

NEWSLETTER

AUTUMN 1986

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES



National Registered Charity No. 287034

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

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

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

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

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

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Heather Broughton
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Brian and Micheline Johnson
'The Mount', Trueman's 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

AIMS

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

CHRISTINE'S ANSWERING MACHINE'S REPORT: in lieu of a Secretary's Report

"This is Little Chalfont 2789, The Society for Mucopolysaccharide Diseases (The MPS Society) and the private number of Christine and Robin Lavery. We are not available at present, blah, blah, blah..."

How many of you have been inconvenienced by this message? Don't I know. I am fairly worn out and I am less than a year old. Christine's husband (E.T. or Dennis Thatcher's clone) is fairly worn out too, and I know he tears his hair out when he 'phones home and I answer him with his own voice. Why couldn't they give me a proper accent, standard BBC or broad Belfast, instead of this mongrel doggerel?

Anyway, I've been very busy and help the efficiency of the Society. I've taken very important messages over the last few months, new families, medical, overseas. It seemed a bit down market when I first came here, to a semi-detached, not like working for a multi-national company. But don't you believe it, it's surprising what goes on and what snippets you learn. Did you know about Colin and Mary Gardiner's barbecue, David and Michele Brooks-Daw's South-West Area family day, or Dr. Donald and Mrs. Ros Garrow's (3rd) Family Fun Day ("they" call it Donald's Do!)

Everyone gets better at these and similar events every year. They ought to too, they keep nattering to each other. Worse still, whilst I try to mind my own business, sitting quietly by the 'phone in the hall, there are constant comings and goings, and printing being dropped in by those enthusiasts from Clear Image - you should see the new MPS colour posters of Christopher Archard and Gethin Robins, they're absolutely wonderful and say in pictures what 10,000 words could not describe (thank goodness for that, my microchip is already overloaded). Look out at the Conference too for Dr. Diana Chase's newly published guide.

You would think that as it's the fourth conference coming up they'd have made life easy for themselves by now. Not a chance. I've been kept very busy - there's lots of co-ordination with Mary O'Toole, Pete and Maggie Archard, Sue and Dan Butler, Pat Isaac and Mary Gardiner. I could imitate their accents quite easily now. Who do they think they are? Are they trying to compete with the United Nations? They've got their old medical and family friends from Austria and West Germany, and for the first time this year they are going to welcome professionals from the USA and Japan as well as families from Canada and America. Altogether they will have nearly 100 families and 50 professionals. Being British myself I am very glad to see all parts of the British Isles being represented, with, for the first time, families from Northern Ireland and also the Irish Republic.

Psst! I think **They** are coming back...."

"Chris! The answering machine is playing up again. Sometimes I think it's got a mind of its own. Since it is so clever perhaps it would dictate your secretary's report for the newsletter?"

"Okay, Robin, see what it says. But I want to add a personal note of my own - to thank all our good friends in the Society and supporters, family and professional, for all their encouragement during our pregnancy. It was difficult at first but all is well now and I am on course for a little girl by Christmas."

Christine Lavery (and her answering machine)

CHRISTMAS PARTY

Saturday 13th December 1986 at 1pm

Newton Hall
Chapelton, Sheffield

[Junction 35 on M1 (Pennystone and Rotherham)]

This year Heather Broughton is organising the party with the able assistance of Sean and Pauline Mahon. It is a family party and grandparents and other relatives are welcome too. Please support them - we want to see as many families as possible there.

The party is from 1pm till 5pm. It starts with a buffet lunch, followed by a visit Father Christmas and Entertainment.

The charge will be £2 per adult - **all children free!**

Our Grand Raffle will be drawn at the party- Perhaps you will sell the winning ticket and be able to collect the prize!

If any families would like to come but feel the return journey will be too much in one day, please contact Heather Broughton, Tel: 0742 451589
or Pauline Mahon Tel: 0742 304069
who will try and arrange overnight accommodation.

DON'T MISS IT !!

M.P.S. HOLIDAY

As you may already know from reading Mary O'Toole's article in the summer edition of the newsletter, it was decided not to proceed with the holiday home project. However it was decided to use the interest from the money already raised to subsidise a group holiday for MPS families.

It has been proposed that a holiday for around twenty families each year would utilise the interest made to the full. With this in mind, we are now in the process of assessing several suitable group holidays for 1987 and we will be sending out the details shortly.

The holiday will probably take the form of self catering, either in cottage, chalet, flat or caravan, with the possible choice of one in the North as well as the South.

I hope you will take the opportunity over the next few weeks to decide if your family would like to take advantage of the MPS holiday. Once the details have been finalised we will have to move quickly in order to secure arrangements. Consequently, your swift response would be appreciated.

Mary and Colin Gardiner.

GROWTH DAY

Great Ormond Street Hospital

Friday 17th October 1986

Organised by the Association for Research into Restricted Growth in conjunction with Contact a Family and the MPS Society.

Restricted Growth - A Parent's View.

A programme of talks and discussion for parents with children affected by a wide variety of disorders whose common denominator is restricted growth.

Limb Lengthening - Its Applications to Achondroplasia.

A programme of talks by doctors who have developed and currently use the techniques of limb lengthening, with fellow doctors considering the wider applications.

Application forms with this newsletter or from Christine Lavery.

NAIDEX '86

National Aids for the Disabled Exhibition.

15th, 16th, 17th October 1986

Alexandra Palace, Wood Green, London.

This is a very good exhibition and worth a visit if you can get to it.

Admission is FREE

Further details from Maggie Archard: 0462 673830

BIRTHS

It is with great pleasure we announce the safe arrival of Thomas Hale.

He was born to Stella and Steve on June 24th and weighed in at 8lb 12oz.

(You may remember Stella's article in the last Newsletter when she shared her experiences of the chorionic villus test and fetoscopy she underwent whilst pregnant)

Congratulations!

