

Newsletter

Summer 1994

The Society for Mucopolysaccharide Diseases



National Registered Charity No. 287034

Management Committee

Alf King (Chairman)	0424 216432
4 New Park Ave, Bexhill-on-Sea, East Sussex TN40 1QR	
Dr Bryn Neal (Vice Chairman)	0494 774421
"Hawthorn" Weedon Hill, Hyde Heath, Amersham, Bucks. HP6 5RW	
Mary O'Toole (Vice Chairman)	081 444 8461
8 Elmhurst Ave, London N2 OLT	
Pauline Mahon (Treasurer)	0742 304069
41 Stumperlowe Crescent Rd, Sheffield, S10 3PR	
Lynne Grandidge	0244 531163
41 The Boulevard, Broughton, Chester, CH4 OSN	
Kieran Houston (Chairman, Northern Ireland Committee)	0504 884168
15 Barrack St., Strabane, Co. Tyrone, BT 82 8HB	
Tony Eyre	0666 825215
7 Elmer Close, Malmesbury, Wilts. SN16 9UE	
Martin Sutcliffe	0629 824478
The Cedars, Summer Lane, Wirksworth, Derbyshire, DE4 4EB	
Alan Beavan	0858 463757
Tower House, Rushes Lane, Lubenham, Market Harborough, Leics. LE16 9TN	
Wilma Robins (Welfare Rights, Co-opted)	0708 443157
77 Hillview Ave, Hornchurch, Essex RM11 2DN	

MPS Office: 55 Hill Avenue, Amersham, Bucks. HP6 5BX

Christine Lavery (Director)	Tel 0494 434156
Sue Balmforth	Fax 0494 434252
Joan Evans	
Mary Gardiner (Northern Co-ordinator)	0772 815516
15 Sidney Avenue, Hesketh Bank, Near Preston, Lancs. PR4 6SU	
Charles O'Toole (Newsletter Editor)	081 444 8461
8 Elmhurst Ave, London N2 OLT	
David Briggs (Annual Draw Co-ordinator)	0777 700046
7 Humber Street, Retford, Notts. DN22 6LZ	
Sue Butler (Sales)	0494 483185
Spriggs Holly House, Spriggs Holly Lane, Chinnor Hill, Oxon OX9 4BY	



The Society for Mucopolysaccharide Diseases

55 Hill Avenue, Amersham, Buckinghamshire HP6 5BX
Telephone: 0494 434156 Fax: 0494 434252

The MPS Society is a voluntary support group, founded in 1982, which represents over 700 families in the UK with children or adults suffering from Mucopolysaccharide and related diseases. It is a registered charity, entirely supported by voluntary donations and fundraising by members, and 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 Great Britain 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 supports two specialist MPS clinics at the Royal Manchester Children's Hospital and at the Hospital for Sick Children, Great Ormond Street, London. The Society also funds three biochemists, one at Manchester Children's Hospital, one at the Christie Hospital, Manchester, and one at the Institute of Child Health, London. It encourages and assists contact and co-operation between parents and professionals and maintains links with sister societies in Europe and throughout the world.

There is at present no cure for MPS diseases, but much can be done to improve the treatment and care of sufferers. The slogan of the Society is:

"Care today, hope tomorrow"

Contents

Director's Report.....	3
Chairman's Message and Future Events.....	4
Milestones.....	5
Future Events '94.....	5
Childhood Wood.....	6
Grand Draw.....	7
Barbeque Sheffield.....	8
Area Family Training Weekend.....	9
Teenage Holiday May 94.....	10
Chris Isaac and Helen Skidmore (reports).....	12
Jennifer Johnson in Disneyworld.....	13
Daniel Anthony.....	14
Sarah Lowry Award.....	15
Hoather and Graf Families.....	16
Marathon Report.....	16
Corcoran Family.....	16
Tony Eyre (Profile) & Hullavington Charity Challenge.....	18
Wheelchairs.....	19
Progress in Research (John Hopwood).....	20
Austrian Conference and International Working Party.....	22
Derian House Children's Hospice.....	23
Cerebrospinal Fluid Shunts.....	24
Thanks to Ann Ridley.....	24
Towards gene therapy for Hurler disease.....	25
Attendance Allowance (Under Two's).....	26
Wheelchair Donated.....	26
Chris Bennet Marathon Walk.....	27

Deadline for Autumn Newsletter

15th of October 1994

Directors Report

After nearly eight years working for the Society we recently said good bye to Linda Golding. Linda came to work temporarily in 1986 and has been with us ever since!

At the moment Linda is enjoying a relaxing Summer at home. On behalf of all the families I would like to say thank you for all your help, support and hard work over the years, and wish you well in whatever you do in the future. Linda - You know where we are if you get fed up with the housework!

In the last few weeks we have had an escalation in Conference bookings especially amongst families who have only recently received an MPS diagnosis for their child or children. The conference at the Stakis County Court Hotel, Northampton, 23-25 September 1994 has more families than ever booked in. We still have a small number of rooms available so if you are wanting to come please contact the MPS office immediately.

How did you spend the May Bank holiday week? Nine of our teenagers with MPS were on holiday at the Exmoor Calvert Trust with Mary Gardiner and myself and ten volunteers from the Royal Logistics Corps at Hullavington, Wiltshire.

Each of the youngsters gained experience in a range of outdoor activities including sailing, canoeing, abseiling, orienteering and horse riding. We had outings to Ilfracombe, Lynton and Lynmouth including riding the rack railway and MacDonald's in Barnstable. The highlight of the week had to be dinner and karaoke evening at the local pub. Chris Isaac and Helen Skidmore have written reports on the holiday on page twelve and you can see some of the photographs on page ten and eleven. The Corps volunteers got on very well with the young people and did a wonderful job in helping them have an enjoyable and exciting time. Our warm thanks to them and to the staff of the Calvert Trust.

Thank you to all of you who are distributing our new fundraising leaflet and raising money for the Society. However much or little you raise or donate to the Society your efforts are very much appreciated.

With the Sun pouring in through the MPS office windows may we wish you an enjoyable summer holiday.

Christine Lavery
Director



Linda Golding, Christine Lavery, Sue Balmforth and Joan Evans in the MPS Office.

Chairman's Message

The annual general meeting of the Society for Mucopolysaccharide diseases will be held at Stakis County Court Hotel, Northampton, on Sunday 25th of September at 9.30am.

By order of the Committee

A.G. King (Chairman)

As usual, the Annual General Meeting of the Society will be held at our conference in September and as I have mentioned on previous occasions we do need new members for the committee. If you would like to serve on the committee yourself or you know someone whom you feel would be an asset to the committee, please let me know.

In the past nomination forms have been sent out. To save costs we are not doing this this time - it is sufficient if you let me know in writing your name and address if you wish to stand personally or the name and address of the person other than yourself you wish to nominate. Please do ensure that this person is willing to serve on the committee.

Anyone who wants details of what is entailed please telephone me on 0424 216432. The written nominations should be sent direct to me at my address which is shown on the front cover.

I will repeat what I have said on many occasions in that we must have continual new blood to ensure that our society continues to progress. Please do therefore consider nominating yourself or some other person.

A.G. King (Chairman)

Future Events

<u>Date</u>	<u>Event</u>	<u>Contact</u>
August?	North East Family Outing	Barbara Arrowsmith
11 Sept	Visit to Cotswold Wildlife Park	Ron Snack
23-25 Sept	MPS Family Weekend Conference	MPS Office
22-23 Oct	Northern Ireland Mini MPS Conference	MPS Office/Keiran Houston
5th Nov	Grand Raffle Draw, Retford, Notts.	David Briggs
27 Nov	North East Christmas Party	Barbara Arrowsmith
4th Dec	Christmas Party, Sheffield	Pauline Mahon/David Briggs
4th Dec	Northern Ireland Christmas Party, Co Derry	Kieran Houston
11th Dec	Christmas Party, Milton Keynes	Ron Snack

Milestones

New Families

Rebecca and Stephen Ellis from Huddersfield, whose son, **Daniel**, born 25/8/91 has been diagnosed with Sanfilippo disease.

