

NEWSLETTER

SUMMER 1993

# THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES



National Registered Charity No. 287034



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## The Society for Mucopolysaccharide Diseases

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Telephone 0494 434156

The MPS Society is a voluntary support group, founded in 1982, which represents over 500 families in the UK with children or adults suffering from Mucopolysaccharide and related diseases. It is a registered charity, entirely supported by contributions raised 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 UK and Northern Ireland, who offer support and links to families in their areas. It provides an information service for families and professionals. At the present time it funds a Consultant Paediatric Post 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"**

**The annual general meeting of the Society for Mucopolysaccharide Diseases will be held at the Stakis Grand Hotel, Stoke on Trent, on Sunday 19th of September 1993 at 9.45am  
By order of the Committee - A.G. King (Chairman)**



## Milestones

### Births

Congratulations to **Anita and David Little** of High Wycombe on the birth of their son **Ryan** on the 29th of June 1993.

Congratulations to **Sugrab and Fazal Hussain** of Sparkbrook, Birmingham on the birth of their daughter, born on the first of March 1993, a sister for **Farkha**.

Congratulations to **Paula and Scott Woods** from Binfield in Berkshire on the birth of their daughter **Charlie** on the 7th of June 1993, a sister for **Leanne and Scottie**.

### New Families

**Dr Sherlala and Mrs. Elallus** from Glasgow, whose son **Mohammed**, aged two, was diagnosed as suffering from Mannosidosis.

**Angela Newton** from Carlton, Nottingham, whose son **Daniel**, age five, suffers from Hunter disease.

**Rhian and Bob McKnight** from Lougharne, Dyfed, whose daughter **Sarah**, born 14/9/92 has been diagnosed with Hurler disease.

**Peter and Jean Hawkins** of Finchhampstead, Wokingham, whose son **Andrew**, born 5/3/83, suffers from Sanfilippo A disease.

**Mrs. Sheila Brigden** of London SE12, whose daughter **Tracey**, who suffered from Sanfilippo disease, died in 1980, age eighteen.

**Mrs Begum of Nelson**, Lancs, whose son **Omar Sharife** has been diagnosed with Morquio disease.

**Mohammed and Razia Begum** of Peterborough, whose son **Mohammed**, born 20/4/93, has been diagnosed with I-Cell disease.

**Mr and Mrs Ali** of Birmingham, whose son **Ibra**, born 1/11/86, suffers from Morquio disease.

**Nusrat and Ishtiaq Ahmed** of Walthamstow, East London, whose daughter **Maryan**, born 10/12/91, suffers from Morquio disease.

**Mrs G Deacon** of Cranfield, Beds, whose son **Michael**, who suffered from Hurler disease, died in 1958 age sixteen.

**Colin Holland**, age twenty eight, from Leicester, who suffers from mild Hunter disease.

**Derek Denham**, age eighteen, from Ayr, who suffers from mild Hunter disease.

**Marie McCall**, age thirty nine, from Alness in Ross-shire, whose suffers from Scheie disease.

### Deaths

**Matthew Hall** from Shoreham by Sea, who died on the first of February 1993, age 13 years. Matthew suffered from Hunter disease.

**Gregory Coles** from Stoke D'Abernon in Surrey, who died on the twenty eight of June 1993 age one. Gregory suffered from Sialic Acid disease.

**Elizabeth Davis** from Strabane, Co Tyrone, who died on the 23rd of June 1993, age twenty two years. Elizabeth suffered from Sanfilippo B disease.

Our thoughts are with the grieving parents, relatives and friends of these children and young people and with all those grieving for children lost through MPS diseases.

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**Deadline for Autumn Newsletter  
Friday 15th October 1993.**



## A short note from the Chairman of the Management Committee

On page one of this newsletter you will find the formal notification of the Annual General Meeting of the Society to be held at our conference in September. I mentioned last year the need for new people to join the committee and this need is still there. We should like if possible four new members and if you know someone whom you feel would be an asset to the Committee or if you would like to serve please nominate them or yourself.

A nomination form is with this newsletter. If you are nominating someone other than yourself please do ensure that the person is willing to stand. The term of office is normally three years. If you want any further information please telephone me on 0424 216432. The completed nomination form should be sent direct to me at 'Baobab', 4 New Park Avenue, Bexhill on Sea, East Sussex, TN40 1QR.

Our committee comprises ten people with powers to co-opt - full information is in the Rule Book which has been sent to every member.

Please do seriously consider nominating yourself or someone else. We must have continual new blood to ensure that our Society continues to progress.

It would be very much appreciated if the nomination forms could be sent to me well in advance of the date of the Annual General Meeting. (Sunday 19th of September 1993).

Alf G. King



Jamie and Jason George from Bristol, twins age four with Sanfilippo disease, with their brother Matthew enjoying the sun at the Area Family Day in Wales. (see page 6)

## News from the North West

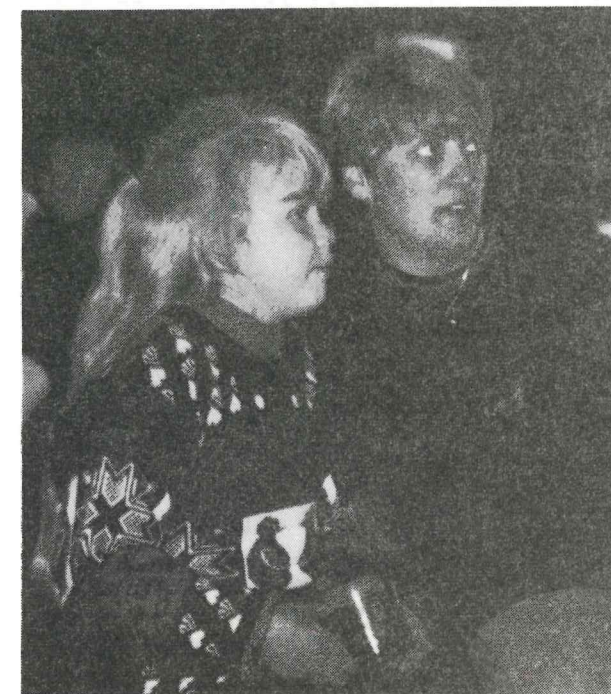
The North West has held two Area Family Days since the last newsletter. In April there was a family luncheon and and get together which gave everyone the opportunity to chat and exchange news and ideas. The children, meanwhile, were entertained by our volunteers and "Uncle Tex" with his fluffy friends.

In June David and June Gilford once again invited us to hold our annual barbeque at their farm in Nantwich. Twenty nine families enjoyed the sunshine and the company of many friends and professionals. I am sure everyone would wish me to take this opportunity to thank David and June for their kind hospitality.

Mary Gardiner.



Rachel Kermode (Sanfilippo) sorts out a problem with the help of volunteer Mikhail, at the North West Area Family Day



Sarah Yates with her mother Beverley at the North West Area Family day. Sarah is eight and suffers from Sanfilippo disease. They come from Dukinfield in Cheshire.



## WELSH AREA FAMILY DAY SUNDAY 4TH JULY

Tredegar House, near Newport, Gwent, - home to one of the greatest Welsh families - The Morgans, later Lords Tredegar - for over five centuries - was the chosen venue for recent Welsh Family Day.

Blessed with superb weather families, friends and helpers from Newport division of the Red Cross met for a picnic lunch funded by the HTV Cymru / Wales 1992 Telethon.

