

Newsletter

Autumn 1994

The Society for Mucopolysaccharide Diseases



National Registered Charity No. 287034

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"Care today, hope tomorrow"



Emily Hayward, (Hurler disease, age three) from Crawley, near Winchester at the MPS Garden Fete organised by the Nowell family in Wells, Somerset, on 3rd of July.

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Deadline for Winter Newsletter

22nd of December 1994

DIRECTOR'S REPORT

for

Presentation by

Mr A G King

at the Society's AGM

Sunday the 25th of September 1994

The past twelve months have seen a significant increase in demand on its support services both to affected families and the professionals involved. Mary Gardiner and Christine Lavery have responded to many crisis situations in the areas of education, health, welfare benefits, specialised equipment, housing and respite care. This case work severely stretches the manpower resources of the Society but at the same time is viewed as a vital and unique resource available to MPS families when the statutory bodies and other agencies withdraw. Visits to newly diagnosed and bereaved families continue to be a priority.

In April the Society saw its effort to encourage a comparable MPS clinic, to that at Manchester, established at the Hospital for Sick Children, Great Ormond Street. Currently it is held every third Thursday and led by Dr Ashok Vellodi. As Mary Gardiner serves the Manchester clinic and families attending or hospitalised so Christine Lavery carries out a similar role in London.

In research the Society has continued to fund the work of biochemists, Lesley Heptinstall at the Royal Manchester Children's Hospital and Ruth McDermott at the Christie Hospital, Manchester.

At the Institute of Child Health the Society has provided 50% funding for biochemist, Cathy Meany, who is working on the Hunter gene and took up post on the 1st of September 1994.

Our area families have done sterling work which was 'rewarded' with a training weekend at the Keilder Centre in Northumberland in the middle of March. Bridge building was on the agenda but no one believed this was meant literally!! On a more serious note the weekend co-ordinated by Christine and Mary covered much new ground and I believe gave the Area families opportunities to acquire new skills and extend their knowledge.

The second planting of the 'Childhood Wood' took place on Friday the 25th of February when 17 oak saplings were planted in memory of MPS children and young people who have died. Nearly 100 family members and guests braved 6 inches of snow to reach the 'Childhood Wood'.

In June more than 100 family members came to help clear debris from the wood and weed around the trees. Quite an impression was made but there is still much work to be done and we expect to have another working party in 1995.

Our Family Holidays were again an outstanding success and for the first time we were able to offer an activity holiday at the Exmoor Calvert Trust, for physically disabled teenagers affected by MPS. This was supported by 10 members of the Royal Logistics Corps, Hullavington, Wiltshire but I will say no more as Sergeant Neil Whitewick will be speaking on the holiday following the AGM.

On the overseas front the European Database is growing dramatically and has received support from all the European MPS Societies as well as individual families and professionals. The database has attracted a tremendous amount of interest and has played a major role in bringing together as a cohesive group the 'European Working Party'. In April representatives of 12 European Countries met at the 2nd European Working Party at Kirchberg preceding the Austrian MPS Society Conference.

As you will hear from our Treasurer and assistant Treasurer the financial position of the Society is pleasing but there is not scope for complacency if the Society is to continue to keep pace with its members needs and expectations.

Many people, trusts and corporate donors have generously made donations or fundraised for the Society over the past 12 months and it is not right that one individual is singled out. We are grateful to everyone for their contributions, big or small. Without this the work of the Society would be severely hampered.

Christine Lavery
 Director
 19/9/94

New Committee Members

Welcome to **John Brennan, Peter Stuart and Jon Lawrie**, who were elected to the committee at the annual general meeting on the 25th of September. **Bryn Neal and Wilma Robins** remain as co-opted members.

Congratulations!

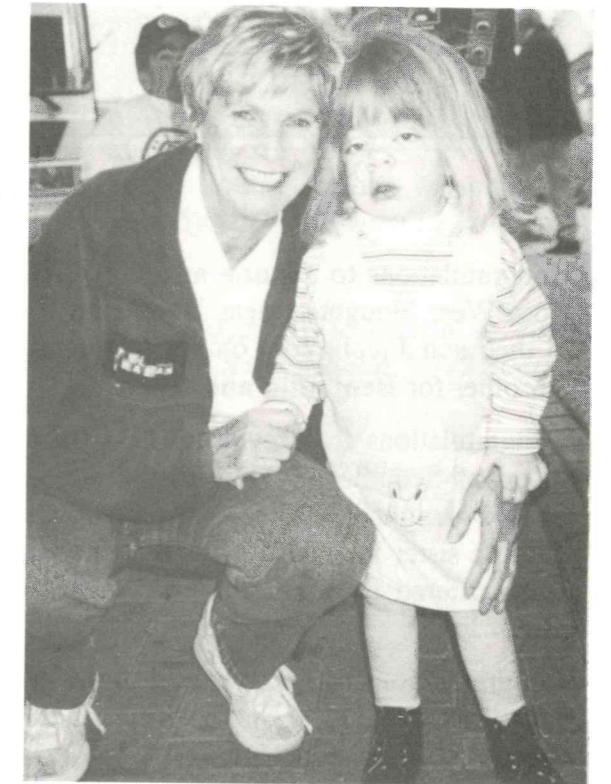
Congratulations and best wishes to **Mary Gardiner and Rob Paget** on their forthcoming marriage on the 21st of January 1995.

