

NEWSLETTER

SUMMER 1991

**THE SOCIETY FOR
MUCOPOLYSACCHARIDE
DISEASES**



National Registered Charity No. 287034

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The Society for Mucopolysaccharide Diseases

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The MPS Society is a voluntary support group, founded in 1982, which represents over 300 families in the UK with children or adults suffering from mucopolysaccharide and related diseases. It is a registered charity, which is entirely supported by contributions raised by its members and it is run by the members themselves. Its aims are:

- To act as a parent support group
- To bring about more public awareness of MPS
- To promote and support research into MPS

The Society operates a network of Area Families throughout the UK and Northern Ireland who offer support and links to families in their areas. It provides an information service for families and professionals. At the present time it funds a Consultant Paediatric Post at the Manchester Children's Hospital. It maintains links with sister societies in Europe, North America, South Africa, Australia, New Zealand and Japan.

In most cases there is at present little treatment for MPS diseases but much can be done to improve the care of sufferers. The slogan of the Society is:

"Care Today, Hope Tomorrow"

Fundraising

Sean and Pauline Mahon have just reported that fundraising for the past eight months is well up to target, which in the current climate is a tremendous success. Donations from companies are down a lot, but this has been compensated by the tireless and ingenious efforts of families, advised and encouraged by Ron Snack.

This newsletter is published quarterly and distributed free of charge to sufferers from MPS disorders in Great Britain and to their immediate families. It is distributed around the world on subscription. Copies are also sent to those members of the medical profession who are directly concerned with MPS, many of whom make a donation towards our costs, for which we are most grateful. If you wish to be added to the circulation list, please contact Christine Lavery at the above address. Annual subscription charges are £7.50 in Great Britain and £15 Sterling elsewhere.

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GERMAN/ENGLISH EXCHANGE

Michael Kraft, aged 12, would like to spend some time with a British family in the summer of 1992 to improve his English. Michael lives in Vienna and is the son of the founder of the Austrian MPS Society, Mrs Marion Kraft.

If there is any family whose son would like to do an exchange trip next year, please contact:-

Mrs Marion Kraft
 A-1090, Wein
 Sensengasse 5/70,
 Austria.

NEW FAMILIES

We are pleased to welcome **Cary Saunders**, whose thirteen year old son, **Marc**, is suffering from Mannosidosis.

Julia Cosgrove, from Salford, whose twenty month old son, **Alexander**, is suffering from Maroteaux Lamy disease.

Linda and Howard Pack, from Neston, Cheshire. Their two year old daughter, **Lois**, has been diagnosed as suffering from Scheie disease.

Mrs Elaine Bastin, from Swansea. Elaine is foster mother to **Jason Nicholas**, aged eight. Jason suffers from Hurler disease.

Doctors Ali and Pernia Arshad, from Whitefield, Manchester, whose son **Jibreel**, aged twenty two months has been diagnosed as suffering from Morquio Disease.

The family of **Carly Barker**, aged four and a half, from Leyton, London, who has just been diagnosed as suffering from Sanfilippo Disease.

Parmjit Rehal, and her family who live in Leeds. Parmjit's son **Hardey**, aged four and a half has been diagnosed as suffering from Sanfilipp Disease.

BIRTHS

Congratulations to **Monty and Doreen Russell** on the birth of their daughter **Hannah Jayne**, born 23/5/91. Weight, six lbs, 13oz, thirteen weeks early. A sister for **Gemma** and **Matthew**.

Congratulations to **Mr and Mrs Khezer** on the birth of their daughter **Sabia**, on 7/5/91. A sister for **Shabana**, **Zallayna**, **Shequa**, **Fazana** and **Omera**.

MENTAL HEALTH FLAG DAY

The Flag Day was not so successful for us this year - I have received £675.00 so far, and there may be another cheque to come yet. I know that there were a few problems experienced by some people who wanted to collect, but did not receive their equipment in time from Mental Health.

Notwithstanding these problems we will soldier on, and for anyone who would like to take part in the collection in 1992 there will be forms available at the Conference at Stoke-on-Trent.

This really is a simple way to raise funds for us so please get your names down early.

Ron Snack

DEATHS

It is with deepest regret that we announce the deaths of both **Linda and Michael Ward** on 10th of May 1991. Both children suffered from Hurler disease. They both died in Charing Cross Hospital. Linda was aged four when she died and Michael died the day before his second birthday. Our deepest sympathies to Mr and Mrs Ward and their family at this very sad time.

We are very sorry to learn from Diane Bayliss of the recent loss of her husband **Bill Bayliss**. Our thoughts are with Diane, Julie and all their family at this sad time.

We are very sorry to learn of the death of **Adrienne Smith**, from Australia. Adrienne died on the 25th of May, aged seventeen years and two months. She suffered from Sanfilippo disease. Our thoughts are with her mother **Ros**, and with her family at this sad time.

IN MEMORY

Our grateful thanks are passed to everyone who donated money to the Society in memory of Stephen Harvey, Timothy Bryan, Colin Snack, Carol Hubbard, David Criddle, Geoff Butt (Uncle of Natalie Pidden), and D Gibbons (Grandfather of Harry Brennan).

THANKS TO THE NORTHWEST FAMILIES

Linda and I would like to thank all the families who were at the NW Area Barbecue at Gifford Dairy, Nantwich, recently for a wonderful afternoon. Although the sunshine was rather intermittent the warmth that came through from everyone who was there was worth more than all the sunshine.

Thank you all.

Ron Snack

NORTH OF THE BORDER

A lot of money is raised by our families in Scotland, and I must make mention of one of our new families, Keith and Pauline McLachlan of Penicuik. Although their son, Daryl, was only recently diagnosed as suffering from Hurler Syndrome, they have raised over £3000.00 for the Society by holding a Karaoke Night, a Male Aerobics event and various raffles.

Thanks to the McLachlans and all the friends who helped.

