

NEWSLETTER

SUMMER 1986

# THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES



National Registered Charity No. 287034

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## SECRETARY'S REPORT

It is six months since I wrote for the newsletter and so much has happened, keeping us all very busy. By now you should all have received your copy of our 1985 Parent Conference Report and samples of the new fund raising leaflet. We were thrilled with the favourable comments received regarding these publications, and would like to thank Pat Isaac for masterminding the layout of the fund raising leaflet and the families who kindly allowed us to portray their children. We also owe a big thank-you to Kate Farminer and her mother for writing up, and preparing for print, the conference report. Anyone wanting a supply of fund raising leaflets should let Pat Isaac know and further copies of the conference report can be ordered from me, priced £2.

We are very sorry to lose Catherine Grant and Robin Lavery from the Management Committee. Many families will remember Cath at our conferences but may not have appreciated that her affection for Simon and her support to Robin and myself, was a contributing factor in founding the Society.

Robin has always felt a little uneasy about his dual role as a Trustee and Chairman of the Management Committee and has decided that after two years, it is appropriate for him to move aside for a new Chairman. This not only brings a fresh face and ideas but further strengthens the Society by spreading both the tasks and the responsibilities as widely as possible.

I am sure that you will wish to join with me in offering them our sincere thanks for all their hard work and at the same time welcome Mary O'Toole as our new Chairman.

Many hours hard work and 18 months wait, finally paid off in March when the DHSS agreed to give us our first grant of £1,000 slippage money, to pay for a poster to spread the word of MPS. Choosing the right picture was hard enough, and coming up with a phrase to make people look, think and take note of the Society, was even more difficult. At the end of the day the Committee decided to have two types of posters printed. The first one is at the printer now and the second will follow a later in the year. Anyone wishing to have a poster for awareness or fund raising purposes, should let me know. If anyone has, or knows of, a supply of tubes suitable for posting the posters to families, do let us know. If you can send me a tube when sending for a poster, it would be a great help.

Our second grant from the DHSS was specifically to provide part-time secretarial help for the Society. Shirley Frith started working three mornings a week in April, and with her keenness to learn and interest in the Society, she is worth her weight in gold. Some of your children will remember the Sunday trip to Heathrow and Concorde at last year's Conference; Shirley was a helper on that outing and her husband Brian, who works for British Airways, brought along all the B.A. Hostesses - I'm sure the Dads will remember!

The Society has continued to receive excellent media coverage in many parts of the Country. On a national level, you may have seen the BBC news showing the removal of Helen O'Toole's 'Halo', or the Woman's Own article (for week ending 31st May) recording Helen's story. On the first day of publication we heard from a new Morquio family who had seen the article, and I am sure there will be more. Over £5,000 in donations were received as a result of the Sunday Times article (February 16th) and we understand that in the coming weeks there will be a follow up. Remember, if you have an article published in a newspaper, do let us have a cutting for our Record Book - we are now running into the second volume!

After much deliberation the Committee have decided not to take the Holiday Home Project forward at the present time. (See Mary O'Toole's article on page 3) It has been agreed that the Society will arrange two subsidised group holidays in 1987. We are grateful to Mary and Colin Gardiner for offering to take this project forward.

Dr. Martin Bax has now received over 200 responses to his questionnaire. These have been entered on the computer and provide an excellent basis for compiling a comparative study. If anyone has not completed a questionnaire and would like their child to be included in this study, please obtain a blank questionnaire from me as soon as possible. Dr. Bax, who has now moved to the Westminster Children's Hospital, is in the process of appointing a new clinical psychologist, to replace Irene Sclare who recently left the project. The Management Committee and Trustees have agreed to fund this part-time post for 12 months, and Martin and his new clinical psychologist plan to visit as many of our MPS families as possible in the forthcoming months. On Sunday at the Conference, Martin will be describing the developments of the project so far.

Robin and I would like to thank the Austrian, West German and Swiss families for making us so welcome at their first Parent Conference in Scharding. We met a lot of lovely people and learned a lot from our experience. Our visit demonstrated that MPS has no boundaries and that our problems are similar to those of MPS families in other countries. Our already common bond enabled us to communicate, despite my non-existent German and Robin's few hours of learning (English? Editor) from a Walkman tape, to and from the office. We were not only able to put families in touch with British families, but in the much rarer types, link them up world-wide. Marion and Erich Kraft were our hosts for the five days and from the moment we set foot in Austria we were treated like Royalty.

Please may I take this opportunity of sharing some personal news and ask for understanding if letters etc. have not been answered as promptly as we should like. (If anyone has telephoned or written in for information and not received a reply, do please let me know). On our return from Austria I was unwell and soon discovered I am expecting another baby. Our first blow came when I was admitted to hospital seriously ill and had to undergo an emergency laparoscopy. Despite everything the baby survives and we will have to wait until 8th July for an amniocentesis. It was particularly disappointing not to be able to benefit from the new chorionic villus test, but the severity of the infection in my uterus prevented this. We would like to thank all the families who have shared our anxieties over the last few weeks, it was good to have so many friends who understand.

It was obviously most disappointing that Robin and I could not embark upon our planned visit to Baltimore to see Dr. Kopit's new clinic for 'little people' nor address the Canadian MPS Society's Parent Conference. Nevertheless, we were thrilled that at very short notice, Dan and Sue Butler were able to step in and represent the Society. We look forward to receiving their report of the visit in the next Newsletter.

If we did not see you at the camping weekend (6-8th June), perhaps you can come to Dr. Garrow's Garden Party on 20th July. If not we look forward to seeing you at the Conference.

Christine Lavery

Thank you to all those who have made the many contributions to this edition of the Newsletter and our apology to those who have suffered abbreviation or alteration for reasons of space. Please keep all your news coming in and let us have it please, as early as possible. **The last date for articles for the Autumn Newsletter will be 29th August 1986.**

Peter and Maggie Archard

## HOLIDAY HOME PROJECT

In the early days of the Society a fund was started to raise money for a caravan, to provide a holiday base for families. Later the idea expanded to consider a specially equipped house, with room for two or more families. A questionnaire was sent out which indicated that forty-five families would use such a facility and a working party began the task of assessing whether the project would be viable. A great deal of hard work was put in by a number of families who were enthusiastic about the idea of a holiday home.

Questions were raised, however, to which there were no satisfactory answers. Who for example would be responsible for organising bookings and for the management of the house? Even if a caretaker were employed there would be problems, major repairs for instance, with which he could not deal. We were told that it would be necessary to continue raising £5000 a year for the cost of maintaining a holiday home, and we learned that other charities were closing theirs.

Enquiries also revealed lists of cottages/houses suitable for the handicapped which we could rent and of activity holiday centres catering for the disabled and their families. One of the disadvantages of the Society owning a holiday home would be its fixed location, making it difficult for many families to reach. If we organised one or more holidays a year in rented accommodation, we could try out different parts of the country. Some families might prefer to go on their own choice of holiday but might need financial help from the Society or another charity.

At the recent family meeting at Potterspurty Lodge we discussed these alternatives with the 20 or so families present. On a show of hands, only one family felt we should invest in bricks and mortar; the rest favoured alternatives such as those outlined above.

The Management Committee met in May and considered the position. We discussed whether to send out another questionnaire to establish whether members of the Society, whose numbers have doubled since the original questionnaire, would wish funds to be invested in a holiday home or for the money raised so far to be used in other ways to help families to have a holiday. The problem we faced was that, for one reason or another, not one of the working party members remained in a position to invest the amount of time required to take the project further. We felt that it would be time wasting and unfair to ask families to make a choice, knowing that if the majority opted for a holiday home, we would, at the present time, be unable to proceed to acquire one.

It was therefore agreed, that for the time being, the fund should be a holiday fund rather than a holiday home fund, that the money should be invested in the most profitable manner and the interest (and if necessary, some of the capital) be used to support alternative holiday schemes. Plans are already being made for next year - details to follow in the next newsletter.

Further fund raising for this project will not be necessary but I would like to thank all the families and individuals who have worked hard to raise the £13,000 presently in the fund. Many thanks as well to the members of the working party, for all the time they gave.

Mary O'Toole  
Chairman of the Management Committee.

## LIFE IS WHAT YOU MAKE IT!

We may be small, but don't let that fool you, our tongues can be as sharp as anyone else's - Simon (our brother) can give evidence of that! We've been brought up as any other family, the usual arguments etc. Mum and Dad have always treated us in accordance with our age - and not our size.

Being three years difference in Nicolina (26) and I (23), everywhere she's been, I've turned up three years later! We both attended a normal primary school at West Huntspill, where we used to live. Nicolina was then on crutches, and apart from being excused from some of the harder P.E. (which neither of us liked anyway!) we were accepted like any other children.

At the age of 11 it was impossible for either of us to go on to a secondary school; with all the carrying of books and changing of classes every lesson, we just could not have coped. So we became weekly boarders at Princess Margaret School in Taunton. This was the first time we'd been in total contact with other disabled people, although there were none who shared our disability.

At Princess Margaret's there was nothing which anyone couldn't join in with, so, alas, there were no more excuses from P.E. - or physio', as it was known! Nicolina won a gold medal during a weekend of swimming at Stoke Manderville. I tend to swim like a brick, but I did horse riding which was good exercise for my hips, since they are both dislocated. I rode at a gymkhana in front of Princess Anne. We also took part in plays, made invaluable friends, as well as both acquiring a good sense of humour. Lessons were the same as at any other school - English and maths etc..

