

NEWSLETTER

SUMMER 1987

**THE SOCIETY FOR
MUCOPOLYSACCHARIDE
DISEASES**



National Registered Charity No. 287034

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This Newsletter is published and distributed free of charge to sufferers of the MPS disorders in Great Britain and, where they are children, to their immediate families. It is also distributed around the world on subscription and copies are sent to those members of the medical profession who are directly concerned with MPS, many of whom make a donation towards our costs, for which we are most grateful. If you wish to be added to the circulation list, please contact the Newsletter Editors at the above address. Subscription charges are £5 in Great Britain and £10 Sterling elsewhere.

CASH FLOW

In your last Newsletter, almost every other page seemed to include some reference or other to the commitments that the Society were entering into and the fund raising efforts that would be needed to sustain our activities.

In several articles this time you will see reference to the remarkable sums that some events can raise thanks to the ingenuity and hard work of a few individuals and the unselfish contribution of time and energy by the many who work to raise sponsorship on the Society's behalf.

It is a pleasure to record the Society's appreciation of these efforts and, through a few brief words from those involved, attempt to convey some of the atmosphere that distinguishes certain of these special events. These are, however, the tip of the MPS iceberg, for across the country, less publicised but no less important, events take place all the time. Coffee mornings, car boot sales etc. etc., raise funds that may not necessarily appear dramatic individually, but which collectively are fundamentally important. Those of you whom have received the Newsletter regularly will know that we have endeavoured to acknowledge every contribution, albeit briefly. As the number and range of events, activities and contributions has increased, it has become progressively more difficult to do this within the constraints of time and space available.

In the future, whilst we will identify major events and unusual fund raising efforts, the Newsletter acknowledgement of the huge number of individual efforts can only be in collective terms. In positive terms, this is a very good thing because it means that the very necessary steady flow of funds is being maintained. In the future we hope to include a graphic representation of how the Society is progressing towards meeting its annual fund raising target and we hope that you will be inspired to keep the funds flowing.

Don't forget, every pound in our account is exactly the same as the others, whether it arrived by itself or with several others! Don't forget also please that pounds held by you can't be regarded as available to the Society and the Trustees will, quite properly, not permit the Management Committee to make commitments that would not be covered by 'cash in hand'. As our activities and sponsorships have grown, this has become ever more important in relation to preparation of future plans and expenditure. So, if you have £99 tucked behind the clock on the mantelpiece, please send it to Stella Hale, our Treasurer, NOW - you can always send the £1 you were waiting for "to round it up", a little later.

Peter Archard

The next newsletter will be published before the conference and because of the holiday period it is imperative that items for inclusion be with us **as soon as possible**.

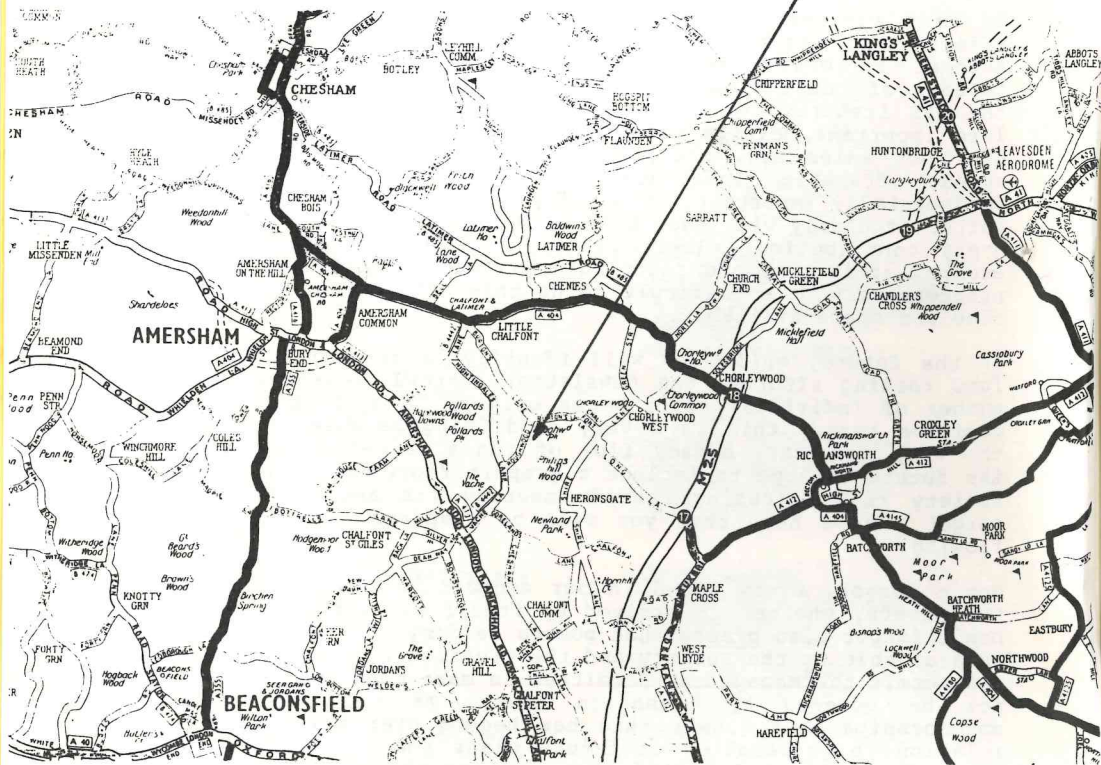
BIRTHS

Pat and Rosemary Dawson are pleased to announce the safe arrival of Oona Kathleen on 13th June 1987; a sister for Bridget.

DR. GARROW'S GARDEN PARTY

Just a reminder to you all about the Garden Party of the year! Dr Garrow is kindly allowing us to use his garden again and arrangements are well under way. We hope as many families as possible will join us - come in the morning and bring a picnic lunch, and if you can, bring your own "stall", otherwise all offers of help will be gratefully received! Details from Christine

Remember - Sunday 19th July at:- Roughwood Farmhouse,
Roughwood Lane,
Chalfont St Giles, Bucks.



DR. BAX RESEARCH PROJECT - UPDATE

The Management Committee have recently agreed to grant Dr Bax further funding to enable his team to expand. The extra funding will allow Dr Bax to continue his work with Sanfilippo children. A member of his team will help Dr Bax by visiting Sanfilippo families whose children are having problems with their sleep patterns. They feel that improving the sleeping patterns of Sanfilippo children will enable the parents to get more rest and ultimately cope better during the day.

Christine Lavery will be very pleased to hear from families who feel that they would benefit from participating in such a scheme.

THE COURAGE TO CHANGE: REFLECTIONS OF MILD FORM OF MPS II

Part 2 - Bill Sellmeyer's own story

In the summer of 1983 I had carpal tunnel syndrome surgery on both hands. I remember sleeping at night and having knifing pain race from my elbow to my wrist. To regain sensation I would pour water on my arms; this would happen about three times a night. The surgery was not difficult but the nurses and doctors gasped at the sight of my nerve - it was black.

