Newsletter

Spring 1994

The Society for Mucopolysaccharide Diseases

National Registered Charity No. 287034

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The Society for Mucopolysaccharide Diseases

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The MPS Society is a voluntary support group, founded in 1982, which represents over **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 the 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 a Consultant Paediatric Post and two biochemists, one at Manchester Children's Hospital and one at The Christie Hospital. 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

Deadline for Summer Newsletter

30th of June 1994

Director's Report

Holidays for teenagers also!

For the first time, as well as our two Summer family holidays in Yorkshire we are taking eight physically disabled teenagers who have MPS on holiday to the Calvert Trust on Exmoor at the May bank holiday. Once again we are fortunate that a group of Army volunteers from Hullavington will be joining us for a week of orienteering, watersports and most of all fun! We look forward to sharing the youngsters experiences in the next Newsletter.

Area Family Weekend.

Adventure was also on the agenda for the Area Family Training Weekend held in March at the Kielder Centre in Northumberland. Read all about it later on in the Newsletter.

Visit to Spanish Conference.

Some of you have realised from contact with the MPS office that I was overseas for part of March and April. Early in March I was a guest of the **"Asociacion A. Para Problemas De Crecimento"** who held their second conference in Seville. I was thrilled to be invited to speak on the work of the Society.

European Database for MPS Diseases.

As you know the European Database is up and running and presenting a considerable challenge to Joan and me as we work with an increasing number of MPS Societies, professionals and families throughout Europe.

Study visit to America.

Because of the rarity of the MPS diseases it is also important that similar data for the United States of America is available. I was invited by CSL, the Australian Company which is investigating the prospects for Enzyme Replacement Therapy, to undertake a feasibility study and spent seven hectic days meeting a range of experts as well as key people in the American MPS Society. Less than 24 hours after my return from the USA I was on a hovercraft to Germany to progress the German effort towards the European Database followed by a few days holiday. I would like to thank the MPS Societies of Spain, America and Germany for their generous hospitality and kindness during my visits.

Annual conference places.

On the home front work has continued towards the annual Conference. Whilst the deadline is now up we do have a few spare places for MPS families and urge you to get your application forms in very soon to avoid disappointment.

New Fund-raising Leaflet!

With this Newsletter you will receive a copy of our new fund-raising/awareness leaflet. I hope you will be as pleased with it as we are. A big thank you to Mary Gardiner our Northern Family Support Coordinator who master minded it and to the families who generously allowed us to use their pictures. These leaflets are available from the MPS office and can be provided in quantity for fund-raising purposes.

Christine Lavery

Director.

Southern Family Support Coordinator.

Milestones

Births

Congratulations to **Sharon and Darren Allen** from Acocks Green Birmingham of the birth of a healthy son **Matthew Thomas** (9lb.50z) on the 4th of April, a brother for **Daniel.**

Congratulations to **Eddie and Virginia Chou** from Stanwell, Middlesex on the birth of a healthy son, **Edward,** on 9th of February, a brother for **David and Julie.**

New Families

Mr and Mrs Ashworth from Adlington, near Bolton, whose son Mark, born 9th of June 1980 has mild Hunter disease.

Mrs Gemma Boyle from Londonderry, Northern Ireland, whose daughter Deborah, born 31st of March 1989 suffers from Scheie disease.

Mr and Mrs Carpenter, from Telford in Shropshire whose son Donald Steven, born 21st of September 1982 has been diagnosed with ML111.

Daz and Amanda Lemon from Talke, Stoke on Trent, Staffs., whose son Benjamin, born 22nd of December 1991 has been diagnosed with Hunter disease.

Alison and Neil Pickard from Southampton, whose daughter Nicole, born 31st of October 1990 suffers from Sanfilippo A disease.

Keith and Karen Stewart from Crumlin, Co. Antrim, Northern Ireland, whose son Lloyd, born 11th May 1993 has been diagnosed with Sialic Acid disease.

Deaths

Robert Culley from Alveston near Bristol who died on the 10th of February 1994 age fourteen. Robert suffered from Hunter disease.

Sarah Lowry from Harpenden in Hertfordshire who died on 25th of February 1994 aged nineteen. Sarah suffered from Maroteaux-Lamy disease.

Amber Le Page from St Peter Port Guernsey, died on 20th of February 1994 age sixteen. Amber suffered from Hurler disease.

Christopher Shorthouse from Sutton Coldfield, Warwickshire, died on the 25th of February 1994 age eleven. Christopher suffered from Hunter 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.

Future Events 1994

Date	Event	Contact
5 May	Golf Tournament in aid of MPS Strabane Golf Club, N. Ireland	Keiran Houston
22 May	North West Picnic Haigh Hall, Lancs	Martine Brennan
22 May	Yorkshire Area Barbecue Sheffield, South Yorkshire	Pauline Mahon/David Briggs
29 May to 4th June	MPS Teenage Activity Holiday Calvert Trust, Exmoor, Devon	MPS Office
18 June	South East Area Family Day Tillgate Park, Crawley, Sussex	Mary Gooch
19 June	Working Party, "Childhood Wood" Nottinghamshire	MPS Office
26 June	London and Shire Counties Barbeque, Milton Keynes	Ron Snack
26 June	Northern Ireland Family Barbecue Ballycastle, Co. Antrim	Sylvia Blackburn
3 July	Edward Nowell's Garden Party South West Family Day, Wells Somerset	Shirley Eyre
10 July	MPS Stand at Forest Open Day Sherwood Pines, Nottinghamshire	MPS Office
- July	Midlands Area Outing Twycross Zoo, Leicestershire	Sue Hodgetts
23-30 July 30 July to 6th Aug	MPS Family Holiday, Filey, Yorkshire	Mary Gardiner
-August	North East Family Outing Lightwater Valley	Barbara Arrowsmith
-August	Midlands Area Outing Drayton Manor Park, Leicestershire	Sue Hodgetts
11 Sept	London and Shire Counties Visit to Cotswold Wildlife Park Burford, Oxfordshire	Ron Snack
23-25 Sept	MPS Family Weekend Conference Northampton	MPS Office
October	MPS Mini-Conference Northern Ireland	MPS Office/Keiran Houston
December	North East Area MPS Christmas Party	Barbara Arrowsmith
4 December	Yorkshire Area MPS Christmas Party Sheffield	Pauline Mahon/David Briggs
4 December	Northern Ireland MPS Christmas Party Co. Derry	Keiran Houston
11 December	London and Shire Counties MPS Christmas Party, Milton Keynes	Ron Snack

If you would like more details of the above events please phone the appropriate contact. Addresses and phone numbers of Area Families inside back cover.

Second Planting of Childhood Wood

On Friday 25 February 17 oak saplings were planted in memory of MPS children who have died. Nearly 100 family members and guests braved 6 inches of snow to reach the "Childhood Wood". In the absence of Paddy Tipping MP, who'd slipped and broken his leg a few days previously, Sir Andrew Buchanan welcomed everyone to Nottinghamshire and read "Remember" by Christina Rosetti.

Because of the weather it wasn't possible to plant the trees on this occasion, but families were able to pick their spot and place the plaque. We are most grateful to Chris and Fiona, the Forest Enterprise Wardens for planting the trees on the families behalf when the snow melted.

Don't forget that the planting of spring bulbs, anemones round the trees is allowed. We are also looking at the possibility of introducing bluebells into the wood.

Childhood Wood Working Party

Sherwood Pines,

Nottinghamshire.

Sunday 19 June 1994 10.00am-4.00pm

You are invited to join a working party to clear wood and debris lying in the "Childhood Wood". Whole families are welcome and some activities for children will be laid on. We are also trying to secure help from the Red Cross but if you have a friend, grandparent or any other relative who can help you supervise your children please bring them along.

