

Newsletter



The Society for Mucopolysaccharide Diseases

National Registered Charity No.287034

Spring 97



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* Address may have changed by the time you receive this Newsletter.



The Society for Mucopolysaccharide Diseases

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Telephone: 01494 434156 Fax: 01494 434252

The MPS Society is a voluntary support group, founded in 1982, which represents over 800 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 fund-raising, and run by the members themselves. Its aims are as follows:-

- 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 research projects at the Christie Hospital, Manchester, Royal Manchester Children's Hospital, Bristol Children's Hospital and 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"

Front Cover:

*Gavin Fitzgerald (Hurler) aged 4 years old
with his sister Rachel.*

CONTENTS

Page 3	Director's Report- News of the Society
Page 4	Chairman's Report
Page 5	Trustee News
Page 6	Milestones
Page 7	Area Family Support - Wales
Page 8	Area Family Support - First Welsh Clinic
Page 9	Area Family Support - Wales cont.
Page 10	Area Family Support - Northern Ireland Clinic
Page 11	Area Family Support - Northern Ireland Conference
Page 12	Family News - Helen's New Chair
Page 13	Family News -cont.
Page 14	Family News
Page 15	Family News - Mums and dads need not apply
Page 16	Family News - MPS Conference 1997
Page 17	Family News - Kristina's Diary
Page 18	Information - GIG Sibling Conference
Page 19	Information - 'Guide to Children's Palliative Care'
Page 20	Information - 'What is a Children's Hospice?'
Page 21	Information - cont.
Page 22	Information - Richard House - London's First Children's Hospice
Page 23	Information - Rules for Disabled Facilities Grants
Page 24	Information - cont.
Page 25	Information - Makaton
Page 26	Information - Child Bereavement
Page 27	Information - Pupils with Medical Needs in School
Page 28	Information - Is there life outside the Family?
Page 29	Overseas News - Australia - Vaughan Glasson
Page 30	Overseas News - cont.
Page 31	Overseas News -cont.
Page 32	Overseas News -Finland - Jussi-Pekka
Page 33	Overseas News - Taiwan - David Chou
Page 34	Overseas News - Spain
Page 35	Fundraising - Charity begins at Work
Page 36	Fundraising - Lisa Nurse - Amy Bray
Page 37	Fundraising - Kristina Briggs - Keegan Lovick
Page 38	Fundraising - Donations
Page 39	Fundraising - Funds Raised

Deadline for the 1997 Summer Newsletter
26th June 1997

Please send us lots of photos

DIRECTOR'S REPORT

Since the beginning of January Mary Pagett, Joan Evans and I have had the opportunity to meet many of you personally at the Welsh and, Northern Ireland Clinics and NI Regional Conference. We saw record numbers of families and professionals at the Area Support Family Days held in Liverpool and Harrogate when Dr Ed Wraith and Alan Cooper from the Royal Manchester Children's Hospital spoke on MPS and related diseases, DNA and gene mutations, and future research. We shall be no less busy leading up to the summer when the Scottish Clinic and Conference will take place. Dr Wraith and Alan Cooper will be travelling South in July as the guests of Robin and Mary Gooch and the South East England Area Support Network to speak at their Family Barbecue. We look forward to seeing as many families there as possible.

The Trustees have already met twice in 1997 and in March spent considerable time reviewing the Society's Strategy for maintaining and improving support to families. In principal they agree that we desperately need two new Development Officers, one in the Northern Office, the other in the Southern Office.

These two posts will enable the Society to do two things. Firstly to specifically address the needs of MPS families from all ethnic minority groups who because we have problems communicating in their language and as many families have no private transport do not benefit from the activities of the Society, and in particular our advocacy work. Mary and I have identified a number of problem areas for all MPS families around, home adaptation, respite care,

home care, education and palliative care. The Society's expertise advocating the needs of MPS families can really make a difference.

Secondly, we need someone to 'Support the Supporters'. Yes we have substantially strengthened our twelve Area Support networks throughout the UK, but to keep this going we need to provide on going support to those volunteer families, keeping them up to date on all aspects around caring for an MPS child in the community and offering training opportunities.

Unfortunately that's the easy part - the difficult part is generating another £75,000 per year to fund the additional posts. I have recently submitted another application to the National Lottery Charities Board and now we have all our fingers and toes crossed. However a concentrated effort from families and friends is essential if we are to achieve our goals.

If you have any contacts in commercial companies and industry that would help, please do let us know. I wonder how many of you work, or have relatives and friends that work for major retailers e.g. Marks & Spencers, Tesco, John Lewis, or companies like BT, Shell. This information is really valuable in targeting such companies for financial support. As we've said before whenever an opportunity to fundraise or generate a donation presents itself **" Please think MPS "**.

In the meantime we will keep thinking MPS Families and keep working for you all.

Christine Lavery Director

CHAIRMAN'S REPORT

I am writing my Report just after the March meeting of Trustees and propose to touch on issues that have involved me during the first quarter of 1997.

The RMCH, BMT Visit

At the end of January, I was invited to visit Dr Ed Wraith in the company of Mary Pagett (Director of MPS Services North) and John Brennan (MPS Trustee) at the Royal Manchester Children's Hospital (RMCH) when Dr Wraith was reviewing the progress of MPS children who have had a bone marrow transplant (BMT). I was very impressed with the rapport between the children, Dr Wraith, parents, nursing staff and the MPS representatives. After the clinic, I toured the biochemical labs where much of the diagnostic work is performed for a wide range of MPS disorders. Dr Wraith then took me round the modern facilities and we concluded with a discussion on the use of gene therapy.

Jeans for Genes

10 October 1997 is J4G Day and in February I attended a meeting at Great Ormond Street Hospital to hear about the campaign. The organisers at GOSH plan to target all schools and major businesses and with the aim of raising £2m for genetic research. MPS will benefit significantly from this appeal and if you are not already on the mailing list please write for an information pack to Jeans for Genes National Appeal. FREEPOST (SWB20118), Bournemouth, Dorset, BH8 9BR.

'All in the Genes'

Much has been made in the national press about the sheep called 'Dolly' and

the technology to produce a clone. I was invited to a preview of 'All in the Genes' a TV programme shown by Carlton on 11 March which mentioned Dolly but more importantly, looked sympathetically at many of the issues raised by the potential of gene therapy. Pictures of MPS children and their parents were movingly portrayed with links to the Childhood Wood and Mary Pagett expressing her feelings, not only as an MPS employee but as a mum who has had an MPS child. I hope that Carlton will be able to supply a video of the programme for use by the society.

The future of MPS

Many thanks to the people who contacted me with their views about the future of the MPS Society. At the Trustees meeting we discussed 'Towards 2000 - A Strategy for the Millennium', which touched on many issues fundamental to MPS sufferers, parents, supporters and friends. We concluded that the work of the society is expanding and there is an urgent need for additional resources. The expertise of the MPS staff is now recognised nationally and internationally. Our Director, Christine Lavery was tasked with submitting applications for grants to cover additional work within the UK and actioned to report back to Trustees in June. **Paul Leonard**



Pictured above are Paul and his son, Christopher who suffers from Fucosidosis and is five years old.

TRUSTEE NEWS

Unless you have met at one of the conferences most of you will wonder what the Trustees look like so we decided to publish some photos so that you can put a face to the name.

Rogues Gallery

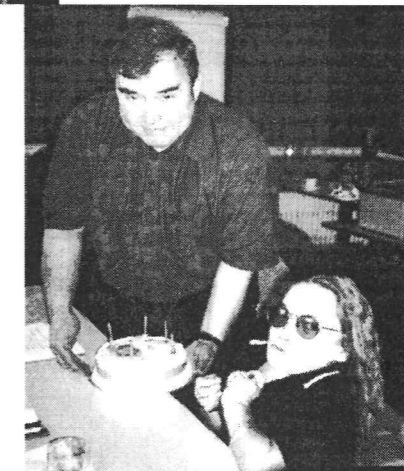


Right: Paul Leonard (Chariman) whose 5 year old son, Christopher suffers from Fucosidosis and whose son, John died aged 6 years.



Centre: Dr Bryn Neal (Vice Chairman) presenting Sarah Long (Morquio) with her birthday cake.

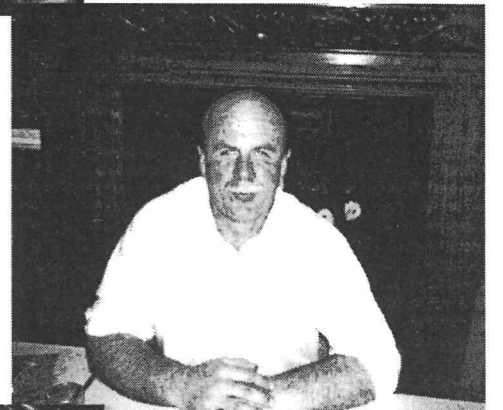
Above: Jon Lawrie whose 11 year old son, Stuart suffers from Sanfilippo Disease.



Sarah is the first MPS sufferer to be a Trustee.



Left is Peter Stuart whose 6 year old daughter, Jessica suffers from Hurler Disease.



Above: John Brennan, father of 10 year old Harry (Sanfilippo)

Right: Wilma Robbins is the mother of Gethin who died in 1984 aged 5 years old (Hurler)



Watch this space for the rest of the Rogues Galleryto be continued..

MILESTONES

New Families

Mr and Mrs Brown from Edinburgh whose son, Aiden aged 1 year old has recently been diagnosed with Hurler Disease.

Mr and Mrs Davies from Llangollen whose son, Ben aged 4 years old has recently been diagnosed with Morquio Disease.

Mr and Mrs Hamid whose 11 month old son, Aroosa has been diagnosed with Morquio disease. The Hamid family live in South Manchester.

Mr and Mrs Mc Greavey from Newry whose son, Coalan has recently been diagnosed as suffering from Gangliosidosis. Coalan is 1 year old.

