

NEWSLETTER



SPRING 1985

**THE SOCIETY FOR
MUCOPOLYSACCHARIDE
DISEASES**



National Registered Charity No. 287034

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AREA SUPPORT FAMILIES

Northern England

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

East Central England

Neil and Jane Reid; "Meadowlark", 9 Huddleston Way, Sawston, Cambs.

South East England

Robin and Christine Lavery; 30 Westwood Drive, Little Chalfont, Bucks.

South West England

Peter and Marlene Sanderson; "Ashley Cottage", 6 Northfield Road, Tetbury, Glos., GL8 8HB.

Wales

Michael and Patricia Skidmore; 'Horizons', 5 Chapel Close, Wyesham, Monmouth, Gwent.

WHAT ARE THE AIMS OF THE SOCIETY?

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

FOREWORD

How quickly the Newsletter comes round; at least that's how I see it as Editor. Well, I can't deny that I thoroughly enjoy being a part of it and I think I can safely speak for Peter as well.

I do hope that you find the Newsletter helpful and interesting. However if anyone has any bright ideas or comments, please let us hear them. We can take criticism. Perhaps we could set up a Comments Page.

However, may I draw your particular attention this time to the Questionnaire drawn up by Catherine Grant on the important issue of the Caravan/Holiday Home Fund. There is no need to reiterate what she says but I do ask that you read it carefully. Funds for this scheme were raised by some of you, especially for it and so involve you directly. As you will appreciate, at this moment in time, the Fund is not healthy enough to purchase a Holiday Home, bearing in mind the Society's commitment to Research, the Conference and the Newsletter, which we could not do without. Ultimately, however, the Trustees will have the final decision on whether to go ahead with the scheme or not, but obviously influenced by your response to the Questionnaire.

May I remind you here about subscriptions for the Newsletter which is free to MPS Families but is £5.00 per annum to anyone else, e.g. grandparents and other relations, Medical Profession and other supporting organisations. Anyone who is paid up and wishes still to receive the Newsletter, would you please send your subscription to: The Newsletter Editor, Cottage Design Studio, 6 Northfield Road, Tetbury, Glos., GL8 8HB. Cheques payable to: The Society for MPS Diseases please.

Marlene Sanderson
Newsletter Editor

DOUBLE TROUBLE - DOUBLE JOY

When our son Daniel was just over three years old he was diagnosed as suffering from Hunter's Syndrome. Our daughter Laura was one and a half at the time and although we had her we were obviously absolutely devastated at such distressing news. After a few months we accepted the inevitability of the disease and considered the fact that eventually Laura would become an only child - which both my husband and I had been and did not want Laura to be. It is a very lonely position. Neil said he would like another child to help fill in the gap which would eventually occur but as I had been diagnosed a carrier of Hunter's Syndrome and the risks were high of carrying another affected foetus - I obviously had strong reservations on a decision to expand our family. The fact of knowing I'm always poorly during pregnancy and not knowing at what stage Daniel would be and if he would need extra care and attention at a vulnerable time, were all things to be considered. Also the terrible consequence that if we went ahead with another pregnancy and it was found to be affected, how would we feel at the decision to terminate. It was then I decided if we went ahead and I had tests which would confirm whether the foetus was affected, I would have termination and would call that final but at least we would have tried. Knowing how much Neil wanted another child and for Laura's sake we went ahead.

By March last year I was pregnant but was threatening to miscarry, so had to go into hospital and have a scan where to our amazement we discovered I was carrying TWINS!! En route home after the scan our feelings were mixed to say the least. We both felt elated one moment and yet very sad the next not knowing what would happen if one foetus were affected and the other clear; twins were one of the things we had never even anticipated. Would we have to lose the whole pregnancy?

Dr. Rosemary Stephens from Great Ormond Street Hospital very kindly made arrangements for me to have an Amniocentesis by Prof. Stewart Campbell at Kings College Hospital and she was there to support us both at the time.

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The scan at King's revealed TWIN ONE to be male and TWIN TWO to be female and the fluid was duly taken to test for carrier detection and other diseases. Then followed weeks of anxiety and more threats of miscarriage. We indeed began to wonder whether this pregnancy was meant to be! I was six months into the pregnancy when the results came through and what joy to learn the male was clear - at last Neil and I felt more confident that at last things were going in our favour.

The twins estimated date of delivery was 9 November and at the start of October I was admitted to Rosie Maternity Hospital, Cambridge for rest and told I would be there until after the birth. Two weeks later on 24 October they made their appearance. First Jessica Clare weighing 6lb 11oz, followed 14 minutes later by Joshua Oliver at 4lb 14oz, born by normal delivery.

When these two little bundles of joy (and hard work) arrived it seemed that nature in its own way has compensated our family. Days ahead may be full of hard work, feeds, nappies and caring and love, and all will be worth it.

We can whole heartedly advise anyone in the same position as us who are thinking about adding to their family - don't hesitate, it is well worth it. One has to take some risks in life and thankfully for us it worked out. Who knows YOU might end up with TRIPLETS!!!

Jane Reid.



