Newsletter

The Society for Mucopolysaccharide Diseases

National Registered Charity No.287034

Summer 97

MANAGEMENT COMMITTEE

Paul Leonard (Chairman of Trustees)
***75 Amyland Park Road, Twickenham, Middlesex TW1 3HG**

Lynne Grandidge (Treasurer)
41 The Boulevard, Broughton, Chester CH4 0SN **Tel: 01244 531163**

Dr Bryn Neal (Vice Chairman co-opted)
"Hawthorn", Weedon Hill, Hyde Heath, Amersham, Bucks HP6 5RW **Tel: 01494 774421**

Kieran Houston (Chairman, Northern Ireland Committee)
21 Cavanalee Road, Strabane, Co. Tyrone BT82 8HD **Tel: 01504 884168**

Jon Lawrie
Flat 7, 75 Avondale Road, Gorleston on Sea, Great Yarmouth NR31 **Tel: 01493 440429**

Tony Eyre
7 Elmer Close, Malmesbury, Wiltshire SN16 9UE **Tel: 01666 825215**

John Brennan
105 Barley Cop Lane, Lancaster, Lancs LA1 2PP **Tel: 01524 382164**

Wilma Robins (Welfare Rights)
77 Hillview Avenue, Hornchurch, Essex RM11 2DN **Tel: 01708 443157**

Peter Stuart
18 Hertford Close, The Spires, Ely, Cambridgeshire CB6 3QS **Tel: 01353 667018**

Sarah Long
5 Selworthy Terrace, Combe Down, Bath BA2 5NZ **Tel:01225 835104**

Alison Pullin
15 Martin's Croft, Colerne, Nr. Chippenham, Wiltshire SN14 8PD **Tel: 01225 744160**

Vic Lowry (Co-opted)
16 Maple Road, Harpenden, Hertfordshire AL5 2DU **Tel: 01582 766520**

MPS OFFICE : 55 Hill Avenue, Amersham, Bucks HP6 5BX

Christine Lavery (Director)
Joan Evans
Sheila Duffy

Tel: 01494 434156
Fax: 01494 434252
E MAIL 101716,2774
(CompuServe)

NORTHERN MPS OFFICE :168 Hesketh Lane, Tarleton, Lancs PR46AT

Mary Pagett (Director of Support Services North)
Pam Thomas

Tel: 01772 815516
Fax: 01772 814821
E Mail 106025,3374
(CompuServe)

Sue Butler (Sales)
Spriggs Holly House, Spriggs Holly Lane, Chinnor Hill, Oxon OX9 4BY **Tel: 01494 483185**

Our Home Page on the World Wide Web : http://www.vois.org.uk/mps

*** New Address from 7th August 1997.**

The Society for Mucopolysaccharide Diseases

55 Hill Avenue, Amersham, Buckinghamshire HP6 5BX
Telephone: 01494 434156 Fax: 01494 434252

The MPS Society is a voluntary support group, founded in 1982, which represents over 800 families in the UK with children or adults suffering from Mucopolysaccharide and related diseases. It is a registered charity, entirely supported by voluntary donations and fund-raising, and run by the members themselves. Its aims are as follows:-

To act as a parent support group
To bring about more public awareness of MPS
To promote and support research into MPS

The Society operates a network of Area Families throughout Great Britain and Northern Ireland, who offer support and links to families in their areas. It provides an information service for families and professionals. At the present time it supports two specialist MPS clinics at the Royal Manchester Children's Hospital and at the Hospital for Sick Children, Great Ormond Street, London. The Society also funds research projects at the Christie Hospital, Manchester, Royal Manchester Children's Hospital, Bristol Children's Hospital and the Institute of Child Health, London. It encourages and assists contact and co-operation between parents and professionals and maintains links with sister societies in Europe and throughout the world.

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

"CARE TODAY, HOPE TOMORROW"

Front Cover:
Dr Ed Wraith is photographed here with Karen and Wayne Hoather, their daughter, Katie and sons, Simon and Michael (both boys suffer from Hunter Disease)

We would like to acknowledge Carlton TV for the use of this photograph.

CONTENTS

Deadline for the 1997 Autumn Newsletter
26th September 1997

Please send us lots of photos

DIRECTOR'S REPORT

Over the last 15 years in their own way each family in the MPS Society, helped by friends and relatives, has contributed to the various support and research projects we have undertaken.

The Society's Trustees have distributed over £600,000 to research in Mucopolysaccharide Diseases which has now brought us to the brink of a new era in the understanding of these diseases and the possibility of therapy for some.

In 1993 the Society funded a 3 year project 'Gene Therapy for Hurler Disease'. It was a step every family would have wanted us to take - and yet held absolutely no guarantee that three year's of hard work would lead scientists anywhere, let alone to human clinical trials.

In 1995 we hit a glitch. New safety controls were introduced which needed to be carried out. Another £15,000 had to be raised before the project could continue. Again it was MPS families who organised yet more coffee mornings and ran yet more sponsored walks. One family facilitated a grant from the Al Fayed Charitable Trust that helped the Society to fund the final year.

With your newsletter you'll find a 'Gene Therapy Research Parent Pack'. The covering letter tells of the important news that before long the first 'Gene Therapy for Hurler Disease' will take place. We hope the information will help you understand what every family in the MPS Society has achieved and to consider how, when the time comes, you can raise public awareness by letting local press and media know of this success story.

The Society has three further research projects it wants to fund, two of which might also lead to human clinical trials in the future:

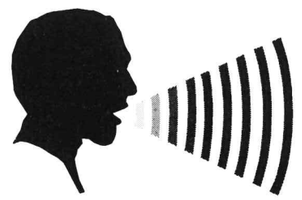
'Gene Therapy for Hunter Disease'
'Enzyme Replacement for Morquio Disease'
'Mutation Analysis for Sanfilippo Disease'

It would be wonderful if the increased public awareness which inevitably will be generated by the media's interest in Gene Therapy helps to fund these projects and also the appointment of two new development officers to support and advocate the needs of over 800 MPS families needing our help today.

If you aren't able to help in this way we do understand.

As soon as we have further information a News Release will be sent to every MPS family in the UK and to the MPS Societies throughout the world.

Christine Lavery
Director



AGM MPS Society

Notice is hereby given that the Annual General Meeting of the MPS Society will be held on Sunday the 14th September at 9.30am in the Stakis Hotel, Northampton.

CHAIRMAN'S REPORT

News about GTAC, the MPS Talk Days, Training Weekend and beyond.....

GTAC

Many of you will have seen 'Dolly' the sheep in the media. Dolly appeared to show that gene manipulation was a reality and soon after the initial publicity, I was asked to attend a meeting organised by the Gene Therapy Advisory Committee (**GTAC**) when many of the issues relating to gene therapy were explored. What I found very pleasing was the wish of all participants to cure life - threatening disorders in children. Your Director, Christine Lavery has now obtained a copy of the TV documentary 'All in the Genes' which includes discussion about MPS children. This will be shown during the MPS Family Conference at the Stakis Hotel, Northampton on the weekend of the 12th 14th September 1997 Conference at Northampton. That conference will also provide an opportunity to hear about the latest developments on MPS research including the work funded by the Jeans for Genes campaign.

Talk Days

The Northern Ireland and Birmingham 'Talk Days' gave me the opportunity to meet many of the MPS children and their families. Everyone was very interested in the talks given by Dr Ed Wraith on MPS diseases and Alan Cooper who covered 'DNA, Genes and Stuff'. A wide range of local health professionals attended and the feedback was excellent. I express my thanks to the Area Support Families, Dr Wraith and Alan Cooper for making these events such a success.

The ASF / Trustee Training Weekend

For the first time, some of the Trustees were able to join the Area Support Families for their Training Weekend. We explored our respective roles and the ways that we can make the MPS Society more effective. Sarah Long, one of the MPS Trustees explained the challenges of dealing with a disability. Her session of putting us on the spot to explain our duties was for me a highlight of the weekend. We concluded with a brain storming exercise which covered MPS problems and solutions. These ranged from the need to recruit additional staff to improving our range of promotional goods. I left feeling that the mystique of what Trustees have to do had been explained and that there was a strong team atmosphere. As a Society, we are lucky to have the talents of so many dedicated staff, Area Support Families and Trustees.

New Trustees Required

If you think that you would enjoy being a Trustee, there will be two vacancies from September 1997. For further information, please contact me or any of the Trustees listed in the Newsletter.

Paul Leonard

MILESTONES

New Families

Caroline Currey's son, William has been diagnosed with Hunter Disease. William from Exeter is 2 years old.

Amanda and Greg Stuart's son, Jack has recently been diagnosed with Sanfilippo Disease. Jack who is 2 year's old lives in Caversham, Reading.

Dominique and Christian Trafford's son, Jack has recently been diagnosed with Hurler Disease. Jack aged 9 months lives in Wallingford, Oxon.

Marianne and Adrian Stimpson's son Dominic was recently diagnosed with Sanfilippo Disease. Dominic from Norwich is 3 years old.

Debbie and Simon Farrow's daughter Jo has recently been diagnosed with Scheie Disease. Jo from Retford is 9 years old.

Deaths

Sadly Matthew Russell died on the 15th April 1997. Matthew from Birmingham was 12 years old and suffered from Hurler Disease.

Sadly David Chou died on the 14th April 1997 in Taiwan. David who was 13 years old and suffered from Hunter Disease and spent several years with his family in the UK.

Sadly Ross Lockyer aged 16 years old died on the 29th May 1997. Ross from Pontypridd suffered from Hunter Disease.