It was the 1983-84 school year and we were expecting our second child. I noted I was becoming more short of breath and I thought I would lose some weight to solve my problem. I lost 12lbs but found that my endurance was not as good as before.

On February 3rd our second son was born. My terrible cough returned and I was put on vitamin therapy to improve my energy level and to help fight infection. Two weeks later I had pneumonia but was able to stay at home. After a week I returned to school to a mountain of paperwork. I made it until May but I noticed many physical changes that were hidden inside me. I was frustrated because I wasn't improving and I felt my teaching wasn't as good. I was frightened that I was losing my love of teaching and to make matters worse I was moved to a different placement because the administrators felt that with my hearing loss I could not correct the speech of students with oral skills. It was ironic to prepare children with hearing impairments for a better future and discriminate against a hearing impaired teacher, but I had no choice and accepted the move.

I was busy finishing up the school year when the terrible cycle kicked in again - my terrible cough, diarrhoea, sleep disturbance and general hyperness. It was nearly summer vacation and summers are always my healing times. Something terrible was happening to me and I went to the urgent care. I did not have pneumonia but for the first time I used a bronchodilator. I was coughing up muco-purulent sputum and was told I had asthma. Three days later I went to a pulmonary specialist and was given medicine and told to stay in bed. All I did was cough in bed and my dreams were just nightmares.

Memorial Day in 1984 was nearly my memorial day. My body craved for sleep and I finally slept, although I was rattling terribly. I tried to wake up and walk but I could not move - my body felt like cement. I tried to keep my eyes open but they closed and I entered a dark dark tunnel. Whilst in the tunnel I felt weightless and moving through it I saw a light at the end but immediately returned to my body. Help arrived and I hung on as I was rushed to hospital. I received my last rites from a priest with my wife holding my hands. I told everyone it was not my time and I prayed to God for life. I was lucky to survive.

REFLECTIONS

A life is not measured by the number of days, months or years that it is lived, but by the effect that life has on other people who touch it. It is not measured by the length of its days or the height of its achievements, but by the breadth of its influence.

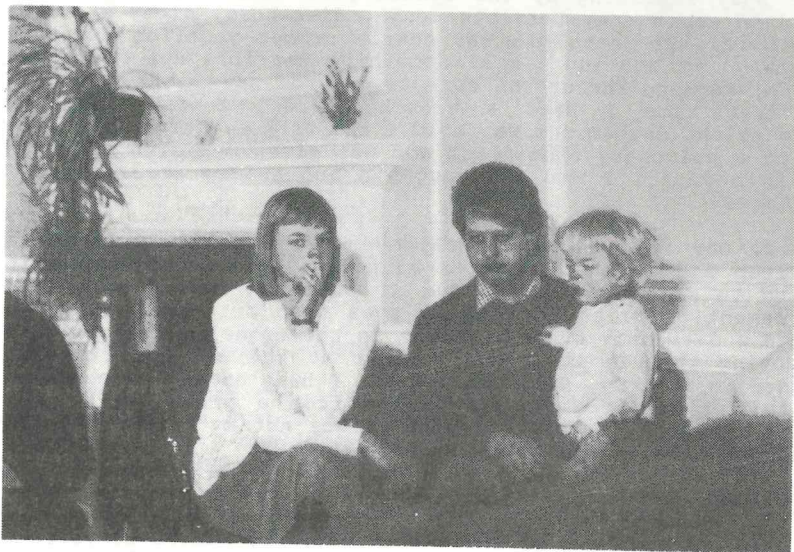
AREA FAMILY MEETING

Sometime during last year's conference it was suggested that we might arrange an area family meeting in the Midlands. The main purpose of the meeting is to exchange information and ideas for activities and support and how the needs of these areas could be better met by the Society. This meeting also gives the opportunity for local families and new families of the Society to get together.

Earlier this year we had a call from Christine, suggesting dates for this event and the task of finding a suitable venue began. We had many ideas and eventually succeeded in finding Hothorpe Hall, a local Christian Conference Centre. This seemed an obvious choice since it is very central, easy to reach from the M1 motorway and can accommodate up to 100 people and has some facilities for the disabled. It has the additional advantage of having many recreational facilities including large grounds. Having arranged the venue and confirmed the date was suitable for the majority of families, detailed arrangements began - finding suitable volunteers to look after the children, booking an Entertainer and contacting the press and arranging a photographer.

Perhaps the most difficult task was finding volunteers at short notice as it was half term. Neighbours and friends were a great help as the Red Cross and other voluntary organisations were unable to assist. We were lucky that the weather on the day was fair so that travelling was not a problem.

Mary & Robin Gooch - mixed feelings at their first meeting?



The families were welcomed with coffee on arrival. The morning period was for the area families to meet on their own and we

discussed the following:-

1. The day to day running of the Society
2. Holidays.
3. Newsletter.
4. Booklets.
5. Overseas liason.
6. Dates for diary.
7. Feedback on research projects.

During this time there was a creche when the volunteers got to know how special our children are. The older children were able to play snooker, badminton, table tennis etc. or explore the gardens. We were joined at lunchtime by some local and new families and this provided a good opportunity to chat informally and get to know one another.

In order that the parents of these families could join in the meeting in the afternoon, a magician (Uncle Harry) entertained the children. They seemed to enjoy his show and he had a job getting away.

Business matters discussed in the afternoon covered the snowball, other fund raising and reports from the area families. Tea brought the day to a conclusion. It seemed that most people enjoyed the day and felt that it had been worthwhile. For our part we were pleased that families seemed to appreciate getting together and we very much enjoyed planning it and seeing so many friends and new families.



Our local newspaper subsequently published a full page article together with a group photograph of many of the families attending. As a result many more people in our area are now more aware of the MPS Society and we feel sure that this will help further local fund raising events.

Alan and Deirdre Beavan.

MPS ANNUAL CONFERENCE - 25-27th SEPTEMBER - HEATHROW

Already nearly 60 families have booked places at our 1987 Annual Conference, but we still have room available and will be pleased to have late bookings as soon as possible. If you have mislaid your booking form please telephone Maggie Archard - 0462 673830 for another.

We have made a slight change to our Sunday programme. Professor Rodeck and Dr Rosemary Stephens are leading a session on "Prenatal Diagnosis in the MPS Diseases" and will be answering questions from parents and professionals.

Although the Conference does not formally start until after the buffet supper on Friday evening, we are aware that many families like to arrive early and we are pleased to be able to offer a playscheme for MPS children and their brothers and sisters between 1.30 and 6.00pm on Friday 25th September. We are most grateful to Hounslow Toy Library for providing this facility and hope families will take advantage of it.

Please note that the date for the balance for conference fees due is August 7th 1987. We look forward to seeing as many families as possible at the Conference so send in your bookings now to:-

Maggie Archard,
48 Lawrence Avenue,
LETCHEWORTH, HERTS SG6 2EY

CALLING TEACHERS IN SPECIAL SCHOOLS

We have received a request for help from a teacher in a school for children with severe learning difficulties. Sean O'Sullivan has a pupil who suffers from Hunter's Syndrome and he has asked us to help him contact other teachers who also have pupils with MPs.