Ron Snack

FLORIDA HOLIDAY

Our daughter Emma is eight years old and has Hurler Disease. She has had a bone marrow transplant. Emma was thrilled to be nominated by the Society for a trip to Florida this year with the National Holiday Fund for Sick and Disabled Children. She was delighted when she heard that she was accepted for the trip, along with Victoria Oldaker, another MPS child. On the trip Victoria and Emma became room mates and very good friends.

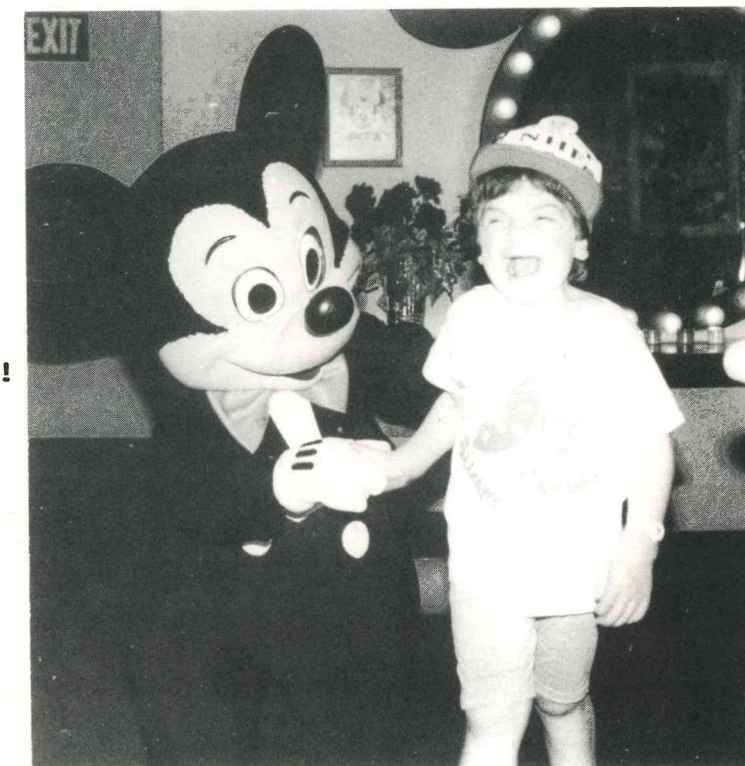
They set off for America in April this year, along with another ten children and fourteen adult helpers. As well as being the only Scottish child on the trip, Emma was also the youngest.

Emma had a marvellous time and was very well looked after. The only time she was homesick was when she telephoned home. The team leader said she was "a little gem" and the life and soul of the party and that she wasn't backward in coming forward! Those of you who have met Emma will probably agree with the last two comments!

We would like to thank the Society for nominating Emma and hope that more MPS children can benefit from this kind of holiday.

Cath and Jim Maclean
5 Tern Avenue
Inverness, IV2 3YN

**Emma Maclean meets
Mickey at Disneyworld!**



THE OLDAKER REPORT

I was very excited when told that I had been nominated with another little girl, Emma Maclean, for a trip to Florida. When the great day came we all met at the Hilton Hotel at Gatwick in the Presidential suite. Here Emma and I met our helpers, Mandy and Victoria.

The night before the flight Emma and I had little sleep because we were so excited. We boarded the Virgin Atlantic flight at about 10.00 am on Sunday morning. The stewardesses were absolutely fabulous. I was allowed to do the safety demo with all the kit. The food and films were absolutely great.

When we got to Florida we travelled to the hotel in a coach, and so it was only on the next day that we met with our three buses. They were called The Good, the Bad and the Ugly. Everything was fabulously well done and I must say thank you again to the National Holiday Fund.

Access for the disabled was good. We spent our time between rides being pushed in wheelchairs, so even the able bodied had trouble keeping up with us. Even the most disabled children in the group showed their appreciation and enjoyment of the rides.

The best ride of all was Thunder Mountain Railway. We had real problems trying to get Emma off it. The best visits were Disney World, The Epcot Centre, and Sea World.

I was very glad to come home. The flight felt very long and jet lag struck me hard. I was so very sad when I had to part from such lovely and marvellous new friends.

Victoria Oldaker

PS Hi Emma, this is "wee Toria" writing!

MORE NOMINATIONS PLEASE!

We were delighted to hear how much Victoria and Emma enjoyed their trip to Disneyworld in April. We were all the more pleased to be asked to nominate two more children for the October trip. Helen Skidmore and Caroline Sweeney, both from South Wales, have been chosen. From the reports back from children who have been on previous trips we know they will have a wonderful time.

The National Holiday Fund always sets special requirements for nomination to each trip. October's trip is a wheelchair trip and the places offered were for two girls aged between eight and eighteen.

If you think your child would be likely to benefit from such a trip and as a family you are unlikely to get to Disneyworld, then please do contact the MPS office. You never know when we might be offered more places.

Emma and Victoria
Step out together
in Florida

Christine Lavery



SARAH HAS CERVICAL FUSION AT MANCHESTER

Sarah Kilvert is aged eighteen and suffers from Morquio disease. She lives with her parents in North Wales. Like many Morquio children she has suffered from instability of the cervical spine, which if untreated, can cause damage to the spinal cord. In a delicate operation bone is taken from elsewhere and grafted onto the upper spine at the back of the neck. The patients upper spine needs to be kept in a fixed position for several months while the graft grows. This is done by means of a metal "halo" firmly fixed to the head and attached to the body by means of a large plaster cast. After much heart searching, Sarah and her family decided to go ahead with the operation at Manchester Children's Hospital in June of this year.

(There is further information about instability of the cervical spine and about spinal fusion in the conference report 1990, pages 36 to 49, and in the Morquio leaflet).

Sarah's mother has sent us a photograph and a brief report on her progress.