FLAG DAY FOR THE SOCIETY

A Flag Day for the MPS Society was held on 5th January 1985 in Milton Keynes and the following is an account of the arrangements made and the build-up to the big day.

Lindy and I first started to arrange a Flag Day or Street Collection back in September 1984. We contacted our local council but were told that all Saturdays in 1984 were booked. We went ahead with an application for the first Saturday in January 1985 as we thought there would be plenty of people about looking for bargains in the Sales. After we sent in the initial application, the council wrote to Christine Lavery, because hers is the name the Licence was to be issued. Once the licence for a Street Collection in the Borough of Milton Keynes was issued, we then had to obtain separate permissions to collect inside the covered shopping centre at Central Milton Keynes and the Shopping Centre in Bletchley. That was all the paperwork finished, almost. It was then a matter of twisting enough arms to persuade people to come along and hold tins on the day. Actually it was no great problem. All my friend's from work and from bell ringing and Lindy's friends from around Milton Keynes readily agreed to help.

The "Day" dawned and all the collectors were issued with their letters to say they were collecting on behalf of the MPS Society. They also signed for their collecting tins, ready primed with some copper and a funny hat to wear, anything to get people's attention. As the day wore on and collectors finished their "shift" they were replaced by the afternoon crew. Five-o'clock seemed to come round quite quickly and it was all over bar the counting. Even that took quite a while as the vast majority of the money was obviously in coins, although there were twelve single £1.00's. The grand total was around £168.00 and we were very pleased with that. The only paperwork left was a financial statement to the council but Christine took care of that.

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If anyone else fancies organising a Flag Day, you may find the following helpful:-

Apply early for a licence (Councils seem to be very helpful.) Make sure you have any extra permissions needed for shopping centres etc. Get plenty of help, and make sure everyone knows when and where to meet. Wear comfortable shoes. Thank everyone afterwards.

Lindy and I really enjoyed the whole day and found that a lot of people genuinely showed interest in the MPS Society, rather than just put money in the tin, so the day really served two purposes.

Ron Snack



Colin Snack with
his Mum and Dad
on the MPS Flag Day.

DAVID'S TRIP TO DISNEYLAND

It all started when Roy & Jill Williams who run the Pentwyn Community Centre, asked if I would mind if they put David's name forward to go to Disneyland, through the Les Evans Holiday Fund for Sick and Handicapped Children. The funds were being raised by patrons of Canten Cross Pub, Cardiff. Roy and Jill knew the landlord and as they didn't know a suitable child, they suggested David. Well all the forms were sorted out and they contacted David's doctor at Heath Hospital and all agreed that he could make the trip, and as David has speech problems etc., I was able to go with him. We met all the people at the pub and they were super, and just before we left they gave David £200 to make sure he had a good time. Words cannot explain how I felt, total strangers up to a few weeks previously and yet I felt I'd known them for years. They were really kind to David and I. Well after sorting out passports - visas etc., the great day arrived and Graham and Jane took us to Sheraton Heathrow Hotel to meet Les Evans, Doctor Richard Gardener who was travelling with us, Colin Roberts 17yrs, Kelly 7yrs. and her mum. We all had lunch and said our goodbyes to relatives, then off we set for Heathrow, handed in our luggage, passports etc., and then straight on the plane. We were first on board so the Air Hostess took us to see the cockpit. This was great fun and then we settled down for our 11 hour flight. David slept for only ½ hour, he was much too excited and didn't want to miss anything. When we arrived at Los Angeles, Joy and Keith were waiting to greet us. They would be looking after us for our 2 weeks stay. They were a smashing couple and David didn't give me a second thought. Joy held out her hand and off he went. We stayed at The Hacienda Hotel, El Sagundo, California. Our rooms were huge and David and I had a 5ft. bed each, very comfortable, especially from David's point of view because the TV in our room had 13 channels and had cartoons practically 24 hours a day. This was also good for me, because David was waking 3.00 a.m. in the morning ready to start the day, so I

just switched on the cartoons. At least I could rest. We went to so many places, I could write a book, but here are just a few. Disneyland twice, Knotsberry Farm, Universal Studios, M.G.M., Boat Trip. Visited a school, Fire Station and had a Thanksgiving with Joy & Keith in their own home. We also had a marvellous day up in the hills (that is 8,450ft up) and we drove into a snow-storm, it was marvellous. David thought he was about to see Father Christmas around every corner. David's little face was a treat, when he saw Mickey Mouse, Snoopy etc. The 'A' Team in action and best of all when he sat in Knight Rider's Black car and it spoke to him. Naturally I bought him a toy car which speaks. It's his prize possession. David kept very well most of the time and only had two days when he was rather poorly, so I kept him in for a day and it seemed to do him good, so after that it was all go.

The holiday went much too quickly and David still talks about all the things he saw; little details that I'd really forgotten. It was a trip of a lifetime and I don't know who enjoyed it most, David or me thanks to those very special people at Canten Cross Pub.

Pat Criddle



David and Friends
at Disneyland.