Mr and Mrs McGratton whose daughter, Catherine aged 16 years has recently been diagnosed with Morquio Disease. The McGratton family live in Bangor, Co Down.

Mr and Mrs Onion from Staffordshire whose son, Jack aged 1 year has recently been diagnosed with Hunter Disease.

Mr and Mrs Pollock from Blackpool whose six month old son, Callum has recently been diagnosed as suffering from Hurler Disease.

Mr and Mrs Richards from Gloucestershire whose daughter, Hayley aged 1 year has recently been diagnosed with Hurler Disease.

Mr and Mrs Oyemade from London whose 6 year old son, Jonathon, has recently been diagnosed as suffering from Sanfilippo Disease.

Mr and Mrs Heisig from Newbury whose 4 year old son Jonathan has recently been diagnosed with Sanfilippo Disease.

Mr and Mrs Natrella's 10 month old son, Christian has recently been diagnosed with Hurler Disease. Christian and his parents live in Bath.

Deaths

Sadly Beaupascal Denyer died on the 22nd of February 1997. Beau aged 5 years old suffered from I Cell and our sympathies are with Tanya and Peter.

Sadly Coalan McGreavey from Newry who suffered from Gangliosidosis and was 1 year old died at the end of February 1997.

AREA FAMILY SUPPORT



Pictured opposite are
Helen Skidmore
{Hurler, BMT},
Ann Canton {Scheie}
and friend.



The Welsh Christmas Party was held on the 8th December at Clyndach Hall, Swansea. There was once again a great turn out with 35 adults, family and friends and 26 children. After eating at 2 pm everyone was entertained by the Mr Blobby followed by Father Christmas's arrival at 4pm. The day was enjoyed by everyone including face painting, balloons and a gift stall. We would like to thank Sue, Winford and her family for their hard work which made a very special day possible.

Ann and Mike Kilvert
Area Family Support, Wales

Pictured above is Chris Jones {Sanfilippo}, opening his present and below some of the children participating in the games.



AREA FAMILY SUPPORT

**First Welsh MPS Clinic
University Hospital of Wales, Cardiff
28th February 1997**

The first Welsh MPS clinic came to fruition on the eve of St David's Day. Dr Wraith and his clinical nurse specialist, Lorraine Burnett from the Royal Manchester Children's Hospital joined Dr Graham Shortland, Consultant Paediatrician at the University Hospital of Wales to jointly review thirteen children and young adults suffering from MPS.

Between consultations there was ample time for families to meet up with old friends and meet some of the newer members of the Society over a cup of coffee and a running buffet of sandwiches.

We hope that all those who had appointments felt the time was well spent. For one family it was an opportunity to cast aside a mistaken diagnosis of MPS and now look to the future with an even

rarer diagnosis but one that happily should be far less life-threatening than Hunter Disease.

On an even happier note whilst we all sat in the outpatient clinic Ceri Coleman whose 7 year old son, Joseph has Aspartylglycosaminuria was working even harder than any of us giving birth to their third son. We only knew when Andrew arrived single handed with Joseph for his clinic appointment. Needless to say it wasn't long before I had left the clinic in the capable hands of Alison Pullin (Trustee) and was making my way to the Maternity ward!

I would like to thank Graham Shortland for his support in setting up this clinic, to Ed Wraith and Lorraine for their time and to say that we are now planning the next two Welsh clinics for Autumn 1997 and Spring 1998.

Pictured opposite are Ceri and Andrew the proud parents.

FIVE YEAR OLDS with physical disabilities in Wales will now be eligible for assessment for powered wheelchairs, Welsh Secretary William Hague told the Muscular Dystrophy Group in Wales in a letter.



AREA FAMILY SUPPORT



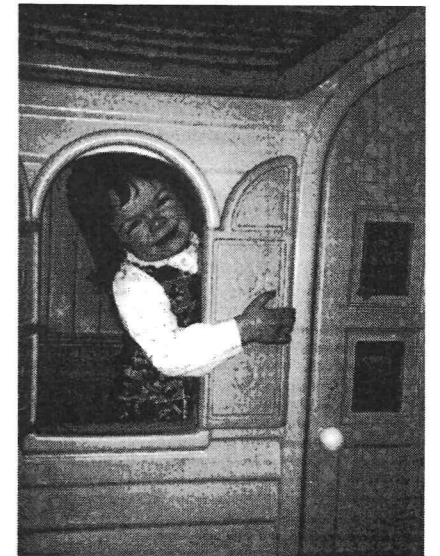
Six year old Craig Pope (Sanfilippo) with parents and Allison Pullin (Trustee)



Joseph Coleman (AGU)

**First Welsh MPS
Clinic 28th February
1997**

**These are pictures
of parents and
children having tea
and relaxing at the
clinic.**



Sarah McKnight (Hurler, BMT)



Ross Lockyer (Hunter, BMT) with Mum, Mary

AREA FAMILY SUPPORT

**NORTHERN IRELAND CONFERENCE AND CLINIC
21ST AND 22ND FEBRUARY 1997**



Above: Children in the Creche.



Above: Parents and delegates at lunch



Above: Kyle Shiels (Sanfilippo) and parents

Through the generous financial support of the National Lottery Charities Board and the DHSS for Northern Ireland, the MPS Society was able to offer the first MPS clinic for our children and families in Northern Ireland. This was followed by a one day Conference on MPS and Related Diseases.

In the clinic Dr Wraith was joined by Dr Fiona Stewart, Consultant Geneticist, Belfast City Hospital and other interested health professionals, as he endeavoured to see all 19 patients in just the one day.

Christine, Joan and I were on hand throughout the weekend to help where needed. At one point Christine, Joan Dr Stewart and myself were seen bodily carrying young Shaun McCawille, aged 6 years (MPS II) into the ladies in a bid to change his nappy.

The third one day MPS Conference to be held in Northern Ireland was well supported by families and professionals and was our most successful yet.

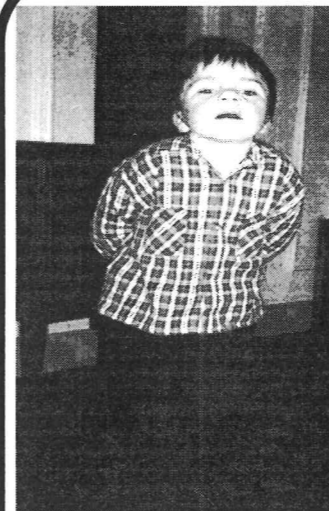
It was an opportunity for our new Chairman, Paul Leonard, to try out his control methods on Christine and I to keep the conference to time (not an easy task in Northern Ireland).

We should also like to say thank you Bernie Houston and the two volunteers who did a marvellous job of entertaining the children throughout the conference.

Mary Pagett
Director of Family Support Services, Northern

AREA FAMILY SUPPORT

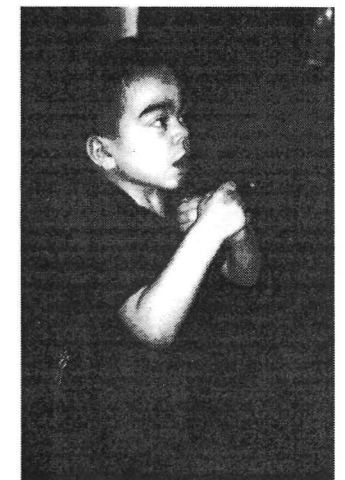
Northern Ireland MPS Clinic and Conference 21st and 22nd February 1997



Cillian Boushel (Hurler, BMT)



Gavin Fitzgerald and his sister, Rachel



Above: Shaun McCawille (Hunter)

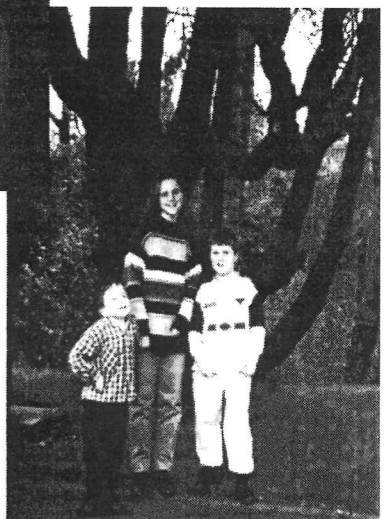


Above: Karen Ryan (MLIII)

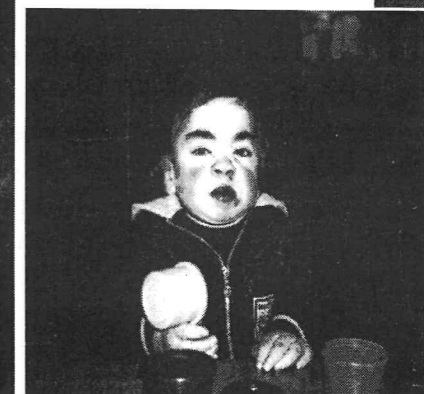
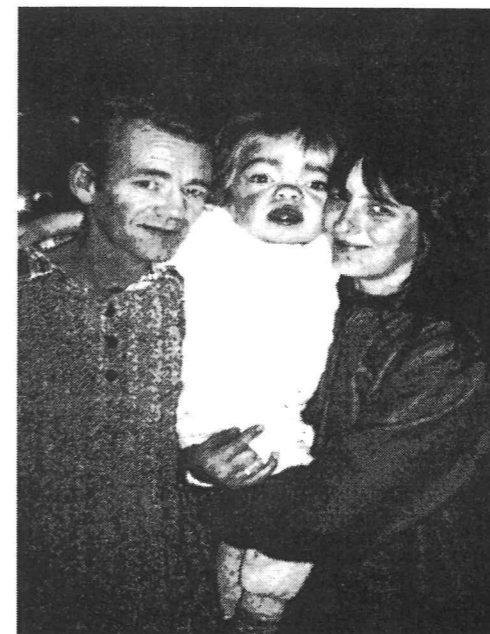


Left: Lucia Dawson (Hurler) and her parents

Left: Alison Murphy (Hurler)



Below: Michael Copeland (Hurler)



Above: Cillian Boushel (Hurler, BMT) with his sister, Grainne and his brother Donal.