Heartfelt thanks and acknowledgements to **David and Monica Briggs** and family for the very effective and efficient work they put into the raffle over a number of years. The Society is now seeking someone to take over this important work. If you are interested please contact Christine Lavery for preliminary discussions.

Thanks and grateful acknowledgements to **Jenny Broome and Martin Sutcliffe** who stepped down from the committee this year. Jenny and her husband Roger have been very active workers for the Society since it started.



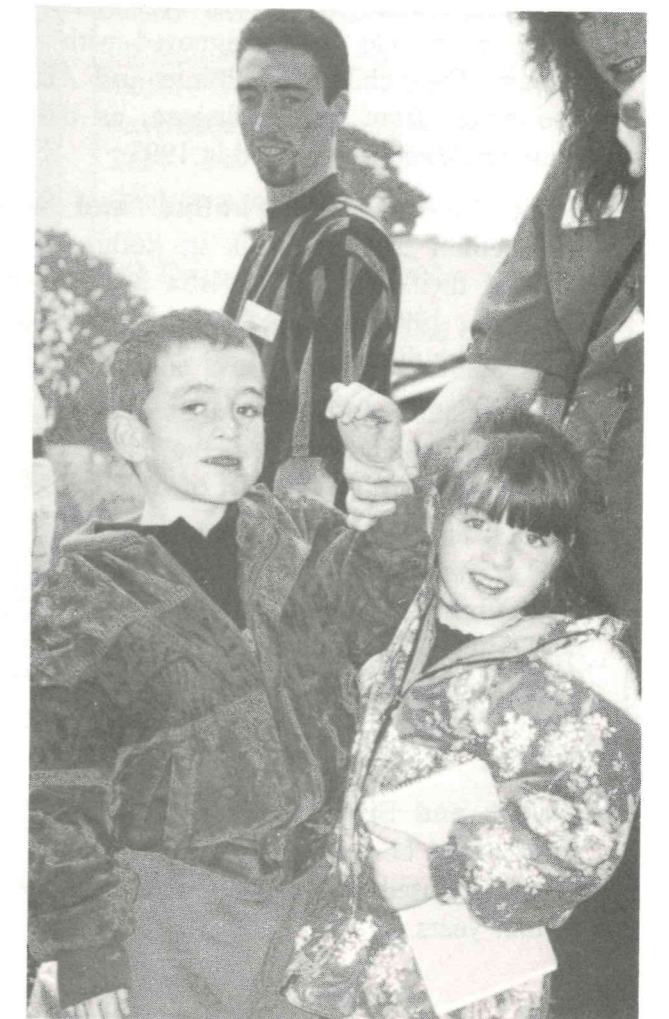
Helen Patterson (Volunteer) and friend.



Pat Criddle from Cardiff, with Jessica Stewart (Hurler, age 3) from Borehamwood.



Teenagers enjoying themselves on the outing. Karl and Wendy Hitchin from Croydon with Sam (Sanfilippo aged 6) and Kara.



Milestones

Births

Congratulations to **Joanne and Gary Adshead** from West Houghton near Bolton on the birth of their son **Jacob**, born on 3rd of August 1994, a brother for **Benjamin and Lucy**.

Congratulations to **Trevor and Barbara Rollinson** of Scunthorpe, Humberside on the birth of their daughter **Lexi Rose** on the 16th of July 1994, a sister for **Amy**. Their daughter **Gemma** who suffered from Hurler disease, died on the 5th of July.

Congratulations to **Bridget and John Ward** of East Acton, London on the birth of their son **John** on the first of July 1994, a brother for **Martin**. Their children **Linda and Michael** who suffered from Hurler disease died on the same day in 1991.

Congratulations to **Nora and Tom Corcoran** from West Ealing in London on the birth of their son **David** on the 7th of August 1994. Sadly, David has been diagnosed with Hurler disease. Their children, **William and Amanda** also suffer from Hurler disease, as did their daughter **Marian** who died in 1993.

Congratulations to **Pauline and Keith McLachlan** from Penicuik in Lothian on the birth of their daughter **Aleisha** on the 9th of December 1993, a sister for **Daryl**, who suffers from Hurler disease.

Congratulations to **Mr and Mrs K Basra**, from Isleworth, Middlesex, on the birth of their daughter **Banita** on the 21st of August 1994.

