NEWSLETTER SPRING 1987

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

National Registered Charity No. 287034

Chairman of the Management Committee	MARY O´TOOLE 8 Elmhurst Avenue, London, N2 OLT Tel: 01 444 8461
Hon. Secretary	CHRISTINE LAVERY 30 Westwood Drive, Little Chalfont, Bucks. Tel: 02404 2789
Hon. Treasurer	STELLA HALE 6 Laurel Way, Ickleford, Nr. Hitchin, Herts. 0462 54544
Fund Raising Officer	PAT ISAAC ´Beckdell´, Church Road, Fiddington, Nr. Bridgwater, Somerset. Tel: 0278 732800
Overseas Secretary	SUE BUTLER Spriggs Holly House, Spriggs Holly Lane, Chinnor Hill, Oxon. Tel: 024 026 3185
Donations Secretary	WILMA ROBINS 77 Hillview Avenue, Hornchurch, Essex RM11 2DN Tel: 040 24 43157
Newsletter Editors	PETER & MAGGIE ARCHARD 48 Lawrence Avenue, Letchworth, Herts. SG6 2EY Tel: 0462 673830

SECRETARY´S REPORT

It is sometime since I wrote for the newsletter and on a personal note, Robin, Andrew, Benjamin and I would like to thank all the families and friends who sent their best wishes on the birth of Lucy. Our delight at our baby daughter has perhaps brought home to us more than ever the sadness we feel for families less fortunate.

In the Winter Newsletter you will have read that Peter and Maggie Archard were expecting a baby in July and that they had opted for a chorion biopsy. You will read in their article on page 2, that at 15 weeks Maggie had an amniocentesis which established that the fetus had a rare chromosome abnormality unrelated to MPS. Subsequently the pregnancy was terminated and I am sure you would like to join with me in expressing our sadness at this news.

On a happier note, on 21st. February the Society held a very successful Area Family business meeting to discuss the Society´s future plans. It was very pleasing to hear how enthusiastic and active the Area Families are. However, please do remember not to leave all the initiative to your Area Family; if you have a good idea for fund raising or want help in organising a local activity, then do tell them. Area Families, like you and I, have day-to-day difficulties and would value your support (even if it is only moral support). During the meeting the Management Committee was able to announce that, commencing 1st April, the Society will be funding Dr. Diana Chase, formerly at the Paediatric Research Unit at Guy´s Hospital, to carry out basic research with a view to isolating the enzyme related to the Hunter Syndrome. (see page 5 for Diana Chase´s explanation of her work and it´s importance).

As you will know from Mary Gardiners articles in the last two newsletters, the Society has organised two MPS group holidays this year and we are pleased that the places have been taken up very quickly. It was agreed at the last Trustees/Management Committee meeting to arrange a further holiday for August 1987 in the Lake District, so do contact Mary urgently if you would like to have an MPS holiday in the Lakes - the details are on page 4.

The cook book is continuing to sell well and we have more than covered the printing costs. We still have plenty so send your orders to Pat Isaac - the cook book makes an ideal Easter gift! It was featured in "Womans Realm" on March 14th in the article "What´s Cooking" on page 35, so we are hoping for more orders.

By the time the newsletter arrives on your doorstep, Robin and I will have been to West Germany´s MPS Conference. We will be meeting MPS families from Austria, Switzerland and Germany and, for the first time, Belgium and Holland too. We look forward to recalling our experiences in the summer newsletter.(The deadline for which will be at the end of May!!! - Ed.)

Finally, the 1986 Parent Conference Report is being sent with your newsletter. It is nearly twice the size of previous conference reports and we are most grateful to Kate Farminer who wrote it up and to her mother who slaved over the typewriter. Thankyou to you both. One report is free to UK families and professionals who subscribe. Further copies can be obtained from me, priced £2.

Christine Lavery.

LIGHTNING STRIKES TWICE!

In the last Newsletter we mentioned that we were expecting a baby. We have received many good wishes and we are sorry to now have to say to those of our many friends who may not already be aware, that the fetus was found to have a major chromosome abnormality and that we decided not to continue with the pregnancy.

We are very much aware of friends within the Society (and without) who are expecting babies and that their anxieties may have been increased by our experience. We are aware also, that it has raised a question in the minds of some prospective parents and others, as to the value of the chorion technique in comparison with amniocentisis. The advantage of the chorion biopsy is that it enables a far earlier test for inborn errors. Of course, it is the hope always that this will bring with it an earlier reassurance of the absence of problems. Should less happy news have to be given, it is clearly as well that this be at the earliest opportunity so that the decision that is likely to follow is less traumatic. In our case a chorion was taken at 9 weeks into the pregnancy and it should be said that it is was (Maggie says!), without pain or discomfort.

Tests for specified metabolic disorders and, routinely, for chromosome abnormalities are carried out elsewhere and results are normally expected in 2-3 weeks. Our first anxieties arose when it was suggested, some 3 weeks later, that although everything appeared to be in order and that a little girl was on the way, it would be as well to have an amniocentisis as a check. The results of that check (confirmed by two separate laboratories) revealed the abnormality and the termination took place 10 weeks after the first chorion biopsy.

Quite why this abnormality was not picked-up within the first 2 weeks or so, as part of the routine testing, is less than clear and is one of the points upon which we are hoping to receive clarification. However, we think it important to put our situation into perspective. We have experienced the sadness and disappointment that many couples face, the odds of which are quite unaffected by our previously having had an MPS child. In searching for MPS, the laboratories had found an entirely unrelated and totally different problem. The reality is that had we not needed to check for MPS, we may well have become parent members of some other support group - perhaps even Newsletter Editors?

It is not for us to give medical advice to others on the merits of the chorion technique - we are not qualified to do so. However, as "consumers", we feel bound to say that our experience suggests that prospective parents would be well advised still, to ask that a chorion result be reinforced by a subsequent Amniocentisis, unless that first result has positively revealed some abnormality. In other words, prospective parents should regard an "all clear" from a chorion biopsy as a provisional result rather than final.

Thank you to all of those who have sent us their best wishes. Thank you also to all of the doctors and nurses of Queen Charlotte´s Hospital for their sensitive, sympathetic and excellent care.

Peter and Maggie Archard.

HI, I´M YOUR NEW TREASURER

The Society is planning some major expenditure over the coming year, so we are looking to you all for some help. We are now committed to funding the first year of research projects led by Dr. Martin Bax and Dr. Diana Chase to a total of £25,000 a year. This is in addition to that most important event, the MPS Conference, which is expected to cost about £18,000.

Although our funds look healthy now, and we can cover this years expenses, we need to raise money for next year. So that research papers can continue and our Conference can take place, we have set a target to raise £50,000 over the coming year.

Our biggest fund raising event this year is the snowball, so please help make it a success, but don´t forget that all of the many smaller events and donations remain essential if we are to do all that we have set out to do - keep it coming!

Stella Hale.

NEW FAMILIES

We are very pleased to welcome the following new families to our Society:

Mr and Mrs Roe from Kent, whose daughter Faye has been diagnosed as suffering from Sanfilippo Syndrome.