"KILVERT'S DIARY"

Here is Sarah with two of her cousins, the second weekend after her cervical fusion at Manchester. The "halo" is made of really tough material and so is she! We are so grateful to Mr Cowie, Mr Ross, Ed Wraith, the sisters and nursing staff and everyone at Manchester.

Sarah goes back next week for her first x-rays after leaving hospital. Everything went really well, so we have no reason to presume that it will not stay that way. Looking forward to seeing you all in September at Stoke.

Love and best wishes

From the Kilvert family
Clifton Flat
Pool Road
Newtown, Powys

When some one is pinned down in a "halo" what they really appreciate is getting lots of postcards and letters. Why not send Sarah a card during the holidays?

PETROL TOKENS

Thanks to everyone who has sent me petrol tokens. Although it really does take too many tokens to be able to obtain any substantial items, I have managed to get several decent prizes for raffles/tombolas, and of course these will all bring in funds for us.

Please keep sending me the tokens whenever you can.

Ron Snack

"The long hot summer" for Sarah Kilvert in her plaster cast and Halo.



LONDON MARATHON

This year our Society had five runners in the London Marathon, and I would like to thank John Battersby, Rob Burgess, Charles Cook, Stephen Farrow and Keith German for all the effort they put in to running to raise funds for us. I have already received over £1800.00 - with more to come.

Thanks also to all of you who collected sponsors for our runners.

Ron Snack

POSTAGE STAMPS

I would like to pass on thanks to Paul Hubbard who is still beavering away soaking used stamps off of their envelopes and selling them to raise money for MPS funds. If anyone has stamps they would like to pass on to Paul please bring them to the Conference where they will be collected together.

Ron Snack

WHY DON'T POLAR BEARS EAT PENGUINS?.....

I wasn't quite sure what to expect of the day. Lindy and Ron Snack had invited us to go on an MPS picnic with them to the Cotswold Wildlife Park. The only trouble was, they weren't taking the Duplo building bricks that we usually build a tower with. Oh horror! what were Alan and I to do all day? Without the Duplo would this MPS day be as good as the rest? We've been to some of the family days at Bradwell Common, but this was something different!

We didn't have time to think about building towers once we'd got inside the park. Compared to the zoos I've visited, this place looked a bit small but, my legs told me, it was just the right size for a day visit and I think we managed to see all the animals (except for some of the specimens in the Insect and Invertebrate House, they were either very well camouflaged or out for a walk!!!)

After the group had parked their cars, we arranged where and when to meet for lunch and went off on our own safaris. First we saw the spider monkeys then we went in to see the fruit bats. I thought these were good, as the day and night for the bats had been swapped about. This meant that they were flying about during our day so we could get a good look at them and I guess that lights were turned on at night to make the the bats go to sleep. Ron didn't seem too keen on the bats and Lindy didn't 'hang around' for long, but I nipped back for a second look.

We concentrated on the animal houses near the entrance before lunch. Apart from the bats and insects there were the freshwater and seawater aquaria and the Reptiles and Amphibians. We made special note that some snakes would be allowed out between 2.00 and 4.00 'for a walk' Ron decided we had to go back for that, Lindy was not so sure.

The picnic shelters had been built since the last visit, we were very glad that we didn't have to use them, the sun shone all day. I think it was a bit too bright for Leanne, who had come with her family on their first trip out with this MPS local group, her brother Scotty seemed to enjoy the day and told me that he liked the goldfish. Lunch over, the decision was what time for the cricket match?

We didn't feel like too much rushing about after lunch, so we took the train from Bradwell to the Tortoise Terminus. We then walked back along the route the train followed, but this time stopping to look at the animals. Alan liked the big pussy-cats the most, but I wouldn't let him take a tiger home, two cats that catch birds are enough. I dread to think what a tiger might bring back and it would never get in through the cat-flap! Lindy was looking forward to the Farm Animals section, but decided she liked watching the rhinoceroses and zebras. (I had to include the zebras so that I could try all the letter keys on the computer. Now, where can I fit in the 'X'?).

Snake time approaching! Lindy decided she needed a well earned rest so we met her under the tree later. Forward our intrepid snake-charmers! Two

great big pythons were out for a stretch, and what a stretch! There were many people gathered about, I didn't see Matthew, but Rebecca said that she had touched a snake and discovered that snakes aren't slimy. In fact they felt like very supple leather. Ron had decided that he was going to tell Lindy that he'd touched a snake even if he didn't quite pluck up the courage, but we have photographic evidence that he really did! This was almost the highlight to Ron's day, but overall, he preferred the meerkats. They were just like the ones on that television programme.

The arrangement was that we meet at the penguin pool at feeding time to watch them have their tea. Sadly there were only 3 penguins there, the rest had suffered some kind of viral infection and died. We believe you Ron, that last time, feeding time was worth watching!

Time now for The Match of the Day. Too hot for football, it was going to be cricket. The cricket was too slow, so two teams were picked and we played rounders. Two rounders later we had lost the ball! Next (I've used the 'X'!!!) team in. Uncounted rounders later we got them out. I don't think anyone kept score but that didn't matter. Alexander, (I've scored another X) the demon bowler, did a very good job for his team and we all ended up ready to drop. All this after a day walking around the Park. Time to go home. Thank you all for a most enjoyable day. It was good to be able to have a chat with you at lunchtime and as we saw you walking around the zoo. I hope you enjoyed the day as much as we did. By the way, my very favourite was the Tropical House with the humming-birds flying about and the alligator in the pool. I can't decide whether my next most favourite was the bats or an enormous owl whoooo couldn't quite decide which way round his head was screwed on!

See you at the next (there's that X again) event,

Time Marchbank.

.....BECAUSE THEY CAN'T GET THE WRAPPERS OFF!