After lunch 34 children enjoyed a magic show followed by pony and boat rides in the park, whilst the parents heard Dr Ed Wraith speak about 'Gene Therapy' and Susanne Goodall on 'Ty Hafan' the proposed Children's Hospice



**Bethan Hosking and her mother Gay have a heart to heart. Bethan is age 7 and has Sanfilippo disease.**

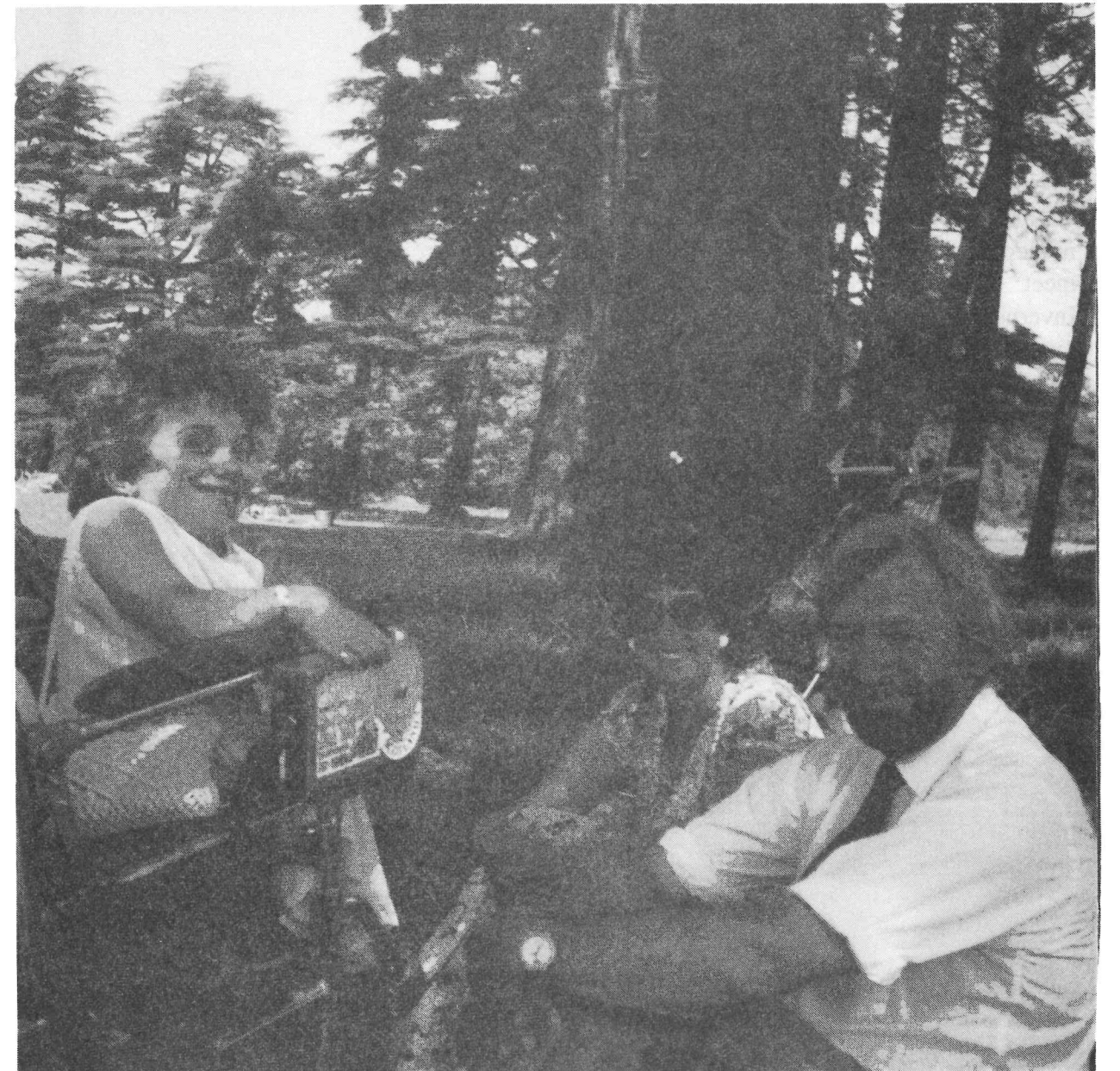


**Amie Oliver age two (MLIII) from Penryn in Cornwall with her mother Alison.**

## NEW AREA FAMILY FOR WALES

**Mike, Anne and Sarah Kilvert**, Windy Way, Nantoer, Newtown Powys SY16 1HH. Tel. 0686 624387 have kindly agreed to take on the role of Area family for Wales. Sarah's older brother Carl died from Morquio disease at the age of 4 years. Sarah herself also has the condition and as you will see from the photo of her with the Rt. Hon. Nicholas Scott on the front of the Annual report is doing very well following cervical fusion last year.

Anne, Mike and Sarah have raised a lot of money for the Society and been very involved over the years and we are most grateful now they feel ready to take on the role of Area family for Wales. I know all the families will support them in their efforts. Mike always need a new project to be getting on with. How about an MPS team for the London Marathon Mike?



**Sarah, Ann and Mike Kilvert at the Welsh Area Family Day. Our best wishes to them in their new role.**



## Scotland

Bungee Jumping in Inverness is just another of the many events I managed to get to. Thankfully, I didn't have to jump! I left that to experts like Ian Russell and friends. Ian came up with the idea of holding the first bungee jump in the Highlands. The profits were to be divided between the Society and the Child Development Unit that Ian's son Sean had attended.

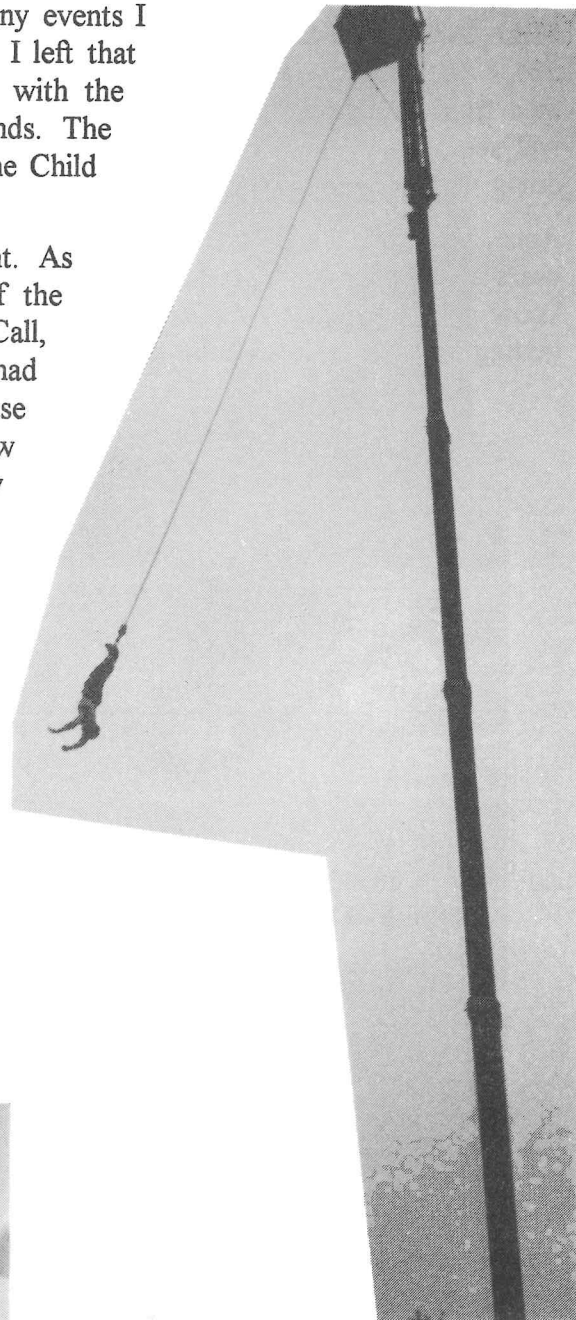
There was a great deal of publicity about the event. As always this had its effect in promoting the work of the Society. One result was that a lady called Marie McCall, from Alness in Ross-shire contacted the Society. She had been diagnosed as suffering from Hurler/Scheie disease three years previously by her eye specialist but knew little about the condition. She did not know the Society existed until she heard about the bungee jump. Having met Marie I am sure she will be an inspiration to many other Scheie sufferers.

The whole weekend was very successful and enjoyable, all credit to Ian Russell and his numerous fellow workers. It was also good to meet old friends again and make new ones. Inverness holds some very special memories for me as this is where I first met a child with MPS when I was nursing there. I was only eighteen at the time and little did I know how my future would be shaped by MPS. Anyone contemplating a visit to the Highlands won't be disappointed as it is truly a beautiful part of the country.