He is particularly interested in finding out what sort of work other teachers have done with their pupils and, if appropriate, to discuss any strategies that they may have adopted to deal with aggressive behaviour.

If you are a parent and feel that your child's teacher may be able to help, please show him or her this article. As Editors, we would be delighted to print any articles written by teachers because they would be of interest to parents as well as the many other teachers on our mailing list. It would be so beneficial to all our children if teachers can 'pool' their knowledge and experience in dealing with our very special children.

If anyone can help Sean please contact him direct:

Mr Sean O'Sullivan,
50 Park Road,
Banbury,
Oxon OX16 0DN

Tel: 0295 66929

FUND-RAISING EVENTS

Joanne Melleney and nursing colleagues held a sponsored fancy-dress, three-legged pub-crawl and disco.

Gaye Finch organised a staff "weigh-in" weekly at school.

Molly Griggs sold her musical compositions.

Gillian Lister and Helen Potts collected money after reading about Adam Watts in the newspaper.

Alan Byrne organised throwing silver coins at a bottle of whiskey at Trinity Volleyball Club, Glasgow.

Glenys Cantello organised a jumble sale.

Mr & Mrs Probert had a collection at Southmead Hospital Social Club

Sheila Baker & Brian Beale ran in the Wolverhampton Marathon and collected sponsors.

Cambuslang (Glasgow) 1st Dist. Brownies, Guides & Rangers held 4 events -filling Smartie tubes with pennies, tupperware party, cake and candy stall and a raffle - to raise funds for MPS.

Catkin High School OAP Bowling Club had a raffle on their outing.

Graeme Lees, Steven McNichol & Scott Cambell from Kilmarnock held a jumble sale and sweet stall.

Mrs I. Carnick did a sponsored swim.

Benenden Chest Hospital Staff Social Club held a dance.

Class 2E of High Wycombe School had various events in Spring term.

Tanya & Angela Bunsell, Philippa & Victoria Knibbs, Katie Wright and Alistair Latimer held a mini-fair.

Mrs Thelma Pidden held a coffee morning.

Mrs Coulson had a coffee day.

Benton Park School, Newcastle upon Tyne, held a concert.

Charity Boxes

The Society acknowledge with thanks, the funds that continue to be regularly received from MPS collection boxes around the country.

Donations in memory.

The Society gratefully acknowledges the many donations in memory of Julia Broome.

Robert and Pam Hayward have donated money raised through various fund raising events held in memory of their daughter Angelene who died in 1983.

MPS FUND-RAISING ITEMS

The following items are available on a sale-or-return basis for coffee mornings, fetes etc. All items have the MPS logo and/or name.

BOOKMARKS.....*.*.*.NEW.*.*.....	60p
KEY FOBS.....	50p
PENCILS (with rubbers on end).....	15p
PENS (retractable) white with coloured top.....	20p
PENS (retractable) mixed colours (blue ink).....	25p
BADGES.....	15p
BALLOONS (to be blown up).....	20p / 25p
CAR STICKERS with logo and name plus one of the following slogans:-20p

"CARE TODAY - HOPE TOMORROW"

"MPS FOR SHORT - LIKE OUR CHILDREN'S LIVES"

"LIKE YOUR CAR THIS DISEASE ACCELERATES - HELP US TO SLOW IT DOWN"

COOKBOOKS.....£2.95 + 45p p+p.

All the above can be ordered from me by telephone or letter either singly or in bulk. There is no need to pay until you have sold them. Please try to give THREE WEEKS NOTICE of items you require, as I can not keep a large stock and may need to re-order. If you find you have not sold all your goods we would prefer you to send them back, rather than hang on to them, if you have not got another event planned soon after. This is because the Society's money is tied up in this stock and we need to KEEP SELLING the goods to make a profit on our sales. If several families keep small amounts of goods waiting to be sold, it soon mounts up into hundreds of pounds.

Also available for fund-raising events:-

- * Fund-raising leaflets.
- * Blank headed posters to advertise your event.
- * Charity boxes with labels.
- * Posters with photographs and slogans:-
 1. "MPS gave him just 6 years - will you give to MPS"
 2. "Gethin didn't grow up - please help others live"

Pat Isaac (Fund-raising co-ordinator).

AMERICAN SOCIETY CONFERENCE

The American Society organised a very exciting programme for their Conference at Stanford University this April and it seemed there would be much to be learned if representatives from our Society attended. Dr. Bryn Neal and I were chosen to go and we were not disappointed. We heard presentations on carrier detection, respiratory complications, the future of research, gene therapy, bone marrow transplantation and speech and hearing problems. We taped all the talks and I have been attempting to produce resumes (I now have great admiration for Kate Farminer who writes our Conference Reports each year!) The talk on respiratory complications was particularly interesting as we have not yet addressed this topic at one of our conferences. I hope soon to have a full transcript of this talk available for members who are interested.

The cost of the trip was kept to a minimum thanks to some careful shopping around for budget priced tickets and to the hospitality of friends and MPS families. Bryn and I were very warmly received and made to feel very welcome by the American organisers. We felt very much at home when we saw the posters of Christopher and Gethin looking down at us. The American Society uses our logo too and the trip emphasised for me the importance for the future, of regarding our Society as part of a wider international organisation. By sharing our knowledge and resources we have a better chance of making progress towards a better quality of life for our children and an eventual cure for the diseases.

Some 50 families attended the Conference from all over the continent and there was plenty of time to mingle in the relaxed atmosphere of the sunny quadrangle where we had our lunch and coffee breaks. (Pity we can't share the California climate as well). Bryn and I distributed Martin Bax's questionnaire which we hope will be returned and broaden the base of our knowledge of the various diseases. Several families have joined the British Society and we were particularly pleased to have met the family of a child with MLIII who will be a contact for the other families with this rare condition.

We were most interested to meet and interview Bill Sellmeyer who has Hunter's Syndrome and who is married with two sons. Bill is writing a series of articles for our newsletter and he spoke at the Conference. We were also able to make several valuable contacts with professionals from the States and to link them with doctors in this country.

Before the Conference I was able to spend some time visiting Helen Sigwald, the nurse who accompanied Dr. Kopits to our Conference last year. I was delighted to see Dr. Kopits as well and to visit his Centre for Skeletal Dysplasia. I was also able to call on Dr. Amato who also spoke at our last Conference. Dr. Amato was most apologetic that he had taken so long to write his reports on the patients with Sanfilippo Syndrome that he examined at his 'clinic' at the hotel. In fact Dr. Amato moved from West Virginia to a hospital in Baltimore the week after our Conference and as we saw, he has not had time to unpack! He hopes to have the reports sent out very soon.

Mary O'Toole.

MPS IN TENTERDEN

Last August we travelled from East to West Kent to visit my cousin Leslie and his wife Jean who live near Tenterden. We had told them previously that our grand-daughter Natasha was suffering from Sanfilippo Syndrome but it was not until then that we were able to explain the full implications of MPS, the Society and how Natasha was affected.

The next morning Jean phoned to say that they would like to show their concern in a positive way by organising some fund-raising events in the Tenterden area and hopefully make people more aware of MPS.