From Princess Margaret's at the age of 16, Nicolina went on to pass an 'accessment' into St. Loyes College in Exeter for eighteen months of further education. At first she hated the thought of going, even more so when she discovered that they had black iron bedsteads! After the eighteen months, she went on to a different department where she trained as a key punch operator. I also got into St. Loyes for further education and completed a training course in copy typing. We both left with diplomas.

It was at college we discovered how different we really were. Nicolina settled in quickly, always going places, taking part in the various activities such as the Ten Tors expedition across Dartmoor, pushing herself in her wheelchair. Whereas I tended to like coming home at weekends, and since we had then moved to Taunton, Dad would come and collect me.

College played an important part in our lives, it taught us both to be independent. There was no one to do our washing or run behind us checking we had eaten properly and making sure we were o.k. It also meant we were perfectly capable of working a forty hour week in a normal office environment and getting a proper wage.

As for employment, just like anyone else, things don't look too bright at the moment. Nicolina has worked on two MSC schemes, each lasting twelve months, and I've worked on one. But this doesn't stop us from applying for all the suitable vacancies in the local newspaper, and sometimes we get through to interviews. The main thing is not to give up, even though sometimes it can be frustrating when you know you are capable of working.

It's a good thing we get on well - apart from the occasional disagreement. Nicolina takes part in the disabled drama group 'ENCORE' and is also their Chairperson. I have just become their Treasurer. I enjoy making tapestries and any kind of handicrafts. We both enjoy letter writing and have several pen pals. Our tape recorder is also always in constant use - especially playing Barry Manilow cassettes - two years ago we even managed to attend a Barry Manilow concert at Wembley, it was fantastic!

Our latest achievement is passing our driving tests for the first time. It has always been our ambition to drive, and finally in March of last year we sent in an application to the Motability Scheme to buy an automatic Mini Mayfair. It was delivered to our dealers in Taunton in August. The next step was to get it adapted. The nearest place was South Molton in Devon. Luckily we were going away on a family holiday to Guernsey, so the waiting wouldn't seem so long! Nicolina and Simon went with a garage man to Devon to decide on what was to be done. When we came back from Guernsey our car was ready and waiting. Because we can both use our feet, we decided against hand controls. We had extended foot pedals, a false floor, a flip over hand brake (as neither of us had the strength to move the usual one), an extension on the gear stick and a built up cushion. It has also been adapted so that an able bodied person can drive if necessary.

We were lucky in having a super driving instructor, he hadn't taught a disabled person before, so it was literally a case of his life being in our hands! Nicolina unfortunately got glandular fever in the middle of learning, so it slowed her down slightly. I took my test in March and Nicolina's was on the 10th of April - the day before her birthday, it could not have been a better present. We still can't believe we are mobile, even now. It's a feeling that is impossible to describe, definitely a dream come true. We have ordered a wheelchair for Nicolina, which is designed especially to fit in the boot of a mini, and Simon has designed and is making us a rack at college to fit on the back of the car so we can carry two wheelchairs, as I need mine for shopping etc..

Both of us feel the reasons we've got on with our lives is because we have always had love and support from our family and friends, also, we have concentrated on the positive side of everything. It is no good sitting back and dwelling on all the things you can't do. Life is definitely what **YOU** make of it.

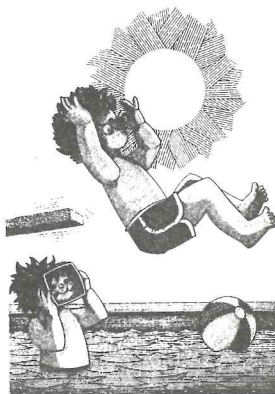
Sarah Stangoni.



## SWIMMING FOR THE DISABLED

**Benefits of swimming:-** Swimming helps to overcome the fear of water and helps to produce a sense of ability to overcome other fears. It improves co-ordination, provides skills to enable the pupil to participate with other members of the family, and develops the ability to follow directions. Having grommets in the ears should not prevent swimming, if, with the doctor's permission first, dry cotton wool is placed in the ear and sealed over with vaseline to make a water tight seal, and a swimming cap is worn.

**Aim:-** Encouragement, achievement, relaxation, progress. At ALL times keep safety precautions.



**Exits and Entrances** should be progressive where possible, encourage independence. Do not rush the swimmer, let them sit on the side and splash and watch others play. Go down the steps backward if able to walk, otherwise let the helper be balanced in the water and let the swimmer slide in - with the swimmer's hands on the helper's shoulders and the helper's hands on the swimmer's waist.

If transferring from a wheelchair, make sure that the brakes are on and a towel is on the pool-side to avoid abrasion where there is poor circulation. **Never** carry a child on a wet pool-side.

### Games and Toys .

These help to keep enjoyment as the main theme for a lesson and with careful thought, these can be used to teach skills progressively. Use inflatable toys, and empty 'jif' lemons and washing-up liquid bottles, brightly coloured, which can be filled with water.

A tape recorder can be used - children respond to music.

With the relaxation these bring, the pupil is enabled to make full use of the freedom and buoyancy that the elements of water provide, and the pupil is free to move about without the hinderance of calipers or wheelchair.

### Safety to be taught early

Breathing - emphasis on exhalation - blowing a table tennis ball along the water.  
Regaining the feet - from the front and back lying position.  
Resting - floating and treading water.

### Support by helpers

The swimmer should feel secure, but should be allowed as much freedom as possible, bearing in mind the safety factor. Helpers should be at eye level with the pupil in the water, it may be necessary for the helper to kneel on the pool floor. Support should be given for the supine (on their back) - mouth and nose clear of the water. A help for some MPS cases is to rest the head of the pupil on the shoulder of the helper, whose hands will then gently support either the hips or shoulder blades of the pupil, depending on build. The aim is to have the pupil in a safe horizontal position feeling comfortably supported.

In a **prone** position, the helper gives support by placing their hands under the armpits or rib-cage. This allows for free movement. For leg practices, the hands should be placed under the hips, with the pupil's hands on the helper's shoulders.

## AIDS

**Polyotter Float Suits** are an excellent aid as they have removable floats and give optimum buoyancy in fresh or sea water, and leave the arms free of arm-bands. Children's sizes range from 20" to 30" going up in 2" stages, adult sizes also available from :-

Pollyotter Ltd.,  
Elliott House,  
Church Street,  
Kingsbridge, Devon TQ7 1BY

Cost - from £11.

**Airlines Floatation Jacket.** These bubble jackets fit like a life-jacket and are made in material similar to the plastic bubble packaging used these days. They are made to measure in 28 days. (Measure from the navel down, between the legs, up the back, over the shoulder and back to where you started from (!), wearing what would be worn under the jacket when measuring).

Available from:- 7A High Street,  
Glastonbury,  
Somerset.  
Tel: 0458 32238

Cost - £5.50

**Swim Collar.** This is a most useful head support for the handicapped with weak neck muscles or large heads that require support. It is inflatable with two safety valves and ribbon ties under the chin.

Available from:- The Swim Shop,  
52-58 Albert Street,  
Luton, Bedfordshire LU1 3PR

Cost - £5.20 inc. p&p junior size.

### ALL THESE AIDS MUST ONLY BE USED WITH THE SWIMMER UNDER CONSTANT SUPERVISION

There are numerous swimming clubs for the disabled in the country, if you don't know of your nearest one then write to the National Association of Swimming Clubs for the Handicapped, who have a register. A booklet is available, price 50p, from:-

NASCH Administrator, Mrs. R. Leeson,  
219 Preston Drive,  
Brighton,  
Sussex BN1 6FL

St. Christopher Sports Club for the Handicapped meet at 6.30pm each Monday at Lord Butler Leisure Centre, Saffron Walden, and anyone living near will be most welcome to visit us and join in the swim.

Muriel Kenworthy ASTA,  
18 Farmadine,  
Saffron Walden, Essex.  
Hon. Sec. Region 3, NASCH.

## MPS COOK BOOK

Much hard work has been put into the compilation of our MPS cook book, and our thanks go to Julie Macintyre who has gathered up over 100 wholefood recipes from many well known people, as well as MPS families and friends. Margaret Thatcher has shared her favourite recipe for oatmeal biscuits, Neil Kinnock describes his own recipe for Welsh cakes, and not wishing to show any political bias, David Steele and David Owen have also contributed their favourite recipes.

We have now passed the draft to the printer and we are awaiting the typeset version. The book is expected to be priced at around £2 - £2.50 but this will depend on printing costs and the number we can sell. The Society intends to market the book and is looking for lucrative outlets for bulk sale, i.e. Round Table, Lions, Church, Companies etc. If you have any ideas, or if you can help, please let us know.

Tell your family and friends about the cook book. We would appreciate an idea of advance orders. The cook book should be ready for launching at our Parent Conference in September.

Christine Lavery

## DIDN'T WE HAVE A LUV-ER-LY TIME..... THE DAY WE WENT TO CRICKET ST. THOMAS?

Six families from the South-West area ( the Brittons, Brooks-Daws, Hills, Holroyds, Isaacs and Piddens) met up on June 1st for an MPS family outing to Cricket St. Thomas Wildlife Park near Chard in Somerset. There were 31 of us altogether, including grandparents, and a total of 7 MPS children. We seem to be mostly Sanfilippo families here in the South-West ( Aleviqne, suffering from Hurler's Syndrome and Christopher with Morquio were the odd ones out, though they didn't seem to notice!)