**Ian Russell heading for the ground without a parachute in aid of MPS funds.**

**Marie McCall found the Society and Mary Gardiner in Inverness, thanks to the Bungee Jumping!**



## The Childhood Wood

The story of the establishment of "The Childhood Wood" was told in the spring newsletter. Since then there has been continued interest and many people have contacted the Society to say how moved they had been by this living memorial to the children we have lost. I visited the wood in May and I am pleased to report that good relations have been established with the rangers who watch over Sherwood Forest. It was also most useful to visit the information centre. However I have some very sad news to report. The night after my visit, the information centre was razed to the ground by a fire. Arson is suspected. As you would expect it is going to take some time to rebuild it. The question of whether such an incident can be prevented in future is a major issue.

On a more positive note the saplings are flourishing and a number of families have visited the wood since February.

We are already beginning to prepare for the next planting, which is likely to take place in the February half term in 1994. We would like to hear from any families whose MPS child has died and who would like him or her to be remembered with their own tree and nameplate in the Childhood Wood. If you have already let us know we will be writing to you in the Autumn with fuller details about the planting ceremony. Any other bereaved families who would like to attend please let the MPS office know. If there is sufficient demand for accommodation we will consider booking rooms in the Holiday Inn Hotel.

**Christine Lavery**

## Report from Mary Gardiner, Northern Co-ordinator

The past three months have been extremely busy ones in visiting families and tackling the many issues arising from families caring for their MPS child or children. In particular I have been pleased with successes in supporting applications for adaptations to homes. In several instances also housing transfers have been obtained.

Since the setting up of my office in the Royal Manchester Children's Hospital the benefits have been enormous. This is especially so when families attend appointments or are resident in hospital. For example young David Chou who suffers from MPS II (Hunter disease), spent eleven weeks on Heyward Ward and had to go to the operation theatre on many occasions. It was a very stressful time for his parents but I am happy to say that David is now at home and smiling again.



**David Chou with his mother Virginia, at the Royal Manchester Children's Hospital, Pendlebury.**



## Mary Gardiner's Report (continued)

We also had TJ Pienaar who suffers from MPS II (Hunter) who travelled from Johannesburg to see Dr Wraith. Their stay was only a short one but Lyn and TJ did manage to meet several MPS families. I know Lyn would like me to mention the kindness, warmth and love shown to them at Francis House Children's Hospice. Since her return Lyn has shown a great interest in helping other MPS families in her own country. We would like to wish her every success.

## Northern Ireland

In April Christine Lavery and I travelled to Northern Ireland for what turned out to be a very succesful trip on many accounts. Margaret Kearney and Kieran Houston joined us as the local representatives when we met with the officials from the Department of Health for Northern Ireland. The meeting was most successful. As a result of it we hope to see a new project which combines family support and a new specialist clinic for Northern Ireland in the near future. We also met with several families one evening. This enabled Christine and me to gain more insight into the needs and difficulties of our friends in Northern Ireland. While we all appreciate the problems associated with MPS, the disease can cause even more anxiety and pressure for families when there is not good back up from statutory and voluntary services. I am sure that in acknowledging the problem we can make a start in getting better provision for MPS children and their families.

Mary Gardiner

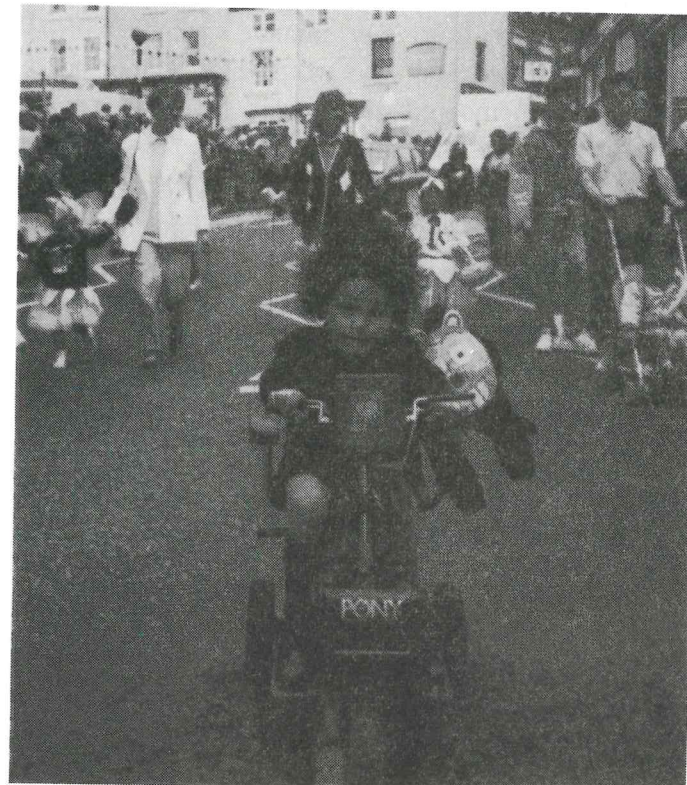
## Birmingham

It was a very hot day in June when Dr Wraith, Larrain Burnett, staff nurse at the Willink Unit and I went to Birmingham for their "Gene Research Day", hosted by Sue and Jeff Hodgetts, the new area support family for the West Midlands. Dr Wraith spoke on recent developments in Gene Research and about possible treatments, their likely advantages and disadvantages. This gave everyone food for thought and there were many questions afterwards. Thanks to Sue, Jeff and friends for making it all possible.

Mary Gardiner

## Dennis the Menace!

Henry Sutcliffe, Morquio, aged 6, scatters all before him as he takes part in the Well Dressing Parade at Wirksworth in Derbyshire at the Spring Bank Holiday. No wonder they gave him first prize in the 6-11 Fancy Dress Competition. Martin Sutcliffe, a man of many talents, designed four well dressing displays. A collection was taken for MPS.

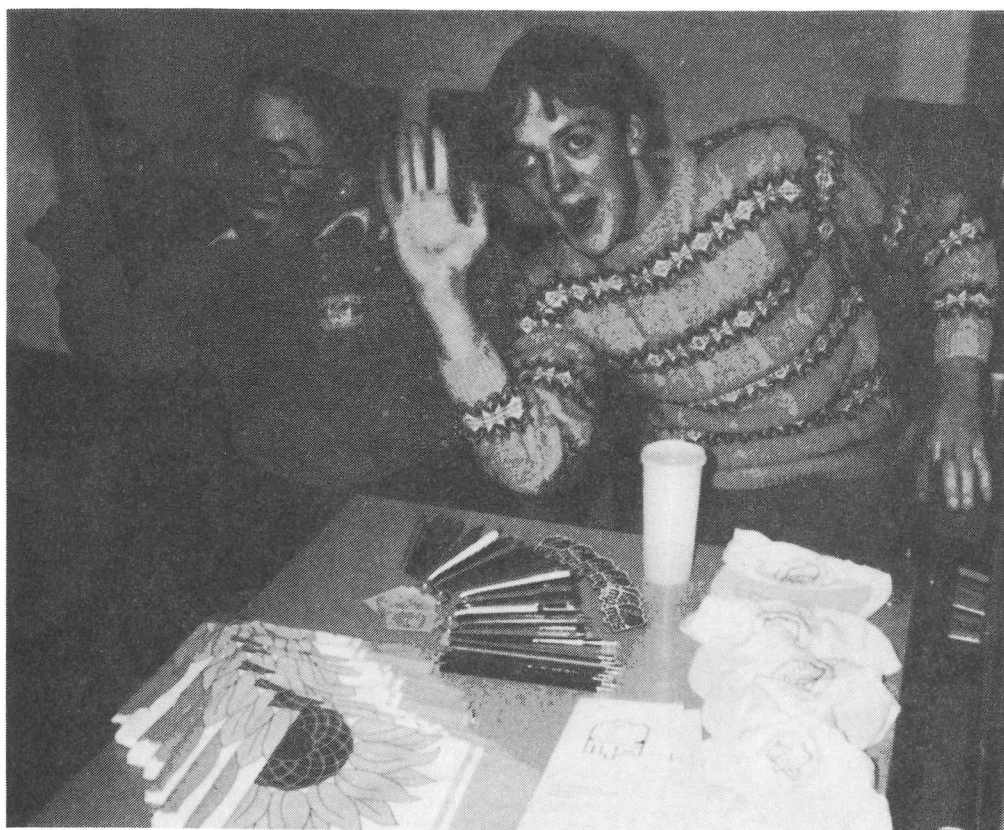


Kieran Houston, Chairman NI Committee, accepting a cheque for £500 from Angela Saunders, Trust Administrator for Ulster Telethon. As seen from Mary Gardiner's report on the previous page the group is very active in pressing for improved services as well as in family support and fundraising.