New Families

Graham and Dawn Cawthorne from Heddon, near Hull, whose daughter **Lauren**, born on 30th of August 1993 has been diagnosed with Hurler disease. Lauren is the youngest of five children.

Wadah and Sina Obad of Liverpool whose son **Ahmed** born on 2nd of January 1990 has been diagnosed with Hunter disease at the age of four years.

John Sartain and Donna Curley of Alexandria in Dumbartonshire, whose son **Mark**, born on 7th of January 1994 has been diagnosed with an MPS disease.

Mr and Mrs Wright from Blackburn, Lancs., whose daughter **Kelsie**, born on 1st of January 1993 has been diagnosed with Hurler disease.

Sandra Pollard of Ashton under Lyme, whose daughter **Charlotte**, born on 23rd of February 1993 has been diagnosed with Hurler disease.

Dallas and Stephen Rickett from near Newark, Notts, whose twin children **Thomas and Charlotte**, born on 24th of December 1986 have been diagnosed with Sanfilippo A disease at the age of seven.

Natascha Meyer from the Netherlands whose daughter **Fleur**, born on 30th March 1993, has been diagnosed with Hurler disease. Natascha is interested in helping families in the Netherlands to come together.

Stephen Simms a new adult member from Chiverdale, West Midlands, who suffers from Morquio disease. Stephen is now aged twenty nine.

Deaths

Martin Haigh from Huddersfield, who died on the 25th of October 1994, aged fifteen years. Martin suffered from Sanfilippo A disease.

John Leonard from Oulton Broad in Suffolk who died on the 9th of October 1994 aged six. John suffered from Fucosidosis disease.

Marie Jobson from Tregirls, near Padstow, Cornwall who died on the 19th of September 1994 aged nine. Marie suffered from Hurler disease.

Our thoughts are with the parents families and friends of these children at this sad time and with all families who have lost someone through MPS diseases.

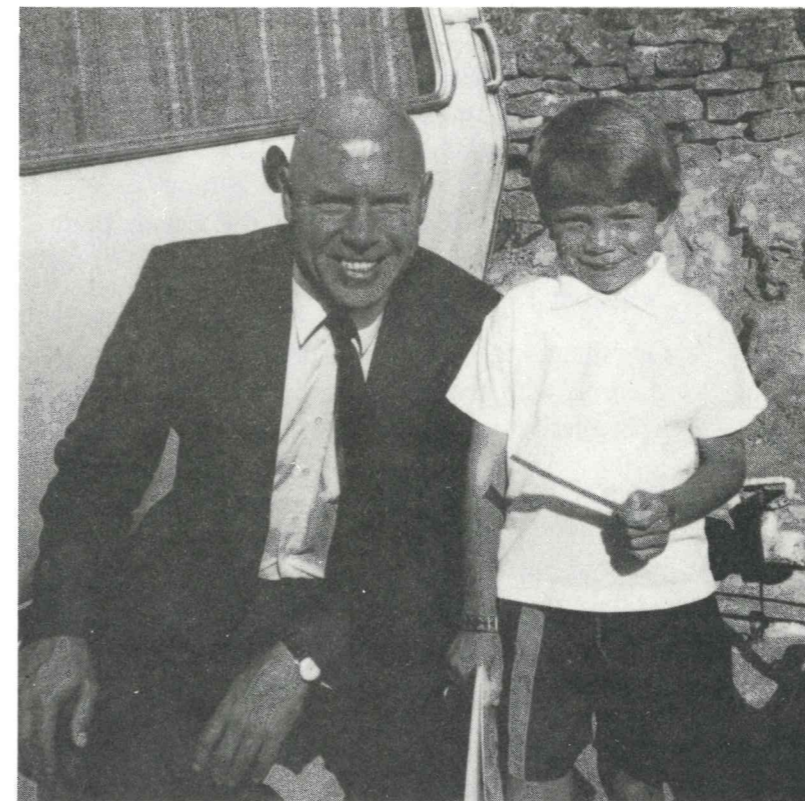
Christmas Parties

North West Christmas Party Sunday 20th Nov. 1 - 5pm at South Cheshire Masonic Hall, Wybunbury Rd, Willaston, Nantwich, Cheshire. *Contact Bill and Sylvia Blackburn 0270 626809.*

Sheffield Christmas Party Sunday 4th December 1.30 - 5.30pm at St Martin de Porres Church Hall, Worksop Rd, Sheffield. *Contact Pauline and Sean Mahon 0742 304069.*

South West Christmas Party Sunday 11th of Dec. Charlton, near Malmesbury, Wilts
.....*Contact Tony and Shirley Eyre 0666 825215.*

Welsh Christmas Party Sunday 11th of Dec. 1 - 5pm Clydach Hall, Swansea
.....*Contact Kilvert family 0686 624387*



Toby Parfitt with his friend, Dave Culpin, who raised over £400 by having his head shaved.