FAMILY NEWS



After something like a two year wait, the photograph above shows Helen in her wonderful new Mangar chair.

We are all very grateful to Miles Swinbourne of Mangar (in picture) and also Allison Lomax of Gerald Simmonds (also in picture) for their care and attention to detail for Helens' complete comfort.

The chair is 'custom built' and has Jay seating fitted which looks and feels extremely comfortable and alleviates the problems of sitting in one position for long periods. It is with gratitude to the viewers of Blue Peter for their collection of junk mail, and Jamont who recycled the paper and gave the proceeds to Whizz Kidz who funded the chair and enabled Helen to find independence and self esteem.

We had looked at and had demonstrations of many powered chairs over a long period of time but Helen felt most comfortable in the Mangar Freestyle with its elevating power bringing her up to adult standing height which means she is not left out of conversations when meeting a group of people who inadvertently ignore her. Other benefits are more practical such as reaching shelves in supermarkets, cupboards and the cooker in the kitchen, post boxes, and so the list goes on.

During our first visit to Monmouth town we were stopped by Grannies whose grandchildren collected paper, and lots of people who just wanted a demonstration of this wonderful machine which Helen was very happy to comply with until we began to worry that the battery would not last for us to get back home.

Monmouth is only a very small town and therefore having lived here for some 20 years we are fairly well known, but for another reason we cannot be missed in the main street and visitors and complete strangers cannot fail to acknowledge us. Helen chose bright red tyres for her chair and the bellow cushions which elevate are red and black, We managed to persuade her not to introduce a third colour which would have been yellow!

During the past year Helen has become very interested in gardening and I couldn't resist including this photograph of her Gertrude Jekyll or Vita Sackville West impression, dead heading her Mesembryanthemums which she had planted under her apple trees. We call the seat she is sitting on her 'Tonka toy' which is very useful because it allows her to move around small areas weeding

FAMILY NEWS

and planting and under the seat there is space to keep her adjustable gardening tools.

We are entering a new phase in Helen's life where she will be leaving school next July when she is 18 and I must admit to having some reservations about the future. Hopefully we can find a place in a college where she can expand her gardening interests and continue to find some stimulation in further education. Will she be happy in a new environment having been with the same people for some 7 years or more?

Will she be looked after properly?

How will she cope?

What happens after college?

As a TV soap addict, Helen would be quite happy to stay at home all day in front of the box.

Having enjoyed a number of relatively medical problem free years, I find that with many changes on the horizon, once again I am having to learn to take one day at a time. After all we have all come a long way since the day of her diagnosis and on a recent annual visit to Great Ormond Street Hospital, Helen asked whether she would still have to make journeys to London when she is an old lady! I laughed whilst trying to think of an answer with thoughts of joy, achievement, concern and sadness.

For those readers who do not know us, Helen suffers from Hurlers Syndrome and received a bone marrow transplant at the age of 2 years old.

Pat Skidmore



We are very happy to report that Mangar International have decided to place an advertisement in our Newsletter. This is the first advertisement we have published.

FAMILY NEWS

Segufix Bed Belts

If you have a bed belt which you no longer require please return it to the MPS Office in Amersham.



Sales and Donations Welcome

If you have any used equipment which may be useful to another family please let us know so that we can advertise it in the newsletter..



Energy Saving Grants

Did you know that if you receive any of the benefits such as DLA, DWA, Attendance Allowance or Income Support etc. you may be eligible for a grant to insulate your loft, hot water tanks and draught proof your windows and doors?

To find out if you are eligible phone

**Home Energy Efficiency Scheme
on Freephone 0800-181667**

Another Fundraising Idea

Go Direct



When you have finished with laser and ink jet cartridges you may wish to contact the above company who will collect these and pay a donation to your favourite charity MPS!!!!

If you are interested please contact

**Go Direct Imaging Ltd
Tel: 01993 709007**



Parents at Work

Remember if you have problems finding work which suits your circumstances including suitable childcare and hours then contact.

**Janet Mearns
Parents at Work
45 Beech Street
London EC2Y 8AD**

Tel: 0171 588 0802

FAMILY NEWS

BACK↔CHAT BACK↔CHAT BACK↔CHAT BACK↔CHAT

BACK↔CHAT

MUMS AND DADS NEED NOT APPLY

We are looking for ideas from young adult and teenage MPS sufferers and also from their brothers and sisters.

We are aware that your parents probably try to deal with all the physical, medical and practical problems which occur. But you may have concerns which you feel are not very important to your parents but which are very important to you as a teenager or young adult either suffering from MPS or as a sibling to an MPS sufferer.

This page or hopefully two pages would cover issues relating to young people.

We would like to have a forum where you can express your feelings and these can be discussed via this Back Chat page.

You need not be identified if you are unsure of the reaction to your questions.

Hopefully the AIM of this page is that young people can voice their feelings and concerns with other young people who are experiencing the isolation of growing up with different concerns to their peers.

*As an example why not send us your thoughts on?????????????
Disco, clothes, friends?????????????/*

BACK↔CHAT BACK↔CHAT BACK↔CHAT BACK↔CHAT

BACK↔CHAT

Announcement of 1997 Research Grants

The Society for Mucopolysaccharide Diseases (MPS) is the only national charity and support group specifically for children and young adults with Mucopolysaccharide and Related Diseases, their families and carers in the UK.

The MPS Society will be receiving applications for research grants during April, May and June 1997.

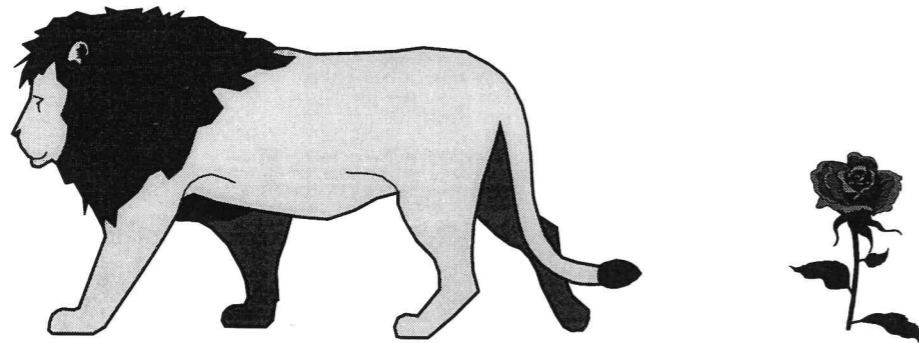
In 1996 we were able to award international research grants totalling £150,000.

For details please write to:

**Christine Lavery, Director
The Society for Mucopolysaccharide Diseases, 55 Hill Avenue
Amersham, Buckinghamshire HP6 5BX**

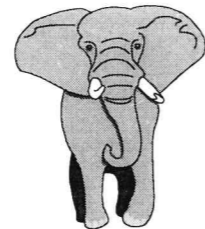
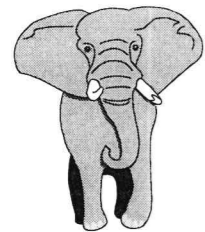
All applications are rigorously peer reviewed.

FAMILY NEWS



The Society for Mucopolysaccharide Diseases
Fifteenth Annual Conference
12 -14 September 1997
Stakis Country Court Hotel, Northampton

If you still have not booked there is still time. Do not miss out on the Conference and remember if you have any concerns financial or other please contact the Amersham office.



This is another idea for making donations which the MPS Society would benefit from directly and the income is spent on helping MPS sufferers.

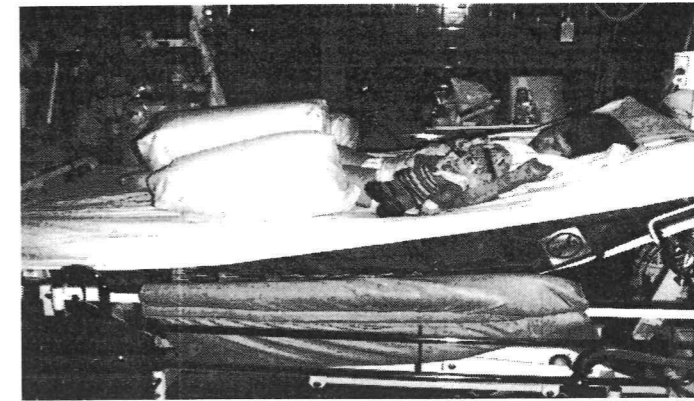
If you are a tax payer, the best way to make an extra contribution to the charity is by means of a deed of Covenant. By attracting significant benefits from the Inland Revenue, the value of your donation will increase by at least 24% by the time it reaches us.

An annual donation of £50 for example will be worth £64 to the charity. More examples are given in the panel. The same, incidentally, applies to single donations of £250 or more made under the Gift Aid scheme.

This applies to Donations made by deed of Covenant.

Amount you give	Amount we can claim	Amount we receive
£75	£18	£93
£100	£24	£124
£400	£96	£496

FAMILY NEWS



Pictured opposite and below is Kristina Briggs in her special new bed which was paid for by the Retford Lions Club and Nottinghamshire County Council. Kristina is 14 years old and suffers from Sanfilippo Disease.

The following is a copy of the correspondence going between Kristina's parents and her school.

11th March *Dear School* - thought you might be interested to know that there is a program on TV tonight called "Network First, All in the Genes". It is about genetics and the MPS Society was involved in the making of the programme. It is on at 10.40pm. Can you let everyone at the school know in case they should want to watch it. Mum & Dad.