Marquee

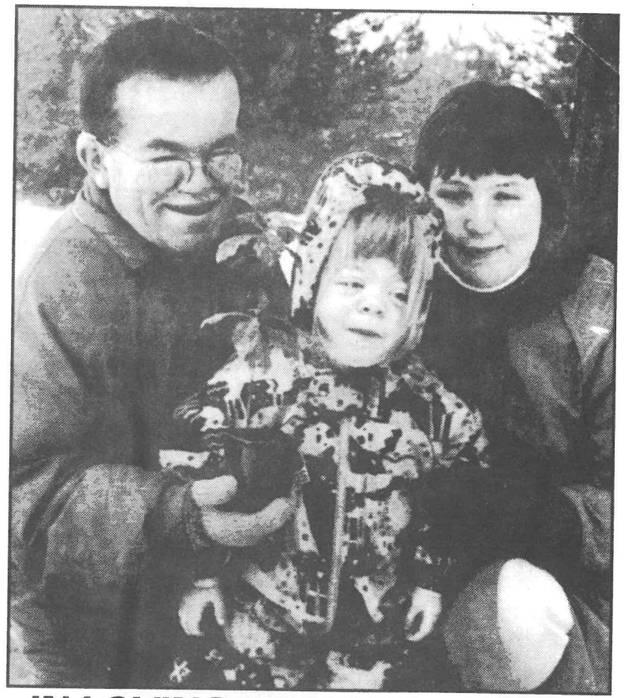
A Marquee will be erected adjacent to the wood in a quiet copse with a pond. Don't forget nets and jamjars for the children, also a change of clothing in case they get wet.

Lunch

A buffet lunch will be provided but please bring your own drinks. Hot and cold drinks can be purchased from the visitors centre.

Please reply

A form asking for details of those planning to come is enclosed with this Newsletter.



IN LOVING MEMORY... **Paul and Eleanor Gunary, of Bulwell, help Jessica Stuart, three, plant an oak sapling in the Childhood Wood, Clipstone. Jessica, of Borehamwood, planted the tree in memory of her brother Thomas. The forest has been created in remembrance of people who have died from mucopolysaccharide disease**

Spain

Asociacion A. Para Problemas De Crecimento. 4-6 March 1994.

This meeting in Seville was a little different from the MPS Conferences we are used to. The reason being that support to MPS families in Spain is covered by the umbrella of restricted growth rather than Metabolic Diseases. As a consequence most MPS families known to the association have children with Morquio disease.

However, both the organisation and professionals were very interested in the range of families in the British MPS Society, what we offer and how the Society is funded. It is early days for specialist support groups in Spain. **Dr. Ana Vernet Bari** presented a full paper on the clinical pattern of MPS diseases and it wasn't difficult to recognise that MPS families in the UK are fortunate that the clinical expertise available means our children can receive treatment, for hydrocephalus or cervical instability, for example, before damage is irreversible. I sincerely hope that it won't be too long before Spanish MPS families can benefit in this way.

Sadly, for one thirteen year old girl I met with Morquio disease, any treatment is too late. As a result of cervical instability she is totally paralysed, permanently ventilated and has lived the last 5 years on the Intensive Care Unit (ICU) of her local hospital. Just before I left my hotel for London a mother arrived to see me with her 14 year old daughter Rebecca who has Morquio. Her walking has almost gone but her spirit and smile are infectious. We discussed the possibility of Rebecca seeking medical help in this Country. As both Britain and Spain are member of the European Community and there are arrangements within the Community for meeting medical costs we are hopeful that this will happen. At least five Italian children with Morquio disease have received their cervical fusion at Manchester since I attended the Italian MPS Society Conference in 1991.

Thank you **Theresa Barco** for all your hard work.

Christine Lavery

Germany

Children's Hospice Initiative for Germany

In March 1993 we welcomed to Britain three members of the Children's Hospice movement in Germany. They are all parents of children with MPS who had come to England to learn more about Children's Hospices and to visit Martin House, Francis House and Helen House. Inspired by what they had seen and learnt the Children's Hospice initiative for Germany took on a new urgency.

The Committee have now produced a leaflet and poster and give talks seeking financial support. They have raised to date over 100,000 DM. Unlike the United Kingdom there is no tradition of fund-raising or donations to charities which makes the task all the more challenging.

A number of ex-patriot organisations including the British Embassy are raising money for the first Children's Hospice in Germany. Many of the British MPS families know first hand the benefits of a Children's Hospice for the whole family. How can we help Germany?

If you work for a German Company or Bank or know one in Germany who might be interested in the project please tell them. If you want a leaflet (written in German) explaining the Kinderhospiz please ask the MPS Office or write to:

Richard and Elizabeth Volk,

Kinderhospizverein e, V.,

Beethovenstrasse 6,

53489 Sinzig,

Germany

Tel: 010 49 2642 7022.

News

New Funding for the Society's Support Activities in Northern Ireland

We were delighted to learn that the Department of Health and Social Services in Belfast, Northern Ireland have recognised the work of the MPS Society by making a grant of **£3,000** towards family support in the Province.

In the coming months a family barbecue and Christmas Party are planned (see future events). We are also investigating the possibility of a mini-Conference (Saturday - Sunday) in mid October. Dr Wraith has kindly agreed to speak and we will open it up to all parents, professionals and interested friends and relatives. Once the date and venue are finalised we will be writing to all MPS families in Northern Ireland.

News from Germany

Over Easter we had an opportunity to visit with Jurgen and Brigitte Zumbro and their 16 year old daughter Natalie who has Sanfilippo disease, at their home in Bochum.

Jurgen and Brigitte founded the "Gesellschaft fur Mucopolysaccharidosen" in 1985. They have been regular visitors to our Parent Conferences over the years and we hope to welcome them to Northampton in September.

Sadly, neither Jurgen and Brigitte have enjoyed good health over the last year and at a time when Natalie has stopped walking and had difficulty with feeding. During our visit we learnt of a special message technique that the Zumbros have used on Natalie to encourage swallowing and chewing. The instructions are written in German but the accompanying illustrations are fairly self explanatory. Details are available from the MPS office but we would urge you to discuss this technique with your doctor and/or physiotherapist to ensure it is in your child's best interest.

Christine Lavery

Area Family Training Weekend 18-20 March 1994 Kielder Water, Northumberland

Eleven Area Families, Alf King, Mary Gardiner and I found ourselves only a few miles south of the Scottish border for a weekend of learning and team building. The programme included discussions on confidentiality, financial management of Society funds, fund-raising, support to the bereaved family as well as talks on the work of the Northern and Southern Family Support Coordinators and the role of the Trustees.

The Calvert Trust on Kielder Water provides superb facilities for families wanting an activity holiday where a member of the family is disabled. It offers a range of water sports, horse riding, rock climbing, abseiling and orienteering. Even so our Area Families didn't know what they had let themselves in for when they embarked on a session called "bridge building".

Dividing up into teams of five, one team were taken off to build a bridge across the river and operate an aerial runway. The other teams had to negotiate a challenging assault course transporting two buckets of water and convey it to the bridge to be conveyed across the river. One member had to be blindfolded and another stay mute. Team work was essential and everyone agreed that the course had been personally challenging.

The Volk Family Christening

Emily Claire and Hendrick Oliver, the 11 year old Sanfilippo twins of Richard and Elizabeth Volk were baptised along with their healthy brother Tilmann Ludwig (5 years) and sister, Sophia Leonora (6 months) at an Easter Day Service in the church next door to their home in Sinzig near Bonn. Over 100 people celebrated with the Volk family including many of the Rhineland MPS families.

Fund -raising with the Fire Brigade

We are Karen and Wayne Hoather and we have two sons, Simon aged six and Micheal aged five who suffer from Hunter Syndrome and a healthy daughter named Katie.

Our recent fund raising began early 1993 when we received a leaflet from Mary Gardiner about her "**Jeans for Genes**" campaign. Up until this time, we had always been told there was no hope of any halt to the disease our precious sons suffer.