By booking our party in beforehand, we managed to get cheaper party rates and further reduced rates for our MPS children - a point worth remembering if anyone else is organising an outing in another area. We **did** manage to confuse the gatekeeper though and somehow managed an enormous discount on our train ride! The weather was pleasant and we spent the day picnicking together and looking at the various animals' tricks (THEM not us!) - elephants, snakes, monkeys, penguins, flamingoes and heavy horses to name but a few. Bill Pidden gave up his delegated task of trying to keep all 31 of us together quite early on, and we settled for an average of 20!

The children soon made friends with each other while the adults renewed friendships or met new faces, swapped stories and ideas about those 'difficult' clothes, fund raising events past and future, and reflected on how our MPS children altered our view of the world. Most popular with the children was the adventure playground with life-like Wild West Fort and the ride on the Scenic Railway through picturesque woodland and past lakes with seals, to the far end of the park.

Like all MPS gatherings, on the walk back everyone ended up looking after everyone else's children, there was so much to talk about and not enough time to say it in, and much taking of photos. (Has anyone ever succeeded in getting four young Sanfilippo children to pose together for a photo yet?) After an enjoyable day we left for home with promises to arrange another event soon, our batteries recharged in the company of other MPS families - a day of not having to 'explain' our MPS children and not feeling 'different' for a while.

Thank you to all the families who came and made the day so successful - and thanks to the Beavan family, whose article in a newsletter and report at the Area Family Meeting about their area's outing, inspired me to organise ours.

Pat Isaac.

## DONALD'S "DO"

The 20th July is bound to be a gloriously sunny day - the weather has been ordered specially!

Dr. Donald Garrow is once again allowing us to take over his "grounds" to enable us to raise money for MPS. Last year 11 MPS families came and a great time was had by all. The Garden Party is open to the public from 2pm until 5pm, but any MPS families wishing to come should arrive at any time during the morning and bring a picnic lunch.

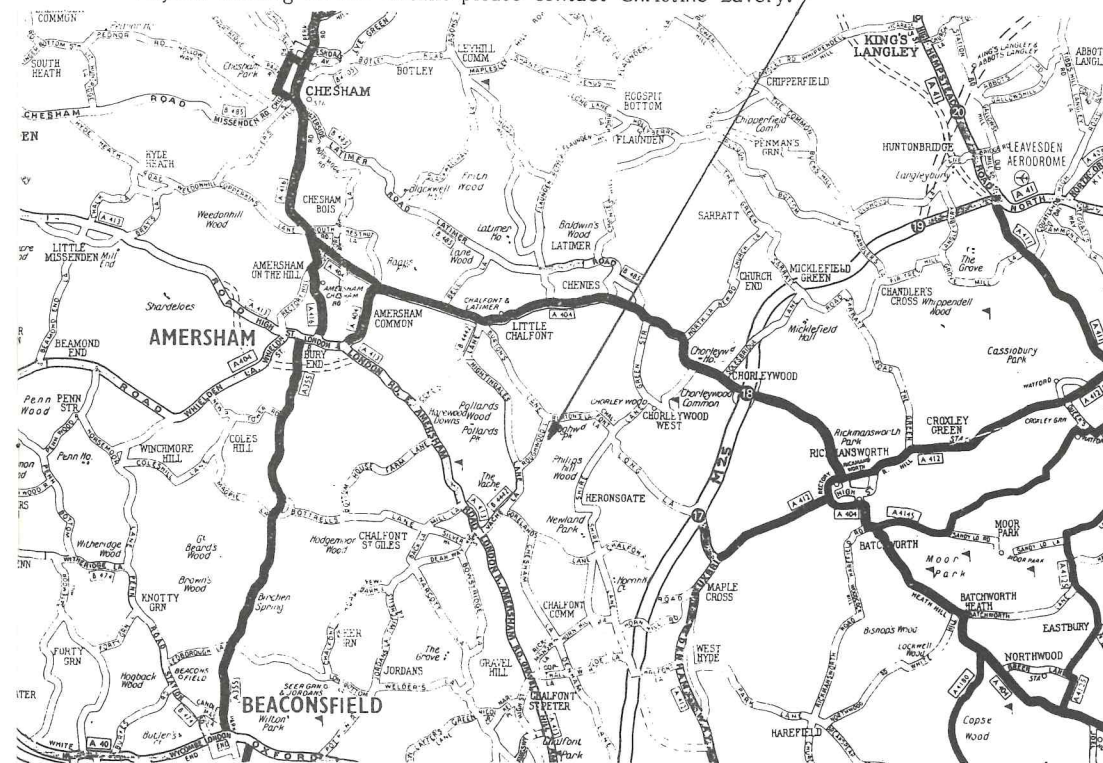
We usually have stalls and games or side shows and anyone wishing to bring either will be welcomed with open arms. Otherwise we have a Tombola and cake stall, so any contributions will be gratefully received. We can always use an extra pair of hands too - even just to steady wobbly children on the pony rides.

I'm sure you will have a delightful day - sitting under the trees, sipping tea and indulging in cream cakes (blow the diet for one day!) and listening to the Misbourne Orchestra playing live! Bring your swimsuits and towels too - Donald has a lovely pool.

So, don't forget -20th JULY 1986- at:- **Roughwood Farmhouse,  
Roughwood Lane,  
Chalfont St. Giles,  
Bucks.**

Look out for MPS posters in Chalfont giving directions.

Anyone wanting further details please contact Christine Lavery.



## DIVIDED WE MAY BE...

Victoria is a long stay hospital patient in Alder Hey Children's Hospital in Liverpool. Having her in hospital was not an easy decision to make, nor was it an easy way out. The latter can often be read in unknowing eyes.

Victoria is now eight years old and has Sanfilippo Syndrome, complicated by diabetes. When we lived in Chester, Victoria, after her diagnosis in 1981, attended the nursery in our local special school and went to a community home for respite care. However, her behaviour was even more difficult when she came home and she tended to become more aggressive. Brian and I found ourselves at each others throats constantly - I was up most of the night with Victoria and the only way I snatched 40 winks was to sleep with her. So we never really had any time to ourselves. Charlotte was being pushed out more and more, although we tried so hard to give her attention she would shut herself in her room and read or play - thank goodness for Sindy!

Unfortunately she developed "baby" eczema which was brought on by emotional stress; she still gets it when things worry her, especially when Victoria is ill. Brian was not in the best of health with his diabetes and by now he had also had a mild stroke. Working away from home frequently did not help either. Our family life then was virtually non-existent. I had many 'heart to hearts' with our Social Worker who was extremely supportive. Between her, our G.P. and paediatrician we were advised to consider letting Victoria stay in the home for longer - the going and coming home was too unsettling. It was decided that she could stay there and still travel to the same nursery every day. She now knew her routine and seemed more settled and much happier.

We missed her dreadfully at home but at the same time discovered what a mess our lives had been. It may sound corny, but it was almost like being re-born, Brian and I seemed to be beginning all over again and Charlotte became happy and carefree. Of course it meant that we would always be a divided family but nevertheless a happy divided family. We felt we did the right thing for all members of our family, although I must admit I do feel a little guilty, especially at our MPS gatherings.

We would always visit Victoria at weekends and during school holidays and take her home or to see family or friends. However, after a time the staff at Yeoman House, who were absolutely fantastic with her, found Victoria's medical needs and laundry problems too much. (They were also having to employ an extra member of staff for her during the night.) It was decided that a hospital would be more suitable. There was nothing in the Chester district so the Royal Liverpool Children's Hospital in Heswall agreed to have her as a long stay patient.

Victoria settled in well, attending school every day and being the centre of attention the rest of the time! She did become very poorly on several occasions and through these events it was discovered that she had diabetes! This made Brian feel even worse about her condition because, not only had we, as carriers of SF, given her this dreadful disease, he had also passed on his diabetes. Even now when he is with her I can see the hurt in his eyes.

So now with the added problems of insulin and diet we realised that hospital was the best place for Victoria. Keeping a hyperactive child stable was a job that only the medics could do successfully. We would still visit Victoria as before, weekends and school holidays, our lives seemed quite settled, although Christmas and birthdays were always hard. But the staff on Holbrook ward were very loving and caring people and cousins always enjoyed Victoria's parties!

The most devastating blow came when it was announced that the hospital was to close. I just wanted to run away and pretend that none of this had ever happened! We were so angry because by now Victoria looked on Holbrook as her home. We decided to fight the closure and fight we did, but decisions had been made and the hospital eventually closed.

In January 1985 Victoria went with some of the children and staff to Alder Hey, Liverpool, which was a long way from us, but for her health and happiness there was no alternative. I must admit that when we moved to a larger house with a lovely big garden, I toyed with the idea of Victoria coming home. I dreamed all sorts of alterations to accommodate her as her condition deteriorated. But then I had to think of Charlotte, how happy she now was, doing gym and going to Brownies etc., how Brian frequently worked away, and, for myself, would I accept a teaching post if offered one? It may, perhaps, sound rather selfish, but we had to keep our sanity, remembering what things had been like before and how really low we had been. I did not think I had the strength to survive all that; I admire those that have.

