumn 1985 Newsletter if not). It is very easy to apply. Write to Blackpool and wait for form HHS.330 to be returned, then take this and all your documents to your local licencing office, with section 2 completed on the back of your log book in your child's name and your own, with your status e.g. Father. You will then be issued with your new tax disc. (After this, your main Post Office can issue discs). It takes from two to three months and your refund will be back-dated to the date of authorisation of exemption.

Yellow 'HELP' pennant for disabled persons.

The Department of Transport has developed a yellow 'HELP' pennant which can be attached to a car window to attract attention. The Department say all road users have a responsibility to help, if it is safe to stop and do so. This could be very useful to a parent alone with a child in the car. The pennant also displays the 'disabled wheelchair logo'. I have not got a pennant yet, but the A.A. or Department of Trade will be able to advise how to obtain one.

Car Seats

MPS children often need large car seats or seat belts that fit in all the right places. Occupational Therapists in all areas should be able to help with this problem. Contact your local hospital and ask for Occupational Therapy, often home visits can be arranged. You can then ask about other aids and explain any problems you may have.

I have on loan a car seat, bath insert, hospital cot, ramp, 'sticky' mat to hold plates steady, high chair, pushchair with rain-cover and a small potty-chair: so as you can see, she can help in many ways.

I hope these notes help you to know what aids are available. I have passed on information about help I have received, maybe other families have discovered aids or services available which they wish to share. It would be a good way to ensure that none of us have problems that other families can help us to solve. If anyone has any questions, please write to me or 'phone, and I will try and help if I can.

Sarah Corbett
25 Alladale Place,
Hodge Lea,
Milton Keynes,
Buckinghamshire.
0908-312440

STAMP NEWS

Since the last Newsletter we have continued to work hard at the stamps and have raised another £56+. This all goes into MPS funds so please keep saving and bring them along to the Conference in September.

Carol Hubbard
71 Preston Road,
Harold Hill,
ROMFORD RM3 7YU.

MPS COOK-BOOK

The cook-book is now in the process of being typed, before printing, and, hopefully will be ready for sale before too long! Several famous people have sent me recipes for inclusion - Margaret Thatcher, Neil Kinnock, Dr. David Owen, David Steele, Dafydd Wigley, Elinor Bennett, Linda McCartney, Terry Wogan, Esther Rantzen, Blue Peter, Simon Weston (man of the year), Ken Coley, Anton Mosimann-Cuisiner from the Dorchester, Sarah Brown (B.B.C's vegetarian cook).

It will be printed as cheaply as possible, as I hope that it will sell on a wider scale if it is priced at around £1. If everyone who bought a book of raffle tickets bought one it would be a good start wouldn't it?

Wouldn't it also be nice if we could brighten up the book with happy pictures of MPS children **eating**. If you have any photographs that you feel might be suitable, please send them to me as soon as possible.

More news next newsletter,
Julie Macintyre,
31 Elizabeth Avenue,
Bagshot,
Surrey.

SANFILIPPO DIAGNOSIS

Diagnosis seems to come fairly late for Sanfilippo children; at least that has been our impression. Families often learn about Hurler and Hunter before the child is aged three. We checked out our database to see what the statistics revealed - we have 76 known Sanfilippo cases, of which development is recorded on only 40.

Of the 40 for which we have information, 8 children were diagnosed before they were 3 years old! However, in every case the child had an older Sanfilippo brother or sister who had already been diagnosed.

New diagnoses (where there is no known previous history in the family) appears to be confirmed only after the age of 3 years. Our records show the following details:-

Age at diagnosis	No. of cases
3yrs. to 3yrs.11months	8
4yrs. to 4yrs.11months	10
5yrs. to 5yrs.11months	7
6yrs. to 6yrs.11months	2
7yrs. to 7yrs.11months	1
8yrs. to 10yrs.11months	0
over 11 years	4
Total	<u>32</u>

Robin Lavery

NEWSLETTER

Please let us have your items for the Summer Newsletter by no later than 26th. May.

Peter and Maggie Archard.

DEATHS

We share in the sadness of those who are now missing the following children who have recently died:-

Simon Fisher of Hull, Humberside. Simon, aged 22 months, died on 9th. December 1985. He suffered from Hurler Syndrome and had put up a great fight following a second bone marrow transplant.

David McCormick of Port Glasgow. David, aged 7 years, died on 28th. December 1985. He suffered from Hurler Syndrome.

Anne Marie Mahon of Sheffield, South Yorkshire. Anne Marie, aged 2 years, died on 1st. January 1986 following a bone marrow transplant. She suffered from Hurler Syndrome.

Joanne Hale of Ickleford, Hitchin, Herts. Aged 17 months, Joanne suffered from Sialic Acid Storage Disorder and died on 16th. January 1986.

Joanne Carter of Havant, Hants. Joanne, aged 14 years, suffered from Sanfilippo and died peacefully on 2nd. January 1986 at Tadworth Court Childrens Hospital.

Louise Broome of Reading, Berks. Louise, aged 15 years, suffered from Sanfilippo and is greatly missed by her sister Julia who is also afflicted. Louise died peacefully at home on 11th. February 1986.