Mr and Mrs Harford and their son Richard from Cheltenham. Richard has Hurler´s Syndrome.

A QUICK IDEA FOR FUND RAISING

You´ve heard of a "mile of pennies"??? Well, how about writing out in LARGE letters:

"THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES"

and getting people to cover it with pennies (or even 20p pieces!) This could be done at any event e.g. Garden Fayre, coffee morning, school fete etc. and would hardly take any time to organise.

Pat Isaac.

STAMP NEWS

Paul and I have had a short break from sorting through the hundreds of stamps that you have all collected for us, owing to the sad loss of our dear Linda. But it is now back to the grindstone, and we have managed to catch up with ourselves at last. We are glad to say our backlog has now raised the sum of £66.60p over the last few months, so continue to save the stamps and encourage others to save them too. Don´t forget you can bring them along to the next conference.

Carol and Paul Hubbard.

FAMILY CONFERENCE 1987

Hopefully, you will find with this newsletter a Conference programme and booking form. Due to the enormity of the organisation necessary, we will be returning to the Post House Hotel at Heathrow again this year. Christine Lavery does the 'negotiating' with the hotel and being 15 minutes drive away is a distinct advantage, especially with baby Lucy in tow!

Following the very hectic programme of last year we have decided to make this conference more leisurely (though probably not for the organisers!) and allow more time for parents to meet together whilst the children are on the outings etc.

This year the price will remain unchanged but it should not be forgotten that the Society does subsidise the conference weekend considerably, so any extra financial help towards the cost is always appreciated - so keep on with the fund raising!

Because of the demand for accommodation from families and the costs involved we cannot offer more than two places per family for adults over 16 at the subsidised rate, but space permitting, grandparents and professionals will be welcome for the weekend at the full rate. Those who did not attend on the last two occasions may like to note that all rooms have an en-suite bathroom, colour television, air-conditioning and tea/coffee making facilities. Please complete your booking form carefully so that we can fully appreciate all the needs of your family.

Once again the children will be spending Saturday at Thorpe Park; Sunday's programme is yet to be arranged. Most fortunately, many of the volunteers that have helped in previous years have kindly offered their services again. They are all quite experienced and the organisers meet with them and brief them on individual children's needs beforehand. DO NOT FORGET TO BRING YOUR CHILD'S BUGGY OR WHEELCHAIR AND WARM OUTDOOR CLOTHES. There will also be a creche for children too young (ie under 2) or too ill to benefit from the adventure of the outing. As usual we will provide babysitters and patrol for your children to enable you to enjoy the parents dinner and dance on Saturday evening.

In the past, families who have found the costs of the conference and/or travelling expenses prohibitive, have found financial support available through their local Lions or Round Table. If you would like to come to the conference but cannot meet the costs, please let Christine or myself know and we will write on your behalf; YOU can help by letting us know the address of your local Round Table and Lions (available from your library). All problems will be dealt with in the strictest confidence and we will do our best to help.

As the Friday evening buffet was such a success last year, we have decided to repeat the exercise. Food will be served at 7pm and be available to ticket holders only so please indicate on your booking form if you wish to join us.

I look forward to hearing from you and to seeing many of you again in September.

Maggie Archard.

THE NEEDLE IN A HAYSTACK

You will have read in the last newsletter, the article by Dr.Olsen of The Kennedy Institute, concerning work being carried out at the Cell Enzymology Unit. Similar work is carried on at other research laboratories of course, particularly directed at attempting to identify and examine specific enzymes; The Prince Phillip Research Laboratories of the Paediatric Research Unit at Guy's Hospital is an example. The following article is by Dr.Diana Chase, who has been involved in that work at Guy's. Dr.Chase's contract with the research unit recently came to an end and following very careful evaluation of her thesis against the other commitments that the Society has, it has been agreed that funds should be provided to enable her to continue her investigations.

Nothing is certain of course, and neither could it be, but there is every reason to be cautiously optimistic that significant progress might soon be achieved. It seemed to both the Management Committee and the Trustees that the importance of such a break-through as the isolation of the specific enzyme concerned with Hunter's Syndrome, is such that the Society could not possibly decline to support any efforts that offered a reasonable possibility of success, if it were within our abilities to do so.

Of course, this will further stretch our resources but it is within our capacity for fund raising; indeed, the efforts that our families and others make will be given a renewed incentive and the task will be assisted by having identified targets. Regretfully, however, we have to be realistic and even as we committed the Society to one project, we have had no option but to decline another request for substantial funding. Dr.Chase will be periodically reporting her progress and, of course, continuation of the funding will depend upon that.

In her article, Dr.Chase describes the objectives and nature of her work in a way that I am sure many of you will find as refreshingly easy to read and understand as did I. We wish her every success and will keep you informed of any developments.

Peter Archard - on behalf of the MPS Management Committee.

Each one of the MPS diseases is the result of a small change in the genetic material of chromosomes i.e. a mutation in a gene. The mutation has slightly altered the instructions on how to build a particular protein. Every protein has a very specific structure and function, and any slight modification in its structure can often prevent that protein from functioning correctly. Thus, while a normal gene carries the instructions on how to build a normal, active, fully-functioning enzyme, a mutant gene may carry instructions on how to build a modified version of that protein which might be competely non-functional or inactive.

An MPS disease is due to the lack of activity or function of one particular enzyme, specific to that disease. Children with Hunter's Syndrome for example, lack the activity of the enzyme related to that condition, although all their other proteins and enzymes are probably functioning normally. Such children may be able to build a protein that is very similar to the normal active enzyme, but which is unable to function correctly due to a slight

modification in its structure. This is similar to something you may have experienced when having a new key cut - although the new key looks identical to the old one, the new key simply will not open the door! A very slight change in shape has meant that the new key will not function correctly, and has to be re-cut.

The future of basic research into MPS diseases is threefold:-

1. To determine how an inactive protein differs from the active enzyme, and to see if there are any ways in which the inactive protein can be altered and thus made to function correctly.

2. To identify the precise change or mutation that has occurred in the gene, and to use this as a very accurate and reliable means of carrier determination.

3. In the long term, to treat the affected children, possibly by inserting a normal gene into an affected child so that he or she would then have the correct information on how to build a normal, active, fully-functioning enzyme.

However, before we can identify the precise changes that have occurred in the mutant gene, we need to know what the normal gene is like. Similarly, in order to compare the active, normal enzyme with the modified, inactive protein, we need to know precisely what the normal active enzyme is like.

The first step to all this is to thoroughly investigate the normal active enzyme, and in order to do this you need to separate it from all the other proteins and enzymes found in the body - just as you can´t fully appreciate a cornflower if your garden is over-run with weeds!!! Some proteins are relatively easy to isolate or purify, but others are much more difficult for one reason or another. Unfortunately, all of the MPS enzymes seem to fall into the category of difficult proteins!

I have spent three and a half years at Guy´s Hospital studying various aspects of Hunter´s Syndrome. One of the main parts of the research has been to try to isolate or purify the Hunter´s Syndrome enzyme. Starting with a mixture of many thousands of different proteins, I have been able to narrow this down to a mixture of 4 or 5 proteins. This is an achievement of sorts, but unfortunately all the detailed studies that will give useful information about the enzyme, must be done on an absolutely pure enzyme i.e. this enzyme must be separated from <u>all</u> other proteins and must not be part of a mixture.