Toby Parfitt and friends from Shepton Mallett Infants School, Somerset, raised over £1000 for the Society through a school fayre in July. His mother Carol said. "We are all in a daze about how much was raised, and Toby just couldn't believe it. The children worked very hard and we are very grateful to Toby's teacher, Hannah Grimes and the PTA."

Hannah Grimes said. "The children did all the work and the parents took a back seat. Toby is a very popular boy in the school and has a lovely character."

Toby and his sister Hannah continued their fundraising at the Nunney Street Fayre on the following Saturday.

Toby is eight and suffers from Hurler/Scheie disease. He now attends St Pauls School, Shepton Mallett.

Twelfth Annual Weekend Conference

A large group of families and helpers enjoyed a sparkling and refreshing conference at the **Stakis Country Court Hotel** just outside Northampton from the 23rd to the 25th of September. Many new families attended as well as long established members, and for them it was a good introduction to the Society. Visitors from Russia, Germany, Austria, Holland and the United States were welcomed.

Dr Ed Wraith gave an update on progress in the direction of Gene Therapy, emphasising that this may eventually be a useful treatment for some conditions for patients who are identified at a very early age. There are very considerable obstacles to be overcome. For patients who have suffered brain deterioration, as for instance in Sanfilippo, this may not be of benefit.

Dr John Marshall from the Australian Company, CSL, reported on the work that his company is doing to assess whether **Enzyme Therapy** can be developed as a viable market product. Dr John Hopwood has made great progress on the initial laboratory work, and information about the potential numbers of patients worldwide who might be able to benefit is being built up through the International Database. Dr Marshall explained the many steps needed and obstacles to be overcome before factory production would be possible and it is established that the returns will meet the substantial costs.

A useful observation was that it may well be that Enzyme Therapy and Gene therapy can be used in combination, so the two lines of development may not be in conflict with each other.

Dr Ashok Vellodi from Great Ormond Street Hospital gave a



Colin Arrowsmith and Joanna Broughton at the outing.

full and frank account of the history of bone marrow transplantation for children with MPS diseases. His information supported the view that for some conditions, the benefits of this treatment may well outweigh the risks when it is possible to do early transplantation from well matched related donors. However for many MPS children it is now clear that bone marrow has very limited likely benefits and high risks.

The seven "special interest" afternoon group discussions were well attended. Lively discussions took place and parents had an opportunity to share knowledge and experience with each other and to make friends and offer mutual support. This year there was a separate group for MPS adults, which gave people a chance to talk away from their carers. There will be further reports on the talks in later newsletters.

Deirdre Bevan and helpers took over the creche and did sterling work over the two days.

The children's outings were a success. Not only did **Martine and John Brennan** organise the evenings entertainment on Saturday night, Martine and friends wowed us with their cabaret group "**Second Chance**" and the dance floor shook until the riot police were called in to clear it at 1.00am.

Our thanks to the volunteers who cared for the children with their usual skill and cheerfulness, particularly to our steadfast friends from **Amer-sham Baptist Church**. Our thanks also to the management and staff of the hotel who took care of our creature comforts and were most efficient and helpful. The swimming pool was voted "well good". Verdict. **Better than the average conference.** The hotel is already booked for next year.



Christine Lavery with **Robert Crawford** from HTV and **Edward Nowell** at MPS Garden Fete at Wells on 3rd of July. (See report page twenty).

Susie Graf from New York with her daughter **Frederica (MLII)**. Susie and her husband **Johann** and **Fredy** came to the conference along with **Marie Capobianco**, President of the American MPS Society and stayed on to work with Christine on the International Database of MPS sufferers. They took time out to go shopping and bought a hat. But what a hat!

Conference Letters

It is now two weeks since I attended the Saturday session of the MPS conference in Northampton. I am writing to say how much I appreciated the day. I found the lectures interesting, varied and stimulating. I was involved for four years as a part time classroom assistant for Matthew Hardy and I can imagine something of the help the conferences are to parents of MPS children. The atmosphere was one of efficiency and friendliness.

I enjoyed, (if that is the word), the talk about preparing brothers and sisters for a death in a family and about counselling afterwards. A comment I would like to make is that children in a class where a child dies also need help in understanding the death of a friend. Often a child is kept with their peer group and so may have been friends of the child who dies for a number of years. Some are 'special' friends who enjoy helping the MPS child and will spend their playtimes with him too. This was very much the case with Matthew who had such a super smile and was loved by all the children in his MLD school.

The fact that Matthew would not get better was not hidden from the children. Their questions were answered directly. The class teacher also kept in mind that Matthew could die suddenly, particularly more recently, as he was more poorly.

We had talked in advance with the head about matters like a special service, and how to respond to his death. The day we heard that Matthew had died we told the children in the afternoon and gave them a letter to take home, so that the parents understood if the children were sad. There were other obvious helps that can be offered. Perhaps this might be a subject of interest to other schools in this situation?