Victoria took a long time to settle, by now her drugs and diet were changing according to her many individual needs, staff were changing, routines were different and there was no school for her. Victoria became desperately ill and we thought we were going to lose her. But all the specialist doctors and equipment were to hand and she pulled through. If she had been at home who knows?

Victoria now goes to a special school, she is an established walker in the Alder Hey corridor, and overall I would say a happy child in her own way. We visit as always at weekends and school holidays but with it being so far away we do not manage trips back home or to family very often because an hour outward and the same returning is a lot for Victoria, and our British weather does not encourage such journeys either! Of course it also means that our weekends are always booked and we never really go visiting elsewhere. Although I must admit that Grandma and Grandad are very supportive, when the need arises they always step in when we take a summer holiday.

What I am finding though, which is to be expected I suppose, is that Victoria identifies more with her "second family" and naturally U ward has now become her home. That is hard to accept. The staff, being her "second mums" tell me tales of what she has been up to, choose her clothes, see to her hair etc. etc. It makes me feel rather inadequate and sometimes, on grey days, I feel that maybe it was an easy way out. But when she is poorly I certainly know that she is in the right place.

The staff, I know, love Victoria so perhaps she is lucky in that sense - love from two families MUST be a good thing. Being realistic and looking at everything in perspective, Victoria's health and ours, divided we may be but a united and loving family we will remain.

Micheline Johnson.



Victoria's  
Eighth  
Birthday

## TESTS AND MORE TESTS

Our daughter Joanne was born in August 1984 and from the outset we were aware that she was somewhat different. Early tests and consultations indicated a storage disorder, but we were to wait 12 months before a diagnosis was arrived at. In the early months she set about moulding us into the sort of parents she wanted. We felt she 'peaked' at about six months and soon after we had to learn new skills - tube feeding, physiotherapy and trying to pack a lifetime into a few months.

Little progress was being made on her diagnosis but at about 11 months we were offered some hope of a pre-natal diagnosis by cell comparison. Arrangements were made to take a skin biopsy from Joanne which could be used, and so we decided to go ahead. Shortly after the pregnancy was confirmed we also, at last, got a diagnosis; Sialic Acid Storage Disorder, Joanne was the first recognised case in this country.

Our consultant at G.O.S. arranged for a pre-natal test to be performed at King's Hospital; I telephoned and received my first appointment within a week. Our local hospital were happy to babysit for the day and I left Joanne there feeling very guilty, though I was assured she would be spoiled for cuddles.

On the first visit at 7 weeks pregnant, I was scanned to confirm the dates and the fetus was checked for any obvious problems. They wanted to try a chorion biopsy at 12 weeks and, as a back-up to confirm the results, a fetoscopy at 18 weeks. We returned to collect Joanne to find the staff had been concerned about her all day. Yes, we reassured them, she always breathes like that and no, she did not need her feeds reduced - how do they cope with sick children?

The chorion biopsy was much easier than I anticipated, there was a well designed bed - no uncomfortable leg stirrups. I was scanned first then a lot of time was spent swabbing to sterilise the whole area. They then clamp open the cervix, which is not as painful as it sounds, and insert a small tube and remove a few cells by suction. I didn't really feel anything and it was over before I realised - it's more interesting for husbands because they can see what is going on from the scan. The fetus was checked afterwards to let me see it was okay and the whole thing was over in about 15 minutes. We had our first results within a week, because Joanne's cells were so abnormal they felt that signs of the disorder could be easily found if it were present. Other tests which involved growing the cells, took about three weeks but fortunately, all the tests were clear.

Over Christmas Joanne's condition deteriorated rapidly. She had been sleeping a lot more and getting quite puffy, now we realised she had kidney failure. We hope she did not suffer; she fought so bravely. We lost so much when she finally left us on 17th January. I was due to go in for the fetoscopy 3 days later, I was now able to keep this appointment.

The fetoscopy involved two nights in Kings. On the first day they scanned very thoroughly, and even checked for Talipes which Joanne was born with. On the second day I was heavily sedated, which also affects the fetus, and the fetoscopy was performed. It is similar to amniocentesis but involved an endoscope being inserted into the uterus so that a skin biopsy and samples of blood could be taken from the fetus, which could also be viewed. The sedation is necessary so the fetus does not move during the process. The results were given to us the same day, although I was not really awake enough to register this. The next morning they scanned again to check the fetus had not suffered adversely.

It has not been an easy pregnancy but I am sure we will be able to look back when it is over and thank Joanne for making it possible and giving us the confidence to go ahead.

Stella Hale.

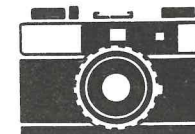
## PHOTOGRAPHIC COMPETITION

Details of the competition were given in the Spring Newsletter but David tells me that, so far the number of entries is disappointing. I'm sure that you are saving your best efforts for the summer, but please don't be 'shy', let David have lots of photographs to make the display at the conference a good one and to make Camilla Jessel's visit worthwhile and her task of judging a difficult one!

One other reason (or is it two?) for making lots of entries is to stop me or Pat Isaac winning by default! (see Davids little 'piece' on page 21 - thank you David!)

David is moving house in the near future so please send your entries to him 'care of' his 'agents':-

David Brooks-Daw  
C/O Linden Lea,  
Wild Oak Lane,  
Trull,  
Taunton, Somerset.



## CHRISTINE'S NEW (EXTRA?) JOB

I am sure that many of you will be interested in hearing about Christine Lavery's new job. She works long and tirelessly for MPS with no monetary reward so it's nice to hear that she is using her skills and experience - and getting paid for a change!

She is working on a pilot project to train parent leaders of rare handicap groups in conference techniques, which is funded by the Mental Health Foundation for 12 months. The grant enables eight rare handicap groups to participate in the organisation and running of the 1986 MPS Conference. Christine will subsequently help these groups to organise their own parent conferences in 1987. She is working in close liaison with Ann Worthington of the "In Touch" trust and with Helen Fraquet of "Contact-a-Family".

There are about 80 established rare handicap children's groups in the country and it is hoped that a number of these will come together on 12th June at the National Children's Bureau in London. Christine has organised the seminar so that they may all meet up and discover more about the organisation and running of self-help groups. Sue Butler and I will be attending on behalf of the MPS Society.

We all wish you the best of luck with the project, Christine, but I am sure there is no-one more capable of the job!

Maggie Archard

## HOLIDAY FOR FREE

Barry Round Table, from Barry Island, South Wales, have offered members of the MPS Society the use of their chalet bungalow between September 13th and October 1st 1986 free of charge.

It has a dormitory that sleeps 9 and one downstairs bedroom containing one double bed, one single bed and one cot.

We are most grateful to Barry Round Table and I am sure some of our families will be able to take advantage of their very generous offer. Does anyone wish to holiday there following the Conference?

For further details please contact :- Dean Caddy (of Barry Round Table)  
Tel: Barry 742 605



## THE LONDON MARATHON 1986

We had two runners in the Marathon this year - Malcolm Hector from Somerset and Barry Lewis from South Wales.

MALCOLM HECTOR completed the London Marathon for the fourth time, in 2 hours 47 minutes. This was well outside his previous best, nevertheless he managed to complete it despite injury to his Achilles tendon early on in the race. Malcolm has also had problems with training this year. His own tiny baby was critically ill for several weeks before the race and had to undergo major heart surgery. We can only hope that she is on the mend now, although her problems are far from over. In spite of his own problems, Malcolm was determined to run for the Society and I'm glad to see that his efforts have been rewarded by the amount of money we have raised so far. Malcolm also raised a handsome sum by getting his own sponsors as well. The total received as at June 2nd is approximately £1,420.

Please try and get all the sponsorship money to me by June 20th at the latest. When you have lots of money to collect up, it is often the last few pounds that you are kept waiting for. If you have not managed to collect it all by June 20th, please send me what you have got already and then send on the last bit later, rather than keep it until you have got it all in.

Pat Isaac.



Pat Isaac chats to Malcolm Hector at the Somerset fun run (a warm-up for the real thing?).

BARRY LEWIS, aged 39, a football referee from Pontypridd, South Wales, hopes to have raised over £350 for the MPS Society in this year's London Marathon. Barry started training three months prior to the race, running 30 miles per week for the first fortnight, 40 miles per week for the second fortnight and then on to 50 miles per week up until one week before the race, 18 miles being the longest distance run at any one time. Barry also had extra training refereeing two football matches each week.

Barry, who also competed in the 1982 London Marathon, started off along with other runners in fine style but developed stomach cramps after the first four miles. Undaunted, Barry ran his heart out and finished in a time of 4 hours 15 minutes, well outside his personal best but nevertheless a remarkable achievement bearing in mind his discomfort.

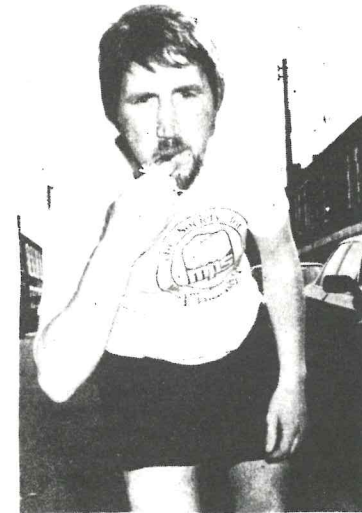
Besides actually running, Barry also worked hard getting sponsors. On behalf of the MPS Society I would like to thank Barry, for his supreme effort, and his wife and daughter for their tolerance and support given to Barry.