We decided to go "public" and we approached our local paper, the Rochdale Observer, who covered our story with a full front page spread at Easter Weekend 1993. From there onwards the money came pouring in. The story was also covered by the Daily Express. That is how the Greater Manchester Fire Brigade got involved. My father was in the fire brigade since I was a baby and his long time "buddy" Peter Gribbon, now the county fire officer, read the story and gave the firemen permission to raise funds for MPS genes research. This resulted in the sum total of £8,000.80p being presented on the 10th February 1994.

In addition we have personally organised two Cabaret Nights, and a fashion show, and on our behalf there has also been a mammoth sponsored swim, numerous raffles, darts matches, a ploughman's lunch, a lingerie party and many other events to total so far in excess of £20,000.00.

We hope to continue to support those people who are still raising money for us locally but personally are hoping to let other people do their "bit" for a little while as caring for the boys and Katie and leading our lives as well as all the fund-raising is certainly starting to take its toll.

Come on MPS families, if we can do it, I'm sure you can and try, God willing, to pay for the research and hopefully a cure for our beautiful special children.

Thank you to Peter Gribbon, Peter Tyrell, Bernard Warr, John Harding, Steve Toukington and everybody who supported the fund-raising events.

Karen and Wayne Hoather

5 Upper Passmonds Grove,

Denehurst Park,

Rochdale, Lancs. OL11 5AH

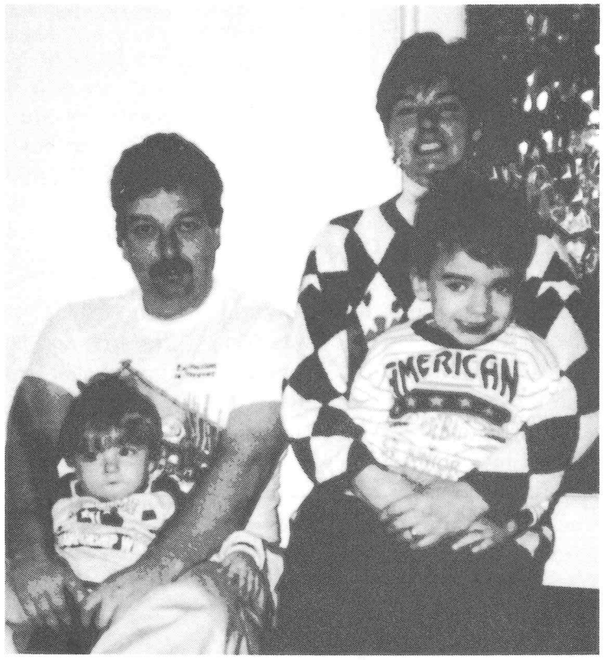
Karen, Wayne, Simon and Michael Hoather from Rochdale accepting cheques for over £8000 from members of the Greater Manchester Fire Brigade in February 1994.

Lynne Grandidge, Committee member

Hi! My name is **Lynne Grandidge.** I am a self employed bookkeeper working mainly from home. I have been married sixteen years to Chris and we have two children, Steven aged five and Ian aged one. I joined the management committee in September. My son Steven suffers from Sanfilippo and was diagnosed at two and a half years old which was the time we joined the society.

My hobbies are horses and reading. Steven loves the horses and I often take him to watch me riding or my friends at shows and horse trials.

Chris is a regional transport manager which means travelling quite a lot. He likes steam trains and sometimes takes Steven to watch or ride on them when they run nearby.



Chris, Lynne, Steven and Ian Grandidge, from Broughton, near Chester. Welcome to the MPS Committee, Lynne!

We like to get out as much as possible even though Steven cannot walk too far. We also try and have a holiday each year. Steven loves going away to different places. Last year we went to Disneyworld which he thoroughly enjoyed and so did we.

We go to the Northwest Area family days which can be recommended as a fun day out, with time to chat to other people who understand.

Walking the length of the land for MPS and other charities

Chris Bennett is a young and energetic fireman serving in the Greater Manchester Fire Service. He is going to walk "solo" from Lands End to John O'Groats starting on the 3rd September 1994. It is expected to take him about 57 days but no more than 60 days to complete the walk using mainly public walkways and national trails.

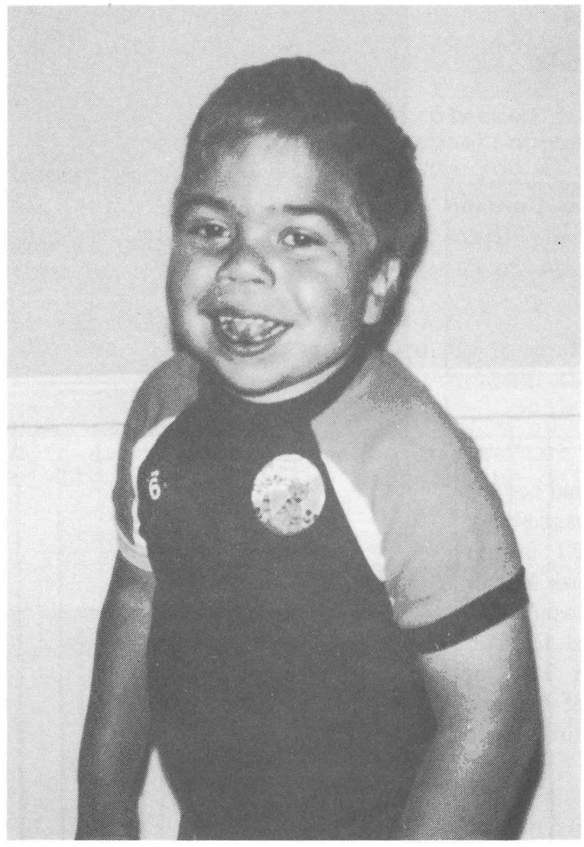
The MPS Society is one of four charities who will benefit from his efforts. The money will be raised through a national raffle - First prize is a car. It is hoped that as many families as possible will buy at least one ticket and manage to sell to friends etc.

This is not our national raffle but as we are one of the charities to benefit the least we can do is show our appreciation by helping. If anyone is interested in joining Chris for part of the walk, especially our friends in Scotland then I will be happy to give you further information or put you in contact with Chris personally.

Mary Gardiner

Robert Culley - In Retrospect

Our son Robert, a sufferer from Hunter syndrome, died on February 10th this year, age fourteen. As one of the "Founder Members" of the Society many of you will have known him through the years and will share with us the sense of loss that his passing has caused.



We were indeed fortunate that we were searching for support at the exact time that Christine was proposing to form the Society. Robert was therefore in at the start. Those were his "Hooligan" years, he would run and run and create little whirlwinds of chaos wherever he went.

Particularly clear in our memories is the first MPS conference in Birmingham when he was in reins and he ran us up and down the corridors and in and out of the kitchens. Similarly at the second conference in Harrogate we had that feeling of dismay when we looked at the dining room all beautifully laid out for tea.

Robert was a great table cloth puller and grabber. No need to worry though, when with MPS friends one doesn't need to explain.

All things pass and Robert slowly became less of a handful and entered what we now appreciate were his plateau years. He was content to spend a long time at one activity, such as building sandcastles, or just watching television while chewing a plastic toy. Skills gradually dropped away, so slowly that only by looking back one realised what was being lost. Through that long slide he always remained content. Even when tube fed he kept his dignity.

After a brief struggle on a clear starry night, Robert's spirit departed for its new life. His funeral was very positive, the little church was filled with all his friends, so many people whose lives he touched and so enriched in the process. So finally in the wintry sunshine we laid his body to rest in the soft clay of the Severn Valley.

Although we feel his loss with utter sadness, when looking back over his life we appreciate all the more the good years, and realise that every time he lost a skill he died a little, so at the end it was just one more loss. Now he does not have to lose any more.