CHRISTOPHER AND THE MYSTERY OF AN INCORRECT DIAGNOSIS

Our family consists of myself, Pat, husband Dave, Natalie aged 8, Bryn aged 6 and Christopher who was 4 last October. Until Christopher was 3 years old, we lived in blissful ignorance, thinking that we had three ordinary children. Soon after his third birthday, in a routine annual visit to the hospital for a slight hearing loss, the new paediatrician said he was not happy with Christopher's growth and would like to do some tests to find out what was causing this. It sounds funny to say this, but we had not noticed anything wrong up till then. Christopher had been a big baby and we were proud of his size, as Bryn our second child had been very tiny and we had been more concerned about him. Then began many tests. We had to wait nearly 5 months for the results, by which time, we had decided inwardly that doctor's hadn't found anything wrong. To our disbelief we were told last Easter that Christopher had Hurler's syndrome - the most severe of the MPS diseases - that he would hardly grow any more and that he would become severely mentally retarded. I will always remember my feelings - all my strength seemed to drain away and I felt like an empty shell. I dropped Christopher from my knee feeling stunned. After a while as we groped our way through the darkness of time, I began to read articles in the 'Women's Own' about Hurler's children, and friends working in hospitals obtained articles on MPS from medical journals. They just didn't seem to tie in with Christopher so I began questioning. At first you think no doctor could make such a mistake, but since then I have read a lot on the subject of MPS and have learned to question. Then I heard about the Society via the BBC and eventually about 2 months after the initial diagnosis, wrote to Christine telling her about Christopher and the fact that our consultant was surprised that he showed no signs of mental retardation - he was 3½ years old by this time and seemed quite 'bright'. Christine 'phoned me immediately and I wish I had contacted her earlier. She gave me the first ray of hope, telling me that there were

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three types of Hurler's, all showing the same enzyme deficiency. By chance later on that day, Dr. K. Hugh-Jones, to whom I had written in desperation about bone marrow transplant, 'phoned me about family donors. I asked him about the diagnosis and he was sure that Christopher could not have the severe form of Hurler's, if he was not mentally retarded at this stage. Then began months of pestering to find out the truth. Between us, Christine and I had decided that Christopher might have Morquio Syndrome and to cut months of agony short, eventually in September, 5 months after the initial diagnosis of Hurler's and 11 months after we were first told he wasn't growing properly, it was confirmed that Christopher was suffering from Morquio Syndrome, Type A (severe). For a while after this, we almost felt that there was nothing wrong with Christopher, as we had escaped Hurler's. Then it sank in again that he does have a very serious illness and we had to come to terms with it for a second time. In spite of his initial mistaken diagnosis, our own consultant has been very helpful. I understand the many problems presented to the medical profession because of the comparative rarity of MPS diseases, but I write this in the hope that concerned doctors can look at the problems from the parents point of view and that future parents can be spared the unnecessary agonies of diagnosis that we have suffered. "First of all the bad news - and then the not so bad" is not a policy I would advocate to anyone. Since the initial diagnosis we have spoken to many doctors some have realised the parents need to know the truth, while others have been more concerned with the medical ethics involved. I can't help feeling that we would have been kept waiting for an accurate diagnosis for many more months had we been content to sit back. A willingness to share information and listen to parents must be fostered in the future. I also feel strongly that we should have been visited by our own G.P. or Health Visitor soon after we were told the dreadful news - but we were left alone in our sorrow. To be fair the hospital social worker offered to see us, but we couldn't face talking to a total stranger at that point.

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We lived with a Hurler's prognosis for 4 months and to all those parents who do have to live with the reality of Hurler's - my heart goes out to you. I hope the funds I have been raising for MPS and the Bone Marrow Unit, will in some way help to lighten your load a little also. The strength I have received from telephone contact, the Newsletter and meeting other parents at the conference has been tremendous and I thank Christine and Robin so much for instigating this Society.

Although I have just about come to terms with his illness, when Chris is asleep and I kiss him on my way to bed, I often ask "Why him?" His latest question is "How do you grow big" and I'm still searching for the answer in my heart.

Pat Isaac.



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Sentinel Newspapers.

HARRY AND GEORGINA TAYLOR'S CHRISTMAS PARTY

Mary, Colin and Catherine Gardiner, Chris, Andrew, Ben and I, along with other families were kindly invited by Georgina and Harry to attend their MPS Christmas Party in Stoke on Trent on Saturday afternoon, 1st December. This also turned out to be two days before Christopher Taylor's 6th birthday, so there was a lot to celebrate.

To our knowledge this is yet another 'first' by MPS families and although Christmas 1985 is a long way off, some of us must think to do the same in our areas this year. We came away excited and regretful when it had finished; you see I think it was a landmark for all of us MPS families. The point is, usually when we meet, in two's or three's or at 'open houses' or at the Conference, conversation most often is about our cares and problems as MPS parents; until recently the opportunity to meet MPS families has been rare and of course it has been natural and sensible to exploit every valuable second in MPS talk. But Georgina and Harry's party was different. The kids and parents and the Lord Laylor of Stoke on Trent and Mrs. Dimmock (even with the dignity of their position and Chain of Office) thoroughly let their hair down and had a jolly good time. We have now become relaxed and trust each other. We knew that if we had a specific problem the answer could wait. The priority, unspoken and unthought of by anyone, was relaxation. The answer could wait until tomorrow: a friendly and possibly expert view or solution was only as distant as a 'phone call, a letter or a casual meeting.