Tony Lockyer.

## LONDON MARATHON DONATIONS

Thanks to the following people who have collected sponsors and sent in money for the London Marathon:-

Pat Isaac  
Andrea Crosland  
Gaye Finch  
Pat Widgey  
Wilma Robins  
Colum Devlin  
Carol Westland  
Jean Towing  
Myra Williams  
Debbie Goulden  
Moiria Biggin  
Sandra Hubbard  
Zina Fear  
Stella Hale  
Ann Canton  
Anne Hill  
Liz Matthews  
Mrs. D. Rock  
Mrs. P. McIntyre  
J. & H. Hathaway  
Malcolm Hector  
Ann Hughes  
Maggie Williamson  
Ruby Hall  
Val & John Challen  
Paul & Carol Hubbard  
Jackie Sweeney  
Glenys Cantello  
June & Dennis Evans  
Mr. & Mrs. W. O'Meara



Barry Lewis

## THE LONDON MARATHON (Part II)

Both Paul and I have joined the St. John Ambulance Brigade. I have always wanted to be a nurse from a very young age, but because of my size I felt I would never be accepted at a hospital. I wanted to achieve something and get as near as possible to nursing. So I feel I have fulfilled a little of my ambition by becoming a nursing member of the St. John.

The London Marathon was fast approaching and a chance came up for St. John members to do a duty. Both Paul and myself put our names down and we were really pleased when we were chosen to go.

The 20th April arrived and we dragged ourselves out of bed at 6am - we must have been crazy! What a morning it was, pouring with rain and freezing cold (still, we needed the rain!!!). We packed ourselves some lunch, even though it was to be provided, we were informed there might not be enough to go around. Once we were ready we set off to meet the rest of our division at our meeting headquarters. When we were all assembled we divided ourselves between available cars and set off to London.

We arrived at our post at the Isle of Dogs at 8.45 and met up with the Bethnal Green and Weybridge divisions, ready to start a hard days work. We did not have very long to set up our equipment, so we had to 'get our fingers out'.

The Weybridge division has the most beautiful mobile unit, rather like a 'Jumbulance' so their team was stationed in this wonderful unit, with a doctor available. The rest of us were divided into small groups along the road side to deal with all the cramp and blister cases, anything more serious we escorted to the mobile unit for the doctor and his team to care for.

My little group grabbed a bus shelter and set up chairs and table with our ralgex sprays and plasters etc., ready for the mad rush of casualties. By now I was freezing cold and soaking wet and very tempted to wrap some of the insulation sheets around me. It was a really great atmosphere, as by now there was quite a crowd waiting for the first of the runners to pass.

I was, of course, looking out for our MPS runner, Malcolm Hector, although I had no idea what he looked like, I just hoped he was wearing an MPS T-shirt. I must have been kidding myself as the runners came by in crowds - I was going cross-eyed for looking! I was also looking out for one of our nursing members who entered. I did manage to spot the back of her go by.

By now we were beginning to treat many of the runners so I did not get a chance to look out for Malcolm. We did not stop. I have never massaged so many legs (with cramp) in all my life! I may have even massaged Malcolm's for him (legs that is). Eventually we were asked to go and have a cup of tea in the mobile unit and somebody else relieved us. The wind seemed to have got stronger and on approaching the unit my hat flew off down the road, so I had to chase after it. I felt like one of the runners, I should have joined them and raised a bit more for MPS!

It was wonderful to see all the wheelchair entries, they are so courageous and well deserve their medal at the end, as everybody else does of course.

I did manage to get some sponsors for Malcolm and raised £40. It was not much, but better than nothing. We were really busy so I never did get time to eat my lunch. We were treating the last of the runners by now and it was soon time to pack up all our things and set off on our journey home. Cold and exhausted, we made our way back to the car. We enjoyed ourselves so much and it gave me such satisfaction to be of some help to others.

Carol Hubbard.

## FAMILY CONFERENCE 1986

At the time of going to print more than 70 families have booked places at the Parent Conference in September. The response this year has been most reassuring, with so many applications received within the deadline we set. It makes life easier for the organisers, being able to plan ahead, but we do appreciate that some families are not able to commit themselves too far in advance. There are still a few places to fill - if you wish to attend but are in financial difficulties please let us know - all contacts will be dealt with in the strictest confidence.

May I remind you that the balance of monies due should be sent to me by **August 8th** after which time your Conference tickets will be sent to you. **No further reminders will be sent and after that date deposits cannot be refunded except in exceptional circumstances.**

Meanwhile the organisation goes on and we look forward to renewing old acquaintances and meeting new ones in September.

### Attention - Sanfilippo Families

Dr. Stephen Amato, who has wide experience of patients with Sanfilippo Syndrome, will be speaking at our Conference on the "Management of the Sanfilippo Child".

He has very kindly offered to run a 'clinic' at the Post House Hotel, Heathrow, on Friday 26th September, before the Conference starts.

**Anyone who wishes Dr. Amato to see their child should get in touch with Christine Lavery (Tel: 02404 2789) as a matter of urgency - to reserve one of the FEW appointments that will be available.**

If you would like your child to be seen please ask your G.P. or consultant for a letter of referral to bring with you (or send it to Christine in advance).

### Dr. Martin Bax

Dr. Bax has also generously offered to run a 'clinic' at the Hotel for any child with behavioural problems - for both MPS children and normal siblings suffering as a result. Please contact Christine Lavery who will arrange an appointment.

Maggie Archard

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### PUT YOUR HOUSE IN ORDER!

**Very Important :** Please can you let me have all outstanding money for pens, cards and badges sold by JUNE 30th at the latest ( and let me know how many you still have left to sell).

It is the end of our financial year on June 30th and the accounts have to be up-to-date and audited then.

PLEASE MAKE SURE THAT YOU GET THEM TO ME BY THEN IN ORDER TO AVOID CAUSING EXTRA WORK. THANK YOU.

Pat Isaac.

\*\*\*\*\*

## THE FIRST AUSTRIAN FAMILY CONFERENCE

SCHARDING, 19 - 20 APRIL 1986

Sponsored by the Society and THE INCHCAPE TRUST, Christine and I visited Vienna and Scharding in Austria from 17 to 21 April to attend the first MPS Family Conference in Europe, outside the British Isles. The Society has enjoyed close co-operation and friendship with Austrian families and specialists since our Harrogate conference in 1984. Searching for new treatments, furthering research, comparing notes on developments, country by country, and linking the rarest cases, does mean looking further afield than Britain. So we were pleased to take up Marion Kraft's invitation and excited by the prospect of sharing in Austria's first conference. On hindsight it is a pity that no-one was available to take up a similar invitation from our Australian friends last year. Their conference was immediately following our own and the organisation of a visit and its financing was, sadly, just too much to take on.



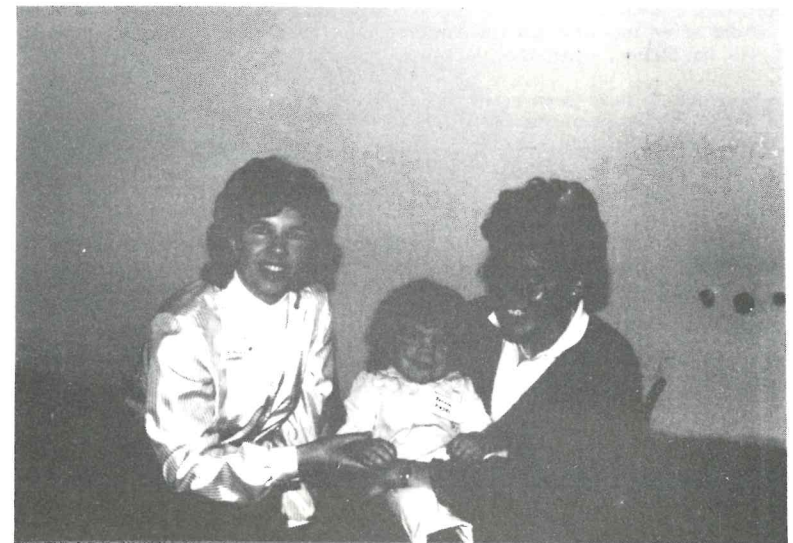
The welcome in Vienna by Eric, Marion, Michael, Barbara and "Auntie" Kraft and by Dr. Susanne Kircher, was overwhelming. Their regard for their friends in Britain and the hospitality and friendship extended to Christine and me, is a story in itself. We were also warmly welcomed by Dr. Sybille Fleischhacker and Dr. Hannelore Steinbock (whom you may remember at Heathrow). Dr. Steinbock invited us to the St. Anna Kinderspital, Vienna, the fourth oldest children's hospital in Europe, but, inside, the most modern hospital we have seen, and thoughtfully designed for the comfort of parent, child and professional alike. St. Anna's has the most up-to-date facilities, including a bone marrow transplant unit (although this hospital will not perform BMT on MPS cases).