Mrs and Mrs Aksar, from Rochdale whose daughter **Sobia**, born 2/11/89, and son **Bilal**, born 29/10/93, have been diagnosed with Morquio disease.

Mr Chris Shead from Harold Wood, Romford, Essex, whose son **Ian** born 30/8/89 has been diagnosed with Hunter disease.

Clare and Ned Murphy from Ballincollig, Co. Cork, Ireland, whose daughter **Alison** born 21/7/93 has been diagnosed with Hurler disease.

Denise and Gavin Brown from Hemel Hempstead, Herts. whose son **Adam** born 17/12/90 has been diagnosed with Sanfilippo disease.

Ted and Dawn Nelson from Trotton, Petersfield, West Sussex, whose daughter **Tessa** born 10/9/90 has been diagnosed with MLIII disease.

Diane Bulloch from Bishop Auckland, Durham, born 5/10/47 who suffers from Morquio disease.

Ray and Sandra Martin from Harrogate, North Yorks. whose daughter **Katie** born 18/5/89 suffers from MLII disease.

Judith and Graham Evans from Bridge of Weir, Renfrewshire, Scotland, whose daughter **Joanne** born 22/2/86 suffers from Morquio disease.

Steve and Frances Gee from Cottenham, Cambridge, whose daughter **Eleanor** born 6/8/89, suffers from Sanfilippo disease.

Mrs Donna McLellan from Pollock near Glasgow, whose daughter **Emma** born 8th May 1991 has been diagnosed with Sanfilippo disease.

Deaths

Mohammed Begum from Peterborough, who died on 20/3/94, aged eleven months, from I-Cell disease.

Matthew Hardy from Haddenham in Bucks. who died on the 22nd of April 1994 aged 13. Matthew suffered from Hunter disease.

Gemma Rollinson from Scunthorpe who died on the 5th of July aged seven. Gemma suffered from Hurler disease.

Abigail Milward from Leamington Spa in Warwickshire who died on the 11th of June aged three years. Abigail suffered from MLII disease.

Joanne Greenwood, of Winsford, Cheshire, who died in October 1989 aged 15. Joanne suffered from Morquio disease.

Our thoughts are with the parents, families and friends of these children at this sad time and with all families who have lost someone through MPS diseases.

Childhood Wood Working Party, Sherwood Pines, Nottinghamshire

On Sunday 19th of June nearly one hundred adults and children arrived to help clear weeds and dead wood from around the saplings in the Childhood Wood. It was hard work but by the end of the day everyone felt satisfied by the improvements that had been made. Every child's tree was lovingly tended and hundreds of daffodil bulbs were planted within the wood. If you have an opportunity to visit the wood next Spring it should look a picture.

All the saplings are surviving and are now becoming well established. Our thanks to all those who helped to organise the working party.

Directions for visiting the wood are as follows:

(From the direction of Nottingham). Take the A614 towards Doncaster. You will see Rufford Abbey well signposted on the right. After Rufford Abbey turn **left to Edwinstowe** at Rose Cottage. You will pass Sherwood Holiday Village (Center Parcs) on the left.

Turn **left** again at the next traffic lights by the Robin Hood Pub onto B6030. After 1.2 miles turn **left** into the forest road at the signpost for **Sherwood Pines Forest Park**. Follow directions to the car park.

From the car park follow the **white walk** for the disabled or the **blue trail** walk. This will take you alongside the Childhood Wood.



Voices of the Forest

We might have played
Where you now play
But Nature was unkind
We lost an all important gene
And so our fate was signed
Our lives were sadly blighted
But folks were always kind and
In these woods lie memories
For those we left behind.
Now in the peace of Sherwood
'Neath newly planted oaks
Our small plaques tell the story
Of so many little folk.
We will be long remembered and
We leave this ray of hope
That for MPS in future
Will be found an antidote.
Ken Ballard

1994 Grand Draw

Hello again! This is my sixth year as Draw Co-ordinator and sadly my last. Due to re-training and one or two other problems I feel I cannot give the time to develop the draw to its full potential. So it is with regret that I have advised the management committee of my intention to stand down after this year's draw.

However this does not mean that I am not going to be the usual pain in the neck this year. So stand by to receive your draw tickets. If the printer can manage it, I hope to start posting the tickets out in early August. I will also be bringing spare tickets to the conference just in case you should require many many more to sell. Don't forget you can also return any sold tickets and money to me at the conference.

We have four excellent top prizes this year.

1. **£750 'Going Places' Travel Voucher.**
2. **P&O Cross Channel Ferry Ticket for a car and two people.**
3. **Mid Week Break for up to six people at Haven Holiday Camp.**
4. **BA Flight Simulator ticket for 2 people, (age twelve and over).**

And many other prizes.

With all the tickets will be a full list of prizes and all the information you should need, including the last posting dates. However please do not hesitate to contact me (see inside front cover), if you have any queries about the draw or if you wish to donate a prize, money, bottles of whisky, bacardi, rum, brandy..... Oops, sorry I'm getting carried away again.

May I take this opportunity to thank you all immensely for your help and support with the

draw over the last five years and with this year's draw. Without it the Society would be at least £30,000 the poorer, (not counting this year).

My time as co-ordinator has not been without stress but I'm glad I said yes when I was asked to take over the task. It has allowed Monica, Emma, Kristina and myself to meet and talk to many other MPS families, which has been a great pleasure for us. Co-ordinating the draw has also been an education in many ways. So we thank you all.

Best wishes

David Briggs.

Draw promoter: David Briggs, 7 Humber St, Retford, Notts, DN22 6LZ

Registered under section 5 Lotteries and Amusements Act 1976 with Chiltern District Council. Number 236.

Wanted!

Do you like receiving and posting letters, and making lots of phone calls? Do you enjoy wrapping things up? Do you get excited folding paper? Does it make your day when you visit the bank and deposit lots of (other people's) money?

Is licking stamps as good as eating a twenty ounce steak to you? Does opening parcels give you a buzz, even when they are not for you? Are you good at organising?

Then write to the MPS Office immediately and offer your services as Draw Co-ordinator.

B-B-Q Sheffield, May 1994

What can you say about the Area Family Day at Sean and Pauline Mahons' in Sheffield on the 22nd of May? Well the answer is Super, Marvelous, Great, Stupendous, Fantasmagorical. Better than a Burger King Burger. (I admit to being biased as I was one of the very wet few

who acted, and I use that word advisedly, as cooks...) As usual Sean and Pauline and the rest of their family spoiled us rotten. I would like to pass on thanks to them all from all of us for a great day. For the first time ever it dared to rain on our B-B-Q. Well. I for one was, how can I put it, **WET!** At last we managed to get everything cooked and went inside to join the others and dry out as I was **WET!** So were Kevin and Sean. It was nice to see old friends and catch up on what was happening and how everyone was. Everyone could see how **WET!** I was. However it seemed only a few minutes from when I was **WET!** to when I was dry and we were loading up the car to go home. Well we can now look forward to the next one. Oh! By the way did I mention it was raining, I got **WET!**

David Briggs

Cooks, **David Briggs, Sean Mahon** and **Kevin**, wet but undaunted.