So it seemed that everyone apart from poor George and Harry, hadn't a care in the world, and George and Harry's act will be hard to follow.

We were glad we were invited and glad for Harry, Georgina and their family and friends that all their hard work was so much enjoyed and appreciated.

Robin.



THE CANADIAN BRANCH OF MPS

CANADIAN BRANCH

The Canadian Society is now incorporated, after receiving permission from the provincial government to raise funds in the province of Manitoba. However there is still more form-filling to get over, which will give permission from the federal government to raise funds throughout Canada. It is almost five months since we first applied for a Tax exempt and Charity number, we are still not registered as a charitable organisation. There is a lot of Red Tape.

Locally the fund-raising has been going very well. A Youth Group held a dance for the Society and a lot of friends and relatives have sent donations. All the local service clubs have sent donations also. So far One Thousand, Six Hundred Dollars have been raised.

The Society consists of only five families. these being ourselves, a family 500 miles South of us and a family 500 miles West of us. In Canada 500 miles is a fairly close distance and we have been fortunate enough to have met with both of these families.

Other than these we have not been able to contact any other families. I am finding this a bit discouraging, since I have distributed information leaflets to medical officers throughout Canada. We are having problems getting any Canadian Magazines to publish anything about the Society.

Hopefully things will pick up and we will be able to locate more families.

Sheila Lee
Secretary

NEW YEAR 1985

I suppose it's always at the back of one's mind that belonging to a specialist Society may be O.K. but much depends on how useful it is, and if it is useful how long it will remain useful. It's a hard world and if you let your guard down too far someone or something will probably disappoint you. Anyway I tend to think like this. I start off on this negative note really to emphasise my contrasting thoughts; I really do believe we/you/us/ the Society has arrived and matured. If the Society as a formalised organisation were to disappear tomorrow, or were to reduce its activities (which it most certainly won't) there will never be an occasion again when MPS families need to be isolated, alone or ill-informed. First of all our grapevine is well established and even if the present clutch of Society officials lost interest tomorrow there are spread around the country a good number of mums and dads who not only feel strongly about the bond we have made between ourselves but on no account would allow the position to revert back to only three years ago when hardly any parent had any communication at all with another family.

It was hinted (by me) at the Harrogate Conference that 'The Society' should not be thought of as some anonymous and faceless machine run by middle-class, clever-sticks in the affluent South. As a matter of fact, if it matters, some of us could be called middle-class, and a few others affluent, but the point is the Society's achievements to date have depended on many people's joint and separate efforts all over the country. Indeed, if we had had any idea that the Society would have grown up so fast, turned out to be so important to everyone and taken the form and feel it now does we should not have called ourselves 'The Society' but the 'Family for MPS Diseases'. Apart from the cost in legal fees to change our name I hardly think we can go around calling ourselves for short 'The Family' meaning you, me, us, and the MPS family 20 miles down the road.

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It sounds just like the Sicilian Mafiosa. Mind you, I do sometimes wonder whether the Mafia approach is not developing our style if you consider the way we are all supportive to each other and to 'The Family' - sorry I mean 'The Society'. Just look at Pat and Mike Skidmore's account in the last newsletter of the complicated and selfless effort by families in Wales and the South to ensure the car window stickers arrived at Harrogate.

Why should I be so confident and optimistic about our Society's future in 1985? There are several signs and developments:-

1. The Dr. Martin Bax research project is taking off with enthusiasm shown by many families (if you haven't completed the participation slip sent with the last Newsletter, please return it to Christine as soon as possible.) The team working with Martin are also keen and I know we can look forward to useful and helpful co-operation.
2. New families are coming forward to help with arranging local 'at homes' or fund raising events.
3. We have got offers of help from Jenny Broome, Jean Bennett and Mary O'Toole to organise the next Family Conference, subject to funds being available we intend to hold this near Reading, Berkshire, on the weekend of 20/22 September. This will be convenient for Jenny and the location also seems fair to those who have travelled North in the last two years.
4. A feature on MPS and the Society was carried in the January edition of 'District Nurse' an important journal so far as spreading awareness is concerned.

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5. The D.H.S.S. has approved a grant for a modest word processing and computer system for use by the Society (we shall have to consider our position under the new Data Protection Act 1984 - but since we are habitually careful to protect personal details we hope compliance will be easy to meet). We must thank Peter Archard for his negotiations with the DHSS.
6. On the international side Helen Coppock and Ros Smith have been consolidating their Australian Society since the Harrogate Conference. Sheila Lee in Canada has formed a Society there and probably most pleasing because it was unexpected. Dr. Suzanne Kircher sent a copy at Christmas of the New Austrian Information Sheet, which she, Dr. Lubec and ERich and Marion Kraft have put together. All the overseas groups use our house-style and logo which will help to identify us all as a world-wide family. We wish all our overseas freinds every good fortune in 1985.
7. The Christmas Raffle realised over £2,600.00 for an outlay of about £450.00 in prizes, printing, postage and licence. Everyone took part in this throughout the United Kingdom and we were very pleased that the prizewinners were also well spread across the United Kingdom (we would have been rather embarrassed if most prizes had gone to people in Buckinghamshire and Hertfordshire.) Thanks go once again to Maggie and Peter Archard for leading the hard work.
8. The Christmas cards were very popular too, and in fact we had to order a second print run. We haven't completed the auditing but we expect to be well in profit. Both the raffle and cards all helped towards MPS awareness.