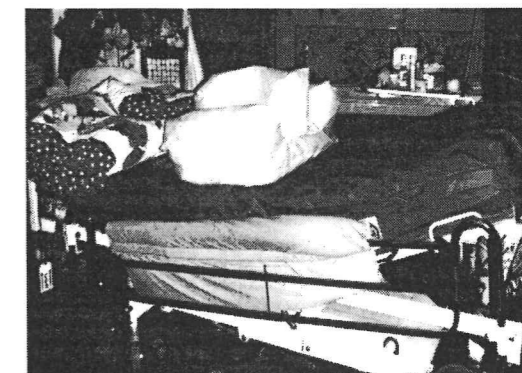
13th March *Dear Mum & Dad* - Another good day and Kristina has been awake most of the time. I have seen half of the programme and found it really interesting. Ed Wraith is not what I expected. My image of him was tall dark and distinguished, not sporting

a ponytail. He came across as such a lovely caring man, *is he married?* p.s. Is Kristina sleeping better at night?

13th March *Dear School* - Sorry to disappoint you but Ed is married with teenage children. Kristina has been settling between 2 and 3am and has slept soundly until 8am. 14th am Asleep by 12.30am!!!!did not wake up until 8am!!!!!!

14th March *Dear Mum & Dad* - Kristina has been fine and lovely all day. Slightly sleepy but soon woke. Could you please send some suppositories and gauze. Hope you have a nice weekend and I would like to join a fan club called E W G (Ed Wraith Groupies)

Any one interesting in Joining?



INFORMATION

The following meeting will be held at St Alban's Centre, London
Thursday the 15th May 1997

If you are interested in attending please contact GIG
{ Details at the bottom of this Page }

GENETIC INTEREST GROUP PROGRAMME

Addressing the Special Needs of Siblings Thursday May 15, 1997

9:00: Coffee and Registration

9:30: Chair's Introduction

9:40: Rosemary Tozer, University of York - 'Setting the Scene'.
Identifying the Special Needs of Siblings'

10:10: Emma Briggs, MPS - 'My experience as a sibling'

10:20 Christine Lavery, MPS - ' Genetic testing and Sibling issues'

11:00: Tea Break

11:15: Small Group Discussions : Discuss the special needs of siblings

12:00: Round up Discussion

12:30: Lunch

videos to be shown during lunch break: 'The Other Children' & 'We Were The Other Children' produced by MENCAP

2:00: Pauline Shelley, Contact a Family - Parent Workshops:

Addressing the Needs of Siblings.

2:30: speaker to be announced - 'Running a Sibling Group'.

2:50: Liz Harker, Tuberosus Sclerosis Association - 'Designing an information Leaflet for Siblings'.

3:10: Claire Dilworth, Christian Lewis Trust - ' Play Therapy for Siblings.

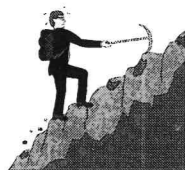
3:30: Coffee Break

3:45: Small Group Discussions: Practical Ways of Helping Siblings

4:30: Round Up Discussion

5:00: Close

For further information please contact GIG at
Farringdon Point, 29-35 Farringdon Road, London EC1M 3JB.
TEL: 0171 430 0090 FAX: 0171 430 0092 EMAIL: 101 366.760@compuserve.com
GIG is a Registered Charity Number 803424



There are still some places left for the MPS Family Holiday and for the MPS Teenage Activity Holiday. If you are interested in either of these holidays please contact:

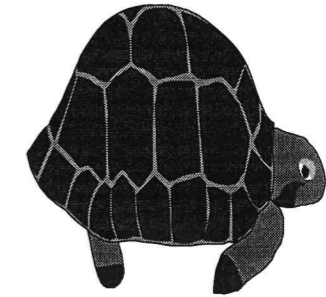
Mary Pagett
MPS Society, 168 Hesketh Lane
Tarleton, Lancs PR4 6AT



INFORMATION

If after reading this letter from David Briggs you feel you would like a copy of the Palliative Care Document please contact:

ACT
65 St Michael's Hill
Bristol BS2 8DZ
Tel: 0117 9221556



Copies are provided free to parents.

Dear Christine,

Thank you for the copy of the Guide to Children's Palliative Care Services Report. As you know Kristina's condition has been of real concern to us since the nine weeks in hospital last year. Trying to motivate the local Health Trust has been difficult. After eight months of constantly banging on doors we have finally made some progress. Due in a large part to the report and the information it contained. Certainly the recommendations at the start raised a few eyebrows and sent a couple of bodies scurrying back to their respective departments.



Kristina's OT certainly took notes to use when battling the various services she deals with. Suddenly the Wheelchair Services have been able to cut 6 to 8 weeks off their original estimate for making Kristina a wheelchair. Also they have agreed to do all the fitting at school and all of a sudden most of the difficulties in making it to fit Kristina's needs have disappeared.

The sections on page 10 were useful

in making it clear to the professionals that they had obligations under the Children's Act and that we were aware of them. It was also helpful to mention the UN Convention in 3.7 as no one had heard of it.

Most useful were the parts related to supplying sufficient aids and disposable material (i.e. page 25, Management of the child's physical symptoms). As you know we were struggling to obtain such basic things as suction catheters and syringes to give drugs with. This situation is much improved and we can now spend less time arguing with the Health Trust and more time on Kristina.

If you have the opportunity please pass on to those responsible for the report how much I am impressed with the way they dealt with the subject of palliative care and their recommendations. Could you also mention that the report has certainly helped our efforts to improve the support we get for Kristina. I also expect it to continue to be of use in clearing up a couple of problems that still exist.

Thank you for sending us a copy of the Palliative Care Document.

DAVID BRIGGS

*Father of Kristina aged 14 years
(Sanfilippo)*

INFORMATION

WHAT IS A CHILDREN'S HOSPICE?



The purpose of a children's hospice is to provide support and relief to families of children with life threatening/limiting conditions in the form of respite care in a home from home environment.

The burden of caring for a very ill child can be immense and parents quickly have to become experts, attending to their children twenty four hours a day, seven days a week. In time, the parents and family have to cope with their child's death.

The support some families receive from community and hospital professionals cannot be underestimated but sometimes they would love to just have a full nights sleep, a lie in, go to the cinema together, spend time with their other children or just "re-charge their batteries".



In a hospice they can choose to do all of these in the knowledge that staff are available to take on the caring role for them in an informal homely setting. Some families will choose to "opt out" of the hands on care enjoying a total break but still being present for their child. Others will want to continue with the care routine and seize the opportunity to share thoughts and concerns with others in similar situations, gaining strength and support. Still others will share care with the staff choosing to look after their child when they are around but enjoying a late night out together or a day out with their other children. Some parents will be happy to let their child

have a break from their own daily routine in the hospice, while they themselves enjoy a break in their own home.

When their child eventually requires terminal care, some families will want the 24 hour support of staff but feel that a hospital setting is not for them. Having built up a trustful relationship with the hospice staff, it may be the ideal setting for the family to cope with the eventual death.

WHO WILL USE THE HOSPICE?

Children up to the age of 19 years whose condition means that they will probably die before they reach adulthood. Medical diagnoses will range from muscular dystrophy, malignant tumours, metabolic and neurological degenerative conditions such as Batters Disease, MPS and adrenoleucodystrophies. Other children may be so profoundly handicapped that their life expectancy is limited.

Children and families will be welcomed irrespective of race or religious beliefs.

HOW LONG CAN THEY STAY?

Short term respite of long weekend or mid week breaks will be offered with one or two week stays being available once or twice a year in order for families to take a holiday.

Ten beds will be available; eight will be pre-booked and two beds reserved for emergency use, to cover Periods of family crisis or terminal care.

INFORMATION



WHAT FACILITIES WILL BE AVAILABLE?

Children will have their own bedrooms, activities room, music, computer and "messy play" rooms. The lounge and dining room are like those of an ordinary house (except perhaps a bit bigger!) and there is a large kitchen where the parents will be welcome to assist the cook with cooking if they would like to.

There is also a Jacuzzi, hydrotherapy pool, multi-sensory room and chapel. Parents will have their own bedrooms, kitchen and sitting room.

There is also an attractive garden with play and leisure facilities and a paddock area where our two Shetland ponies, "Robin" and "Bambi" will provide much amusement.



WHO WILL THE STAFF BE?

The team will be multi-disciplinary and will consist of qualified nurses, supported by other professionals such as physiotherapists, occupational therapists, teachers, play specialists, social workers and suitably trained unqualified staff.

The medical cover will be provided by a G.P from the nearby surgery and a local paediatrician will be available for advice and support.

WHAT WILL IT COST?

The service is free to families and children and no charge is made for

meals. The hospice is a registered charity and entirely dependent on voluntary donations.

WHO CAN REFER A CHILD TO THE HOSPICE?

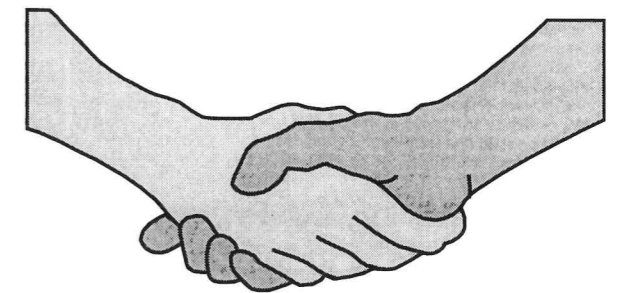
Referrals will be accepted from any source provided that the agreement of the family has been given. Medical confirmation of the child's condition will be obtained before a decision is made to offer the family the hospice services.

Referrals may be made in writing or by telephone to Joan Anderson (Head of Care) or Peter Lee (Doctor) at the address below.

FURTHER INFORMATION

Please contact the Head of Care, Joan Anderson RGN RSCN or the Administrator, Jean Miles, if there is any more information we can help you with. Telephone 01962 774895 or write to The Police House, Micheldever, Winchester, Hampshire S021 3DF.

