

**NEWSLETTER**

**m<sup>u</sup>p<sup>s</sup>**

**AUTUMN 1984**

**THE SOCIETY FOR  
MUCOPOLYSACCHARIDE  
DISEASES**



**National Registered  
Charity No: 287034**

<b>CHAIRMAN OF TRUSTEES</b>	Mr. G.C. Nichols C.B.E., D.F.C.
<b>TRUSTEES</b>	Mr. G. Grant Mr. R. Heath M.A. Mr. R.J.O. Lavery
<b>HONORARY SECRETARY</b>	Christine Lavery 30 Westwood Drive Little Chalfont Buckinghamshire Tel: Little Chalfont 2789
<b>HONORARY TREASURER</b>	Diana Fudge F.C.A. 22 Kingsley Park Whitchurch Hants RG28 7HA
<b>MEMBERS OF THE MANAGEMENT COMMITTEE</b>	Robin Lavery (Chairman) Peter Archard Susan Butler Catherine Grant S.R.N.,R.S.C.N.,H.V.Cert.
<b>HONORARY FUND RAISING OFFICER</b>	Lorraine Stenson 27 Raymond Plain Welwyn Garden City Herts
<b>NEWSLETTER EDITOR</b>	Marlene Sanderson Ashley Cottage 6 Northfield Road Tetbury Gloucestershire GL8 8HB
<b>MEDICAL ADVISORS</b>	Dr. D. Garrow B.M., F.R.C.P. Dr. B.L. Neal M.B.B.S.,M.R.C.P.G.,D.Obst.,R.C.O.G.
<b>ACCOUNT</b>	MPS, Barclays Bank Ltd Chalfont Station Road Little Chalfont, Amersham, Bucks

#### AREA SUPPORT FAMILIES

##### *Northern England*

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

##### *East Central England*

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

##### *South East England*

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

##### *South West England*

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

##### *Wales*

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

#### WHAT ARE THE AIMS OF THE SOCIETY?

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

#### NOT! the Secretary's Report

Usually this column is written by the Secretary or is sometimes given over to another VIP (very industrious person). NOT this time folks. You've got me; Christine, Peter and Maggie, Bryn and Donald etc., are all lying exhausted in a heap in the corner getting over the Harrogate Conference. They haven't the strength to lift a finger to prevent me from saying silly things and doing just as I please with this blank page of paper.

First of all for those who could not make it to the Conference this paragraph is not compulsory reading (being a sensitive person myself I'm not keen to stir up envy). Tributes must go to Helen Coppock, Ros Smith, Gwen Griffiths, Dr. Tony Pollard (Australia) and the Family Kraft and Dr. Suzanne Kircher (Austria). Fancy coming all that way for such a brief occasion and how brave they were to mix in with us funny British. And mix in they did; our weekend would not have been the same without them. Eric Kraft, a brave or foolhardy man asked Honorary Secretary for a dance and with the natural talent for the waltz, whisked her off her feet (some of the time). "Eric, we're returning your toes with our next batch of hair samples for Dr. Lubec" We were glad too that many of the 'Professionals' were able to stay over the weekend. We know they too enjoyed themselves. Dr. Martin Bax and Irene Sclaire started their MPS Research Project and contact with families with a bang (once more on the dance floor). Mind you it wasn't all pleasure for the Professionals. Dr. Diana Chase, Suzanne Kircher and Elizabeth Spellacy performed a delicate emergency operation in a hotel bedroom over Sunday lunchtime; packing up clothes and belongings for two of the Christmas Card and Raffle salespersons, (how else can Dennis explain he's missing a sock and a pair of briefs). Others were more fortunate. Dan the Van spent the weekend picking up strangers in a borrowed Range Rover (I'm sure you can get arrested for less) and that recluse of the Computer Room Colin "Bones" Gardiner got a star part in the Creche.

Just off the A1(M) at Letchworth, Herts., is an eating establishment, "The Happy Archard". We go there many times, including on the way up to Harrogate and on the return journey. I don't think Peter will mind me saying this but he and Maggie should have taken more of the lime-light. They certainly deserved it. Most of the hard work and thought that went into the organisation of this years weekend was theirs.

Kate Farminer has once again captured the spirit, as well as the invaluable detail of the weekend. I have seen her excellent draft report and I know when published it will be a valuable record and helpful to those of you who missed the conference.

I won't labour much further on the topic but will just say how much we appreciate the hard work and thought put in by our Professional speakers: their talks were by no means standard lectures taken off

and dusted from the shelf. And as for Bryn's inspirational working group I need say no more.

As I write Marlene Sanderson is busy editing the remainder of the Newsletter and I believe all the important notices which will bring you up to date are included elsewhere. Looking further ahead a number of ideas have been generated on family meetings/open houses. Yet another weekend, even a Butlins Holiday. Several people have kindly written to us, following Harrogate, with ideas and offers of support. These all require digestion, but I hope we may have more to say in the next newsletter. In the meantime besides the record of the conference, we are trying to put the first official Annual Report to bed, which amongst other things will tell you where our funds come and go to. Peter and Marlene Sanderson have an awful lot of hard work to put in on the editing and print side, on top of the work they put in for the conference too. But they are always good natured. Then it's their turn and mine to put the feet-up for awhile and wish you and your children a very Happy Christmas.