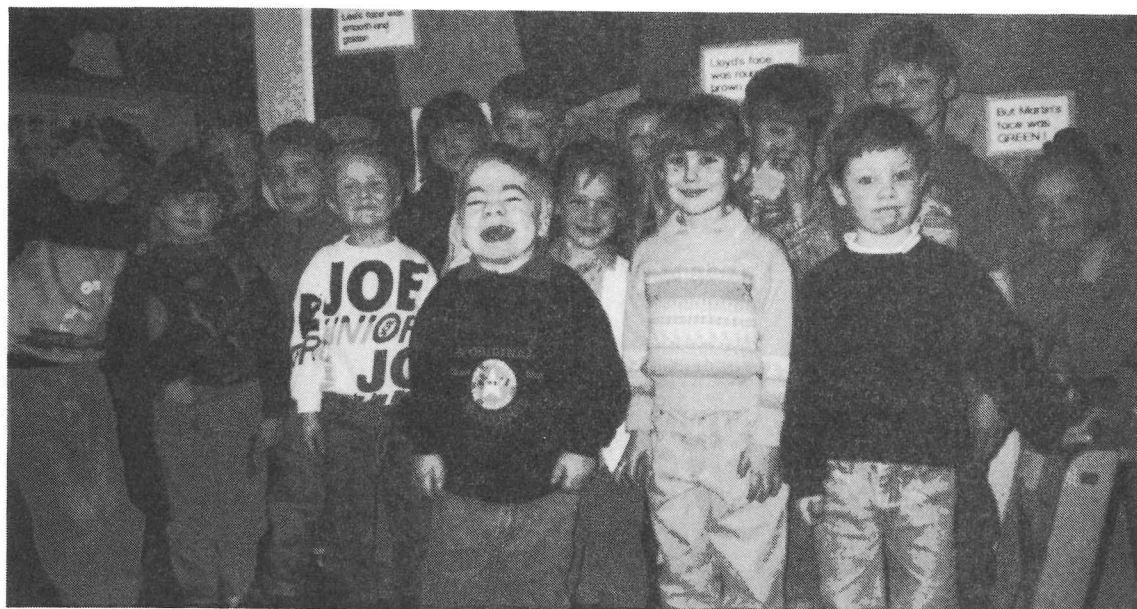


Carissa Aggett age two from Bridgend, Mid Glamorgan, with her grandmother, her mother Karen and her brother at the Welsh Area Family Day (P. 6)





Alex Butler and his friend Jason of the Focus Pre-Vocational Group at Amersham College manning the MPS stall at a fundraising event. The group of twelve who themselves have learning disabilities raised £552 for the Society at the end of their summer term.



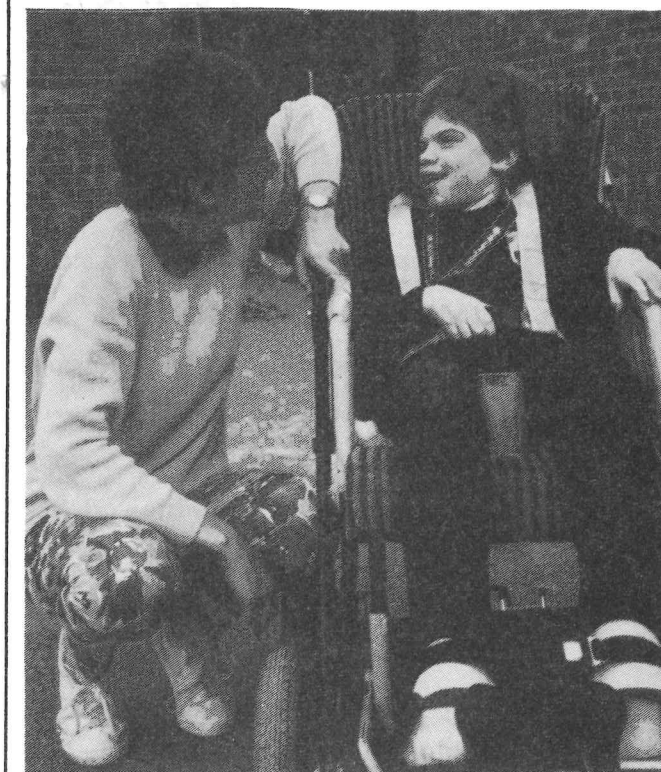
This lovely photo is of Simon Hoather with his school friends from Whittaker Moss County Primary School, Rochdale. I had the opportunity to visit the school to talk to the children about Jeans and "Genes". The children had a good grasp of how we inherit different bits from our parents. They also had good fun teasing me when I had several children together from one family looking for family likenesses in them. Still, I got my own back when I discovered twins in the class. The school raised £145 for Gene Research and Therapy by holding a "Jeans for Genes Day". I hope you agree they are a great group of children. Well done! **Mary Gardiner.**

### ★ Marathon Runners

I am pleased to be able to send you cheques to the value of £1081 which I received in sponsorship for the London Marathon this year. I am a PE teacher at a special school in Kettering and I have known and worked with the Murphy sisters for many years. Kath Murphy thought you might like this photo of Lizzie and myself, with Lizzie examining "her" marathon medal - I don't think she was very impressed. Lizzie is a tonic to us all and it was with her and Caroline in mind that I put my efforts into completing the Marathon.

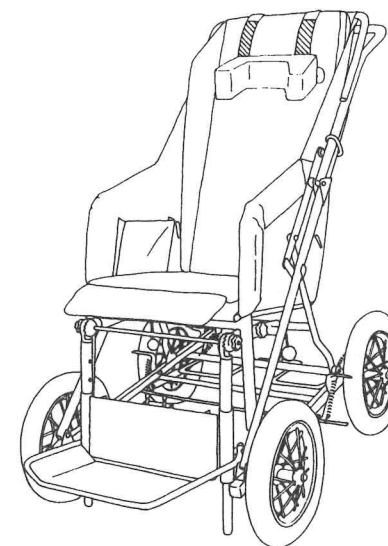
**Sheila Jowsey**

Many thanks to **Mike Willoughby**, Sheila Jowsey and our other Marathon runners who put so much effort into publicizing the Society and raising money again this year. Mike Kilvert has floated the idea of applying to enter an MPS Marathon Team next year. Interested? Please contact the MPS office.



Best wishes to Robert Cullley who came out of hospital in Bristol in July after recovering from a fracture to both legs.

An Alvema 400 wheelchair in good condition has been donated to the Society by a family. If you feel you could use it please contact the office.



**Shabana Shoukat** went to Disneyworld in Florida earlier this year with the National Holiday Fund and had a wonderful time. Shabana is almost twelve and comes from Aston in Birmingham. She suffers from Morquio Disease. Well done Shabana! Send us some pictures soon.

**Lorraine and Samantha Mullen** from Islington in London will be flying out to Disneyworld in October, also with the National Holiday Fund. It is wonderful that they are getting a trip at last because they were previously promised a trip but were let down by the fundraisers. Have a wonderful time.

If your child would like to be considered for a trip to Florida please contact Christine at the MPS Office. The conditions laid down by the organisers are that the child should be mature enough to appreciate the holiday and should not have been there before. We can only nominate children and the final choice rests with the organisers.