Using modern equipment and techniques currently available, I hope to isolate the protein of interest from the mixture of 4 or 5 proteins. This technology is not available in the Paediatric Research Unit at Guy´s Hospital, but I have been offered the use of facilities in the Protein Chemistry Section at Unilever laboratories near Bedford. There the latest techniques are daily in use, and I hope this will enable me to achieve several goals in the next twelve months. These goals are to isolate the active enzyme and to investigate its structure. Structural studies cover many aspects of a protein or enzyme, and can involve :-

a) obtaining protein sequence information, and

b) detailed studies of the enzyme´s ´active site´ i.e. the part of the enzyme that actually does the work! (Although a large proportion of a key is the handle, it is the grooved or notched part that actually opens the lock.) Two of these goals are:-

1.Purification of the Enzyme
Normally, to isolate or purify an enzyme, you identify a starting material that has lots of that particular protein in it - I´m using normal amniotic fluid. You then pour this liquid down a series of different columns, each column will separate proteins according to one parameter. For example, one type of column will separate proteins according to size, acting rather like a series of sieves. In this way you can separate small proteins from medium sized proteins from large proteins. The Hunter´s Syndrome enzyme is medium sized, so although there will be many other proteins in the mixture that are more-or-less the same size, at least all the small and the large proteins can be separated and removed from the mixture. In the starting material, the Hunter´s Syndrome enzyme may be at a level of one in a thousand, but after sieving to remove the small and large proteins, the Hunter´s Syndrome enzyme might now be at a level of 1 in 200 different proteins! At least this is a step in the right direction! Many such steps should enable you to separate the one protein of interest from all the other proteins found in the starting mixture.

2.Protein Sequencing
A protein is a long string of amino acids, much like a long string of beads of many different colours. Imagine that there are twenty different colours of beads and that the average ´string´ has 300 beads on it. Clearly then there are millions of different combinations of coloured beads that could make up a string of 300. The Hunter´s Syndrome enzyme can be imagined as being just <u>one</u> such combination. The beads are in a very definite and specific order in any one combination, and it is this sequence of the 20 different colours that makes one string of beads different from the others. Similarly it is the specific order or sequence of the 20 different amino acids that gives a protein its unique properties.

Using the same analogy, a protein sequencer is a sophisticated machine that can systematically cut off one single bead from one specific end of the string of beads. Another specialised piece of equipment will enable a skilled person to identify the colour of that bead. For practical purposes you cannot sequence a whole string of beads in one attempt. A good sequencing run will sequence a length of about 20 beads. Sometimes you have to cut the complete string of beads into pieces, then these pieces can be separated and several may be sequenced individually. In this way you can start to get some information about the unique sequence of coloured beads that constitute that particular string, or rather the unique sequence of amino acids that constitute that particular protein.

If I achieve these goals in the next twelve months, it will be the first step towards an understanding of the normal enzyme, identification of the normal gene and a fuller understanding of MPS diseases.

Dr. Diana Chase.

CAMPING WEEKEND IN SOMERSET

This year our annual weekend 'camp' will be at Fiddington, near Bridgwater in Somerset, from Friday evening, 12th June, until Sunday 14th June. Everyone is welcome to join the 'regulars' Bring your own tent or caravan and join in the fun!

The site looks marvellous with lots of amenities - including swimming pool, shallow boating lake, pony rides, children's play area, off licence(!) and farm pets - you can even learn how to milk a goat (but preferably not after visiting the off licence!)

Perhaps one big advantage of the camp site is that it practically backs on to the Isaac's back garden! If anyone would like to come but feels that their MPS child is not well enough to camp, please get in touch with Pat Isaac who has very kindly offered to accomodate a child plus one parent to enable the other parent to camp with other siblings.

There are plenty of things to do and see in the locality and we often go out together - usually looking like 'rent-a-crowd'. We hope to have a barbecue on Saturday evening with families from the South-West joining us.

Please let Pat Isaac know at least TWO WEEKS IN ADVANCE if you intend to come so that she can book enough pitches for everyone. Pat's telephone number is at the front of the newsletter and she will be happy to supply details to anyone interested.

Directions - Leave the M5 at Bridgwater, junction 23 or 24, take A39 West for six miles. Turn right to Fiddington, then follow camping signs.

In 1986 there was some competition for available tent space!

DONATIONS

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

A.Stone; D.Hughes; Ann Makepeace; British Steel Corporation; Wives of Masonic Lodge Buchanan, Glasgow; Mrs B.Boyd; Mrs B.Cox; Mrs G. Thomas; Mr & Mrs J. H. Evans; Farnborough Ladies Circle; B. C. Tilbury; Mr & Mrs Frith; Mrs McMurtie; Mr & Mrs N.Reid; Mr & Mrs Hornblow; Joyce Wilson; Mr & Mrs Hutchinson; Mrs E.Sharpe; Mrs Kelly; Mr & Mrs Prestwich; Mrs Toker; Mr Smith; Mr & Mrs Young; Mr & Mrs Chilton; Mrs Singh; Mrs Thompson; Mr & Mrs Tilbury; Mr & Mrs Obeney; Mr & Mrs Paulan; Miss E.Jenkins; Mr & Mrs Magill; Mr & Mrs Russell; Miss M Garde; Mrs Kenyon; Mrs Mould; Mr Honour; Mr Kirby; Mr P Roe; Patricia Cole; Mrs Denham; Miss K Ginger; Mrs Kerr; Jean Kendall; Mirium Harris; Mrs Ashmore; Mrs Thwaile; Lilly Research; Halecn Ltd; D.B.Mack Ltd; Hettich Ltd; British Rail Engineering Ltd; Harrison & Clough Ltd; Rimmel International Ltd; Rionda de Pass Ltd; Crewe Railway; Cranford Arms,Wolverton; Little Chalfont Golf Club; Westburn Nursery School; Morley Ladies Circle; Thames-down Federation of Business & Professional Women; Ben Hardwick Memorial Fund; Youth Custody Centre, Wetherby; Moonbeam Majorettes Chapletown; Pause For Thought Group, Kent; Tuesday Group Ladies, Lutterworth Methodist Church; Spiritualist Church, Chesham; Springhill Baptist Church; St.Johns Presbyterian Church, Runcorn; Caroline Sweeney gave money she received from Mrs Peathing for being a brave (MPS) girl.

Charity boxes
S.Hodgetts; Keenthorne Garage, Bridgwater; Fred Foote; Apple Tree Cottage Hotel, Keenthorne; Mrs.Appleton; Mr. Wallace, High Heaton; B. & A.Hudson; Cycoed Post Office; Derek Broughton; Mary O'Toole.

In memory
Donations in lieu of flowers and in memory of Linda Gannon, Alyn Scullion Wilson and Mr.C.Roberts (Micheline Johnson's father).