HELEN STEPS OUT

Many of you who have delighted with Helen O'Toole's determination to get on her feet after her pioneering cervical fusion last December, will be thrilled to hear that she continues to make steady progress and can now walk around the house and short distances outside.

Just before the end of the school summer term I was invited to an assembly at Helen's school, Holy Trinity in East Finchley, to receive a cheque on behalf of the Society for £1,500. The occasion itself was touching in that everyone from pupils and parents to teachers and headmistress joined together with the canteen staff led by Mrs. Betty Cartwright to raise such a grand sum.

I always knew that this would be a very special assembly, but little did I know what Helen had up her sleeve. After the presentation Helen whispered that she had a surprise to show everyone. In front of the whole school she walked four steps, learnt the previous day. Looking on, it was moving to see all those 5-11 year olds straining their necks to witness a momentous achievement.

More than £10,000 has been raised for the Society since Helen's story was first published and 9 year old Samantha Dymond has now undergone the same operation, performed by Mr. Andrew Ransford at University College Hospital.



Helen at "Donald's Do" in July.

Recently an article appeared in the 'Toronto Star' which made me reflect and endorsed my opinion that going to a foreign country for medical help should be a very last resort and that it is essential that the Society promotes and facilitates an exchange of medical expertise and techniques, encouraging doctors from overseas to share their knowledge with the British medical profession.

Jinene Iverson is 9 years old and suffers from Morquio Disease. Reading Jinene's story was like reading Helen's. Back in February Jinene underwent a cervical fusion by Dr. Kopits at the International Centre For Skeletal Dysplasias in Baltimore. Jinene and Helen have many things in common not least their very positive approach to life, so much so that it inspired neighbours and school friends to raise funds. That is where the similarities in the story stop. Sadly, fund-raising has had to become an essential part of Jinene's family's life, as it is estimated it will cost her parents \$40,000 (£30,000) in medical bills and expenses.

Reading Jinene's story brought it home to me just how valuable a medical triumph was achieved in bringing Dr. Kopits' expertise to England and at the same time saving Helen's life. It doesn't bear thinking what the cost emotionally and financially would be if we had to send our Morquio children to the United States for treatment. As the months and years go by and more British Morquio children are treated in the UK by British doctors working under the NHS, the initial costs met by the Society for Helen's operation will become insignificant.

We will be forever grateful to Dr. Kopits and Helen Sigwald for imparting their knowledge and giving their time and to Mr. Andrew Ransford and his team at University College Hospital for working alongside Dr. Kopits and the Society to bring about this unique experience.

Christine Lavery

NEW FAMILIES

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

Anthony and Shirley Eyres from Clevedon, Avon, and their 18 month old son Sam who suffers from Hurler's Syndrome.

Joe and Colette Lee and their children Colette and David. The family live in Liverpool and David, 11, has Sanfilippo Syndrome.

Samuel and Susan Zadok from Surrey and their 4 year old daughter Serena who has Sanfilippo Syndrome.

Keith and Kim Obeney from Dagenham in Essex. Their children are James, 5, and 1 year old Scott who suffers from Hurler's Syndrome.

Mrs. Farooqui and her daughter Azeem, aged 18 months, who has Morquio Syndrome.

CHRISTMAS NEWSLETTER DEADLINE

Please let us receive your articles for the next newsletter by **28th November 1986** at the latest - to enable us to go to print before Christmas !!

DONALD'S "DO"

Poor Mrs. Garrow, this seems to be becoming an annual event, when we take over her beautiful garden for a day and turn it into a glorified street market! It is almost becoming an annual MPS family day too - this year saw at least 16 MPS families in a 'gathering of the clans'. They all came armed with the contents of their attics for sale on the White Elephant stall and loaded with 'goodies' for my Home Produce stand. Many even brought their own money-making 'schemes' with them.

With not **too** much chaos everyone pitched in to set up the various stalls. All the children 'helped' (and none actually fell in the swimming pool). Poor Carol Hubbard was banished to the kitchen to wash a ton of strawberries. I think the Garrow family took pity on her and invited her to lunch but Carol did not shirk her duties and carried on regardless.

The rain waited until everything was ready and all the tables were groaning under the weight! There then followed a frantic scramble for polythene and plastic macs in an effort to keep things dry - it's more difficult to sell things when you have to wring them out first! We picnicked under the trees - soggy sandwiches again! But by the time the gates were opened the sun was shining brilliantly.

The children's Entertainer was worth his weight in gold! Nobody saw the children for a whole hour, they sat spellbound watching his magic tricks and Punch and Judy. The afternoon was most successful, some parts of it were even quite sedate with cream teas served to the accompaniment of the Misbourne Orchestra playing on the lawn. We all had great fun and at the end of the day we had £667 profit in our MPS pocket.



Jessica and Joshua Reid "tucking in".



We are immensely grateful to Donald and Ros for allowing us to use their 'pitch' and to all the families that came from far and wide. Not forgetting a big thank you to all the visitors who supported us by attending and digging deep into their pockets.

Maggie Archard.

CHRISTMAS RAFFLE

Once again the raffle is upon us. Last year we raised over £2,000 and this one should be even better. We have over 30 prizes, with the top prizes being as follows:-

- | | |
|--------------|-----------------------------|
| * 1st. Prize | Video Recorder |
| * 2nd. Prize | Microwave Oven |
| * 3rd. Prize | Bosch Electric Hammer Drill |
| * 4th. Prize | Electric Kettle |

The tickets will be ready for distribution at the Conference so lets hope you've brought an empty suitcase to take a load home to sell to friends, neighbours, relatives and the milkman (see Fer Pidden's news on page 21!).

