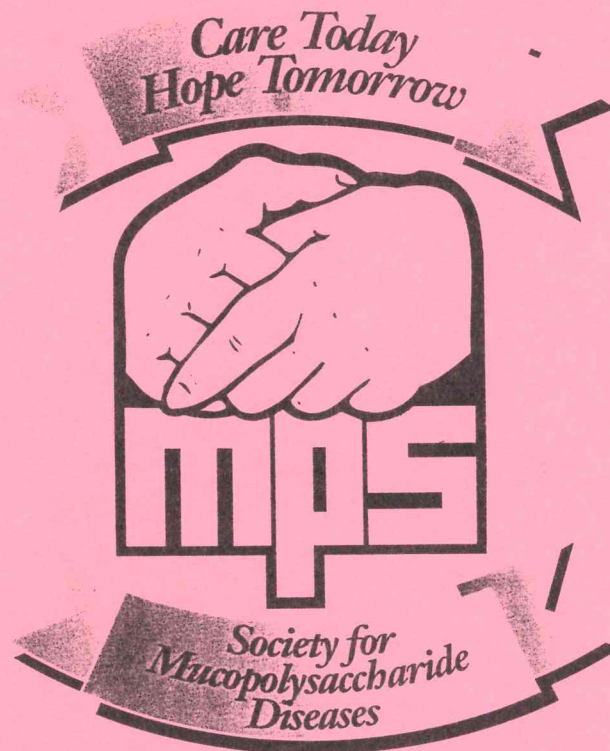


Newsletter

Winter 1993

The Society for Mucopolysaccharide Diseases



National Registered Charity No. 287034

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The Society for Mucopolysaccharide Diseases

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The MPS Society is a voluntary support group, founded in 1982, which represents over 700 families in the UK with children or adults suffering from Mucopolysaccharide and related diseases. It is a registered charity, entirely supported by voluntary donations and fundraising by members, and run by the members themselves. Its aims are:

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

The Society operates a network of Area Families throughout the Great Britain and Northern Ireland, who offer support and links to families in their areas. It provides an information service for families and professionals. At the present time it supports a Consultant Paediatric Post and two biochemists, one at Manchester Children's Hospital and one at The Christie Hospital. It encourages and assists contact and co-operation between parents and professionals and maintains links with sister societies in Europe and throughout the world.

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

"Care Today, Hope Tomorrow"

Booking forms for the Family Conference at the Stakis Hotel Northampton are included with this newsletter. In order to help the organisers, please return your booking form as soon as possible. If finding the deposit is difficult at this time please return your form with a note to this effect.

Contents

Directors Report	3
Milestones	4
Future Events	5
MPS Centre South of England	5
Music in Aid of MPS	6
Mark Simpson	7
Fundraising	8
Christmas Celebrations	10
Thomas Thacker	13
Edward Nowell, Pam Tubb	14
Michael Watkinson	15
Childhood Wood	17
Poem, Sarah Lowry	18
Letter from Japan	19
An International MPS Family (Motomura)	20
London MPS Clinic	22
Recent Advances in Therapy for MPS (John Hopwood)	23
Quality control for MPS tests	26
Dental Care for a Sanfilippo Child	27
"Souper Lunch" Soup Recipes	29
Emma Vigus	29
Photos	30
Grand Draw Results 1993	31
Fundraising Donations	32
London Marathon	32

**Deadline for Spring Newsletter
Thursday 31st March 1994.**

Director's Report

How the months have flown! Soon I will be completing my first year in post. Our new office has paid dividends. Gradually we are establishing systems for coping with the many, many communications we receive from families, relatives and friends, professionals, volunteers and fund-raisers. This has all had to be fitted in between thousands of phone calls, visits and letter writing.

Sadly Ann Neal left us at the end of October, having been unwell for some time. Many of you will know Ann because of the fantastic energy she exudes organising and running our Family Conference Weekend. Behind the scenes, Ann has for several years covered the two days that Linda Golding does not work in the MPS office. I know that you would all wish to join me in thanking Ann for all her help and enthusiasm over the years, both as a volunteer and as a member of staff in the MPS office.

Having said that, I am pleased to say that Ann is on the mend and keen to play a major part in the conference organisation for 1994.

And now I would like to welcome two new members of staff.

Sue Balmforth started in the office two days a week, picking up where Ann left off. Sue lives in Little Chalfont and is the mother of two boys, Giles aged seventeen and George age eight and a girl Kate who is fifteen.

On the first of December Joan Evans started

working two and a half days a week to take on the task of loading onto the computer all the data collected for the **European Database**. Those of you who have already kindly provided information for the database will appreciate just how much work is involved.

In addition we have to co-ordinate the translation of the questionnaire into all European languages before sending it out to all the MPS societies in Europe, as well as to individual families and professionals. We are grateful to CSL for a grant to cover all the costs of this very important project.

Despite many changes in the organisation of the MPS Society, I believe we have been in touch with more families in person this year than ever before and it is a pleasure and privilege to meet so many of you.

In the process of completing questionnaires for the European Database, Mary Gardiner and I plan to meet many more families in 1994.

Our best wishes for a peaceful New Year.

Christine Lavery.

Director/Southern Family Support Co-ordinator



Seasonal Society Activities: Robert Culley, Christopher and Natalie Britton, Annette Puddy, Christopher Rees with families and friends at South West Christmas party.

Milestones

New Families

Philip Scott and Jane Roberts from Hastings, whose daughter **Heather**, born 26th of February 1991 has been diagnosed with MLIII.

Ann and Edward Jones of Walthamstow, London, whose son **Adrian**, born 1/1/87 has been diagnosed with Scheie disease.

Suleman and Khadija Bhaiyat from Leicester, whose daughter **Sumeya**, born 15/5/83 suffers from Fucosidosis.

Saad and Samina Saud from Billericay in Essex, whose daughter **Miriam** born 20/11/86, suffers from Morquio disease.

Linda Daley from Wythall in Worcs. whose son **Darren** who was born on 8/7/68 and died on 1/1/75 suffered from Hunter disease.

Karen and Mick Wheeler from Old Woking in Surrey, whose daughter **Rhianneth** born on 7/11/92 suffers from MLII.

Jean and Paul Leonard from Oulton Broad, Suffolk, whose sons **John** born on 4/8/88, and **Christopher** born 24/7/91, suffer from Fucosidosis.

Jackie and Chris Longley from Longlevens in Gloucestershire whose daughter **Faye** born 29/5/90 suffers from Morquio disease.

Marlene and Stephen Parkinson from Tamworth in Arden. Marlene is a carrier of Hunter disease.

Deaths

Stephen Cafferty from Limavady, Co Derry, who died on the 21st of November aged ten. Stephen suffered from Hunter disease.

Sharaz Hussein from Bradford, who died on the 22nd of October 1993 aged ten. Sharaz suffered from Morquio disease.

Gay Hosking, wife of Peter and mother of Bethan and four other children, who died suddenly on 9th of December 1993. The family live near Tregar in Dyfed.

Our thoughts are with Peter and the children at this sad time and with the families of Stephen and Sharaz.

Future Events 1994

- | | |
|-----------------------------|---|
| 17th Feb. | World Premiere of a work for the harp by Malcolm Williamson given by Elinor Bennett in London. (see page 5) |
| 25th Feb. | Tree planting at Childhood Wood, Sherwood Forest, Nottingham. |
| 19th/20th March | Area Family Training Weekend, Northumberland. |
| 22/24th April | MPS Support Groups Working Party, Kirchberg, Austria. |
| 29th May/4th June | MPS Teenage Activity Holiday, Exmoor. |
| 19th June | Working party, the Childhood Wood. |
| 3rd July | Edward Nowell's Garden Party and SW Family Day, Wells, Somerset. |
| 23/30 July | MPS Family Holiday, Filey Yorkshire. |
| 30th July/6th August | MPS Family Holiday |
| 23/25th Sept. | MPS Family Weekend Conference, Northampton. |

MPS Centre for the South of England

We are pleased to learn that **Dr. Ashok Vellodi**, Consultant Paediatrician at the Chelsea and Westminster Hospital, who was formerly in charge of the bone marrow transplant unit at the Westminster Children's Hospital, will move to **The Hospital for Sick Children, Great Ormond Street**, to set up a service for metabolic storage disorders, including MPS and allied conditions. Dr. Vellodi's remit is to develop a comprehensive service for the assessment and management of children with these disorders, similar to the one that currently exists at Manchester. The support services for this are already well in place, so it will be possible for children to come to the unit and have a complete assessment, including investigations, without having to travel from

one hospital to another. Another important area that Dr. Vellodi has been invited to develop, in conjunction with adult physicians, is a comprehensive service for adult patients with storage disorders, so important for ongoing care.

In addition to the service aspect, Dr. Vellodi has been asked to set up a research programme. The Institute of Child Health, which is affiliated to the hospital, already has several ongoing research projects. It is envisaged that trials of enzyme replacement therapy and gene therapy would be conducted and monitored.

Alf King

Chairman of Management Committee

World Premiere - Music in Aid of MPS

The world premiere of a new work for the harp written by Malcolm Williamson, to be given by Elinor Bennett at a concert in aid of the Society for Mucopolysaccharide Diseases will be held at the Purcell Room, London on 17th of February 1994.

Elinor asked Malcolm Williamson to compose music to celebrate the lives of all those children who suffered from MPS and in particular her own two sons, Alun and Geraint, who died a few years ago.