Fund raising and sponsored events
Janine Bryans held a jewellery party.
Pat Isaac Chris Lavery & Ron Snack each held a 'Xmas Cheers' morning
Judy Holroyd and Pauline Mahon each held a coffee morning.
The Beavan & Peach families organised a cheese & wine party
Ron Snack collected at Milton Keynes Tesco and at Judo club.
Crawford Arms, Milton Keynes had a collection.
Women's Friendship Circle, Ashford, Middx, had a bring-&-buy sale.
Glenys Cantello & Jackie Sweeney gave commission from Webb Ivory.
Glastonbury Rotoract made a mile of pennies.
Carol Smith and Ruth Matta both had Tupperware parties
Jane Porfitt did ploughman's lunches.
David & Barbara Watt collected sponsors for Wilson Plews & Brian Anderson who ran in the Glagow Marathon.
Collingham School,Wetherby, held a coffee morning
2nd Hythe Brownies held a sponsored silence.
Sedgemoor Mr.Infants,Bridgwater,collected at their Xmas concerts.
Margaret Horsley held a sale in her village hall.
West Quantocks Round Table Fun Run.
Carol Bryan was sponsored in a slim by her tupperware ladies.

Continued on the next page.

Fund raising and sponsored events - continued

Margaret Bottom, Doreen Russell & Alan Byrne each held raffles.
Pat Criddle & Jenny Hardy each had a stall.
6th High Wycombe Guide Co. had an Open Evening.
Rotary Club, Hythe held an Old Tyme Music Hall.
Mrs Lowry and Mrs Broughton (family & friends) went carolling.
Cannington W.I. Drama Group had a pantomime.
B.B.,Stonelaw Parish,Glasgow had 24hr sponsored games marathon.
C.Devlin & friends in Gaelic Football Club, sponsored 5 mile run.
R.& L.Snack held a street collection & sponsored bell ringing.
Christ Church Schl,Finchley had spon. swim,walk,cycling & silence.
Mrs Lamb & Class 6 & 7,High Wycombe Schl. held a bring-&-buy sale.
Andrew Jordan and Michael Ludlow ran in the New York Marathon.

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COFFEE SNOWBALL

Because of the commitment to research projects, about which you have already read, the Coffee Snowball fund raising effort is so important. We have decided to make each snowball pack smaller, but to try and start many more than the 50 packs originally intended. If you have not already volunteered, please give it a go - perhaps one of your friends or relations would start a pack? You, as a starter family inviting at least 6 guests, will only have to pay in £3 (as a minimum), but we would like you to stress to your guests, the vital importance of carrying on the snowball down to the last level. Each pack will bring in £618, but the last level potentially will represent more than £18,000 to the Society!

Please encourage all your guests to pay their money in to the bank as soon as they have held their snowball. Payment can be made directly into the bank using the special tear-off bank giro form, which will not cost you anything provided you pay it into any BARCLAYS bank. You may send the form and a cheque to me if you would rather. Of course, you may also pay more than 50p per person into the account, ie.if anyone gives you a larger donation, or if you hold a small bring-and-buy sale with your coffee hour etc. No receipts will be issued but we will give you a running total in each newsletter.

The coffee snowball packs are bundled so that when the person starting a snowball takes off the outside elastic band they will find a form on top telling them to invite 6 people. When the guests each pay their 50p, the slip at the bottom of the form can be torn off and the money paid into the bank. (There is nothing to stop you inviting more than 6 people and paying in more than £3 but asking only 6 of them to carry it on). The starter pack splits into 6 smaller packs - one for each of the next 6 who are to carry on the snowball. When they take off their elastic band, each one has a form to invite 5 and their pack splits into 5 smaller packs, one for each of their guests, and so on down to 2. Your Area Family will be able to demonstrate it to you if you are are unsure! There is a total of 517 leaflets in a starter pack. (and a pint of blood from each of the bundling volunteers - Ed.)

Do get in touch with me or your Area Family as soon as possible - we do need lots more families to volunteer - PLEASE!! Opposite, we have printed a replica of one of the snowball forms.

Pat Isaac

PLEASE INVITE ☐

The Society for Mucopolysaccharide Diseases

30 Westwood Drive, Little Chalfont, Buckinghamshire.

Registered Charity No.287034

COFFEE SNOWBALL HOUR

The purpose of this "Coffee Snowball" is to raise money to finance research and treatment for Mucopolysaccharide Diseases.

We are asking you to hold a coffee hour to help MPS children and their families. If everyone plays their part it will mean nearly 62,000 people participating.

The MPS Society has three aims:-

1. To act as a parent support group
2. To create more awareness of MPS Diseases
3. To further research into MPS

WHAT ARE MUCOPOLYSACCHARIDE DISEASES?

They are rare, life-threatening diseases which cause severe progressive handicap, often both physical and mental. The tragedy for these children is that life is in reverse. They appear normal at birth and by the time the disease manifests itself sufficiently to cause concern, these very special, lovable children may be toddlers or older, making it very difficult to accept that in most cases they will die before reaching adulthood.
AT PRESENT THERE IS NO CURE.

SIMPLICITY IS THE ESSENCE OF THE SNOWBALL.

50 MPS families invite 6 people for coffee for which they will donate 50p. Each of these 6 then invite 5 of their friends for coffee. These 5 then invite 4 and so on.

All we ask you to do is invite, from as WIDE AN AREA AS POSSIBLE, a few friends upon whom you can RELY TO CONTINUE THE SNOWBALL AND TO TRY AND ENSURE THAT THEY DO. You may also wish to have a bring-and-buy stall (optional).

At level 6 MPS will benefit by £150
At level 5 MPS will benefit by £750
At level 4 MPS will benefit by £3000
At level 3 MPS will benefit by £9000
At level 2 MPS will benefit by £18000

So you see it is vital to keep going to level 2 to reach our target of £30000. If you have any problems holding your coffee snowball DON'T JUST OPT OUT - send your form back immediately to address at bottom or contact:-

Christine Lavery, Bucks..... 02404 2789
Jane Reid, Cambs..... 0223 834570
Heather Broughton, Sheffield..... 0742 451589
Marlene Sanderson, Glos..... 0666 53628
Mary Gardiner, Merseyside..... 0704 213438
Pat Skidmore, Gwent.....0600 4466
Barbara Arrowsmith, Newcastle..... 091 2812062
Deirdre Beavan, Leics..... 0858 62182
Micheline Johnson, Clwyd..... 0244 533641
Michele Brookes-Daw, Somerset..... 0823 71661
Fiona Byrne,Glasgow.....041 643 0034

The first snowballs will start from April 1987 and if possible, finish by 31st August 1987. Try to hold yours within 2 weeks of being invited to the previous one.

Pay your money directly into the MPS Coffee Snowball Account in any Barclays bank, using the attached slip, as soon as possible, or send a cheque with the slip to the address below.