Congratulations

Congratulations to Klaus and Alison Menker (*Coles*) whose son Nathan was born on the 2nd April 1997.

Congratulations to Peter and Tanya Steenhoven (*Denyer*) on the birth of their 7lb. 5oz healthy baby girl, Tia who was born on the 18th May 1997.

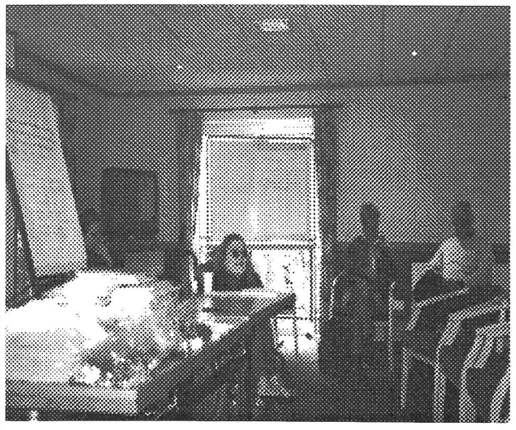
AREA FAMILY SUPPORT

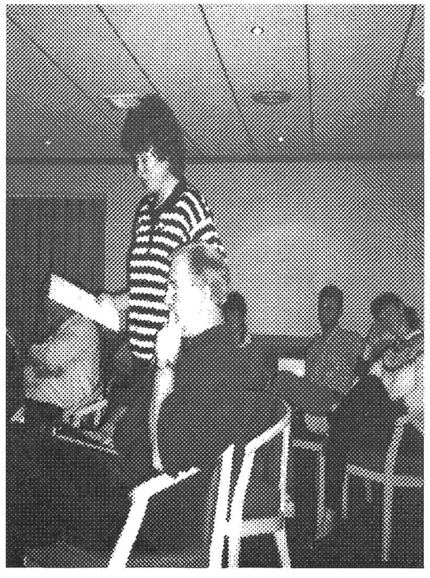
Area Family Training Weekend

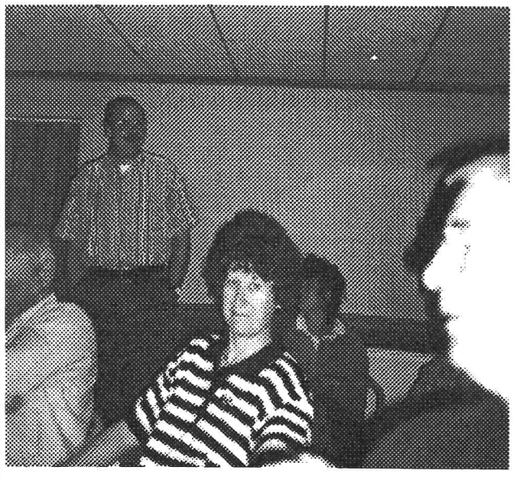
The Area Family Training Weekend was held in Derbyshire on the 25th - 27th April.

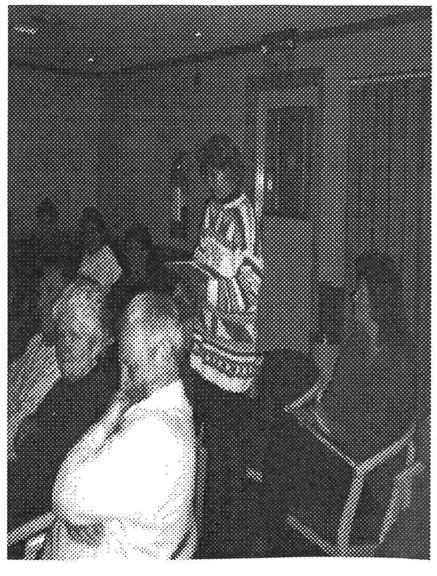
For the first time Trustees joined the training this year and everyone found the weekend informative and enjoyable.

The photographs show some of the families being put through their training.



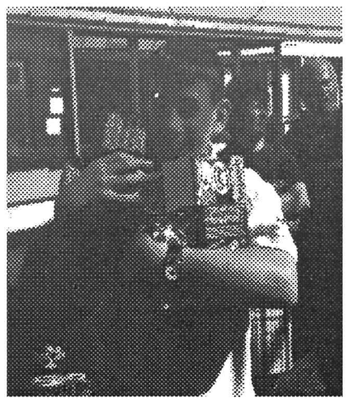






AREA FAMILY SUPPORT

South West MPS Easter Egg Hunt - 13th April 1997



Pictured here are some of the families who are obviousley having a great day.

South West MPS Easter Egg Hunt - 13th April 1997

On Sunday the 13th April nine families gathered together for an Easter Egg Hunt at Larkrise Special School in Trowbridge.

We enjoyed a lovely buffet, all home-made prepared by a lady at the school called Margaret who also served us with constant tea and coffee all day.

The weather was wonderful, brilliant sunshine and lovely and warm. We spent most of the afternoon outside. We were lucky enough to have the Easter eggs donated by Nestlé and were able to hide them before they all melted! Each child was allowed to find 2 Easter eggs and this they did with amazing speed.

We then took some photographs for the Newsletter and for Nestlé. We spent the rest of the afternoon basking in the sun, watching the children play in the playground, on the slide, in the playhouse and round the gardens.

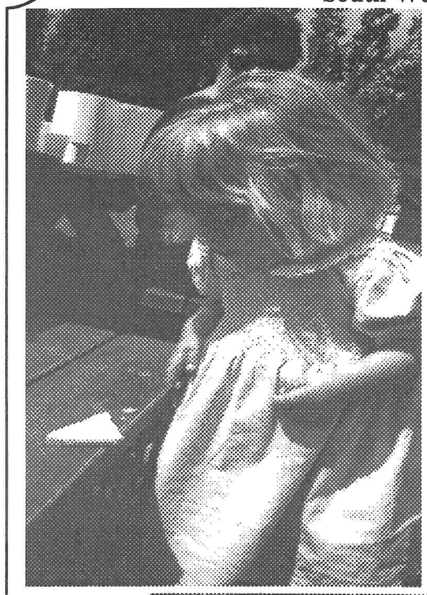
After a final cup of tea from Margaret, we said our goodbyes at about 4.30pm. Our next meeting is at Bicton Park near Exmouth, courtesy of the Hill family on Sunday the 8th June.

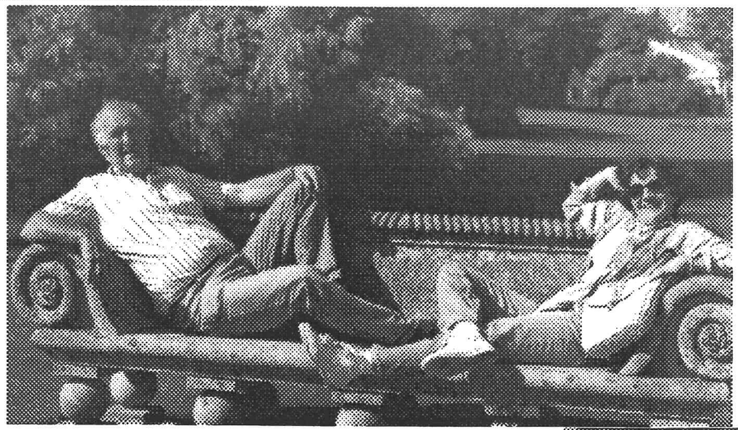
The Christmas Party has been booked at the Thimble Mill Restaurant, Stakis Hotel, Bath for Sunday the 7th December, from 12.30 - 4.30pm.

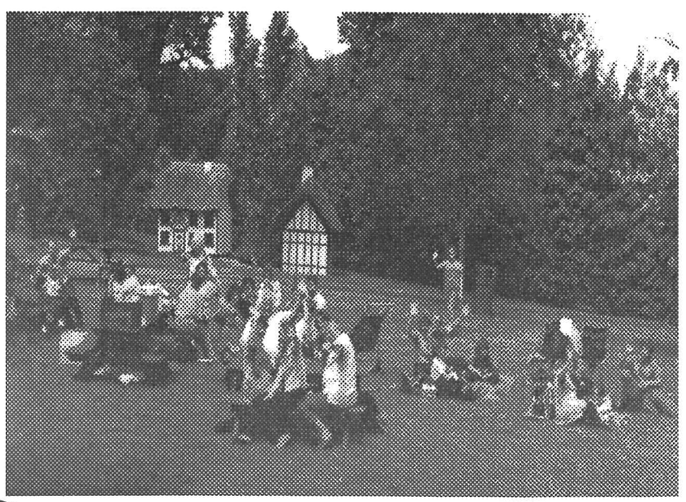
Jackie Chisling

AREA FAMILY SUPPORT

South West Family Day Out







AREA FAMILY SUPPORT

South West Family Day Out

On Sunday the 8th June 1997 we had a lovely day out at Bicton Park in Devon. The weather forecast was not very promising but thankfully, as usual, wrong, and we had a lovely afternoon.

We were able to spend all our time outside picnicking and chatting by the adventure playground where the children were well catered for.

Various folk went for a short walk in the gardens or for a train ride with their children - or someone else's.

We decided to all meet up at 4.00pm for tea and cakes in the gardens and stayed chatting until closing time.

We had a lovely day out especially all the children as there was so much for them to do.

Our only sadness to the day was that the Chisling family did not join us as they had been involved in a car accident and had spent the afternoon in hospital being checked out.