The conversations that Elinor had with Malcolm Williamson during the difficult years when Alun and Geraint were ill - and

afterwards - sustained and enormously helped her to cope with the grief of caring.

"Day that I have loved"

Elinor and indeed every one of us who know and have loved MPS children are deeply grateful to Malcolm Williamson for consenting to write this beautiful new work, "Day that I have loved," based on a poem by Rupert Brooke and dedicated to those children and their families who suffer from this tragic disease.

If you would like tickets to the concert, please complete the enclosed form and return to the MPS office as soon as possible.

Christine Lavery

MPS Radio 4 Appeal

On Sunday the 14th of November, Elinor Bennet, International Welsh Harpist and mother of two sons who had Sanfilippo, made a very special appeal on behalf of the Society.

Elinor shared with several million listeners her personal experience of how she and her husband **Dafydd Wigley** coped with the care of Geraint and Alun and mourned their loss.

Thank you very much Elinor for the time you gave in planning and making the programme. I hope you will be as thrilled as we are that your effort raised £4,642 so far.



Shabana Shoukat from Birmingham, showing how much she enjoyed her trip to Euro Disney with her health visitor and helper, **Beryl Holmes**. Beryl did magnificent work in raising the money for the trip. Shabana, age twelve lives in Birmingham and she and her brother **Jibram**, age seven suffer from Morquio disease.

York boys achieve triple gold success.

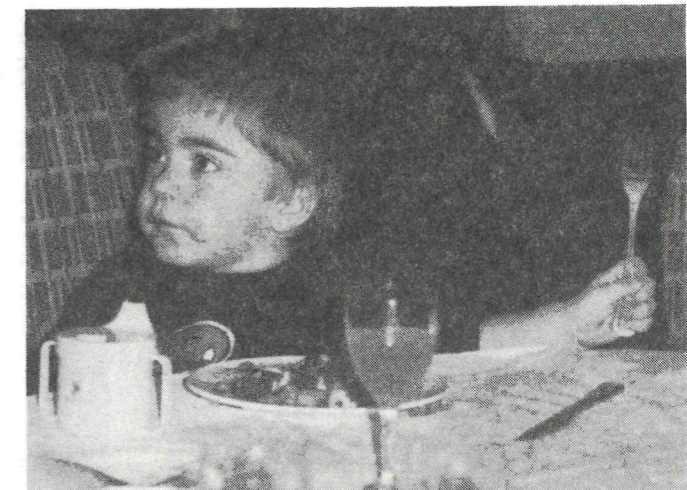


Wayne Cumberland, Mark Simpson and Gareth Walder, proudly displaying their medals.

Three York boys have won gold medals at a nationwide sports championship. The three friends, Gareth Walder, Wayne Cumberland and Mark Simpson were successful at the national junior championships organised by the British Sports Association for the Disabled.

Mark Simpson, aged thirteen, of Oak Tree Lane, Haxby, won the gold medal for the precision club. The boys, who attend Northfield School, Acomb, were representing Yorkshire and Humberside at the games after earlier winning qualifying rounds in Wakefield. They faced competition from 250 athletes taking part in the games at Blackpool. They all proved that disability is no barrier to sporting success, as Walder suffers from cerebral palsy, Cumberland has physical disabilities to his feet and Simpson has Morquio Syndrome. Walder's mum, Cath, said "These children took part in the games without disabilities. As far as they are concerned they are simply athletes competing with each other". Bill Ford, teacher at Northfield School said, "Their achievements reflect the very hard work and training they have put in during the last three months and I am very proud of them.

Luke Chapple (Sanfilippo) from Birmingham about to show of his fork bending powers at the conference in September 1993.





That daring young man.

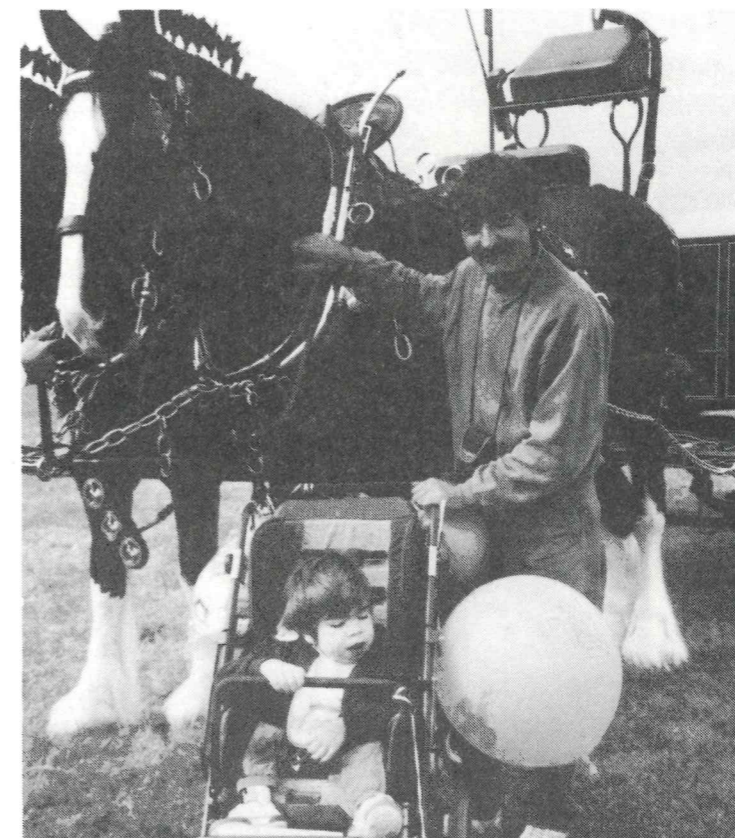
In August, Bolton Fire Station organised an auction of promises to raise money for MPS gene research. John Burlison, from Oldham, Lancs. bid for one hour micro gliding. Being the type of person he is he asked everyone at the conference in September to sponsor him when he did the flight. John successfully completed his tour of the skies and landed with no bones broken. As you can see from the photo he let them dress him up for the part. Many thanks to Bolton Fire Station - to John for turning the event into another fund raising venture for the Society and to all those who sponsored him.

Mary Gardiner

The over 21 team from the Red Lion Pub who were the victors at the Essex Fun Day.



The Towersey Morris Men have really excelled themselves with a donation of £500. The "Bagman" (fourth from the left in the back row), was so moved by MPS and all it stands for when the group collected for us three years ago that he worked very hard to encourage people to give again. Matthew gave him a wonderful smile at the presentation. **Andy and Jenny Hardy**



Jamie Fisher (Hunter disease age eight) with his father Robert at the Essex Fun Day in Thorpe-le-Soken in September. A wonderful time was had by all and a large sum was raised in aid of the Society. Another heartfelt thank you to **Tom and Maureen Fryer** from Tendring who have now organised this very enjoyable event for several years.

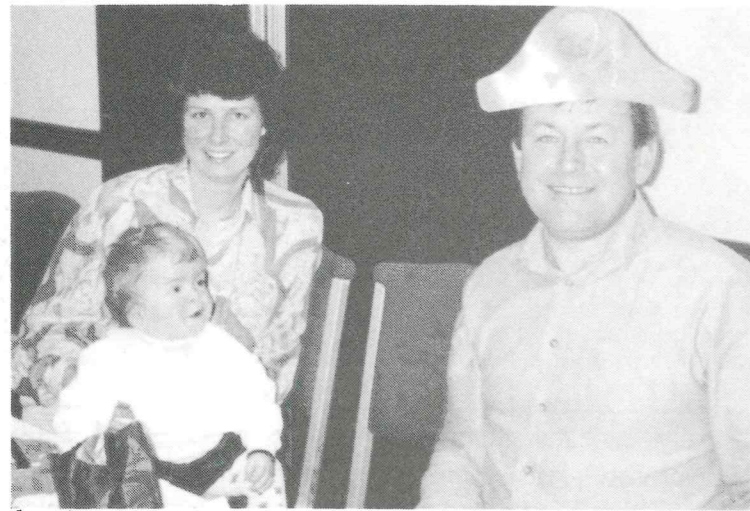
The inter pub competition was won by the Red Lion Pub and the triumphant team are shown on page eight.

Christmas Celebrations

Northwest Party 5th of December

Once again the Northwest hosted its Christmas party at the Haydock Thistle Hotel.

We were joined by Miss Sarah McKnight and her mum and dad. Sarah is a little girl who suffers from MPS I and she lives in Wales. The day of the party Sarah was being admitted to the Bone Marrow Unit at the Royal Manchester Children's



Sarah McKnight with her mum and dad at the party.

Hospital, so it was lovely that they decided to cut their journey and join us for the party. I am sure everyone would like to join me in wishing Sarah a speedy recovery and a successful transplant.

My grateful thanks to all the following people who contributed to the party, our young volunteers, Catherine and Mikhail, our not so young volunteers Christine and Irene, to Martine Brennan and friends who entertained us with a marvellous selection of music, to Claire Arrowsmith from Newcastle upon Tyne with her loud command of English and her wonderful organisational abilities, to Bill and Sylvia Blackburn who gave a great deal of time behind the scenes to make the day lovely for everyone, to Father Christmas and lastly to all the families and friends who came along, joined in and had fun.

As it is Christmas with the new year about to start, may I wish everyone joy, peace, happiness and the strength to face the challenges of 1994.