Robin Lavery  
Honorary Wingeing Pawn to the  
Australian Branch of the MPS Society.

P.S. Do you like that Helen & Ros?

### MPS CHRISTMAS CARDS & CHRISTMAS DRAW

As promised our very special Christmas Card was printed on time and by now most of you will have received some packets to sell on our behalf.

For those who were not at the Conference, I hope you will forgive us for sending some to you on spec. It is hoped that these 12,000 cards and 35,000 draw tickets will bring about the greatest amount of awareness of these diseases and at the same time help to raise funds.

We still have a small number of cards and Draw tickets left, if you can sell more please do ring or write and I will post them off to you by return of post.

Let's make it a bumper awareness campaign this Christmas.

Christine Lavery  
Secretary.



### THE AUSTRALIAN SOCIETY

The first physical meeting of the Australian Society took place in November 1983. Three family days have been held since and a further meeting is planned for November 1984.

A number of families had talked over the telephone and/or had formed friendships before the Society's first meeting. We, the NSW group of parents, are a closely bonded group. Physical contact has not been possible as yet between our families from interstate.

Letters, meeting reports and recently, a news-sheet are the basis of our contact with interstate families. We are endeavouring to have our Information Sheets forwarded to all diagnosed families in Australia, including those whose MPS child may have died.

The Society has applied for registration as a charity. Accordingly, we have had to devise a Constitution, following a prescribed set of recommendations.

An Executive committee consisting of president, secretary, treasurer plus a minimum of two others was decided at a general meeting attended by thirty or so people connected with MPS. This committee meet regularly to plan meetings, discuss correspondence or to guide the advances of the Society.

It was decided at a general meeting that we would have family day/discussion group meetings four or five times per year when all families of MPS children are invited as well as doctors, teachers and so one who are interested in the Society and MPS children.

As of October 1984 our membership of parents stands at 25.

We have one primary aim: TO PROVIDE SUPPORT FOR FAMILIES OF MPS CHILDREN.

Helen Coppock  
Secretary  
24.10.84

## 1984 PARENT CONFERENCE from an Australian point of view

When I first received Christine Lavery's invitation to attend the 1984 Parent Conference for the U.K. Society for MPS Diseases, I thought, "Terrific! Imagine the benefits to be gained by an Australian representative attending the Conference." Following a Committee meeting shortly after, it was decided to try to raise sufficient funds for our president, Mrs. Ros Smith and myself to attend.

Numerous letters were sent to companies, organisations and so on explaining our situation and asking for help. Well, as most of you know, we achieved our objective as we were in attendance at Harrogate.

I don't think that I will be able to express my feelings when meeting and being welcomed by members of the U.K. Society. The warmth friendship extended to us made us feel as though we were part of the world-wide family of MPS - not an isolated group of people in Australia, far from the rest of the world.

The Conference programme had prepared us for an extremely interesting and varied number of speakers. We were not to be disappointed; each speaker enabled us to gather certain facts and information that would be of benefit to those connected with MPS in Australia.

The most noteworthy aspect of the weekend would have to have been the repore established between parents, who in many cases had not had contact since the previous year. The parents workshops showed the value to be gained through discussion on topics such as education, how to obtain certain aids, the death of a child and how one copes, and various treatments for MPS children.

The need for the Conference was shown many times. Necessity to encourage the repore between families (parents and children) and to become aware of and understand the needs of the families is vital. Similarly, educating the medical profession and community of those needs will lead to a better understanding of MPS diseases and the research currently taking place.

Many ideas were noted that will help us to organise a Conference in Australia along similar lines. The help needed by volunteers was one factor that was particularly noteworthy.

Without the accommodation and hospitality provided by members of the Society in England, it would not have been possible to attend the Conference and so gain the knowledge that can help us so much here in Australia.

Our sincere thanks and warmest wishes go to all in the U.K. and an invitation is extended to contact us if anyone is planning to visit Australia or would like to write to an Australian family.

Helen Coppock  
Secretary.

### LORRAINE STENSON

Lorraine joins the Management Committee as Fund Raising Coordinator. She will be ably supported by Paul. So far as I am concerned, Jamie is on the team too. I missed his Memorial Service so he remains a great pal of mine.

Paul, Lorraine and son Jamie have been a terrific influence on Awareness and Fund Raising in Hertfordshire and Welwyn Garden City particularly and are deeply committed to our Society. They are full of novel and ingenious ideas.

Please give Lorraine your full support. Give her your bright and tried fund raising ideas and take advantage of her own suggestions and methods.

Robin Lavery

## 1984 CONFERENCE REPORT

Congratulations to all the conference organisers! The Committee have certainly worked hard to get as much information as possible to as many people as possible. Notes taken at the conference will be printed and circulated so that all the members can benefit from the weekend's talks and discussions - it's a shame we can't send out samples of the terrific meals too!