The next day the Krafts drove us to Scharding, about 150 miles from Vienna on the West German border, for the start of the conference. Scharding is a tranquil and charming medieval town, and it was there that we caught up with other friends - Brigitte and Juergen Zumbro and Family Hermann (from West Germany) and Family Schwaiger (Austria). We also met old correspondence contacts for the first time, the Families Gorbach and Zieroff (both West Germany). One important piece of paper the Krafts took to Scharding was a printed German translation of Dr. Martin Bax's research questionnaire for distribution to interested families. The questionnaire seemed to be popular and hopefully the contributions from Scharding will help Martin with his statistical base on MPS.

The conference was opened by Marion and Susanne. Juergen Zumbro announced the formation of the West German Society, during the course of the conference. The significance was, that, unlike Austria and Britain, the Germans could not form a society without members under German law. For Juergen, the Austrian weekend was the first occasion when he had been able to bring German families together at a formal meeting, so as to constitute the new German Society. Kindly, Juergen spoke for a few moments to the families and to Chris and myself in English, to thank the British Society for the inspiration and help we had given.

Marion Kraft and Dr. Susanne Kircher had purposely arranged the conference on the borders with Germany, knowing from Juergen and others that there was substantial interest there. This was a practical, commonsense aspect of the arrangements. It also had significance for us, in that it seemed a very unselfish, non-nationalistic arrangement to make. MPS is rare and knows no boundaries. International links are important. We were glad to be part of this wonderful occasion.

Christine was invited to make a short speech, in English, which Susanne kindly interpreted. Chris highlighted international links made so far, the incidence of cases, UK research and the link with Dr. Lubec in Vienna. Above all, she emphasised the need for families present to support their key voluntary helpers in Austria and Germany. This was how the British Society was able to go forward. There was so much work that the burdens had to be shared, by willing and able people. You can imagine that her speech was not that short after all, especially after translation. Nonetheless, we believe it was well received.



The conference lectures were on familiar topics and since they were in German, we ducked-out and met the children instead. Well organised, the Austrians had managed to get the speakers' papers reproduced in time for inclusion in the programme. Speakers were Dr. Susanne Kircher, Dr. Hannelore Steinbock and Marilies Schwaiger (who led the syndicate sessions). A new name to us was Dr. Edward Paschke from the University of Graz Kinderklinik, who spoke on problems of diagnosis. We have copies of the papers, which are well laid out and presented, and of interest - MPS German is quite like MPS English!

There were about 24 families, from all parts of Austria, West Germany (including Berlin) and Switzerland. And we managed to talk to nearly all of them. Our British Society is now enriched with many new friends, many of whom are interested in correspondence links, and some of whom will wish to come to Heathrow in September.

We met several rare cases, including MLI, MLII and MLIII, and a little Hurler girl, Danielle, aged 5, who has normal mental ability (we were assured about the diagnosis). She and Christian (MLII aged 6) are adorable but their parents, for some reason or another, were not keen we should have taken them home with us!

Martina and Marion are two ladies in their early twenties with MLIII. These sisters hold down full-time jobs and were able to speak to us a little in English. They are keen for pen-friends.

We could see that some of the families were a little apprehensive, meeting other families for the first time, but Marion Kraft and colleagues managed to contrive a relaxed and informal atmosphere, aided by the friendliness and comfort of the inn at which we stayed.

It was hard to part with Scharding and many lingered on, not wishing to leave the friendship and fellowship which was so much part of the weekend. We have not yet established a French connection so it would be inappropriate to say "MPS sans frontieres". Besser ist "MPS ohne Grenzen", vielleicht? Or "Jeder fur Jeden" which approximately translates "Each for Everyone".

My guess is that the First Austrian Conference will give a significant push forward to the formation of self-help groups in other European countries. Marion and Eric, Susanne, Drs. Steinbock and Fleischhacker and Marilies Schwaiger may only realise, like we did after the first British conference in 1983, how significant their first event will have been, when they look back on it after several years.

We were proud to have been associated with it on behalf of our British families. And we do congratulate them. Juergen and Brigitte have intimated that it is the German's turn next, possibly in May 1987.

Robin Lavery  
4th May 1986

## FUN RUN AND FAMILY DAY, MARCH 23rd.

The morning of March 23rd. proved to be fine but a bit on the chilly side. The Somerset Fire Brigade had very graciously vacated the fire station at Nether Stowey, thus enabling the gallant band of organisers some protection from goose pimples. Christine Lavery was supposed to start the race with a gun, but for some obscure reason it couldn't be found. (It had been muttered that some participants felt nervous about our Hon. Sec. being armed), so it was decided to use a whistle. A whistle could not be found, the nearest being on the person of one of the marshals half-way round the course!



The next problem was the starting rostrum, which was on top of six foot of scaffolding, but without any steps. This however, proved no deterrent to our leader, although some remarks were overheard to the tune that "I'm sure Princess Diana doesn't have this problem". The race was eventually started, with an excellent number of entries in both the junior and senior classes.

Two adult members of the Society completed the six mile course, Dan Butler (bravely combating the onset of flu) and Judy Holroyd who ran three miles with her son William aged 11 years, who suffers from Sanfilippo Syndrome. William is to have a special certificate and medal presented to him from the West Quantocks Round Table. Lucinda Butler, Andrew Lavery and Natalie Isaac all completed the junior course and collected quite a bit of sponsor money for MPS. Dave Isaac took the easy route and opted to "marshal" (wrapped in about ten coats against the wind). Peter Archard was there with camera. And what was Robin Lavery doing? Would you believe this story - he said he couldn't run because his wife said he looked a "wally" in his track suit! (And what's your excuse for not running, David? - Editor).

The event was organised by West Quantocks Round Table for MPS and, although the final total hasn't been added up yet, it will be in the region of £1400. We are most grateful for all the hard work and effort put in by the members of the Round Table.



William Holroyd looking better after his run than some observers!



Natalie Isaac on the home run.

After the run all the MPS families made their way to Fiddington Village Hall where the ladies magically produced a palacial buffet while the men concentrated on the technical details of getting the beer on tap! Nine families came, eighteen adults and nineteen children. Half of the hall was screened off with chairs so the children (including those over thirty-five) could play in peace, without being pestered by 'biggies' all the time! The lunch proved to be a valuable time to renew old friendships and also to meet new families. Peter "Lichfield" Archard was there again with his camera and muttering about how he was going to win the MPS Photo Competition at the Conference this year. He was on his knees taking pictures for most of the afternoon, although somebody said this could be due to the beer!(noted!!!Editor)

Eventually lunch came to an end and the families retired to "La Maison Isaac" which, due to foresight and good planning, was about 100 yards walk from the village hall. Everyone enjoyed the day enormously, and the fact that everything went so smoothly was due almost entirely to all the hard work and organisation put in by Pat Isaac, so we all owe you a very big thank you Pat.

David Brooks-Daw.



Malcolm Hector, one of the MPS runners in the London Marathon, receives his trophy as winner of the 1985 Fun Run. This year he came second.

## HELEN LOSES HER HALO

Those of you who read the Spring Newsletter will know that my 8 year old daughter, Helen, who has Morquio Syndrome, had an operation at Christmas to fuse the bones in her cervical spine. The surgery was performed by Dr. Steven Kopits from Baltimore who came over specially to treat Helen and to teach two English Consultants the skills he has acquired in dealing with this particular problem in Morquio patients. Helen then had to spend four months in a full body cast with a steel 'halo' screwed to her skull.

At the end of April we went to our hospital for an X-ray with our hearts in our mouths, remembering the failure of Helen's previous fusion operation. The X-ray showed that the cervical vertebrae had fused but there was still a tiny gap before the base of the skull. Thanks to Dan Butler and his firm, the X-ray was sent over to Baltimore and Dr. Kopits advised a delay of three weeks. A second X-ray showed that the gap had closed and we at last received the call we had been waiting for, to say Helen's 'halo' could come off.

The actual removal was simple; a matter of unscrewing the 'halo' and cutting through the plaster cast. Helen was frightened momentarily at feeling herself without support but recovered within five minutes. We were amazed at how quickly she was able to support her head and sit up unaided. Ten days later she can sit comfortably for long periods, crawl and take a few steps with her hands held. Helen has hydrotherapy once a week at a tiny and gloriously warm pool attached to a special school. She loves this but needs persuading to stick at the more routine physiotherapy sessions.

When we invited Dr. Kopits to England last October to talk at a seminar, we hoped to engage British consultants in discussions of methods of treating the skeletal problems suffered by Morquio patients in particular. We had not anticipated the possibility of Dr. Kopits returning to demonstrate his technique! Obviously there are different methods of fusing the cervical vertebrae and we hope the Society can continue to stimulate discussion among the medical profession about the respective merits of each. As a 'consumer' I can say that this method, although physically tiring for the family, was almost pain-free and certainly not a great ordeal for Helen, **And** it works, Helen being Dr. Kopits' 26th success!

## Coping with the press

When Helen had recovered from her operation, it occurred to us that her story might be of interest to the press and an opportunity to achieve publicity for the Society. We were fortunate in finding Denise Winn, a freelance journalist, who wrote an excellent piece for the 'Sunday Times' which has brought in new members and over £5,000 in donations from as far afield as Peking, Indonesia and the Gulf States. From that article came the other contacts, BBC news, Woman's Hour, Woman's Own and the London Standard. I have sometimes felt embarrassed at the amount of attention Helen received as I am very aware that other children have endured far more and been just as brave.