Mary Gardiner, Northern Co-ordinator

Southwest Christmas Party

Our party was held at Yatton Village Hall on the 5th of December and it went really well. Families came from as far as Swansea and Cornwall

Sadly it will be our last party at Yatton as we are moving, possibly to Malmsbury. We hope to see you in the new year and we wish everybody a very happy Christmas and a peaceful new year.

Tony, Shirley and Carly Eyre.

Christopher Rees (MLIII, age 6) from Swansea with his dad Winford enjoying the party at Yatton.



North East Christmas Party 28th of November

John and Barbara Arrowsmith hosted a very successful Christmas Party which was well attended by families in the area. Father Christmas heard about the party and called in to see the children and to check that he had the right presents for the right children.

Many thanks to Barbara and John and to all their families and friends who helped with the catering and the children's games and who helped make it a special day.

Eastern Area Christmas Party.

A party for families in Yorkshire, Notts. Lincs. and Humberside was held on the 5th of December in St Luke's Community Centre, Scunthorpe, close to the home of Andy and Angela Seymour, whose son David, age eight has Sanfilippo disease. It was attended by thirty two adults and twenty four children. They were helped by a group of youngsters who over the years have held small fundraising activities in aid of their special friend, Gemma Rollinson. Gemma looked extremely glamorous for the occasion in a little black dress with black boots to match.

The party was a great success, thanks to the efforts of everyone. Peter Binnington, David's teacher, entertained the children and held them captive for three hours. The parents were grateful. A wonderful man!

The day came to an end with a visit from Santa with his dog "Rudolf", a huge St. Bernard who allowed the children to fuss him while Santa handed out the goodies. Another successful party!

Pauline Mahon

Gemma Rollinson and friends with Santa





Carrie Ann Little at Milton Keynes

Little Chalfont MPS Christmas Fayre

Some of the volunteers who answered the telephone during the MPS radio appeal decided that they would like to do more. With only three weeks to get organised, John and Mary Stacey set to work. They made super notices and handouts, not to mention all the cakes and homemade biscuits. Tesco and Amersham International lent their support with donations towards the hire of the hall and the cost of purchasing refreshments. On the day the number of visitors was disappointing and lessons were learnt for next year. The Christmas Fayre must be on a Saturday in late November. However, over £330 was raised on the day. It was a great effort. Thanks to everybody who helped and supported MPS.

Christine Lavery

Taking Milton Keynes by storm!

Our intrepid fund-raisers, Ron and Linda Snack, with Linda's parents, Nobby and Lil Sherman were let loose in central Milton Keynes early in December. They took over the community kiosk to hold a tombola in aid of the Society. Over £400 was raised on the day and half again was matched by Abbey National.

They were out again in the warmth of Milton Keynes shopping centre on Saturday 18th of December, with a band of volunteers rattling our charity collection boxes. The tremendous sum of £472 was collected.

Ron has lost no time getting ready for next year. The 1994 collection will take place on Saturday 17th of December. The shoppers will be there in their thousands, but Help! we need more volunteers. A morning, an afternoon, or even a couple of hours - your help would make all the difference. Please contact Ron Snack (see back cover).



The Hardy family and Alan Marchbank at the Milton Keynes Christmas Party

Thomas Thacker

Dear Christine,

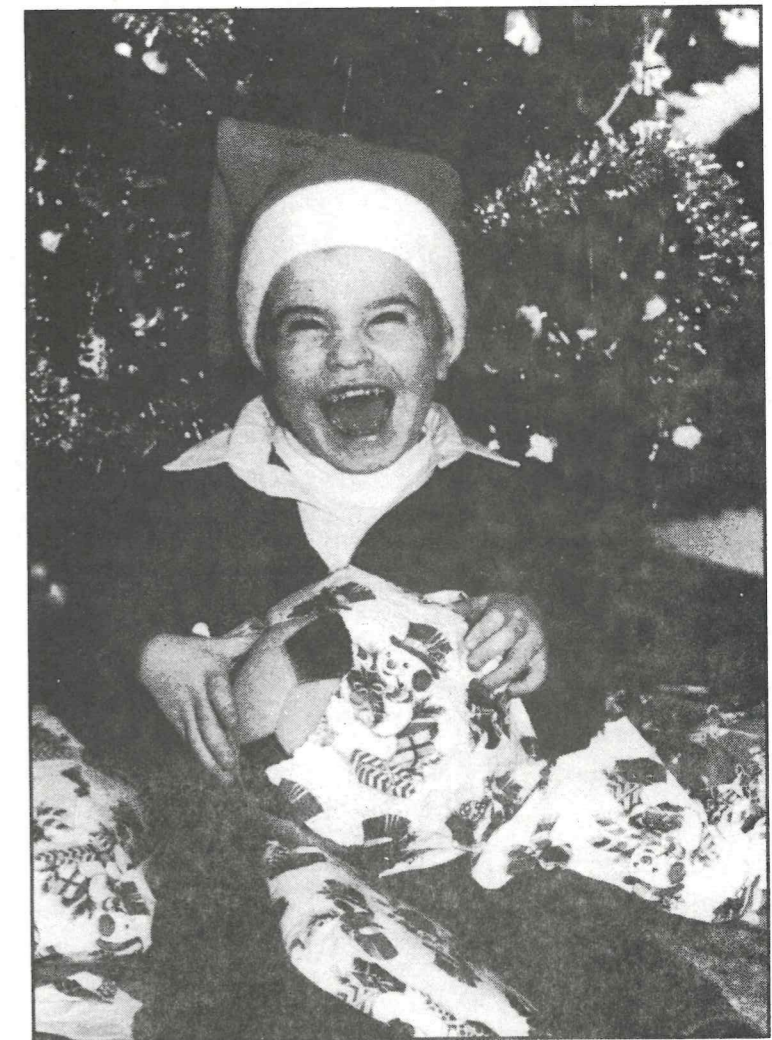
Many thanks for all the help and support you have given us in recent weeks.

As I mentioned, we took Thomas for his assessment today for an Alvema Buggy. Thomas played his part excellently - a cup of tea was sent flying and he had the receptionists watching him from their desks, open-mouthed! We should receive the buggy in about seven to ten days. It is great to push and manoeuvre and Thomas looks very comfortable and secure. I'm so relieved because that is one problem off my shoulders. I know your letter made all the difference. Once again, grateful thanks. We would never have got this far if it wasn't for you and the Society. I can still remember our first telephone conversation so plainly.

Julie Thacker

20 Herolf Way,

Harleston, Norfolk, IP20 9QA



Flashback. . . to last Christmas, which proved a gift-wrapped affair for Thomas Thacker.

My family and friends thought that we would like to send Leanne to Disney World in Florida for a holiday of a lifetime. Everyone was so kind in helping with the fundraising. Leanne really enjoyed the flight and she was a very good girl on the plane.

We went to the magic kingdom first. She had a lovely time meeting Micky and Minnie Mouse. At first she did not like them, I think it was because they are so big. Leanne liked the fast rides and she went on one called Splash Mountain. She loved the big fish at Sea World and she liked swimming in the pool at the hotel. The weather was nice and hot and Leanne has a lovely colour.

She was not too good coming home on the plane. She could not sleep and we were the only people to stay awake.

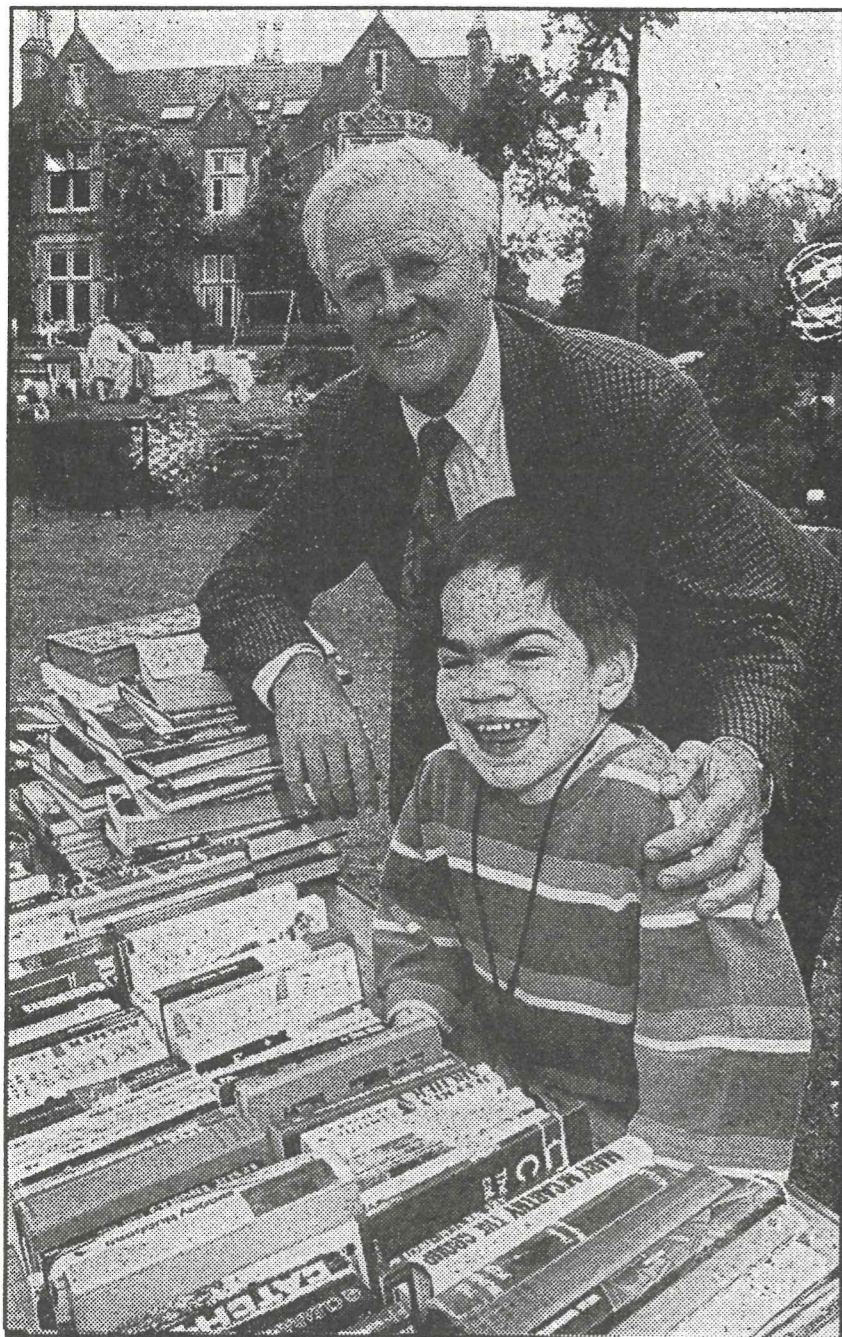
I would like to say a big thank you to my brother Leslie for all the hard work he put in and to my mum for coming with us as a helper for Leanne. I have to go now because Leanne has just got out of bed again!. Thank you.