With sincere thanks in anticipation,

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

DATE_____
Cashier's Stamp

bank giro credit

CODE NUMBER 20-41-12

BARCLAYSAVE DEPOSIT ACCOUNT

BARCLAYS BANK PLC
HITCHIN

ACCOUNT
MPS COFFEE SNOWBALL

Paid in by | 91335839

NO OF ITEMS | FEE | FORMAN

Notes £50
Notes £20
Notes £10
Notes £5
Notes/Coin £1
50p
20p
Silver
Bronze
TOTAL CASH
Cheques PO's etc
HSE/REM £

PLEASE DO NOT WRITE OR MARK BELOW THIS LINE

THE LONDON MARATHON

For those of you who, for one reason or another, feel unable to take part in the Coffee Snowball, we are providing an alternative method of fund raising for you!

In order to raise that much-needed money for research mentioned earlier in this newsletter, we need to keep the £££££££s rolling in.

Last year, because of the efforts of the runners concerned and of the 40 families who collected sponsors for the society, we raised nearly £3600 on this event - The London Marathon; you may have heard of it! We are again lucky to have two volunteer runners for MPS:

Dave Percival, from Cambridgeshire, a wheelchair entry,
(see his story opposite)
and
Reg. Roberts from Newbury.

Reg Roberts is an acquaintance of Sue and Dan Butler. He has raised thousands of pounds for various charities (including Cancer Research, Mental Handicap and the Royal Berks. Hospital´s Childrens Unit in Reading), mainly by running in half-marathons. Reg is 56 years old and is hoping to achieve a veteran´s time of 4 hours as this will be his last marathon.

Please see if if you can get sponsors for them, please write or telephone me for a form and I will send one straight away.

If you have ever watched all those Marathon runners on television just think how much more exciting it will be knowing you´ve sponsored one of the thousands of runners and trying to spot his MPS vest on T.V.! (something like backing a horse on the Grand National??!!)

We are very grateful to Reg and Dave for offering to help our cause and we wish them both the very best of luck in the Marathon on May 10th. We look forward to seeing them on T.V. and to hearing from lots of families who would like sponsor forms.

If you live in the Midlands, we have also got two runners in the Wolverhampton Marathon in April which you may prefer to support - please send for sponsor forms immediately.

P.S. There is nothing to stop you from doing a Coffee Snowball and getting sponsors for the London Marathon!

Pat Isaac.

SUMMER NEWSLETTER DEADLINE

Articles, items, announcements and other contributions for the next Newsletter should be with us by no later than the end of May, for publication in the second half of June (subject to "dates for your diary" items being taken over the telephone up to the evening of Saturday 6th, June).

Peter and Maggie Archard.

DAVE - THE MARATHON MAN OF CHARITY

On a Bank-Holiday Monday twenty-two years ago, Dave Percival was involved in a motor-cycle accident in which his back was broken, leaving him unable to walk unaided.

Dave spent 11 months in Stoke Manderville Hospital where he underwent rehabilitation. He spent three years confined to a wheelchair and for the following five years he was able to get about with the aid of crutches. Nowadays he uses crutches to get around at home and in and out of his car. He uses his wheelchair for longer distances and also at LKB Biochrom in the Science Park, Cambridge, where he works.

A spell in hospital four years ago pulled him down physically and this meant he had to undergo physical exercise to restore his strength. This led to an almost fanatical desire for fitness, which he has put to good use by taking part in various sponsored activities, raising cash for several charities.

In Spring of 1983 Dave entered a six-mile sponsored "walk" in his wheelchair for a cancer victim in his local village of Sawston. Since then Dave has founded a Sports and Social Club for both the disabled and able-bodied which now has more than 100 members. He has also raised approximately £15,000 for such charities as The Mentally Handicapped, Cancer Relief, MPS Society, British Olympic Team Appeal and the Cystic Fibrosis Research Trust - all this by pushing his wheelchair in determined efforts in marathons and half -marathons around the country.

Among many other marathons planned for 1987, Dave has been accepted, for the third year running, to compete in the London Marathon to be held on Sunday May 10th. He is competing to raise money for several charities - amongst them MPS - but he needs your help in getting sponsors, so please make the effort and ask your friends, neighbours, local shops etc. to sponsor him.

Please do make an effort because, after all it is Dave´s own effort that is the hardest - incidentally, he has lost count of the number of times his wheelchair has needed tyre replacements and how many pairs of gloves he has worn through.

Look out for Dave and if you can be in London personally to cheer him on (wearing MPS sweat bands - marathon number W 42) make sure you are wearing an MPS sweatshirt (see page 19! Ed.)

Sweatshirts are excused for those looking out for him on T.V. but please do at least get those sponsor forms from Pat Isaac and get them out in circulation in your neighbourhood!

On 22nd June, Dave is doing a sponsored push in the Outer Hebrides on the Isle of Lewis, departing from Stornaway, covering about 170 miles in total. However, he has been looking for information about the island, its inhabitants and its weather. He can find very little and would very much appreciate any information that could be passed to him before the event, especially if anyone has relatives or friends in the Scotland/Hebrides area. Dave can be contacted at 38 Lynton Way, Sawston, Cambs. tel: 0223 834065.

Jane Reid.

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

As doctors surrounded my bed, they handed me two reports about Mild Hunters. The moment was so profound that I cried inward tears. I was astonished at seeing the report which was written in the United Kingdom. The doctors left me, recognising the moment was so profound that I needed to be left alone. Whilst lying in bed I kept focusing on the faces of the young men and boys in the report, and I could see myself along with my brother and cousins in those faces. I cried when I read about their medical problems and could see the sorrows in their lives. At that moment I realised that I was fortunate to be alive as I had scary experiences in my life after surgery, pneumonia, and a collapsing airway. At that moment I also realised that I had to make a choice to speak out for those who have died and for the betterment for all, from the mildest to the most profoundly affected individuals.

I hope to share parts by writing about my different experiences as an ongoing story. I would like to write to those across the "pond" and build a bridge of hope, each individual´s life has meaning even though we must dig real deep to find meaning to suffering.

Part one - Falling through the cracks

Showing up at the Genetic Clinic was a difficult chore for me because I was living life to its fullest. It meant taking time from my busy job as a teacher of the deaf. I resented it because I could not see the benefit of such a visit. A doctor referred my family members but because I was the only one to live in a city where genetic testing could take place, I was the chosen one.

Testing was quite extensive; urine samples, x-rays, stripping down to my underwear and standing under hot lights for pictures, and laying on a table and having body parts measured while students took notes. It was all very humiliating and no one told me why. I was not aggressive in standing up for my rights and I buried my hostile feelings. Of course, I answered many questions about my medical history: my hernias, hearing loss at three, adenoids and tonsils removal, and heart murmer at the age of thirteen. What was so special about that kind of information?

Then five years later, when my brother was having tests on his heart for possible surgery, the genetic counsellor rushed into his room. She told us that my brother and I had Hunter´s Syndrome. I remember my mouth opened in surprise and I said "What is Hunter´s Syndrome?" A few weeks later the counsellor sent a three page summary of this disease and left me in deep mourning for three days. Because of my achievements I was labelled as ´very mild´ and wondered what this meant for me. I gave this information to my doctor trusting that all the information in the report was true for my condition. I was sceptical of much of the information and went on in my daily life. I truly became sceptical when I learned that my wife was to have a baby. The report said that very few Hunter individuals were fathers.