Extra tickets can be obtained from:-

Ron Snack,
16 Wandsworth Place,
Bradwell Common,
Milton Keynes MK13 8BT
Tel: 0908 666819

The raffle will be drawn by a famous personality, well known politician or by anyone who can spare the time!!! The draw will take place at the Christmas Party in Sheffield in the early part of the afternoon on Saturday 13th. December, before the 'Christmas spirit' overcomes everybody! (see page 2 of this newsletter).

SWEAT SHIRTS

We are now ordering sweat shirts in royal blue with the MPS logo - pocket size. They are English made and of very good quality. Those that already have them are very pleased and it's difficult to persuade the children to part with them for washing!

There will be a limited selection of sizes at the conference but you may order them by post from Sue Butler.

Children's sizes: 24", 26", 28", 30", 32" all at £6.00 each.

Adult's sizes: small ; medium ; large all at £9.00 each.

extra large (XL) & extra-extra large (XXL) at £9.50 each.

Please note that we will have to charge postage at 50p per shirt.

If you wish to order shirts, please contact

Sue Butler
Spriggs Holly House
Spriggs Holly Lane
Chinnor Hill, Oxon
Tel: 024 026 3185



"RENT - A - CROWD"

CHRISTMAS CARDS

Enclosed with this newsletter you will find samples of the TWO designs for our unique Christmas cards for MPS. An order form is on the back and if you would like cards on a sale or return basis, please send the form as soon as you can to avoid the last minute rush.

The cards sell at 70p for a pack of 5 of the same design. The actual cost to the Society is approximately 36p per pack to produce them, so you see we are making almost 100% profit. Of course, we have to take the postage out of this but you may be interested to know that 50 packs costs the same price to post as 20 packs. The postage on 50 packs works out at 4p per pack, so we make a profit of 30p on each packet sold. For smaller packages, postage works out to be more expensive (up to 10p per packet) and so profit is less but still worth it.

My supply of brown paper for packaging has run out. If anyone can help with (free!) supplies of brown paper I would like to hear from them.

We also spread awareness of the Society by sending the cards, so I do hope you like them and enjoy selling them!

Pat Isaac

P.S. Don't forget to send me the money as soon as you have sold them all!!!

THE DESIGNERS

Our thanks go to the two artists whose designs we chose for this year's Christmas cards. We thought you might like to know a little bit about the artists, so we have included a 'pen profile' on both of them. They have both raised money for MPS in the past and no doubt will be selling hundreds of cards to all their friends for us this year! This is the first time either of them have had their cards in print, although they both often design individual cards for their friends.

Maggie Williamson - Snowmen

After graduating with an Honours degree in Art from University College of Wales, Aberystwyth, Maggie went on to Manchester Polytechnic, where she gained a teaching diploma in Art. She worked as an art teacher in secondary schools in London, Manchester and Macclesfield for several years before having her own family. She was brought up in Manchester but is now living in Macclesfield. Nowadays she works mainly in water colours and does private commissions - not forgetting the summer months marking exam papers. Maggie is married with two children, Daniel aged 8 and Susannah aged 4 years.

Joe McCabe - Monk and Robins

Joe is a Liverpudlian but has lived in Burnham-on-Sea in Somerset for the past 15 years. He works for British Telecom at the Long Range Radio Station, talking to ships in all parts of the world. Joe has had no formal art training but his interest in cartooning developed from doodling. Meeting Laurel and Hardy once outside a Liverpool pub as a youngster might also have started it, he muses with tongue-in-cheek! Joe says that cartoonists see things in a different light from everyone else and, even though he tries, he cannot get himself to paint serious pictures - everything turns out with a humorous slant. He has now embarked on an 'A'-level art course to try to rectify this. His cartoon-type drawings have been used to illustrate Telecom instruction booklets in several countries. Joe is married to a teacher who is always involving him in drawing in school and he's a Rolf Harris look-alike!

NICE ONE ALEX!

We are very happy to reproduce a letter sent to Alexander Butler from the County Commissioner of Scouts in Buckinghamshire. Alex suffers from Mild Hunter's Syndrome and will be 13 in October.

Dear Alex,

I have heard a lot about you recently in connection with your involvement with the 1st. Radnage Scout Group, particularly in view of the fact that you are not always as well as you would like to be.

The example you have set to the cub scouts, scouts and leaders in your group has been a very high one, and I have just heard from the Chief Scout that he has awarded to you the Medal for Meritorious Conduct in recognition of what you have achieved in your scouting. The Chief Scout asks that his congratulations be passed to you, and I would like to add my own sincere congratulations on the well deserved award.

I am sure that there are many times when the pain you suffer must make it difficult for you to keep active and cheerful, but you manage to do just that, because you are the sort of person who carries out his scout promise and scout law.

Congratulations again on the award, Alex. I have written to your District Commissioner to let her know, and I am sure that she will be in touch with your group to find a suitable time and place for the presentation of the award. Would you please let your parents know of the honour that the Chief Scout has given to you.

I enclose the ribbon of the award so that you can wear it straight away on your scout uniform.

I look forward to meeting you soon.

Best Wishes,

David H. Way.
County Commissioner, High Wycombe, Bucks.



DAGENHAM TOWN SHOW FUN RUN

Paul spotted an advertisement for the Dagenham Town Fun Run in a magazine and thought it would be a great opportunity to enter and raise money for the MPS Society at the same time. He had an idea that his friend might join him so they could train and raise the money together. His friend Andy was only too pleased to help in some way (I am glad they did not rope me into this - what a thought!).



The day of the Run was July 13th so the two lads did not have much training in front of them. We obtained sponsor forms from Pat Isaac and Paul and Andy started to 'threaten' people for their money.

On the day they had no-one to cheer them on, so I went along to give them a little support. Loaded with picnic lunch and plenty of water to revive them both, we made our way to Central Park Dagenham. The atmosphere was electric. There was plenty of activity as it was also a Town Show with Fun Fair, Side Shows and plenty of food stalls - so no-one went hungry. Unfortunately we had to head for the starting line for the run, so food at this stage was definitely out of the question.