The Woods Family at the Cotswolds

Society for Mucopolysaccharide Diseases

S A L E S G O O D S

ITEMS	COST
Pens, Multicoloured	0.25p
Pencils, Multicoloured	0.25p
Key Fobs	0.50p
Book Marks	0.60p
MPS Ties, Maroon and Navy Blue	£6.50p
Lapel Pins / Blue	£1.95p
Plastic Badges, Blue	0.25p
Tea Towels	£1.99p
Christmas Cards	
Santa's sack	0.80p
MPS Robins	
(Per pack of five cards)	
SWEAT SHIRTS	
CHILDREN'S 24" - 32"	£7.75p
ADULTS	
Small, Medium, Large	£11.00
X - large XX - large	£12.00
COLOURS	Royal blue, Yellow, Pink Red, Burgundy, Black, White, Turquoise.
TEE SHIRTS	
Children's 22" - 32"	£3.00
Adults	£6.00
Running Vests	£6.50
POLO SHIRTS with embroidered logo	
Children's 22" - 32" (white, red and royal blue)	£8.00
Adults (all sizes) (Black, white, royal blue red and turquoise)	£11.50
POST AND PACKAGING PER SHIRT	0.60p

Enquiries to

Sue Butler, Sales Organiser
Spriggs Holly House
Spriggs Holly Lane
Chinnor Hill, Oxon.
OX9 4BY

Tel: 0494 48 3185

FIRST PARENT CONFERENCE FOR MPS FAMILIES IN ITALY

21-23 JUNE, 1991

Castiglion Fiorentino, Tuscany

We knew when the British MPS Society decided to organise the Second International Conference for Manchester in 1990 that the benefits would be wide spread. Amongst the large number of key professionals we welcomed were 3 from Italy.

Little did we know when we said our goodbyes to these three at the Manchester Conference, that we would all meet again so soon. Although no Italian MPS Families were able to make the trip to Manchester nothing was going to deter them from putting the newly formed Italian MPS Society on the map.

This they did most convincingly by organising and holding a First Parent Conference for MPS Families in Italy. The Conference had all the ingredients of the British MPS Conferences with the additional bonus of a picturesque venue and glorious weather.

Back in May when the British Society first learnt of the forthcoming conference it was with regret that the invitation to Robin and Christine Lavery, was declined. The prime reason being that it was our eldest son's thirteenth birthday and we would not consider splitting the family on such an occasion. There was obvious disappointment at the Italian end to the extent that they offered to help with costs. Further contributions from the MPS Society and the Lavery purses meant that with just 48 hours till the Conference was due to start Andrew's birthday treat was hastily rearranged and it was agreed Robin and I and the three children would travel to Tuscany for the weekend!

We left London by air for Pisa where we picked up a hire car and drove the 150 miles to Castiglion Fiorentino (some 70 miles South of Florence). When we left the motorway, and just when we were wondering how we would find this tiny village amongst the vinyards there in front of us in true MPS tradition was the most enormous poster announcing the conference. We couldn't understand much of the writing but we instantly recognised the logo, Simon's hands.

As we arrived at the Conference centre, the highest point of a traditional walled hill town it seemed as if the whole town was out to welcome us. It was an emotional moment and one we shall never forget as our International MPS Family grows. Lucy and I received bouquets of red roses and 15 minutes after arriving I found myself on the platform making a speech through an interpreter who appeared as nervous as I did. The same evening we were treated to a display of medieval flag throwing with all the villagers taking part, from small children to senior citizens, before adjourning to a restaurant for the seven course meal.

Although we were served by excellent interpreters, we decided not to attend a majority of the talks as the subjects were already familiar to us. We used our time to visit the creche and a specially designed school with gardens, ramps and everything for the children's comfort. The helpers were a mixture of local people and the Red Cross Society. It really was a community affair even the local police used the excuse

of visiting the Conference Centre to escape the heat of the midday sun.

Dr Susanne Kircher and Marion Kraft from the Austrian MPS Society also made the journey to Italy and over dinner on Saturday evening we were able to usefully use this time to talk about the future of MPS as an International network. Usually Marion and I are arranging conferences and there is no time to talk.

Following mass, the Conference reconvened on Sunday morning and a hectic couple of hours were spent talking to parents and taking photos. We met a range of children including those with Hurler, Hunter, Sanfilippo and Morquio disease. We also had to contain our views when we met with at least two families where in our lay opinion their child had been wrongly diagnosed. Our experience with the Morquio children left us feeling that future Italian Conferences must address the problem of the cervical spine. It appears that there is a lack of expertise and appropriate treatment available in Italy, and it is unacceptable that Italian children with Morquio should be left to become quadraplegic and die unnecessarily.

Perhaps these observations, most of all, highlight the importance of the Society's involvement overseas, the need to share experiences for the benefit of all MPS and ML children worldwide.

Thank you to all the Italian people, doctors, parents and volunteers, especially Laura Fuzi and Anna Brusco, for such a warm welcome and congratulations on a most successful Conference. Also thank you to Vito Brusco and Rosetta for speaking English the whole weekend. We fell in love with Tuscany.