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9. We believe the Harrogate Conference did a lot to make lasting friendships. Some of us were fortunate to meet again in December courtesy of Harry and Georgina Taylor - see the write-up on their Christmas Party in this issue. We believe get together's, and certainly the idea of Christmas parties (and summer picnics or Bar-B-Ques) will be popular and a way of getting families together locally. If you are interested in arranging or helping with one, do please come forward. Harry and Georgina cleverly managed to fund theirs through local sponsorship, but the Society is prepared to help with a modest contribution towards an event subject to advance clearance with "H.Q."
10. At Christmas, Maggie and Ian Westlake, now returned to California sent the Society masses of American cuddly toys. We feel these should be used for raffles and draws. A very kind and unusual gesture, and we shall have to ensure good homes for these little American orphans.

We have had several favourable comments on the Annual Report, distributed at the same time as the Newsletter, and fortunately no complaints or criticisms as yet. We hope you found it useful and helpful. As the first it was pretty hard to write and for Diana Fudge probably quite a nightmare. Didn't Peter and Marlene do a good design job? The report really is important to present ourselves to the outside world and the Sandersons certainly have not let us down. What everyone on the Committee did get was masses of Christmas cards and personal letters. We could not possibly return our greetings to everyone but they were very much appreciated. Joanne Crook, the designer of that happy little Snowman, might be quite surprised that some 10,000 were sent all round the country, and some of us even had families of Snowmen lining our shelves and walls. Keep the letters rolling in to the Newsletter and don't forget Lorraine who wants you for a Fund-raiser.

All the best in 1985.

REFLECTIONS

Charles was a bonus - our loving, lovely little boy was totally unexpected and yet his four short year's had the most profound effect on anything or anyone in our lives - past, present or future.

We were told that it was possible that we would never have children but after almost six and a half years of marriage, Laura was born. In a few days of 'Baby Blues' I was convinced that she was a Downs Syndrome child - perhaps the most dreadful disease I could envisage - at that time.

I was very pregnant with our second child and due to go into hospital that night to have the birth induced. I wept as I bathed our daughter, because I felt I could never have as much love for the new baby as I had for this little girl. How inaccurate are our emotions in pregnancy!

Charles was born on 6th November 1978, rather hurriedly, but a normal healthy delightful baby boy. Our family was complete. I just could not believe how fortunate we were!

At seven months Charles was not sitting up. A well-intentioned friend suggested that this was not "normal" and that she would be concerned if Charles were her child. The first seeds of doubt had been sown. Charles suffered from almost permanent infections and was generally "unwell". Our G.P. maintained that there was "nothing untowards" and that Charles would grow out of it." After several periods in hospital for minor problems, an E.N.T. consultant suspected something more sinister. 14 days after his third birthday, Sanfilippo disease was confirmed.

We were devastated when we learned what the prognosis was. Down's Syndrome seemed a preferable option. If only we had had such a choice.

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The one hope for Charles lay in a bone marrow transplant. We had but a little time to live without hope before Charles was on the waiting list for a bone marrow transplant. This was the middle of January 1982. It was 9 months before Charles went into hospital and the tension between my husband and myself was enormous. The agony of waiting for the call to go into hospital put a tremendous strain on the whole family. Having researched the disease, we knew that Charles was suffering irreversible brain damage with every day that passed.

In the middle of September Charles was in hospital. He had two transplants, both of which failed despite tremendous medical and nursing efforts. Charles died on the 29th October 1982, a few days before his fourth birthday.

Charles's short life was so special and yet so dynamic. Both my husband and I have changed as individuals. Certainly the trivia of life no longer seems important and the important things are no longer taken for granted as a "right".

I truly believe that we all, as parents of MPS children have an obligation to all our children and that is to "think positive" and capitalise on what we have got (however little it may be) and not what we have not got. Our over-riding principle has to be that we will "never make comparisons". I would add here that I wish I could present myself as a paragon of virtue and righteousness. Unfortunately I still have days when my every thought is negative and all my speculation is on "what might have been!"

Somehow we have to pick up the pieces of our shattered lives and fit them together again in order to move forwards. We owe it to ourselves and, more importantly to our very special, precious children.

A bereaved mum.

MOULDING SEATS WITH EXCELITE

Moulded seating for handicapped children is certainly not a new idea. Indeed, moulded seats are now produced in many centres using a variety of methods and materials. The main disadvantages with many of these forms of seating however, include the considerable length of time to produce them, long waiting lists for their provision, and the high cost of producing them. Thankfully, a simpler system of individually moulded seating has been developed using a material called "Hexcalite".