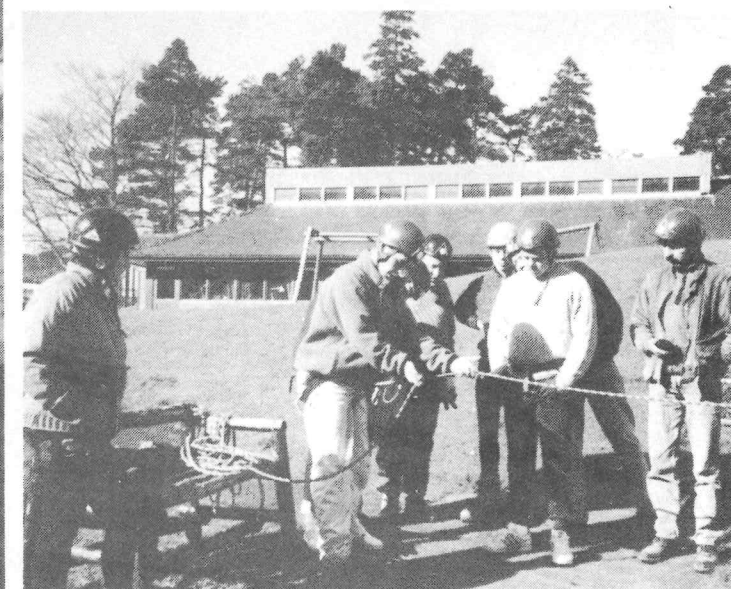
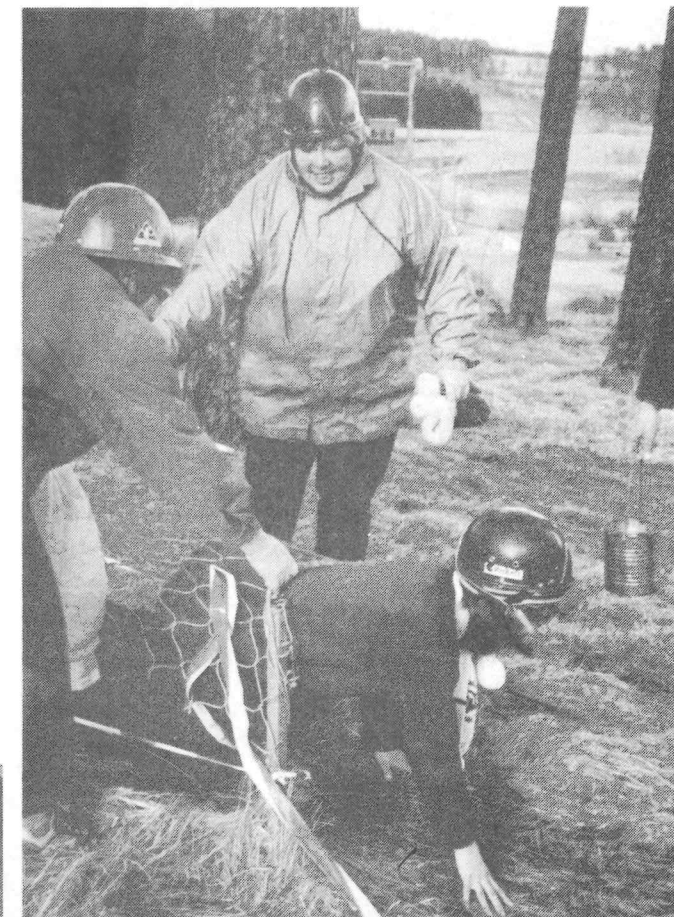


Marie Coppobianco President of the National MPS Society USA, and **Joan Cohen**, Treasurer, met with Christine Lavery in the Spring to discuss co-operation on gathering information about MPS. Congratulations on securing funding to develop a database similar to the European database! We look forward to seeing you at our conference in September.

Area Family Training Weekend

What did they get up to on that weekend? No one has sent me a report. When I speak to Christine Lavery or Ron Snack they just turn pale and change the subject. Luckily the papparazi were out in force with their long lens cameras, so I have got the pictures. But the pictures are not easy to understand. Remember this was a group of middle aged, sober, sensible, people who wanted to improve their skills in supporting families under stress, a task which involves them in a lot of talking on the phone, some letter writing, sometimes organising barbeques and outings, and long meetings, usually over a lot of food and drink. To train for this, they do what...

Perhaps you can explain it to me. Here are the photos. A fiver for the best caption to any of the numbered pictures below. Answers on a postcard to the MPS Office. The winner to be announced at the conference in September. I'm serious about this.





Helen Skidmore goes sailing with two gorgeous hunks, The one on the left is **Ben Lavery**. Helen is fifteen and comes from near Monmouth in Gwent. She suffers from Hurler disease but has benefited from a bone marrow transplant.

Below, **Myles Broughton**, 13, from near Sheffield, takes his turn in charge of the Drascombe Lugger. Myles suffers from Hurler/Scheie disease.



The holiday for teenagers at the Calvert Trust Centre, Wistlandpound, Exmoor during the May Bank holiday weekend, was a great success. Further reports on page 12.

Aidan Kearney age 16 from Ballycastle, **William Todd** age 14 from near Bushmills, Co Antrim and **Mark Ashworth** (back row) age 14 from near Bolton, take a photocall with some of those fantastic army volunteers. **Lucy Lavery** and friend are also in the picture.



Tanya Hookway, from North Bideford in Devon enjoyed a day out visiting the holidaymakers with her daughter **Kallie** aged two who suffers from Hurler disease.

Chris Isaac & Helen Skidmore's Holiday Reports

Dear Christine and Mary,

I am writing to thank you for the wonderful time I had at Wistlandpound. It was great being there and the company was good. I was sorry that I missed the first half of it but I think that if I came when I was ill I would not have enjoyed it.

The rest of it was excellent and it was one of the best holidays I have ever been on. I really enjoyed the football game and it was good watching it on video. The treasure hunt in the canoes was the best part I think! Swimming was good because I could show everyone what I could do.

I don't think the archery was so good, but I think it was a new experience to learn from so it was good in that way. I think everyone else enjoyed it. The abseiling and the assault course were good fun as well.

At the leaving party it was great especially the dancing! It was all great and I am glad I went. I hope to go next year if you are going to arrange it.

When we were leaving I think I left behind the sheet of paper with all the addresses on. If possible could you please send me the addresses of the M.P.S people who went so I can get in touch with them.

Thanks again for a great holiday,

Chris Isaac.



On Sunday 29th May, Mum, Dad and I set off from Monmouth for Exmoor, we left my brother Richard at home because he had lots of studying to do for his A-Level Examinations.

As we had plenty of time Mum decided we would take the scenic route along the coast, but this turned out to be so long and busy we had to take a short cut and eventually arrived at Wistlandpound one hour later than expected. Joanne, my room mate for the week thought that we were never going to arrive. Trust Mum!!

After saying good-bye to Mum and Dad my week's adventures began in glorious sunshine which lasted for most of the week.

Our Activities included Sailing, Horse riding, Archery, Abseiling, Swimming, Games and finally a party and Disco in the local pub.

I think that out of all of the activities that we did sailing a boat was the most exciting, although my bottom got dangerously near the water at times, a water fight made sure that everyone got wet by the end of the day.

Probably my second favourite activity was the Party/Disco in the local pub, we did not leave the pub until 11:00 but don't tell my mum. We had a lot of fun and a good sing song.

I would like to thank Christine and Mary for organising the holiday, not forgetting our great friends, the Army, who carried me everywhere, a special thanks to Chris for the fights and to Alison for the loan of her shoulders in the pool so that I could splash Chris, and Jackie for carrying and dressing me. It was a great holiday.

Helen Skidmore

Jennifer Johnson in Disney World

In April this year Jennifer Johnson went on a trip of a lifetime to Disneyworld in Florida. Jennie is aged eleven and suffers from Hurler/Scheie disease. She travelled with a group of other children with disabilities in a trip organised by the National Holiday Fund.

Jennie had a wonderful time and brought back two albums full of photos.

The National Holiday Fund have developed a programme of special holidays for children, particularly to Florida. They provide specially trained escorts and medical supervision and their organisation now has an enormous amount of experience in doing this. Several MPS children have travelled with them over the past few years and the reports back have been glowing. A special thank you to the National Holiday Fund for their generosity towards MPS young people.

Another group of girls suffering from MPS will be travelling with NHF in October 1994. This year the offer is open to girls only, so sorry boys! Perhaps your turn will come later.

There is a way for families to get some help with a Florida holiday. See the information below about "Give Kids the World".



Jennifer Johnson, aged 11, from Edinburgh, with a friend she met in Disney World in April. How come everybody meets the same people in Florida?

"Give Kids the World"

This is a Florida based American Charity which provides cost free holidays for children with life threatening diseases and their families in central Florida at Walt Disney World. Children and their families (up to six people) can be accommodated free at a special kids village for up to six day. There are free meals and transport and an organised programme including DisneyWorld, MGM, Sea World and other attractions. Families are met at Orlando Airport. Travel from home to Orlando and back is not paid for. "Give Kids the World" can be contacted at:

210 South Bass Rd, Kissimmee, Florida 34746. Phone 407 396 1114. Fax 407 396 1207

We don't know anyone who has been on this holiday so we cannot give a report on it. If you do contact them please let the MPS Office know how you get on so we can tell other people.