The first event was a Garden Party in September, held at the home of two dear retired ladies. It was attended by the Mayor and local M.P., the Press gave coverage to the event and £500 was raised. To further publicity, the local branch of the Anglia Building Society made over it's window for a display featuring the Society and Natasha. The younger element then took a hand when Jean's daughter Sarah and husband Frank ran a Coffee Morning with raffle, bring-and-buy and cake stall, and again raised £500.

Planning then began in earnest for a Cheese and Wine party to be held in the Spring coupled with a Grand Raffle. During this time Jean was making marmalade for sale (over 200 pots of the stuff), donations were being received and other organisations were giving the proceeds of some of their fund-raising events to MPS. The party was held at Tenterden Town Hall; a delightful historic building beautifully decorated for the occasion with masses of flowers. I'll let Natasha tell you how it all went (see page 26).

Ten days after the Cheese and Wine party our phone rang at 7.30am it was Jean. In her post was a letter from Tenterden Rotary Club explaining that they were going to have a charity shop for four days in 11 days time and were intending to donate the profits to MPS, could we help publicise it etc.? A lady in Tenterden had died and asked that the Rotary Club dispose of her personal belongings, and they chose this way to do it. What no-one had appreciated was the quantity and condition of the goods. As the job of sorting and pricing began it became apparent that there were masses of goods that were new, over 100 pairs of shoes and clothes still in their wrapping paper. On opening day the shop was stacked high, with further goods kept in reserve for subsequent days.

Christine Lavery and Lucy (having missed the Cheese and Wine) came for the day, accompanied by her parents, to officially "open" the shop, but the Press photographer hardly had time to click his shutter before they were almost mown down by the rush of customers who had been queuing outside. The first day of the sales had nothing on this!!

The money was coming in so fast that it was deemed wiser to bank it and one Rotarian spent most of the day with the paying-in book at the bank next door. £1,000 was taken on the first day alone! The second day (Saturday) saw an influx of tourists to the town and also gave the opportunity for some P.R. work - leaflets were disappearing fast. At the end of four days the profit for MPS was over £2,000.

Later, Jean and I were invited to a Club Luncheon to receive the money, part of which was specifically for the purchase of another 'Halo', and to give a talk to explain MPS, the work of the Society and the need for further fund-raising. This was a first effort for us but we were able to congratulate ourselves that:

- 1) nobody went to sleep
- 2) we appeared to keep the interest of our audience
- 3) afterwards we had some quite favourable responses.

Somehow I don't think it is all going to end there!

Pamela Macintyre.

MOBILITY ALLOWANCE

The following article is reprinted from the RADAR Bulletin (The Royal Association for Disability and Rehabilitation):-

"The campaign to obtain an extension of the criteria for mobility allowance continues. On 24th March, the All Party Disablement Group met with John Major, the Minister for Social Security and Disablement, to discuss ways that the criteria could be extended to deaf/blind people, those with a profound mental handicap and those with severe behavioural problems. These are people who need someone with them at all times and it is estimated that it will cost about £10.5 million to cover the 10,000 individuals concerned.

The problem is finding the exact wording which will cover only these groups. For example, one suggested phrase which encompasses these people is those who need "continuous physical intervention" for mobility purposes. However, this could also apply to very young able-bodied children for whom mobility allowance is inappropriate.

The outcome of the meeting was that negotiations will continue over the exact wording of regulations with DHSS officials. In the meantime, the Department will investigate to ensure that the existing scheme is working to maximum effect. The Group will be having another meeting with the Minister in the near future."

As some of you will know, Christine was invited by RADAR to speak to the All Party Disablement Group at the House of Commons on May 12th. Unfortunately, due to the election being called, the meeting was postponed and Christine now expects to address the Committee in the House in early July.

The main issue will be on Allowances (particularly Mobility Allowance) and respite care. Christine would very much like to hear from any families who have a view on any ideas for exact wording for Mobility Allowance to take in the needs of MPS children and in particular those suffering from Sanfilippo Syndrome.

Emma Hartley and Paul Johnson



Simon Meek



Lee Kelly



Adrian Twigger and Paul



CHILDREN AT THE FIRST MPS HOLIDAY IN

WESTON-SUPER-MARE - 16-23 MAY 1987



Terri O'Meara



Colin Snack and Richard Harford

THE THINGS THEY DO FOR MPS!!

Saturday 7th February seems so long ago now, but it was then that we travelled to Bury St. Edmunds in Suffolk to be present at a gathering of student nurses (Peter did not need too much persuading!) They were set to perform a sponsored, three-legged race around the town and we were met in the Hospital grounds by Dracula and his bride, two firemen, some St. Trinians pupils playing truant, surgeons, ladies attired only in nightwear, court jesters, pensioners, prince charming, an airman, little Miss Muffett, Andy Pandy and some very "bonny babies".

It was a warm, sunny, almost summery day (but then it was February!) and the participants were keen to be off. Perhaps their enthusiasm was something to do with the fact that their checkpoints were pubs and they were obliged to consume a measure of ale at each! A few words of thanks on behalf of MPS sent them hobbling on their way - it was a three-legged race remember. The less energetic of us took the car to a strategic car park and strolled gently through the Abbey grounds to the finishing post - also a public house. On the way we spied several red-faced characters shuffling their way through the town, collection boxes swinging and clearly enjoying themselves, despite all the effort involved.



The participants - a merry bunch before the first public house!



The winners received their prizes as this strange collection of characters took refreshment and rested in order to restore themselves for later that evening, when a full-scale disco was arranged in aid of MPS.

What a terrific bunch of people. Our thanks go to all of them for their efforts and for an enjoyable day. Particular thanks go to Maggie's cousin Joanne Melleney (a fireman for the day!) who performed a magnificent feat of organisation, both of the sponsored race and of the disco - Chrissy would have loved the antics and the costumes.

All told, the sponsorship, collection boxes and disco raised over £825. The added bonus, of course, is that there are now many more potential nurses and doctors who are aware of MPS - they were all so keen to know as much as possible about the disorders. Who knows, perhaps one of them will come into direct contact with one of the disorders at some future stage in their career and they will look back and remember something of the information they took away with them that day.

Peter & Maggie Archard.

CADBURY COUNTRY CLUB INVADED

This headline could well have appeared in the West Country Gazette after the first MPS holiday. We also raided several pubs but let's start at the top.

Cadbury Country Club is a delightful building just outside Yatton in Somerset. Four families visited the club on the Monday at the beginning of the holiday to assess its suitability for our night out on Friday. We found, to our delight, an indoor swimming pool, adventure playground, sauna, restaurant with dance floor and a separate disco. A few enjoyable hours were spent here on Monday with the kids having a great time and Keith enjoying the sauna. Arrangements were made to return on the Friday evening, minus the kids, who were to be looked after by volunteers from the Red Cross.

Our favourite evening venue was soon established as the White Hart on the Wrington Road, mainly due to the children's room and the equipment in the garden. I am sure we will all remember Mary showing us how a trampoline works! The children also enjoyed the climbing ropes and swings while the adults retired to the children's room for liquid refreshment. I am sure that there are not many pubs that have sweet machines that work without money, but we were soon awash with "cola balls" to prove that this pub had just that.