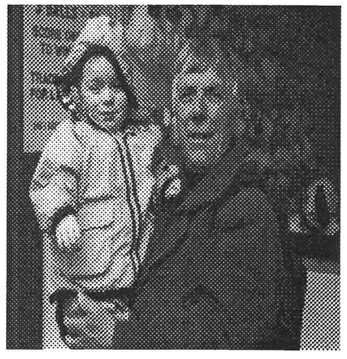
Thankfully no one was seriously hurt we wish them well and hope to seen at the next get-together.

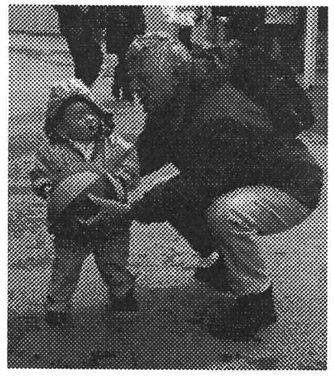
Anne and Gordon Hill

AREA FAMILY SUPPORT

North West Family Day at Camelot Theme Park - 11th May 1997

Despite the rain in the air we had a good turn out, 16 families including some for whom this was their first family event.
There was much cheering and even more booing at the knights during their jousting and generally everyone had a super day.
No-one was sick as they were turned upside down and shaken about on the rides - Not me!
Towards the end the rain became heavier but undaunted many families took this opportunity to join Sooty and his friends.
Pam Thomas



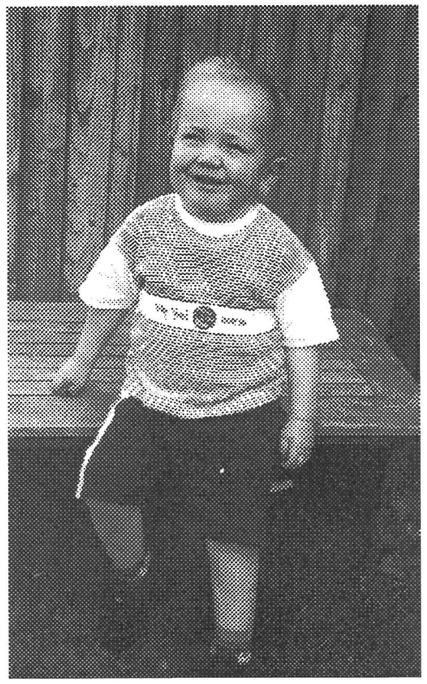


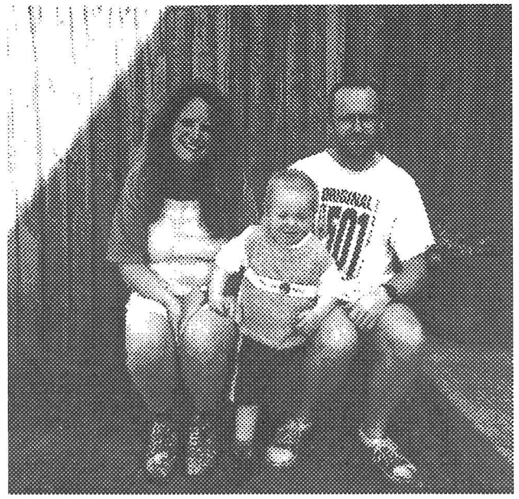
Pictured above are Mark and Philip Weir (Mannosidosis)

Bill Blackburn has fun with Jack Onion (Hunter)

Pictured here with the Gladiators are Daniel Groghan (Hunter) and Davic Oulton (Hunter)

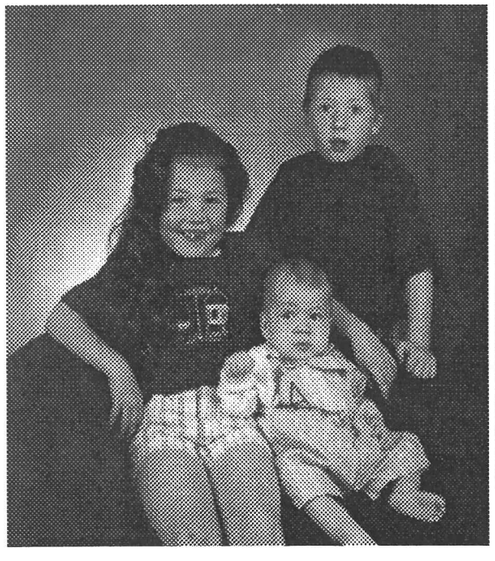
FAMILY NEWS

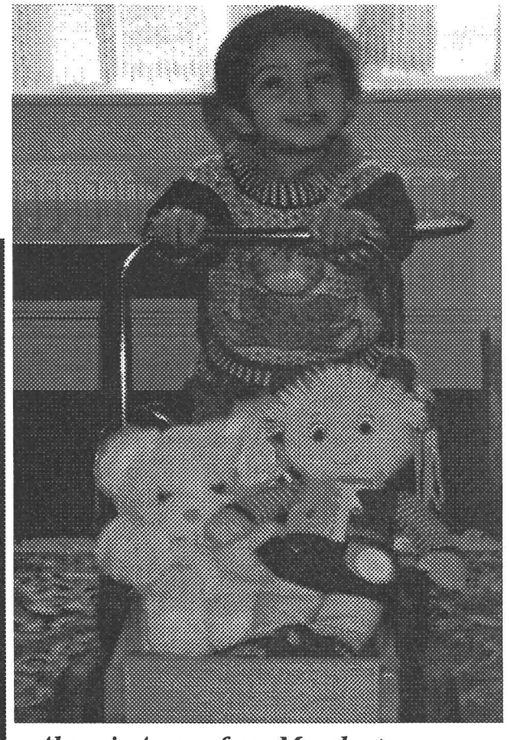




Pictured above and is Jack Stuart and his Mum and Dad. Jack who is 2 years old suffers with Sanfilippo Disease.

Pictured below is Callum Pollock aged 10 months (Hurler) with his sister and brother.





Above is Aroosa from Manchester. She is 15 months old and suffers from Morquio Disease.

FAMILY NEWS

MPS Family Day at Helen House

For sometime now many Children's Hospices around the country have recognised that some families who may benefit from the care and support they offer cannot take the steps needed for themselves.

In the past the MPS Society has been invited to arrange for MPS families to visit on an agreed date and for either myself or Mary to participate in that day. Some of you will recall the wonderful days we had at Little Bridge House, Rainbow House and the Children's Hospice for East Anglia. Therefore we were absolutely delighted to receive an invitation from Mary Thompson, Head Nurse at Helen House to bring a small group of MPS families to the Children's Hospice on the 28th April 1997. Two families took up the offer and spent a very enjoyable time discovering Helen House and meeting the care team. The sun shone and the children had a wonderful time in the garden.

Thank you to everyone at Helen House for making the day possible.

Christine Lavery

Pictured above is Keegan with Kerry's year old twin sisiters, Lorna and Lorraine

Pictured above is Kerry Little, aged 5 years (Hurler) with her Dad

Opposite is Kerry with Keegan Lovick, aged 2 years (Hurler)

FAMILY NEWS

Nine families attended the Scottish Clinic this year and it was lovely to meet up with the children and young adults again.

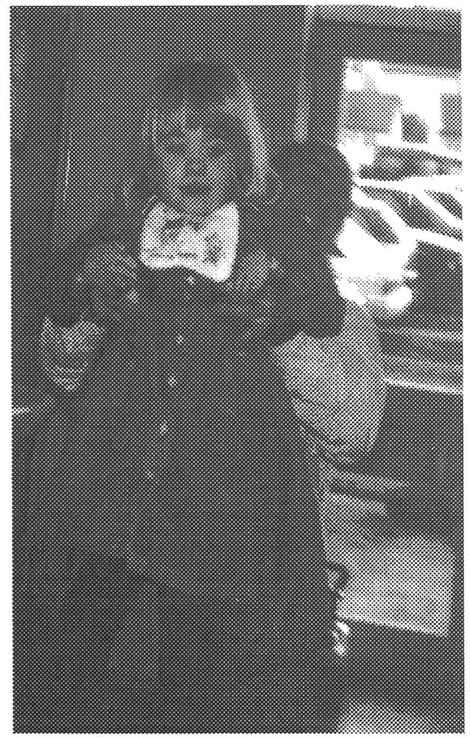
We owe our grateful thanks once again to Alan and Fiona Byrne, Area Family for Scotland, who did a splendid job of organising appointments and ensuring everything ran smoothly on the day.

Grateful thanks are also extended to Judith Evans, Joanne's Mum, who initiated the clinic at the Royal Alexandra Hospital and to Dr Cameron Shepherd, Consultant Paediatricain, who kindly offered his facilities at the Paediatric Unit, which, I must add were excellent as there was plenty of room for the children to run around and lots and lots of toys to play with.

Finally and not least, our sincere thanks go to Dr Ed Wraith, without whom none of these specialist clinics would be possible.