Christine and Robin Lavery

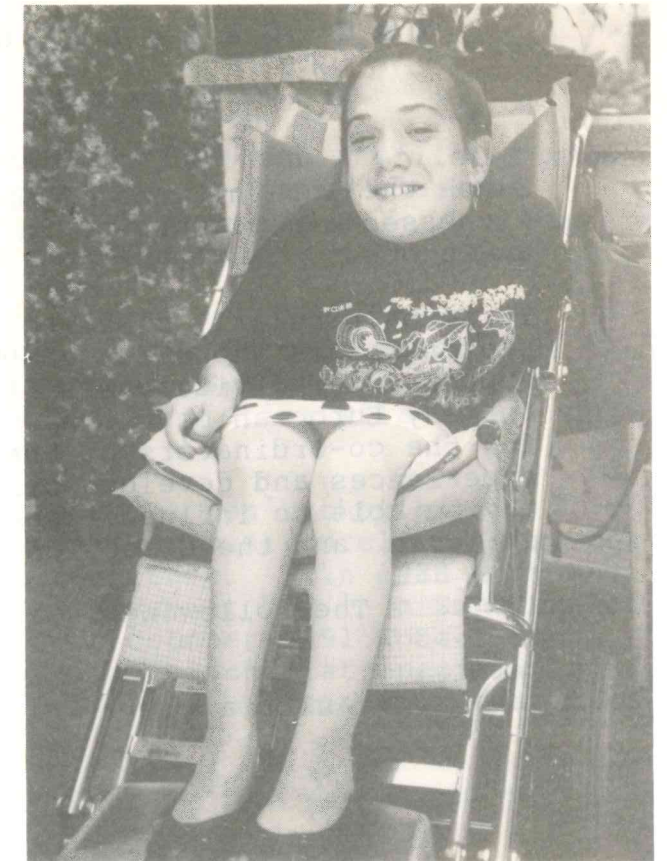


A boy with Marateux-Lamy and his sister

At the Italian Conference



Elisa Brusco (Sanfilippo A)
Lucy Lavery and friend (Hunter)



Eighteen year old with Morquio
Eighteen year old with Sanfilippo



THE GROWTH OF OUR EUROPEAN
MPS FAMILY

Since the International Symposium at UMIST in 1990 we have witnessed a rapid growth in establishing National MPS Societies in Europe.

It is particularly pleasing to learn that many of the professionals who attended UMIST are now enthusiastically supporting individual MPS families in setting up MPS Societies in many European countries. I feel the time is nearly right for the co-ordinators of these Societies to meet to share experiences and develop policy. With our combined strength we may be able to influence good practice in the management of MPS children and the direction of future research.

The following is a list of European MPS Societies.

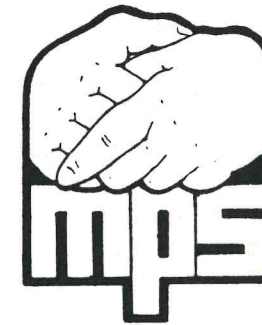
Austria	Marian and Erich Kraft A - 1090 Wein Sensengasse 5/70 Tel: 010 43 222 42 7468
Belgium	Irene and Huub Temmink Sazantenstraat 5 1850 Grimbergen
Germany	Jurgen and Brigitta Zumbro Stadtgartenring 97 4630 Bochum 6 (Wattenscheid) 010 49 2327 81424
Holland	Nico and Corry Van Diepen Pastoor Van Rielstraat 6 5051 TK Goirle 010 31 13 341264
Ireland	Mary and Brendan Hayes Fairy Hill Monkstown, Co. Cork. 010 353 21 842 067
Italy	Luigi and Anna Montemezzi Viale Dante 5 37011 Bardolino (Verona)
Poland	Marek and Joanna Popek Os Kochanowskiego 4/31 43 - 190 Mikolow
Spain	Theresa Barco Luz Arriero, 2 Casa 3 Bajo A 4010 Sevilla

If you are planning a holiday near any of these families I know they would be pleased to hear from you. Where telephone numbers are given they are direct dial from the UK. The Van Deipen and Temmink families are co-ordinating a joint group between Holland and Belgium.

You may be interested to know that we are in regular contact with individual families in Switzerland, Sweden, Norway and Czechoslovakia and we anticipate that Societies will be set up in these countries in the future.

One might fairly ask, what of France? Don't they have families who need support? The answer must surely be yes, but as yet, France remains untrodden territory. In 1988 Mary and Charles O'Toole by chance met a mild Hunter boy in a Supermarket and trailed him to his family! In October 1991 Robert and Caroline Fisher visited Irene Maire, a biochemist specializing in MPS diagnosis at her clinic in Lyon. So at least awareness is spreading.

Christine Lavery



**The Society for
Mucopolysaccharide Diseases**

9th PARENT CONFERENCE

20th-22nd September 1991

**STAKIS GRAND HOTEL
STOKE-ON-TRENT
STAFFORDSHIRE**

This year's conference is now fully booked. This year will be very strongly a family conference with very few professionals. Over seventy families will be coming. People on the waiting list will be contacted if any places become available.

We look forward to seeing you at Stoke!

LETTER FROM POLAND

Thank you for the translated information folders that you sent us; they are very valuable, the more so as they are written in very good Polish.

We had our first conference for MPS parents on the 11th of May in Warsaw. We were very pleased to be able to produce a full programme of lectures. All the speakers came from the Centrum Zdrowia Dziecka in Warsaw and they are all familiar with MPS problems. We had lectures on rehabilitation and on physiotherapy, and a lecture by a heart specialist.

Forty parents came from all over Poland. The conference lasted eight hours and we were very pleased with the results.

Some of the problems we face are that there is no rehabilitation available for any of the MPS children. This is especially true in the small towns. There is almost no equipment available and the prices are out of reach. There is no social welfare for poor families. As you can imagine our Society has very few funds.

However, we have had quite a few successes

the goods we received from the Scottish Area family nappies from the Australian MPS Society
 Buggies from the German Society
 Six respirators which we were able to buy

We have started to publish our MPS Newsletter, and we would like to print lots of information from your society. There is a huge demand for all kinds of information on MPS diseases. We plan to make copies of your material. Thank you for what you have already sent us, but we will still be asking for more!

Next year we would like to organise a meeting for parents and children together. This is what we want to do most and we will try to do everything to get it done. Now there is holiday time until September. We really hope to meet you all at the Third International Symposium and parent conference in Germany in 1993.

Everything is all right here. We don't know if we will be able to go on holiday this year. Kamila is weak and she has got spinal curvature. Magdalena is finishing her first year at school and she will probably go on a "healthy holiday", because children in our region are more contaminated and not so healthy as in other parts of Poland. Magdalena often says she will go to England because it is a very clean country. We would love to go abroad but we haven't enough money as yet.