Daniel Anthony

Dear Christine,

Just a note to how much we have appreciated the help and support you have given us over the years and the past few weeks in particular. As you can see from the photo, the results are well worth all the effort you put in. I know that we would not have obtained Daniels Alvema chair if you had not managed to put so much pressure on so many people. Thanks also to Ed Wraith and our local paediatrician for their help.

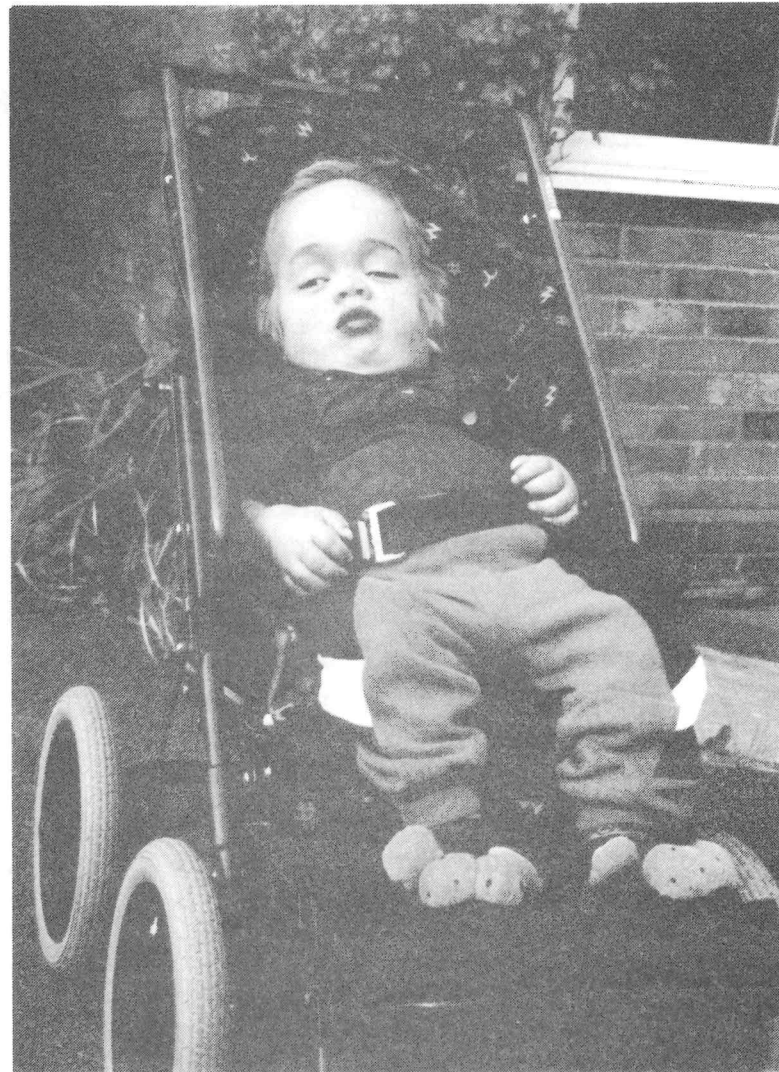
I wish I had tried for an Alvema chair earlier, as it has changed Daniel's life. He is so comfortable and cozy now. Thank you also for giving me Kieran Houston's phone number too, with regard to the oxygen. We phoned Kieran, and not only was he most helpful on the phone, but he also sent us a lot of information, diagrams and samples of endotracheal tubes etc., as well as photos of his son Liam with the oxygen tubes in place.

Thanks again for the support that the Society gives so unstintingly. It is wonderful to know that you are there to offer advice, information and practical help when needed.

Yours sincerely,

Graham and Janet Anthony

39 A Bucklesham Rd
Ipswich, Suffolk, IP3 8R



Daniel Anthony, now comfortable in his hard won Alvema chair. Daniel is aged seven and suffers from Hurler disease.

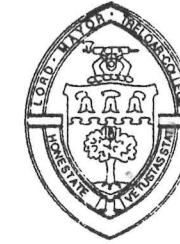
Do you have problems getting the most suitable equipment for your child? Your first port of call is the Occupational Therapist at your local Social Services, who should be able to suggest and prescribe what your child needs.

Under the Children Act 1989 every child with disabilities can be registered with Social Services and is entitled to an assessment of the services needed, and a statement of what will be provided. If you are not happy you can take the matter further. From their wide experience of MPS children, **Christine Lavery** or **Mary Gardiner** may be able to give expert advice on the needs of your child, and if necessary take the matter up with local services on your behalf. Do not hesitate to contact them.

Headmaster
H Heard, MA, MCoIP

Head of Further Education
Dr P J Lones, BSc, CBiol, MIBiol

Telephone 0420 83508
Facsimile 0420 542708



LORD MAYOR TRELOR COLLEGE
HOLYBOURNE
ALTON
HAMPSHIRE
GU34 4EN

12th June 1994

Dear Mr. and Mrs. Lowry and Kate,

As you are aware, Sarah's tutors at Alton College asked for her work to be forwarded so that she could be accredited for those parts of the course that she had completed. I am sure that you will be proud to hear that she has been awarded the full BTEC National Diploma and we are all pleased that her dedicated efforts have met with the success that they deserved.

I felt that you also ought to know that at the completion of the course her fellow students decided to club together for an award to be presented annually in memory of Sarah. It is the "Sarah Lowry Award" for the student who best exhibits her qualities of "good humour and dedication".

Both staff and students felt her loss very deeply and it is a comfort to have this permanent memorial of her time with us.

Please thank Kate for forwarding her work-it could not have been an easy task.

I am sure that I speak for all of us from both Alton College and LMTC, who attended Sarah's funeral when I say that it was a most touching service, during which all our sympathies went out to the three of you.

I do hope that as time heals some of the immediate pain you will take comfort in the many happy memories you must have of Sarah. I came to know her best during our year's French together- and when I look back on some of those sessions I cannot help but smile at her constant humour and determination to succeed. Our thoughts are with you all.

Best wishes

Gill Plumley

(Alton College Liaison Tutor)



The **Hoather** family from Rochdale and the **Graf** family from Long Island, New York, met up while on holiday at MGM in Florida in the spring. Wayne Hoather holds **Fredrika Graf**, who suffers from MLII disease. **Simon** Hoather age 7, and **Michael** age 6 suffer from Hunter disease. On the right is their sister **Kathy**. **Johann Graf** is the manic looking person at the back.

Susan Graf, wife of Johann seen here with Fredrika, now works for the American MPS Society on the International Database of MPS diseases. This has been made possible through funds provided by the Australian company CSL. Congratulations to the American Society for their success in getting this important project funded and under way.



Marathon Men do it on their toes

Could you please say a very big thank you to all the sponsors, runners, families and friends who were so supportive towards the London Marathon in April. Michael, Sarah and I would particularly like to thank and congratulate Don Corbett, Kevin Ball and Dave Riklands on running for MPS. Although we never actually got to meet, we spoke several times on the phone.

The day of the race was very cold, so I am sure it was not easy for those who ran. Michael went well until eighteen miles. Unfortunately he then had severe cramp and had to walk almost all the remaining eight miles. But he did it! He said he enjoyed every moment and he keeps telling me he is going to do it again.