The Wessex Children's Hospice Trust is a registered charity. Registration Number 1002832.



INFORMATION



Anthea Hare is the Care Co-ordinator and Specialist Adviser for Richard House which will be London's first respite care centre providing specialist care for children with life limiting and life threatening conditions and their families. She has written this article.

Richard House London's First Children's Hospice

Richard House Trust has embarked on a capital appeal to raise £3.8m to build and equip Richard House which will be built in Beckton, East London on Docklands designated land. The charity was recently awarded a grant of £616,318 from the National Lottery Charities Board under the Health and Disability and Care programme.

Families may be referred from any London Borough but it is expected that most families will live in the London Boroughs of Newham, Tower Hamlets, Hackney, Waltham Forest, Barking and Dagenham, Redbridge, Camden, Islington, Barnet, Enfield and Haringey. Building Richard House in an area of great cultural diversity presents a unique opportunity for everyone involved to be innovative and courageous in designing and equipping the building, and most importantly, in establishing the patterns of care and support.

'**Looking Forward To Tomorrow**' is the motto for Richard House and to make sure it is a place for living, activities and facilities will be planned with that foremost in mind. The range of activities will include play therapy, multi-sensory play and off site

activities to meet the needs of babies, toddlers, pre-school and older children and young people. There will also be quiet areas for conversation, quiet games and story telling.

The sense of being a place for living must also extend to the whole family and especially to brothers and sisters. They must all see Richard House as a bright and happy place where they too can have fun, play games and go on picnics, but it is also a place which faces the challenges of tomorrow without fear and it will still be there after a loved son or daughter, brother or sister has died, to offer support, friendship and counselling to the whole family if requested.

I have both personal and professional experience of what it means to care for a child with a profound disability or life threatening illness. My late brother Richard (after whom Richard House is named) was severely disabled by the pervasive development disorder Autism which affects both social and communication skills. His unexpected death in 1971 at the age of 26 gave me a greater insight into what siblings experience when a brother or sister dies. Later, during my professional

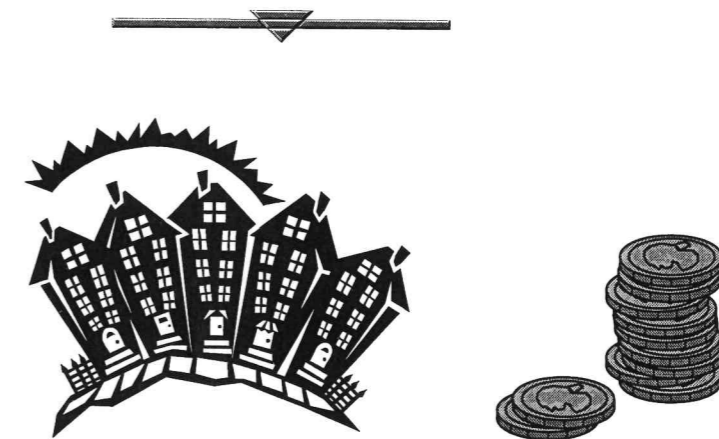
INFORMATION

career as a Paediatric Nurse I met many families who desperately needed to be able to share in the care of their sick or disabled child with people who would not only provide safe and loving care but also be able to support the whole family. From these personal and professional experiences came the idea for Richard House.

Richard House Trust has three main aims:

- To provide a service focusing on individualised respite care for children from birth to 19 years in a home-from-home setting which is flexible, accessible and responsive to the family's needs. This will include a versatile day centre which will also be open during the evenings and weekends.
- To provide outreach and domiciliary care which focuses on the child's home, nursing care, respite care, terminal care and other practical support. In addition, to provide bereavement counselling and support for carers, brothers and sisters.
- To provide hospice care which will focus on providing flexible, individualised palliative and supportive care. To provide the best quality of life for the child and family, which can continue into bereavement for as long as may be required."

For further information contact Anthea Hare, Tel. (0171) 511 0222



Rules for Disabled Facilities Grants

Items that are unchanged from the rules which applied under the 1989 Local Government and Housing Act:

- DFGs are mandatory for the items specified in the Act
- The Housing Authority must decide whether it is reasonable and practicable to award the grant
- There are also discretionary DFGs
- The limit for mandatory DFG is £20,000 in England. The parents of a disabled child under 16 years are means tested for a DFG and the mortgage or other outgoings are not taken into account

FAMILY NEWS

Items that are different from the 1989 Act:

- Discretionary DFG may be used for mandatory items
- There is a new mandatory item (section 23.1b) which is for 'making the dwelling or building safe for the disabled occupant and other persons residing with him.' This has been included specifically with the needs of children with challenging behaviour in mind.
- The Housing Authority's budget for DFG in England will be ringfenced and all DFGs, both mandatory and discretionary, will have to come from it, unless extra credits can be found. (Meanwhile the allocation for Renovation Grants will be cash limited, with no provision regarding extra credits.)
- Properties no longer have to be made fit before DFG may be given. Social Services may nominate someone who is not an Occupational Therapist (a GP for example) to carry out an assessment for DFG, if there is a long waiting list
- Payment of DFG after approval has been given may, in exceptional circumstances (i.e. where it would not cause hardship to the applicant) be deferred for up to 12 months from the date of the application, where the LA is short of resources.

Note: This Act has abolished mandatory Renovation Grants (RGs). All RGs are now at the discretion of the housing authority.

Changes to Minor Works Assistance (MWA) in the 1996 HGCR Act

- What used to be MWA is now called Home Repairs Assistance (HRA)
- The maximum is now £2,000 per grant or £4,000 in 3 years
- It may now be given to anyone who is "elderly, disabled or infirm" and the "disabled" includes disabled children. who were not eligible for MWA. This change does make it possible to use HRA to help some disabled children.
- HRA may be used for mobile homes, moored boats and other categories of dwelling not eligible for MWA

Factors from the Housing Act 1996 (as distinct from the HGCR Act 1996)

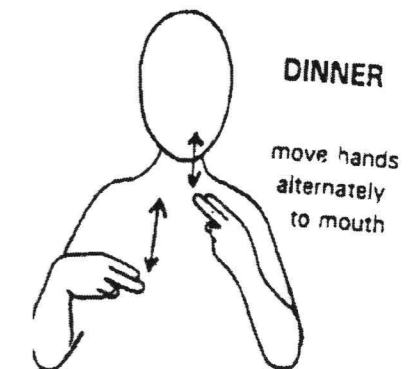
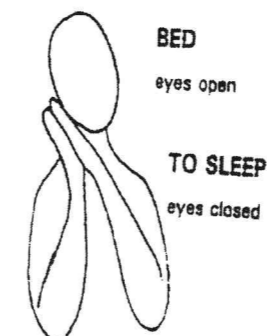
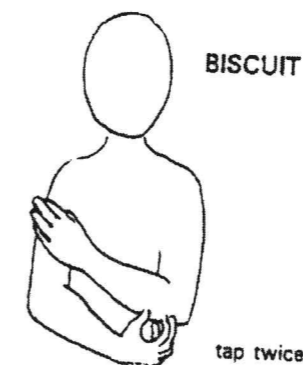
- Groups who are to be given priority for housing by local authorities include those living in "unsatisfactory housing conditions" and the guidelines are expected to indicate that "unsatisfactory housing conditions" includes accommodation which is inaccessible or unsuitable due to disability.
- Accommodation offered to homeless people must be suitable for a person with physical disability if there is one in the household applying.

INFORMATION

For those of you interested in learning more about Makaton sign Language for you and your children :

Please contact : **Margaret Walker**
31 Furwood Drive
Camberley
Surrey
GU15 3QD

Tel: 01276 681368



INFORMATION



Child Bereavement

"Children in Focus" is a specialist service which has been developed by David Chadwick, who co-ordinates a group of funeral directors offering services to families at this very sensitive time. The emphasis is on the needs of the brothers and sisters of the child who has died, as well as parents. David Chadwick writes:

"Child bereavement is gradually being recognised as an area of major importance by professional bodies nation-wide. For years a small minority have campaigned to bring the needs of bereaved children to the forefront of the professional agenda. Working in partnership with hospitals, doctors and other professional bodies, funeral directors can potentially offer immense support and practical advice to grieving families. With the correct training they can also do a lot more to develop their services to take into account the needs of the bereaved siblings along with those of their parents. This is important, for it is believed that where children are offered help, advice and the chance to be fully involved in saying last goodbyes through the funeral, they will be better equipped to work through the bereavement in the long run."

"As parents reading this article, you may feel justifiably cautious about agreeing with this sort of thinking but it is the needs of parents that spurred the initiative called Children in Focus."

The project has been designed with a great deal of expert assistance and many months of research to offer parents a range of products and services that will help them to feel more confident about allowing their children the chance to say their own last goodbyes. By concentrating upon the needs of siblings, we are trying to support parents as they cope with their children's questions, fears and insecurities in the months following the death.

The Children in Focus scheme offers:

- *Practical advice and support about children's funerals*
- *A new range of products specifically designed to take the needs of grieving siblings into account*
- *A network of funeral homes available to parents in their local area through a free telephone number (see below)*
- *Information about related services which can offer follow up help and counselling should the need arise.*

For further information please contact:

**David Chadwick
Project Manager
Children in Focus
7 The Green
Wooburn Green
High Wycombe 10 OEE
Freephone 0800 801 4881.**



INFORMATION

Supporting Pupils with Medical Needs in School

The Department for Education and Employment (DfEE) and the Department of Health have jointly issued a new Circular (No 14/96) under this title. Accompanying the Circular is an attractively presented Good Practice Guide which includes eight proformas related to medical interventions in the school setting.