Hexcalite is a rigid white mesh, (like a rigid string vest in appearance) which becomes wonderfully floppy and mouldable when placed in water at 71 degrees centigrade. It has been known to hospitals, in particular Occupational Therapists for a number of years and has been largely used for making splints. However in Occupational Therapy departments in an increasing number of hospitals, a lot of work has, and is, being done to develop the use of Hexcalite for seating with severely handicapped children and adults.

These moulded seats may take the form of:

- a. an insert for a buggy or a pushchair
- b. an insert for a wheelchair
- c. an insert/chair for the home or classroom

All of these aim to help the child by:

- a. Improving posture and thus preventing and reducing deformity. Good posture will also assist respiratory and digestive functions.
- b. Produce more even weight bearing and thus reduce the risk of pressure sores.
- c. By holding the child in a stable position, the child will have more confidence to let go of the chair and use his hands for play.

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Briefly, a moulded seat is made using the method below:

A Bean-bag containing thousands of polystyrene balls is first placed in the buggy or wheelchair. The child is then correctly positioned on the Bean-bag, whilst the air is evacuated from the bag, causing the bag to become rigid and retain the impression of the child's body. The child is then removed from the Bean-bag, and the Hexcalite heated in hot water so that it can be moulded to fit over the contours of the bag. Two layers are usually sufficient and the chair is then further strengthened by putting polythene tubing around the outline of the mould. Minor adjustments can be made at this stage and pommels, straps added if necessary. The mould is then checked, lined if necessary and a cover made from stretch terry towelling. Except while positioning the child during the initial casting, the moulding and production can be completed by one person in less than two days. The completed seat is light to move, has good ventilation and can be scrubbed clean with warm water and soap.

I have only recently become involved in moulded seating, however in the short time I have been using the Hexcalite, I have been very impressed with its versatility and benefits. I do not know how many Occupational Therapy departments are involved in this form of seating, however if you are interested, I do recommend that you contact your local O.T. department who will hopefully be able to assist you and your child.

If anyone is interested in further details, I can be contacted at Musgrove Park Hospital, Taunton, Somerset. Telephone: (0823) 73444, Ext. 4202.

Mrs. Alison Batstone. Occupational Therapist.

A SUPER HEALTHY IDEA FOR FUND RAISING

We are Ian and Julia Macintyre from Surrey and our daughter Natasha aged 6 is suffering from Sanfilippo Disease. We have another daughter Kirsten who is 2½ and is well.

After reading the last newsletter asking for ideas on Fund Raising, I came up with the idea of producing a Wholefood Cookery Book, as I love experimenting and devising my own recipes (much to Ian's delight or distaste depending on how they turn out!) This would be with original recipes (i.e. not completely copies from another persons Cookery Book) as problems with Royalties ect. would then arise.

I did think of combining this with General Recipes from other Regions (as all families are spread over Britain) but think that it may be better to stick to the theme of Wholefoods and Health (thought this might be appropriate) to start with. This is of course dependant on whether we get enough recipes for Starters, Main Course, Sweets etc. The idea would be for Wholefoods (not necessarily completely Vegetarian).

Obviously if at the same time I was sent enough general recipes then another General Cook Book could be published at a later date (Hopefully I could also get some famous personalities to send in their favourite recipes).

At this stage could everyone reading this Newsletter send me a copy of their favourite recipe - either Wholefood or other - or if they feel enthusiastic several recipes! Also I would be grateful if anyone has any ideas concerning the whole project.

Hoping to hear from you soon.

Julia Macintyre
31 Elizabeth Avenue, Bagshot, Surrey, GU19 5NX
Tel: (0276) 74740

MPS SOCIETY ADOPTED BY DARWEN MOORLAND
HIGH SCHOOL

As a result of a letter which I wrote to Mrs. Finney one of our Senior Mistresses (who teaches Learn to Live) about the MPS Society and which she very kindly brought to the attention of the School at one of our meetings, the school decided to adopt the Society as one of the Charities which the School helps each year.

We have had a Gurning competition which raised £25.00 and one of the winners gave his prize back to the Charity.

Our local paper has also written about the Society. I think it is a good idea for the brothers and sisters of MPS children to write to their school and see if they can help. As we are from Bolton and only moved to Darwen a couple of years ago, I thought it was very good of our school and I would like to say a special big thank you to MOORLAND HIGH SCHOOL through our Newsletter.

Anna Kirkman Aged 11 years.

NEW FAMILIES

Heather Broughton whose two children, Joanne aged 5yrs and Myles aged 3yrs have just been diagnosed as suffering from Hurler/Scheie disease. They come from Sheffield.

Rosemary and Harry Nurse from London. Their 13yr old daughter Lisa has recently been diagnosed as suffering from Sanfilippo disease.

Hazel Smart whose parents live in Newcastle-upon-Tyne wrote to us from Winnipeg, Canada to tell us that her 4yr old son, Tyler has been diagnosed as suffering from Hunter disease.

Mr. & Mrs. Zierof from West Germany. Their 8yr old daughter Nicole is suffering from Sanfilippo disease. They would very much like to hear from any family who can read and write in German.