All lined up and ready to go, the race was started with the music from 'Chariots of Fire'. I then stood and watched until they arrived back from their 10km run; they returned quite exhausted but happy knowing they had raised £85.20 between them.

We ate our picnic then walked around all the events. Paul had to visit the St. John Ambulance mobile unit to be treated for a twisted ankle, he felt a fool as he is himself a member. We had decided to take a helicopter trip but changed our minds when we saw the charges - £10 each for just 5 minutes. Instead we watched the motorbike displays and the police on horseback demonstrating their skills and then decided to make our way home after a very enjoyable day.

Carol Hubbard

FAMILIES AND FRIENDS

The shock and grief that grandparents feel when they learn that a beloved grandchild has MPS is devastating, but the next thought quickly following is - "What can I do?" Thank goodness there is the Society, which brings families closer together and helps share the burden. We feel that in supporting this we are helping in a practical way.

We have found that MPS has a "credit" side. There is, of course, the love that Natasha brings out in all of us - and that is something everyone of you reading this knows all about I'm sure. It also brings families and friends closer together. Nothing demonstrated this more clearly to me as when we had a coffee morning in August. Friends and family rallied around in support and turned out lashings of "nick-nacks" and made cakes by the dozen.

Great Grandma (incapacitated by strokes) knitted dish-clothes and typed (with one finger!) several dozen "invitation" slips to pop in doors. Great Grandad wrote price tickets in his very best sign-writing. Grandad was out in his shed turning bowls and bud vases, and I was filling the freezer with scones and cakes as fast as Julie and I could bake them.

Natasha's other Grandma had already sold £20 worth of jam before she turned up to help on the day, complete with "Guess the Weight" cake. Auntie Ann made a beautiful "Guess the Birthday" Care Bear cake, and her sole job on "THE DAY" was to look after Natasha - Natasha loves her Auntie Ann.

Cousin Paul, aged 10, took over "Bowling for a Bottle of Wine" (the same as "Bowling for a Pig" but a better prize!) and his sister Rebecca was in charge of "Guess the Weight" cake. Natasha's sister, Kirsten (aged 4) and cousin Stacey (aged 3) were too little to help in a positive way, but they joined in noisily in all the games and enthusiastically bought back lots of their own old toys, which had appeared on the toy stall.

The weather kept fine and the garden was resplendent with bunting. Many friends helped with their expertise in the kitchen and we all had a wonderful time. When we added up our takings - we couldn't believe it - **£340 !!**

Mollie Griggs (Natasha Macintyre's Nan).

A PROJECT FOR GRANDAD

When visiting Julie and Ian (our daughter and son-in-law) it was very noticeable how much Natasha enjoyed sitting in her new chair, which was supplied through the National Health. Thinking what an asset this would be at our home when the family visit, I made some enquiries into cost and much to my concern found it would be around £200. Being somewhat 'handy' with wood, I had a good look at it and decided that if I went about it the right way, I could make one for around £10.

It is basically a three-sided box on legs with a large removable tray for food and toys. I had a good start for when a neighbour moved some time ago he gave me a perfectly good kitchen chair which we really had no need for. This was what I used and adapted.

I have written out the instructions and if you would like a copy of these and sketch plans please send a SAE to Maggie Archard, 48 Lawrence Ave., Letchworth, Herts.

I will be at the Conference in September so I look forward to seeing you there.

Son Griggs (Natasha's Grandad)

FIT 'n' FAMOUS COOKBOOK

FIT- because the recipes are mainly wholefood - delicious but good for you.

FAMOUS- because many famous people have donated their favourite recipes. (including contributions from: Margaret Thatcher; Anton Mossiman; Lynda McCartney; Sarah Brown; Blue Peter and many others)

Our exclusive cookbook is now ready for sale.

Price £2.95 (+35p p+p)

Please sell as many as you can, and don't forget, it makes an ideal Christmas present!

An order form is enclosed with this newsletter, please send your orders to:-

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

We would like to thank Julie Macintyre and her family and friends for all the hard work she has done, gathering recipes etc. Without her, this book would not have been possible.

EVERLASTING PLAYDOUGH - FOR FUN OR FUNDS!

This playdough is a good way of keeping the children amused. It has a different texture from the ordinary playdough and will keep for ages wrapped in a polythene bag, or airtight container.

Recipe

Mix together:

- 2 cups of plain flour
- 1 cup salt
- 2 cups cold water and colouring
- 2 teaspoons cream of tartar
- 2 tablespoons oil

Method

Stir in a saucepan over a low heat until a 'ball' of dough forms.
Turn onto a floured board.
When cold knead until smooth.

Everlasting playdough is a good idea to sell on a stall at a coffee morning to raise funds. You can sell it for 50p. for a 1lb 'ball'. Wrap it in a re-sealable plastic bag. If you use really vivid colours (such as the food colouring sold by specialist cake shops) it will sell really well.

Pat Isaac

CANADIAN CONFERENCE

When Christine was taken ill and Robin asked me if, on behalf of the Society, I would go to Canada in their place, it was with great excitement, but trepidation, that I agreed. Having lived in Canada a few years ago, it was an opportunity not to be missed. I had sleepless nights wondering whether I could represent the Society as it should and would have been if Christine and Robin had attended.

A week before I was due to leave it was decided that Dan should accompany me. We had a wonderful flight, with very few passengers we had first class treatment. Our first stop was Baltimore and we landed around 3.30 local time. The hotel that we were booked in to was not far from the harbour, and we walked down there to find all kinds of food bars situated under one roof. Helen contacted us and made us feel so welcome and then we retired, after a very long day.

The following day we did the 'tourist bit' visiting the new aquarium. Baltimore is really welcoming to tourists and so much is being done to the town; areas in the harbour are being reclaimed and warehouses are being converted into restaurants and museums. The evening found us in company with Helen Sigwald, whom we were so pleased to see once more, having met her at Christmas when she came to assist Dr. Kopits with Helen O'Toole's 'halo', (she will always be Helen's favourite nurse).