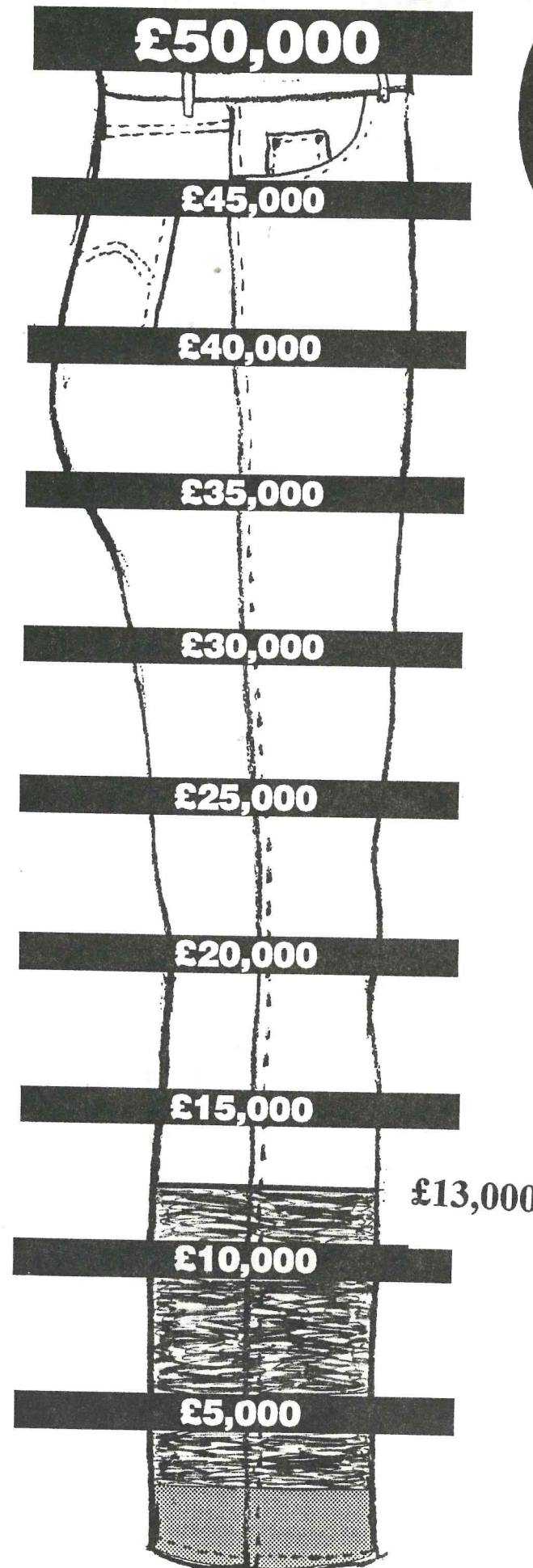
## Thank You Schools !

Tarleton County Primary, Nr Preston  
 St Vincent De Paul, Salford  
 Stonelaw High, Rutherglen, Glasgow.  
 L. M. Radford, Sale Cheshire.  
 Summerville County Primary, Salford  
 Dominican College, Portstewart, NI.  
 Trull CEVA Primary, Nr Taunton  
 Critchill School, Frome, Somerset  
 Stella Maris, Bideford, Devon  
 St. Josephs Primary, Antrim NI  
 Benton Park Primary, Newcastle upon Tyne  
 Haddenham St Mary's First School, Bucks.  
 St John's Angell Town RC Primary, Brixton.  
 St Edward's RC Primary, Middlesborough  
 Bury CE High School  
 Sale Grammar School, Cheshire  
 St Joseph's RC Primary Billingham (staff)  
 The John Mansfield School, Peterborough  
 CW Primary School, Brackla, Bridgend  
 Hamstead Junior, Great Barr, Birmingham

Bishop Henderson CEVA Primary, Taunton.  
 Northumberland Heath County Primary,  
 Erith Kent.  
 Brumby Comprehensive, Scunthorpe  
 Rochester Grammar School for Girls.  
 Felling Colegate Primary, Gateshead  
 Penryn Junlor, Cornwall.  
 Whittakers Moss, County Primary, Rochdale.  
 Bidston Avenue Junior, Birkenhead.  
 Central First School, Exeter.  
 Thornton County Primary, Liverpool  
 Blessed George Napier, Banbury, Oxon.  
 St Loanends Primary, Antrim.  
 Beccles Middle School, Suffolk.  
 Rede School, Strood, Rochester.  
 Santley St. School, Clapham, London.  
 Trull School of Dance, Taunton.  
 Broadheath Primary, Altrincham  
 Foxhills Comprehensive, Scunthorpe  
 Cumnock Academy, Ayrshire.

A very heartfelt thank you to all the above schools which contributed towards gene research and treatment, mostly by holding a "Jeans for Genes Day" where pupils and staff were invited to wear their jeans and make a contribution to MPS. This campaign is the brainwave of Mary Gardiner. She is contacting many schools directly but as always the best results are obtained by families connected with the schools approaching them personally. Many schools choose a charity to support each year, so September may be a good time to make contact. Our experience is that schools are delighted to be approached and like to use the "Jeans for Genes" information as part of their teaching. The Leaflets, as well as MPS posters and other publicity materials can be obtained from Mary Gardiner, or via the MPS office. (Addresses inside front cover). As Mary has found out, **not only schools like "Jeans for Genes" days.** Why not try it at work, or in any groups or clubs you are in contact with.

# JEANS for GENES



### Donations to Gene Research and Therapy -July 1993

E Redman  
 JD Singleton  
 NM and BA Condron  
 Mrs CL Robson  
 Questmead CVC Ltd, Rochdale  
 Runinteral Ltd. Stoke on Trent  
 Pendlebury Nurses League, RMCH  
 Wyvern Cargo Ltd. Poole Dorset.  
 Dean Sherrif, Bamford, Rochdale.  
 Girl Guides Association, Winter Hill, Bolton.  
 DB Sherrif, Rochdale  
 Mr and Mrs Cothliff  
 Mrs Bowers  
 Mr and Mrs Redman  
 Mrs Tierney  
 A Tamesider  
 Mr and Mrs Burt  
 JB Callender  
 Mr A Cooper  
 C & ME Lomax  
 MF & D Loran  
 Manchester Vehicle Painters  
 Oldham District Nurses Forum  
 Tesco Store (Angles Social Fund),  
 Rochdale  
 Lisa Butler (sponsored fast)  
 TSB Bank PLC, Rochdale  
 Mr and Mrs Hoather, Rochdale  
 WH Smith, Do it All, Rochdale  
 ANC Knutsford  
 ANC Crescent Stationers  
 ANC, Same Day, Lincs.  
 ANC, Huggins,  
 Mrs Berry  
 Mrs MO Morgan  
 Dr Wraith, RMCH  
 Mrs Rust, Taunton  
 Mr W Carr, Heywood, Lancs.  
 GM Lee, Rochdale

R Hardman  
 T & D Glennon  
 PJ Farrow  
 M S Clarke  
 ME Hague  
 SM Debbat  
 V & D Riley  
 G Smith  
 J White  
 A Taylor  
 G Liddell  
 EPN Godwin, Colwyn,  
 Clwd  
 B Tenny



## Enzyme Replacement Therapy

An Australian Company, CSL, has started development work aimed at producing biosynthetic enzymes and evaluating them in the treatment of MPS disorders. The company are working very closely with Professor John Hopwood at the Children's Hospital, Adelaide, Australia. Development and testing is expected to take several years for each disease. Maroteaux-Lamy (MPS VI) is the disease they will be working on initially. The company gives a caution to parents about the length of time and the uncertainty involved in developing any new treatment.

This news was first announced at the Third International Symposium in Essen, Germany, in May 1993.

The MPS Society warmly welcomes the work being done. We have already worked closely with the company in helping them get to this stage. We will be working alongside MPS Societies in other countries in supporting the work of the company.

Our main involvement will be in collecting data. We will be collecting and passing on statistical information about all children known to be diagnosed with MPS diseases in Europe. This will be combined with information from the United States, Australia and Japan to help show the incidence of the diseases and how they are distributed in the different countries.

Needless to say we will on no account be giving any personal information to the company - just figures. Any information given to the Society is of course kept in confidence.

If you would like to know more about the project, leave a message for Christine at the MPS office and she will get back to you.