BIRTHS

Congratulations to Graham Corfield who now has a baby brother of 8lb. 2oz. Richard Lloyd was born safely to Val and Mike Corfield on 5th. December 1985. Sadly, his sister, Shelley, who had Sanfilippo, died earlier in the year.

Adrian, who has Sanfilippo, and Charlotte also now have a brother. Baby Paul was born to Shirley Twigger and Brian Johnson on 8th. December and weighed in at 7lb. 3oz. Congratulations to all of the family.

DATES FOR YOUR DIARY

March 23rd. South-West Area Family Day/Somerset Fun Run. See Fund Raising Officer's Report in this issue.

March 29th. Area Family meeting (morning) & Area Family Day for Midlands & South-East (afternoon) at Potterspurty Lodge School, Towcester, Northamptonshire.

May 3rd. Welsh Day! At Pat & Mike Skidmore's. All Welsh families and others wishing to attend, please contact Pat for further details at:- 5 Chapel Close, Wyesham, Monmouth, Gwent. Tel:-0600-4466.

May 26th. Deadline for Newsletter items for Summer issue.

June 6th. Free & easy weekend with MPS camping. Bring your own food & tent etc. to Forestry Commission **lower** site near Coleford, Gloucestershire. The site lies 1 mile West of the B4432. Access is via a minor road to Coalpit Hill. Site O.S. grid ref SO 559130 (sheet 162). Details from Christine Lavery.

July 20th. Dr. Garrows Afternoon Garden Party at Chalfont St. Giles, Bucks. Fine weather assured but offers of help and/or stalls etc. will be appreciated. Featuring Misbourne Orchestra! Full details in Summer Newsletter.

September Family Conference at Heathrow.
26th-28th.

December 13th. Christmas Party 12-5pm. at Newton Hall, Chapelton, Sheffield. (close to junction 32 on M1.). Father Christmas being played by Heather Broughton? Further details in Autumn Newsletter (time flies when you're enjoying yourself doesn't it? Editor)

BIGGER THAN HER SIZE

I met an MPS child once
At the conference at Heathrow.
I asked her why she was so small,
And why she didn't grow.

She slightly frowned, and with her eye
She looked me through and through.
"I'm just as big for me," said she,
"As you are big for you!"

Dedicated to all MPS victims, with apology to J.K. Bangs
and to his poem "The Little Elfman".

PHOTOGRAPHIC COMPETITION

Please don't forget our photographic competition, which will be judged by Camilla Jessel during the MPS Conference. She is a fellow of the Royal Photographic Society and has more than 20 years experience in photographing children. Her published works include "Catching the moment", in which she shows how to catch children on film.

September may seem a long way off still, but it is never too early to start. Just to remind you, the rules (which are as few as possible) are:-

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

Please send your prints to:-

David Brooks-Daw
27 Newbarn Park Road,
Galmington,
Taunton,
SOMERSET TA1 4NA.

NEW FAMILIES

We are delighted to welcome the following families to the Society :-

David and Barbara Watt from West Yorkshire. Their 5 year old son, Adam, has recently been diagnosed as suffering from Sanfilippo.

Mr. and Mrs. Sweeney from Mid Glamorgan. Their 4 year daughter, Caroline, has Morquio.

Mr. and Mrs. Whitehouse from Shropshire. Their 5 year old son, Matthew, has recently been diagnosed as suffering from Sanfilippo.

Patrick Scanlon from London. Patrick is 19 years old and suffers from Morquio.

Janine Bryans from Hertfordshire. Janine and her family are fostering Timothy. He is 6 months old and has I-Cell Disease.

Christopher and Judy Holroyd from Avon. Their 12 year old son, William, has been recently diagnosed as suffering from Sanfilippo.

DONATIONS

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

Mr.P.Macintyre, friend of S.Peach, Dr.R.Stephens, Stella Hale, Mr.& Mrs.Allen, Mr.& Mrs.Williams, Mrs.M.Arnold, Mr.& Mrs.Space, Mr.& Mrs.Lowry, Mr.P.Griggs, Mr.W.Griggs, Mr.& Mrs.M.Russell, Mr.& Mrs.Yates, Rev.& Mrs.Hancock, Mr.Hillier, Mr.Hodgets, David and Marion Russell, Dr.& Mrs.Bansal, Mr.& Mrs.Prestwich, Shelley Scarr, Mrs.Hayward, Dr.& Mrs.Ingram, Mark & Penny Latham, Mrs.Eileen Shepherd, Mr.D.Isaac, Mr.J.Williams, Mary O'Toole; Margaret Leask; Sandra Stone; Julie Macintyre; Kevin White; Christine Lavery; Sue and Dan Butler; Carrie Ellerby; Joan Jarman; Jill Jordan.