The following day the 'tourism' was over and we visited the John Hopkins Hospital where Helen is in charge of the Orthopaedic Clinic. Helen designed it and it contains operating theatre, x-ray and developing rooms and plaster rooms; everything needed for orthopaedic problems in one unit. Patients do not have to 'trail' from one floor to another to get their x-rays. Then, of course, there are the inevitable T.V.s in the waiting rooms to keep patients calm (some of them get a bit 'worked up' if they miss their favourite 'soap opera'.)

In the evening we visited Dr. Kopit's clinic - situated half an hour's drive from Baltimore, and surrounded by lovely grounds. Dr. Kopits has taken the whole of one floor of St. Joseph's Hospital and uses it solely for the treatment of the "Little People of America". All the equipment has been scaled down to accommodate people and children who are small. In the waiting room everyone sits at the same level, but alternate seats have a step to enable smaller people to rest their feet. The gymnasium and swimming pool, a recent addition, are Dr. Kopits pride and joy. We felt very proud to be shown around the clinic, I think it's the first of its kind in the world. We ended the day with a delicious meal with Dr. Kopits and Helen, proving that, contrary to popular opinion, Dr. Kopits does sometimes spare time to eat!

The following day we rose at the crack of dawn as we had a very long journey ahead of us - 2,000 miles to Winnipeg, the venue for the very first Canadian Conference. We actually landed and took off ten times! We were welcomed at Winnipeg by Hazel Smart (whose son Tiler has Hunter's) and Ruby Zacharias and were driven to the camp at Lake Gimley (apparently large enough to 'hold' England!) The camp was built for the use of handicapped societies throughout Manitoba, and was built on one level and designed for the use of wheelchairs.

The first family we met were the Beamans from Prince Edward Island, members of our own society. Nearly all the Provinces were represented with distances involved of up to 1,800 miles (most of the families were able to get funding for their air fares). Sheila Lee is the 'core' of the Society in Canada and she works very hard to keep it running smoothly. She is aided by Hazel Smart and Esther Olsen who is Fund Raising Officer. I am pleased to report that she, and husband Mark, will be attending the conference at Heathrow. We also met Maria Copobianco who runs the MPS Society in the USA, and Karen Jako, who I am delighted to say, will also be at Heathrow.

Most of the lectures were a repeat of those we have heard at our own conferences over the last few years. We heard Dr. Kopits speak on anaesthetics and it was lovely to see him spending most of his time with the children, as usual, hoping he can help them and their parents.

As a result of our visit, three more families have joined the UK Society:-

Mark and Esther Olsen from Ontario, with their young daughters Ashley and Linsey, who both have Sanfilippo syndrome.
Lou and Theresa Aruda from Toronto, and 3 year old Andre who has Morquio syndrome.
Cora St.Croix from Newfoundland, and son Dale who is 12 and has Hurler's Syndrome.

We are sure our visit will bring the Canadian and American Societies much closer to the UK and by this we can share medical knowledge and research results in all our countries. Together with our Austrian, German, Australian and South African friends, we are becoming truly international. We flew out of Winnipeg tired but happy in the knowledge that we had made so many new friends all with similar problems to our own.

Our next stop was Toronto where we were met by my old friend and colleague of several years ago; more than I care to remember. We had a private two day visit, catching up on all the news.

We arrived back in Britain, looking forward to reporting to Christine and Robin everything that had happened. We travelled a lot of miles in those 10 days but we feel that the MPS Society will be better for it, and we thank Christine and Robin and the Society for allowing Dan and myself to be part of the new 'International Scene'.

Sue Butler
Overseas Secretary.

MIDLANDS AREA FAMILIES

Owing to our own family commitments we have not, as yet, held any formal get-togethers this year. We have met various families individually and we are currently planning the following events, full details of which will be sent soon:

4th October 1986 - Twycross Zoo - meet at 2pm.

1st November 1986 - Street Collection in Market Harborough.

29th November 1986 - Cheese and Wine Party.

22nd January 1987 - Coffee Morning at "Tumbleweed".

We hope that as many families as possible will be able to join us at these events. We look forward to seeing you at the Conference.

Alan and Deirdre Beavan.

A QUARTER OF A MILLION SPONSORED TRAMPOLINE BOUNCES

Hello, my name is Louise and I come from Glasgow. I was four a few weeks ago and I suffer from Sanfilippo Syndrome. At the moment I am just like most other children of my age, with a few minor exceptions:-

1. I'm not quite as bright as them, although at the moment, no one can really tell;
2. I tend to catch sore throats and ear infections every second week, and, just to annoy my doctor, I develop an immunity to his medicines. Still, they tell me that once I have my adenoids removed it should make all the difference.
3. I don't know what Mum and Dad get up to next door, so for the last year I have made them take turns at sleeping in my room, so that when I wake up they can give me a drink of juice.

I can't understand all those big words in the Muko-Mucopoli-Mucopolysak-MPS magazines but I know they always keep talking about money, so I just thought that it was time that I raised a few pounds while I can still walk, run and play like any other normal kid.

I didn't sleep for weeks. What can I do? What am I good at? Swimming and Trampolining. A sponsored swim? Well I can only swim two breadths with my armbands on, so I don't think I could raise much money there. Wait a minute; a sponsored trampoline bounce - yes, that's it! I'm good at trampolining, so is Derek, my big brother aged 7, he could help. You see, Daddy goes to school like Derek, and plays football and volleyball all day (my Aunt Lynn always says " and you get paid for that as well").