### ★ Bone Marrow Unit to go.

Debbie Rogers of 129 Whitley Rd. Hoddesdon, Herts. (Tel: 0992 467251) recently helped present a petition to Downing Street protesting at the proposed closure of the Bone Marrow Transplant Unit at the Westminster Hospital without any re-provision. (see Spring edition)

In the planned shake out of Hospitals in London, the Westminster is to go, and there are no definite plans to locate the bone marrow unit elsewhere in London. Debbie would be delighted to hear from anyone who is interested in this campaign.

### ★ Radio Appeal

On **Sunday 14th of November 1993** at 8.45 am you are commanded to leap out of your beds and glue your ears to Radio 4. An appeal on behalf of the Society will be broadcast on "This week's good cause" by a celebrity whose name we are not allowed to reveal at the present time - (mainly because s/he does not know about it yet!) Tell all your friends to listen in as well. Our previous appeal was very successful. We shall be standing by at the telephones to accept the offers of donations as they come in.

## The Squadron is on our side

**The 9th Supply Regiment, Royal Logistics Corps, 90 Squadron, based at Hullavington in Wiltshire**, have adopted MPS as their charity. They will be taking part in a number of strenuous sporting events during the Autumn to raise money for the Society. It would be terrific if families could support the team at these events and also if they could raise sponsorship money for them. It adds a special thrill to a day out when you have your own team to cheer for.

**12th September.** They will be fielding eight runners in the Chepstow Half Marathon.

**18/19th September:** A team of eight will be running thirty miles each in the Bury twenty four hours race.

They will also be taking part in a **200 mile run** near Hullavington. The date of this event has not yet been fixed.

It is planned to run a **marathon** on the Airfield at Hullavington sometime in September/October. There will be teams of nine running three miles each. **Any volunteers to get together an MPS team to compete?**

Local families will be circulated with the details nearer the times of the events. Further information about times and travelling directions and who to contact from the MPS office.

### Post Office Campaign

If you are applying for Disabled Living Allowance or Invalid Care Allowance you may find that the form no longer says that you can ask for the allowance to be paid through the Post Office. However it continues to be your right to ask for the money to be paid through the post office and you can write this in on the form. This is particularly important for families who do not have a bank account or building society account. The Society has been sent a leaflet by the National Federation of Sub-Postmasters who are concerned that the Department of Social Security may be trying to limit the choice of methods of payment of benefits. They have urged people concerned about this to write to their MP at the House of Commons.

### In Memory of Lee Lofthouse 18/1168 - 16/1/93

Lee Lofthouse was tragically killed in a car accident in January. Lee's love for his cousin **Dominic Hall** was a wonder to see. He never saw the problems of having an MPS child, only the love.

Even at the time of his death, Lee had a sponsor form pinned to his locker at work to raise money for a parachute jump for the group. Nothing will help us over the loss of such a happy and wonderful husband and son but at the funeral, instead of having flowers, money was donated. We hope that this £1,500 raised will help Dominic and all his friends in the MPS.

**Ella, Brenda and Terry Lofthouse.**

112 Moordown Rd, Shooters Hill  
London SE18 3RG



## Christmas Card 1993 - "The Snowman"



Here is a black and white impression of this year's MPS Christmas Card, a snowman, with children of the Victorian Era. Very different in design from our previous cards! The cards will be on sale in packs of five at the conference at £1.50 per pack.

Cards can also be ordered from Sue Butler (see inside front cover). We still have stocks of previous cards, the Robin, Three Kings and Penguins which can be ordered from Sue Butler.

### It's a Knockout: 5th September 1993

Now in its third year, the Fun Day and "It's a Knockout" Competition held near Clacton on Sea in Essex looks like being the best ever, with the local Radio Station Road Show in attendance.

The Fun Day has all sorts of attractions, side shows, stalls and arena events, leading up to the main event which consists of six local pubs doing battle to win the coveted Knockout Trophy.

This year's hosts, Edward and Judy Spall at the Black Boy in Weeley have been working hard with us to organise the events. Frank Lumber has kindly loaned us a field. Welcome assistance from local families, June, Barry, Karen and Tony Bradley, Mike Francis, Mike and Tracey, and not forgetting my husband Tom for the hard labour and time given. This will be a day to remember and at the same time raise funds for MPS. We invite you all to attend. If anyone would like a stand they would be most welcome.

Maureen Fryer Tel 0255 830984

Promoter

### Punjabi Contact Wanted.

A Punjabi speaking family in St Albans, Herts. would like to have contact with another Punjabi speaking MPS family. Their daughter, age twelve, suffers from Hurler/Scheie disease.

Please contact the MPS office.

# September 1993 Grand MPS Draw

7th of September  
at County Hall  
Nottingham  
by Chairman Notts C.C.

There is still time to sell lots of raffle tickets Further supplies can be obtained from David Briggs.

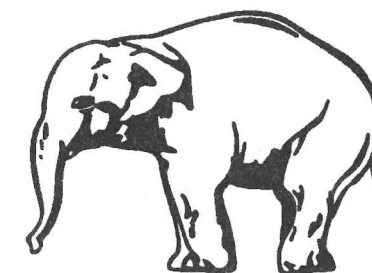
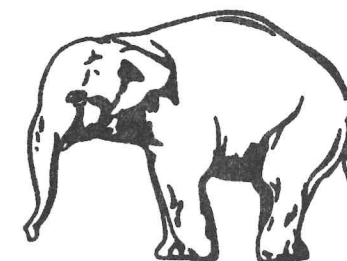
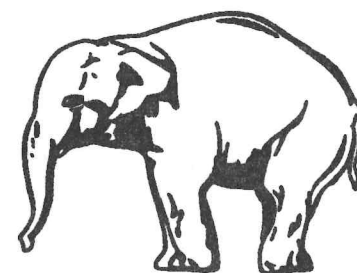
**First prize: Dining room table and four chairs.**

**Second: Weekend at Centreparcs Sheffield for six.**

**Third: 35mm Remote camera, film and binoculars.**

**Fourth: Personal stereo cassette kit.**

**Plus: Dozens of other valuable prizes!**



Promoter: David Briggs, 7 Humber Street, Retford, Notts. DN22 6LZ  
Tel 07777 00046

Registered under Section 5 of the Lotteries and Amusements Act 1976  
with Chiltern D.C. Reg. No. 263.



## International Symposium, Essen, Germany, May 1993

Congratulations to Jurgen Zumbro, Dr Michael Beck and the other organisers of the combined scientific Symposium and Parents conference held in Essen at the end of May. The Sheraton hotel is linked directly with the superb Saalbau conference centre situated in a lovely park in the centre of Essen so it was possible to stroll under the trees in the sunshine and watch the rabbits scampering about and the ducks on the pond between sessions. Doctors and scientists attended from all over the world. The most exciting discussions were on the prospects for gene and enzyme therapy. An Australian Company, CSL, announced the start of development work on enzyme replacement therapy. (See page 16)

The Australian Society attended in force and amazed everyone with their stunning brochure for the 1996 International Symposium to be held near Sydney. Get saving everybody!

There were outings to Starlight Express and visits to local centres of interest. It was delightful to meet old friends. Committee members from well established and new MPS groups shared their successes and difficulties and went away with new ideas and new energy.

What are the benefits of these three yearly jamborees? The scientists who spend all their time working in laboratories say they are inspired to greater efforts by meeting the families and having personal contact with MPS sufferers. Getting to know each other also encourages scientists to share often jealously guarded information. As one researcher put it, "You are much more prepared to share your results with someone you know".



Beatrice Fluckiger, enjoyed meeting other MPS teenagers at Essen. (Morquio disease)



Bill Pidden has a chat with Kristina Briggs in a quiet interval.

## A first visit to the Willink Unit, RMCH

From the day James was diagnosed as having Hunters Disease, nearly five years ago, we had talked about going to see the specialist in Manchester. We had put it off, thinking that it would be just like any other hospital appointment: - trouble finding a parking space, waiting for ages in a waiting room, James screaming with fear as he sees doctors and nurses rushing about looking harried, not to mention bad news. James cannot even watch hospital programmes on television, eg "Casualty", without having a panic attack brought on through bad hospital experiences.

consulting room. We could not believe it - there was no one else there waiting. We had Ed to ourselves! We asked him everything we could think of - we needed practical advice for James' problems and that is what we were given. We were not even disturbed by our daughter, Francesca, who was playing happily in the adjacent room. Neither could we believe how James was reacting: he sang throughout the consultation! He is usually very distressed by the time we see the doctor.