Although the conference document will list aids and allowances to which you are entitled, I'm sure that you, as parents of children with MPS disorders, could provide a wealth of information about aids you have found especially useful, places or people that have proved particularly helpful, and medical treatment that you would recommend.

I would like to invite parents to write to me with details of any resources that have helped their family to tackle problems successfully and therefore helped make the children's lives more enjoyable. I hope to get a co-ordinated picture of what is available and useful, and eventually to send all the members an information sheet.

Please write! Sharing your experiences could solve someone else's problems. I'm going to start the list with the following hints for you to add to.

1. Dycem non-slip rubber mats (from Social Services) not only keep cups on tables but also bottoms on seats (especially wooden school chairs!) Great for children that like to slide off under the table.
2. The school's Dental Officer in our area has been able to put the families in touch with a children's dentist sympathetic to special children's needs and problems (for example: that they won't open their mouths!)
3. Picture-stickers on the inside of car windows provide an unbreakable un-droppable source of amusement for bored children on car journeys.
4. It is not suitable for a child with a mucopolysaccharide disease to become an organ donor. However parents, whether they are MPS carriers, or not, may become organ donors.

I would especially like to hear of experience of surgery e.g. joints, adenoids; and of your opinions on wheelchairs and buggies available. Don't forget to tell me a little about your child too.

Thankyou once again for inviting me to take part in the conference.

Yours

Kate Farminer  
31 Love Lane  
Rayleigh  
Essex

On behalf of the committee I would like to thank Kate for kindly giving up her weekend yet again, further more enduring permanent writer's cramp in order to capture and make notes on all aspects of our Family Weekend Conference.

Kate who has a degree in Human Biology and Child Development has a lot of experience teaching in Special Schools including MPS children, so do please share any thoughts or experiences you have had so that under Kate's expert guidance we can put together a Conference Report crammed with useful information to help make our MPS children's lives more enjoyable.

We would hope to publish this information in January 1985 so please let Kate have your ideas as soon as possible but no later than Mid-December.

Christine

## MPS FAMILY RESEARCH PROJECT

The third aim of our Society is "to raise funds in order to further research into MPS". There were many options open to us. Last year we helped Dr. Irwin Olsen at the Kennedy Institute of Rheumatology, and he told at our first Parent Conference in Birmingham in 1983 of his study of the way in which certain enzymes can be passed from lymphocytes to fibroblasts. Fundamental research at cellular or molecular level is essential if replacement therapy is to be given rationally. One day, genetic engineering with its seemingly magical possibilities may become a practical proposition - correcting mistakes in the genetic code of patients' own cells could supply missing enzymes without the problems of rejection leading to graft versus host disease. This is for the future. Right now, bone marrow transplant is a way of supplying missing enzymes and leading to clinical improvement in children, and manion implantation, though disappointing so far, is an alternative method.

As I pointed out, we might have chosen to support one or other of these or alternatively helped to develop diagnosis, or screening programmes.

However, it seemed to us, that though accurate and early diagnosis is desirable and that replacement of apparently missing enzymes would seem to offer a hope of benefit, it is the patient's clinical response that is the crucial issue. Is improvement after treatment greater than could be expected by chance? A child with a progressive disorder continues to learn new skills. Biochemical tests can demonstrate that the amounts of certain metabolites in the urine have returned to a normal pattern, but are the bone lesions really improved, and is intellectual function altered? Cells deprived during a critical phase of development inspite of being rendered apparently biochemically normal might never learn their proper skills.

The relative rarity of the MPS diseases is responsible for gaps in our knowledge of their natural history. It seemed possible that the proposed survey would, with our active co-operation, because there are enough of us, fill some of these gaps. The dramatic possibilities of treatment could then be judged against the background of illness which is far more variable than generally supposed.

We believe that many families are willing to work closely with Dr. Martin Bax and Miss Irene Sclare on our Research Project, not only to provide during the next few years an ongoing assessment of skills, problems and disabilities but will be able to pinpoint those areas where more help is most urgently needed.

Donald Garrow  
Medical Advisor  
8 November 1984

The MPS Family Project will commence November 1984 and we ask that if any family DOES NOT WISH to be included in this very important project to let me know in writing NO LATER THAN 10th December 1984.

Christine Lavery.

## MPS T SHIRTS

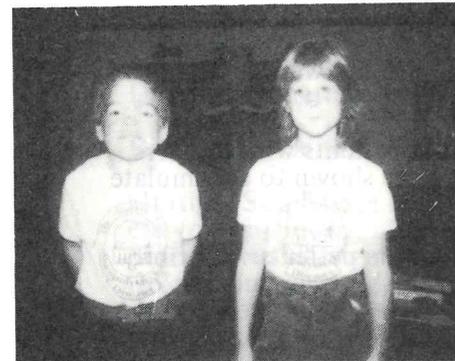
Why don't you buy T Shirts for Christmas presents.

Childrens sizes 22" - 32" @ £2.95 each  
Adults Medium & Large @ £3.95 each  
Plus 30p for Postage

The T Shirts may be obtained from:

Sue Butler  
Spriggs Holly House  
Spriggs Holly Lane  
Chinnor Hill  
Oxon

Or if you have any queries please ring Radnage 3185.