Mrs. Kearle, whose daughter Kathleen is suffering from Hurler disease. Kathleen is 6yrs old and lives in Wales.

Mr. & Mrs. Arrowsmith from Newcastle-upon-Tyne. Their 5yr old son, Colin was diagnosed as having one of the MPS types nearly 3 years ago but they are still awaiting a precise diagnosis.

Mr. & Mrs. Kaye from Sutton Coldfield. Their 3 year old son Daniel is suffering from Hunter disease.

Mr. & Mrs. George whose son Adrian is suspected to be suffering from Mucopolysaccharidosis. Adrian is 2yrs old and they live in London.

Mr. & Mrs. Dallimore from Queensland, Australia. Their 2yr old son Scott is suffering from Hurler disease.

Continued.

cont.

Jennifer and Andrew Hardy from Buckinghamshire. Their 3yr old son Matthew was recently diagnosed as suffering from Hunter disease.

Mr. & Mrs. Benbow whose elder son Peter is suffering from Sanfilippo. Peter is 20yrs old and lives with his parents on the Wirral, Cheshire.

Elaine and Roger Brittain from Bristol, whose two children, Natalie 4yrs and Christopher 2yrs have recently been diagnosed as suffering from Sanfilippo disease.

MPS THIRD PARENT CONFERENCE

20-22 September 1985

POST HOUSE HOTEL
Reading, Berkshire

Programmes yet to be finalised
include talks on Audiology and Orthopaedics
in relation to children / adults suffering

Professionals wishing to attend

on Sat. 21 Sept 9.30 - 4.00

coffee/lunch/tea included £15.00

NEWS IN BRIEF

MONEY OFF COUPONS raised £15.00 up to press. Keep sending them please to: Pat Kirkman, 73 Richmond Terrace, Darwen, Lancashire.

THE CHRISTMAS RAFFLE netted £2,300 thanks to all our members. This was a grand improvement of £1,400 on last year. Let's see what we can do this year.

BRITISH OLIVETTI have very kindly offered to let the Society buy a £4000 Word Processor/Typewriter for £200. This marvellous offer came about as the result of a Coffee Morning held by Gemma Corbett's Grandmother. Gemma comes from Milton Keynes and is suffering from Hurler Disease.

CONGRATULATIONS to Anne Worthington of the IN TOUCH TRUST who was awarded the M.E.B. in the New Year's Honours List for her information service on Mental Handicap over the last fifteen years.

THE MARTIN BAX RESEARCH PROGRAMME: Out of 120 Questionnaires sent with the Autumn Newsletter, over 60 were returned. If anyone wishes to join in the Programme, could you please return the Questionnaire as soon as possible.

PRE-NATAL DIAGNOSIS FOR SANFILIPPO 'A' DISEASE: William and Fer Pidden asked us to let our MPS families know how quickly the result of the pre-natal Chorionic Villi Biopsy was obtained by the Institute of Child Health, in London. Five days after the Biopsy was performed, they were telephoned with the result. Sadly on this occasion the result was positive and a few days later the pregnancy was terminated. Nevertheless Fer thought families considering a further pregnancy would find this information encouraging.

SUE BRAMFORD has a Maclaren Buggy Major which she has very kindly offered on loan to any MPS family who would like it. Her address is: 196 Ferndale Rd., Swindon, Wiltshire. Tel. Swindon 644192.

DATE FOR YOUR DIARY: On Sunday, the 14th April, The Lavery's, Sanderson's, Archard's and one or two other's will be meeting at the BURFORD WILD LIFE PARK at 11.00 a.m. with a picnic. It would be lovely to see as many families as possible who live in the area and are able to join us. Don't forget to bring your picnic. The park is beautiful with a marvellous Butterfly exhibition, play-park and many rare breeds.

DONATIONS

The Society's grateful thanks go to the following 'Busy Beavers' who have been raising money in many different ways:

Caroline of St. Albans School
Jean Kendall has been selling homegrown plants & veg.
Ledgar & Bardstone Womens Institute
Christine has had yet another Book Sale.
Bridget Butler has been saving all the family's ½p's.
Mrs. D. Woodman held a Coffee Morning.
Mr. & Mrs. Lockyer
Mrs. Heather Terrot, Mrs. Elizabeth Davis and
Melodie Pollard held a Coffee Morning.
Liv. Liebery
Lorraine Stenson and her brother
Carol Hubbard
L.W. Lilley
Julie Hill and the Battery Hotel
Pat Criddle
Mr. & Mrs. L. Meas
Nalgo Social Club - Uttleford Branch
Newton Social Club, Bognor Regis
Mr. & Mrs. H. Killin had a Coffee Morning, Germany
Mrs. L.H. Dawson
Pam Tubb
Mary Challand
Maggie & Peter Archard
Sarah Corbett, her mother and friends the Utrills
Friends of Mrs. S. Thomas
Mrs. Eileen Simmons
Mr. & Mrs. B. Poinsett
The REv. & Mrs. E. Essery
Mr. & Mrs. Potter
Mrs. M. Carpenter
Mr. & Mrs. R. Gurr
Mrs. G. Potter
Mr. & Mrs. M. Runham
Mrs. H. Neal
Basildon Scout Group sent a donation in memory of
Mark Townsend.