MPS Scottish Clinic
Royal Alexandra Hospital
Paisley

11th April 1996

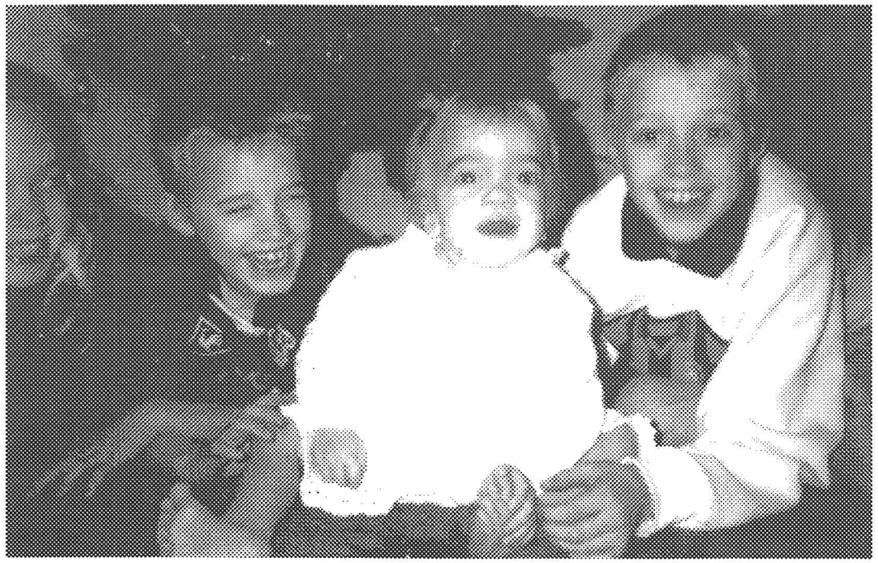


Pictured above are Emma McLellan aged 6 years (Sanfilippo) being swung valiantly by Alan Byrne.

This clinic will be repeated next year, probably aound the same time. Dr Shepherd has kindly offered the facilities at the Royal Alexandra again.

Mary Pagett

FAMILY NEWS

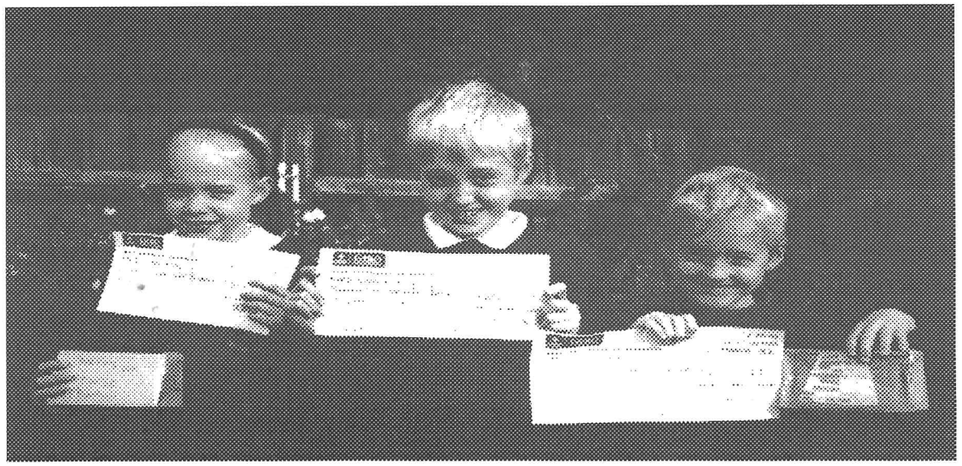


Pictured above are Laura, Andrew, Katie and Gary Devine

Muco Means Mucus
Up in are bedrooms we
Cry a lot
Only God we pray to
Poly means many
Only God we trust well, and Mum and Dad
Luck we need a lot of
Yes, Katie it's you we are thinking of
Saccharide means sugar
A little bit of bone marrow she may need
Cause her body is missing something
Catty or Katie we call her
Hurler is the type she's got
A nasty disease
Regularly she goes to hospital
In Coventry, Birmingham and Manchester
Day after day we cry
Everyone is praying for her.

Poem by Laura Devine aged 10 years old

FAMILY NEWS



Laura aged 10 year, Gary aged 10 years and Andrew aged 7 years.

Andrew, Gary and Laura disappeared one Sunday afternoon to do their "homework". They appeared about an hour later with 2 boxes "to collect money". They went to school on Monday and asked their teachers if they could collect money for the MPS Society. They kept the boxes on their desks and children from their classes brought in pennies from home. It was literally Gary and Laura's idea and action without intervention from adults. They didn't need any encouragement!! They were not allowed to go around the school and were not allowed to fundraise (more later about why). The children brought in their pocket money, chose cheaper crisps etc. so that they had money to put in the box.

The school, Parkgate Primary School, is in an area which is not very affluent and quite of few of the families are single parents and parents who are unemployed which made their achievement even more fantastic. The giving came from the heart.

Not wanting to let this pass by unacknowledged I enlarged the cheques on the photocopier and asked if I could go into the school and thank them for the money raised.

To cut a long story short, I had to attend the assembly for the upper school where it was also announced that the Management Committee had decided that in Spring Term 1998 all fundraising will go the MPS Society. Apparently, they are inundated with requests from charities, so they have made a decision to limit the school to 3 charities a year linked to the 3 terms. So, the MPS Society is now officially adopted for Spring Term 1998. ***I was thrilled as every little bit helps, doesn't it.*** The school children were disappointed it is so far ahead, because they have been practising a variety show but I am sure we can sort that!

Andrew, not to be outdone, decided to do a sponsored silence. He decided on the Tuesday night and received permission from the school on the Wednesday. He telephoned for sponsors that evening and was silent at school from start bell to finish bell on the Thursday! He is thinking of doing it again after more preparation. He is such a chatterbox as well, I don't know how he managed it.

They are full of fundraising ideas, so watch this space.....

Lindsay Devine

FAMILY NEWS

Pictured above are Aiden Brown and his Mum, Angela at the Bankton Primary School, Lothian. The pupils raisied funds by selling treasure maps.

Aiden who is fourteen months old and suffers from Hurler Disease.
He has just recieved a Bone Marrow Transplant at the Royal Manchester Children's Hospital. His 3 year old brother, Aaron was the donor and both boys are doing well.

The following is an extract from the Daily Record giving an account of Angela's thoughts in the lead up to Aiden's operation.

May 6th 1997 - "I now realise just how sick Aiden is and I'm scared of what lies ahead."
May 12th 1997 "We have many doubts about the transplant. At the moment we see a normal, healthy child, but he will soon be quite sick from the chemotherapy treatment."
May 16th 1997 "Aiden has been tied up in his cot and he has been given all kinds of drugs, which make him sick. It was so hard watching him...he looks so small and sad. I wish I could make him better."
May 19th 1997 "We met another family whose baby has been diagnosed with the same disease as Aiden. I hope we were of some help to them."
May 22nd 1997 The big day for Aaron. " Aaron is a wee angel. After the operation, he ate his dinner and then polished off some Smarties! I am amazed".
May 23rd 1997 Transplant Day. "My chest was tight, my heart was beating fast and I was shaking like a leaf. Aaron's donation was fed through Aiden's lines and within half an hour he was back playing with his toys, wondering what all the fuss was about.
May 24th 1997 "Aiden looks great. He has colour in his cheeks and he keeps saying 'Hiya' and trying to give his Grand-dad a kiss. I'm so glad it's all over."

FAMILY NEWS

Fundraising - Sporting Stars Auction

Joanne Plummer, grandmother of James Edwards (Hunter) who sadly died at the beginning of this year has asked us to let all MPS families know of her fundraising function.

She will be holding an auction on the 9th August 1997 and she has sent us a list of the items to be auctioned in case any of our families would be interested in bidding for any of the following:

Will Carling's autographed England Rugby Shirt

Tina Turner autographed picture T shirt and tour programme.

1966 world Cup England Vs Germany programme (in excellent condition)

Matthew Maynard's cricket bat signed by the Glamorgan and Leicester teams.

Welsh football signed by the Welsh squad who played against Turkey in December 1996.

Telephone Your Bid Now

Mrs Plummer on 01222 218007.

Area family Support

Due to heavy commitments elsewhere John and Martine Brennan have decided to step down as Area Family for the North West of England.

I am sure we would all like to thank John and Martine for all their hard work over the last five years and as John is also a Trustee of the MPS Society we will still be in close contact with them.

Joanne and Gary Adshead and Geoffrey and Selma Oulton will be the Area Family Support families for the North West.

Chris and Lynn Grandidge have volunteered to step in as the new area family along with Sylvia and Bill Blackburn for the Potteries and we would like to wish them well.

Forms included with the Newsletter

Please note we have included some information with this newsletter which we would like you all to read.

We have also included order forms for Flowers and MPS Xmas Cards.

FAMILY NEWS

Welsh MPS Clinics

The next Welsh Clinics will be held at the University Hospital of Wales, Heath Park, Cardiff on

Friday 7th November 1997

Friday 24th April 1998

North West/Potteries Xmas Party

This Christmas Party will now be held at South Cheshire Masonic Hall, Willaston, near Nantwich on Sunday the 14th December 1997.

Rail Travel for Disabled Passengers

Railway Companies throughout the UK are committed to making widespread improvements of stations and trains to make travel easier for disabled passengers. If you would like information on concessionary fares and making your journey easier then contact your local Rail Station or contact:

Disabled Persons Railcard Office
PO Box 1YT
Newcastle upon Tyne
NE99 1YT Tel: 0191 269 0303

Superbrush

If you are interested in a special toothbrush with three heads which allow teeth to be brushed on the inside, outside and has a chewing surface all at the same time.

Contact

Dent O Care Oral Hygiene Products
7 Cygnus Business Centre
Dalmeyer Road
London
NW10 2XA Tel: 0181 4597550

Thank you to everyone who supported us last year by buying and selling MPS **Christmas Cards**. You may feel Christmas is a long way off but there are only **175 shopping days till Xmas**. So we are enclosing Xmas Card order forms with this Newsletter.

If you work for a company who send out Xmas cards do ask if they would be willing to use our cards for this.

ACTPACK: Children's Hospices

ACT has produces a publication for use by families and key workers to promote a better understanding of the children's hospice movement. It includes an updated list of current hospices and the numerous services they provide. Free to families and £3.50 to others.
Contact: **ACT, 65 St Michael's Hill, Bristol BS2 8DZ**

INFORMATION

The following is another way to raise money for the MPS Society. We hope that you will think of using this company to send flowers so that the MPS Society can benefit.