"Say not in grief that he is no more,

But in thankfulness that he was"

Andrew Culley

Jeans for genes in Portishead

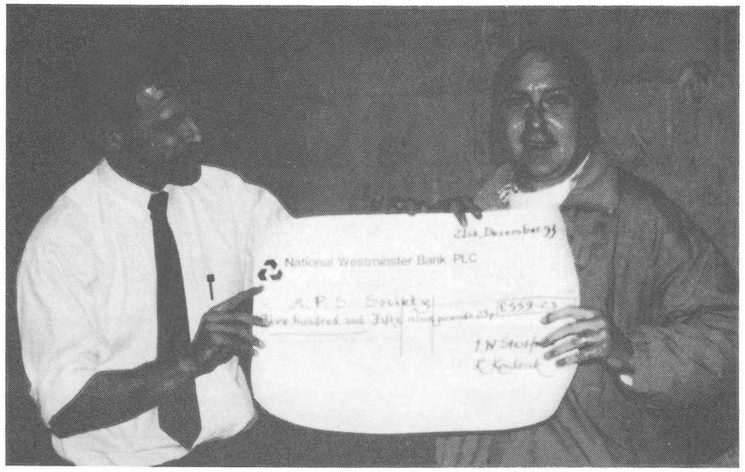
We have a son called Shaun who suffers from Sanfilippo disease. Our local school in Portishead (Gordano School) had raised £559.23 for the Society by having a Jeans for genes day. We went to the school to be presented with the cheque by Mr Hunter who is a teacher there and who made it all possible.

Mrs T Osment

17 Lowerdown Rd

Portishead,

Bristol BS20 9PE



Mr Hunter from Gordano School, Portishead, Bristol presenting a cheque to Peter Osment.

The school held a "Jeans for genes" day to raise the money.

Lynn Pienaar and her son T.J. live in Johannesburg, South Africa. T.J. is four years old and has Hunter disease. They would like to visit England for two weeks between 18th of June and 20th of July and spend some time with MPS families. If you would like Lynn and T.J. as your house guests, please contact **Mary Gardiner. 0772 815516**

Spring Sale!

MPS Ties embroidered with MPS logo

Special Offer £5.50!

(usually £6.50)

Order from MPS Office

Planting trees at "The Childhood Wood" on the 25 Feb.

(See page 6)

Farewell Letter from Ann Neal

Hawthorn
Weedon Hill
Hyde Heath
Bucks

Dear Friends

I felt I wanted to write this letter to you all via the Newsletter. By now most of you will know that because of a bout of ill health in September, I felt I should give up my paid employment with the Society. I am pleased to say that I have recovered well. I have enjoyed speaking to many of you on the telephone and of course meeting you at the Conferences and other events.

My intention was to carry on and organise the Conference for the last time in Northampton this year, but due to reorganisation in the MPS office, this was found to be impractical. So through this letter I would like to say thank you to all the friends that I have made during my years of working for the Society and organising the conference.

I have counted it a great privilege to look after you all and have especially enjoyed taking part in the childrens activities!

Best wishes to you all.

Ann Neal

Kieran Houston - Committee member

I live with my wife **Bernie** and our daughters **Ciara,** age eight and **Niamh** age two in Strabane, Co. Tyrone, Northern Ireland. I work as a building contractor. Our son. **Liam,** who had Hurler Syndrome, died on the 23 of December 1992 age five.

Liam was diagnosed in 1988 when he was six months old . We took him to Manchester to see Dr Wraith, where we also met Mary Gardiner and other MPS families. This was our first introduction to the Society and at the time we found it very helpful and supportive. We have continued since then to be in constant communication with the Society. In the summer of '89 we went on the MPS holiday in Filey and we also went to annual conferences in 1989 and 1990.

The Northern Ireland MPS Organising Committee was set up in May 91 and I became chairman. The following year I was co-opted onto the main management committee. I now travel to England approximately four times a year to attend their meetings.

Kieran Houston

15 Barrack Street, Strabane, Co. Tyrone.

Proud moment for disabled girl's parents -

Down the aisle- tears of joy on Amy's big day.

Tears of joy flowed from everyone's eyes when disabled bridesmaid Amy Oliver trundled independently down the aisle of Budock Parish Church, near Falmouth.

On an aluminium walking aid, designed and built by Falmouth welder Clifford White, Amy (2) followed the bride, her godmother Jacqueline Clark. Her only help was the gentle touch of fellow bridesmaid teenager Nicola Dickinson.

Mrs Oliver told the West Briton: "She was brilliant and went down the aisle without any problems. There were tears all round".

But the wedding was not without it's last minute hitches. It was discovered that the long blue dress that covered the walking aid was not quite long enough and the makers could not find more material.

Mrs Oliver said: "We managed to sort it out and Amy looked beautiful. She enjoyed being the centre of attention. Even the vicar took a shine to her."

Amy is one of only eight in Britain to suffer the incurable disease Mucolipidosis, which causes abnormal brain growth.

Neighbour **Valerie Millington** has set up a trust fund to raise money to send Amy and her parents to Disney World in Florida in the spring so that she can meet her favourite cartoon characters.

Meanwhile Amy's newly married godmother and her husband Duncan Watson are moving to Salisbury. Duncan, a chef in the Army, is based there.

"Cast a brick to attract jade"

I would like to take this opportunity to thank the MPS Society and Royal Manchester Children's Hospital, especially Dr Wraith and Dr Rothera, Mary, Christine, Linda and Ron for all your support during the last eighteen months.

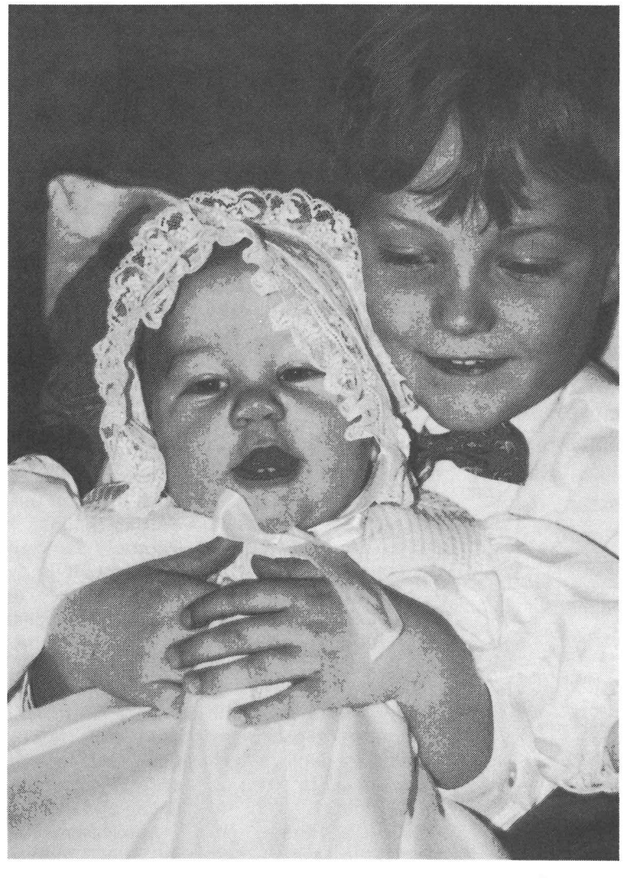
My family and I came to the UK from Taiwan and will stay about three years. (due to my job).

My elder son David, suffers from Hunter Syndrome but this was not confirmed until we visited Dr Wraith in November 1992.

I have to say it is really helpful to have the support of the Society and without your help my family would not have been able to overcome so many difficulties in 1993.

During our vacation in Taiwan in January last year David developed pneumonia. One night he suffered a nose bleed and the mucous caused his airway to be blocked and he lost his breath for three hours. The doctors managed to revive him but he was left with brain damage.

Three weeks later we took David to RMCH and stayed there until 29th of April 1993. David went to the theatre ten times. (A brave little boy). Mary came to us every other week in Manchester and encouraged my wife Virginia constantly.



Tilman and Sophia Volk from Sinzig in Germany on their baptismal day. (See page 8)

That three months in Manchester really gave us a chance to learn how precious life is. Virginia insisted we must try for our third child despite the painful CVS test.

Thank God a new baby joined us on 9th of March this year. Virginia and I have decided to call him Edward after Dr Wraith.