All in all the first MPS holiday was a great success - good accommodation, some decent weather, a lot of good friends and plenty of time to chat to each other.

Thank you Mary for all the arrangements and please keep up the good work.

Ron Snack.

COFFEE SNOWBALL

The Coffee Snowball account at the time of going to press stands at more than £1000. All of the packs should have been started by now - please do your best to remind your friends to keep the snowball rolling down the line. The final layer is the vital target. If you find you have some packs or part of packs left over by the time of the Conference, please return them to us, as each sheet represents cash for the Society (don't forget that we have already paid for the printing which must come out of the profits). If you return them we can find volunteers to continue next year.

The leaflets could be worth up to £3 each and for every small bundle of "please invite 4" (17 leaflets) left idle, for example, the Society would lose up to £20.

If anyone finds they could start a bundle at level 4 (i.e. you invite 4 people, who invite 3, who invite 2 - so that it only has to go down 2 layers after you), please ask as we have some spare.

Many thanks to all those who have participated so far.

Pat Isaac.

WEST GERMAN / AUSTRIAN MPS CONFERENCE - MARCH 1987

Limpach, Bodensee, West Germany

In late March, Robin and I, accompanied by 4 month old Lucy, set off for the first MPS Conference to be organised by the German MPS Society. The venue was a deceptively large but homely guest house in a hamlet about 10 miles north of Lake Constance.

It was particularly important that the Society should be represented at this meeting as Ulrich Kiwus, father of 9 year old Robbie, who has Sanfilippo Disease, was to present up-to-date findings of Dr Martin Bax's research on the Natural History of MPS Diseases. Prior to the conference we sent Ulrich the slides and he translated Martin's text into German. We hoped that the feedback on the research project would encourage other European MPS families to complete the questionnaire. We also aimed to meet many new families and professionals and further MPS links with Europe. We were not to be disappointed.

Jurgen, Brigitte and Natalie Zumbro met us at Zurich Airport and drove us to the West German border at Lake Constance where we took the car ferry. Visibility was nil, with a mixture of snow and rain in the air. (With only a few weeks lapsed since the Townsend Thoresen Ferry tragedy there were a few anxious glances at the bow doors, but of course this was not that kind of ship).

Friday was reminiscent of our conference. Families started arriving early and it soon dawned on us that the number of families attending would be similar to our Harrogate conference. Buffet supper was chaotic with everyone enjoying a traditional cold meat buffet. During the evening we were introduced to Dr Michael Beck and Dr Adrian Sewell from Mainz. Everyone tried hard with their English and we really appreciated this. It was also very helpful to have Dr Sewell in our midst. He moved to Mainz about 5 years ago following a spell working with Dr Charles Pennock at Bristol. We were also introduced to Dr Jean-Marie Mattieu, an Associate Professor in Lausanne, Switzerland. He has in his care a three year old boy with MLI. As is usual at MPS meetings, there was so much that we wanted to hear and ask that the late night was inevitable.

In what has become traditional British MPS Conference style, the MPS children and siblings boarded a coach for an outing to a country park. Robin decided to join the children as he had never had the opportunity to do so at home. He found himself in charge of an energetic 9 year old Sanfilippo boy, Robbie. They got on well and both had a good and, for Robin, exhausting, day! Robbie's condition and that of the other Sanfilippo children made us think. With the exception of one teenage boy, no Sanfilippo children used buggies and we wondered if this had led to the children retaining their walking ability longer? Natalie Zumbro, a 10 year old Sanfilippo, walked us off our feet on a sight-seeing tour, and she too has never had use of a buggy. This is just food for thought. Usually in Britain the diagnosis is followed by a wealth of information on what is available for handicapped children and sooner rather than later the inevitable McClaren buggy arrives. Buggies are certainly helpful in the management of our MPS children but these observations made me wonder if the Minister of Health has shares in McClaren! Also from talking with the German and Austrian

families it appears that their SF children seemed to have fewer disturbed sleep patterns.

The conference was most successful and I was able to understand the presentations and ask questions thanks to Richard and Elizabeth Volk, both of whom speak English as if it were their native language. All the speakers were well received, although one had a rough ride from the parent delegates for advocating a dietary treatment, claims of which he could not substantiate. When really pinned down this doctor could only concede that a carefully planned and well balanced diet could only enhance the child's general health.

Ulrich Kiwus presented Dr Bax's findings most professionally and parents were keen to ask questions and participate in the research.

Saturday evening provided another excellent opportunity to meet new families and renew acquaintances. Many of you will remember Petra Herman and her daughter Antonia (SF) from our conferences and will be pleased to hear that Petra is expecting a healthy son in July. Despite Petra's good news, one of the striking differences between the British and European families was a distinct absence of younger siblings following an MPS diagnosis.

One little Hunter boy became very fond of Lucy and led us to his mother, who couldn't speak English, shouting "Baby, baby". His mother warmly clasped my arm and it was obvious that had we been able to communicate she would have valued sharing our experience of pre-natal diagnosis. Lucy was an excellent ambassador for the MPS Society and Robin and I would not be at all surprised if there was a baby boom amongst MPS European partners in 1988!!

There was no formal programme on the Sunday morning and breakfast seemed to last forever as families hung on to every precious minute remaining of this the first German/Austrian Conference.

In Britain the Society holds a debriefing meeting several weeks later, but because of the logistics of families from three countries convening a separate meeting, a debriefing was held over morning coffee. Robin and I were most grateful to be invited and a number of valuable proposals came out of this meeting:

1. That the British and Germans would share the load of researching, writing and publishing booklets suitable for parents and professionals on the specific types of MPS and ML Diseases.

2. That a working party should be set up to consider whether it feasible to hold a joint British/European Medical Seminar for MPS and ML followed by a Parent Weekend. The Working Party will meet on the Sunday afternoon 27th September following our own MPS Conference.

Robin and I would like to thank everyone for making our visit so enjoyable and in particular families Behrens, Zumbro, Cornils and Kiwus. We were very sorry that Erich and Marian Kraft from Vienna were unable to come but sadly their daughter Barbara who suffered from Hurler's Disease, was seriously ill. She died on 4th April.

Christine Lavery.

SOMERSET SOJOURN

Increasingly, it seems, despite intentions to the contrary, it is difficult to get away at weekends and the camping gear stays stowed from one MPS camping weekend to the next. This year we thought that we would make the most of it by extending the weekend. Weeks ago, lines were drawn in business diaries in expectation of pitching the tent for a whole week of 'flaming' June and the good folk of North Somerset were given notice of the likelihood of an MPS camping weekend advance reconnaissance party.

Saturday 7th June saw weather not dissimilar to the preceding few weeks - it was pouring down. "I'm not very happy about the prospect of pitching the tent in this persistently wet weather", said Peter (or words to that effect!) and we decided to hold off for a while. Sunday, Monday, Tuesday, saw little change (if you discount the fact that the rain became heavier and frequently turned to hail. On Tuesday evening we telephoned Pat Isaac (one of the good folk of north Somerset) to enquire just how heavy was the rain down there. "What rain?" she said!