The circular summarises the legal responsibilities of schools in managing the medical needs of pupils in their care. Among its recommendations are that each school should draw up a policy and a set of procedures for supporting pupils with medical needs, and develop health care plans for pupils who require medication or medical attention at school.



The legal context in which schools are obliged to operate is quite complex. One can feel more than a twinge of sympathy for the teaching staff who should take into account the Health and Safety Acts, the Education Acts, the Medicines Act and the School Premises Regulations. Nevertheless it is essential that all schools have good procedures for supporting pupils with medical needs. Where these do not exist parents will be extremely

unhappy and may well be faced with the uncomfortable choice of removing their child from a school which is the best one for them, educationally and socially.

The Good Practice Guide identifies levels of responsibility for medication in schools as between parents, governors, head teachers, teachers and other school staff, LEAs, school health services, GPs and other health professionals. It also gives help on the contents of school policies and procedures in general, and on the safe handling of medicines and individual health care plans for children. Its final section focuses on "medical conditions which most commonly concern schools" and these are said to be asthma, epilepsy, diabetes, anaphylaxis and allergic reactions. These are certainly common, but there are many more conditions requiring medical support at school. Some specific signposting to the medical requirements associated with other conditions would have been helpful. There is a three page annex of useful contacts and helplines from which schools can seek information.

Copies of the Circular and the Good Practice Guide are available from

**DfEE Publications Centre
PO Box 6927, London E3 3NZ
Tel. (0171) 510 0150
Fax. (0171) 510 0196.**



INFORMATION

Is there life outside the family?

Studying- financial assistance

The following organisations invite applications from carers for help towards study fees. However, the courses they help with change from year to year, so you need to check with each one before making an application.

Laura Ashley Foundation, 33 King Street, London WC2E 8JD
Tel. (0171)497 2503. Helps carers between 18-50 years who have missed out because of caring responsibilities and are suffering severe financial hardship

The Princess Royal Trust Educational Bursary Scheme, 16 Byward Street, Tower Hill, London EC3R 5BR,
Tel. (0171) 480 7788

The National Extension College, Special Needs Scheme, 18 Brooklands Avenue, Cambridge, CB2 2HN. Write for details.



Paid employment

All families of children with disabilities know the difficulties of trying to combine work with caring responsibilities. This traditionally applies to mothers, but fathers also lose out because work demands do not take account of their children's needs. No wonder that fewer than one in five mothers of disabled children are in paid employment compared to three in five of all mothers!

Parents at Work is a voluntary organisation supporting all working parents, is now

campaigning to raise awareness of the particular needs of parents of disabled children. In 1995 a Parents at Work survey of about eighty parents identified the need to develop a special network. They have now produced a directory of parents who want to be in touch with others and are publishing a newsletter to enable them to share their experiences. In May 1997 there will be a conference where parents will be able to meet and discuss their needs. A practical handbook on how to balance the demands of working and caring will be launched at the same time.

The parents' network will be vital in informing the campaigning aspect of the work. It will enable **Parents at Work** to raise issues with employers about making more flexible working arrangements so parents can meet the needs of their children. They will also campaign for more appropriate day care and holiday provision.

If you wish to join the network please contact David Wainwright or Janet Mearns, Parents At Work, 45 Beech Street, London EC8AD Tel. (0171)628 3591



OVERSEAS NEWS

LIVING WITH MPS II

My name is Vaughan Glasson and my condition is Mild Hunter's Syndrome.

Life is a hassle but I guess we all have problems of some kind. Many people may have an individual problem which occurs from time to time but with MPS the majority of sufferers are affected all the time and in more than one way, thereby magnifying simple complaints.

I am twenty years old, currently employed part-time, working as a bookkeeper for Pepes Mexican Restaurant and as an administration assistant for the Commonwealth Rehabilitation Service(CRS). In addition, I am studying accounting at TAFE College. Accounting is not what I really want to do in life but it is one of the few things I can do.

I have come a long way to be where I am. Overcoming many obstacles but not without extensive support from my parents with their generous love and patience. My brother (who is unaffected by MPS), by his attitude, has given me strength to deal with negative attitudes of other people. My relatives and close friends helped with their openness towards me and my condition.

Awareness of my problems

During primary school I attended many doctors, specialists and had a few operations. I did not understand my condition until high school when I was unable to participate in many activities and hence noticed my difference from

others. Fellow students didn't understand my position, never asked, and so the majority had to put up with it without knowing about it. In high school there were a number of groups because of living in the same suburbs or having similar interests. I was accepted into one group in the beginning and appreciated them but by Year 12 I was part of every group at school. I hardly went out at night with the guys or on the weekend as it was a different ballgame for all to have me along. I was left as a friend at school. To go out with friends today is sometimes scary and it's a struggle to keep up. Breathing, hearing and height problems determine what I can manage in regard to what the others get up to.

Since high school I have very few friends who know me and my condition and will give consideration to my well-being while the rest don't know how to approach me and my condition. There are a lot of inconveniences that waste my time when meeting new people such as background noises and limited lighting to see new faces. I am accepted if I am accepted by the host. Depending on their background they may freely talk to me which is rare while others will keep to themselves. I get along better with adults as they have more experience of life and a mature state of mind. (I hope!)

Today I realise that I have to make a lot of effort to make the first move. (Yet it is hard with my problems.)

OVERSEAS NEWS

I have a number of problems, some noticeable and others not so obvious. The main problems are with sight, height, hearing, joints and breathing.

Eyes: Everyone knows that progressively losing one's sight is a scary and frustrating prospect. My eyesight is deteriorating faster than normal. I hope mine doesn't go too quickly. I began wearing glasses halfway through high school and nowadays I can't go without them in case I need to read something or see someone.

Height: Some of you may think height, or the lack of it, is not a big deal, however a couple of problems with it are not being able to see things over the heads of anybody in a crowd and being unable to reach objects from high places. I feel uncomfortable talking to people who appear to be up in the sky. I always feel different, out of place, and still the short bloke.

Hearing: I was born with a hearing impairment and when I had grown enough I began wearing hearing aids. I did not know it in the beginning but I used to become frustrated with myself and others because of this problem. My inability to talk clearly and hear others well, left me isolated, yet I managed to get by because of my ability to read actions and lip read others. I have had many ear infections which have kept me out of the water and consequently have impeded my ability to swim. Every night I have ear drops in both ears which is a bother but on the other hand it enables me to read a chapter of a book while the drops drain in (*hopefully improving my knowledge at the same time*). Speech therapy was a

routine before primary school and I had English tutoring during Primary school. Constructing sentences is hard for me, especially making sense to others. Because of the hearing problem it was only in Year 12 that I began to grasp English and its grammar. I still have to work at my English, slowing my thoughts and speaking more slowly. My speech has undergone many changes and even now some of you may notice errors. Also, I used to dislike talking on the telephone but recently I have gained enough confidence to use these at work, but only with phones that have a loud receiver. It sure beats walking to the next department !

Joints: My most pressing problem is with the joints in my hands. During primary school I had to wear splints on my fingers and wrists every night to keep the bone structure straight. I didn't keep this up as I got sick of them. They caused minor problems such as sweating in the summer and the inability to scratch the itchy spots. In high school I ended up having a carpal tunnel syndrome release operation which released tension in the wrists. This was a positive step as it enabled me to perform activities for a longer period without pain, such as playing the drum set and playing squash.

Physically I have adapted and can hold tools and cutlery, reach objects from high up and put clothes on. It is still a struggle to put socks on my feet though.

During primary school I did most things other kids did like cycling, skateboarding, running, tennis etc..

OVERSEAS NEWS

My ability to do these things made my condition less obvious to my school mates and therefore made them more comfortable with me. Yet my performance was never up to their capacity because of my restrictions. In high school I was advised by my doctor not to play contact sport because of my bone structure and my hearing aids being in the way. Instead of the physical sports and training after school, my main role in school sport was ball boy for the footy, cameraman for the basketball and I also participated in small bore rifle shooting. Everyone accepted me at school because of the forced environment, everyone putting up with everyone else for the six years though I did feel I was cheating on the others and felt left out of the "boys" activities.

Today I have given up most physical activities as I only last for a very short time. However, I do realise the importance of keeping fit and to keep my joints mobile, especially my back, I exercise by regular stretching and walk as often as possible.

Breathing: is my worst problem today, getting worse as I get older. After performing physical activities now breathing is harder and I often experience headaches and occasionally my face goes all red and I'm a wreck for the rest of the day. I overcome this problem by planning my outings, leaving earlier and allowing intervals of rest along the way.

Bronchitis often attacks me these days. It is my worst enemy as it knocks me out for at least a week.

For four years I have been using a machine called CPAP. It is an air-pressure machine designed to keep my airway open. It allows sufficient oxygen to pass through my body enabling my brain to rest and thereby function properly the next day. I have to use it every night or else you would be facing one grumpy bloke in the morning. I thought this would be a threat to my freedom and the last straw of my life, not allowing me to crash for the night at friends' homes without the machine. However, this problem hasn't really eventuated. You would think it noisy but I can't hear it, I feel only the vibration. MY parents and I have travelled to the far west and to the top end of Australia with it. As long as I look after the machine and there is a power point to plug into, I can take it with me anywhere, while everybody else has to put up with the noise.



Above is a picture of Vaughn.

OVERSEAS NEWS

The following is a letter we received from a family in Finland. We would be pleased if any of our UK families would like to write to this family.

Dear Christine

29th February 1996

We are a family from Finland. We have two children: fourteen-year old daughter Pauliina and twelve-year-old Jussi-Pekka. Jussi-Pekka suffers from Hunter disease.

Last May there was organised an MPS meeting for the first time in Finland. It was there where we met, for the first time, other families with a MPS children. We got a lot of information there and we also heard about your Society. Before we were in a way all alone with our problems; even the doctors couldn't always give answers to our questions.