Finally I still have to say that MPS families need the Society. Without the Society we would not have Edward.

Attached herewith is a cheque to the Society. The Chinese have a saying, "Cast a brick to attract jade". Although it is a small amount it is given from the bottom of our hearts.

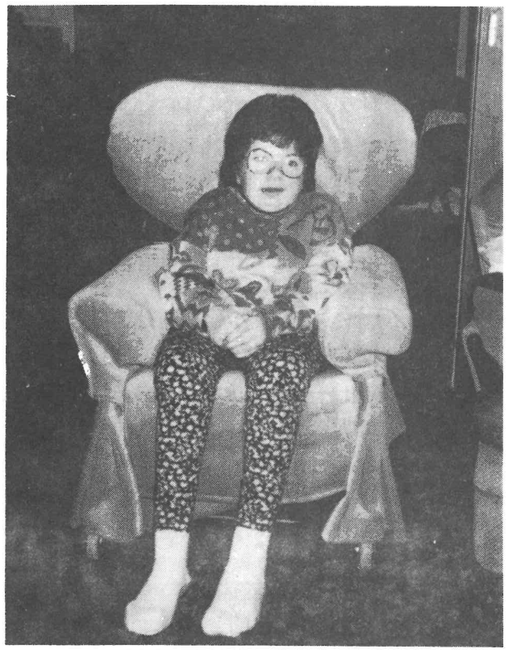
Eddie and Virginia Chou,

5 Chesterton Drive,

Stanwell,

Middlesex TW19 7BT

SITTING COMFORTABLY



Helen is 14 and has Hurler's Syndrome, a mucopolysaccharide disease which makes it difficult for her to sit comfortably because of general skeletal problems. She had a successful spinal fusion operation but requires regular physiotherapy in order to move and cannot even get across the room without her mother's help.

She is lovingly cared for at home, but in the last two years her mobility has decreased and as she is getting older it is becoming more difficult to get her up and down stairs, and to be comfortable during the day.

The family were able to afford a stairlift, but could not at the same time meet the cost of a special chair. Fortunately REACT were able to help towards the purchase of a Symmetrikit chair. It is designed to give therapeutic management of posture, which helps to prevent the development of further deformities. One of Helen's problems is that when sat on the floor she tended to lean to one side, causing the spine to curve unnaturally. The chair has been adjusted to give correct positioning and because of its versatility it will continue to cater for Helen as she grows. The chair is covered in a soft removable washable cloth and vinyl coverings are also available if required.

"It really has transformed her day," her mother told us. "She can now sit comfortably in the window and keep an eye on all the neighbours' comings and goings. We thank you for your assistance in meeting this special need."

Helen Skidmore shows off her "Symmetrikit" Chair. Helen is now aged fifteen and lives at Wyesham, near Monmouth, Gwent.

This caravan in the Isle of Wight can be booked by MPS families <u>at no charge.</u> August is fully booked but there are some vacancies in June and July and more in May and September. If you need help with the cost of a holiday and would like to be considered for this caravan, please contact the MPS office for a referral letter to REACT.

A WELCOME BREAK FOR FAMILIES

Parents caring for a terminally ill child endure considerable mental and physical strain in providing 24-hour care and support.

There is often also an additional financial burden, one or both parents being unable to work full time, and the expense of special diet, clothing, stimulating toys and equipment having to come out of the household budget.

Just getting away for a short holiday can make all the difference, but often is an expense that cannot be met.

REACT has over the past years helped many families to have a welcome break, to stoke up their energy, and to relax in a friendly environment with their child or children.

These requests are increasing and we felt that it could be economically more sensible to have our own REACT mobile home, on a well equipped caravan park, where families could spend a holiday together.

We have therefore purchased a fully equipped 8-berth mobile home, with 3 bedrooms, lounge/dining room, kitchen, shower, and flush toilet on the Haven Warner Holiday Park at Thorness Bay on the Isle of Wight. It is available from Easter to late October at no charge.

The Park is attractively landscaped and has its own beach, indoor and outdoor swimming pool, restaurants, and entertainments for young and old.

Applications for use of the REACT mobile home must be made via your social worker etc. direct to REACT at 73 Whitehall Park Rd, W4 3NB.

A tribute to Marc Dickson

I felt it would be appropriate at this time to write a few words about a very special friend - Marc Dickson. My first contact with Marc was as his teacher for a short time. Then he was an active fellow, and full of mischief, though in some ways he was beginning to show signs of puzzlement when not able to co-ordinate his movements. A short time afterwards when I returned as his permanent class teacher he had lost his ability to move around independently. At the same time he had gained the art of communication at the highest level through his eyes.

At no time was I unaware of how Marc was feeling or of what his wishes were. His eyes truly were the mirror of his soul, and he played an important part within his own class group, teaching them how to be gentle to him, and each other, simply by being there quietly beside them all. Pupils learned how to touch Marc gently, and they too absorbed the quiet of our class snoezelen corner with him, as well as sharing in the more active and noisy activities - where Marc could "opt out" or sleep when "enough was enough".

His health did not prevent Marc from travelling all over Lothian on educational outings with the class, relaxing in the warm water at the Trefoil Pool, crossing the Forth Bridge for a windy walk, and having a class November holiday up north, experiencing winter and then lunch round a log fire up at the Cairngorms, visiting Landmark, Inverness, Fort William and all the points within this triangle. Here at the cottage he shares with his class - the quiet of coming home in the dark under the stars, being in the mist at the top of Cairngorms, trying out different tastes at different restaurants, watching and listening to the Waltzing Waters of Newtonmore, and having picnics by Loch Worlich, Loch Laggan and Loch Inch. A very late night telephone call kept parents in touch with our travels.

Our friendship with Marc's family gave Marc time with us, and he made sure in his own way that my own family was quite aware of his wishes and feelings. These were the times of sitting in the garden enjoying the sun, watching and listening to the late night shows on video or television, or just being cosy watching the flames of the fire. We share these experiences which brought pleasure for everyone, despite the more serious contiuing concerns about Marc's health.

Marc spent time at Martin House, and, with his friend Daniel, became the inspiration for the move to build a hospice for children in Scotland. Started by a small group of parents and committed professionals, the urge to build the Marc Daniel house slowly grew. This small group worked tirelessly for two years, and now the movement has grown and is receiving much support on a nationwide basis. From a little thought, and much determination, will come a hospice for all children and their families in Scotland.

Although Marc died in March, his spirit and strong hold on life itself will remain in our memories, and the hospice will soon provide in Scotland the same help and care given to Marc and his family at Martin House.

A special pupil, a special friend, a special family, thoughts which light up life for us all. A year has slipped away just as Marc did on 23rd March 1993, and yet it is the clear memories of Marc and his life here which lead others to try to achieve as much as possible from life, just as he did, and to carry on where he left off. We remember him with love and affection, and now begin to write the next chapter.

From Patricia.

who taught Marc and learned from him.

Note: It has been decided that the Hospice for Scotland will now be called the Rachel Mc Robert House in acknowledgement of a donation of two million pounds from the Mc Robert Trust.

Michael John Edward Deacon
30 September 1942 - 18 February 1958

Nothing unusual when he was born.

Michael was our first child and weighed 9Ibs 8ozs at birth. We noticed nothing unusual about him and were thrilled when he learnt to stand at 9 months. He walked and talked well by the age of 18 months and started at the village school aged 5 years. He still showed no signs of disability.

When our GP came home from the war he took a look at Michael and asked me to take him to Great Ormond Street Hospital. I wondered why? I took him on the train, on my own, as by this time we had a 12 month old daughter, Pauline.

All I was told was that Michael was slightly backwards so we spent a lot of time teaching him. He was slow but he didn't seem too bad; Michael could ride a bicycle, knew how to go to the shop and went on his own to school the same as any other child. He led a normal life.

"Oh how I wish I had known more about his condition then we would have given him extra care."