After the birth of my son I began to experience two problems. The first was stiffness in my hands; it was becoming more difficult for me to write comments on the students´ papers. The more I strained to write the more pain I would feel. The other problem was getting chest infections. I was constantly getting colds but to maintain my job as a productive worker I worked with colds,

sore throats and upper respiratory problems. I even documented my problems into two months and they were February and May.

I made two bad mistakes, first I trusted that the information on Hunter´s was correct. In my report there was nothing mentioned about chest infections and because I had only mild features of the disease no one became very alarmed. The other problem was my own sceptism, it was my way of coping. If I became afraid then I was sure not to have to accomplish so much.

In the end I felt trapped in a body that looked very much normal. I can remember crying in the doctor´s office - crying for help. I lacked the skills to be taken very seriously with no real information to help me. This all lead of course to working with some pain and it was wearing me down and my chest infections were getting worse. This led to the most profound moment and most traumatic experience in my life, about which I will write when I continue my story.

Bill Sellmeyer
Winsconsin, USA.

MPS SPONSORED PEAL

Having been a bell-ringer for some years, and trying to raise money for MPS funds, a sponsored peal seemed like a good idea. For those that are not in the know, a "peal" on six bells, means ringing 5,040 changes (or rows) without stopping. Gathering the ringers took some time, but on Tuesday 2nd December 1986 everything came together and we rang the peal in 2hrs 56mins.

The money has now all been collected and the total amounts to £358.82p.

Thank you to Christine and Alan Marchbank, Alan Ainsworth, Richard Haseldine and Robert Marchbank for ringing. Also thanks to Trevor Marchbank who could not make the final attempt. Thanks are also due to Julian Reindorp, the Vicar at Great Linford, for allowing us to use his bells.

Ron Snack.

P.S. Are there any other bell-ringing MPS members?

PAYROLL GIVING SCHEMES

These schemes allow income tax relief on gifts to charities of up to £120 per year. An employee can authorise deductions from his pay before tax in the same way as NI contributions. The employer then pays the donation to an agency charity which passes it to the charity of your choice.

We have already registered with the Charities Aid Foundation. This is an easy scheme; if you wish to participate contact your employer and let me know to expect the donations.

Stella Hale,
Treasurer.

FOR WIVES CLAIMING INVALID CARE ALLOWANCE WHOSE HUSBANDS ARE RECEIVING SUPPLEMENTARY BENEFIT BECAUSE THEY ARE UNEMPLOYED

You are probably aware that because your husband is unemployed and has been claiming for you as a dependant in his unemployment benefit, you will receive no back-dated Invalid Care Allowance money. However, you may be able to claim extra supplementary benefit. **Read on:-**

If your husband has been unemployed for over a year and is now on supplementary benefit, he will probably be on ordinary rate supplementary benefit. However, if you claim Invalid Care Allowance (I.C.A.) you can ask to be the main claimant for supplementary benefit instead of your husband and you will then go on to the long term rate which can mean a difference of approximately £11.00 a week.

If you want to be the main claimant, write a letter immediately to your local DHSS office on the following lines:-

"I wish to become the main claimant for supplementary benefit instead of my husband, Mr. ..... As the Government have now ruled I am entitled to have my claim for I.C.A. backdated to December 1984, I wish my claim to be the main claimant for supplementary benefit to also be backdated to that date (or the date you became eligible for I.C.A. if that was later).

The reason I did not apply earlier to be the main claimant was due to the Government not allowing married women to claim I.C.A. This ruling was subsequently over-ruled by the European Courts and I submit the Government rules being illegal as good cause for the lateness of my claim."

See Reg. 1A (6), Supplementary Benefit (Aggregation) Regs. 1981

GARDEN FAYRE AT DR. GARROW'S ("Donald's Do"!)

Following the success of the last 3 years Dr. Garrow has once again very kindly offered us the use of his extensive gardens to hold a Garden Fayre on Sunday 19th. July, to raise money for MPS.

Every year we raise more money and every year more MPS families come along (perhaps by next year we will have to call it an "MPS Family Day" rather than a Garden Fayre!)

The Fayre is open to the public in the afternoon but MPS families are welcome to come for the day and bring a picnic lunch. We always need help manning stalls and if you can bring your own, all the better. There is always plenty of things for the children to do and see - including swimming, so do remember to bring towels!

Dr.Garrow lives in Chalfont St. Giles in Buckinghamshire - we will print a map in the summer edition of the newsletter.

We hope to see many of you there to enjoy the sunshine!!

Maggie Archard.

Association of Carers,
1st Floor, 21-23 New Road,
Chatham, KENT ME4 4QJ

Tel: Medway (0634) 813981

EXEMPTION FROM VEHICLE EXCISE DUTY

You can claim car tax exemption if the person you care for receives Attendance Allowance and:-

1. is between the age of 2 and 5 or over 65, or
2. is unable or virtually unable to walk, and
3. needs to be driven because they are unable to drive themselves.

The car should be registered in the name of the person receiving the Attendance Allowance (even if this person is a child) and this can be done by the following means:-

Enter the name and address of the person in receipt of Attendance Allowance in the car registration document and send same to DVLC Swansea. Meantime, write asking for an application form for VED exemption to:-

(For England and Wales the address is:)

DHSS, 4a Government Buildings, Warbreck Hill Road,
Blackpool FY2 0UZ

(For Scotland)

Scottish Home and Health Department, Room 62, St. Andrew's House,
Edinburgh EH1 3DE

When you receive your exemption certificate you should take it, together with your registration document and insurance certificate to your local Vehicle Licensing Office (the address can be found in your local telephone directory) and you will then be issued with a 'tax exempt' disc.

Registering the car in the name of the person receiving Attendance Allowance does not affect the ownership in any way (the registration document names the 'keeper' of the car, not the owner), nor does it affect the insurance cover of the vehicle.

The person receiving Attendance Allowance does not have to be in the car when it is being used, but it must be used for the purposes of that person.

Please do not hesitate to contact us if you have any queries or require further details.

MPS WEAR - ´T´ SHIRTS and SWEAT SHIRTS

We are continuing with our style of ´T´ shirts but the quality will be improved by having British made. Unfortunately prices had to rise this year, but we still offer good value:-

childrens - 22"-32"..... £3.00 + 30p.p&p. each.
adults - small / med. / large..... £4.25 + 30p.p&p. each.
and introducing the extra-large..... £4.50 + 30p.p&p. each.

We have also introduced a running vest with a large motif - these are provided free for anyone running in a marathon for MPS - so if you have a friend running please ´phone or write to me.

We are looking into the possibility of ordering coloured ´T´shirts (watch this space) but available now, through popular demand, is a range of colours for the sweat shirts. We have available:-
ROYAL BLUE, RED or BURGUNDY with a white motif
PINK or YELLOW with the motif in Royal Blue.

The prices will be the same as last year:-

£6(+50p.p&p).....all childrens sizes - 22"-32" chest
£9(+50p.p&p).....all adult sizes - small/med/large/extra large
we have been promised that the XXlarge size will be available for all our ´XXlarge Dads´!

Please telephone (024 026) 3185 and ask for me, or write with your cheque to:- Mrs. Sue Butler, ´Spriggs Holly House´
Spriggs Holly Lane, Chinnor Hill, OXON.