Cheryl Phillips



Leanne Phillips with a friend she met in Disneyworld

FETE MISSION FOR SHY SPY AUTHOR



Author John Le Carre helps Edward Nowell man the book stall

SPY novelist John Le Carre threw aside his cloak of secrecy at the weekend to help schoolboy Edward Nowell boost a medical charity.

Eddie's all Smileys thanks to Le Carre

Wells 25 years ago, is an old family friend so Edward invited him to open the fete.

He knew the creator of George Smiley would be a good crowd-puller.

The normally publicity-shy Le Carre, whose real name is David Cornwell, was happy to agree.

He said: "I have known Edward since he was born, he's a very

wise and very witty young man with a very dry sense of humour."

"It would never surprise me if he produced a full-length Smiley novel out of his school satchel."

Le Carre's latest book *The Night Manager*, to be published in July by Hodder and Stoughton, deals with the illegal arms trade and the part British officialdom plays in it.

PAM, A DISABLED PERSON

Things stand out with a disability
Many aspects we would rather not see
Some are treated apart from us all
Quite differently and make them feel small
When in a wheelchair a pat on the head
Talk to the mother this they just dread
To be treated so differently along that mile
When to patients alike they just need a smile

I had a disabled girl, Oh what a daughter
You would think she was meant for the slaughter
The nudges and winks as I pushed the wheelchair
Pretending not to mind but we really do care
We too have feelings so tender and true
With our worries and troubles coming out of the blue
So all you people who have not a care
Be patient with disabled folk and *do not stare*

They do not cater for wheelchairs as such
On pavements we have to take with the rush
To rock and to roll and push poor souls around
Nearly ending up on the pavement or the ground
Just watch next time you see this going on
And maybe to *help* and join the throng
Of would be helpers if they knew how
And lift the load from many a brow

Each day we pray that many will see
Our way to salvation and just set us free
From the nightmares and sorrows we folk have to face
Each day that comes round we put into place
Our values and rights as we travel along
With God at our side as we join the great throng.

Written in memory of Pam Tubb by her mother Mary.

Michael Watkinson's Euro Disney Diary

Friday 20th August 1993

Mr and Mrs Dale brought me to Pat's house on Friday evening. I met Brian, Pat's husband and Kathryn, Pat's daughter.

Saturday 21st of August

I had a good night's sleep last night but Pat woke me up at four in the morning to get ready for the plane. I was still eating my breakfast when Eve, Mummy, Daddy, and Hayley arrived on the bus. There was a mad rush to get all the cases and bags loaded. Damon, Mummy's friend was on the bus. He was coming to the airport to wave us off. Everyone was chatting away and getting very excited about the holiday.

Mummy and Daddy and Hayley had never been on a plane before, so they were a little bit worried. A nice lady came to help us go through the baggage check. She took us a special way which was much quicker.

I sat next to my Daddy and my sister Hayley on the aeroplane. We were soon in the air and flying above the clouds. We flew over London and we could see the river Thames. Then we flew over the English Channel and over France. We landed in Paris and we got a taxi to Euro Disney. We had arrived!

The taxi took us to a big pink hotel called the Disneyland Hotel. This was going to be our home for the next three nights.

A girl called Sally, who came from Wrexham, helped to organise us. The rooms were lovely. They had nice big beds and they had balconies. Sally gave me a magic badge. I used it every time I wanted to go on a ride. I didn't have to queue for anything.

After lunch we had a look around Fantasy Land. I went on a lot of different rides. There

was a barrel ride and a Mad Hatter's Tea Party ride. I liked those rides, so did my sister Hayley. We also went on a boat ride called "Children of the World". I liked this ride because it showed all the different children of the world in beautiful costumes. This was Ruth's favourite ride. She made us go on it twice!

My Daddy wanted to go on a ride called "Pirates of the Caribbean". It was a dark scary ride. I wasn't frightened, but my sister was. She said she didn't like the pirates.

That evening we went out to Festival Disney and had a nice meal in a restaurant. Our waiter was Scottish and he was training to be a lawyer, but he was working at Euro Disney for his holiday. He told us there was going to be a firework display soon, so we went outside to see the show. There were lots of beautiful fireworks, all different colours and loud bangs. I really enjoyed seeing them.

Then it was bedtime. I was so tired and so was everybody else. What a wonderful exciting day for us all.

Sunday 22nd August

The next day we went out for breakfast. We found a nice place and we had lots of croissants, pain au chocolat and tea and coffee. I really liked the pain au chocolat.

Then we went outside to the square and met lots of the Disney characters. I had my picture taken with Donald Duck, Mickey Mouse and lots of others. Mickey was very nice to me. He came over especially to say hello.

After lunch we spent the afternoon going on different rides until it was time for the big parade at four o'clock. I loved the parade. There were lots of different floats, with Cinderella, Peter Pan, Beauty and the Beast and many more. Tweedle Dee came over to



Michael Watkinson (Hunter disease) is aged 7 and comes from Colwyn Bay.

see me again and the Pirates came to see my Daddy.

After the parade we went back to the hotel for a nap, because that night we were going to see a show. And what a show it was!

The Buffalo Bill Wild West Show.

When we arrived we were all given cowboy hats to wear. We had to use them during the show to wave while we shouted "yee ha!" very loudly. There were lots of horses, buffalo, cowboys and Indians in the show.

Right at the end of the show Buffalo Bill asked some people from the audience to help look after some gold coins on the stagecoach and not let the bandits or Indians steal them. Ruth put her hand up to be picked to help Buffalo Bill - and guess what - she was!

It was very funny watching her in the show. She said afterwards that it was really great to have a ride on the stagecoach. She was the star of the show!

Next morning at breakfast a few of the Disney characters came to see us. We spent the rest of

the day going round the other parts of the park.

That night we went back into the park Mummy and Eve managed to get a ride on the Thunder Mountain Train. The rest of us got a good place to watch the Electric Light Parade. It was magical. There were lots of floats all made with beautiful coloured

lights. By the time it was finished it was well past my bedtime. What a day it had been!

Tuesday 24th August

Today was our last morning at Euro Disney. We had breakfast with all the characters. Minnie Mouse came and sat with us for a little while. Goofy came to see us and he gave my Daddy a kiss, which made him blush. Mickey came to see us too. He was very nice to me again. Lots of other characters said hello to us. It was great fun.

After breakfast it was time to go to the airport. Daddy and Mummy were not worried at all about going on the aeroplane this time. The captain let Hayley and me have a look at his control cabin and he let me wear his hat.

It was a wonderful holiday of a lifetime for my family and me, thanks to lots of kind people who helped send us to Euro Disney.

Michael Watkinson

News from the Childhood Wood

New Oaks for the "Childhood Wood"

The next planting for the "Childhood Wood" will take place on **Friday 25th February 1994**. We have written to all those families who have lost children during the year inviting them to join us for the planting. If you have lost an MPS child in the past and would now like to plant a tree in memory we would be very pleased to hear from you.

The planting will take place at Sherwood Pines, Clipstone Forest at 2.00pm and will be followed by afternoon tea at the Clumber Park Hotel. We hope that as many families as possible will be able to make the journey to plant their own tree. If this isn't possible we will arrange for the tree to be planted by another MPS family.

Childhood Wood Working Party

We have received a number of requests from families who planted trees last February for a return visit to the forest to be arranged. We feel that the most positive and constructive way of doing this would be to organise a working party of forest rangers, MPS families and friends to assist with weeding and to clear dead wood from the plot. The date for this is **Sunday 19th of June 1994**. We will be writing to all bereaved families in the spring inviting them to join us. If there is sufficient interest we will arrange for a marquee and refreshments and negotiate a special deal with a Nottingham hotel.