Write soon and tell us how you are and what you are doing.

Yours with love,

Joanna and Marek Popek and girls.

TY HAFON - THE CHILDREN'S HOSPICE IN WALES

From research in the past we know that there are families with children who are terminally ill in Wales who truly need a haven at times of stress, crisis, or just downright tiredness. This is what we aim to provide in "Ty Hafon".

Because the word "Hospice" has been used in connection with adults who are terminally ill, the original meaning

"A resting place for weary travellers",

has been lost. We can understand how the word can be offputting to parents of children who, tragically, are in the same situation. May I assure them that "Ty Hafon" will follow the paths of the English children's hospices. They are places of living and laughter, combining skilled care and support for all the family, as and when they need respite. It goes without saying that our service like theirs, will be free.

We are making steady progress with our planning. The governing body and the committee are all working professionals, who give of their spare time very willingly, and ensure that each step is laid on a firm foundation.

We hope to have a small office manned in the near future, made possible by a donation from Telethon. We also have hopes of suitable land becoming available.

"Friends of Ty Hafon" are beginig to spring up in Mid, South and West Glamorgan. We spread the word by talks to any group that wants to hear. Many organisations, clubs and businesses are taking the concept of "Ty Hafon" to their hearts and donations are beginning to roll in.

We are asking for the help of support groups in Wales to tell us the names of families to whom we could be of service. The MPS group locally has been in contact and is fully supportive.

This will be Wales' first Children's Hospice

Help us to get it right!

Mrs Sue Goodall
 1 Gelynog Villas
 Penycoedcae Rd, Beddau,
 Near Pontypridd, Mid Glamorgan. CF38 2RD

Ph. 0443 202525

MPS NORTHERN IRELAND

For some time MPS families in Northern Ireland have been thinking of setting up a local committee. On the 26th of May a meeting to consider this took place at the Dunandry Hotel, Antrim. Seven Northern Ireland families were there, and I attended on behalf of the Society.

There was a lively discussion about the needs of families in Northern Ireland and how these needs could best be met. Everyone agreed that the way forward was to set up a Northern Ireland Organising Committee. They then promptly did this, with members as follows:-

Chairman	Kieran Houston
Secretary	Margaret Kearney
Treasurer	Winnie Larkin
MPS Shop	Ann Kirkpatrick
MPS Sale Goods	Rachel Todd
Minutes Secretary	Patricia Copeland
Committee Members	Seamus Kearney
	Joseph Larkin
	Mr and Mrs Dawson
	Mrs Houston
	Martha Rea

Very useful work was done on a draft agreement between the organising committee and the MPS Society. A proposal was put forward to have headed notepaper with a Northern Ireland insert. It was felt this would be very helpful with fundraising. There was enthusiastic discussion about family days, fund raising, holidays and Christmas parties.

Keiran Houston proposed that the next meeting take place on the 22nd of June in Strabane so that those who wished could take part in the Golf tournament that had been arranged.

It was agreed that more work needs to be done on the relationship between this committee and the Management Committee of the Society. The atmosphere of welcome and enthusiasm made this a most successful meeting.

Margaret Kearney will continue as Area Family support worker as well as taking on the secretary's role for the new committee. Ann Kirkpatrick will continue her very successful work with the shop along with her friend, Martha Rea.

Sharing in this meeting and enjoying the hospitality of the families in Northern Ireland gave me great pleasure and I wish to thank them all and wish them success in their enterprise.

Mary Gardiner



**Its a serious business having your photo taken!
 Northern Ireland Organising Committee
 Historic meeting on the 6th of May.**

Congratulations are due to all our families in Northern Ireland who have been beavering away for the past few years raising money for the Society. It is impossible to thank one person more than another, but I would like to make a special thank you to Ann Kirkpatrick and Martha for the marvellous work they do in the MPS shop and to Kieran and Bernadette Houston for the annual Golf Tournament.

Ron Snack

Welcome to **Alan and Audrey Noble**, a new Area Family for the East Midlands.

Best wishes to the **Lockyer family** on moving house. We wish them every happiness in their new home. Note address and phone number on back page.

Tony and Shirley Eyre had to cancel their Family Barbecue at short notice as **Sam**, who has Hurler disease had to go into hospital. At the time of going to print Sam was home and showing some improvement. Our thoughts are with you.

Ron and Linda Snack, fresh from organising their successful Cotswolds outing, are off to Filey in August to help organise the MPS holiday. A record number of sixteen families will be going.

Pat Isaac's friend, John, raised £100 by shaving off his beard. The Quantock players also did a raffle for the Society. Pat's friend was the leading lady in their play. Odd folk down Somerset way!

W E L F A R E R I G H T S

PROPOSED NEW BENEFITS FROM APRIL 1992

In April 1992 the Government proposes to bring in a new benefit which will replace both the **Mobility** and the **Attendance** allowances for people under the age of sixty five.

The new allowance will be called

THE DISABILITY LIVING ALLOWANCE (DLA)

The DLA will have two parts;

A CARE ELEMENT

A MOBILITY ELEMENT

The "Care Element" will be paid at **THREE** different levels:

Top Level ----- Higher Rate of Present Attendance Allowance

Middle Level ---- Lower Rate of Present Attendance Allowance

Lowest Level ---- To be set at about £10, and available to people who need some help during the day, but who would not qualify for Attendance Allowance at present. This is new!

The "Mobility Element" will be paid at **TWO** different levels:

Upper Level --- Similar to the present Mobility Allowance

Lower Level --- To be set at about £10, for people who are not independently mobile, but who would not qualify for Mobility Allowance at present; for example many Blind people. This is new!

AGE LIMITS FOR CHILDREN

The age limits for the two elements of the new allowance will be the same as under the present rules.