Ed booked us an appointment in the cardiac

*"James usually has a panic attack when he sees a hospital programme on television"*

As James' problems increased, our GP referred him to Dr Ed Wraith at the Willink Unit, Royal Manchester Children's Hospital. A few weeks later we were on our way. We decided to make a long weekend of this trip and stayed in an hotel for three nights and visited Chester Zoo. (We did have the option of staying at Francis House Hospice, which welcomes MPS families visiting the Willink Unit). It was a good omen when we received clear and detailed instructions of the route to RMCH from the M6, so instead of the usual disagreements (euphemism for blazing rows) on which way to go, we glided through the infamous Manchester motorway network and soon arrived at the RMCH car park.

unit which took place almost immediately (what power he must wield), presented a prescription for us at the pharmacy, then collected it, and took us to the physiotherapy department where we were given answers to even more questions we had.

*"He sang throughout the consultation!"*

We went away feeling very positive and not emotionally drained as we usually are. There really does exist someone who understands our problems and knows how to treat them.

Thanks, Ed.

**Bob and Caroline Fisher**  
Great Sampford  
Essex.

By this time we were feeling quite nervous - it was as much our appointment as James'. We found the Willink Unit easily and announced our arrival to the receptionist. Before we even had time to think the words "waiting room" Ed was with us and leading us into his



## Children's Hospices

Since Mary Gardiner and I have taken up our posts within the MPS Society we have made a point of liaising closely with the five Children's Hospices and the many proposed Children's Hospice projects around the Country.

Most children who go to Helen House, Acorns, Martin House, Francis House or the Cambridge Children's Hospice have chronic life-threatening conditions like the Mucopolysaccharidoses. They live at home with their families and visit now and then for short periods of respite. Families are welcome too - parents, brothers and sisters, occasionally grandparents. Sometimes though the family will take the opportunity, while their child is cared for at one of the Children's Hospices, to have a holiday or do things at home which they could not normally do.

A few children go to a Children's Hospice at the end of their lives where a loving, supportive environment awaits the whole family.

Nearly all the Children's Hospices can take eight children at any one time and each child has his or her own bedroom. Parents may choose to sleep in the same room as their child, or alternatively, there is family accommodation providing comfort and privacy.

Each of the Children's Hospices has its own individual character and may differ in what it can offer. They all offer MPS families peace of mind, knowing that when you are physically exhausted by the 24 hour a day, seven days a week care you give to your MPS child, there is somewhere to turn for both you and your child.

There is joy in finding a happy environment where nurses and staff take pride in giving the same quality of love and care that your MPS child/children receives at home.

There is also understanding, and the opportunity to talk with other people who appreciate not only the physical strain of looking after such children, but also the emotional stress and sadness of watching a child's condition deteriorate.

All the hospices accept self referrals and there are no charges.

### \* Existing Children's Hospices

#### Helen House

37 Leopold Street, Oxford, OX4 1QT

Tel: 0865 728251

#### Martin House

Grove Road, Clifford, West Yorkshire LS23 6TX

Tel: 0937 845045

#### Acorns

103 Oak Tree Lane, Selly Oak Birmingham, B29 6HZ

Tel: 021 414 1741

#### Francis House

390 Parrswood Road, Didsbury, Manchester, M20 0NA

Tel: 061 434 4118

#### Cambridge Children's Hospice

Milton, Cambridge, CB4 6AB

Tel: 0223 850306



**TJ Pienarr** with his mum **Lyn**, at Francis House Hospice, where he stayed when visiting from Johannesburg while being assessed at Royal Manchester Children's Hospital. Many MPS families use hospices and not only when children are dying. Many MPS families are active in supporting hospices.

## Proposed Hospices

### Children's Hospice Association Scotland

(Marc Daniel House) 18 Hanover St. Edinburgh EH2 2EN

Tel: 031 226 4933

Have raised £100,000 since 1991. Charitable status was granted in March 1992 and a board of Directors appointed.

### Children's Hospice South West.

(Little Bridge House) 111 Boutport Street Barnstaple North Devon EX31 1TD

Tel: 0271 25270

Have raised over £1 million. There is no doubt that Little Bridge House will be built on a piece of gently undulating ground on the edge of Fremington Village lying close to the River Taw, a few miles from Barnstaple. The first turf will be cut on September 17th 1993.

### North West Children's Hospice Appeal

(Derian House) c/o Preston Nursing Home Midgery Lane Fulwood, Preston PR2 5DX

Tel: 0772 652008

Plans to open at the end of September 1993 with a capacity of nine beds and 4 family flats.



**Hope House**

27a Church Street, Oswestry SY11 2SU

Tel: 0691 671671

Have raised over one and a half million and plan to cut the first turf in September 1993. The hospice will be sited in the village of Morda on the Oswestry to Welshpool Road.

**The Children's Hospice in Wales**

(Ty Hafan) "Gwynfa" Main Road, Church Village Pontypridd, Mid Glamorgan CF38 1RN  
Tel: 0443 218008

Is raising funds and has identified a site in the Vale of Glamorgan.

**East Midlands Children's Hospice**

(Rainbows) COPE House, Tower Street, Leicester, LE1 6WS

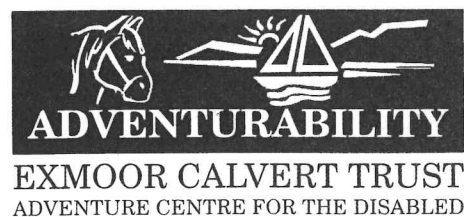
Tel: 0533 549346

A site for Rainbows has already been identified close to the A6 near Leicester. It is planned to dig the first turf in the Autumn.

## Young People's Holiday

A mixed group of eight young MPS sufferers between the ages of nineteen and twenty eight will be off to the Calvert Trust on Exmoor in Devon from the 29th of August to the 4th of September on an Activity week sponsored by the Society. Members of the group suffer from physical disabilities only. Some are walking and some are in wheelchairs. This is a pilot project to test out the possibility of organising a holiday for teenagers next year. An organiser and voluntary helpers are being provided. The activities will be organised and supervised by trained staff at the centre.

If your son or daughter would be interested in a holiday for teenagers or young adults with physical disabilities in the summer of 1994 please let the MPS office know.



WISTLANDPOUND, KENTISBURY, N. DEVON EX31 4SJ

*IT IS WHAT  
CAN BE DONE,  
NOT WHAT CANNOT  
BE DONE, THAT  
MATTERS.*

## Kings College London

### Department of Health Funded Study on the needs of families coping with life-threatening life limiting disorders.

We are working on a national study funded by the Department of Health which is looking at the needs of families caring for children with life-threatening, life-limiting disorders. We would like to talk to families caring for such children so that their views and ideas may be used to improve the support available. We are looking for families living in the following Area Health Authorities - **South West Thames, South Western, East Anglia or Trent.**

Participation in the project would involve an interview which will cover the degree of your child's dependence on you, any additional costs

you have incurred and any support services you would find helpful. The interview will last about one hour and will be arranged at a time and place convenient to you.

You may stop the interview at any time and it will not prejudice the care or treatment of you or your child in any way. Indeed you are not obliged to participate in this study and your participation will not affect the support or care you receive from any source. Your confidentiality will be strictly guaranteed.

The Society will be contacting parents about the project. However, if you are interested in participating in the study please contact: The MPS Office, 55 Hill Avenue, Amersham, Bucks HP6 5BX Tel: 0494 434156.

We look forward to hearing from you.

From the Woods Family

14th July 1993

Dear all,

Just a short note to let you know that we now have a new member of the family. We now have a little girl called Charlie, who was born on the 7th of June. She is well and healthy. We were expecting twins but I lost one early in pregnancy. Ed Wraith did the results from the "amnio" and everything was fine.

Leanne has not really picked up from having the chicken pox in April. She is now being tube fed as she has lost a lot of weight because she could not swallow anything.