On Wednesday morning we left home and, courtesy of the M25/M4, we arrived at the Fiddington camp site an illegally short time later. Tent pitched (on dry ground!) we put our heads in at the Isaac's to see them and, in particular, to say hello to Christopher who had been home only a short time since he had undergone surgery for Cervical Fusion. Although he was trapped in his 'Halo' for the time being, he still managed to get up to mischief and was particularly looking forward to seeing lots of MPS friends over the weekend.

The next three days passed very quickly, with the very fine weather enabling us to see many of the fascinating and beautiful attractions of that part of the country. With the campsite to ourselves the evenings were, to say the least, on the quiet side. When we returned to the site early on Friday evening we were pleased to see that we were no longer alone for the Laverys had pitched their tent and Jill and George Evans had parked their caravan after a long (but legal) drive from Kent. Natalie and Bryn Isaac were joining the party in their recently (that afternoon) acquired tent, kindly purchased and erected for them by daddy Isaac (anything to get rid of the two of them for a couple of nights Dave?). Not being content with merely taking the country air, the young Laverys (Andrew and Ben that is) had also taken the (shallow) boating lake water - literally. They were being dried off and told off, but not necessarily in that order.

With the greetings, tent pitchings and initial visits to the Hon. Fund Raising Co-ordinator and her family attended to, thoughts turned inevitably to food, as it was now quite late in the evening. Others were due to arrive we all knew, but quite when was uncertain and so we set off in convoy to a 'family' public house we had reconnoitred. As parents attempted to encourage 8 'high' children into the restaurant garden, we spotted Sue and Dan Butler driving past. Rear gunner position was occupied by young Mr. Alex. Butler, who passed on an appropriate message to dad at the flight controls. The vehicle slowed to sub Mach 1 and manoeuvred to a perfect touch down in the MPS section of the pub's car park. The number of 'high' children reached double figures!

After a splendid al fresco meal, we all returned to the camp site for the cabaret and happily gathered round to watch Sue and Dan erect their det.des.res. Alexander Butler erected his own tent (suitably far away from parental gaze!) and gleefully pointed out that the Isaac's (new) tent had been erected incorrectly (nice try Dave). As it was being re-erected the second 'act' arrived and Mary and Charlie O'Toole gave us many valuable hints on how to erect a tent by moonlight.

Saturday morning began with Paul and Cheryl Evans giving the rest of the kids (not all young!) a football lesson - play rough do these Maroteaux-Lamy kids! The day continued with MPS sorties to nature reserves, coastal spots and local centres, with an evening regrouping for the widely acclaimed MPS barbecue. First back, the Laverys took to the boating lake again. Regretfully the event was not photographically recorded for posterity, but it appears that Captain Kidd (Christine) had clashed with Blackbeard (Robin) and both crews had been carried away!!! They dried off while they too were told off!

The group were joined for the evening by Bill and Fer Pidden from Wiltshire, Michele and David Brooks-Daw from Taunton and Ann and Gordon Hill from Devon. Four more children joined the crowd.

Sunday dawned (despite several pleas to the contrary!) and the traditional MPS camping breakfast ensued. Once the catering chaos was rectified it was generally felt to be prudent to take down the tents in case it rained - it didn't!

Farewells were exchanged and each family departed as their packing was completed, with those of us travelling in similar direction having arranged a rendezvous at a 'half way' stage of our journey. We left Somerset much as we found it having all had a thoroughly enjoyable weekend. Thanks to the Isaacs for their hospitality, Mother Nature for the good weather, all those who attended (campers and visitors) for their company and the Department of Transport for not having dug up the A1/M25/M4/M6!

Peter and Maggie Archard.

NEW FAMILIES

Cliff and Sue Vivier from Tonbridge Wells in Kent. Their 5 year old daughter Katie has Sanfilippo Syndrome.

John and Winifred Larkin from Belfast have two daughters suffering from Morquio Syndrome, Fiona who is 16 and Bernadette who is 14.

Mrs Davis from Co. Tyrone in Northern Ireland, whose 16 year old daughter Elizabeth has Sanfilippo Syndrome.

Mr and Mrs Ahmed from Glasgow. Their son Waseem, 4, suffers from Maroteaux-Lamy Syndrome.

Douglas and Susan Johnston from Edinburgh, whose 4 year old daughter, Jennifer, suffers from Hurler-Scheie.

Mr Sandeep Christian from London who has Morquio Syndrome.

CHILDREN HELPING MPS

We are very pleased to print the following two letters written by children, telling us how they have been raising money for MPS:-

Concerts in Newcastle

Benton Park Primary School,
Newcastle upon Tyne

Dear Sir/Madam,

To the Society for MPS

We (Elaine, Kelley and Samantha) organised a concert in aid of MPS We have sent a cheque for £104 which we hope will help with the disease. We organised the concert by getting everybody to audition to do something like singing, dancing, gymnastics or playing instruments etc.

In the morning we had a concert for the infants. Then we had a concert in the afternoon for the juniors. All the parents were invited. We had refreshments after each concert. The school cook made some scones for after the concert and Mrs Reid, who used to teach at this school made some tea, coffee and orange juice to sell.

We hope you can use the money for something that will be helpful for the children.

Yours Sincerely,

Elaine and Kelley.

A Mini-fair in High Wycombe

On the 22nd of April we held a mini-fair for our friends and their mums at Vicky and Philippa's house. We sold cakes, marmalade, book marks, gift tags, books, toys, sweets and lots of other things. For refreshments we had tea, coffee and biscuits.

Also we had 'guess the dolls name' which proved to be successful. We sang a few songs and did some magic. Everyone had a good time.

It was nice that our teacher, Mr. Hardy, could bring Matthew along as the sale was in aid of MPS. Matthew is 6 years old and suffers from Hunter's Syndrome.

After the sale we counted the money. The total was £46.

Philippa & Victoria Knibbs
Angela & Tanya Bunsell
Katie Wright & Alistair Latimer
All pupils at High Wycombe C of E Combined School.

NATASHA'S BIG DAY

One sunny weekend in March I thought I had gone for a nice weekend at the seaside, but No..... I had only just woken up and tucked in to my sausages when Mum appeared with the styling mousse and heated tongs and set to work on me. "Hello, Hello" I thought "Something's happening" when I had to put up with an extra scrub in the bath and a generous spray of my 'honeysuckle perfume', a new outfit, red hairslides and boots all to match!

Next thing (with Mum looking very harassed for some reason - she had only had to pack 3 changes of clothes, pants, pads etc., just in case....) we all squeezed into Daddy's car and drove off at a very fast pace (were we late as usual?) Just as I was getting pretty bored of all this and trying to find things to throw over the seats at Dad and Grandad, we arrived. I think I heard someone say we were at Tenterden and that all us children were to behave!

We negotiated the stairs to the main room of the Town Hall and what a sight! Apart from all my close relations there was an ENORMOUS table full of beautiful cakes, and another huge table full of tempting food. For some reason everytime I managed to get to that side of the hall I was grabbed from behind or someone blocked my path - very frustrating!! What did they think I was going to do? I would have only taken a little bite out of each cake just to see what they were like!