Now, after having a few of your Newsletters, it feels great to read how the other families cope and we experience that we are not the only ones contending with this disease. Especially the articles about Hunter boys have been interesting. Reading stories about the Norwegian boy Einar has interested us very much. It is also great to read how the researchers are working hard to find a possible cure. We really hope that they would succeed in this attempt. We wonder if any of the alternative treatment (e.g. homeopathy) has helped?

Jussi-Pekka goes to a special school, driving there by taxi. Once a week he has both physiotherapy and music therapy, which is his favourite. He does not play any more, but enjoys it when we are reading familiar picture books or singing children's songs for him; sometimes he sings tra-la-la even himself. Earlier he could say some words, even some simple

sentences, but today he has only the word "mummy" and babbles some of his own sounds. Mostly he is a very happy and adaptive boy, who whines rarely.

We can not get suitable clothes from shops for Jussi-Pekka. That's why I (his mother, Paivi) sew almost all his clothes by myself. Buying shoes is also problematic, because he has so small and roundish foot. He has a tricycle, which he rides when he wants, but there must be an adult to be responsible for the steering. In January we got a wheelchair for him. He does walk, at least short distances, but his walking is very slow.

We have never met another child with Hunter disease, but I have been writing with another Finnish family with a Hunter-boy. Their son is younger than Jussi-Pekka. I would like to start to correspond with a family with a Hunter boy of the same age or older than Jussi-Pekka (thirteen years old or older).

It would be great to take part in a MPS conference one day, but it may be economically impossible. Besides, we don't speak English. Fortunately my sister has promised to translate your Newsletters into Finnish.

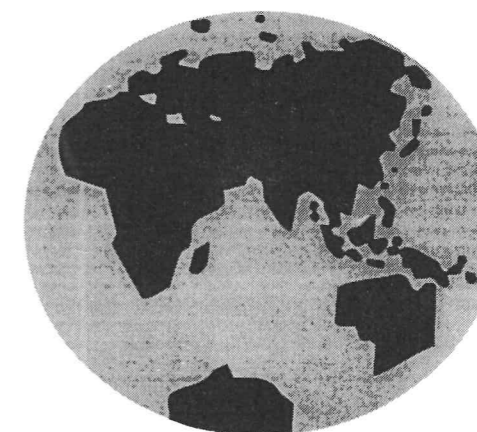
We wish all the best to the Society and its staff.

Paivi and Pekka Wallin
Vauntie 1
Fin-21530 Paimo
Finland

OVERSEAS NEWS



Pictured opposite is Jussi-Pekka who is 12 years old and suffers from Hunter Disease.



TAIWAN

Some of you may remember the Chou family who lived in England before returning to live in Taiwan. After the example of the British MPS Society they decided to set up a society in Taiwan.

Christine, Dr Ed Wraith and Mary Paggett have been invited to next year's Taiwan MPS Conference.



Above is pictured David Chou aged 13 years old who suffers from Hunter Disease celebrating his birthday at McDonalds.



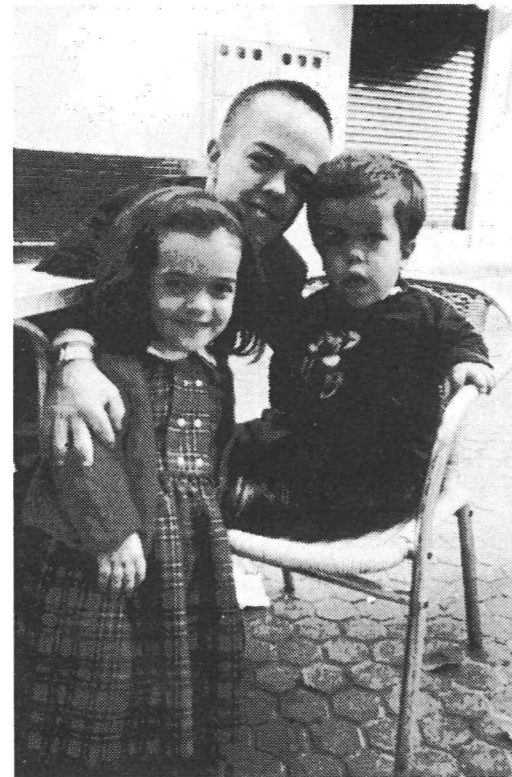
Pictured above are the Taiwan MPS families having a get-together at McDonalds.

OVERSEAS NEWS



Photographed above are Christine Lavery and Matthew Simms of the British Restricted Growth Association, in Seville at the Spanish Conference in February 1997.

Opposite is Matthew with two Spanish children who suffer with restricted growth and below is Christine with a Spanish boy who suffers from Hunter Disease.



Below are Matthew Simms and other delegates from British Societies funded by the EU to talk at this Conference.



FUNDRAISING

CHARITY BEGINS AT WORK

Increasing costs - coupled with an increasing need - have recently placed charities like MPS in a very difficult position, squeezing their resources to the very limit. This squeeze has been made all the more poignant as hitherto reliable sources of support have been hit by both the National Lottery and the recession to name but a few. Although large scale high profile fundraising events and fundraising campaigns do continue to raise both charity awareness and those all important funds. It is becoming more and more vital for MPS to secure their long term survival through the development of regular, on-going sources of income.

'This need can best be met through a donation scheme known as **Payroll Giving**, or **G.A.Y.E. (Give As You Earn)**, and your employer operates just such a scheme. It allows pre-tax deductions to be made from your salary and paid directly to MPS through your employer's Inland Revenue approved.' payroll giving agency. There is a "Charity begins at Work Directory" which is intended to provide you with the means and the

information to take full advantage of your company's Payroll Giving scheme. This publication contains more detailed information about the scheme, comments from a number of prominent and worthwhile charities and, of course, from 1997 details of the MPS Society.

Your company's Payroll Giving scheme is the best way you can provide regular support to the MPS Society. It works for you as a tax-payer and for the charity as a reliable long term source of income which is why, when you participate in your company's Payroll Giving scheme,

EVERYBODY WINS!

To help the MPS Society through your company's Payroll Giving scheme, simply consult with your Personnel or Payroll Departments. They will provide forms and finalise any remaining internal procedures for you. Your employer may even have set up a programme which matches your donation pound for pound, doubling the value of your generosity

so be sure to ask.

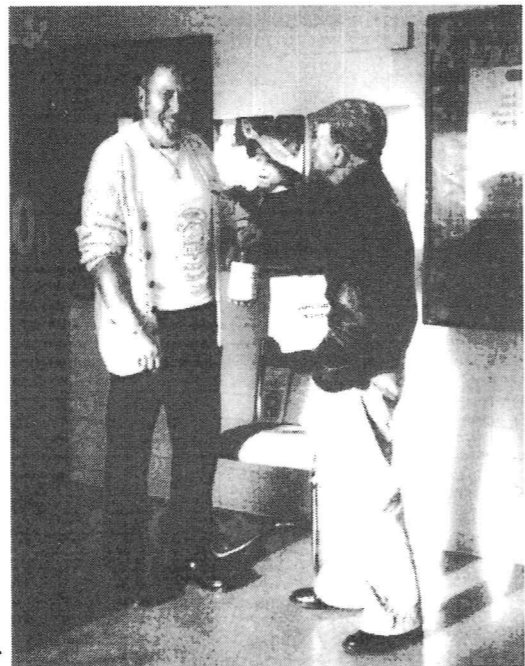
If you would like more information on **GIVE AS YOU EARN** please contact:

Your employer
or
Charity begins at Work
4 Newburgh Street
London W1V 2LH

FUNDRAISING

My name is Edward Hurdle and I am a friend of Rosemary and Harry Nurse whose daughter, Lisa suffers from Sanfilippo Disease. I have on several occasions raised money for the MPS Society by running half marathons. However I am no longer able to run as I did when I was younger.

I have a part time job with Sainsbury's, the Drove, Newhaven and on Monday the 2nd of December 1996, my day off, I made a collection on behalf of MPS. Mr Ratcliffe, the manager kindly gave his permission for me to take up a collection in the main foyer. This gave me an opportunity to meet the customers and to inform them about MPS with the aid of leaflets. One customer did in fact inform me that he would write to the Society regarding fundraising ideas. If I am in the position of raising funds for a charity it will be MPS.



Pictured above is Mr Hurdle who raised £71.14 and we would like to thank him for all his efforts.

Walking for Amy

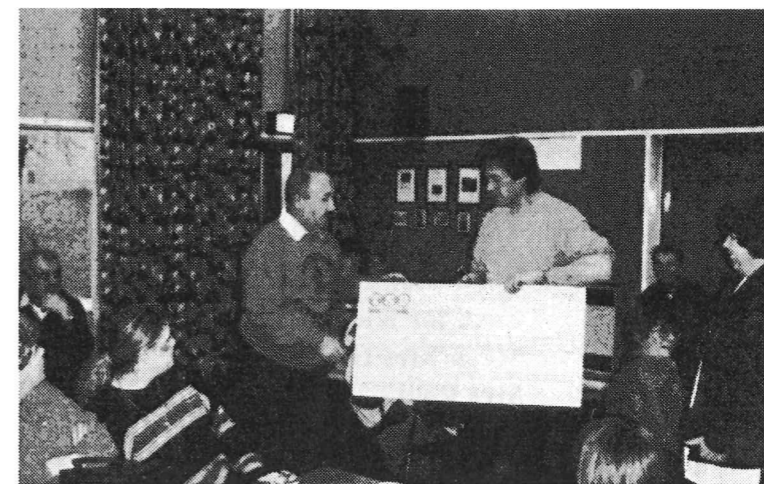
I am writing to let you know that we have now collected all donations from the sponsored walk and raffles we did for Amy.

We would like to thank all the people who took part in the sponsored walk and helped us to raise a grand total of **£2,375.67**.