Spot the XXL!!

DATES FOR YOUR DIARY

Sat. 11th April	Cheese & Wine at Sue & Dan Butler´s - 6pm.
Sat. 9th May	Midlands families - Weston Park - Midday.
Sun. 10th May	London Marathon - Good luck Reg & Dave
Sat. 16th May	Exemption Dog Show (In aid of MPS), to be at Langton Green, Nr. Tunbridge Wells - details from Mary & Robin Gooch - Tel:Burwash 883329
12th-14th June	Camping weekend in Somerset - see page 8
Sat. 20th June	Barbeque at Rusthall, Nr. Tunbridge Wells Tickets & details - Mary Gooch (0435 883329)
Sun. 19th July	Garden party at Dr. Garrow´s - see page 16
Sat. 1st August	Midlands families - picnic - details later.
25th-27th Sept.	Annual Conference,Post House Hotel,Heathrow

CHRISTMAS CARDS

Thank you to everyone who bought and sold our MPS Christmas cards. We still have a few thousand left and wondered if any small firms or businesses would be interested in purchasing our cards and getting them overprinted with their company´s name to send out as their company card for 1987. If anyone has any contacts in business whom they could approach, please do so and contact the Society as soon as possible. In view of the fact that we have so many cards left from last year we will only be able to get one new design printed this year. Last year´s designs will still be available for Christmas 1987.

REMINDER I am still waiting for a few people to send the money for the Christmas cards they have sold. Please could you get it to me as soon as possible? Thanks.

Pat Isaac.

CALL FOR RESEARCH PAPERS

Readers are invited to submit detailed research papers resulting from their work with people who are mentally and/or multiply handicapped for consideration for inclusion in MENTAL HANDICAP RESEARCH which is to begin publication in 1987/88.

It is intended that the new publication, which will accept contributions from workers in many different specialities, will have a multidisciplinary appeal, so authors will be asked to avoid technical jargon in the text wherever possible.

Details of the required format, length and presentation of papers, and the editorial review procedure are now available on request from:- The Editor,Mental Handicap Research,BIMH Publications, Foley Industrial Park,Stourport Road,Kidderminster,WORCS.DY11 7QG

DR. BAX RESEARCH PROJECT NEWS 1987

Our initial study, largely by questionnaires, confirmed (what most families have suspected) that the natural history of the MPS syndromes is much more variable than the average text-book suggests. In order to develop information about the condition we need to broaden our work, and look specifically at problems within each sub-group.

Hurler's: Developmental Assessment.

Although it is generally agreed that children with Hurler's Syndrome are unlikely to live beyond 10 years and that they deteriorate both physically and mentally before death, very little is known either about the usual natural history of this disease or of the extent to which there is individual variation. Claims for the success of the current bone marrow transplant programme are based on the assumption that obvious cognitive deterioration is evident by the age of 6 or 7. However, at the present time there is no data available either to support or refute this (and indeed from our survey, it appears that some Hurler children are still developing after the age of 5, and all Hurler/Scheie and Scheie children are functioning well at this age).

Therefore, apart from the clear theoretical importance of collecting systematic longitudinal information on the cognitive development of these children, there is an urgent need for it in order that this treatment can be properly evaluated. We are starting this Spring to monitor the cognitive development of a number of untreated Hurler children as part of a 3 year project.

Hunter's: Mild/Severe Distinction

The range of severity in Hunter's Syndrome appears to be much wider than in other MPS types - although some children die in their first decade, there are reports in the literature of some patients living a normal lifespan. This has led to use of a distinction between a mild and severe type, made on the basis of clinical signs only since there did not appear to be any biochemical differences. Young, in a recent thesis, has claimed that it is possible to identify mild from severe cases by the age of 6 years on the basis of IQ. However, in many cases this IQ was estimated in retrospect from case notes once the child had died. There would seem to be a need therefore to test out his claim prospectively, using standardised cognitive assessment procedures. Also, in a recent paper from Australia a group of biochemists claim to be able to distinguish mild from severe types of MPS on the basis of the levels of certain chemicals in the urine.

We hope to be able to test out both Young's classification and these new biochemical claims by assessing a group of young Hunter children at home on a regular basis for 3 years, and collecting urine from them at the same time on each visit.

Sanfilippo: Behaviour Problems

All groups of MPS children show higher rates of behaviour problems than normal children but Sanfilippo children have particularly high rates of difficult behaviours. Sleep problems are especially common in children with Sanfilippo Syndrome and Hunter Syndrome.

They seem to us to represent a different type of sleep disorder to that seen in young children around the age of 2. They may be caused by a disturbance of the body's basic rhythms (circadian rhythms). We hope, by using a detailed questionnaire, to get some evidence of this. If this possibility proves correct it might account for why the usual sleeping drugs don't work and it might be possible to think of some other more effective treatment.

We are also anxious to develop ways for families and schools to manage the difficult, disruptive behaviours that present most commonly between the ages of 5 and 9. Although at the moment we do not have the resources to develop a specific intervention programme, we hope to continue to collect information from home and school visits to give us the insight to develop effective management techniques.

Morquio's: Neurological Assessment.

A number of children and young people with Morquio's Syndrome are having an orthopaedic operation (developed by Dr. Kopits) to deal with their spinal cord compression syndrome. In order to assess the value of this operation these patients need before and after studies. These will include a detailed clinical neurological examination of the patient, cardiopulmonary investigations, spinal cord monitor with somato-sensory evoked potentials. The measures will need to be repeated at periodic intervals.

Morquio children particularly are reported as being extremely 'faddy'. Why is this? It could be something biochemical or it could be related to anatomical difficulties. Again by use of detailed behavioural questionnaires we hope to throw some light on this problem.

We are always interested to hear from individual parents or professionals. So if you think of any leads you feel we should be following up, let us know!

Dr. Martin Bax
Mrs. Gillian Colville
Community Paediatric Research Unit
52 Vincent Square, London SW1P 2NS

LECTURE TAPES - CONFERENCE 1986

Audio tapes of the lectures given at the 1986 Conference are now available at £2.50 each (inclusive of postage)

1. Dr. Amato

2. Dr. Kopits

3. Dr. Ingram / Dr. Kopits / Dr. Pennock / Dr. Bax

4. General - Dafydd Wigley / Overseas visitors / Question time etc

Please contact Sue Butler (address on inside front cover).

CERVICAL FUSIONS - A PROGRESS REPORT

Sufferers of some MPS conditions, particularly Morquio Syndrome, may have a life-threatening defect in their cervical spine. A stabilising peg of bone may fail to develop, leaving the spinal cord at risk of gradual compression leading to difficulty in walking, sitting and eventually breathing. Symptoms often start in early childhood, but those who are mildly affected may not have problems until adult life. The defect can be corrected surgically, but routine methods used in other conditions tend to fail with Morquio patients.

Dr. Steven Kopits, an orthopaedic surgeon from Baltimore, has developed a technique for fusing the cervical spines of MPS patients. Accounts in previous newsletters have described Dr. Kopit´s visits, first to address a seminar and later, in December 1985, to operate on my daughter Helen, and to demonstrate his technique to surgeons in Britain.