By the time Michael was 7 years old I could see that he could not straighten his arms, his fingers were not too straight and he was knock kneed. We again returned to Great Ormond Street Hospital.

To a special school - and home again.

When Michael was 9 years old the welfare advised us to send him to a school for backward children at Hemel Hempstead, Hertfordshire. It was there he was given the slipper for wetting the bed. A German doctor saw him and advised us to have special shoes made for Michael, which we did. He also asked me to take him home. Our second son, Douglas was only a baby at the time.

I had Michael home again and by the time he was 11 years I was expecting Jane. The Welfare got on to me again and a week before Jane was born in May 1954 Michael was taken to Cell Barnes Hospital, St Albans. It was heart breaking to visit him, I wanted him home but no one would let me have him. We used to visit once a month, but I would have gone every day if I'd had the chance.

A loving child.

Michael was a loving child, so kind and tender. Oh how I wish I had known more about his condition then we would have given him extra care. He became incontinent but we accepted that. Michael died on 18 February 1958.

Until 1992 I knew nothing about the disease Michael suffered except that it was called "gargoylism". Now I know that Michael had Hunter disease, perhaps not the severest form. My daughter Jane is a carrier and we both went to the MPS Christmas Party in Milton Keynes. There for the first time we met other MPS families including Matthew Hardy who has Hunter Disease.

First meeting with MPS families.

In February I travelled to the **"Childhood Wood"** to plant a tree in Michael's memory. I was assisted in the planting by Sir Andrew Buchanan, Lord Lieutenant of Nottinghamshire. That day was the day I finally put Michael's memory to rest. I am now 72 years old.

Trudie Deacon

Michael Deacon (Hunter disease) aged ten in 1952

Mrs Trudie Deacon with Sir Andrew Buchanan at the Childhood Wood tree planting on 25th of February 1994.

Ron Snack and friends at an outing to London Zoo on the 10th of April.

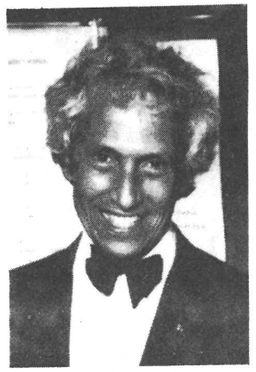
With the help of Robert Culley and Christopher Shorthouse, John Hopwood confirmed the finding of the gene for Hunter disease.

(See "In Memory", page 27)

LAUNCH OF ACT

The Association for Children with life-threatening or Terminal conditions and their families, better known as ACT, was officially launched in London on July 7th 1993.

This new national organisation developed from a research project under the direction of



Professor David Baum at the Institute of Child Health in Bristol.

CHILDREN

In surveying available facilities for affected children and their families Professor Baum's team began to highlight gaps in provision and a lack of recognition of the needs of this group. Until relatively recently it had been thought that the total number of children in the UK suffering from serious life-threatening illnesses was small but ACT's preliminary work suggested that there were likely to be at least 20,000 and that their needs outside hospital were largely unmet.

SIMILAR NEEDS

Such children had previously been considered from the perspective of their particular individual diseases; conditions such as cystic fibrosis, muscular dystrophy, organ failure, cancer or rare metabolic diseases. ACT is the first organisation to acknowledge that all these children and their families have similar needs and should have access to the same services and quality of care regardless of where they live or the condition involved.

The occasion was marked by the publication of ACT's 14-point Charter and its accompanying booklet which sets out the standard of care which should be available for all children with life-threatening conditions and their families. The Charter has been endorsed by 19 organisations concerned with such children and has the full support of the Secretary of State for Health, Virginia Bottomley MP, who in a launch-day message pledged that her Department would work closely with ACT to implement the Charter.

SUPPORT FROM REACT

ACT has a multi-disciplinary membership from which its Council is elected and the organisation aims to encourage the provision of new services, to represent the needs of affected children and to become a resource for information and data. REACT is among the many organisations closely involved with ACT and the trust has generously underwritten three ACT conferences which have done so much to bring together professionals, parents and carers and to address common problems.

Such collaboration and cross reference is vital in breaking through traditional barriers and working towards the ultimate goal of ensuring the availability of a full range of support services for every family in the UK. Only when such services are in place can each family truly exercise choice in their aim to achieve the best possible quality of life.

This article is reprinted with acknowledgements to:

REACT NEWS 1994.

What is ACT?

ACT is the Association for Children with Life threatening or Terminal Conditions and their Families.

ACT welcomes membership by professional bodies, national and local voluntary organisations, children's hospices, parent support groups, small professional units or teams, individual professionals and parents. As a strong collective voice ACT can affect policies, planning and provision of services, training, or any other area which can be usefully approached for the purpose of ensuring the best possible care for these children and their families.

The MPS Society is affiliated to ACT.

ACT
Institute of Child Health
Royal Hospital for Sick Children
St Michael's Hill
Bristol BS2 8BJ.
Tel: 0272 221556

ACT has produced a fourteen point "Charter for Children with Life Threatening Conditions and their Families", which can be obtained on request.

Offers and Information

Dear Editor,

Thank you for publishing my story in the Summer edition 1993. I was delighted when I saw my story in print. My friends were very impressed with the publication.

I said in my story that I enjoyed receiving mail from the MPS Society. I enjoy writing letters to my friends and receiving replies from them. I would be obliged if you could publish a little item on pen pals in the next issue.

I would be delighted to hear from anyone wishing to write to me as a pen pal. I'm sure there are other people like me interested in this project.

Yours faithfully,

Elena McGauran,

Glackbawn,

Calry,

Co. Sligo, EIRE.

Vessa Vision Power Scooter

Vic and Sue Lowry would like to offer a Vessa Vision Power Scooter which belonged to their daughter Sarah, who sadly died in February, to another person with MPS.

The white three wheeled scooter is a very smart modern machine in good condition. It is fitted for right hand drive control. (This can be changed if necessary). It has lights and a seat belt and a rear mounted basket. It is supplied by a firm called "Disabled Living" of Salisbury.

If you would like to know more please contact :

Vic and Sue Lowry,

16 Maple Rd. Harpenden, Herts.

Tel: 05827 69128

Emergency Aspirator

Paula Woods

32 Millgreen,

Park Farm,

Binfield,

Bracknell, Berks.

Tel: 0344 483618

has a Vitalagraph small **Emergency Aspirator** which she would be pleased to let a family have. If you are interested or would like more information, please contact Paula.

Stuart, in common with many Sanfilippo children we know, loves throwing and kicking things. All too often the things are inappropriate and his chosen goal is the TV screen or next door's garden.

We bought him a rather clever ball for Christmas. It is strong and brightly coloured and attached firmly to a long elastic. It's been a huge success with him - he loves the way it always come back to him.

It might also be suitable for some children in wheelchairs who could use the elastic to retrieve the ball themselves. It is called **"The Fitness Ball"**. It cost us £12.50 inc post and packing and came from:

A&N Sport,
30 Lacon Rd.
London SE22.

Kathie Lawrie
36 Dressay Grove
Hull, HU8 9JJ

Fixing Morquio Necks

Key articles published

In 1991 two articles were published in medical journals about treatment of Morquio necks. The authors are a London team of doctors linked with the National Hospital for Neurology and Neurosurgery in London. Among them are Andrew Ransford, Consultant Surgeon and Alan Crockard, Consultant Neurosurgeon, who together pioneered the successful treatment of Morquio necks in Great Britain, following advice from Dr Stephen Kopits of Baltimore.

The plain English version.

The articles are written in highly technical medical language so I have attempted below to give a synopsis in plain English. Because of the importance of the information I make no apologies about oversimplifying the articles. It is most important that families understand these articles and draw them to the attention of their medical advisors.

The problem.

Morquio children suffer from spinal problems both of the lower spine and more commonly of the upper neck where the spine joins the head. This has been a common cause of neurological damage, sometimes leading to paralysis or death either in late childhood or in early adult life.