After a great deal of thought I had decided: " Here's what I want you to do Dad - coach trampolining to about fifty of your pupils, boys and girls, aged 11-16, during your lunchtimes for about 8-10 weeks; ask the school rector for a day off for each pupil and I want you and two other members of staff, your 50 pupils and Derek and me to attempt a Sponsored Quarter-Million Trampoline Bounces. Yes, that's right, a **QUARTER OF A MILLION!** I had calculated that borrowing another four trampolines to add to Dad's two, we could trampoline for two days, starting at 8.30 am and finishing at 3.45 pm.



21..22..23..24.....

Everything went just as I had planned. Derek and I went up to Dad's school for the first few sessions to give a few demonstrations to the beginners, mainly Derek - I can really only bounce, but I can go on for ever.

At first I thought we might attempt the world record, but would you believe it, for one single person the record is 10 days non-stop and for a team like us it's 60 days! I'm glad we decided to give that a miss.

The pupils at Dad's school had a great time. They thoroughly enjoyed trampolining and especially the day off school! Their response to my initiative was to collect sponsors by the hundred - I think that perhaps the cause had a little to do with it - and so on their behalf I have sent a cheque for £1,500 to the Society, with still more to come. My Dad also says thanks to all his friends, to the two members of the P.E. Department and to Stonelaw High School, Glasgow.

Bye for now,

LOUISE BYRNE.

P.S. I completed **MY** 200 bounces in approximately 2.5 minutes.

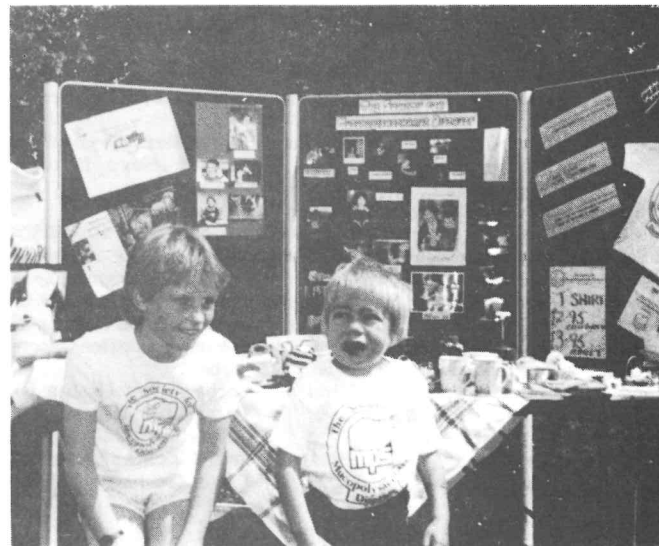
The total collected was £1,660. Well done! - Editor.

STOKENCHURCH FESTIVAL

The combination of the Butlers, Hardys and some very hard working friends and last, but not least, Alex's Grandma, arrived at the Stokenchurch Festival armed with cakes a super tombola and various other regalia to be disposed of! It was one of those extremely hot days in June, the tops 'popped' off the wine, the cokes were hot and the icing ran off the cakes, but we had a great day and made a lot of money for MPS.

The 'Annual Butler Lunch' was also a success even though a lot of the usual guests were on holiday. Once more the weather was great - what has happened to it since?!!

Sue Butler



Lucinda and Matthew
in charge of the Tombola

DONATIONS

We thank the following families, friends, associations and companies for their donations and fund raising efforts and also all those people still sending donations in response to the follow-up story of Helen O'Toole in the Sunday Times in July:-

Mr. & Mrs. Gough; Liz Perkins; Patricia Taylor; Frances Wiebe; Mr. & Mrs. Rich; Elizabeth Knowles; Penny Vickers; Mr. & Mrs. J. Challon; Sue Appleton; Jennie Ruhl; Mr. & Mrs. Deuters; Carol & Paul Hubbard; Janis Chesterman; Mrs. Humphries; G. Nethercot; M. Willcock; Lorraine Poole; Mr. & Mrs. Piromalli; Mrs. Allen; Denise & David Lock; Mr. & Mrs. R. Wederall; Mrs. G. Archard; Mrs. M. Norman.
BBC Children-in-Need Appeal 1985/86; Threshers Off-licence, Hampstead; Renzoku Judo Club, Milton Keynes; Umm Said Golf Club, Qatar; Hythe Town Military Band; Folkestone and Hythe Orchestra; Parkside Playgroup, Streetly; Westbury Nursery, Cambuslang; Inverurie Ladies Circle; Inner Wheel of Sinodun; Little Kingshill Baptist Church; High Wycombe CE School; Gt. Missenden CE School; Holy Trinity School, Finchley; Glendower Prep. School, London; Ysgol Bryn Offa Wrexham Clwyd; Bushey Business & Professional Womens Club; Bank of England; Ciba-Greigy plc (pharmaceutical div.); Shell UK Ltd; Metal Box plc; Cow & Gate Ltd; Royal Insurance plc, Leeds (claims dpt.)

Conference Donations

Gary Brown, Phil Ashton & football team, Birmingham; Electrolux Ltd; Delta Group plc; Rothmans International plc; Nationwide Building Society; Mr. & Mrs. Lowry, Harpenden.

Charity Boxes

Kiln Farm Club; B. & A. Hudson's Shop at Chapeltown, Sheffield; Mr. & Mrs. Mahon, Sheffield; Cath Grant; Woolshop, Little Chalfont; Mrs. Todd, Glasgow; Marks and Spencers, Yeovil; Formation Furniture, Penyrheol, Caerphilly.

In Memory

We are very grateful for donations sent in lieu of flowers in memory of Daniel Reid.