Alexander & Lucinda Butler  
modelling size 28" T Shirts.

Dr. Diana Chase of Guy's Hospital has very kindly compiled the following History of MPS, which we are sure will be of great interest to all our families.

## HISTORY OF KNOWLEDGE OF MPS

### Approximate Dates

- 1917 Hunters syndrome first described.
- 1919 Hurlers syndrome first described.
- 1952 Hunters and Hurlers syndromes first recognised as being due to a build-up of mucopolysaccharides. Previous to this, they had been thought to be due to a build-up of lipid (fat). The term mucopolysaccharidosis first used.
- 1957 Urine from a patient with Hurlers syndrome shown to have higher than normal levels of the mucopolysaccharides dermatan sulphate and heparan sulphate.
- 1961-1963 Sanfilippo syndrome recognised as being a separate disease. Previously it had been considered to be a form of Hurlers syndrome.
- 1962 Scheie syndrome first described.  
Morquio syndrome first described.
- 1963 Maroteaux-Lamy syndrome first described.
- 1964 Hunters, Hurlers and Sanfilippo syndromes were thought to be caused by enzyme defects.
- 1966 Cultured skin cells (fibroblasts) from patients with Hunters, Hurlers and Sanfilippo syndromes were shown to accumulate mucopolysaccharides (GAGs).
- 1968 Co-culturing of fibroblasts from Hunters patients with fibroblasts from Hurlers patients corrected this accumulation of GAGs, i.e. the enzyme defect in Hunter patients could be overcome by an enzyme present in Hurler patients and vice versa.
- 1969 Direct enzyme (Arylsulphatase 8) test for Maroteaux-Lamy available.
- 1970 Hurler and Scheie syndrome thought to be allelic i.e. different mutations of the same gene.
- 1971 Sanfilippo syndrome first sub-classified into two types, type A and type B.
- 1971 Exact enzyme defect in Hurlers syndrome recognised as  $\alpha$ -L-iduronidase.  
Enzyme defect in Hunters syndrome thought to be some sort of sulphatase.
- 1972 Direct enzyme test for Hurlers syndrome available.  
Enzyme defect in Scheie found to be the same as that in Hurlers syndrome.  
Enzyme defect in Sanfilippo B shown to be N acetyl glucosaminidase.
- 1973 Enzyme defect in Sanfilippo A shown to be N-heparan sulphatase.  
Sly syndrome recognised and enzyme defect shown to be  $\beta$ -glucuronidase.  
Tay Sachs syndrome recognised and enzyme defect shown to be  $\beta$ -N acetyl hexosaminidase A.  
Sandhoffs syndrome recognised and enzyme defects shown to be  $\beta$ -N acetyl hexosaminidase A and B.  
Exact enzyme defect in Hunters syndrome shown to be  $\alpha$ -L-iduronosulphate sulphatase.  
First report of Hunter syndrome affecting a girl.  
Direct enzyme test for Sanfilippo B available.
- 1974 Direct enzyme test for Sanfilippo A available.  
Direct enzyme test for Hunters syndrome available.  
Multiple Sulphatase Deficiency shown to be defective for many enzymes including idurono-sulphate sulphatase (this enzyme is defective in Hunters syndrome), Arylsulphate A (this is defective in Metachromatic Leukodystrophy) Arylsulphatase B (this is defective in Maroteaux-Lamy), Arylsulphatase C, and Cholesterol sulphatase.
- 1976-1977 Morquio syndrome sub-classified into two types - type A and type B. Exact enzyme defect in Morquio B found to be  $\beta$  galactosidase, for which a direct enzyme test was available.

1978 Exact enzyme defect is Morquio A found to be N acetyl galactosamine 6-sulphate sulphatase.

Sanfilippo type C first described. Exact enzyme defect being acetyl CoA :  $\alpha$ glucosaminide N acetyl transferase.

1980 Sanfilippo type D first described. Exact enzyme defect being N acetyl glucosamine 6-sulphate sulphatase.

Dr. Diana Chase,  
Paediatric Research Unit,  
Guy's Hospital.

### THANK YOU SUSAN

Susan Heath resigned from the Management Committee in September. She gave her reason as pressing domestic commitments notably the increasing demands of her young family. Unselfishly after two years with the Society, she is really stepping aside because she feels that fresh blood is required from time to time to generate new ideas on fund raising. Besides she could no longer stand my amazing good looks.

Susan and Robert had no associations whatever with MPS when circumstances sucked them into our activities. I knew there would be trouble when she called at our house in the Summer of 1982 when the Society was just a gleam in the eye. She said she would give a year's voluntary help as Fund Raising Officer. I believe all her successful schemes have been legal, they've certainly been a major contribution to keeping us on a sound financial footing. Apart from mischief in her smile Susan is best noted for the 'Coffee Snowball'. You might have had 10kg of deadweight Snowball paper and Elastic Bands slumped on your doorstep this year. As the architect of this scheme she was responsible for cluttering my garage, living room, bedroom, attic, kitchen and car, with tons of the wretched stuff for two years. Nonetheless so far, that idea of Sue's has generated £10,000. But fund raising apart Susan has been supportive in many different ways and at so many events. We are indebted to her for firstly getting involved, then making such an impact, helping to shape and being a founder member of the Society.