Isobel Schwartz, Helen O'Toole and Heideros Wallberg, all have Morquio A disease.

What causes the problem.

The damage is caused by compression or "squeezing" of the spinal cord. What had been considered was that one of the bones of the spine slid over another bone and pinched the spinal cord between them because the ligaments holding them together are unduly lax in Morquios. The current work has shown that the bones and cartilage also become misshapen. There is a little peg called the "odontoid peg" which links the top bones of the spine. This has often been found to be absent or very small in Morquio patients. . It is likely that the failure of the odontoid peg to develop is a result of the undue flexibility and movement in the upper spine. It is considered that the absence of this peg allows the bones to shift around and so cause the damage to the spinal cord. There also tends to be a build up of soft tissue and this also compresses the spinal cord. The tissue is caused by friction due to too much neck movement.

Findings

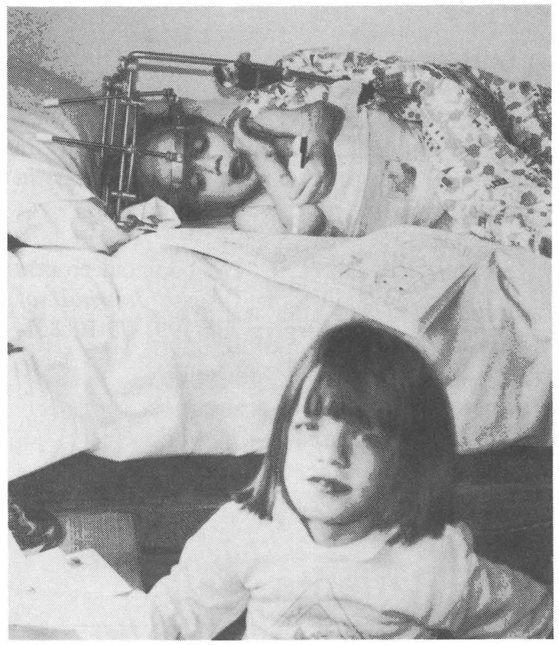
The study looked at a sample of thirteen patients using CT (computerised tomography) scans. This equipment allowed them to see variation in the soft tissues as well as in the bones. Some of their findings were as follows:

The bones at the top of the spine are deformed in all Morquio patients.

This is true from a very early age.

However, the bones are seldom out of place to a major degree initially.

The "squeezing" of the spinal cord is not due to the bones moving around and "pinching " the cord. What in fact happens is that the cord is squeezed by the thickening of the soft tissue in front of the spinal cord. The thickening of the soft tissue is due to undue flexibility and movement between the vertebrae. It is also due to abnormal development of the bone, which is a feature of the disease, but is increased by the extra movement in the neck.



Christopher Isaac with his neck fixed in a "halo" after cervical fusion. He is being visited by Helen O' Toole during the long wait for his bones to fuse together. Helen and Christopher were among the first Morquio patients to be treated in Britain using this technique.

This can begin to cause nerve damage at a very early age.

Early diagnosis is critical - but difficult to achieve.

The problem is difficult to diagnose as the swelling of the soft tissue does not show up on ordinary X-rays. Patients tend to be referred only when there are abnormal X-rays. By this time considerable neurological damage may already have been done.

Treatment

- **Patients can be treated by cervical fusion. This operation can usually be done from the back. In some patients it may be necessary to enter from the front, through the throat. Cervical fusion involves an operation in which the bones in the upper neck are fixed together with wire. Bone material from another part of the body is grafted on and allowed to grow to enable the bones to "fuse" together so they can no longer move about separately. This produces a solid arch of bony material growing from the spine to the base of the skull.**

Three to four months wait.

The neck has to be held rigid for the time that this takes to happen, which can be between three and four months. As Morquio bone is of poor quality it is important that the best bone is chosen for grafting. If the neck is fixed, the swelling around the spinal cord reduces down and the spinal cord compression is relieved.

Recommendations

Mr Crockard and Mr Ransford make the following recommendations:

- **All Morquio patients should be investigated for spinal cord compression between three and eight years. Some will already have been investigated because of concerns about spinal compression that have arisen earlier.**
- **This should be done by CT scan and, if available, MRI scan. (Magnetic Resonance Imaging). Plain X-ray investigation is not adequate.**

- **Evidence from X-rays about undue movement in the bones (subluxation) does not help decide whether an operation is necessary, as the damage is done by the soft tissue and not the moving bones. Some patients with spinal instability grow to adulthood without major spinal cord compression.**
- **Other forms of treatment, such as cervical laminectomy (an operation to widen the tube around the cervical cord) will not help.**
- **Treatment should not be delayed until neurological damage is evident, as this damage cannot then be reversed.**
- **Problems of the lower spine also need to be investigated and treated to prevent compression of the cord at the junction of the thoracic and lumbar vertebrae.**

References

Ashraf, Crockard et al. "Transoral decompression and posterior stabilization in Morquio's disease" ***Archive of Diseases in Childhood,*** 1991; 66, 1318-1321.

Stevens, Kendall et al. "The odontoid process in Morquio-Brailsford Disease"***Journal of Bone and Joint Surgery*** {Br}1991 73-B: 851-8.

The Newcomen Centre at Guy's Hospital Services for MPS Patients.

NEWCOMEN CENTRE
Tel No: 071 955 4072
Fax No: 071 955 4950

GUY'S HOSPITAL
St Thomas Street,
London SE1 9RT

A few months ago I was referred a nine year old girl called Rachel with a relatively common metabolic condition called Phenylketonuria. She had been very well looked after by her local Paediatrician but she and her family felt something was missing from that care - they had never met any one else with Phenylketonuria. Since meeting other children and families they have felt that the care is as complete as it can be. Rachel made me realise yet again how important it is for children with rare diseases and their families to have not only the best possible medical advice but also much more. When a condition is incurable although not untreatable the "much more" is particularly important. It consists of availability of other medical services such as ENT and orthopaedic surgery, dietetic and advice from therapists such as physiotherapists, and psychological support in all its forms. This support can come from professionals but also very importantly comes from other families who have been through the same situation.

Neurological problems are seen in many metabolic diseases, especially the storage disorders such as the Mucopolysaccharidoses. These neurological problems usually fall into five broad categories - developmental delay or regression (loss of skills), motor or movement problems, seizures, behavioural difficulties, deafness and blindness. Developmental delay and/or regression and the behavioural difficulties are often the most difficult things to manage. Careful and regular assessment is necessary to judge progress and it is essential to work closely with both community services and the educational department. The aim is to try to let the child fulfil his/her potential to the full in the best possible environment. Behavioural problems can be managed by various psychological methods but drug therapy is quite often necessary. Then it's a question of balancing side effects against the response. Motor or movement problems require assessment by physiotherapists and appropriate timing of referral and liaison with Orthopaedic Surgeons. Physiotherapists and Occupational therapists can advise about seating and other aids and the occupational therapists are able to help with the management of things like stiff joints giving ideas about suitable toys and equipment for daily living. Seizures may not require regular treatment depending on there frequency but again it's a balancing act between choosing the medication that gives the fewest possible side effects with the best possible fit control. There are many new anti-epileptic drugs now on the market such as Vigabatrin (Sabril), Lamotrigine (Lamictal) and Gabapentin which are much better tolerated and seem more effective than some of the older drugs.

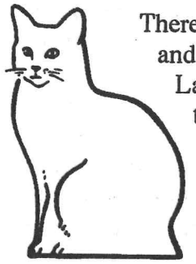
They also seem to have fewer side effects. The drug chosen will depend on the circumstances and the type of fits the child has. Deafness can have a neurological basis or in the storage disorders is usually due to middle ear disease. Again accurate assessment and correction by either treating middle ear disease or providing hearing aids can greatly improve the quality of life. Similarly vision may be a problem because of problems actually with the eye itself such as corneal clouding or due to problems in the nerve pathways which are important in sending the information to the part of the brain which interprets what the child sees.