Midland Bank; The Austin Bailey Foundation, Swansea; Bethlehem Sisterhood, St.Cleares; Ki Computer Services, Leeds; British Rail Engineering Ltd. Crewe; Harrison & Clough Ltd.; Alexandra Rose Day; Little Chalfont Golf Club; National Council of Women, Ickenham and Stanmore branches; Bestobel plc; Lloyds Bank; Deep Sea Angling Club, Hove; Bagshot County First School; St. Nicholas CE Primary School, Harpenden; Rotary Club, Camberley; St. Andrew's Brownies, Harrow; Springhill Baptist Church; Swallowfield and District Horticultural Society;

Charity Boxes

Little Chalfont Post Office; Greengrocers, Hewlett, Downend, Bristol; Rhodes Grocers, Little Chalfont; Cyncoed Post Office, Cardiff; Workmans Garage, Llanishen, Cardiff; Childrens Bookshop, Muswell Hill; Thresher, Cardiff; Heysham Central Post Office; Keenthorne Garage, Fiddington; Apple Tree Cottage Hotel, Fiddington.

In Memory

Numerous donations received make it impractical to mention them individually but the Society is grateful to all who made donations in memory of:- Matthew Blackburn's Grandad; Mr.Shedden, Bedfordshire; Mr.G.C.Thomas, Newtown; Gethin Robins; Joanne Hale; Christopher Archard; Anne Marie Mahon.

Fund Raising and Sponsored Events

Cardiff Diving Club held a sponsored dive.
Nigel Clark of Hove, ran a marathon.
Brian Scurr did a sponsored slim.
Melanie Gore obtained autographed photos from Clint Eastwood and auctioned them.
Puffins class, Glyne School, Bexhill-on-Sea, held a jumble sale.
The Attic Players, Dyfed, in Gethin Robin's memory, donated panto.1st.night's takings
The Welsh School, Gower, Swansea, held Halloween Night Activities and a school shop.
Daniel and Jonathon Hudson, Chapeltown, Sheffield, went carol singing.
All Saint's Church Lubenham, donated proceeds of the Harvest Supper.
Jim Fairlie and Neil Johnston, Perth ran in the Glasgow Marathon.
St.James CE Primary School, Warrington, donated the collection from Nursery Nativity.
Sarah Lowry & St.Nicholas gang, Harpenden CE Primary School, went carol singing.
Audrey Toker, Keighley, had a sweet jar collection.
The Cinque Brass Ensemble went carol singing.
Doreen Russell, Birmingham, held a clothes sale.
Michele Bookes-Daw and her School of Dancing held 2 shows, & her Mum made & sold toys.
Sally Hughes, Cannington, Bridgwater, held a Christmas cheers morning.
Alex Bessey and Craig Knibbs, High Wycombe CE School did a sponsored run.
Molly Griggs, Hythe, held a musical.
131st. Glasgow Co. Boys Brigade held a 24-hour games marathon.
Alan & Deirdre Beavan held a cheese & wine party and a coffee morning.
Basildon District Cubs held a carol service.
A Bristol Venture Scout unit held a fashion show.
Stogursey keep-fit group went carol singing.
Brymore School, Bridgwater, held a whist drive and draw.

FUND RAISING OFFICER'S REPORT

London Marathon

You will remember in the last newsletter I told you about Malcolm Hector, who will be running in the London Marathon to raise funds for MPS. I have since heard that a friend of Tony Lockyer's will also be running for MPS, so they are busy collecting sponsors in South Wales. I hope everyone will try and get some sponsors for our runners and no doubt many of you will have filled up the sponsorship forms already! We have some spare forms, so are sending out another form to as many people as we can - in case you've mislaid your first one. Let's see if we can get a record amount this year. When you send in your money and forms (by June 20th please) you can state where you would like your money to go - choose between these three and let me know if you have any preference:

- (1) Conference and General Fund
- (2) Research Fund
- (3) Holiday Home Fund

If you do not express a preference, allocation of funds will be made at the Treasurer's discretion.

Other Marathons

Several people will be running for MPS in various Marathons and Fun Runs over the Country. So far I have heard of MPS runners who will be taking part in races in Taunton, Nether Stowey, Bristol and Glasgow. Any more? I have some printed sponsor forms which you can fill in for any event. If you want any, please telephone or write to me.

South West Area Family Day

Our local Round Table (West Quantocks) have adopted MPS as their charity for this year and have organised a Fun Run on March 23rd. We are holding an Area Family Day to coincide with this. Christine Lavery will be firing the starting gun and Robin Lavery and other MPS dads and siblings will be running. (I must commission Peter Archard to take some candid camera shots for the next newsletter!) After the run we will be adjourning for refreshments and a chat for the afternoon (and artificial respiration for some? -Editor) I have written to all the families in the area, inviting them for the day - but anyone who can come from further afield would be more than welcome. Please contact me for further details. See advertisement opposite.

Pat Isaac,
"Beckdell", Church Road,
Fiddington,
Nr. Bridgwater,
Somerset.

Tel:-0278-732800



West Quantocks Round Table

AREA 37 - No. 1197



'FUN RUN'

IN AID OF

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES



at **NETHER STOWEY**

10.30am Sunday 23rd March 1986

Further information

Tom Jobson
Castle Stores
Nether Stowey 732325

OR -

Pat Isaac
Beckdell
Fiddington 732800



THESE POSTERS WERE DESIGNED AND PRINTED AT THE BLAKE SCHOOL,
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