As Robert, a great and valued support too, remains one of our Trustees, Susan is not going to escape that lightly.

Robin Lavery.

### SUNFLOWERS? SOMEFLOWERS!

Robert Culley and Matthew Blackburn who ran away with the Sponsored Sunflower Competition in 1983, faced stiff opposition in 1984 and several entries broke last year's record height of 215cm. Gethin Robins isn't one of those "never mind the quality, feel the width types", although his pet flower was comparatively dwarf size at 141cms., at £70 it earned most money per centimetre. Christopher and Lorraine Rock fell short of last year's record by 1cm (there's honesty for you). The record breakers were:

Darren and Debra Horsley - 250cms.  
Katie and Victoria Headland - 255cms.  
Fiona Soutar - 269cms.  
Robert Culley - 270cms.  
Katie and Thomas Farwell - 280cms.  
Angeline Hayward's Mum & Dad and ..... - 311cms.  
Matthew Blackburn - 335cms.

So Robert did well again but Matthew sets the record. It was brave of Angeline's Mum & Dad and I am sure, not surprisingly, that given all the love around, their flower got more support than anyone else's this year.

Unofficially the recorded highest Sunflower grown was Katie and Victoria Headland's which reached 360cms. However that was by October, well outside the competition deadline. But as for you Matthew Blackburn, you know the height to set for yourself in 1985. However I should warn you and your dad to watch out for Sunflower nappers next year.

To date the sunflower competition has brought in over £660. If like last year there are last minute remittances, I'll let you know in the next Newsletter.

Robin Lavery.



*Matthew Blackburn with Dad  
proudly showing off their  
Sunflower.*

## A GRANDMOTHER'S SPECIAL THOUGHTS

I wonder what other grandmothers feel about their grandchildren, the ones who are afflicted with any one of the MPS diseases. I suspect we all have similar experiences. May I share mine with you?

I remember the first time I began to feel that sickening nameless fear. It was only a few days after Lorraine was born: I had been so jubilant that after always longing for a little girl to love, I was now the proud possessor of a granddaughter! I hotfooted it down to Bletchley where she was born but as I gazed upon that sweet little face, an unbidden thought entered my mind; "this child will have to be patient". I brushed away such fanciful thoughts and pondered only on the joys to come.

My second visit found her mother Helen, in a state of depression, the cause of which she couldn't seem to communicate. A nurse provided the answer - something was not quite right with the baby; no-one knew exactly what but her foot was swollen. The doctor had said that in his experience, babies with this usually turned out to be very small. Amazingly prophetic or did he know even then? However, the usual tests were carried out and everything seemed to be in order; we breathed again.

For twelve months Lorraine thrived and became a beautiful child seemingly perfect in every way. Then on one of my visits I was being an admiring audience for that delightful activity called "bathtime" when I noticed the curve of her back. As grandmothers are wont to do I commented upon it. Yes, her parents had also noticed but hadn't dared to admit something may be wrong.

So began the investigations and the awful realisation that Lorraine had some very rare bone disease, no-one seemed to know what kind. There followed weeks and months of attending a physiotherapy clinic where this small being so close to our hearts, was forced to endure all kinds of exercises designed to strengthen her back. As she cried and screamed in protest, her mother and I had to sit outside the room and listen helplessly. Later we were allowed to be with her but I can still recall the heartbreak of those days but we lived in hope that it was all for her good. She was eventually fitted with a corset and calipers but all to no avail.

After two years the question of whether to have another child arose. Would this one be affected? The answers were more or less all the same; the risk would be minimal; the disease whatever it was was too rare to occur again. So eventually little Christopher arrived. Once again we knew the joy a new baby brings but despite reassurances that here was a perfect child, twelve months later the familiar curve in the back was seen. Once again I tried to comfort Helen whilst I felt that same heart-break myself. To have two the same was too cruel. Then we came to know the truth; both Lorraine and Christopher were suffering from Morquio-Brailsford syndrome.

Then began the endless trips to hospitals, the operations on the legs, the ear infections, the corsets and calipers. The feelings of guilt (could it be I who had passed on the gene?) the hope that perhaps a bone marrow transplant could be performed, what future had the children got? These and many other thoughts often occupy ones mind. I believe in God but my faith is sorely tried as I ask the question "Why?". But I continue to pray, as do others, that strength will be given to Helen and Peter to cope with the future and that whatever the children have to face, it will be within their capabilities. I must say that so far this has been so.

In the meantime, despite everything, I still find joy and happiness in my grandchildren and my love for them increases. They are happy children and take a lively interest in life. The words that mean most to me are "Hello Grandma" as I am sure they do to every grandmother of an MPS child. Let us hope that the MPS Society will continue in strength so that future children will not have to suffer as our children do.

Grandmother of Lorraine and Christopher Rock.