They gave her forty eight hours at the most two weeks ago but we should have realized that where Leanne is concerned she always defies people. Leanne is more comfortable at the moment. Although still very poorly, they say she has stabilized. We are just taking each day as it comes at the moment and hope she isn't in any pain. Well, I must finish, as Charlie is just waking for a feed.

Love,

Paula, Scott, Leanne, Scottie and Charlie Woods

32 Millgreen, Parkfarm, Binfield, Berkshire.



## THE ACT CHARTER FOR CHILDREN WITH LIFE-THREATENING CONDITIONS AND THEIR FAMILIES

*ACT is the Association for Children with life-threatening or Terminal conditions and their families. Over the past 18 months a number of us representing a range of health professionals, voluntary organisations and the children's hospices have worked together to draw up the ACT Charter. This was launched on the 7th July 1993 by the Rt. Hon. William Waldegrave MP and endorsed by the Secretary of State for Health, Virginia Bottomley.*

- 1 Every child will be treated with dignity and respect and shall be afforded privacy whatever the child's physical or intellectual ability.
- 2 Parents shall be acknowledged as the primary carers and shall be centrally involved as partners in all care and decisions involving their child.
- 3 Every child will be given the opportunity to participate in decisions affecting his or her care, according to age and understanding.
- 4 Every family shall be given the opportunity of a consultation with a paediatric specialist who has particular knowledge of the child's condition.
- 5 Information shall be provided for the parents, and for the child and the siblings according to age and understanding. The needs of other relatives shall also be addressed.
- 6 An honest and open approach shall be the basis of all communication which shall be sensitive and appropriate to age and understanding.
- 7 The family home shall remain the centre of caring whenever possible. All other care shall be provided by paediatric trained staff in a child centred environment.
- 8 Every child shall have access to education. Efforts shall be made to enable the child to engage in other childhood activities.
- 9 Every family shall be entitled to a named key-worker who will enable the family to build up and maintain an appropriate support system.
- 10 Every family shall have access to flexible respite care in their own home and in a home-from-home setting for the whole family with appropriate paediatric nursing and medical support.
- 11 Every family shall have access to paediatric nursing support in the home when required.
- 12 Every family shall have access to expert, sensitive advice in procuring practical aids and financial support.
- 13 Every family shall have access to domestic help at times of stress at home.
- 14 Bereavement support shall be offered to the whole family and be available for as long as required.

If you would like a copy of the charter booklet this can be obtained from :

**ACT, Institute of Child Health, Royal Hospital for Sick Children, St. Michaels Hill, Bristol BS28BJ Tel 0272 221556**

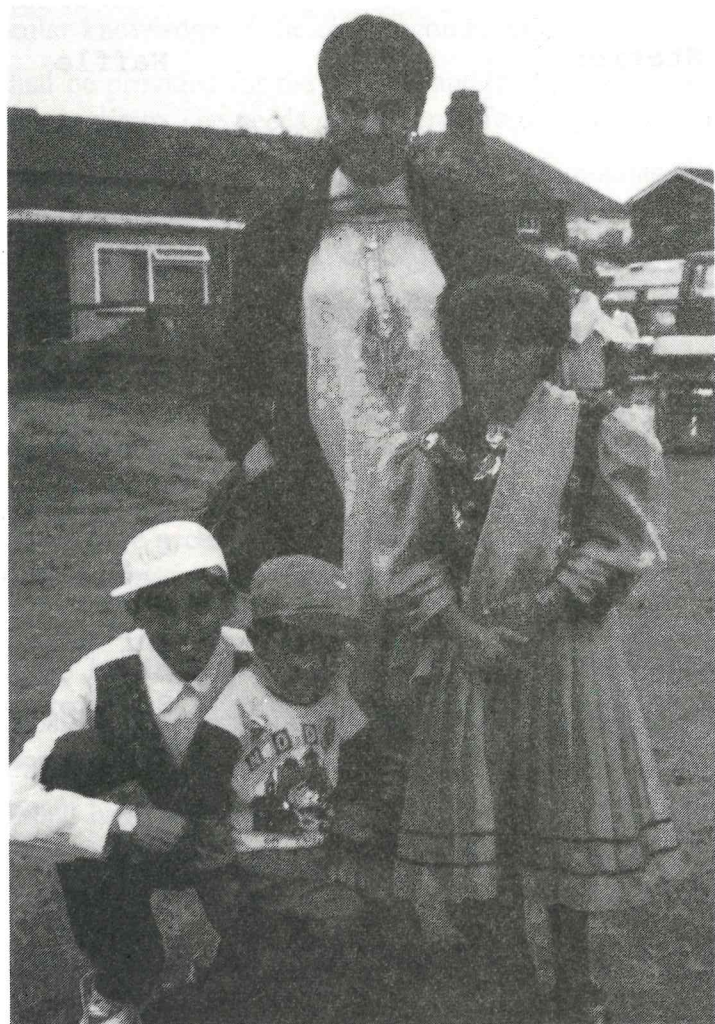
### Fundraising Events

- |                                       |                             |
|---------------------------------------|-----------------------------|
| F Fisher                              | Car Boot Sale               |
| Biggleswade & District Choral Society | Songs of Praise             |
| All Saints Church                     | Weston Wings Carnival       |
| Mrs A Fraser                          | Fundraising Stalls          |
| J & L Windsor                         | Collectin Tin               |
| Mike Kilvert                          | London Marathon             |
| Edward Nowell                         | Garden Fete & Appeal        |
| D Warren                              | Raised                      |
| John & Barbara Arrowsmith             | Disco & Raffle              |
| Roger Strachan                        | London Marathon             |
| J Fraser                              | Collecting Tin              |
| Frodsham Fire Station                 | Raffle                      |
| R & A Thompson                        | Collecting Tin              |
| Y C Hardy                             | Collecting 1 and 2 p Coins  |
| St Clears Post Office                 | Collecting Tin              |
| G Williams & Son                      | Collecting Tin              |
| St Clears CEOU C & E HQ               | Collecting Tin              |
| Christine Butt                        | Flea Market/Coffee Morning  |
| R & P Hayward                         | Sponsorship London Marathon |
| Mrs B Harriss                         | Saved 20p's                 |
| Mrs K Willis                          | Car Boot Sale               |
| Mr T Hosking                          | Sponsorship London Marathon |
| Mrs P Croghan                         | Car Boot Sale               |
| Raw Steel                             | GIG                         |
| Mr and Mrs Blease                     | Raised                      |
| V.E Waggott & Friends                 | Domino Game                 |
| Spiffing Stationary                   | Raised                      |



Sally Barrett  
 Mrs T Pidden  
 J Westland  
 Maryland Playschool  
 Friends of Tony and Shirley Eyre  
 Lawrence School  
 Mrs Lakeman  
 Alan and Fiona Byrne  
 Alan & Amy Bottrell  
 Colderwood Primary School  
 Stonelaw High School (PTA)  
 Houglie Hotel

Sponsored Walk  
 Saved copper coins  
 Sale  
 Toy Sale  
 Barn Dance  
 Collection  
 London Marathon  
 Dance & Raffle  
 Saving 20p's  
 Bring and Buy Sale  
 Raffle  
 Hogmonay Raffle



**Bilal Wali, age four from Lancashire, with his family, at the North West Area Family Day.  
 Bilal suffers from Hurler disease and has had a bone marrow transplant.**

## Area Support Families

**Robert and Caroline Fisher** .....Tel: 0799 86631  
 The Horrells, Great Samford, Saffron Walden, Essex, CB10 2RL

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

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

**Sean and Pauline Mahon** .....Tel: 0742 304069  
 41 Stumperlowe Crescent Rd, Sheffield 10, South Yorkshire S10 3PR.

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

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

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

**Tony and Shirley Eyre** .....Tel: 0934 834537  
 6 Westway Park, Yatton, Near Bristol, Avon. BS19 4JU.

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

### Contact for Scottish Families:-

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

### Northern Ireland Co-ordinating Committee:-

**Kieran Houston (Chairman)** .....Tel: 0508 884168  
 15 Barrack Street, Strabane, Co. Tyrone, BT82 8HB.

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