Christine Lavery, Director

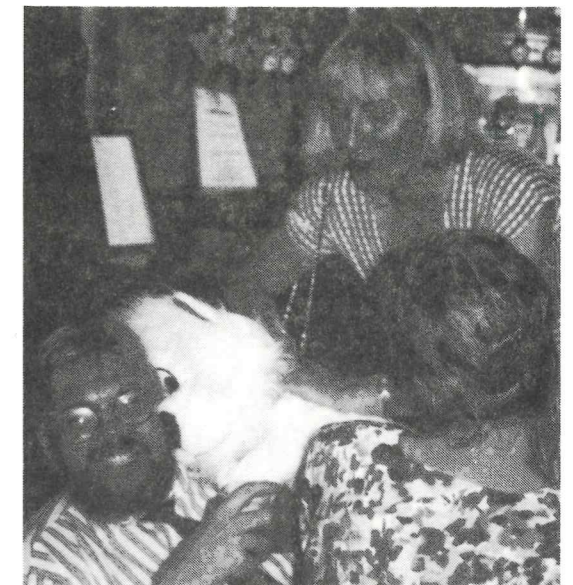
There is just enough space here for a shot of **Mary Gardiner and Ed Wraith** relaxing at the annual family conference.

Caring for Forest Wildlife

I am sure that we are all aware of the dangers to wild life caused by refuse and would not wish to add to those dangers. Unfortunately we are. The forestry rangers at Sherwood Pines where the "Childhood Wood" is sited are worried that the cellophane and ribbons from flowers left at the wood are likely to hurt the local wild life. Unlike the flowers and paper, plastic is not biodegradable and just gets blown around the wood. They have suggested that parents may prefer to sink a vase into the ground into which flowers may be placed and the packaging can be disposed of safely in the bins. The vases can be placed close enough not to damage the tree roots. The rangers would be pleased to help and advise so if you are not sure contact them. Alternatively, a few flowering bulbs may be planted. Again please seek advice from the rangers. After all none of us wish to put the trees at risk and want them to grow strong and healthy for many years to come, a place of beauty and peace we can all visit.

Paul and Ellinore Gunary, Childhood Wood Liaison Assistants.

David and Monica Briggs, Area Family Support



Why Stare?

I've got a face, just like you,
 And two legs and feet for my shoes.
 I've got two arms of which make a pair,
 So tell me please, why do you stare?
 Yes I know, I've got a soft voice,
 That's not my fault, I was given no choice.
 And yes I know, I'm not very tall,
 As everyone says, best things are small.
 Although I can walk, it's not very far,
 That's why I travel on bike or by car.
 I can practically do as much as you,
 Swimming, cycling, I play the piano too.
 So next time you see me in my wheelchair,
 Give me a smile, instead of a stare.

By Sarah Lowry

A letter from Japan

My name is **Katsuya Matta**. I am a teacher at East Kashiba Junior High School in Nara, Japan. Nara is very famous for many beautiful temples. Do you know Todaiji and Horyuji temples? These are in Nara.

I take care of **Takahiro Watanabe**. He is fourteen years old and has severe Hunter Syndrome. He is 115cm tall and 32kg. Up to five years old he could say a few words ("Mum" "Papa".....etc.). Now he can't speak at all. He can only walk and ride a bicycle.

At the moment he goes to school with other neighbourhood students, and does his own studies in the classroom with his classmates. I will tell you about his day:

Taka gets up at about seven o'clock. He can't get up easily, because he can't sleep properly. He goes to school with friends, riding his bicycle or in a wheel chair. During lessons, he looks at various books, makes a calendar, and does other rehabilitation. He also walks and rides his bicycle in the school corridor. When he walks in the corridor, many students and teachers shake his hand. At recess, many friends come to see him. They have a talk and play with him.

Taka likes his friends. When Taka is with them he is always laughing. If he is left alone, he always begins to cry. In this way, he has many people who help him enjoy life. These are comments about him from his friends.

"At the entrance ceremony, I didn't feel good to know my class was Taka's class. But I'm very happy now to be his classmate. Because if I couldn't be his friend, I would just think of him as a disabled person, and I would hate him. I'm ashamed of what I did at that time. When I am with him, I am happy. I'm very happy to have met him. If I hadn't met him, I might have avoided him. Taka is happy to

have a lot of friends!"

"I feel he is very lucky, because he is always surrounded by many friends. Without my knowing it he has taught me a lot of things. He is very important to me. I've learned various things from him."

In this way, Taka's friends study kindness, sympathy and other things by being with him. In Taka's class every student has no discrimination or prejudice about the handicapped. They get along with him and lean on each other.

But now I have some problems with Taka. Please give me some advice.

I hear it often happens that Hunter children gradually become more severely handicapped. And they must be in bed all the time. If you know about this process please (I hear that maybe he will get convulsions and then sleep all the time) give me as many details as possible.

Is it common for Hunter Syndrome children not to sleep regularly? How can we get him into a regular sleep pattern? We think a good sleep pattern can keep him active.

In Japan MPS NEWSLETTER is popular with MPS children and their families. It is very supportive for them. I hope to expand the network of MPS children and families in the world.

Hunter Families:

You can write to **Katsuya Matta** at:
 East Kashiba JAH
 Martagaoka 2 - 12 - 27
 Kashiba City, Nara Prefecture
 JAPAN (or via the MPS office)

An International MPS Family

"Following on an article in a local newspaper on Sunday Sept. 5th, about MPS and my son Tetsuya Motomura, I decided I would like to write more about some aspects of our life with him," writes Sally Motomura.

Before having a child with a disability we, like most people, had no thought that such a thing could happen to us. My husband and I came from opposite ends of the earth, and yet we share this extremely rare recessive gene, which combined to afflict our 3rd child with a devastating condition - something more likely to happen to people who marry their close relatives.

We were getting on complacently with our "normal" lives fraught with the usual stresses, ups and downs, believing that we had three healthy and boisterous boys, when BOOM! - so much that we had taken for granted was thrown into doubt. The assumptions that children "grow up", grow out of their clothes, furniture, bicycles - will someday reach doorknobs, light switches, wash hand basins - climb unaided into a car, run unsupervised to play with neighbourhood children; these and countless other everyday facts of life were no longer certain.

We can make choices in our lives; like choosing a job, spouse, whether or not to have children - but we cannot choose the children's individual make up.

We have slowly been drawn out of years of sadness by the realisation that our son has a whole lot of living to do before his little body will give in. And he is so much in love with life! This love extends far beyond the family. It touches almost everyone who ever spent more than one minute with him, in all the myriad situations he has experienced in France, England, Zimbabwe, Japan and here in the USA. Not everyone who meets him is

immediately aware that he is disabled. Typically strangers are curious at the tot who can hold a conversation. This initial curiosity is soon transformed by the realisation that in this tiny nine year old is a wonderful personality with a great zest for life and love.

From the age of one and a half years, his good ear for music allowed him to "sing" in tune. He will burst into song and dance when happy. His slight hearing loss and difficulties with speech do not stop this enjoyment. As his fine motor skills are also not up to playing an instrument, he is unable to go further than percussion, his kazoo and conducting - which he does with relish at his weekly music therapy sessions. He will sing or hum Beethoven's "Ode to Joy", Japanese and English children's songs, sea shanties, folk and cowboy songs - anything that catches his fancy. How I wish more could come of his talent, but we must be content with music as entertainment for him.

Tetsuya has a vivid imagination, fed by his love of books and songs, and his time spent with his brothers, Kazuma and Jun. He dreams of travel of all kinds - sailing away on a cruise (with himself as captain) to visit the people he knows in Japan, Africa, England and France; seeing the Eiffel tower in his birthplace, Paris; holidaying with mum in a horse drawn caravan in Ireland; travelling through space in a shuttle etc.

He has recently learned from Kazuma how to re-invent his own lego craft instead of sticking to the original instructions. The manipulation of these tiny lego blocks is just one of his amazing achievements. We did not expect him to master writing either, as his hands are very stiff, with poor grip and limited movement. Computers offer an alternative, plus a whole vista of new possibilities. Occupational therapy can help slow the progress of the condition, but nothing now known can stop or reverse it.

He attends karate classes in Mamaroneck occasionally with brother Kazuma, where again he is loved and respectfully allowed to set his own limits. He was awarded a blue belt last spring.

My husband and I never put any pressure on him to achieve anything, not knowing precisely what his limitations will be. As a result he has done it all in his own time, and what a series of miracles we have witnessed! If only all children could be trusted to learn at their own pace, with their own desire to achieve, and love drawing them out, instead of being pushed by the expectations of society.

Society has come a long way since the hide and deny days of the secret garden attitudes - although only fifteen years ago MPS parents could barely find any information on the condition, because doctors and parents did not share what they knew. Thanks to the vision of Mrs Christine Lavery, who started the MPS Society in Britain, Mrs Capobianco, who is president of the Society in the USA, and to the continuing efforts of hundreds of involved parents and professionals in thriving MPS groups around the globe, we now have a place to turn to offering information and hope, if not for our own children, at least for those born in future with these conditions.

Tetsuya was born in Paris, diagnosed with ML III (Mucopolysaccharidosis III) in France, then England and again in Japan. We visited top specialists in these three countries and are still searching

for doctors who really know about his condition. (The top specialists here have waiting lists of two years for a preliminary visit). Our most important source of information has been the MPS newsletters, conference reports and the opportunities to hear about or meet families similarly affected. We know we are not alone, having found a few ML III pen pals around the world.

We make adaptations to our lifestyle to take away the "handicap" from Tetsuya's daily life wherever possible. We chose ordinary furniture that is low enough for him to use without assistance. Children's furniture is usually either too babyish or too large. I find the



same problem with his clothes which usually need to be altered or entirely home made.