## A STICKY PROBLEM

It all began in July 1983, when the first letter was sent to Sandoz Products Ltd., seeking financial assistance in producing Windscreen Stickers carrying a slogan for the Society. Subject to costings they agreed to help and a search was made for printers. Having reached this stage you (the members) were asked to come up with some bright ideas which would put over to the public in a few words, what our Society is all about. There were some excellent suggestions and the Committee chose 5. The final 3 for production being chosen through ballot by yourselves. The result was:

CARE TODAY – HOPE TOMORROW 16.6%

MPS FOR SHORT – LIKE OUR CHILDREN'S LIVES 50%

LIKE YOUR CAR THIS DISEASE ACCELERATES – HELP  
US TO SLOW IT DOWN 30%

ALL THE TIME IN THE WORLD – THESE CHILDREN  
HAVEN'T GOT. THEY NEED YOUR HELP NOW 0%

A £ TO RESEARCH MIGHT MAKE AN MPS CHILD FEEL  
TONS BETTER 0%

Hence the first 3 mentioned are the end result.

We were now into March 1984 and disaster, (at least as far as the stickers were concerned). Michael changed jobs - the housing market went berserk and we were both burning the midnight oil running two Estate Agencies. With a very polite 'prod' from Christine in September, we realised these stickers should be available at the conference at the end of the month. Sandoz were contacted once more to confirm they were still willing to sponsor the cost of producing the stickers. Due to the time gap from our initial contact, their budget had been used up, however all was not lost and by gathering money from various promotional funds they agreed to still assist and on September 17th sent a cheque for £300 for which we are extremely grateful.

Meanwhile the printers were ready to go apart from the fact that they could not cope with the artwork at such short notice. A neighbour of Peter and Wilma Robbins who had already given valuable assistance as a graphic designer to the project was the answer but contact with Wilma established that he was away - on honeymoon! A frantic call

to a friend of ours, David Evans, who happens to also be a Graphic Designer, produced the necessary design in 24hrs. Six days to go and it looked as though we would make it.

The morning before the conference David rang to say the stickers were ready for collection – in Wiltshire! How could we get them up to Harrogate for Saturday? Thinking caps on again – well the Sanderson family live in Tetbury, so a call to them revealed William & Fer Pidden from Westbury which is where the Director of the printers also lives and he very kindly delivered the Stickers to the Pidden's who very kindly transported them to Harrogate. Our round Britain saga had safely come to an end and we could at last close the file on 'Car Stickers'.

If you would like to purchase any of the 3 mentioned, please send to Christine Lavery stating which slogan you would like, price 20p each.

Why Sandoz Products you may ask? Simply because they produce Cyclosporin 'A', a relatively new drug which is used to help stop rejection in Bone Marrow and other transplants. Helen seemed to take gallons of the stuff which resembles car oil! Hence their connection with Mucopolysaccharidosis. Our most sincere thanks to Sandoz, there are going to be some long glances at rear windows of cars in future. Hopefully they will be stationary at the time.

Pat Skidmore

## HELEN O'TOOLE

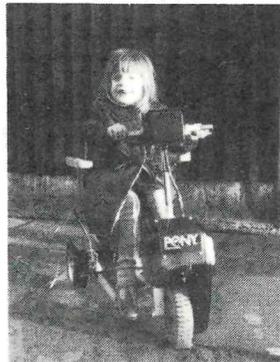
Charlie and I have four children: Kate 9 and Helen 7 who were born to us and Deirdrie and Simon both 20 who joined us as Foster children when they were 16. Helen was found to have Morquio's syndrome when she was 18 months old and until the society was formed I searched in vain for contact with another family. Helen used to ask if she was the only person in the world with Morquio's syndrome. I find it most comforting and supportive to read other people's accounts which sometimes make our problems pale into insignificance.

Helen has a good many physical difficulties to contend with. She has a kink in her spine and wears a brace day and night. She is very knock-kneed and an operation to try and correct this was not a success. Her hearing is affected and after two lots of grommets she now wears a hearing aid (or should do when she hasn't hidden it away). Our current problem is a worry about the weak link in her cervical spine. She has had two falls which have jarred her neck and made her temporarily lose the use of her legs. An operation should be possible when she is older but meanwhile she must wear a collar and we must contain our anxiety.

Helen goes to the same school as Kate where 10 hours extra welfare assistant time means that she can be indoors at lunch-time when it is cold. Last year we bought a marvellous battery operated scooter from Ortho-Kinetics which has changed her life. Instead of being pushed in a buggy she can travel along beside her friends who compete for rides on the arm. She leads a busy life outside school as well, going to art club, Brownies and learning recorder. Most of the time she is a thoroughly happy child but I have discovered that her one wish (in wishing wells, blowing our candles etc) is that "her Morquio's syndrome will go away".

I am afraid that advances in treatment will not be in time for Helen but I pray that one day other children's wishes will come true.

Mary O'Toole



*Helen O'Toole, aged 7 years.*

## JOURNEY OF A LIFETIME

We are Colin and Cathy Hall. We have a daughter Amy aged 7 and Matthew aged 5 who has Hunters Disease.

In March this year our world fell apart, when, after a 2 year battle with many Doctors, they finally came upon a diagnosis of which we had never heard. This was Hunters Disease.