IF YOU ARE ALREADY GETTING MOBILITY
and/or ATTENDANCE ALLOWANCE

You do not need to apply for the New Allowance. The DSS will work out what is the same level under the new law and they should let you know in the next few months what you will be getting. No one should get less than they are getting at present.

If you have any problems, Wilma Robins, our Welfare Rights Officer, will be happy to advise you. (Phone number inside front cover).

Changes in the Health Services

From now on Area Health Authorities will have to pay when a patient is referred to a Hospital or specialist outside their Area. This will mostly be done by **contracts**. For example Barsetshire Area might make a contract with the Royal National Orthopaedic Hospital to do all their hip replacements for them at £6,000 each.

The question is, what will happen when you want to be referred to a specialist with whom your Area Health Authority does not have a contract? The Government has made it clear that patient can't be refused treatment because there isn't a contract to cover them, but what will actually happen about referrals and payment is not yet clear.

One thing that is likely to happen is that Area Health Authorities will try to have patients seen by their contracted hospitals as far as possible. For example, if there is a contract with Great Ormond Street Hospital for paediatric services for children with genetic diseases, how easy will it be to get a referral to Dr Ed Wraith in Manchester?

Christine Lavery would like to hear from any families who have had any problems about referrals to hospitals outside their Area.

Northern Co-ordinator

Back in November 1990 the Society's managers and advisers met for a "think day". This was a chance to sit down, away from ordinary business and to consider "Where the Society is going."

One of the decisions we reached was that if the money became available the Society should try to appoint paid workers as Northern and Southern Co-ordinators. We felt that there was just not enough voluntary time to do the things we thought were needed.

This year we applied to the Children in Need Appeal and we were granted the cost of salary and support for a Northern Co-ordinator for three years. We advertised in June and had nearly thirty applicants. Dr Bryn Neal, Robin Lavery and Jenny Broome shortlisted these down to two. Final interviews are arranged at Manchester Children's Hospital for the 23rd of July, as the newsletter goes to press. Drs Wraith and Neal, Robin Lavery and Jenny Broome will make up the interview panel. So that families can see what is expected of the post, (not all at once!) the full job description is included on the next page.

Christine Lavery

WATERPROOF BEDDING

As Linda and I know the problems that most parents face with their MPS children's incontinence we would like to pass on some information about a company that produces mattress and pillow protectors that we found very useful. The Company is Snugfit (UK) Ltd of Surrey House, 34 Eden Street, Kingston-on-Thames, Surrey, KT1 1ER and the pillow cases and mattress covers are produced from 100% cotton material with a waterproof backing.

We found the pillow cases especially useful as Colin's nose seemed to run even more at night than it did during the day.

I do not know the current prices of these items but I feel sure that Snugfit would be more than willing to provide a list for anyone who may be interested.

Ron Snack

Technology

The Society has just invested in two new computers, one for the office and one for the newsletter editor. This will free up another computer for the Northern Co-ordinator when appointed. The new machines were needed to keep up with the expanding flow of records and information.

JOB DESCRIPTION
NORTHERN COORDINATOR

1 To liaise with Regional Area Families North of Birmingham and in Scotland and Northern Ireland to encourage and develop self-help for families in these parts of the United Kingdom.

2 To encourage, and when necessary, assist regional Area Families, and other experienced and enthusiastic parents, in the arrangement of social and fund-raising events.

3 In consultation with Society headquarters or appropriate Area Families, directly counsel MPS families in the availability of diagnostic, referral and treatment centres and in the provision of statutory welfare services, allowances, respite care and education. Advise on alternative sources of help.

4 To provide practical and moral support to parents and patients visiting the Willink Laboratory at the Royal Manchester Children's Hospital, Pendlebury.

5 To regularly consider with the professional staff at the Willink Laboratory new methods for the treatment and care of MPS children and explore avenues for medical research where patient or family cooperation will be essential.

6 Encourage ethnic minority use and development of the MPS Society's services.

7 To develop major fund raising programmes in the North, involving families, or in direct approaches to potential corporate, trust and regional development donors. To accept on behalf of the Society major donations given at public gatherings which fully acknowledge the efforts and kindness of the donors.

8 To present and represent the Society's interests at speaking and other engagements, at professional and support group conferences and in inter-group plans to develop the Willink Laboratory.

9 To assist headquarters in the national development of the role of voluntary Area Families. To assist in Area Family training including participation in, and programme formulation of, training days or weekend residential training weekends.

10 To report new ideas, concerns or problems to Headquarters on a regular basis, so that these may be given prompt consideration and attention, especially when they demand central policy decisions or have budgetary implications.

11 To prepare a quarterly progress report for submission to the Management Committee. To prepare a draft text to the Annual Report on the Northern Coordinator's activity over the previous year. Submit an draft forward work-plan for approval by the Management Committee.

12 Attend the quarterly Management Committee meetings, normally held on Friday evenings in Little Chalfont, South Buckinghamshire.

Could you please put this poem in the newsletter as a way of saying thank you to Bernadette and Edward Hall for Dominic and all the love we get from him and for the love we feel for him.

Mrs Brenda Lofthouse
112 Moordown
Shooters Hill
London SE18

I A M D O M I N I C

I am **Dominic Russell Hall** and I am nearly three
I have Sanfilippo, but that's not all there is to me
Chips and Biscuits I like to eat,
But best of all, ice cream for tea.

I had two transplants and that was a bind for me
But yesterday I cried because I fell and hurt my knee.

My brother is seven, he's big and strong.
He's my hero, so I try to tag along
Mum says we fight and that's bad for brothers;
But standing together we beat all the others.

Some people say it's all so sad,
But God knew what he was doing when
He gave me my mum and dad.

They love me when I'm good and when I'm bad
And never let me see when they are feeling sad.
So thanks to Mum and Dad and to my big brother
I love being who I am,

Dominic Russell Hall.

FUNDRAISING EVENTS

Yet again everyone has come up trumps with their fundraising - this time everything from dinner parties to discos to sponsored slims. Thank you all and please keep up the good work.