I insisted in all but one of my contacts with journalists that I should approve the proposed article before publication - usually by having it read over the 'phone. This did not always work - editors can substitute last minute alterations or leave out the address of the Society as the Standard did, but I was able to change the most glaring inaccuracies. The time that I failed in my vigilance with one local paper, I was rewarded with "Months of excruciating pain and boredom finally came to an end....."  
**Be warned!**

Mary O'Toole

## MPS CHRISTMAS CARDS

A bit early - you may say! I'm telling you about them now so that you can come to the conference with your orders ready!

We have decided to have two designs printed this year due to the fantastic response we had last year. The Committee had a very difficult choice to make as we had nine excellent designs to choose from. We hope you will be able to sell twice as many now!! Perhaps you could ask in one of your local shops if they would be able to sell any for you (without taking any commission of course). One design is of snowmen and another is a humorous one with a monk and some robins (these 'Robins' creep in everywhere!)

Please do tell your friends and relatives about the MPS cards and gather as many orders as possible. They will be priced the same as last year; in packets of five of one design priced 70p, and will be available from the time of the Conference onwards.

Pat Isaac.

## THE DATA PROTECTION ACT 1984

After 11th May 1986 it became an offence to hold personal data on a computer without being registered as a Data User. It also became an offence to operate knowingly or recklessly outside the terms of registration entry with the Data Protection Registrar.

Accordingly, as the Society is a data user, I submitted an application to the Data Protection Registrar on 1st March 1986 to cover the following computer useages:

- Fund Raising.
- Membership Administration.
- Health Research and Statistical Analysis.

The Act establishes new legal rights for individuals with regard to personal data processed by the use of computing equipment. A Data Subject may:

- seek compensation through the Courts for damage and any associated distress caused by the loss, destruction or unauthorised disclosure of data or by inaccurate data;
- apply to the Courts for the rectification or erasure of inaccurate data;
- obtain access to data of which he or she is the subject.

If you have any doubts or enquiries about the data which may be held on the Society's computers, about you, members of your family or other persons concerned with your MPS child, then I should be grateful if you would contact me.

Robin Lavery  
May 1986

## WHAT, NO UNIFORM?

Our school is the Church of England School in High Wycombe, just opposite Wycombe Wanderers' football ground. Our teacher is Mr. Hardy and he has a son called Matthew who is four. He has a sister who is five months old. Matthew has a disease called Mucopolysaccharidosis. He can't waggle his fingers but, if you give him time to do something he can do it.

Mr. Hardy asked the whole school to collect stamps and recently we decided to have a no school uniform day. On February 29th we came to school in our home clothes but we had to pay a minimum of 30p. Our school has about 330 children in it, so our target was £100. Mr. Hardy told us about Mucopolysaccharidosis in September and we decided to put the money we raised to the MPS fund.

Our uniform is a blue blazer with red trim. Boys have grey trousers, grey socks and grey shirts. Girls wear royal blue skirts or pinafores and white blouses, and in the summer, red check dresses.

We raised £205.23. The money goes towards research and to pay the people who do the research and to buy the equipment for it.

Victoria Knibbs (8) and Stephen Binns (9)  
Class 5/6, High Wycombe C.E. School.

Thank you very much for your letters, Victoria and Stephen, what a good way to raise money. I'm sure the whole school had fun that day - and, of course, 'Sir!' - Editor

## NEW FAMILIES

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

Mr. and Mrs. Connolly from Glasgow. Their 21 month old son James is suffering from Hurler's Disease.

Gordon and Anne Hill from Devon. Their 7 year old daughter Louise has recently been diagnosed as suffering from Sanfilippo Disease.

Mr. and Mrs. Iqbal from London, whose 6 year old son, Bilal, suffers from Sanfilippo Disease.

Julie Maddison and her brother James from Sunderland. Julie is 25 and James is 22 years old. They both suffer from Morquio Syndrome.

Sisters Sarah and Nicolina Stangoni from Somerset. Sarah is 23 and Nicolina is 26. They both suffer from Morquio Disease.

## BIRTHS

Congratulations to Carol and Paul Shorthouse from Coventry, on the birth of Rebecca on 17th January 1986. She weighed 5lb 5ozs and is a sister for Christopher.

Alan and Deirdre Beavan are pleased to announce the safe arrival of Benjamin, brother for Joanna, Thomas and Samuel. Ben was born on 26th February and weighed 7lb 7ozs. The Beavans live in Market Harborough, Leics. Congratulations to all the family.

Congratulations to Colum and Josie Devlin in Northern Ireland on the arrival of Brian, brother for Dermot and Niall, on 15th April 1986.

Baby Elizabeth was born to Eddie and Jill Farwell in Barnstable, Devon. She weighed in at 8lb 3ozs and is a sister for Katy and Tom. Congratulations!

Mr. and Mrs. Piromalli had a son, Simone, in March, brother for Angela and James.

## NEW FUND RAISING LEAFLETS

By now you will have received samples of the new fund raising leaflets we have produced. If you would like more, please ask Christine or myself. They cost approximately 3.5p each to produce and have already paid for themselves. When raising funds for "that charity with the unpronounceable name", it was felt that people more readily identify with children and this is why we pictured some on our leaflet. Although the photographs would probably have been better in black and white, we wanted the printing in our blue MPS colour and so had to compromise.

You may wonder how we came to choose these particular children. Well, there were a number of reasons. Firstly, the parents had expressed a willingness for their children to be used in this way. Secondly, we wanted to have a spread of children right across the country and the children come from as far north as Glasgow and as far south as Somerset. (We haven't found any MPS children in John o' Groats or Land's End yet!) Thirdly, we wanted a fair share of boys and girls. Fourthly, we wanted the children we used to represent all the MPS children we know, and so we tried to pick a child who was 'average' for that type of condition.

We know a lot of your children won't suffer so badly as the ones we have chosen for the leaflet and hope therefore that the wording won't upset you. On the other hand, we know sadly that many MPS children have suffered more than these; so we have tried to achieve a balance. A small leaflet like this cannot adequately describe all our children and their problems or their uniqueness, but the Committee hope that you will agree it will serve its purpose in explaining what MPS is to the general public and those who offer to raise funds to help us all. Any constructive comments about the leaflet will be welcomed.

It is designed so that if you have two leaflets, you can open them out to show both sides and pin them up if you have somewhere to display them when you are having a fund raising event, or perhaps on your notice board at work, or in your club etc. It is **NOT** intended for information for parents of MPS children, especially newly-diagnosed families. We hope to produce more information for parents in the future - but that is a different story. Our old style information sheets are still available for doctor's waiting rooms, hospitals etc.

Pat Isaac.

## DONATIONS

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

208 communications were received following the Sunday Times article about Helen O'Toole and over £5,000 was donated. We were overwhelmed by the generosity shown.

Mrs.M.Pearce; David & Michele Brooks-Daw; Mrs.E.Wheeler; Mr.& Mrs.Price Hughes; Mrs.Simpson; Mr.& Mrs.Jamison; Mr.& Mrs.E.Gregory; Jonathon Dorracott and Sarah Hamilton; Mr.& Mrs.Bearman; Mr.& Mrs.Shadbolt; Mrs.Redman; Mr.& Mrs.Holroyd; Mrs.Whitehouse; Mrs.Vipond; Mrs.Kift; Mr.& Mrs.T.Garrett; Mrs.E.Sanderson; Mrs.Hayward; Sue Wood-Griffiths; Jackie Wilson; L. Rowe.  
Fiddington W.I.; Earley Carnival Horticultural Society; Radnage 1st.  
Scouts - Founders Day Parade Service; Little Kingshill Baptist Church; C.& A. Distribution Tamworth; Tamworth Progressive Club; St.Chads Hopwas Church Council,Tamworth; St.Nicholas C.E. Primary School,Harpending; Hahn's Bakeries,London; West Quantocks Round Table; Malling Round Table; Blackpool Division, Girl Guides Asscn; Sainsbury's; The Inchcape Charitable Trust Fund; The Baring Foundation.

## Conference Donations

Northern Foods; Book Club Associates; News International; National Westminster Bank; The Royal Bank of Scotland; Blue Circle Industries; Reckitt and Colman; The Thames Help Trust; Edelman; Hallmark Cards; Barclays Bank; John Lewis partnership.

## Charity Boxes

Blue Anchor Inn, Cannington; Kiln Farm Club; Central T.V. Studios; Children's Bookshop, Muswell Hill; Dr. Garrow.

## In Memory

We are very grateful for donations sent in lieu of flowers in memory of MPS victims - Scott McCarthy, Louise Broome and Pam Tubb; and also of Jemma Corbett's Uncle Pat.