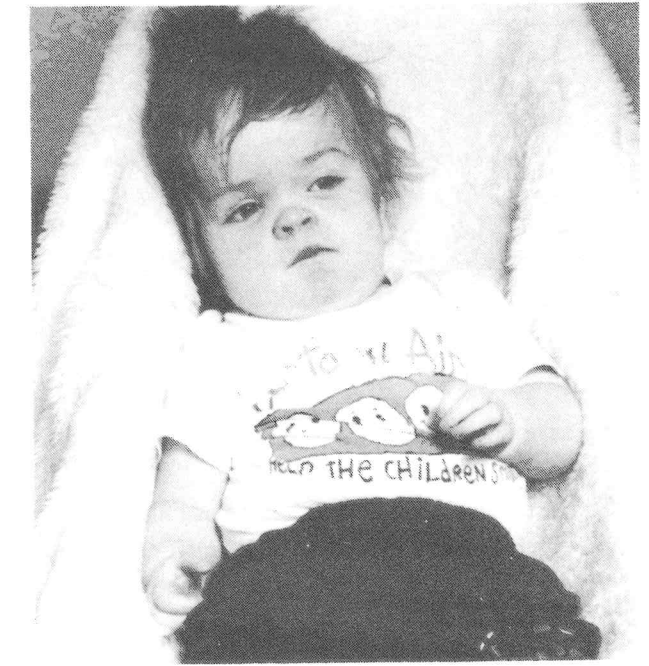
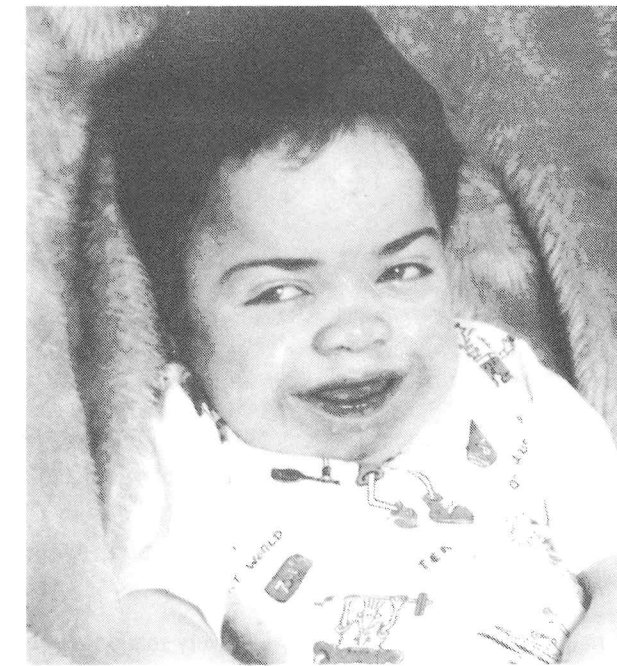
The times of the MPS runners were

Michael Kilvert	5hrs 20mins
Don Corbett	5hrs 4mins
Kevin Ball	4hrs 9mins
Dave Riklands	3hrs 50mins

Hope you and the family are going along fine. Sarah has not been too well, but after a visit to Ed Wraith we are back on a better road. We wish you a good summer and look forward to seeing you at the conference in Milton Keynes.

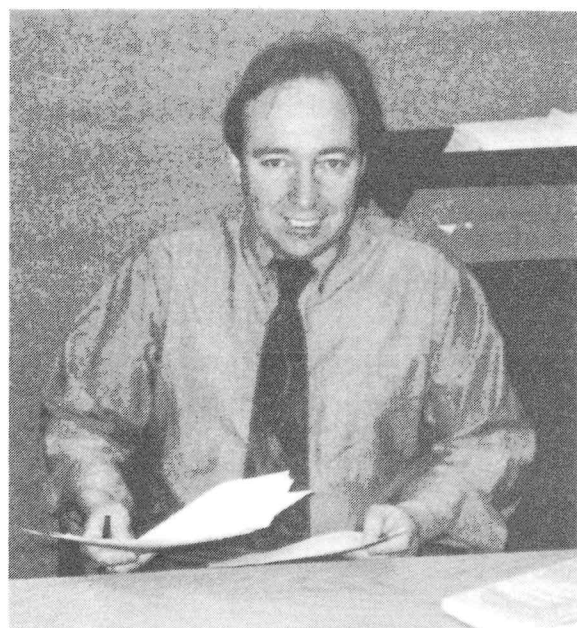
Michael Anne and Sarah Kilvert, Windy Waye, Nantoer, Newtown, Powys SY16 1HH. Phone 0686 624387

If you know anyone else who might be interested in running in next year's Marathon on behalf of MPS, please contact Mike Kilvert at the above address. Team applications have a much better chance of getting places and the Society will help with sponsorship form and support. We have had Marathon runners for many years and it's great for publicity and fundraising.



William Corcoran aged 6 and his sister **Amanda** aged 2 from West Ealing in London. Both suffer from Hurler disease. Their parents **Tom and Nora** have been active in fundraising in their local community. Our very best wishes for their new baby expected soon.

Committee Member Profile - Tony Eyre



I have been a committee member since September last year and I would like to introduce myself and my family. My wife Shirley and I and our daughter Carly live in Malmesbury, Wiltshire, which is a small town north of the M4. The town is famous for a monk called Elmer whose is reputed to be the first person to have flown. Actually I think he just fell off the Abbey roof. We have been the Area Support Family for the South West for a number of years. We were introduced to the Society when our son Sam was diagnosed with Hurler disease. Little did we know how much it would change our lives. We have lost two children to MPS. Our first daughter Hayley died at five months in 1983 and Sam died in November 92 aged seven. I have been working in the communications industry for fifteen years and I am now based at Swindon.

My hobbies include oil painting, reading and most sports. I have played Rugby and Football at local level but now find it energetic switching on the TV. Carly, being an active six year old gives me all the exercise I need. We feel the Society has now been fully integrated into our lives for a long time and we are happy to play a role as long as we are needed.



Hullavington Charity Challenge

On Sunday the 16th of June there we were, six naive volunteers, waiting our instructions to boldly go where where no MPS volunteer had gone before. Tricked into it by Christine Lavery and Shirley Eyre, we were going to be sent through the Army obstacle course against sixteen other teams all younger and fitter than us. Where were Christine and Shirley? Well out of the way, as you can guess. Soaked, bruised and battered, we tackled all ditches, hills obstacles and water traps and finished in a glorious seventh place.

We celebrated over a hard earned beer. Knowing that we had collected over £400 for the Society made the whole day very satisfying.

I would like to thank the Army for a wonderful experience and also thank the team of **Maureen Murray, Julie Seal, Steve Hollyman, Nick Pullin and Kevin Puddy** for their great support in getting me to the beer tent in one piece.

Tony Eyre

Wheelchairs – the problem

The main problems with wheelchairs are:

- Getting one
- Finding out what's available so the user can choose the one that's most comfortable/suitable
- Finding the money for an electric-powered one
- Manoeuvring one
- Helping your relative or friend to feel good about using one

Wheelchairs – the solution

If someone has a permanent or long-term need for a wheelchair s/he can get one supplied through the NHS. The application will have to be made by your relative or friend's GP or hospital consultant. The kinds that are available are: ones controlled by the user; ones pushed by a helper and, in certain circumstances, electric-powered ones. User-controlled electric wheelchairs for out-door use are not supplied by the NHS.

If you want a wheelchair for a short time or for someone whose disability isn't severe enough to get an NHS long-term one, the hospital your relative or friend attends or your local British Red Cross may be able to loan one to you.