Many thanks again for all your hard work.

Mrs Audrey King

4 Tinkers Drive, Winslow, Bucks, MK18 3RD

To Christine,

I really enjoyed myself at the MPS conference. Thank you for letting us stay the night. The hotel was very nice. I had a great time at the American Theme Park. Neil was a very nice helper. When we were at the park Neil talked about an Adventure Holiday to Devon and when we got back to the hotel he showed me the photos of the holiday. He said I would really enjoy it. If there are ever any places I would really love to go.

Love from

Sarah Burgess

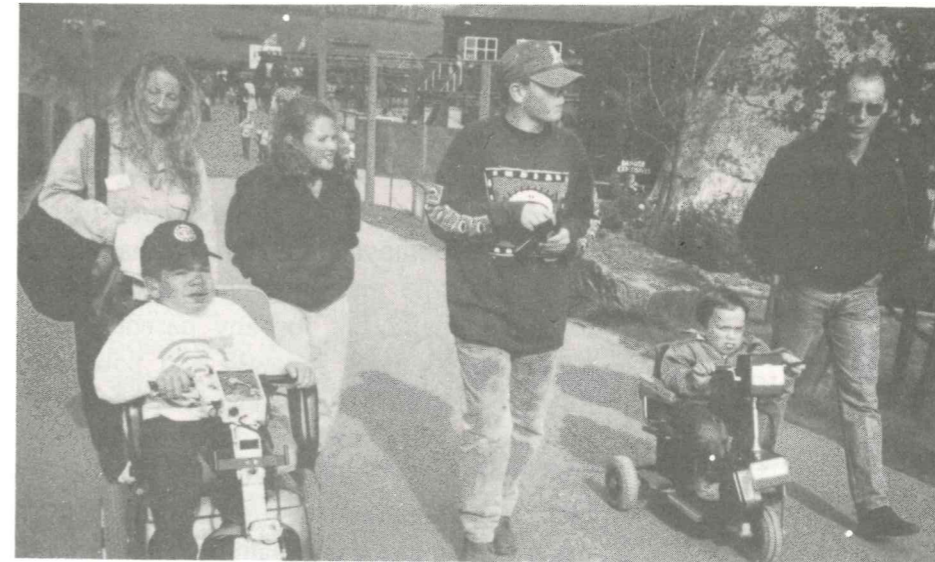
My name is Natascha Meyer and I live in Holland, together with my daughter Fleur, who is one and a half years old and suffers from Hurler disease, and with my son Tobias who is almost six years. It made me very happy to be invited to the MPS family weekend conference in Northampton.

We would like to thank you all very much for making us all feel very welcome and for being looked after so well. We had a great time and it felt very good to be able to share our feelings and experiences with other parents and to see all the children together.

I can say that since Fleur was diagnosed with Hurler disease, the weekend in Northampton has been the best experience I've had in finding ways to cope with her condition and to help her live her life as comfortable as possible.

I would like to thank especially Christine Lavery for being so kind to invite us and for sharing some ideas with me about having a society in Holland. I also want to thank Dr Wraith for giving me a lot of advice on managing Fleur's condition and writing a letter with his advice, which arrived very shortly after I came home from England. This letter will be a great help in finding the best medical care for Fleur. So thank you all again.

Natascha Meyer.



Top Left: Teenagers take off at the conference (with apologies to Rob Paget on right).



Top Right: Emma Briggs at the Childhood Wood.

Right: More conference strollers.

Bottom Right: Picnic at the Childhood Wood.

Below: June Elliott at the Northern Ireland Regional Conference on 22/23 October. (See



Tessa Nelson Loves to Live

We have just arrived home from our first MPS conference and feel enriched both in body and soul.

First let me explain that we were very apprehensive about going. If it hadn't been for our two eldest who were so looking forward to watching Sky TV and going on the children's outings, we would have backed out at the last minute.

Tessa who is four has MLIII disease. She was only diagnosed four months ago. At present she is very mildly affected and looks and acts like a normal four year old. We didn't think we could handle seeing much more severely affected children and we were also nervous about how our children would react. We felt we would rather suffer in silence and keep up the pretence that Tessa was normal for as long as possible.

"We felt we would rather suffer in silence and keep up the pretence that Tessa was normal as long as possible."

But we bit our lips and we went. I think we will probably go to every conference from now on.....

Our children loved it, the outings and the other children. They saw with children's eyes the love of life and fun in the other children, with no preconceptions of their limitations.

We loved it. The speakers were very informative, helpful and amazingly honest. Talking to other parents of MLIII children helped us to get more of an understanding of what to expect in the future. But it also affirmed that Tessa is very much an individual and that we must take every step as it comes and fight all the way, because in the long run only we will know what is right for her.