Finally, and perhaps most important, I must comment on the excellent services we have access to in Mamaroneck. F.E. Bellows Elementary School, where Tetsuya is entering his third year, has given him a wonderful sense of belonging. He has made friends throughout the school and seldom asks "Why am I different?" The school psychologist is standing by, prepared for a time when this becomes an issue. He has speech therapy which has enabled him to become more verbal and to pronounce his words more clearly. (He also has to deal with a bilingual home life).

At school he isn't made to feel "handicapped". His special education class provides academics and skills tailored to his individual needs and his aide enables him to spend as many hours as possible mainstreamed with his regular class, e.g. at art, music, gym, lunch, outings and festival programmes. This is a positive educational experience for both the regular children and for Tetsuya. He feels special in the sense of being appropriately cared for while also feeling included in society as a valued individual. The other children have a first hand experience of a loveable disabled person whom they see is properly accounted for and treated with respect.

Over all I am happy that we are able to give

our Tetsuya a balanced and almost "normal" life at present. We live for the present because we do not know the future. The sand in his hour glass will definitely run out before we are ready, and our little angel will take wing, but I know that his life will not have been in vain. He has already given the world more love than many people manage in seventy years.

Sally Motomura
1360 Colonial Court,
Mamaroneck,
NY 10543
USA

MPS Clinic in London

A special clinic for MPS patients was held in the West Ham Lane Health Centre in East London on the 6th of October. **Ed Wraith** and **Christine Lavery** saw fourteen affected young people and offered advice to their families and to their doctors and other health professionals. The clinic was arranged through the co-operation of four consultants at Newham General Hospital, **Doctors Fernandes, Robinson, Allsop and Allgrove**. Between them they have a considerable number of MPS patients.

Patients suffering from Maroteaux-Lamy, Morquio, Scheie, and Sanfilippo diseases came to the clinic. Eleven of the patients were Asian. Three different languages were spoken by the families, Punjabi, Urdu and Gujarati. Christine had organised four interpreters to help.

In conjunction with the clinic, Ed gave a review of MPS diseases to medical staff at the Academic Unit at Newham General Hospital.

It is expected that this clinic will bring considerable benefits to many families most of whom could never get to Manchester. The families have been given an explanation of the disease in their own languages. It is expected that it will now be possible for the patients to be monitored better locally. The families and close relatives will now be more aware of the need for genetic counselling and better able to use the services that are available.

Recent Advances in Therapy for MPS Diseases

Dr John Hopwood

Head of Lysosomal Diseases Research Centre

Adelaide Women and Children's Hospital, Australia

(Notes from a talk given at the MPS Conference 18th September 1993)

"We cannot do it alone."

Dr Hopwood repeated his views about how important it was for scientists to communicate their thoughts to parents. He reminded parents that he worked with a large team of people and that the work on MPS was done in collaboration with many teams around the world. He thought that progress towards treatment would best be served by close co-operation between scientists.

Cell Biology

By showing slides of normal cells and the cells of MPS sufferers Dr Hopwood showed how these "storage diseases" increasingly interfered with normal growth and development. In the normal cell lysosomes take up about 1% of the volume of the cell. In cells from MPS patients the lysosomes are not able to degrade MPS which is stored in the lysosomes and so they gradually build up to take up to 70% of the volume of the cell. It is easy to understand how this tends to disrupt the normal functioning of the nucleus and of the cell.

What are the faults that cause genetic diseases?

Each cell has a set of chromosomes made from

a string of four coding elements (nucleotides), known by the letters A, T, G and C. These four "letters" recur in different combinations of three letter codes, (for example GAT for the amino acid eucine) which are linked together to make up the "genome", that is the total sequence of codes that determines the characteristics of each individual in a species. There are more than three billion letter codes required for the more than 50,000 genes in the human genome. A genetic disease can be caused by a single letter change in this huge coding sequence. This gives an idea of the difficulty in unravelling the causes of genetic diseases like MPS.

Diagnosis of Disease

There are several stages or levels in the diagnosis of a genetic disease. The ability to understand and treat the disease increases in line with developments in the level of diagnosis.

1 The first level of diagnosis is when doctors are able to recognise the "clinical phenotype". For example, the patient's appearance or their behaviour "looks like" an MPS disease.

2 The next level of diagnosis is when MPS can be identified in the urine. (Mucopolysacchariduria).

3 A more effective level of diagnosis is reached when the enzyme deficiency caused by MPS can be identified by testing the blood cells.

4 The fourth level is when the site of the

genetic mutation can be identified at a molecular level (for example, a single "letter" change is identified in the coding sequence of an MPS gene).

Current Understanding of the Phenotypes

It is now known that there are six severe phenotypes of MPS Diseases. (I, II, III, IV, VI, and VII). These are the names that scientists all over the world have agreed to use instead of Hurler, Hunter etc. Within each disease there is a broad spectrum in terms of severity and the rate of the development of the disease. It is important to be able to predict how severe the condition will be and how fast it will develop before making decisions about therapy. For example if it is known at a very early stage that a person suffers from a mild Hunter disease then parents and doctors would be likely to think very differently about a risky treatment such as bone marrow transplant than they would if it was clear that the child suffered from a very severe form of the disease. Equally, when the results of treatment are to be compared, it is essential to know how the disease was going to progress of its own accord. If you cannot tell whether a patient suffered from a mild condition or from a very severe condition before treatment, it will be very difficult to measure the effect of treatment.

Advances since Manchester.

Considerable progress in the isolation of MPS genes has been made since the International Scientific Symposium in Manchester in 1990. At that time genes for MPS II and VI were described. Since then the genes for I, III and IVA have been isolated. The characterisation of these genes has enabled the identification of many different mutations in each of these five MPS conditions.

Hurler Disease (MPS I)

Dr Hopwood used Hurler disease as an example of the progress achieved in understanding one MPS condition. The conditions known previously as Hurler, Scheie or Hurler Scheie are now known to be genetically the same and are now known as MPS I. In Australia it is estimated that there is an incidence of one in 50,000. There is a great variation in the phenotype. Some patients can be affected very severely and some can be affected much more mildly. However the biochemical differences between the mildest and the most severe clinical forms is very slight.

Dr Hopwood then used one slide to summarise ten years of research in Hurler disease. The key points were that although there are many identified mutations that cause MPS I, there are three or four common mutations that are responsible for most cases. For example, one mutation identified as **W402X** has been found in 34% of MPS I patients. When a patient has been found to have this mutation it is now possible to predict accurately that the disease will have an early onset and that it will be a very severe form. Another mutation, **Q70X**, has been found in 15% of patients and this also indicates a severe form of the illness. Dr Hopwood illustrated the amount of work that is going on around the world on MPS diseases at present by pointing out that over twenty different MPS I mutations had already been identified in 1993.

Progress towards the possibility of Therapy

Animal Models

Animals can suffer from the same genetic diseases as humans. When animals with genetic diseases are found they can be of great value for research. A family of dogs have been found who suffer from canine Fucosidosis. This gives rise to brain damage but little physical damage

to the body. The disease becomes apparent at the age of seven to eight months. It is very severe at thirty months and the dogs die at about forty months.

These dogs have been used by Drs Taylor and Stewart in Sydney to evaluate the effects of bone marrow transplantation. Transplants have been tried at different ages and the level of "neurological disability" in each dog measured. What was found was that if the transplant was done at thirty months, the level of neurological disability remained the same as if there had been no treatment. If the transplant was done at nine months (about the time that the animal was beginning to show signs of the disease), then there was also no improvement. There was a little improvement if they were done at 6.5 months before symptoms appeared, but this improvement was not sustained and these animals also went into decline. The only substantial improvement was when the dogs were transplanted between three to four months, well before any clinical symptoms of disease could be found. These animals continued to do well up to the present time and showed no signs of an increase in neurological impairment.

Implications for treatment in humans.

This study has very important implications for treatment of human patients. The timing of therapy is critical. The message is that if the treatment is to be of any value it needs to be done as early as possible. Sadly, if there are already neurological signs of the disease, then it is too late for treatment to make much difference in preventing or slowing deterioration of the brain. Very early bone marrow transplantation can prevent neurological damage. However there are risks to the life of the patient associated with bone marrow transplantation.

Requirements for Gene Therapy

"Gene Therapy" is a possible future treatment

which would bypass many, but not all of the risks associated with bone marrow transplant. It is now possible to begin to spell out in detail what is required to start gene therapy in human patients

1. There was a need to know the clinical consequences of the disease, that is, how the disease would progress in this patient if not treated. We need to identify the mutations for each patient and to be able to say how severe and how fast the disease progresses in patients with these mutations.
2. Isolate the gene.
3. Safe method of insertion of this gene into the patient.
4. Evidence from animals that there were clinical benefits and no severe side effects.

The use of "Vectors" to insert genes into living cells

A considerable amount of work has been done on finding ways to transport genes into cells. A lot of this work has been focused on the use of viruses. A virus works by penetrating the cell wall and inserting itself into the cell. It is first necessary to make the virus safe by removing the "nasty bits". {See "*Beginners guide to Gene Therapy*" page 24, Newsletter Winter 1992, Editor}. The gene is then combined with the virus and is carried "piggy back" when the altered virus penetrates into the cell. The cell will now have a normal functioning gene and will produce a normal amount of enzyme which will excrete MPS and prevent it building up in the cell and so prevent the symptoms of the disease.