Cheryl, Paul, Helen and Natasha meet Countess Mountbatten

It was nice to see all my MPS friends again who had come a long way. Suddenly, lots of people came into the hall and it got very busy and noisy so I thought I had better go and sit in my chair where I felt safe. However I was just beginning to enjoy myself when next thing I knew we were being whisked downstairs to the Entrance. Again Mummy fussed over me, brushing my hair, wiping my face and squirting perfume all over me! I was pleased to see my sister Kirsten did not escape this treatment although I did notice that she didn't do this to Daddy!

"What on earth is happening" I thought as flashbulbs popped, video cameras rolled and the next thing I saw was a very nice lady in front of me speaking to Mummy - I hear it was Countess Mountbatten of Burma. Mummy put a Cookbook in my hand to present. (I noticed Mummy was looking very nervous at this stage - she hadn't really been worried that I would either throw it or chew it had she?) Of course I did neither and handed it over beautifully - how could she have doubted me! Helen O'Toole presented the Countess with flowers and did the most elegant curtsy that she must have been practising for ages.

We then went upstairs again for something called 'Speeches'. (By the way, has anyone else noticed what a lovely necklace the Mayor wears? I wonder if the bits fly all over the place when it gets pulled like Mummy's pearls do?)

Gosh, it was very quiet - I think everyone was listening to what was being said on the stage. I was alright though! They parked my chair right next to my friend Maggie Archard. "Oh good" I thought "This will be a hoot - Maggie always makes me giggle when I see her". I was just getting into full swing and having a great time and just about to have a jolly good sing-song, when the doors were opened and I was taken from the room. Spoil-sports! Still, I did at last get a plate of sausages and crisps which cheered me up!!

Apparently, I missed Paul and Cheryl Evans going on stage with their gifts to present to the Countess. I missed the raffle, the tombola, Uncle Phil's Band Music and Countess Mountbatten handing over a whopping big cheque to Mary O'Toole, but I was not worried I was enjoying myself. When everyone started to leave they were also looking very happy (was it the convivial company or the wine I wonder?) and were laden down with cakes, flowers and Tombola prizes.

At long last I was let loose out of my chair to run around in the empty hall. Everyone helping looked very happy and very tired, especially Uncle Lesley and Auntie Jean, who had done so much hard work in organising the event. At long last the clearing up was done.

We all piled into the car, tired and aching for a sit down (except me - I was high as a kite and ready for anything and was soon to prove it with a romp on the beach when we arrived at Nan and Grandad's). Kirsten and I were rewarded with lollies as, apparently, we had been so good.... I did have such a good time, can we do it again next week!!!

Natasha Macintyre.

FIRST NORTHERN IRISH FAMILY MEETING - BELFAST MAY 30th

Most years Charlie and I take the girls over to Ireland to visit relations and on our last two trips we have had the pleasure of staying with the Devlin family in Omagh. The Devlins have two boys with Morquio Syndrome like our Helen. Last summer Josie Devlin invited two other families to meet us and this gave us the idea of organising a larger meeting.

With the co-operation of Dr John Nelson who knows many of the MPS families in Northern Ireland, I arranged a family afternoon in a hotel in Belfast. Invitations were sent to the eight families who were already members of the Society and via Dr Nelson to others who had not yet joined. I also wrote to the six member families from the South and was pleased that the McGaurans from Sligo were able to make the trip.

In all nine families came, bringing a total of 12 children between them. (We were sorry that the Stewarts' car breakdown prevented them from joining us).

The afternoon went very well. The children watched videos in an adjoining room giving the adults a chance to talk, to learn more about the Society's activities and to ask questions of Dr Nelson. Two of the families who came have now joined the Society; welcome to John and Winnie Larkin and their daughters Fiona, 16 and Bernadette, 14, who are both very mildly affected by Morquio Disease, and to Mrs Davis and her daughter Elizabeth, 16, who has Sanfilippo Disease.

Dr Nelson announced at the meeting that he will shortly be leaving Ireland to spend a year in Perth. We are grateful for his support and help to the Society and wish him and his family well.

It would be a pleasure to see some of the Irish families at the Conference, but it is of course an expensive trip for them. We hope however that this year's meeting in Belfast will be the first of many and that it will be possible to organise a similar event in the South.

Mary O'Toole.

DATES FOR YOUR DIARY

- Sat. 18th July Coffee Morning and Sale: 10.30.- 12 noon
home of Andy & Jenny Hardy. Tel: 291173
- Sun. 19th July Garden Fayre at Dr. Garrow's home.
- Sat. 1st August Midlands families picnic.
- Sun. 2nd August N.W. Area- Chester Zoo - from 10.30am.
- Sun. 6th Sept. N.W.Area at the Blackburn's, Nantwich 2pm
- 25th-27th Sept. Conference - Post House Hotel, Heathrow.
- 14-16th October Naidex Exhibition - London.

NORTH WEST LEISURE GROUP

A meeting was held in April at Micheline and Brian Johnson's home, in order to form a 'leisure group' in the North West. Several families attended and it was agreed that we should organise a few outings for the summer months.

The first day out was a fund-raising event, organised by Sheila Benbow from Greasby, Wirral. The Premier Archers held a charity shoot in aid of MPS. Sheila kindly invited everyone back for light refreshments afterwards. The charity shoot raised well over £500 for MPS - so well done The Premier Archers and Sheila.

The 7th June was our day to Camelot Theme Park and despite the cold, windy weather we all enjoyed ourselves. Poor Bill Blackburn will never be the same after the roller coaster but Pat Kirkman kept going back for more! We did go home exhausted and wet but the "wet" was more from the water rides than the weather.

See opposite page for future North West Area events.

Mary Gardiner, Area Support Family.

DEATHS

It is with great sadness that we report the deaths of the following members of the Society. Our thoughts are with their families and friends at this sad time.

Julia Broome died on April 1st at the age of 18. Julia suffered from Sanfilippo Syndrome. Roger and Jenny lost their other daughter Louise just a year before.

Barbara Kraft from Austria died at the age of 6 on April 12th 1987. Barbara had Hurler's Syndrome.

John Bradford who underwent BMT for Hunter Syndrome 4 years ago, died peacefully at home on Easter Sunday 19th April 1987. John was 8 years old.

IT IS STILL NOT TOO LATE TO CLAIM INVALID CARE ALLOWANCE

The Secretary of State for Social Services has announced the extension of the deadline for married women to claim Invalid Care Allowance with full backdated arrears. Married women may make claims for ICA up to 31st AUGUST 1987 and still have their payments backdated to 22nd December 1984.

To make sure that no one has been missed, the DHSS will write to the other Attendance Allowance beneficiaries who are paid by local offices when their order books are renewed.

RECEIPTS

When the Society started we decided to send personal letters to everyone who donated any money. Now the Society has grown and the amount of money coming in has also increased (thankfully!), it is becoming impossible to keep up with all the letters of thanks. (All of us are volunteers and most of us have other demanding jobs - but devote most of our own spare time to MPS)

This has meant that in some cases it has been taking quite a while for people to receive personal letters of thanks. It seems clear that most people donating or raising money usually only require a receipt to show their friends that the money has arrived safely. So in future we will mainly be sending out receipts unless people specifically request an individual letter of thanks, which will, of course, take a bit longer.