If you're getting one on loan you'll most likely have to take what you're given. Sadly many people find this is the case with any wheelchair given to them by the NHS. The chair should be matched to the user, though – taking into account his/her needs and preferences as well as the home environment. Try to get to see an occupational therapist; find out what's available and try a few out. There are books to help you: The Disabled Living Foundation (DLF) have two directories in their Information Service Handbook series: *Manual wheelchairs* which includes ramps and harnesses, information and advice and *Powered wheelchairs, scooters and buggies* which includes insurance, information and advice. They are £10 each. Cheaper are their advice notes: ISD14 *Choosing a wheelchair* and ISD13 *Choosing an electric wheelchair* £2.00 each. All from: 380-384 Harrow Road LONDON W9 2HU Tel: 071 289 6111

From RADAR you can get *Choosing a wheelchair* written by Judith Male and Bert Massie who have first-hand experience. £4.55 incl p&p from 25 Mortimer Street LONDON W1N 8AB Tel: 071 637 5400

The Carer July 1992

If the wheelchair your relative or friend wants is not available through the NHS you may be able to get help with the cost. Suggestions about how to get grants etc are in Carers Factsheet 1 'How to find out about gadgets and equipment to aid daily living'. You may be able to get favourable hire purchase terms for electric-powered wheelchairs from Motability:

Gate House
Westgate
HARLOW
Essex
CM20 1HR

Tel: 0279 635999

Pushing a wheelchair is a skilled job. There's a right and a wrong way of going up and down kerbs etc and the wrong way can mean discomfort or even injury for both of you. Ideally you should get training from an occupational therapist or physiotherapist. Ask your GP or at the hospital (there's more about this in the Cut Out and Keep on Lifting and Moving, March 1992). There are also a few helpful booklets: *'How to push a wheelchair'* published by the Disabled Motorists Club and available from RADAR, price 85p

'People in wheelchairs – hints for the helpers' published by the British Red Cross, 75p incl p&p, from: 9 Grosvenor Crescent LONDON SW1X 7EJ Tel: 071 235 5454

'Assisting a wheelchair user' published by Scriptographic and available from Carers – send a 9"x6" SAE marked 'wheelchairs'

Wheelchairs and cars don't seem to go together as well as users would like. Helpful information is in *'Motoring with a wheelchair'* from Radar, 55p, and *'Method of loading a wheelchair into a 2-door car'* DLF advice note ISD15, £1.50.

Many frustrated but innovative users' friends have designed and put into production racks etc to carry wheelchairs by car. DLF will be able to tell you more.

A wheelchair can give its user freedom to move about and therefore have more control over his or her life, which is good. Other people's attitudes and behaviour can make the user feel powerless and insignificant, which is bad. Think about it. How you would feel being talked at by people two feet above your head; being propelled to who-knows-where without being asked or even told; having your space filled with coats, shopping etc?

Clothes are designed to look and feel good when people are on their feet. People who spend a lot of time sitting are more comfortable in clothes designed for it – for example trousers with high backs; fronts that don't wrinkle and pinch at the tops of the legs. DLF have two booklets: CW1 *'Clothing for men who use wheelchairs'* and CW2 *'Clothing for women who use wheelchairs'* £2.00 each. They also have a clothing advisory service.

If the person you care for spends a lot of time in the wheelchair, be alert to the danger of pressure sores. Get advice on prevention – sheepskins, special cushions etc – from the DLF, an TO or nurse.



ADELAIDE CHILDREN'S
HOSPITAL

72 King William Road
North Adelaide
South Australia 5006
Telephone (08) 204 7000
Facsimile (08) 204 7459

Department of Chemical Pathology
indial 61-8-204.7101
Departmental facsimile 61-8-204.7100

28 March, 1994

JJH/sl

Mrs. Christine Lavery,
Director, The Society for Mucopolysaccharide Diseases,
55 Hill Avenue,
AMERSHAM BUCKS. HP6 5BX,
ENGLAND.

Dear Christine,

Re: Progress in Mucopolysaccharidoses Research during 1993

Thank you for the invitation to write a brief summary about this topic.

This has been another year in which considerable progress has been made by a large number of researchers studying mucopolysaccharide (MPS) disorders in many different countries. During the years 1990 to 1993 the genes for Maroteaux-Lamy (MPS-VI), Hunter (MPS-II), Hurler (MPS-I), Morquio A (MPS-IVA) and Sanfilippo D (MPS-IIID) syndromes were isolated and characterised. However, these genes were isolated only after a long-term commitment and effort by many different investigators to purify proteins/enzymes involved in each of these syndromes. Sequence information obtained from the purified proteins was then used to isolate each gene, which in turn made possible mutation analysis of patients and the development and evaluation of patient treatment methods, such as enzyme replacement therapy and gene replacement therapy.

During this past year, more than 28 different mutations have been identified by a large number of investigators as causing MPS-I. Importantly, several mutations were shown to occur with relatively high frequency in some MPS-I patient populations. For example, two mutations in the Australian and Scandinavian populations account for more than 70% and 80%, respectively, of all MPS-I patients. Any combination of these two mutations in MPS-I produces patients with very severe clinical presentations. These patients have a predictable and very severe clinical prognosis. This means that these patients, when treated with bone marrow transplantation (BMT), can be compared with patients with the same mutations that have not received BMT to provide some conclusion about the clinical gains to be derived from BMT.

During the past year, more than 30 different MPS-II mutations have been defined by a number of research workers in different countries. Unlike MPS-I, there were no common mutations found in the large group of MPS-II patients thus far studied. This means that most MPS-II patients/families have unique mutations and therefore each new MPS-II family will probably require mutation analysis to be performed. Definition of individual mutations in this X-linked disorder enables the accurate detection of carriers in female relatives and may assist in the prediction of patient clinical phenotype.

Sanfilippo A, B and C (MPS-IIIA, -IIIB and -IIIC) syndromes remain the only MPS disorders yet to have their genes isolated. Protein/enzymes for MPS-IIIA and -IIIB have been purified, and MPS-IIIC almost purified. It is therefore likely that the genes for these Sanfilippo syndromes will be isolated over the next year or so.

During the year, at least another 12 mutations have been identified in the gene coding for the enzyme involved in MPS-VI. Again, like MPS-II and MPS-IVA, common mutation types were not found. Importantly, the isolation of the MPS-VI gene has allowed the production of recombinant enzyme which may be useful for the treatment of MPS-VI patients by regular injection in a process known as enzyme replacement therapy (ERT). An Australian company, CSL Limited, announced at the 3rd International MPS Conference in Essen that they have initiated development work aimed at producing biosynthetic enzymes and evaluating them in the treatment of several of the MPS disorders. The development and evaluation of ERT is expected to take a number of years for each disorder, with MPS-VI being the initial candidate for development and study. Successful ERT and gene replacement therapy trials in a mouse model for MPS-VII were also described during the meeting in Essen.

Except for a brief mention of the Essen meeting, I have purposely not named or referenced the source of the reported studies and findings. I believe that the work reported from many different investigators in a number of countries and institutions illustrates the rapid progress now being made in MPS research and should encourage us all to believe that patients and families will derive considerable benefit from this research in the not too distant future. However, there is still much to do, as the isolation of MPS genes and the identification of mutations causing MPS is only the beginning.

I enjoyed the opportunity to attend your 1993 Annual Conference and wish you and all the members of the UK MPS Society every success for your next meeting.

Yours sincerely,

Professor John J. Hopwood
Head
Lysosomal Diseases Research Unit

Cervical Fusion News

Congratulations to **David Jones** of Felling, Tyne and Wear who has just had a cervical fusion at Royal Manchester Children's Hospital and is now up and running around in his halo. David is aged nine and suffers from Morquio disease. Best wishes to David and to his parents **Carol and Ronnie** in these anxious months while you are waiting for the fusion to "take". We pray all goes well.

All those people with Morquio disease who have had a fusion and who know what it is to be confined to a halo please write to David and send him cards and pictures.

David Jones, 3 Planasway, Whitehills Estate, Felling, Tyne and Wear, NE10 8LG

Austrian Conference and International Working Party

It was all work with just a little play at the Austrian MPS conference which took place in the beautiful alpine village of Kirchberg in the Tyrol at the end of April. Many families and professionals attended from Austria, Germany and central Europe. It was combined with a meeting of The International Working Party for MPS and Related Diseases, an informal group which represents MPS Societies throughout the world.



Charles O'Toole, Mary Gardiner, Christine Lavery, Brian Fowler and Adrian Sewell resting outside a hilltop chapel during a break from the Austrian Conference.

The international meeting was ably chaired by Dr Susan Fang-Kircher, Secretary of the Austrian Society, who is no stranger in Britain. Reports were presented from more than ten societies throughout the world. One important item on the agenda was co-operation about a European Database for MPS. It was agreed that data would be collected by the British Society, with the help and support of other groups.

It was also agreed to start an **International Newsletter**, perhaps to come out twice yearly, as a means of helping with communication between the different societies. I have rashly agreed to be the editor of this newsletter and would be grateful for articles suitable for international circulation.

Charles O'Toole

Mrs Catherine Rush

of Tunbridge Wells has produced a tape of religious songs, the proceeds of which she is donating to the Society.