A MINIMUM OF £2.50 TO MPS FOR EVERY BOUQUET DESPATCHED.

SEND A BEAUTIFUL FRESH FLOWER BOUQUET
AND HELP RAISE FUNDS FOR
THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES
FROM JUST £9.99 INCLUDING DELIVERY

Whatever your reason for sending flowers, by using Flying Flowers - Europe's favourite flowers by post company - you will help MPS raise funds. For each bouquet you send Flying Flowers will donate a minimum of 25% (see order form for details) back to MPS.

Prices start from just £9.99 and include...

- **Flowers and greenery**
- **Delivery by 1st Class Post (UK/Eire)**
- **Protective Gift Box**
- **Flower Care Kit**
- **Decorative Presentation Wrap**
- **Gift Card with Your special message.**

To order simply complete the coupon and post to **MPS Bouquet Offer, Flying Flowers Ltd, The Jersey Flower Centre, Jersey, JE1 5FF.**

Alternatively telephone 01534 865665 (8am-6pm 7 days) and quote reference **MPS/SU97/A** (to ensure donation is made), bouquet code and credit card details.

We have included two order forms with this Newsletter. More can be obtained from your Area Family

INFORMATION

The following story was sent to us by Dr Ed Wraith who found it in the American Journal of Medical Genetics.

The Christmas Present

Robert W Marion
The Centre for Congenital Disorders, Department of Paediatrics, Montefiore Medical Centre Albert Einstein College of Medicine, Bronx, New York

Telling parents that their child is affected with a genetic disease is undoubtedly the worst part of our job. Often painful and always distressing, it's unfortunately something we cannot avoid as so many of the conditions with which we clinical geneticists deal have such terrible prognoses. In these situations, we are forced to act as both judge and jury. Because he is affected with a disorder, we have found the child guilty, and it's our role to condemn him to death and his family to a life of grief. And, in most cases, once the diagnosis has been confirmed and the news delivered, we're helpless to do anything to avert the predetermined outcome. We can't fix the child, and we often can't significantly alter the course of his illness. At best, in an attempt to make his existence acceptable, all we can really hope to do is orchestrate some of the events of the child's life.

That's what happened the first time I saw the Sweeneys.

It was the Friday before Christmas, and the Garwood Children's Rehabilitation Centre had that feeling of forced festivity that tends to envelop children hospitals at that time of year. It seemed as if every last inch of the place was decorated with tinsel and blinking lights, garishly-dressed evergreens, and giant menorahs. In spite of all these carefully-arranged, cheerful decorations, a feeling of helplessness and hopelessness still hung in the air. Amy McDonald, a second year fellow in genetics, and I were standing in the hallway talking with Benjamin Sontag, the Executive Director of Garwood, when we first saw the Sweeneys. Mother, father, and son were rapidly walking down the hall toward the outpatient department. From my position, I could only see the boy in profile; Amy was able to see him straight on. We saw the child for only a few seconds as, clutching the hands of his parents for support, he walked past us. But that brief glimpse of the boy was enough. His large head, his coarse facial features, his thick, claw-like hands, and his stiff, spastic gait, told us more than either the fellow or I needed to know. I looked at Amy, she looked at me, and our jaws dropped.

"What's wrong?" Ben asked, noticing the change in our demeanour.

"That boy ..." Amy began.

"What about him?" Ben asked, looking down the hall, probably taking notice of this family for the first time. "He's got a mucopolysaccharidosis," I replied.

"I'm sure he does," Ben said. "What's a mucopolysaccharidosis?"

"A storage disease," Amy responded. "They're a group of disorders that usually cause degeneration of the central nervous system and early death."

"You can tell all that just by seeing the boy pass in the hall for a few seconds?" Ben asked.

"Sen, if we couldn't tell all that just by seeing him pass in the hall, we wouldn't deserve to be your genetics consultants," I replied.

"It looks to me like he probably has Hunter syndrome." Amy added.

"Hunter syndrome I know about," Ben said. "At least I know enough to know that Hunter syndrome is not a good thing to have."

Amy and I nodded. We better go find out who that kid is and why he's here," I said.

By this point, the family had disappeared around the corner that led to the outpatient department. Amy and I followed down the hall after them and, seeing that the parents had settled themselves in the waiting area, and that the boy had quickly begun to attack the waiting area's well-stocked toy chest, we entered the reception station.

"Who's that kid?" I asked Joanne, the clerk. "Thomas Sweeney," Joanne replied, "your first patient of the afternoon."

After pulling the boy's chart from the "To Be Seen" basket, I began riffling through it. I found the genetics consult request form and as I read it, my heart sank. :'He's a three-year-old who was referred to us for evaluation by Eileen Woods. the audiologist," I mumbled in Amy's direction.' He has hearing loss and global developmental delay."

"Does it say anywhere that he has Hunter syndrome?" Amy asked. I turned the pages of the chart. Results of an audiogram revealed that the boy had a mild-to-moderate conductive hearing loss. A note from Eileen briefly outlined the boy's history: a year before, the note reported, he had been able to say a half-dozen words; more recently,

not only had he not gained any new words or started putting them together in sentences, he'd apparently lost all ability to communicate verbally-

Except for these notes and some insurance information, the chart was empty. "No, no diagnosis listed," I said to Amy."We'd better go talk to Eileen."

We found the audiologist in her office, doing some paperwork. "Thomas Sweeney's here to see us," I said, taking a seat across from Eileen's desk. "Just looking at him in the hall. we're pretty convinced he has either Hunter syndrome or some other mucopolysaccharidosis. Eileen. do you know if anyone's raised this possibility with the parents in the past?"

The audiologist smiled sadly and shook her head. "Apparently not," she replied; I saw him for the first time about two weeks ago. His parents made the appointment themselves because Tommy's speech is so far behind. They've been worried about him for over a year, but their paediatrician has been blowing them off, telling them that he's just a little slow in getting started but that he'll eventually catch up.

"Terrific." Amy interrupted. "That's very helpful." "The parents knew Tommy was more than just a little slow and since they weren't getting any help from their doctor, they finally decided to take matters into their own hands. When I saw him, I knew he had something, but I wasn't sure what it was.

"How did you get them to make an appointment to see us?" I asked.

"That was easy. Since the audiogram showed that he had significant hearing loss, I told the parents that sometimes these problems were inherited, and that

INFORMATION

INFORMATION

it might be a good idea for Tommy to see a geneticist. It didn't take a lot to convince them; they're so concerned, they made the earliest possible appointment with you. The mother told me that they've put off having more children until they get an answer about what's causing Tommy's problem. They're very nice people, and they're scared to death."

"They have good reason to be," I said. "You remember what happens to kids with Hunter syndrome?" Eileen nodded her head. An excellent audiologist who'd worked at Garwood for a long time, Eileen Woods had had a lot of experience with children and adolescents with various forms of mucopolysaccharidoses. Over the years, she'd carefully and methodically documented the inevitable slow, steady deterioration of their speech and hearing.

"Do you have any feel for how they're going to take this news?" Amy asked.

The audiologist hesitated for only a few seconds.

"They're going to be devastated," she said.

I nodded my head, and Amy and I left her office.

Because it was the Friday of a holiday weekend, most everyone at Garwood had planned to leave work early, in an attempt get a jump on the traffic. Before starting with the Sweeneys, I wanted to make sure that all the tests needed to confirm the suspected diagnosis could he performed. Amy and I went into our office and started making phone calls. I called the X-ray tech, to see if she'd be able to do a skeletal survey in about an hour, while Amy called the lab. to make sure they'd be open to draw the: blood, collect the urine, and box all the specimens so that they could be mailed to our reference lab. In neither case were the people on the other end of the phone exactly overjoyed about the prospects of working up a child for a mucopolysaccharidosis that afternoon. But both reluctantly agreed that if we got the patient to them by three o'clock, they'd do what needed to be done. After hanging up the phone. 1 sat back in my desk chair and sighed. "I hate this part?" I said sadly to Amy. "I hate having to tell them. But we've got to do it, so we might as well get it over with." As I was beginning to rise, Amy said, "Bob, are you sure you want to do this"? "What do you mean?" I asked, and sat back down in my chair. "Look, it's three days before Christmas If this boy has Hunter syndrome, he's had it for three years, right?" - "Right," I replied. "And if he's had it for three years, isn't he also likely to still have it next week and the week after that?" I nodded my head. - "Right," Amy continued. "Christmas is going to be hard enough for these people as it is. Look at what they're going through: they know something's wrong with their only child, something that's preventing him from being able to speak. It's got to be frustrating for them, but at least without a name for the condition or a prognosis, they still can hold onto some hope. I'm sure that, deep down, they both believe that whatever is wrong can be fixed with either medication or surgery, or that it might even resolve on its own. Do you agree?" I again nodded my head, and Amy continued, "Now think of what Christmas will be like if we tell them that their son has an incurable neurodegenerative disease that will not only prevent him from ever being able to communicate, but will also wind up killing him by the time he's twenty." Thinking about Amy's words for only a few seconds, I nodded my head.

INFORMATION

"You're absolutely right, Amy," I finally responded. "Telling them today would destroy whatever joy they might have had over the next week. And there's nothing that would be gained from telling them. No, you're right. There's absolutely no reason for us to tell these people today that we think their son has Hunter syndrome. It would be different if we had some treatment to offer, or if there was a pregnancy involved," Amy Went on."But there is no magic pill, and Eileen just told us that they're holding off having more children until they know for sure exactly what's wrong with the boy. Making the diagnosis today, next week, or even next month won't change anything."