One of our first thoughts was to take Matthew to Lourdes. This we did and what a trip it was. Colin couldn't get away because of business commitments and so my sister came with us for moral support.

As soon as the boat left Newhaven, there was a strange but wonderful atmosphere on board. Half of the cafeteria had been turned into a hospital and what a cheerful place it was.

The train was comfortable but very hot but by this time we had made many friends and Matthew and Amy were always being taken off somewhere.

The week that followed was something to be treasured forever.

A visit to the mountains - Throwing the Bishop in the river fully clothed - Picnics everyday. Whatever the handicap no-one was left out. Where we went, so did the Wheelchairs, pushchairs and stretchers. We attended Mass everyday - once in a barn - once in a field - once near a mountain.

Why was the Pilgrimage so special? Because everyone was happy.

This trip has given me an inner strength to look after Matthew and cope with situations as they arise.

Matthew made me realise what a happy child can do for others. He was the only child who would not wear his name badge, but by the end of the week everyone knew and loved the "cuddly Blond boy" and his sister from Shoreham.

If any readers have ever thought about going to Lourdes but are apprehensive "Go ahead" There's a little miracle there for all of us.

Cathy Hall

## IDEAS FOR FUND RAISING

Yet again the Lavery's, Archard's and their team have pulled off another successful conference. This was the second one I have attended and I really enjoyed the chance to meet old friends from last year and make new friends this year. To keep this sort of activity going we all must do our share of fund raising, after all it is our Society, not just the Committees and active fund raising families. I know that it is very difficult for families with affected children to spare time for fund raising, but if every family could make an effort, I am sure that the Society could fulfill all its hopes and dreams.

Here is one simple idea:

Maggie Archard and her very good friends held Tupperware Parties this year. The gift you receive for holding the Party was raffled and because the Party was for the Society the Tupperware Dealer donated a few gifts of her own. The Dealer gave 10% commission on goods sold and extra money for every party booked to the Society instead of the hostess choosing a gift. So if you could hold a Party of some sort and donate the commission to the Society, you may only raise a couple of Pounds but it all helps, or even put a collection box in your local Pub or Club.

I have had a variety of Parties myself from Tupperware, Linen Warehouse, Make-up and even an Ann Summer's ( which much to Robin Lavery's disgust, I wouldn't let him attend)

As you all know I only joined the Committee as Fund Raising Officer in September and hope I can do as good a job as Susan Heath has done over the last two years. If you have any ideas please write to me and I will try to put them into action.

So let us all pull our weight and fund raise so that maybe we can all meet again next year, Hoping to hear from you all soon.

Lorraine Stenson  
27 Raymonds Plain  
Welwyn Garden City  
Herts. AL7 4TE.

## SANFILIPPO FAMILIES

Seven years ago when our elder son Richard was diagnosed as having Sanfilippo, I felt the need to be in touch with other parents. I managed to contact three other families and our magazine started. Gradually our numbers grew and eventually had to split into two groups North and South and of course because of the MPS Society making us known we are getting more new families. So the time has come again for us to divide into smaller groups, six being an ideal number.

Any new families wishing to join should get in touch with me please as soon as possible, giving age details of children. Also each group must have an editor (doesn't that sound grand) so please state if you are willing. This just means organising the folder, chasing it up when it gets lost and is the contact for new families. Quite simple!!

Please don't be put off at having to write a letter. Ours are usually hurriedly scrawled and the spelling leaves much to be desired, but what does it matter.

Old members can carry on as usual with the folder, it will be sometime before I have reorganised everyone.

Write or 'phone:

Linda Matthews  
The Gables  
Standon  
Stafford  
ST21 6QZ  
Tel: Standon Rock 487

## DONATIONS

The Society's grateful thanks go to the following children and adults who raised money growing Sunflowers. Apparently the children in the North grow much taller ones than in the South.

P. Robins	Fiona Soutar
Matthew Blackburn	Ann Reynolds
PMC & HR Rock	Deborah Horsley
Robert Culley	Susan Patan
Pauline Headland	

Also Carol & Paul Hubbard who had a vast number of Sponsors.

I apologise if I have missed anyone, the letters are probably still somewhere between Little Chalfont, Basingstoke and Redneye. Many thanks to all who took part in the Competition.

We also thank the following who have taken part in various sponsored events.

Peter Lintott who ran in a charity marathon  
Brenda from Hazlemere whose boys had a Sponsored Swim  
Marlene who finds time for Coffee Mornings in between editing the Newsletter.

The following people have made donations for which we are also very grateful.

J & R TRistram  
Mr. & Mrs. Carr  
Linda & Howard Matthews  
Mrs. Bagshaw  
Audrey Hodges  
P. Gardiner  
E. Watyard  
Mrs. E. Sanderson  
Gethin Robins  
Mrs. Robinson a friend of Pat Criddle's.  
Dr. Garrow who had a successful Garden Party  
Dr. Susanne Kircher, Mrs. E. Sanderson, Mr. & Mrs. Hoy  
John & Cynthia Hyde  
The Crown Hotel had two  
Charity Balls during our stay.

We also have received donations from Golden Wonder Crisps.