Colerne Club and Institute	Raffle
Isuzzana Kiss, Purley	Dinner Party
Glasgow Keep Fit Association	Sponsored Aerobics
Sid Shiff and Friends	Collecting Boxes
Alan and Amy Bottrell, Glasgow	Saving 20ps
Alan and Fiona Byrne, Glasgow	Dance
Shabnum Haq, Rochdale	London Marathon
Rachel Todd, Co Antrim	" "
Fatma Ahmed, London	" "
Paul Hubbard, Romford	Sale of Stamps
VAT International, London	Collecting Box
St Clears Post Office	Collecting Box
B and L Scurr, Milton Keynes	London Marathon
Lorraine Dickson, Edinburgh	Disco
16th West Bromwich Brownies	Bring and Buy Sale
Pam Croghan, Stockport	Collecting Box
Ladybridge Residents Club	Collecting Box
Pam Croghan, Stockport	Collection at wedding
Monkhouse Sports, Cheadle Hulme	Collecting Box
Miss E Nichol, Lytham	London Marathon
B Ingham, N Ireland	Collecting Box
Sally Barratt, Lesley McGrath & Chris	Sponsored Walk in memory of Stephen Harvey
	Collecting Box
Pam Croghan's parents	London Marathon
Dave and Monica Briggs	" "
Mr and Mrs Puddy, Somerset	" "
Pam Croghan, Stockport	" "
Mrs Taundry, Malvern	" "
Mr and Mrs Reade, Cheshunt	" "
Mrs Murray, Holytown	" "
Mr and Mrs Graham, Annan	" "
Rob Burgess, Luton	" "
Carol Westland, Reading	Mental Health Flag Day
Rachel Hall, Manchester	Sponsored Swim
Mr and Mrs Hayward, Gwent	London Marathon
Susan Rees, Swansea	" "
Dr and Mrs Dagnall, Bolton	Plant Sale & Coffee Morning
Mrs Turner, Lowestoft	London Marathon
The Gooch Family, Tunbridge Wells	Stall at Heathfield Show
G Bryant, Reading	Great North Run
Mrs Finch, Bridgwater	Staff "Weigh-in"
Quantock Players, Somerset	Raffle
John Taylor, Fiddington	Sponsored Beard Shave
N W Area Family Day	Raffle
Pauline McLachlan, Penicuik, Scotland	Karaoke Night, Raffles and Sponsored Male Aerobics
	Raffle
Garden House Kindergarten	Well Dressing
Wirksworth County Junior School	Clothes Sale
Wilf and Fer Pidden	Tombola Stall
F Mummery and Miss C Howley	Sponsored Slim
South Road Canteen	Fundraised
Marilyn and Howard Turner	

Mrs K Hoather
 K Puddy
 Penygoddfer Primary School
 Pauline Mahon and Jo Wood
 N and C Rock
 C and J Norsworthy
 H and K Whaddicor
 D and R Todd
 H Ringland, P Wake, T Sraifton
 Andrea Brooks
 J and K Lawrie
 Marie Millar
 Friends of Copthorne School
 Mr and Mrs Grant
 Benton Park Primary School
 Mary Gardiner's Brother
 R Binnie, Scotland
 W & W McLachlan, Scotland

Collecting Boxes
 Football Match
 Harvest Festival Collection
 Dinner Party
 Fundraised
 Collecting Box
 Half Marathon
 Collecting Box
 Great North Run
 Soup and Roll Morning
 Webb Ivory Sale
 Diet Correction Class
 Various F/R Events
 Collecting Bottle
 Fundraised
 Collecting Box
 Jumble Sale
 Raffle



Over one hundred and ten people attended a barbecue organised by **Bill and Sylvia Blackburn** at Nantwich. The children had a whale of a time with donkey rides, bouncy castle, and lots of other games. Many thanks to Gilfords dairy for the use of their garden.

AREA SUPPORT FAMILIES

Neil and Jane Reid Tel: 0223 834570
 19, Hillside, Sawston, Cambs, CB2 4BL

Alan and Deirdre Beavan Tel: 0858 62182
 'Tumbleweed', West Gate Lane, Lubenham,
 Market Harborough, Leics. LE16 9TS

Alan and Audrey Noble Tel: 0664 77494
 1 South View, Burrough on the Hill,
 Melton Mowbray, Leics.

Mary Gardiner Tel: 0772 815516
 15 Sidney Ave, Hesketh Bank,
 Near Preston, Lancs.

John and Barbara Arrowsmith Tel: 091 2812062
 140 Newtown Rd, High Heaton,
 Newcastle on Tyne NE7 7NH

Sean and Pauline Mahon Tel: 0742 304069
 41 Stumperlowe Crescent Rd.
 Sheffield 10, South Yorkshire.

Alfred and Judy King Tel: 0424 216432
 4 New Park Avenue, Bexxhill on Sea
 East Sussex, TN40 1QR

Bill and Sylvia Blackburn Tel: 0270 626809
 11 Beatty Road, Nantwich,
 Cheshire.

Ron and Linda Snack Tel: 0908 666819
 16 Wandsworth Place, Bradwell Common,
 Milton Keynes, Bucks.

Tony and Mary Lockyer Tel: 0443 217787
 Blaen-y-Wavn, Salem Lane,
 Church Village, Pontypridd,
 Mid Glamorgan, CF38 1PT

Tony and Shirley Eyre, Tel: 0934 834537
 6 Westway Park, Yatton,
 Near Bristol, Avon.

Contact for Scottish Families:-

Alan and Fiona Byrne Tel: 041 643 0034
 3 Jedburgh Ave, Rutherglen,
 Glasgow, G73 3EN

Northern Ireland:-

Margaret Kearney Tel: 026 57 62073
 12 Coleraine Rd,
 Ballycastle, Co. Antrim