I continued to nod my head. "There's only one problem:" I said. "They're already here for their appointment. I don't feel comfortable seeing them and not telling them what we think." The office remained silent as both Amy and 1 thought through this problem, trying to come up with a solution. Finally, reaching for the phone, I broke the silence. "I'm just going to have to lie," I said. As I dialled the number of the outpatient department's reception station, I added, "Now, Amy, I want you to understand, I'm not encouraging this kind of behaviour. But occasionally, not telling the truth is in the best interest of the patient and his family." After two rings, the clerk picked up the phone.

Joanne, I said, trying to sound as pained as possible, "this is, Bob Marion. I'm sorry to do this. I know I have a patient waiting out there, but I've developed a terrible migraine headache. I have to take some medication and lie down for a while. Would you apologise to them for me and reschedule them for the first Friday in January?"

When I emerged from my office a half hour later, miraculously free of my headache and ready to see my next patient, the Sweeneys were gone. Amy and I saw the remainder of the patients scheduled for the genetics clinic that afternoon. When we left a nearly deserted Garwood, I was still thinking about the Sweeneys, still turning over in my mind whether we'd truly done the right thing.

During their visit in early January, Amy and I finally had to face telling them of our concerns. As expected, the session was a rough one. The couple, understanding all too well what we were saying, at first denied that Tommy had anything worse than just some mild hearing loss, but ultimately, faced with all the evidence we presented, they came to accept our conclusion. As they held onto each other, both crying softly, we told them that no matter what the workup showed, regardless of whether Tommy had Hunter syndrome or not, we'd be there for them, always available to offer information and advice, to follow their son during the years to come, and just to talk.

We did a complete evaluation of Tommy that afternoon. X-rays of the boy's bones showed that he had dysostosis multiplex; a urine sample showed equal but markedly elevated excretion of dermatan sulfate and heparan sulfate; and an assay of iduronate sulfatase performed on a blood sample revealed a complete absence of enzyme activity, confirming the diagnosis of Hunter syndrome. It's been more than a month now since I called Mr Sweeney's office to tell him that the lab tests had confirmed what we all already knew. The boy, who

INFORMATION

almost immediately began a course of vigorous physical, occupational, and speech therapy, has already shown some improvement in his motor skills, but his lack of speech continues unchanged. I check in with Tommy's mother and father at least once a week, trying to assure myself that they're weathering this emotional storm. They seem to be doing as well as can be expected. Mrs. Sweeney told me last week that although falling asleep at night continues to be difficult, she and her husband have finally achieved something of a milestone: they've been able to make it through the day without crying.

While at Garwood for clinic yesterday, I spoke with Mr. Sweeney. We were talking about how life had changed for the family since Tommy's diagnosis was confirmed, and, for the first time, we discussed Christmas. "You can't imagine how perfect that day was," he said. "Our house was filled with laughter and happiness. Our parents came for dinner, we exchanged presents, and of course, as the only grandchild on either side, Tommy was the centre of attention. When I think of what's happened since then, I can't believe how happy we all once were. I'll always remember that last Christmas; it was the last time that our world seemed anything like normal."

After a few minutes, we said good-bye and after hanging up the phone, I just sat in my office chair, thinking. I've turned over in my mind many times since that late December day whether or not telling that lie was the right thing to do. Though, in general, it's difficult to justify lying to patients, I've decided that in some situations it may be acceptable. Holding back the news from the Sweeneys on that Friday before Christmas was one of those justifiable situations; by not seeing the family, Amy and I made sure that they'd have one last memorable holiday before their lives were irretrievably changed.

That lie was our Christmas present to the Sweeneys.

RESEARCH

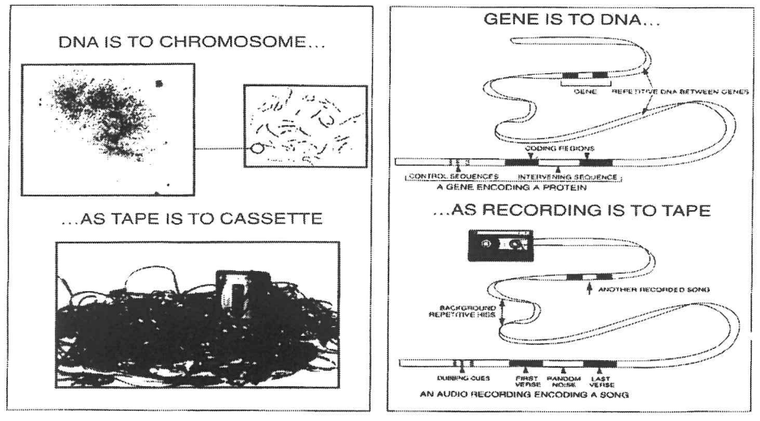
Genetics Guide

This is a feature in a series of articles reprinted from" The Progress Guide to Genetics": published last Autumn by The Progress Educational Trust and written by Prof. Marcus Pembrey, Professor of Paediatric Genetics and Vice Dean of the Institute of Child Health, University and Honorary Consultant Clinical Geneticist at Great Ormond Street Hospital for Children NHS Trust, London.

Human Genetic Research and Improved Genetic Diagnosis

There are 75,000 - 100,000 genes spaced along the 23 chromosomes that make up a single set as in an egg, and this is why it has taken a multi-million pound, international research effort, called the Human Genome Project, to start mapping individual genes to particular locations on the chromosomes and then defining the chemical structure of each gene. Knowing the location of a disease gene is the first step in developing a useful diagnostic test. The transmission of the section of chromosome that contains, amongst others, the disease gene of interest can be tracked through the family pedigree and the genetic status of Family members predicted. This allows carrier testing or diagnosis of the disease state in the developing baby. Gene tracking has proved very helpful to Families trying to maintain family life and reproductive confidence in the face of a known genetic risk.

However, if the actual flaw in the gene that is causing all the trouble is to be defined and its effect on the body understood; if the reason why some flaws are dominant and override the influence of the healthy copy is to be determined; if overcoming the genetic malfunction by gene therapy is to be contemplated in the future, then the disease gene has to be discovered and its structure - the DNA sequence - worked out. To define the structure of a gene is to open the door to a new level of understanding of how it works and influences development, health and disease. That is why scientists get so excited when their search for a particular gene culminates in success. That is why affected families who have followed the research, even helped in it perhaps, feel a surge of hope for the Future at the announcement of the news. To understand what these discoveries mean, it is necessary to have an idea of what genes are, how they work and how they sometimes go wrong.



RESEARCH

MORE FUNDS NEEDED TO MAKE A WISH COME TRUE

Those of you who have been members of the Society for some time may remember our first appeal on "The Week's Good Cause" which was given by Gavin Campbell. It featured my daughter, Helen, who has Morquio disease and ended with these words -

"When Helen O'Toole was little she used to wish as she blew out her birthday candles that her MPS would go away. It may be too late to cure Helen but with your help we can find a cure for other MPS children in the not too distant future."

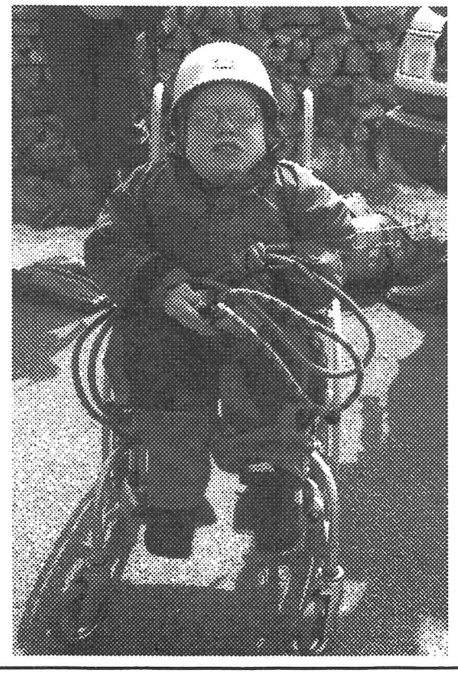
Many years later Helen is 19 and away at college. She is doing well but struggling with severe physical disability and hearing loss. During those years, like so many of you I suspect, we have had our hopes raised and then dashed by talk of possible treatments; amniotic implants, bone marrow transplants and finally enzyme replacement therapy. Research takes such a long time and it is hard for us all when that is something our children do not have.

The Society has been asked by John Hopwood from Australia, (well-known to many of us from Conferences and one of the foremost researchers in our MPS field) for a grant of £42,500 for a very exciting research proposal which just might bring some new hope. The research is described in the next article. The project is aimed initially at producing enzyme for Morquio patients, using lessons learned from work with Maroteaux-Lamy cats. We would hope that experience gained in this project would in turn help towards work for other diseases.

The Society is committed to funding this research. Now we all need to fundraise, talk to possible donors and get that money back into Society funds. **Perhaps this time another small child's birthday wish may one day come true?**

Mary O'Toole

Pictured opposite is Helen on the MPS Activity Holiday.



RESEARCH

Therapy for Morquio Patients using Enzyme Replacement

We have recently reported extensive studies evaluating the effect of enzyme replacement therapy in Mucopolysaccharidosis type VI(MPS VI) This MPS known as **Maroteaux-Lamy** syndrome, like others, is characterised by extremely severe bone pathologies stiff immobile joints, heart and respiratory dysfunction. Recombinant; DNA technology was used to prepare large amounts of normal 4-sulphatase, the enzyme deficient in MPS VI. The work systematically evaluated the clinical effect of enzyme replacement in cats that have an inherited MPS VI condition with tile same clinical difficulties as human MPSVI patients.