But most of all we were astounded by all the parents we met. They all have such incredible capacity for enjoyment. Here we have a group of people who are suffering one of the worst torments imaginable for any parents, and yet exhibiting so much strength and patience and love. Being an MPS parent teaches you more profoundly than anything how to live and to give thanks for each moment. All the world religions propound this great truth, but how many people live it and gain so much from it?

Tessa is very happy and has lots of friends. She really enjoys her visits up to Great Ormond Street, especially the train and the tube rides and all the toys when we get there. She goes to playgroup and a Montessori nursery in the village and will be starting at the village school in September 1995.

Dawn Nelson,

2 Mill Hatch Lane, Trotton,

Petersfield, Hants. GU31 5JX



Dawn and Tessa Nelson at Playgroup

FIRST REGIONAL MPS CONFERENCE COOKSTOWN NORTHERN IRELAND

22- 23 OCTOBER, 1994

Nineteen MPS families gathered at the Glenavon Hotel for the first Regional MPS Conference organised by the Society. All known MPS families in Northern Ireland with a living child with MPS attended.

Following a buffet lunch, **Professor Norman Nevin**, a leading Consultant Geneticist in Belfast spoke on the 'Pattern of Inheritance in MPS' and it was particularly helpful that he was able to speak with a specific knowledge of resources in Northern Ireland.

Dr Ed Wraith, Consultant Paediatrician at the Royal Manchester Children's Hospital gave two presentations, Clinical Manifestations in MPS and, Research and Treatment. These two talks stimulated considerable discussion and prompted intelligent questions from the floor.

Meanwhile the children affected by MPS and their healthy brothers and sisters were entertained with face paints and balloon crafting.

A private evening meal for the parents and professionals was followed by an opportunity to disco dance or relax over a drink in the lounge.

On Sunday morning three workshops addressed the issues of 'Brothers and Sisters'. Feedback suggested that there are still a lot of parents who need considerable support and guidance themselves before being able to fully address the needs of their healthy children.

Christine Lavery and Mary Gardiner made presentations on 'Adapting Your Home', and illustrated the Society's activities by showing slides from the 1994 Teenage MPS Activity Holiday attended by two boys from the province.

Over Sunday lunch six MPS families from the Republic of Ireland discussed with Mary and Christine a way forward in establishing an MPS Society in the South.

We should thank all the volunteers, the staff at the Glenavon Hotel and Keiran and Bernie Houston for all their help in making this meeting possible. The meeting was a great success and is a very important development of the Society in Northern Ireland. Hopefully it will encourage developments in the rest of Ireland as well. We wish them every success. And what about Scotland? A regional conference next year perhaps?

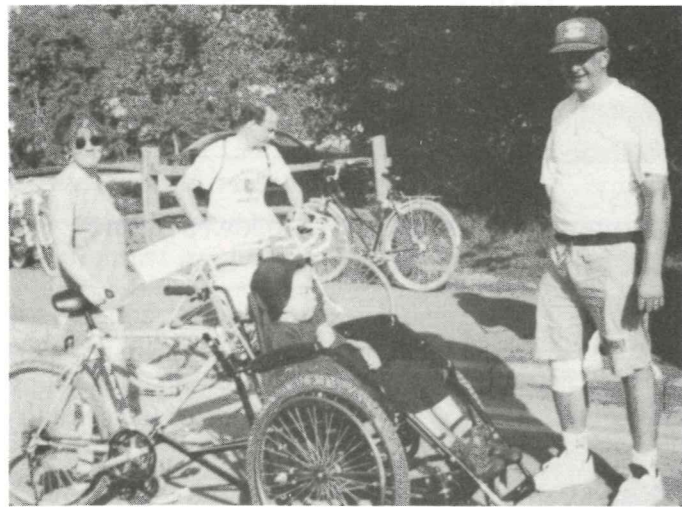
Christine Lavery
Director

A short ride on the cuckoo trail.

Last winter, our good friends the Jones', who have helped and supported us a great deal since James' diagnosis, suggested a sponsored bike ride.

After much planning we decided on doing the "Cuckoo Trail" on the 3rd of July. This is a disused railway track which has recently been renovated. The distance was about fifteen miles and it was not too long or too steep.

We dearly wished that James, our ten year old son who suffers from Hunter disease could take part. Eventually we found a cycle hire firm near Seaford who specialize in hiring bikes of various designs for handicapped children and so James was able to come with us.



James Gooch goes cycling in style along the Cuckoo trail.

Finally the day arrived. Thankfully the weather was fantastic. We reckon about one hundred and ten people took part with ages ranging from four to sixty, the majority riding, but with some on foot.

Everybody had a great time. The chain on James special bike snapped with about a mile and a half to go and I had to push him the final distance. Everything else went according to plan. After the event, thanks to the Jones', we all had a wonderful barbeque and just the odd drop of the old "amber nectar"!