McMinns of Chesham  
Mr. R. Riding of United Way, Merseyside.  
3M United Kingdom PLC Charities Aid Foundation.  
Martin & Carolyn Wright Charities Aid Foundation.

A special thanks goes to a new member of our Society, Pat Isaacs who has generated a great deal of money and the following have contributed:

Mr. & Mrs. Robinson  
Mrs. M. Williamson  
Mrs. G. Warlow  
Mrs. C. Penfield  
Mrs. M. Dunning of Quantock Flower Club  
Mr. C. Middleton, President of Bridgewater Lions  
The Messenger Newspaper Group in Altringham.  
John & Brenda Pedlar  
Mr. & Mrs. W.J. Morrison  
Mr. & Mrs. D. Grimshaw  
Mrs. Sandra Clark  
Mr. & Mrs. T.W. Flanagan  
Mrs. Ivy Laughten  
Mrs. M. Bygin and staff of Eastover School  
Mr. J. Nicholson  
Mrs. Diana Hancock  
Mrs. Vera Price  
Mrs. Pat Isaacs

Another special mention and thankyou must be sent to Mike and Sara Corbett who have sold record amounts of Raffle Tickets and Christmas Cards and Stationery.

## 'BOOTS' FOR THE RAIN?

Some time ago I inquired at Boots the Chemist about Rain-capes for the wheelchair which I desperately need right now. The assistant in the AIDS department for the disabled told me that they didn't stock them but suggested I write to Boots at Nottingham which I did promptly.

I had a nice reply from them asking for the Make, Model No., or dimensions of Toni's wheelchair and this I did again. Another reply from Boots stated that the Manufacturers could make one and it would cost approx. £4 and could be delivered to Boots in Swindon in about two or three weeks, where I could collect it.

If any family wanted one of these Rain Capes may I suggest that they write to:

I.M. Smellie,  
Medical Merchandise Controller,  
Boots the Chemist,  
City Gate,  
Nottingham NG2 3AA.

I am sure if anybody wanted anything special for our children or their wheelchairs, they would consider making and producing more.

Sue Bramford

## NEW FAMILIES

Mr & Mrs' Brooks-Daw and their child Alevique aged 7 years, who is suffering from Hurler disease from Somerset.

Mr. & Mrs. Callison whose daughter Natasha aged 9 years is suffering from Hurler disease. They also had an older daughter Andrea who suffered from Hurler disease but has now died. They live in Hampshire.

Mick and Sarah Corbett from Buckinghamshire whose daughter Jemma aged 2 years is suffering from Hurler.

Mr. & Mrs. Hyde from Mid Glamorgan. Their son Gavin aged 3 years and daughter Sarah aged 5 years are both suffering from ML 111.

Debra Goulden from Cheshire whose son Lee aged 1 year is suffering from Hurler.

Mr. & Mrs. Lee whose child Brandy aged 1 year is suffering from Hurler disease. Shelia whose first child Rachelle also suffered from Hurler but died while she was very young. They come from Canada.

Mary and Tony Lockyer whose son Ross aged 4 years is suffering from Hunter disease. They come from Mid Glamorgan.

Mr. & Mrs. Smith whose baby Aara died aged 29 days from Sly disease. They come from Middlesex.

Carol and Mark Fisher from South Yorkshire, whose son Simon aged 8 months is suffering from Hurler disease.

## NEWS IN BRIEF

The Raffle and Whiskey Rollacoin raised £161.21 at the Conference Dinner and Dance. The evening proved to be most entertaining and was thoroughly enjoyed by everyone.

Our love and congratulations go to Jane and Neil Reid on the safe delivery of their twins, Jessica Clare and Joshua Oliver on the 24th October 1984.

'THE WOMAN' magazine are doing a Christmas article on the Lavery family which will be on sale from 22nd December. The Feature will be mainly about how Christine and Robin finally came to the decision following Simon's death that a Society for MPS diseases was desperately needed, and how it has subsequently grown from the original idea that it would benefit one or two isolated families.

With Christmas fast approaching, PLEASE remember to save all your used stamps and send them to CAROL HUBBARD at the following address:

71 Preston Road  
Harold Hill  
ROMFORD  
Essex

## DEATHS

We were most saddened to learn of the deaths of the following children:

Lisa Wilson aged 14yrs of Rickmansworth, Herts  
Susie Bertodo of Harpenden, Herts  
Robert Davis of Walsall, West Midlands, aged 11½yrs

All these children had been suffering from Sanfilippo Disease.

### **A VERY SPECIAL VERSE**

*A meeting was held quite far from earth  
"It's time again for another birth"  
The Angels said to the Lord above  
"This special child needs lots of love  
She may not run or laugh or play  
Her thoughts may seem quite far away.  
In many ways she won't adapt  
And she'll be known as handicapped.  
So lets be careful where she's sent  
We want her life to be content.  
Please Lord find parents who will do  
This very special job for you.  
They may not realise right away  
The leading role they have to play  
But with this child sent from above  
Comes stronger faith and richer love  
Soon they'll know the privilege given  
In caring for this child from heaven.  
Their priceless child so meek and mild  
Is heaven's very special child."*