Copies of the tape can be had from the MPS Office for £4.50 inclusive of postage. Our thanks to Mrs Rush for this generous donation.



Side One

1. Be Still. D. Evans. Thankyou Music.
2. How Precious. Phil Rodgers. Thankyou Music.
3. When I Look Into Your Holiness. Wayne & Cathy Perrin. Integrity's Hosanna Music/Thankyou Music..
4. Father I Place Into Your Hands. J. Hewey. Thankyou Music.
5. I Will Give Thanks. Brent Chambers. Scripture In Song.
6. The Steadfast Love. Edith McNeil. Celebration Services.

Side Two

1. Spirit Of The Living God. Paul Armstrong. Restoration Music.
 2. God Of Grace. Chris Bowater. Sovereign Lifestyle Music.
 3. God Forgave My Sin. Carol Owens. Word Music
 4. I Worship You Almighty God. Sondra Corbett. Integrity's Hosanna Music/Thankyou Music.
 5. Reign In Me. Chris Bowater. Word Music.
 6. O Let The Son Of God Enfold You. John Wimber. Word Music U.K.
- Vocals: Catherine Rush. Keyboards: John Chambers. Recorded at Emmaus Studio. Stamford. Engineered and Mixed by Keith Barwell. Front Cover Design: Joan Gough
All proceeds from this tape are donated to:
The Society for Mucopolysaccharide Diseases.
Registered Charity No. 287034

DERIAN HOUSE CHILDRENS HOSPICE

Chancery Road, Astley Village, Chorley, Lancashire PR7 1DH.
Telephone Reception: 0257 233300. Appeals Office: 0257 234860/271271.
Fax: 0257 234861.



Dear Sir/Madam

I am writing to inform you about Derian House Childrens Hospice. This information might prove useful for some children/families who seek the support of your network. You might include this information in your next Newsletter.

Derian House opened in 1993. This House offers a Hospice Service for children with life threatening or life shortening conditions who live in the North West.

The main focus of the Service provided is respite care. This care is given in a 'home from home' atmosphere by experienced care team members. The team provide respite support for family members by taking over the care of the child while these members take some needy rest. The respite service enables family members an opportunity to spend some time to meet the needs of other family members and themselves. At Derian House all members of the family can stay with the sick child if they wish. We have excellent family accommodation. There are 4 self contained fully fitted flatlets which can be made available for family members wishing to stay.

Derian House is able to offer a service for up to 9 children. Nine bedrooms are available completed to a high standard, 4 of the bedrooms are fitted with mechanical hoists so as to facilitate comfort of the child. Other facilities are well developed including a well equipped Playroom, Games and Sensory Light room, a Hydrotherapy Pool and a Jacuzzi. The House is surrounded by beautiful gardens.

Derian House also offers a terminal care service. Working closely with a local GP and Community Care Workers, the team maintain the comfort of the child and support the family through this very difficult time. Paediatrician support is offered by Dr. Clark, Consultant Paediatrician, Royal Preston.

Plans are underway to develop the service we offer further. We aim to establish support groups for bereaved families, a support group for siblings of children with a life threatening illness. We are also establishing an education resource service to meet the needs of professional care workers.

Derian House is a caring relaxed and friendly environment. If you feel that you know a child/family living in the North West region who might benefit from the service we offer, then please contact the Senior Nurse. You will be advised as to the procedure for referral.

We hope that we will be able to assist you.

'Derian House: a Childrens Hospice for the Community.'

Yours sincerely

Michael Farrell & The Care Team.

Cerebrospinal Fluid Shunts

The following article is based on notes of a discussion led by Dr Ed Wraith, Consultant Paediatrician at the Royal Manchester Children's Hospital, at the annual conference in September 1993. The notes have been checked by Dr Wraith.

Inside the hard bony structure of the skull is the brain. The delicate structure of the brain is protected by a liquid cushion all around it. This protects the brain from injuries and shocks, for example when a person suffers a blow to the head.

This liquid is known as Cerebrospinal Fluid (CSF). It circulates in a similar way to the circulation of the blood. It is produced and absorbed around the brain and the spinal cord.

It flows through channels similar to the arteries. Very occasionally these narrow channels block so the fluid cannot circulate from the brain to the rest of the nervous system.

When that happens the fluid builds up around the brain and causes pressure inside the rigid box of the skull. In babies the skull can expand to a certain extent, but in older children the bones of the skull are fused tightly together.

The way to prevent the pressure causing damage is to divert the flow of cerebrospinal fluid from the brain to another part of the body. This is done by a catheter inserted into the fluid in the ventricles of the brain. This drains the fluid away into a blood vessel, or more com-

monly into the abdomen, where the fluid is absorbed.

Hydrocephalus is the name given for the condition where this problem arises. The incidence of hydrocephalus varies between the different types of MPS. The condition is simple to test for by means of a brain scan.

Hydrocephalus is common in children with MPS II (Hurler Disease). About four out of ten Hurler children will have hydrocephalus.

In a number of children this does not need any treatment at all. However, for some children it is causing great pressure inside the head. This causes headaches. It can also cause difficulties with vision because of the pressure on the optic nerves. Treatment is needed in these cases.

If the head is allowed to grow very big this can make nursing very difficult in the later stages of the disease and for this reason alone CSF Shunts are advisable for all MPS children who have hydrocephalus.

The operation is a common operation in a paediatric hospital and usually takes around one hour to complete. In MPS children the risk of the anaesthetic far outweighs the risk of the procedure.

Following the operation, the child is seen regularly in the outpatient clinic by the neurosurgeon who checks that the shunt is working correctly.

Charles O'Toole

Thanks to Ann Ridley

Ann, who lives in Lutterworth, Leics., with her husband Robin and her son Mark is one of the founder members of the Society, attending the first conference in Birmingham in 1982. She lost her daughter Sarah to Hurler disease in 1981. A trained nurse, for eleven conferences she has looked after the children in the creche, while the parents attended the meetings. Sadly, Ann is unable to continue this year, due to ill health. We wish her a speedy return to health and join with the many MPS families whose children she has cared for to offer her our heartfelt thanks for her devoted, skilled and unobtrusive care.

Towards gene therapy for Hurler's Syndrome

In Hurler syndrome, the symptoms of the disease are caused by the failure of the cells of the body to produce an enzyme called L-iduronidase (IDUA). One of the more effective forms of treatment for this disorder, in carefully selected patients, has been bone marrow transplantation from a healthy donor. This leads to levels of IDUA in the blood of the treated patient similar to that of the donor and can lead to improvement in or prevention of many of the complications of Hurler's syndrome.

Not all children with Hurler's Syndrome are able to benefit from bone marrow transplantation, since rejection of the transplant may occur if the donor is not a close relative. Even then the donor and host may not be similar enough to avoid rejection of the transplant or serious graft versus host disease (GVHD).

An alternative approach is being developed in collaboration between scientists from Manchester and Adelaide supported by the MPS society and the Cancer Research Campaign. This approach aims to insert a normal copy of IDUA gene into the bone marrow cells of affected patients (gene therapy). The "cured" bone marrow would then be put back into the patient and lead to reversal of the symptoms of Hurler's Syndrome in much the same way as transplantation with a normal bone marrow.

A virus has been manufactured which contains a normal copy of the IDUA gene. The virus has been altered to make it harmless by removing the genes necessary for its survival. Although this virus cannot now spread and cause any disease, it can efficiently transport the IDUA gene and cause production of the enzyme in bone marrow cells. The virus has been shown to lead to effective and long lasting production of the IDUA enzyme in blood cells made by the bone marrow when they are grown in flasks in the laboratory.

In addition, the cells in these cultures were cured of the distension of their lysosomes which is characteristic of Hurler's Syndrome. The results so far are very encouraging and have taken us a long way down the road to a gene therapy approach to Hurler's Syndrome, and possibly to other MPS disorders. Much work remains to be done in the laboratory before this can be translated into a generally available treatment. Nevertheless, bone marrow gene therapy for Hurler's Syndrome is more than ever a realistic goal.