A favoured target for insertion of altered virus is the "stem cells" in the bone marrow. These are young cells which reproduce and which are the source of the mature cells throughout the body.

The process would involve taking some bone marrow from the patient and isolate the "stem cells". Introduce the altered virus to these cells and then infuse the cells back into the patient. The stem cells would continue to grow and reproduce the introduced gene. This would produce the missing enzyme which would remove MPS from the patient's body and prevent damage from further storage of the MPS.

Gene Product Therapy. (Enzyme therapy)

Another option for treatment is through the replacement of the missing enzyme. This was currently being explored initially in relation to MPS VI (Maroteaux-Lamy). The first requirement was to find an efficient method of

producing large amounts of enzyme. This had now been achieved through the medium of cultured Chinese hamster ovary cells. At Adelaide good results had been achieved in the treatment of Maroteaux-Lamy cats. Dr Hopwood showed on slides the improvement in one particular cat called "Alfred" which had severe symptoms of MPS VI disease at the age of six months. Alfred had been given an injections of the enzyme every two weeks and after four weeks had been back on his feet again and showed great signs of improvement. Thus it seemed possible to produce enzyme that was likely to provide an effective treatment for Maroteaux-Lamy disease. The challenge now was to see if this could be done on a large scale.

John ended by showing slides of Woolongong, near Sydney, the site for the next International Symposium in MPS diseases in 1996.

Request for help towards a national quality control scheme for MPS laboratory tests.

Mrs Janet Stone, Senior Biochemist, from the Paediatric Chemical Pathology Unit at St Michael's Hospital, Bristol, has written asking for the help of the Society towards establishing and running a national quality control scheme for the diagnosis of inherited diseases. The laboratories at Bristol ran a quality control scheme for analysis of urinary mucopolysaccharides for a short time in 1991. This highlighted the very varying reliability of results from different laboratories. They were unable to continue at the time because of difficulty in obtaining sufficient urine samples from MPS patients.

If all laboratory tests can be brought up to a high standard this will allow early and accurate diagnoses to be reliably done. So MPS families have a lot to gain from helping this scheme.

The British Inherited Metabolic Disease Group now feel that it is a priority to re-establish a quality control scheme for MPS patients and that is why Janet is writing to us at this time. However they will need help in obtaining urine samples. The scheme will be run in cooperation with the Willink laboratory at Manchester, so it may well be possible for patients to give urine when they attend a clinic at Manchester. Janet is very aware of the difficulty in collecting urines from MPS children but would be grateful for any help from parents in this important work which is likely to be of great benefit in improving the quality of tests.

Christine Lavery will be writing to families in the new year asking for help in collecting urine samples. If you have any queries please contact Christine at the MPS office.

Dental Care for a Sanfilippo Child

Robbie underwent a dental operation recently. This has prompted me to write about dental care. He had seven fillings and four extractions. The operation was performed at the Royal Children's Hospital in Brisbane.

Robbie tolerated having his teeth cleaned until he was about nine years of age. He has never been really keen at teeth cleaning time. We wondered at the wary look on his face at those times and whether he thought his parents had finally snapped and were coming at him with a lethal weapon. But no! It was just the humble but dreaded toothbrush. Both Dad and Mum had to be present - one with his head in a headlock trying to get the toothbrush into his mouth while the other held his waving arms and kicking legs.

"He thought his parents had finally snapped and were coming at him with a lethal weapon."

He used to clamp his teeth down on the brush so it couldn't be moved. So, at the suggestion of his teacher at the time we bought an electric toothbrush. He clamped his teeth down on that until it stopped whirring. After that we gave up and decided that the only way to keep his teeth clean was to make sure that he had plenty of good food that would help the process - like grated apples, sticks of celery, carrots, etc. Then in the last couple of years he got to the stage where it was difficult for him to chew those foods.

His distress was caused by bad teeth.

As a result in the early months of 1992 he was becoming quite distressed, sometimes all day. It was only when his dad, Terry, thought he spotted some holes in Robbie's teeth on some of the rare occasions that he could get his mouth open that we realized that his distress

could be caused by bad teeth and that dental work needed to be done.

We thought it was due to the mysteries of his condition.

I remember at the time we were putting his distress down to the mysteries of his condition, as we often do when there aren't any immediate answers. I am glad we looked a bit further to see if there was any physical reason for the distress.

We took him to see the state school "Dental Van" dentist who was at another school. I will not elaborate on that visit other than to say that the message written on the dentist's face as we left was that he had just experienced a dentist's nightmare.

Something had to be done for Robbie as he was becoming increasingly distressed. Robbie was referred to the Brisbane Dental Clinic. As usual, we were filled with trepidation at meeting someone new who had to examine Robbie, even though we had been told that the dentist there was used to examining difficult children.

In a headlock

What a pleasant surprise! We realized that our fears were unfounded as we watched the dentist examine Rob. Rob still struggled. Dad held his torso and arms, I held his kicking legs. The dentist had Rob's head in a headlock but he was gently talking to him and soothing him as he quickly checked inside his mouth. A major feat! Rob calmed down and let his mouth be examined.

He had a lot of dental work to be done. He had to have a general anaesthetic and we knew there were risks to that. However we decided

that his quality of life was more important and that meant fixing his teeth.

Since then Rob has let us clean his teeth. He seems to have learned to enjoy it after a time. He still doesn't like the feel of the brush in his mouth, but he will let us keep brushing now. Perhaps he knows that it is doing some good. We have used toothpaste combined with an anti-plaque treatment and a mouthwash, which

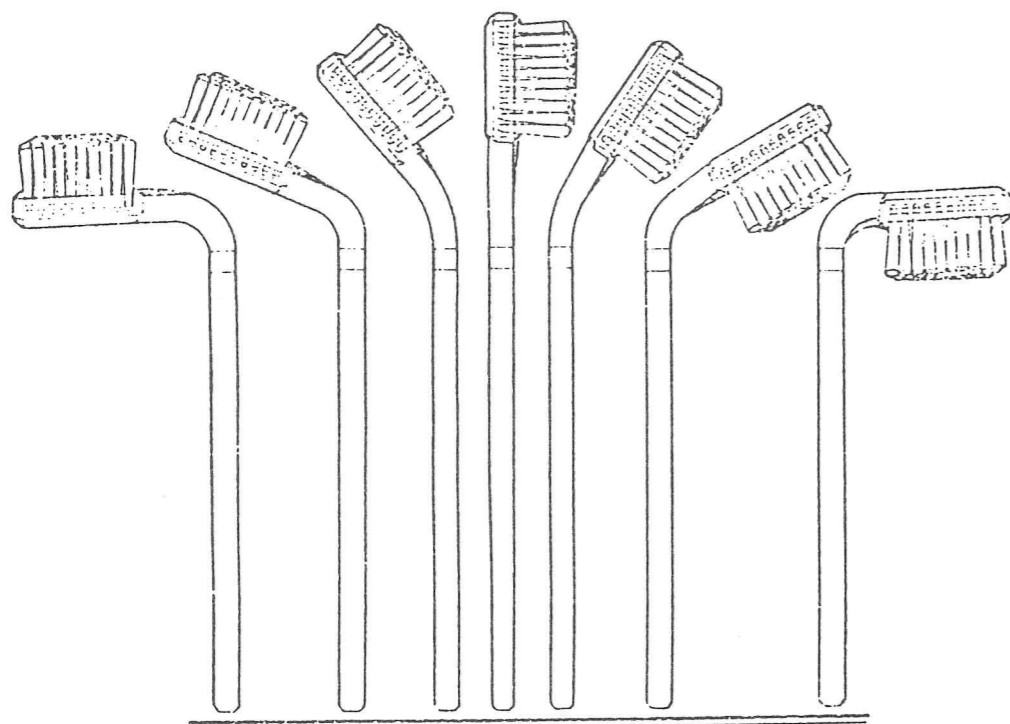
helps with the bad breath he gets. We wish now that we had persisted in trying to clean his teeth when he was younger, although, in reality, I don't know whether we could have done things differently.

Helen Brown

Reprinted with acknowledgement to "The Linking Hand", newsletter of the Australian MPS Society, March 1993.

GENERAL INFORMATION

ADAPTING YOUR TOOTHBRUSH

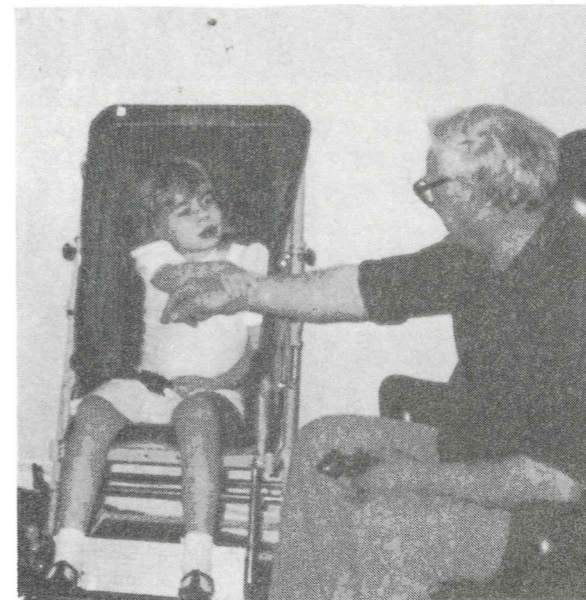


Some types of toothbrush can be easily angled to accommodate children with restricted movements who find using a normal shaped brush inadequate and unsuccessful for good mouth care. According to the particular restriction, you or your child may need two or more brushes with different angles to enable better access to all of your teeth. By watching how the person uses an ordinary brush you will be able to assess where the difficulties in brushing are. Adaptation of the toothbrush can then be made to ensure better contact of the brush on the tooth and gum surfaces, for more efficient cleaning.