Our investigations clearly demonstrated an excellent clinical response to therapy for all pathologies, particularly in preventing or considerably reducing bone pathologies. We were able to show that it was important to begin the therapy as soon as possible and to use a high dose of enzyme to maximise the clinical response, particularly bone pathologies, to this therapy .

Morquio syndrome, also known as Mucopolysaccharidosis type IV(MPS IV), is another MPS in which patients also develop severe bone pathologies. We have been encouraged by the excellent response of the MPS VI pathologies to enzyme replacement therapy; to now believe that a similar response should be possible for Morquio patients. However the major technical hurdle to achieve this therapy for patients is the production of relatively large amounts of the normal enzyme, 6-sulphstase, that is involved in this MPS. In 1995 we reported experiments describing a Chinese hamster ovary cell culture systems able to produce recombinant human 6-sulphatase, albeit in low yields. In light of the encouraging results we have had in evaluating: enzyme replacement therapy in MPS VI we have started a research project to evaluate a number of novel techniques to enable the economic production of large amounts of recombinant 6-sulphatase. We are hopeful that in two to three years we will be able to identify a system to produce high yields of recombinant human 6-sulphstase. We would then be in a position to consider the feasibility of clinical trials of enzyme replacement in **Morquio** patients.

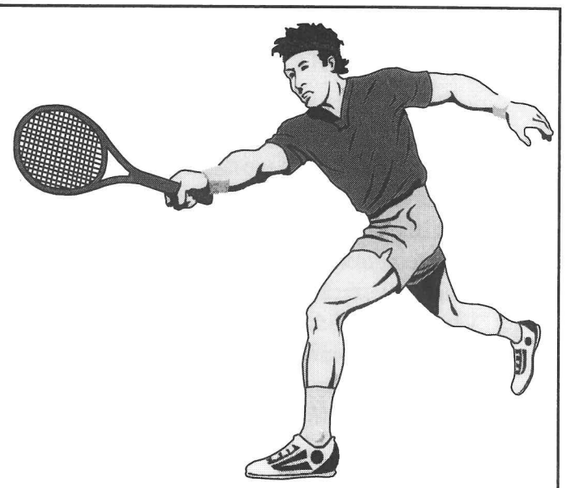
I am reporting our progress in our research program to achieve enzyme replacement therapy for **Morquio** patients on behalf of the team at the Women's and Children's Hospital, Adelaide, Australia and the many collaborators we have around the world.

John J Hopwood

Lysosomal Diseases Research Unit
Adelaide 21st June 1997

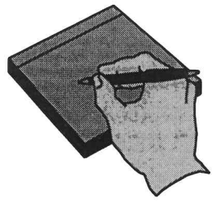
FUNDRAISING

MPS Sales



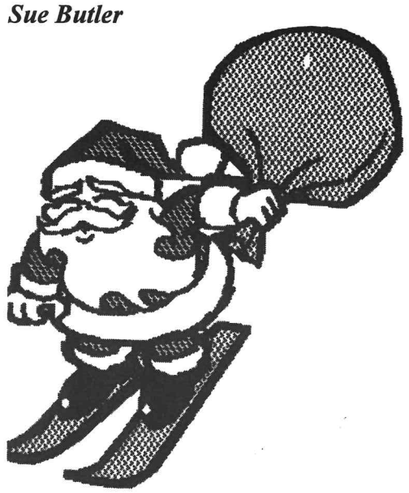
The Society has a wide range of very good quality polo shirts and rugby shirts with an embroidered logo. Our sweatshirts bear a printed MPS logo on the left breast. We also stock pens, leather bookmarks, key fobs, rulers, pencil cases and lapel badges. All these items have the **MPS** logo on them. Order forms will be with the Autumn Newsletter.

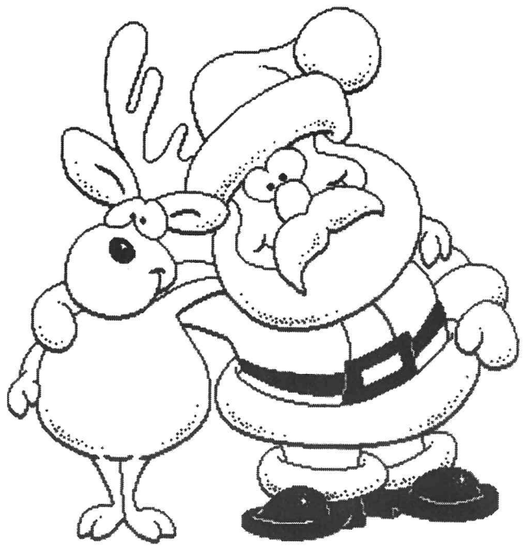
We are currently exploring the purchase of other items including a golf umbrella.



Although many of us haven't yet had our summer holidays please can we remind you of the **MPS Christmas cards**. These can be purchased at the MPS conference or ordered on the enclosed order form. Please do support the **MPS Society** by purchasing our Christmas cards.

Sue Butler





FUNDRAISING

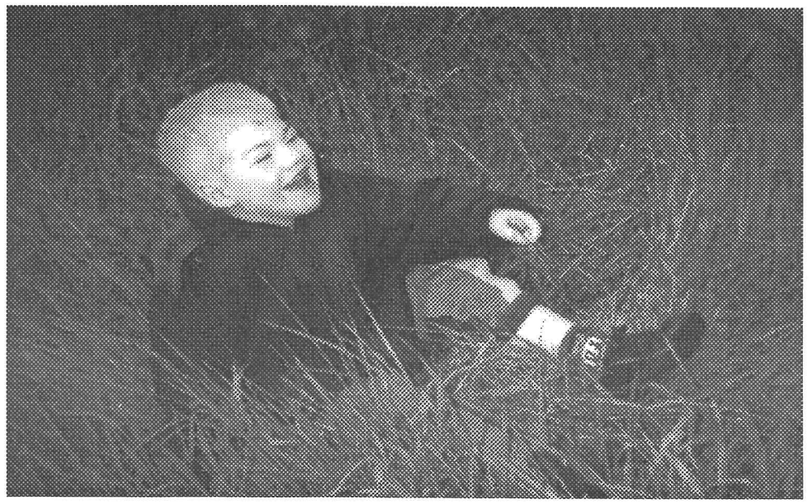
Hillmount Health Studio Northern Ireland

Six members of the Hillmount Health studio took part in a fun run or the 10 mile walk at the recent Belfast Marathon. Included in the photograph is my twin sister Eunice and as you can see we are not identical.

We are very grateful to all who took part and would like to thank them for raising a total of £915 for the MPS Society.

Allison Shields.

(Mother of Kyle aged 4 years old and who suffers from Sanfilippo Disease) Kyle is pictured below



FUNDRAISING

Back in Janauary 1997 the Lions Club held a twelve hour Badminton Marathon and said they would like to raise some money for Annette and for the MPS Society.
Although Kevin is not a member of the club, he completed the stated time and raised through sponsorship £196.00. The Lions raised the rest, bringing the total to £400.00.

We would like to thank all those who were involved.
Yvonne and Kevin Puddy. *(Parents of Annette aged 13 years old who suffers from Sanfilippo Disease)*

FUNDRAISING

Entertainment Bristol Style

An Evening Concert Party performed by the "Legion-Airs"

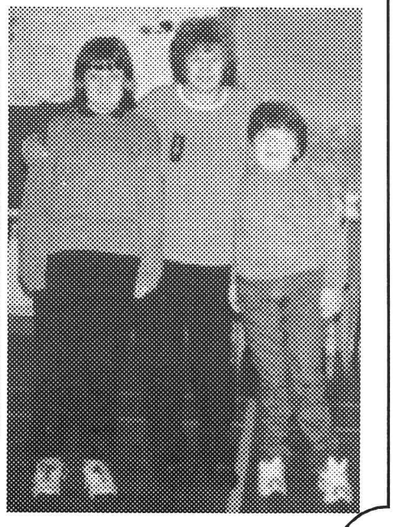
"Yes, of course we will be pleased to attend your Annual Concert in Bristol and yes, of course, we will be delighted to accept a cheque on behalf of the MPS Society"!!
I put the 'phone down and wondered who on earth these generous folk were that wanted to donate the proceeds of their evening concert to MPS. We soon found out.....
The day of the concert arrived and yes, we must allow plenty of time to get to Bristol for the 7.30 start - enter the "Pidden Factor"! We didn't reckon on the local council who, in their infinite wisdom, now do major road works at night.....twenty minutes late we arrived at the Hungerford Community Centre and crept in as the show had begun. My hopes of a quiet and discreet entry into the hall disappeared as we realised the only empty seats in the entire hall were placed centrally in the front of the hall - for all to see- with a large, empty table!
Never mind. The remainder of the evening was excellent and extremely entertaining, a mixture of song and dance with various (and dubious) comedy acts - the well endowed comedian with the 3 foot willy brought the house down and will linger in my mind for always.
At the end of the show, over two hours of great entertainment and a raffle later, the purpose of our visit arrived and we were beckoned on stage to receive - on behalf of the MPS Society, a donation cheque for £1,000. What a fantastic effort.
As Fer and I drove home that night, the songs and jokes fresh in our minds, we both felt privileged to have been invited to such a warm hearted evening with such generous folk.
Thank you again Pensford and Whitchurch British Legion and all those in Bristol who contributed to such a worthwhile evening.

Bill and Fer Pidden (Parents of Natalie aged 16years who suffers from Sanfilippo disease.)