There are a number of centres around the country who provide services for children with metabolic diseases, particularly the Mucopolysaccharidoses. At Guy's Hospital we try to provide a comprehensive service for both children and adults with metabolic disease, particularly those where there are neurological problems. It is a relatively new service but we hope that it will expand to provide the sort of service Rachel and her family found so helpful. The planned move of our department to St Thomas' Hospital should not affect this service in any way.

Dr Jane Collins MSC MD MRCP
Consultant Paediatric Neurologist

Animals with MPS Diseases

Humans share the the greater part of their genetic make up with other mammals. It shouldn't be too surprising then to find that some genetic problems in people can be found in other animals as well.



There are cats with Hurler Disease and others with Maroteaux-Lamy. There are also Maroteaux-Lamy dogs. There are Hurler dogs and Sly dogs, not to mention Sly Mice. There are dogs with Fucosidosis.

Scientists are extremely interested in animal models because they can be very useful in the study and the treatment of the disease in humans. If, for example a dog has the damaged Hurler gene then it will show very similar symptoms to those of a child with Hurler disease.

New treatments can be tried out on animals. Not only is it more acceptable, (for many people at least) to try out uncertain treatments on animals; but also it is usually easier to find enough animal "guinea pigs" to test how the treatment works in different individuals. For rare conditions like MPS, it may be difficult to find enough individuals to test the effects of a treatment or to make comparisons about their symptoms. For example, the number of Morquio patients in the world who have had bone marrow transplants does not run to more than three or four, and they are on different continents. The cost of studying these patients in different parts of the world would be very great and the small numbers would make the results of little use.

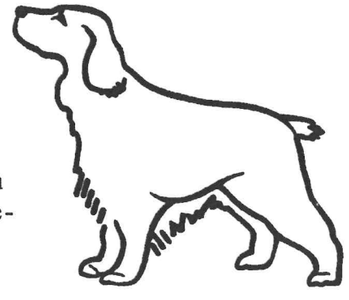
However colonies of the affected animals can be bred in a relatively short period. Often the animals which suffer from the disease are unable to breed, but their relatives who are carriers can be bred from. In this way a large number of individuals with a condition can be made available for study. The genes from the different individuals can be compared to see what variations there are and the range of defects that can be found in the genes.

For the same reason it is far easier to do controlled studies in rare disease with animals rather than with human patients.

In addition animals like mice mature much more quickly than humans and some of the longer term effects of treatment can be checked for in the mature animals. For example it is possible to check in a relatively short time whether bone marrow transplants or enzyme treatment or gene therapy help with the neurological problems

of dogs suffering from canine Fucosidosis. (See Newsletter Winter 1993, page 25)

Finding and breeding and keeping animals with severe health problems is not easy. It depends on a close co-operation between researchers and veterinarians. So progress towards treatment may depend as much on a Canadian dog keeper keeping her kennels clean, as on John Hopwood poring over his microscope in his laboratory in Australia. Some people may find it distressing and repugnant that animals are used in this way, but much of the progress that has been made the understanding and treatment of genetic diseases has come from the use of animals, and they play a vital part in current research.



In Memory

Robert Culley **21/7/79 - 10/2/94**

Christopher Shorthouse **12/5/82 - 25/2/94**

Within a period of two weeks both Robert Culley and Christopher Shorthouse died. In recognising the passing of these boys it is appropriate that we remember that they were instrumental in the discovery of the Hunter gene. Back in 1986 Robert's parents, Andrew and Vivienne and Christopher's parents, Paul and Carol, along with the families of over fifty other Hunter boys permitted a team of doctors to take blood samples for research which was being carried out by Professor John Hopwood at Adelaide Children's Hospital, Australia. Both Robert and Christopher were found to have a complete deletion of the suspected gene. During a press conference to announce the discovery back in August 1990 Professor Hopwood said, "In order to prove we had isolated the right gene, we had to demonstrate that a patient with the clinical condition had total deletion of that particular candidate gene. Until you have that you can't really call it the Hunter gene. This is what we found with Christopher and Robert. They have provided our final proof".

Sarah Jane Lowry **14/11/74 - 25/2/94**

It is with great sadness that we learned from her parents, Vic and Sue Lowry, of Sarah's death. Some of us had the pleasure of being on holiday with Sarah last August when seven young adults with MPS enjoyed a week full of adventure and fun at the Exmoor Calvert Trust. Sarah loved her visits to the local and when she wasn't joining in the activities she spent her time embroidering cushion covers which her mother marketed for her. Sarah was due to take up her place at Northampton University in September and had planned a solo trip to Australia for the Summer.

MPS Centre for the South of England

Following the announcement of the MPS Clinic to be set up at the Hospital for Sick Children, Great Ormond Street, London, by Dr Ashok Vellodi, I am pleased to tell you that the first clinic has taken place.

At present the MPS Clinic will take place on the second Thursday morning of each month but as demand grows the time will be extended.

Two MPS families were seen at the first clinic and it was good to be able to spend time with each family. One family had moved over from the old Westminster Children's Hospital and the other was a patient of **Dr Rosemary Stephen's** before her retirement from Great Ormond Street in 1988.

If you would like further information on the clinic and the services offered please contact:

Dr Ashok Vellodi Tel: 071 242 9789

or the MPS Office.

Day that I have loved

Elinor Bennet

The World Premier of a new work for the harp, "Day that I have Loved", written by Malcolm Williamson, was given by Elinor Bennet at a concert in aid of the MPS Society at the Purcell Room on the South Bank on the 17th of February.

A large number of the 250 tickets were sold and it was lovely to see a small number of MPS families and professionals in the audience.

Thank you Elinor for a wonderful evening. In the next newsletter we will be able to tell you how much was raised for the Society.

Fundraising Donations

Abbey National Staff Milton Keynes	In lieu of Christmas Cards
Abbey National Charitable Trust	Matched Funding
Abbey National Retail Premises	Christmas Card Wall/Matched Funds
John Arrowsmith	Great North Swim
K&P Ballard	Sale of Foreign Coins
Elinor Bennett	Concert
J&J Burlison	Webb Ivory
Cathkin High School	Staff Common Room Fund
Crazy Sonja and her Mates	Carol Singinf etc
Dalsetter Rise PO	Collecting Tin
Mr Davies	Donation
S&A Fraser	Raised
Maureen Fryer	Raised
C&G Gooch	Raised
GMC Fire Services Chadderton	Raised
Hallamshire Hospital Ward H2	In lieu of Christmas Cards
Hayle Community School	Carol Concert
June and Vernon	Donation
D & J Kent	Marathon
Laugharne Ladies Darts	Raffle
J & K Lawrie	Collecting Box
Marros Farm	Donation
MPS Northern Ireland	Raffle at Christmas Party
Muswell Hill Children's Bookshop	Raised
Mrs Oxenbury	Raised
A Palmer	Sold Christmas Cards
Pendine Social Club	Games Day and Raffle
Reliance Security	Raffle
B & J Roberts	Raised
Royal Mail	Sponsored Cricket Match
Sedgemore Manor School	Staff Weigh In
Mr Sexton	Donation
Sid Shiff	Raised
Spiffing Stationery	Raised
Linda & Ron Snack	Tombola/Flag Day
John & Mary Stacey	Christmas Fayre
Peter Stanley	Guitar Recital
Stocksfield Cricket Club	Fancy Dress Pub Crawl
Stonelaw High School	Sponsored Swim/Raffle
E&L Tailford	Quiz and Raffle
TA Carmarthen	Christmas Raffle
Mrs Todd	Collecting Box
Tom, Dai. Olive and Friends	Christmas Raffle
Towersey Morris Men	Raised
Tremoilet CPS	Christmas Concert
Wakefield Farm Shop	Collecting Box
J Warren	Christmas Cards & Paper
Karen Weedall	Sold Webb Ivory/Collecting Tin
Whitland YFC	Harvest Festival
I Wicks	Cans for Recycling
Wirral Guild of Craftsman	Park Tea Bar

Area Support Families

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