An alternative source of cells which can be used to cure patients are the blood-forming cells which are found in the umbilical cord. Laboratory experiments have shown that the IDUA gene can also be transferred to these cells. This raises the possibility of treating children by transferring the IDUA gene to their own cord blood cells immediately after birth, and work is continuing to assess the potential of this approach.

□ The Hurler's Syndrome Gene Therapy Team.

Leslie Fairbairn, Elaine Spooncer, Ruth McDermott, Linda Lashford & Mike Dexter - *Pater-son Institute for Cancer Research, Christie Hospital NHS Trust, Manchester.*

Alan Cooper, Guy Besley, Andrew Will & Ed Wraith - *Royal Manchester Childrens Hospital, Pendlebury, Manchester.*

Don Anson & John Hopwood - *Adelaide Women and Childrens Hospital, Adelaide, South Australia.*

Attendance Allowance

A recent Commissioners case has successfully established that the age two bar on entitlement to attendance allowance applied up to April 1990 was ultra-vires, ie illegal.

Section 35 of the 1975 Act which set up attendance allowance simply did not give the Secretary of State any powers to limit entitlement by age. The two year old bar was introduced by regulation. But since there was no primary power to have such a limit, that regulation was held to be ultra-vires.

Therefore a number of claimants - who were entitled to attendance allowance before their second birthday may be due up to eighteen months payments of the allowance for the relevant years. However, establishing entitlement now, potentially up to nineteen years late for some people, will pose problems.

What to do

Obviously some claims will have been made for children under two. Where these were refused on the grounds of age by the DSS Adjudication Officer an appeal should be made to a Social Security Appeal Tribunal. If you can give reason for the delay in appealing, such appeals should be heard, even if years late. Reasons to give for the delay obviously should include the fact that there was no chance of being successful, given the previous interpretation of the rules concerning this age bar.

However many claimants and potential claimants were never given a decision by the DSS Adjudication Officer. Instead they were merely sent a leaflet telling them that the allowance was not payable to children under two.

In this case people should do one of the following:

- a) *Push the DSS Adjudication Officer to now make a decision on the original claim. If the decision is unfavourable, appeal as above.*
- b) *Ask for a previous claim for supplementary benefit or income support or another "claim in writing" to be treated as a valid claim for attendance allowance.*
- c) *Ask your MP to push the Secretary of State to make an ex-gratia payment for the eighteen months allowance which would have been payable if your claim had been allowed, ie if the law had not been interpreted wrongly at the time.*

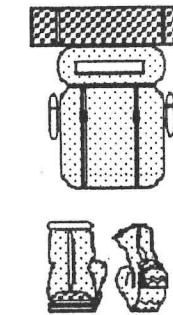
There is a greater problem for people who could have but never did make a claim. You should use both a) and b) above in establishing that a claim was made in all but name.

Wheelchair Donated

An Alvema 400 wheelchair in good condition has been donated to the Society. If you feel you could use it please contact Jenny and Andy Hardy on 0844 291172.



GREATER MANCHESTER
COUNTY FIRE SERVICE.



P. A. Gribbin QFSM, M.I.Fire E,
County Fire Officer & Chief Executive

Divisional Commander 'D' Division

Your Reference

Our Reference CB/PM

Contact Fm. Bennett
Tel. No. 061-483 0378

Date

CHRIS BENNETT 1157 MILES MARATHON WALK SUPPORTING FOUR CHARITIES.

Dear

I am a 30 year old Firefighter serving in the Greater Manchester Fire Service. During the last 12 years I have served at Whitehill Street, Ashton, Thompson Street and currently at Lisburne Lane fire station. I have often been considered an extrovert. My hobbies include keeping reptiles, my prize possession being a 10ft Burmese Python called Oscar.

With the support and full backing of the County Fire Officer, I propose to do a solo walk of some 1157 miles from Lands End to John O'Groats. The walk will commence on the 3rd September, 1994 and will be done on public walkways and National Trails with the minimum use of roads.

I have been granted leave from the Fire Service to complete this challenging walk for needy charities.

The charities which will benefit are as follows:-

- 1] **Cancer Research Campaign** - Reg charity No. 225838. Supports the Paterson Institute for Cancer which is within the Christie Hospital complex to the tune of £5 million per year to look into the cure for cancers.
- 2] **Society for Mucopolysaccharide Diseases** - (MPS) Reg. Charity No. 287034 One baby born every 10 days will suffer from MPS. These are rare life threatening diseases. No cure exists but research continues.
- 3] **Welephant Trust** -Reg.Charity No. 327084. Aftercare for children involved in fire. Supports burns units throughout the country and promotes national fire safety.
- 4] **The Fire Service Benevolent Fund** - Reg. Charity No. 212959. Supporting widows and orphans of firefighters throughout the country.

With the assistance of my colleagues, the four charities listed and the power of the press, it is hoped that we can generate a great deal of public interest. Radio and Television coverage is being sought regionally. Our Local Press are already involved and one National paper, the News of the World, has already done an article with the promise of more to follow.

In conjunction with this event we are running a National Raffle that is to be promoted throughout the fire service. We have secured four extremely attractive prizes:

1st Prize: Citroen AX (Sponsored by Citroen UK Manchester).

2nd Prize: A Caribbean Holiday for two (Sponsored by Miss Elliss Travel).

3rd Prize: Concorde trip to Paris for two with Champagne lunch (Sponsored by Goodwood travel).

4th Prize: Five star weekend break for two (Sponsored by Copthorne Hotels).

As you can see a lot of time, effort and thought has gone into the organisation of this event, and it is hoped that with your help we can further promote our aims. We feel that both the prize draw and the unusual nature of the walk would make an ideal storey for you to cover.

I look forward to receiving an early reply with any helpful suggestions or assistance. Should you require any further information or you would like me to contact you to discuss the proposed event, please write to me C/o The Fire Station, Lisburne Lane, Offerton, Stockport. SK2 5NP.

Yours faithfully,

Fm. C. Bennett

Fundraising Success

A special acknowledgement to **Ron Snack** for the enormous effort he has put into contacting companies and trusts this year in order to raise funds for the Society. This has been very successful.

We do not have a list of fundraising events for this issue but we will have a full list in the Autumn Newsletter.

Area Support Families

Martine and John Brennan Tel: 0524 382164
105 Barley Cop Lane, Lancaster, Lancs. LA1 2PP

Robert and Caroline Fisher Tel: 0799 586631
The Horrells, Great Samford, Saffron Walden, Essex, CB10 2RL

Suzanne and Jeffrey Hodgetts Tel: 0827 56363
6, Godolphin, Tamworth, Staffs. B79 7UF

John and Barbara Arrowsmith Tel: 091 2662999
11 Penfold Close, Fairways Est. Benton, Newcastle on Tyne. NE7 7UQ

Sean and Pauline Mahon Tel: 0742 304069
41 Stumperlowe Crescent Rd, Sheffield, South Yorkshire S10 3PR.

Mary and Robin Gooch Tel: 0435 883329
Highbank House, Swifehill, Broadoak, Nr Heathfield, East Sussex, TW21 8XG

David and Monica Briggs Tel: 0777 700046
7 Humber St. Retford, Notts. DN22 6LZ

Bill and Sylvia Blackburn Tel: 0270 626809
11 Beatty Rd, Nantwich, Cheshire, CW5 5JP.

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

Tony and Shirley Eyre Tel: 0666 825215
7 Elmer Close, Malmesbury, Wilts. SN16 9UE

Ann, Michael and Sarah Kilvert Tel: 0686 624387
Windy Waye, Nantoer, Newtown, Powys, SY16 1HH

Contact for Scottish Families:-

Alan and Fiona Byrne Tel: 041 6430034
3 Jedburgh Ave, Rutherglen, Glasgow, G7 3EN.

Northern Ireland Co-ordinating Committee:-

Kieran Houston (Chairman) Tel: 0504 884168
15 Barrack Street, Strabane, Co. Tyrone, BT82 8HB.

Margaret Kearney (Secretary) Tel: 026 57 62073
12 Coleraine Rd, Ballycastle, Co. Antrim, BT54 6DU.