To bend the toothbrush simply warm the neck end of the brush in hot water to make the plastic pliable. Gently bend the neck into the required angle and leave to cool. Additional adaptations for the handle can be made for a better grip either by inserting the handle into a cork or ball or simply taping padding to the handle. Suitable brushes for bending are Sensodyne search Range, Oral B, Wisdom Quest.

"Souper Lunch" Soup Recipes

Jenny Hardy and friends have produced a very useful and attractive booklet as a result of several "Souper Lunches" held at Haddenham to raise money for the Society. Proceeds from the sale of the booklet will help fund research into MPS diseases. If you would like to purchase our "Souper Lunch Soup Recipes", please send a stamped addressed envelope with cheque or postal order for £2.00 to Jenny Hardy, 48 Churchway, Haddenham, Bucks. HP17 8HA. We are sure you will enjoy tasting the variety of soups and helping MPS at the same time.



Pat Scarr has an **Orthokinetics Buggy** for sale as seen here with her daughter Shelley who died in 1991.

The buggy is in good condition and is very reasonably priced at £350.00 plus the cost of forwarding.

Pat Scarr, Phone 091 4172011

84 Raby Road,

Oxclose, Washington,

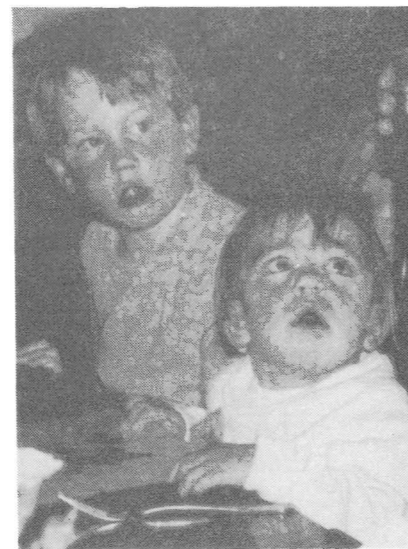
Tyne and Wear, NE 38 OLX

Emma Vigus, age twelve from Hayle in Cornwall. Emma suffers from Sanfilippo Disease.





Sue Hodgetts, Midlands Area Family, from Tamworth, with pupils of **Thomas Barnes School**, Hopwas, Tamworth, who raised over £100 for the Society. Instead of giving food for the Harvest Festival the parents and children donated money to the Society. There are only about 80 pupils in the school. What a generous school!



Some more conference photographs. Sorry there is not room for more!



The Society for Mucopolysaccharide Diseases

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

1993 GRAND DRAW

1ST	DINNING ROOM TABLE & CHAIRS.	33257.	N. GREENWOOD.	ROCHDALE
2ND	WEEKEND AT CENTREPARCS.	34855.	J. RICHARSON.	LINCOLN
3RD	35mm REMOTE CAMERA + FILM +.	31816.	RONNIE.	WORSLEY
4TH	PERSONAL STEREO CASSETTE KIT.	27296.	J. SLATER	BOLTON
5	SILK SCARF.	08781.	R. MCDONALD	GLASGOW
6	SILK SCARF.	37946.	MRS YOUNGS	BUCKS
7	GARDEN KNEELER, SPRAY AND GLOVES.	12164.	SCARROTT	SOLIHULL
8	SIGNED BOOK OF BEDTIME STORIES.	48192.	S. EASTLANDS	LLEWELLYNS
9	B & D WALLPAPER STRIPPER.	35685.	S. WOOD	
10	BOTTLE OF CHAMPAGNE.	19700.	D. ROGERS	HODDESDON
11	VICTORIAN HOUSE STYLE BOOK.	23711.	J. EDWARDS	ELTHAM
12	£5 CROWN COIN IN DISPLAY CASE.	07617.	J. COURTNEY	DONCASTER
13	BOTTLE OF WHISKEY.	07566.	L. KILBOURNE	DONCASTER
14	£15 MARKS & SPENCER GIFT VOUCHER.	22845.	R. THOMPSON	DARLINGTON
15	PIE SERVER, SAUCE LADLE + SPOONS.	26959.	D. OLDFIELD	FITZWARREN
16	VISIT TO DENBY POTTERY + UMBRELLA.	43363.	N. HICHENS	
17	V-NECKED SPORT SHIRT WITH DESIGN.	06825.	NICKLIN	
18	CLASSICAL ANIMAL STORIES.	48923.	M. JONES	MID-GLAMORG
19	POWERGEN GOLF UMBRELLA.	30304.	D. THORPE	CHESHIRE
20	TSB SWEATSHIRT AND ANGLIAN PEN.	12171.	F. MAGRUE	SOLIHULL
21	D. I. Y. KNIFE MASTER SET.	11910.	V. GRANT	FOKESTON
22	D. I. Y. BATTERY TESTER + WIRE STRIPPER.	01670.	N. APPLEBY	LEEDS
23	ALLIANCE & LEICESTER UMBRELLA.	09261.	D. MCGREADY	GLASGOW
24	BOOKS ON MINING x 2.	43500.	RICHARDS.	
25	£10 W. H. SMITHS GIFT VOUCHERS.	36106.	GIBSON.	
26	TSB STOPWATCH & T SHIRT.	01780.	C. GAMBLE	MAPLE HOUSE
27	101 DALMATIANS (BOOK).	40165.	K. NIGHTINGALE	PETERBORO'
28	BUM BAG & LEATHER WALLET.	27295.	S. HIGHAM	BOLTON
29	TALES FROM UNDER THE SEA (BOOK)	23615.	GEORGE	COVENT/GDN
30	RADIO TRENT BASEBALL CAP & BUMBAG.	02150.	R. AWAN	MANCHESTER
31	4 x 3 HR BLANK VIDEO TAPES.	23034.	P MCENTEE	WIDNES
32	A FISH CALLED WANDA (VIDEO).	07010.	T. KURTEN	
33	FISHER PRICE TORCH/LANTERN.	20825.	WILLIAMS	
34	FRAMED PRINT.	07741.	D. MEEK	DONCASTER
35	BOTTLE OF WINE.	01729.	P. HIORLS	PONTEFRACT.

Promoter:- DAVID BRIGGS. 7, HUMBER STREET, RETFORD, NOTTS, DN22 6LZ.

Registered under Section 5 of the Lotteries & Amusements Act 1976 with Chiltern D. C.
REG No. 263. Drawn 7th September 1993

Fundraising Donations

Mrs Maureen Fryer, Friends & Family	Fun Day & Various Fundraising Events
Andrea Brock	Souper Lunch
John Arrowsmith	Great North Swim
Mary Moulding	Book of Poetry
Pauline Mahon/Jo Woods	Charity Dinner
Cedric and Christine Gooch	Raised
Edward Nowell	Edward Nowell Appeal
Aegon Sports & Social Club	10 Mile Walk
Kathleen Jordan	Raised
Brian Sara	Great North Run
Pam Croghan	Collecting Tins
John Cooper, Bill Haker & Ivor Peters	Music Concert
Christine Butt	Coffee Morning
Terry Ballard	Swag Bag
The Simpson Family	Bonfire Party
E Taylor	London Marathon
Caroline Fisher	Stall at Local Pub
Marilyn & Howard Turner	Canoe Race Bristol-Windsor
Ann Fraser	Raised
Bob & Rhian McKnight	Raised
Commission of European Communities	Brussels Half Marathon
Miss Barfoot	Great North Run
AIB Bank	Collecting Tins

London Marathon

Even as you read this, Mike Kilvert is pounding up and down the hills at the back end of Wales preparing himself for the London Marathon in April. Sponsorship forms for the Marathon are included with this newsletter. For several years now we have had runners in the Marathon and families have supported their efforts by collecting sponsors. If you know anyone who would like to join with Mike in running for MPS please ask them to get in touch with him. (Address back page)

Area Support Families

Martine and John BrennanTel: 0524 382164

105 Barley Cop Lane, Lancaster, Lancs. LA1 2PP

Robert and Caroline FisherTel: 0799 586631

The Horrells, Great Samford, Saffron Walden, Essex, CB10 2RL

Suzanne and Jeffrey HodgettsTel: 0827 56363

6, Godolphin, Tamworth, Staffs. B79 7UF

John and Barbara ArrowsmithTel: 091 2662999

11 Penfold Close, Fairways Est. Benton, Newcastle on Tyne. NE7 7UQ

Sean and Pauline MahonTel: 0742 304069

41 Stumperlowe Crescent Rd, Sheffield, South Yorkshire S10 3PR.

Mary and Robin GoochTel: 0435 883329

Highbank House, Swifehill, Broadoak, Nr Heathfield, East Sussex, TW21 8XG

Bill and Sylvia BlackburnTel: 0270 626809

11 Beatty Rd, Nantwich, Cheshire, CW5 5JP.

Ron and Linda SnackTel: 0908 666819

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6 Westway Park, Yatton, Near Bristol, Avon. BS19 4JU.

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Northern Ireland Co-ordinating Committee:-

Kieran Houston (Chairman)Tel: 0504 884168

15 Barrack Street, Strabane, Co. Tyrone, BT82 8HB.

Margaret Kearney (Secretary)Tel: 026 57 62073

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