For the same reason, space in our newsletter is being taken up by lists of names of people who have donated money, many of whom never see our newsletter, so in future we will print only actual fund-raising events undertaken (to give everyone else ideas!)

Many thanks to Wilma Robins who has been our 'official thank-you letter writer' for the past few years.

Pat Isaac for the Management Committee.

FROM SMALL ACORNS....

I am always touched by the response of children to MPS and their caring attitudes.

Two little neighbours of ours, Emily and Anna, opened a "Picture Shop" in half term - their very own idea completely. A coloured picture appeared on their gate with the words:

EMILY AND ANNA'S PICTURE SHOP
PICTURES 10p and 15p - ORDERS TAKEN
ALL PROCEEDS IN AID OF MUCOPOLYSACCHARIDE DISEASES

Each picture was painstakingly executed and they raised £2 that day - which, if you work it out, at 10p a picture makes 20 pictures!

Our local Brownie pack raised £20 with a "sponsored silence", which I thought was the most difficult thing they could have tried! I was tempted to ask whose idea it had been, perhaps one of the parents or even Brown Owl, but I thought better of it!

Molly Griggs.

IS YOUR CHILD TUBE-FED?

A tube-feeding support group has recently been set up by a mother who is tube-feeding her own child. Further information from:-

Mrs Barbara Kemp, 20 Legion Road, Poole, Dorset. Tel: 0202 670672

RESEARCH TRUST FOR METABOLIC DISEASES IN CHILDREN

The RTMDC are holding their Sixth Parent Conference on Saturday 19th September 1987 at Crewe and Alsager College, Crewe, Cheshire.

The programme is as follows:-

- 9.30am Registration
- 10.00am Welcome by Mr Peter Green, Chairman.
INTRODUCTION OF SPEAKERS
- 10.10am Parents Voice - Mr Mike Kelly
THE LOSS OF A CHILD.
- 10.30am Lenore Hill, Head Nurse, Martin House Hospice
COPING-THE PROSPECT OF BEREAVEMENT WITHIN THE FAMILY UNIT
- 11.00am Questions
- 11.15am Coffee
- 11.30am Parents Voice - Mrs Julie Sydee
METACHROMATIC LEUKODYSTROPHY
- 11.40am Dr Mary King
ASPECTS OF THE LEUKODYSTROPHIES
- 12.30pm Lunch
- 2.15pm Parents Voice - Mrs Kit Davis
LEIGH'S DISEASE
- 2.30pm Parents Voice - Mrs Kate Wall
A RARE DISEASE - DICARBOXYLIC AMINOACIDURIA
- 2.45pm Dr Susan Hall - British Paediatric Surveillance Unit
THE POTENTIAL ROLE IN MONITORING METABOLIC DISEASES IN UK
- 3.30pm Tea
- 3.50pm Questions
- 4.30pm Close of Conference

If anyone is interested in the RTMDC forthcoming conference please contact the Conference Secretary before 31st July 1987 at:-

Conference Secretary, RTMDC,
9 Arnold Street,
Cheshire CW5 5QB

GIVING BY COVENANT - A SIMPLE AND EFFICIENT WAY TO RAISE MONEY FOR THE SOCIETY

I am sure there are some readers who would like to support the fund-raising activities of the Society but find it very difficult to devote the time to such activities. Or maybe some of you know of relations, friends or companies, who, with a little gentle persuasion, would be happy to make a regular contribution to our funds.

There is a very easy and effective way of providing financial support and that is by use of a Deed of Covenant. This is beneficial to the Society in 2 ways. Firstly, for any contribution you or your friends/relatives etc. make through a Covenant with the Society out of hard-earned after-tax income, the MPS Society is able to reclaim the tax you paid to the Inland Revenue and use that to increase the value of your contribution. To be able to reclaim the tax, the same amount has to be given for at least 4 years. So for every £5 donated we get £6.85 per annum or £27.40 in four years, but the donor has only paid £20.

For every £50 per annum donated for the next four years, the Society could claim an extra £74 making a total of £274 over four years. This is assuming the donor is paying tax at the standard rate which is 27% at the time of going to print. (If the donor pays tax at a higher rate, HE may also be able to claim Higher Rate Relief which will reduce the cost of the donation to him).

The second benefit to the Society is that it enables the Management Committee to depend on the income and plan its expenditure accordingly, because Covenant payments are made for a guaranteed period.

Enclosed with this newsletter is a leaflet with attached Covenant form and Bankers Order. Perhaps you know someone who could use it?

Any amount can be covenanted (although for administrative reasons it is probably not worth covenanting less than £5 per annum) but remember the same amount must be paid at least 4 times over the next 4 years and is usually done through a bankers order.

If you would like any more forms or if you have any queries about this, please contact the Treasurer or Fund-raising Co-ordinator (addresses and telephone numbers on inside front cover).

The value to the MPS Society, both through the tax refund and long term commitment, makes covenants a valuable asset to us all.

Pat Isaac (for the Management Committee)

A big "hand" to Pat for designing the Covenant Form - Editor.

BEYOND THE CALL OF DUTY!

We are proud of the co-operation between the MPS Society and the medical profession - but wonder if asking Senior Orthopaedic Registrar Mr Ben Taylor, to deliver a bed-pan from London to Pat Isaac in Bristol was stretching it a bit too far!! It certainly would not fit into his briefcase! Thanks Mr Taylor!

AREA SUPPORT FAMILIES

Robin and Christine Lavery
30 Westwood Drive, Little Chalfont, Bucks.HP6 6RJ
Tel. 02404 2789

Neil and Jane Reid
'Meadowlark', 9 Huddleston Way, Sawston,
Cambs. CB2 4SW
Tel. 0223 834570

Alan and Deirdre Beavan
'Tumbleweed', West Gate Lane, Lubenham,
Market Harborough, Leics.
Tel. 0858 62182

Peter and Marlene Sanderson
'Ashley Cottage', 6 Northfield Road, Tetbury, Glos.
Tel. 0666 53628

Colin and Mary Gardiner
35 Church Road, Banks, Southport, Merseyside.
Tel. 0704 213438

John and Barbara Arrowsmith
140 Newtown Road, High Heaton,
Newcastle Upon Tyne, NE7 7NH
Tel. 091 2812062

Heather Broughton
160 Ecclesfield Road, Chapeltown, Sheffield S30 4TE
Tel. 0742 451589

Brian and Micheline Johnson
'The Mount', Truemans Way, Hawarden, Deeside, Clwyd.
Tel. 0244 533641

David and Michele Brooks-Daw
St. Mary's Lodge, Wellington Road,
Taunton, Somerset TA1 5AS
Tel. 0823 271661

Contact for Scottish families:-

Alan and Fiona Byrne
3 Jedburgh Avenue, Rutherglen, Glasgow G73 3EN
Tel. 041 643 0034