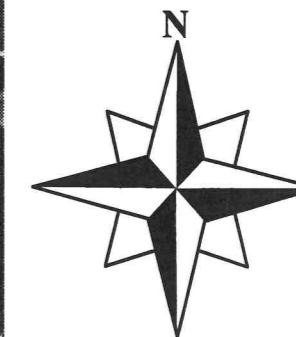
Moira, Ian, Katie and Amy Bray.



FUNDRAISING



Pictured above is John Hobson of the Littlemoor Motorcycle Club presenting a cheque for £628 to Jon Lawrie at the Clubs Christmas Party.



Earilier this year the Littlemoor Motorcycle Club from Ollerton adopted MPS as its charity.

The Club intend to continue fundraising and I would like to thank them for all their efforts.

In July 1996 the Club organised a coast to coast run to raise funds for the Society. The run was from Blackpool seafront to Filey seafront.

David Briggs Area Support Family {Yorkshire and East Coast}

We are Keegan Lovick's grandparents. Keegan has Hurler Disease and is two years old. He is a very happy boy who brings us all a lot of joy.

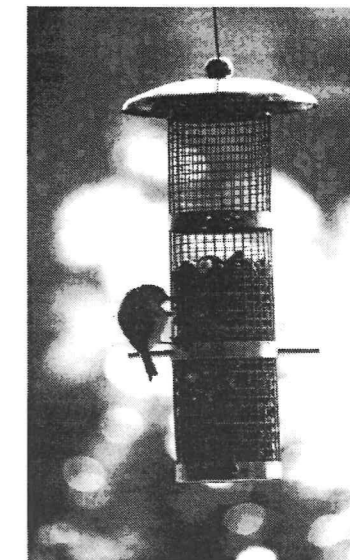
using photographs people had taken of interesting things and then sticking them to piece of card as a postcard. She bought envelopes and then encouraged people to buy them as Thank You notes, etc.

A very dear friend of ours decided that she wanted to do something to raise money to help Keegan and the MPS Society.

The lady's name is Mrs Peggy Draper and we would like to say a big Thank You to her.

She hit on the idea of

Mary and Brian



Above is an example of the photgraphs that Mrs Draper uses. She has already donated £50 to the MPS Society.

FUNDRAISING

DONATIONS

The Society is grateful to the following who made donations.

Mrs J Evans	Royal London Insurance
Mr and Mrs Canton	Cash for Kids
Mrs G Hughes	Mr & Mrs Hancock
Mrs Egan	Mrs Reid
Trudie Deacon & Jane Heritage	Mrs Sophie Sarin
Mr Phillips	Hettich Jewellers
Mrs V Wright	P C Gluckstein Charity Trust
Mrs C Garthwaite	Chesterton Ladies Circle
Mrs McNamara	Barclays Bank
DVLA & Lucas	Ben & Joshua Lemon
The Glynwed Charitable Trust	E Lightfoot
Mrs Angela Marriott	A Woodford
Mr and Mrs Maver	Dysart Development Ltd.
Peter Leijdekkers	Mr and Mrs Pack
R F Walker	Mr C R Gibbs
Bertram Books Ltd	Nutricia
The Topsy Toad Pub	NLCB (Scotland)
Eastern Electricity	Margaret Tarr
Colin & Josie Devlin	Rodborough Tabernacle URC
Ann Fraser	Mr and Mrs Woodhouse
Bass Taverns	Jackie Chisling
Cater Allen Holdings	Department of Health
Dr J Ritchie	Sarah Rogers
Scottish Daily Record	The Cadogan Charity
The Sandford Trust	NLCB (Wales)
Clifford Chance	Henderson Admin. Ltd.
Guildford Lions Club	Millfield Prep. School
Circuitt & Hinchcliffe Ltd.	John Carlton- Smith

FUNDRAISING EVENTS

The Society is grateful to the following who held fund-raising events.

David and Michelle Brookes Daw - The Nutcracker (Trull School of Dancing)
 Glenday, Harpenden - Scottish Dance School
 Christine Gooch, Tunbridge Wells - Knitting
 Mrs Peggy Draper, Witney - Using photographs for Notelettes etc.

FUNDRAISING

Stonelaw High School, Rutherglen - Sponsored swim
 Prospect Contract Furnishing, Hitchin - Raffle at Xmas Dinner & Dance
 Northern Ireland MPS Xmas Party - Raffle
 Sandra Singh, Coventry - Fancy Dress at Tesco's
 Boots staff especially Tigger - Cycle from Lake District to Hitchin
 Binns, Scunthorpe - Sponsored Walk
 Forbes & Lesley Hadden, Cheltenham - Raffle & Coffee Morning
 Peter Snelgrove, Cleckheaton - Cycled from Mirfield to Lands End
 The Student Union, Somerset - Ragweek
 The Oddballs Golfing Society, NI - Golfing Tournament
 Friends and family of Mr and Mrs Longley - Sponsored Swim
 Meet a Mum Association, hanham - Auction, Cake Sales & other events
 Mr and Mrs Creighton-Griffiths, Cardiff - Tracey Stewart's Bike Ride
 from Adelaide to Darwin

CHARITY BOXES

Monkhouse Sports, Cheadle Hulme
 Billy Ingham, Belfast
 Royal Oak Pub, Chapeltown
 Ann Kirkpatrick, NI
 The Chip Shop, Kidsgrove
 Val and Dennis Mort, Swansea
 Rise - Post Office, Dalsetter

DONATIONS IN MEMORY

The Society is grateful to the friends and relatives of

Bronwyn Frain (Michael Armstrong's Grandmother) Richard Mort

James Edwards Harry Smith (Daniel Croghan's Grandfather)

STAMPS

DVLA, Croydon Ann Thompson, Darlington Mrs E Shields, Kilkeel
 Mrs F McConnell, Kilkeel Mrs L Ricketts, Whitstable Mrs Garthwiate, Jersey

We would like to thank all those who sent us stamps but did not include their name.

Area Support Families



East Anglia

Robert and Caroline Fisher
The Horrells, Great Samford, Saffron Walden, Essex CB10 2 RL
Tel: 01799 586631

Julie and Trevor Thacker
20 Herolf Way, Harleston, Norfolk IP20 9QA
Tel: 01379 854204

Zelda and Paul Hilton
17 Stanley Drive, Sutton Bridge, Nr Spalding, Lincolnshire PE12 9XQ
Tel: 01406 351524

South East

Robin and Mary Gooch
High Bank House, Swifehill, Broadoak, Nr Heathfield, East Sussex TW21 8XG
Tel: 01435 883329

Michael and Karen Wheeler (*Only until July 1997*)
'Gildon', Balleagers Lane, Horsell, Woking, Surrey GU21 4SB
Tel: 01483 826135

Potteries

Bill and Sylvia Blackburn
11 Beatty Road, Nantwich, Cheshire CW5 5JP
Tel: 01270 626809

Geoffrey and Selma Oulton
37 Saville Road, Liverpool 13, Merseyside
Tel: 01514 752941

South West

Bill and Fer Pidden
5 Westbury Leigh, Westbury, Wiltshire BA13 3SE
Tel: 01373 865117

Gordon and Anne Hill
8 Hacker Close, Newton Poppleford, Nr. Sidmouth, Devon
Tel: 01395 567735

Home Counties

Mark and Rachel Wheeler
26 Tamarisk Avenue, Reading, Berkshire RG2 8JB
Tel: 01734 861063

Gavin and Denise Brown
32 Ellingham Road, Adeyfield, Hemel Hempstead, Herts HP2 5LE
Tel: 01442 395907

Wales

Ann and Michael Kilvert
Windy Way, Nantoer, Newtown, Powys SY16 1HH
Tel: 01686 624387

Area Support Families

Midlands

Sue and Jeffrey Hodgetts
6 Godolphin, Tamworth, Staffordshire B79 7UF
Tel: 01827 56363

Zerina and Sajjad Shah
37 Lowe Street, Wolverhampton, West Midlands
Tel: 01902 656147

Monty and Doreen Russell
71 Templemore Drive, Great Barr, Birmingham, west Midlands B43 5HF
Tel: 0121 6864779

Yorkshire and East Coast

David and Monica Briggs
7 Humber Street Retford, Nottinghamshire DN22 6LZ
Tel: 01777 700046

Barbara and Trevor Rollinson
43 Crosby Avenue, Scunthorpe, Humberside DN15 8PA
Tel: 01724 864115

North West of England

Martine and John Brennan.
105 Barley Cop Lane, Lancaster, Lancashire LA1 2PP
Tel: 01524 382164

Joanne and Gary Adshead
10 Church Lane, West Houghton, Nr. Bolton, Gt Manchester BL5 3PP
Tel: 01942 810109

North East of England

John and Barbara Arrowsmith
11 Penfold Close, Fairways Estate, Benton, Newcastle on Tyne NE7 7UQ
Tel: 0191 2921234

Ann Thompson
7 Sunningdale Green, Darlington, County Durham DL1 3SB
Tel: 01325 489920

Elizabeth and William Armstrong
21 Weldeck Gardens, Hartlepool, Cleveland TS26 8LB
Tel: 01429 236074

Scotland

Cath and Jim McLean
"Woodlee" 47 Oakdene Court, Culloden, Inverness, Highland IV1 2XL
Tel: 01463 791816

Clint and Karen Stevenson
6 viewfield Street, Harthill, Shotts, Lanarkshire ML7 5SN
Tel: 01501 752712

Alan and Fiona Byrne (*Telephone contact only*)
3 Jedburgh Avenue, Rutherglen, Glasgow G7 3EN
Tel: 0141 5695376

Northern Ireland

Kieran Houston (Chairman)
21 Cavanalee Road, Strabane, County Tyrone BT82 8HB
Tel: 01504 884168



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The Society for
Mucopolysaccharide Diseases

55 Hill Avenue, Amersham, Bucks. HP6 5BX Tel: 01494 434156 Fax: 01494 434252
Registered Charity No. 287034