Fund Raising and Sponsored Events

The following ran in various fun-runs and marathons:- Paul Hubbard and Andy - Essex; Mr. Roberts - Reading; Janice Russell - Edinburgh; Mrs. C. Maddison - Tyne & Wear; Marcus Lamb - High Wycombe; P.J. Stevens - East London; David Brooks-Daw - Taunton; "Shoulder of Mutton" ladies played Taylors Estate Agents at darts in Milton Keynes. Richard & Audrey Hodges held a Bingo Evening in Melton Mowbray. Jo Busby held a coffee morning at which Sue Lowry sold Avon items. Mrs. E. Braybooks, Devon, held a bring-and-buy stall at a coffee morning. Mr. Griggs makes bird tables and boxes to sell for MPS funds. Elizabeth Robinson and Steven Dean had a plate smashing stall at Tetley Gala Day. Ella Davidson and friends in Kilmarnock, held a jumble sale. Mrs. Russell (Matthew's Nan) from Birmingham, raffled a blanket. Vera Roy had a sponsored slim, supported by girls at Alan Bradley's factory, Jarrow. Nicola Cuff took part in a sponsored roller skating marathon. Susan Clark, a pupil at Andy Hardy's school, saved her crisps money. Children of Stonelaw High School Rutherglen, collected 'pennies for charity' for MPS. Children at Stonelaw Sunday School gave to MPS instead of having attendance prizes. Fer Pidden held a coffee morning. The Butlers held a lunch, and with the Hardys had a stall at Stokenchurch Festival. Pam Macintyre held a stall at a Boat Fair at West Langdon, Dover. Yvonne Crabtree & Bidy Bale did a sponsored parachute jump, coffee morning & disco. Glen Hughes did a sponsored London to Brighton cycle ride. Jacky Cantello and friends had a sponsored slim. Barbara Watt had a book party. Sylvia Blackburn held a pottery party and draw. Pam Hildrew gave a staff lunch. Andy and Jenny Hardy had a coffee morning. Christine Isaac had a boot sale. Mr Jarrett organised a collection in Yeovil. Gaye Finch held a clothes party. Alan Byrne did a sponsored trampoline bounce. Pat Isaac had a tupperware party.

THE LONDON MARATHON

The final total received from families for sponsorship of the London Marathon is **£3,582.29**. This has been received from a total of 39 families in the Society and their friends.

The following people have sent their sponsorship money since the last newsletter:-

Our sincere thanks to all of you:

Jaque Hyde
Dr. Garrow
Mr. R. Nurse
Mrs. J. Brown
Tony Lockyer
Barry Lewis
Rachel Todd
Edward Wright
Carole Smith
Mrs. M. Hall
Jackie Scanlan
Marion Astbury
Katie Bottom
Pat Kirkman
W. McGinn

Christine Isaac
Mrs. C. Mansfield
Bill and Sylvia Blackburn
Mrs. L. A. Boulter
Mrs. S. Hodgetts
David and Barbara Watt
Mr. and Mrs. Harriss
Andy and Jenny Hardy
Margaret Horsley
Robert and Pam Hayward
Gabrielle Stewart
Peter and Helen Rock
Fatma Ahmed
Doreen Russell

STAMP NEWS

The stamps are still coming on well. Since the last newsletter we have managed to raise approximately £20, so do keep on saving them.

With Christmas fast approaching please ask friends and relatives to save them too. You might like to ask your local schools, clubs and groups to collect as well.

Send used postage stamps, British and Foreign, to:-

Carol and Paul Hubbard,
71 Preston Road,
Harold Hill,
Romford, Essex RM3 7YU

MONEY-OFF COUPONS

Pat Kirkman is still, very kindly, cashing in money-off coupons from packets off food and cleansing products. Unfortunately she is being sent all sorts of coupons from magazines and newspapers which cannot be redeemed. Please note that only coupons from actual brought products are of use. But please keep sending these in to:-

Pat Kirkman,
73 Richmond Terrace,
Darwen,
Blackburn, Lancashire.

INVALID CARE ALLOWANCE

**Are you entitled to Invalid Care Allowance?
If you look after someone who receives attendance
allowance, or if you have done since December 1984
you may qualify for ICA and backpay IF YOU APPLY NOW**



In June this year, Mrs. Jacqueline Drake won her two and a half year battle to be paid invalid care allowance (ICA). She argued that the rule which prevented women like herself claiming was discriminatory and had been unlawful since 22nd December 1984. This was the date when an EEC Directive came into force which prohibited discrimination in the social security system on grounds of sex or marital status. The European Court of Justice decided that the UK Government was in breach of the Directive in not paying ICA to married women and gave its decision in favour of Jackie Drake. At the same time the Government announced the end of discrimination and that married and cohabiting women caring for someone on attendance allowance could now claim ICA.

The Government then agreed that all those fulfilling the conditions for all or part of the period since December 1984 could claim up to £1,800 in backpayment of benefit. However, the Government set a deadline for these claims to be made - the end of this year - 31st December 1986.

The Invalid Care Allowance (ICA) Steering Group represents over fifty disability, carers' and women's organisations. This group, which came together in 1982 with one of its main tasks being to tackle discrimination in ICA, sponsored Jackie Drake's case. Jackie had responded to a request in the Association of Carers newsletter for someone to bring a test case. The first step was to take the case to a Social Security Tribunal which awarded her ICA in the light of the Directive. It was when the DHSS appealed that the case went to the European Court for decision.

Throughout the long process of the case, the Steering Group campaigned to get married women to apply for ICA and by the date of the European Court decision, 16,000 had done so. In all 70,000 married women stand to benefit from the extension of ICA, and the group is now intensifying its campaign.

WE WANT TO MAKE SURE THAT ALL THOSE WHO MEET THE RULES APPLY BY THE DEADLINE FOR BACKPAYMENT CLAIMS - 31ST DECEMBER 1986.

Our advice is: "If you are a married woman or if you are living with a man as his wife, find out if you can claim ICA. If you are aged less than 60; earning less than £12 a week from paid work; or looking after someone who gets attendance allowance, you will meet the rules for claiming ICA. However, if you or your husband already gets widow's benefit, invalidity pension or retirement pension, you will not normally be able to claim ICA as well. If you are on supplementary benefit, you should take advice on whether to claim."