Thanks to our friends and relatives who took part and helped us raise a substantial amount for MPS. A very enjoyable way to raise money for the Society. Why not try it?

Robin and Mary Gooch

High Bank House

Broad Oak, Near Heathfield, Sussex, TN21 8XG

South East Area Family Day.

About seven families turned up for our Area Family Day which was held this year at Tilgate Park Crawley. The weather was very good and everybody enjoyed themselves.

Robin & Mary Gooch

Dear Christine,

I wrote to the Disabled Living Allowance Agency to check how strict are the rules about Vehicle Tax Exemption for a disabled person. 98% of the time our car is used only when Fay is in it, but very occasionally we need to use it for something else.

They replied, in effect, that the Exemption is only valid when the disabled person is travelling in the vehicle.

Therefore, if you don't have another vehicle for your own use, it is advisable to pay for your road tax disk. Otherwise you might be charged with having no tax disk and your insurance could be void.

Gordon Rowe

Erith, Kent

Football fundraiser

Three years ago I wrote to Rangers Football Club asking if they would consider MPS as one of their charities for "Can Collecting" prior to home matches. The waiting list was enormous, but on April 26th of this year we finally got our big day - at a match against Dundee United.

Any match would have done, for, despite the fact that the stadium holds 46,000 and is about to be increased to 59,000, every match is all ticket and sold out. My son Derek is number 8,543 on the waiting list for a season ticket.

The organisation for each charity on match days is extremely efficient. You are allowed thirty collectors, and all must meet one and a half hours before kick off. We each arrived with two collecting cans and a bucket (explanation later). The charity steward took our group around the stadium, dropping us off at strategic points to catch the maximum number of supporters.

The gates opened at two pm and we were allowed to collect for exactly one hour before being met by the steward. The fans arrived slowly at first, but in the last twenty minutes or so they poured in. Early on they were happy to

put their money into the cans, but in the ten minutes before the game they just threw their money into the buckets as they were in a hurry to get upstairs.

At the end we could not believe how successful we had been. **£1132.00** in one hour. **Who says we Scots are mean!**

Now I issue a challenge to football supporters of other teams - Beat that Manchester United, Liverpool, Arsenal, Newcastle, or any other team.

Seriously though, this was an easy way of fundraising, by comparison with other methods - although it did take a little organising in advance.

A small hint - several sixth form girls from my school offered to help and they proved to be extremely popular collectors - forget the guys!

Finally, may I offer Rangers Football Club and all the volunteers a sincere thank you for all their help.

Alan Byrne

Glasgow



Beaupascal Denyer (MLII, aged four), from near Guilford, and

Rhianneth Wheeler, (MLII, aged two) from Old Woking in Surrey relax at Derian House Hospice, while visiting Dr Ed Wraith at Royal Manchester Children's Hospital for a consultation.

Northwest Family Picnic Day - May 1994

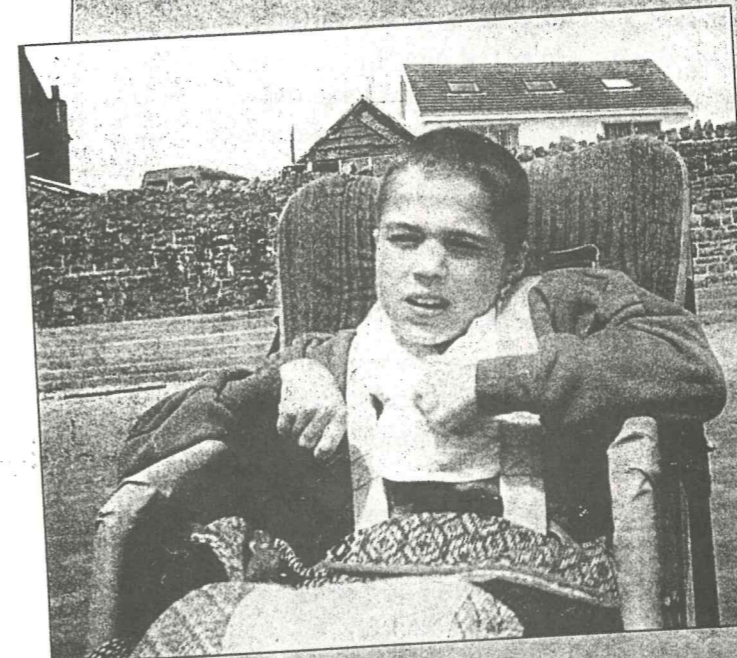


Daisy Morris (Assistant to Mary Gardiner) with Bilal Wali aged five, his mother Nahid and family, from Radcliffe, Manchester at the Picnic. Bilal suffers from Hurler disease and had a bone marrow transplant three years ago.



Mary Gardiner, Simon Hoather, Daz Lemon, with Ben and Michael Hoather and friends at the picnic. All three boys suffer from Hunter disease.