Helen spent over four months in a plaster cast, with a metal frame or ´halo´ screwed to her head. Her spine was successfully fused and the halo was removed in May last year. Since then, I am delighted to say, she has continued to progress steadily and she now walks almost as well as before surgery in spite of severe knock knees (our next problem!) The most striking improvement is in her energy level. Before surgery she was starting to crawl rather than walk; now she walks upstairs and is trying to skip! She had given up P.E. lessons at school but is now enthusiastic and trying everything she can manage. It is wonderful to see improvement instead of steady decline and we are convinced of the benefits of a successful fusion.

The two British surgeons were convinced as well. Mr Ransford from University College Hospital, London, operated in May last year on Samantha Dymond, aged 9 from Essex. When Dr Kopits returned to speak at our Conference last September and to see patients at an informal clinic at the hotel, he was shown an X-ray of Samantha´s cervical spine. He was delighted to confirm that the fusion had been achieved and to know that he had been successful in teaching his method to another surgeon.

An orthopaedic registrar from U.C.H., Mr Ben Taylor, who works with Mr Ransford, has interested himself in the problems of MPS patients. The Society was pleased to fund his trip last autumn to the States, to attend a conference on spinal cord monitoring and to spend 10 days with Dr Kopits. Mr Taylor was present for most of Dr Kopit´s clinic at the Post House Hotel where he met several patients who needed cervical fusions and who were able to be referred to U.C.H.

Caroline Sweeney, aged 4, from Caerphilly in Wales, came to London last November for surgery and is still in a halo. An x-ray taken after two months was most encouraging and we all hope Caroline will soon be back on her feet again.

In February Glenn McKee became the first adult patient to be treated by this method at U.C.H. He will shortly be joined in hospital by Patrick Scanlon who will celebrate his 21st birthday in a halo! We all send our very best wishes to Glenn and Patrick and will be thinking of them in the tedious months ahead.

Mr. Witherow, the surgeon from Bristol who was able to observe Helen´s operation, plans to use the halo method when operating on 6 year old Christopher Isaac later this Spring.

The Society has helped with the cost of this treatment programme by purchasing a second halo and frame and on behalf of the Society I am able to give support and practical advice to families and patients having cervical surgery. Dr Martin Bax has recently met with Mr Taylor and a programme of monitoring patients before and after surgery is to be developed.

Mary O´Toole.

OVERSEAS NEWS

Calling all families everywhere, especially new ones, that includes our friends ´down under´, across the Atlantic and below the equator. If you would like contact with a family in another country please contact me and I will make the necessary enquiries to make it possible. Exchanging views between countries on the practicalities of caring for our MPS children can be very helpful.

The brothers and sisters might also like to exchange letters and become pen-friends. In fact, any child wishing to have a pen-friend can write to me and I will endeavour to find you one. (Please let me have details of yourself - name and age - and whether you want a girl or boy as a pen-friend).

We would love to hear from more of our overseas families, do send a photograph and the story of your child and family. You can write in the form of a letter, keeping separate anything you wish to be kept confidential, information which can be used for research and put on Christine Lavery´s MPS computer file. Any new families wishing to help with Dr Martin Bax´s research programme, which is being funded by MPS (UK), please write for a questionnaire to fill in which is, again, confidential.

Best wishes, and I hope to see a pile of airmail letters dropping through my postbox in the near future.

Sue Butler (Overseas Secretary).

YET ANOTHER IDEA FOR FUND RAISING - FOREIGN COINS

Quite often foreign coins appear in our local change but even more often friends returning from a trip abroad have coins that they could not spend. These usually find their way into the oddments drawer at home. Will you ask your friends to pass on coins when they return from holidays or business abroad, and when ´spring cleaning´ this year to turn out those previous collections for us.

A London dealer has promised between 80% and 90% of the exchange rate value on delivery to him so let´s get the coins rolling in! Please pass your collections to any Management Committee member or to your Area Family or bring them to the Conference.

Ken Ballard.

MPS GROUP HOLIDAY

FELL FOOT PARK, NEWBY BRIDGE, ULVERSTON, CUMBRIA.

22nd - 29th AUGUST 1987

A third group self-catering holiday at Fell Foot Park in Cumbria, has been arranged for August 22nd 1987. As many of you may know, the Lake District is an area of outstanding beauty with some seventeen lakes, tarns, streams and valleys, each possessing its own unique character.

Whatever your choice of activity, you are sure to find it in the lakes; from walking, rockclimbing, golf, horse-riding, boating, fishing to just taking in the wonderful beauty of the countryside. Fell Foot Park is one of the National Trust parks. It is situated at the bottom of Lake Windermere and covers some 20 acres for all to enjoy. The park itself offers boating, fishing, picnic areas and adventure playground for the children, to name but a few of its facilities.

We have confirmed a booking of seven chalets, each of which accommodates up to six people. There is also a site for touring caravans but unfortunately they will not take advance bookings as the site only accommodates 26 caravans. If anyone should wish to take their caravan, there are many sites close at hand should Fell Foot Park be full.

There are only a few places left, so please do let me know quickly if you wish to take advantage of this holiday. The price per family is £70 for the week and once again it is being subsidised from the money already raised.

I would at this point like to thank everyone who has been involved in making these holidays possible; firstly, and most importantly, everyone who has raised funds for the "holiday". I know that fund raising can be both hard work and fun, but without you out there working as hard as you do to raise the money, none of this would be possible. Secondly, to everyone, past and present, who spent many hours on the holiday project and lastly, to Pat Isaac and Wilma Robins for their 'leg work'.

One last note. I do hope the group holidays are a success; certainly it will give everyone time to get to know each other in a relaxed atmosphere and, who knows, maybe some life-long friendships will result, after all, who else understands an MPS family better than another MPS family?

Mary Gardiner, Holiday Organiser.

Do let us know how your holiday goes - send us a few lines for the Newsletter, but no more than three pages, please!!! (Ed.)

BIRTHS

Congratulations to Pam and Robert Hayward from Gwent on the safe arrival of Jonathan Robert on March 4th. Jonathan weighed in at 8lb loz.

AREA SUPPORT FAMILIES

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

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

* **Alan and Deirdre Beavan**
  'Tumbleweed', West Gate Lane, Lubenham,
  Market Harborough, Leics.

* **Peter and Marlene Sanderson**
  'Ashley Cottage', 6 Northfield Road, Tetbury, Glos.

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

* **Mike and Pat Skidmore**
  5 Chapel Close, Wyesham, Monmouth, Gwent.

* **John and Barbara Arrowsmith**
  140 Newtown Road, High Heaton,
  Newcastle Upon Tyne, NE7 7NH

* **Heather Broughton**
  160 Ecclesfield Road, Chapeltown, Sheffield S30 4TE

* **Brian and Micheline Johnson**
  'The Mount', Truemans Way, Hawarden, Deeside, Clwyd.

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

Contact for Scottish families:-

* **Alan and Fiona Byrne**
  3 Jedburgh Avenue, Rutherglen, Glasgow G73 3EN