The important thing is to get claims in NOW. Claim form NI.212 can be obtained from local DHSS offices, Citizens Advice Bureaux or other local advice centres. The Steering Group's guidance leaflet on filling in the form is available from:-
The ICA Co-ordinator, c/o YWCA Regional Office, 16/22 Great Russell Street, LONDON WC1B 3LR. (Please send a SAE.)

There is still confusing and conflicting information circulating about ICA. The Steering Group has had a lot of enquiries from mothers asking whether they can claim ICA in respect of their children. The answer is of course "yes", providing the rules for claiming are met. Many may not yet have heard that married women can now claim ICA so it is worth mentioning this to others at schools and clubs etc in case they are among the 40,000 still to claim.

Jane Atkinson, Co-ordinator, ICA Steering Group.

FER AND FRIENDS

A few weeks before my coffee morning I made some advertising posters using the new MPS leaflets to display in local shops. Having not embarked on anything of this nature before, I must confess I was very apprehensive and the day before I was wondering if I would make any money at all!

18th June was a beautiful hot summers day and I had butterflies in my tummy but I had my friends and Natalie's Grandma and her friends, all came to help. Even friends of friends ended up at the kitchen sink for the morning! Everyone was very busy - buying, selling, coffee making, washing up or selling raffle tickets. That is except me! There was nothing left for me to do but wander around chatting to people. I was intending to take some photos for the newsletter but in the hubbub and excitement of the day, it completely escaped my mind.

I had a wonderful morning. There was something in the atmosphere that really lifted me up. Some people came that I had not seen since Natalie started special school, even the helpers from the relief care home that Natalie occasionally goes to, came complete with bean bags and two of their charges. Everyone seemed to have a good time.

All the members of the Westbury Keep Fit Group who could make it on that day came to my coffee morning. The group also donated the proceeds of their last meeting of the season, which was £17. A very big thank you to Ann Brown for her kind and generous gesture.

The following day the milkman asked about the extra pints of milk, and when I told him what it was all about, he said that he would not charge for the extra milk. I also asked him if, in the future, he would distribute notices about my coffee mornings and he was happy to agree. (Milkmen of England, Scotland and Wales beware MPS! - Ed.)

On arriving to help me with my coffee morning, one of my friends told me that her husband had a cheque for £200 for MPS from his staff charity committee. I just could not believe it. Cow and Gate baby foods staff charity committee mainly supports only local charities, but I must have been presented to the committee as the local branch of MPS! Thank you Rosemary and Richard Ambar.

At the end of that day I was quite tired and full of mixed feelings; anti-climax after the elation and excitement of the day and the build up to it; achievement, fulfilment, happiness, sadness and, most of all, hope for the future and restored belief in the good side of human nature.

The total for the day had come to £201.70 with the contributions of the keep fit leader and the milkman in addition to which the £200 from Cow and Gate staff charity committee was an unexpected bonus.

I look forward to organising another 'do' sometime in the future.

Fer Pidden.

DEADLINE FOR THE CHRISTMAS EDITION IS THE END OF NOVEMBER.
POST EARLY FOR CHRISTMAS!

CARRY ON CAMPING (AGAIN)

On Friday 6th June we joined the Laverys, Archards, Butlers, Isaacs and the O'Tooles at Bracelands Camping Site in the Forest of Dean, for what now seems to be an annual camping weekend and one which we look forward to. Once again the weather looked like being kind. After a quiet evening settling in we were all up nice and early on Saturday morning. After a 'quick shop' with Christine and Peter in Coleford to obtain food for the barbeque which we were to have in the evening, we had a picnic lunch - Matthew having now perked up with the arrival of food- he had been propped up against Maggie most of the morning dozing as usual!!

('quick shop'? - we doubled the turnover of the supermarket and acquired 3 hernias - and that was just carrying the wine!! - Editor)



Matthew enjoys the rain

Lunch over, the children were anxious to start the walk along the forest trail, so off we set, but unfortunately it started to rain quite heavily and we had to turn back as Matthew was getting too wet, but the rest of the 'intrepid explorers' carried on and thoroughly enjoyed the walk. The rain did stop after half an hour and everywhere soon dried up. By this time the O'Tooles had arrived - it was lovely to see Helen without her 'halo' and we were delighted that everything had gone so well for her. The other children couldn't wait to tell Charles about the afternoon walk - I think they all consider Charles to be the best 'leader'!



"Because it was there!"

All the barbeques were lit and the menfolk ready for action (they did the cooking!!) We were joined by the Sweeneys, Cantons and Skidmores; some of the families whom had been together for a Welsh Area Day at Monmouth. A super barbeque was enjoyed by all with no burnt offerings (which was quite surprising in view of the amount of liquid refreshment flowing!) Now for the surprise of the day - unknown to some of us, Robin had been filming our antics on the video camera and we were able to watch the film on our small black/white television in our awning - it is funny enough watching yourself on film, but with voices as well it was even funnier - anyhow we all had a good laugh.





The Skidmores enjoy a 'double'!

Sunday morning - the weather was fine again and the children were ready for off, so we packed picnics and headed off in a convoy of cars to Speech House. We abandoned the cars and 'rent-a-crowd' were on the move again! We had a lovely walk through the forest and ended up by a lake - it was quite hot by now and the children decided to have a paddle - Christopher Isaac wanting to be the first one in. After relaxing there for a while we started to make our way back with Alexander Butler striding out with his dog leading the way - he took a wrong turn - the dog's fault! - but to be fair no-one had told him we were returning by a different route, past a gymkhana to give added interest to the children!

The weekend almost at an end now, we said our goodbyes over icecreams, and made our way home after what had, once again, been a thoroughly enjoyable and relaxing weekend and who knows, perhaps some more families may join us next year - the more the merrier!

Bill and Sylvia Blackburn (and Matthew)