Mrs. A. Dyer
Mrs. D. Blake
Mrs. E. Don
Miss M. Tickner
Mrs. B. Mercley
Mrs. I. Ellison
Mr. & Mrs. H. Pickup
Mrs. M. Taylor
Audrey Hodges held a Mini-Market
Laura Merrigan has been collecting $\frac{1}{2}$ p's from her
visitors.
Robert & Pam Heyward held a raffle.
The Commercial Hotel in Sheffield held a raffle.
Mrs. C.A. Danes from Scotland held a Coffee Morning.
Francis and Audrey Toker
Heysham Post Office collecting Box.
Margaret Leask held a Coffee Morning.
Susan Paten
Sue & Alan Butler held a Discoe.
Mrs. H. Beach who collected from friends.
Mrs. L. Parish held a Coffee Morning.
Anne Canton
Womens Citizens of Waltham Forest.
Mrs. A. Davis held a Coffee Morning.
Mr. & Mrs. L. Briggs
Mrs. R.D. Hall
Mr. & Mrs. Farwell
Mr. & Mrs. Wigley
Mr. Hugh Williams
Mr. & Mrs. D. Russell
Cyncoed Post Office Collecting Box.
Rachael Todd
Heysham Nuclear Power Station canteen.
Pauline A. Runham
Mrs. Charmaine Fowler had a Make up Demonstration.
Mrs. J. Burgess
Dr. Ian Young
M.F. Garde
Heathcote School
Mayat Arthwtan
E.M. Davies

Tipputts Inn, Nailsworth
S.P. Paton
Little Chalfont Post Office Collecting Box.
Mrs. E. Sanderson
M. Prestwich
Langer & Bainstone P.T.A.
Mrs. Bagshaw
Shirley Twigger
Ladies Group in Monmouth via Pat Skidmore.
Peter White
Linda & Ron Snack
Niel & Jane Reid

The following donations have been raised by Pat Isaacs who has worked so hard for the Society since she joined last August. Our most grateful thanks fo to her and all her sponsors:

The Rotary Club of Bridgewater, Mrs. Sally Hughes, Mr. & Mrs. Smith, Mrs. Vera Price, PN & JM Newcomb, Mrs. G. Finch, Mr. David Clegg of Sedgmoor Manor School, Mr. J. Fairhurst of The Blake School, Llantwit Major Round Table, Lyngford Park CP. School, Mrs. A. Chamberlain, Nether Stowey Playgroup, Mr. J. Pearce of Fiddington Carol Service, Mrs. Nancy Small organised Carol Singing, St. Mary's Primary School, Stogursey Primary School, Cannington Primary School, Eastern Primary School, Brynmore School, Mrs. Penny Waller, Mrs. Linda Randall, Bridgewater Twins Club, Mr. & Mrs. D. Bryn Morgan, A.W. Wilkey, Mr. & Mrs. I. Mackenzie, Windwhistle Primary School, Bernw VC Primary School, Mrs. Val Dickie, St. Joseph's R.C.V.A. Primary School.

The following Companies have up to now responded to the Fund raising for our next Conference and we would like to offer our grateful thanks, for without them we could not hold the Conference.

Capital Radio; Johnson & Johnson; Avon Cosmetics, Northampton.

Please accept our apologies if 'Thank you' letters seem rather a long time in being sent out, but cheques are cleared by the Treasurer before she sends the letters on to me. School holidays can also delay thank you's, as we all have children and as we run the Society on a voluntary basis, you can see by the above lists, that we have been extremely busy over the last few months. We are very grateful to everyone who raises funds for the Society, but please be patient with us if you don't receive replies by return of post.

Happy Fund raising.

Sue Butler
Donations Secretary

DEATHS

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

Edward Bellman aged 2yrs of London died suddenly in Westminster Children's Hospital on 9th November 1984. He appeared to be doing well after a bone marrow transplant for Hurler disease and certainly was the life and soul of the nursery at the Harrogate Conference.

Mark Towning aged 13yrs of Basildon, Essex died at Turner Village Hospital, Colchester on 26th December 1984. Mark was suffering from Sanfilippo disease.

Alyn Wigley aged 13yrs of Caernarfon, North Wales died in hospital just after Christmas from Sanfilippo disease.

Tragically Geriant, brother of Alyn has died also of Sanfilippo disease.

Gethin Robins aged 5yrs died peacefully in Hospital in Wales on December 30th 1984 whilst spending Christmas with his grandparents.

Our thoughts are with the parents of all these children during this sad time.

THOUGHTS OF A
MENTALLY
HANDICAPPED PERSON

Why am I like this? Where do
I belong?

God created life for me, so
why has it gone wrong?

No one knows the answer or
who I was made to be
If anyone could understand
then through my eyes they'd
see.

And yet I have emotions,
whether they're good or bad-
Sometimes I am happy and
also I am sad.

But if I am so different why
do I laugh or cry?

God gave me a life, so my life
I will live

And to everyone who helps
me, my affection I will give.

As long as there are people
who want to help and care
I know that deep inside of me
I do belong somewhere.