## Fund Raising and Sponsored Events

Mrs. Sheila Randall, Cannington, held a clothes party.  
Liz Robinson, Beeston, held raffles and other events.  
Mary & Pam Tubb had an open day and bring-and-buy on Pam's 40th birthday.  
Class 6, High Wycombe School had a stamp sale and whole school had a no-uniform day.  
The Beavers, Tamworth, held a jumble sale.  
Jane and Neil Reid had a clothes party.  
Doreen & Monty Russell, Birmingham, held a school reunion raffle.  
Mrs. Jill Southby, H.V. from Birmingham, raffled a Cabbage Patch Doll.  
Pottersbury Lodge school, staff and children, held a coffee morning.  
Mrs. Denise Jaggard, Potters Bar, held a book party.  
The Stanmore branch of the National Council of Women held a coffee morning.  
The Norfolk Constabulary held a sports club quiz.  
Dan Butler underwent a sponsored slim!  
Holy Trinity Church,Attleborough, donated part proceeds of their annual bazaar.  
Jean Kendall, H.V. from N.Herts, sold home grown fuchsias for the Society.  
"Slimmers" from N.H.D.C. planning office regularly fill a collection box!  
Ruth Harvey and Mark Jones ran in Yellow Advertiser Half Marathon, N.Essex for MPS.  
Terry Matfield ran in the Havering Half Marathon.  
Thelma Pidden held a coffee morning.  
Fer Pidden and Ann Brown held a charity stall.  
Lin Inglis had a bring and buy stall.  
C. Westland raised money for the High Wycombe Half Marathon.  
Ann Canton held an 'Oriflame' make-up party.

Special thanks to Amersham Round Table who donated money to enable us to buy an additional set of display boards.

## SUMMER FUND RAISING IDEAS

Here are two simple ideas you might like to try, to raise funds for the MPS Society this summer.

### Car Boot Sales

At this time of year you will often see 'Car Boot Sale' advertised in your local paper. These are quite simple ways of making money if you are a 'beginner' to fund raising. What you need to do is this:

- a) Collect up as many saleable goods as you can before the date of the sale. These can be anything you like. Items which sell well are all types of bric-a-brac like ornaments, costume jewellery, pictures and interesting objects of all kinds. You can also sell plants or cakes or anything you like really. Go round your friends and ask them for anything they don't want - make sure you've got plenty to sell on the day.
- b) Fill up your car boot or hatchback on the day of the advertised sale and arrive in plenty of time to get a good 'pitch' as near to the entrance of the field or car park as you can. Pack a folding table with you, if you have one, as well.
- c) When you arrive at the sale, you open up your boot and lay out your goods so that they can be seen. Unlike a jumble sale, it is usual to mark a price on your goods, but be prepared to bargain!
- d) You will have to pay for your pitch, usually about £3, to the organisers, then anything you make on top of that is yours to keep for MPS.
- e) Not everybody sells their things for charity, so make sure you have a sign up saying that the proceeds will be going to the MPS Society, with a fund raising leaflet displayed if possible. Then people will be interested to find out what it's all about.
- f) At the end of the sale, you just pack up your left-overs and count up all your money. Try and have someone with you to witness how much money you have collected on behalf of the Society. Then send in your cheque as soon as possible to the Society. Perhaps you could do a little write-up for the newsletter, telling us how you got on.

### Alternatively:

You might be a very good organiser and be able to organise a Car Boot Sale yourself. In this case you will need more helpers, a large piece of ground which you can rent cheaply or for nothing, and plenty of time to organise it.

It is essential that you advertise the sale in your local newspaper. You then collect £3 from all the people who come to sell from their cars and collect an entrance fee from all the people on foot who are coming to buy. You can also have your own car boot. This way you will make much more money, but of course, it will take a lot more time to organise. You can also sell refreshments and make a profit on them too.

### Flower Arranging

Have you a big garden with lots of flowers?.....and are you or any of your friends any good at flower arranging?

Save all your lids from coffee jars etc. These make ideal containers for small table arrangements. Fill them up with wet oasis and then do a small flower arrangement with flowers from yours or a neighbour's garden, and sell them at any function that may be arranged. It depends on the flowers and size but you can charge anything from 50p for a small arrangement, upwards.

I hope some of you will be able to have a go at one of these ideas and I look forward to reading some more of **your** ideas in the next newsletter. Do send some in.

I am hoping to produce a booklet of fund raising ideas for the Society as soon as I have time, so if you have any good ideas I could include, I would be very pleased to hear from you. Meanwhile keep up the good work!

If you need any advice on fund raising please drop me a line and I will try to help. But please be prepared to wait a couple of weeks for a reply or a parcel of pen etc.

Pat Isaac

Like many of you, Pat has an MPS child to look after, two other young children, a job and a home to run. She loves getting your letters, but please understand that she receives several every post and there just are not enough hours in the day to enable her to reply as quickly as she would like - Editor.

## WILTSHIRE WILES

By the time you read this, Fer Pidden will have held her coffee morning on June 18th. She tells me that it is intended to be a "bring everything and buy everything" sale as well, with a raffle thrown in - I am not sure if the sale includes Bill's car!!! Will it beat Natalie's grandmother's coffee morning which raised £111 in 3 hours?

Fer has the help of a Westbury keep fit group and, as you will see from the donations page, they organised a charity stall which raised more than £70. Ann Brown, the group leader, and all the members are thanked by Fer and the Society.

How about this for further fund raising ideas? Last summer Bill and Fer had some building work carried out and they 'sold' their **old** tiles to the plumber for an MPS donation! Next came the carpet people, who were unfortunate enough to present the Piddens with a flawed carpet. Complex barter and negotiation followed and resulted in another £30 contribution to MPS funds.

It just goes to show - where there's a will, there's an MPS donation!

## WHO ARE YOU

In months gone by, the newsletter regularly contained short pieces by families in which they introduced themselves and gave us all a brief insight to their lives. In the last year or so the Society has been joined by dozens of new families and yet all we know of them is through the brief note that regularly appears in the Newsletter.

"Who wants to know about us?", I can almost hear some of you saying. Well, the fact is that I am quite sure that all of us do. The Society is all about family support and the reassurance and comfort that comes from sharing experiences; fears, hopes, sorrows - the good and the bad times. We each are different, as are the special children that many of us are, or have been, lucky enough to love, but there is a common factor that makes **your** family of very special interest indeed. So please let us hear from you with just a few details of your family, and if you have a photograph that will be especially welcome (and can be returned). Micheline Johnson has given us details of her family's recent experiences on page 10. Who of us cannot identify with her and her family? Who of us cannot be moved by her story and gain a little from their experiences?

Please let us hear from you, no matter how briefly.

Peter Archard



## AREA FAMILIES

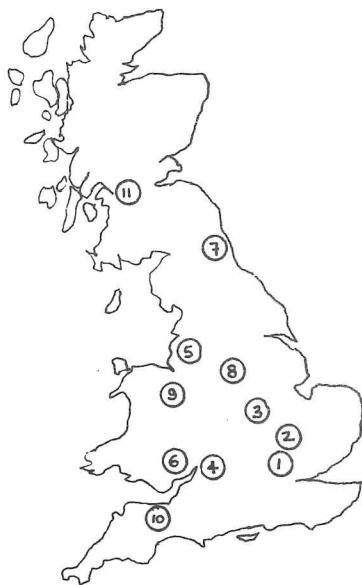
We would like to extend a warm welcome to David and Michele Brooks-Daw who have kindly offered to take over as Area Family for the Counties of Cornwall, Devon, Somerset and Avon. This will reduce to a more practical size, the very large area that Peter and Marlene Sanderson took on over two years ago, and they will continue their support role in Gloucestershire, Wiltshire and Dorset.

The role of 'Area Family' is an informal one, offering more localised help to our MPS families. Many of our Area Families are bereaved, but some have taken on this role in the lifetime of their MPS child. The help Area Families can give, varies from family to family and all have differing experiences amongst the MPS diseases and concerning Bone Marrow Transplant and Amnion Implant.

Please **DO** make contact with your Area Family. Let them know if you are in difficulties or want help with meeting other families in your area or with fund raising events. If the Area Family themselves can not help, they can notify me or endeavour to put you in touch with someone who can answer your questions.

Remember, support can be mutual and local area groups can function best if everyone supports each other.

Christine Lavery



General location of the Area Support Families - See list opposite

## AREA SUPPORT FAMILIES

- 1 **Robin and Christine Lavery**  
30 Westwood Drive, Little Chalfont, Bucks.
  - 2 **Neil and Jane Reid**  
'Meadowlark', 9 Huddleston Way, Sawston, Cambs. CB2 4SW
  - 3 **Alan and Deirdre Beavan**  
'Tumbleweed', West Gate Lane, Lubenham, Market Harborough, Leics.
  - 4 **Peter and Marlene Sanderson**  
'Ashley Cottage', 6 Northfield Road, Tetbury, Glos.
  - 5 **Colin and Mary Gardiner**  
35 Church Road, Banks, Southport, Merseyside.
  - 6 **Mike and Pat Skidmore**  
5 Chapel Close, Wyesham, Monmouth, Gwent.
  - 7 **John and Barbara Arrowsmith**  
140 Newtown Road, High Heaton, Newcastle Upon Tyne, NE7 7NH
  - 8 **Heather Broughton**  
160 Ecclesfield Road, Chapeltown, Sheffield S30 4TE
  - 9 **Brian and Micheline Johnson**  
'The Mount', Truemans Way, Hawarden, Deeside, Clwyd.
  - 10 **David and Michele Brooks-Daw**  
N.B. Temporary address:-  
c/o Linden Lea, Wild Oak Lane, Trull, Taunton, Somerset.
- Contact for Scottish families:-
- 11 **Alan and Fiona Byrne**  
3 Jedburgh Avenue, Rutherglen, Glasgow G73 3EN