FUNDRAISING

Please find enclosed cheque for £50.00 which was raised at our charity evening on the 23rd April 1997. This evening was arranged for four of our Guides to receive their Baden Powel awards this is as far as Guides can go before moving onto Rangers or Young Leaders. We also included Green Trefoil Guides, Emma McLean, Carolann Ramsay and Clhoe James who arranged the buffet as part of their badge. Emma explained to everyone what MPS means and thanked everyone for coming. As a Guide Company we are also a charity but each year we raise money for another charity and so it gave it great pleasure to help MPS this year. Emma is a wonderful young lady who works very hard to make her mark in the company which she has done in the short time she has been with us. Emma has been made up to seconder of the Scarlet Pimpernel Patrol. This evening has made a lot of people aware of MPS for the time, myself included, and aware of the hard work involved.

Joyce MacRae
Guide Guider
1st Balloch Girl Guides
Culloden, Inverness.



Fundraising

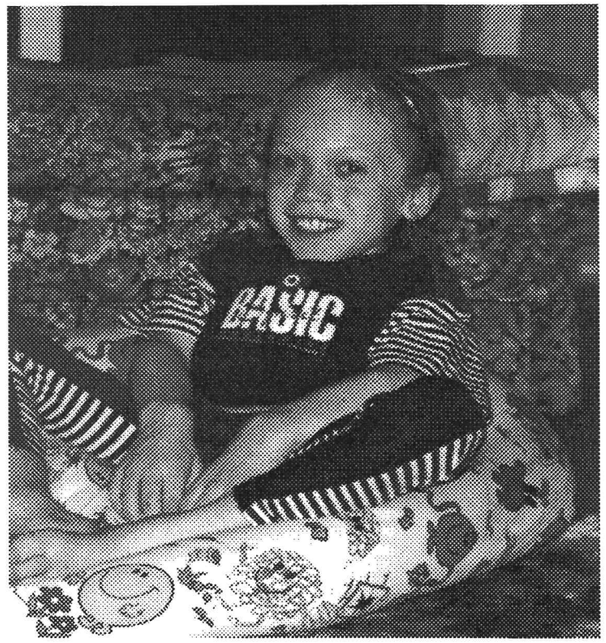
Our loyal supporters have done us proud once more.
The ***'old faithfuls'*** have kept up their good work and new
friends have participated too.
We are grateful for every
donation small or large.

Your support ensures that we
can continue to support all the MPS families who need
the Society's help in one way or another.

Christine Lavery
Director

FUNDRAISING

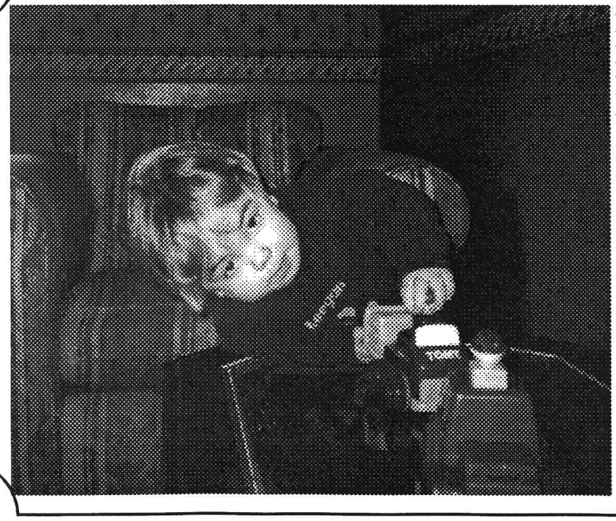
Fun Day at Bridge of Weir Primary School



Pictured opposite is Joanne Evans aged 11 years old (Morquio) with her usual lovely smile.

Joanne's school, Bridge of Weir Primary has raised the magnificent sum of £3,135.22 for the MPS Society.
They held a sponsored obstacle race for all the children in the school, approximately 400 children including Joanne.

Glasgow Taxi drivers also donated £50.00
This is the most the school have ever raised at one event and we would like to thank the school and every one involved for their wonderful generousity.



Pictured opposite is Keegan Lovick whose Mum and Dad, Rob and Melissa would like to thank Rob's dad and Melissa'a step-mum who took collections from their colleagues at Rover and St Hilda's College,Oxford.

A total of £70.00 was donated to the MPS Society.

Keegan is 2 years old and suffers from Hurler Disease.

FUNDRAISING

DONATIONS

The Society is grateful to the following who made donations.

Vernons Pools Ltd.
Bidwell & Co
Newsdouble Ltd.
Barrs Hill Guild
Rutherglen Community
Esmee Fairbairn Trust
M.D.I.S.
Cripps Harries
Sappi Europe
Sartan Club
Larkrise School
Douglas Heath Trust
Mr J Gibbs
Geoff & Joanne Naylor
Baltic Exchange
John Lewis Partnership
Tibbett & Britten
Redlands Centre
Delta plc
Amicable Friendship Trust
Retford Inner Wheel Club
Medical Ins. Agency Club
French
United Assurance Group
Mars UK Ltd.
Mr and Mrs Heisig
RTZ CRA Group
Foreign & Colonial Ltd.
John Ellerman Foundation
Rutherglen Brownies & Guides
Morgan Crucible Company Ltd.
Mr and Mrs Hinde
Department of Health
Clydebridge Workers Welfare Fund
Marks and Spencer
Grand Charity
Oversley Service Station
Mr and Mrs Moran
Adam Sutcliffe
Clive Gibbs
London & Scandinavian Metal Co Ltd.
Vauxhall Motors
M J McTiffin
Norman Franklin Trust
Druck Ltd.
Christopher Laing Foundation
The Economist
Queens Parade Antiques Ltd.
Chivas Bros. Employees Fund
Mr and Mrs Wilson
Mrs Taylor
Bendrigg Trust
GM Buses

FUNDRAISING EVENTS

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

Old Un's MCC, Shirley - Ponytail Sale.
Sandra Singh, Coventry - Shakespeare Half Marathon
Edge Hill Junior School, Stapenhill - Making and selling cakes
Mrs P Short& Jenny Hardy, Haddenham - Sale of home made jam.
John Murray, Holytown - Return of Empty Pop bottles

FUNDRAISING

Cardiff Medical Centre Sports & Social Club - MPS Quiz Night
Thelma and Fer Pidden and Majorie Butt, Westbury - Collection of Coppers
Bridge of Weir Primary School, Joanne Evans - Sponsored Obstacle Race
Mark Price, Thornhill - Sheffield Marathon in memory of James Edwards
Mannie Foster & Brian Baker, Kingswood - Car Boot Sale
Diane Riches, Brislington - Raffle Trev Challinor, Lincoln - London Marathon
Hillmount Health Studio, Belfast - Fun Run and 10 mile walk at Belfast Marathon
Trevor Rollinson, Scunthorpe - Beer Barrel Lifting Jackie Chisiling, Trowbridge - Car Boot Sale
Mr and Mrs Gibbs, Swanage - Sale of Salt Dough Items
Andrew, Gary and Laura Devine, Keresley - sponsored silence and collection in school
Lions Club, Shepton Mallet - Batlmenton Marathon Phyl Johnson, Catford - Knitted bed socks
Jane Heritage and Trudie Deacon - Making and selling marmalade
John and Mary Stacey, Studland - Selling Spiffing Stationery Items
Michelle & David Brookes-Daw, Taunton - Sale of Raffle Prizes
Mrs Maureen Lord, Saffron Walden - Lent Lunch Mrs Chalmers, Bootle - Cookbook
Marina Foster & Brian Baker, Bristol - Series of Car Boot Sales
Mr and Mrs Cockman, Verwood - Cans and Bags returned to Sainsbury's
Alan and Fiona Byrne, Rutherglen - MPS Dance and Raffle
Bray family and friends, Sheffield - Methodist Church coffee morning and Walking for Amy

CHARITY BOXES

Dalsetter Rise Post Office, Hull Mary Ellen Toole, Wells Mr and Mrs Harvey, Erith
Oversley Mill Service Station, Alcester Stanshawes Service Station, Yate
Mrs K Jordan, Broadmead T. W. Coulter, Antrim Mrs Todd, Glasgow
Friends of Michael Thompson, General Accident Life, York
Keegan Lovick's Grandad and Grandmother, Oxford P Lomas, Nottingham

DONATIONS IN MEMORY

The Society is grateful to the friends and relatives of

Ross Lockyer Mr Leslie Harrison Mrs Alice Pope
Pat Skidmore's Mum Beau Denyer Tom Fuzzard

STAMPS

The Bailey Family Mr and Mrs Ballard Irene Wilks Ray & Sandra Martin
Mrs Tiley Jackie Chisling Mrs Garthwaite

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

AREA SUPPORT FAMILIES

East Anglia

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

Julie Thacker — **Tel: 01379 854204**
20 Herolf Way, Harleston, Norfolk IP20 9QA

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

South East

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

Potteries

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

Lynn and Chris Grandidge . — **Tel: 01244 531163**
41 The Boulevard, Broughton, Chester CH4 0SN

South West

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

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

Home Counties

Mark and Rachel Wheeler — 01189 **Tel: 01734 861063**
26 Tamarisk Avenue, Reading, Berkshire RG2 8JB

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

Wales

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

Area Support Families

Midlands

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

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

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

Yorkshire and East Coast

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

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

North West of England

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

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

North East of England

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

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

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

Scotland

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

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

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

Northern Ireland

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

The Society for
Mucopolysaccharide Diseases

55 Hill Avenue, Amersham, Bucks. HP6 5BX Tel: 01494 434156 Fax: 01494 434252

Registered Charity No. 287034