THE LONGEST WAIT *TESTIMONY*



John Hodgetts is 13 and suffers from a life-threatening metabolic condition, Sanfilippo disease. Sufferers rarely live beyond 14 or 15 years. His mother, Suzanne, talks to CLARE McCORMACK about the pain of knowing her son is slowly dying

When our doctor first told us that John was suffering from Sanfilippo, the doctor called it by its old name. "Your son has Gargoylism," he said, and all I could see was a vision of my beautiful child turning into a monster.

"It was a terrible shock. When he was born, John was a perfect baby. It was only at three or four that the problems started. He was in and out of hospital with chest infections and a hearing problem, and his speech was starting to deteriorate. It was visits to friends with children of the same age as John that really showed the problem up. It was obvious he wasn't keeping up with them.

"We were worried, of course, so we took him for tests. He was five when he was diagnosed. His younger brother, Carl, who's nine now, had to be tested as well. Those were the worst six weeks of my life - coping with the shock of John and then waiting to find out if Carl had it as well. I couldn't help but cut myself off from Carl while we were waiting. I couldn't bring myself to cuddle him until we found out that he didn't have Sanfilippo too. I somehow felt that cutting myself away from him would make bad news hurt less.

"We were actually given a false sense of security by John's first diagnosis. All we were told was that he would probably

be institutionalised if he lived that long. No-one sat us down and explained that it was a terminal illness. We didn't know anything about support groups, and the information we got was from standing in bookshops, scouring through the medical books to find two lines about it. "We believed that everything would be OK until 18 months later, when we happened to come across a newspaper report about a child with the same condition. We hadn't realised till then that it was life-threatening, or even that John would lose his skills and his speech. It was a terrible shock - I still remember my mother crying for hours and hours.

"You certainly learn who your friends are when you're faced with something like this. Some disappear because they can't cope with it and they'd rather not speak to you.

"We couldn't cope at first, either. We'd never even heard of Sanfilippo. It's a genetic condition, and my first reaction was guilt, feeling that I'd given it to him. Then I was angry that this had happened to my child.

"The grieving process starts right from diagnosis, so we've been

through the anger and the guilt now. As years go by, that lessens and you learn to cope with it. But it will still hit us very hard when John dies. Children with Sanfilippo usually live until their early teens - John is 13.

"We've already made plans for the funeral. Some people are shocked and can't understand how we can do it - but we know we wouldn't be in the right frame of mind afterwards, and we want it to be right for John.

"We've talked about where we'd like John to be at the end, whether in a hospice or at home, and we've decided home would be best.

"John's in the late stages now. He's forgetting how to eat, and has to be fed liquids. But he's still trying to walk, and he loves to go swimming, which is easier for him. He goes to a special school, where he's in the special care unit, and to Helen House, a hospice in Oxford, a couple of times each year. We go with him and stay in the parents' flat. It's a lovely place - the staff are very caring and they really get attached to the children.

"John can't communicate verbally, but he's a very happy lad. He's always smiling, and his eyes tell a lot. It's impossible to say exactly how long he's got left, but personality has a lot to do with it, and John's still what we call "wicked" - he still finds things funny he shouldn't. If he sees someone trip up in the street,

'If he sees someone trip up in the street, he'll start laughing and I have to put my hand over his mouth'

he'll start laughing and I have to put my hand over his mouth!

"It's difficult to understand why this is happening - it's difficult not to think, "Why is God doing this to us?" You can't help questioning why children suffer. When Carl asks why God cured the lame girl, but not John, it's difficult to find an answer for him. But we're given the strength to cope with it as a family, and we get a lot of help and support from our friends in church.

"When John was first diagnosed, I didn't think I'd be able to cope. Now we're the Midland area support family, going out to new families whose child has just been diagnosed, and being called out to families at hospices to offer support. Seven years ago, I'd never have imagined I'd be able to do something like this, but the strength just comes to you. And it helps to be able to help other people in the same boat."

Help and information regarding Sanfilippo is available from MPS (Mucopolysaccharide) Society, 55 Hill Avenue, Amersham, Bucks HP6 5BX

3 Planesway
Whitehills Estate
Felling
Tyne and Wear
NE10 8LG

DAVE THE BRAVE

Being told that your child needs a cervical fusion is like being hit with an anvil. The first thing that comes to mind is, your child has enough to cope with without going through major surgery. I went numb and must have been in shock for hours. How could this be? David was so active, he hardly uses his wheelchair and copes with most situations admirably. The MRI had shown that David needed his fusion. Armed with a hundred questions, we visited Mr Cowie. He was very reassuring, explained the op in great detail to Ron and I and drew pictures of the procedure for David. We found him very reassuring and more importantly, David liked him.

The staff were great on our arrival at Manchester Royal Children's Hospital, David promptly left us and set off to find some friends, which he did. That evening before the fusion was probably the worst of my life. David and I sat cuddling each other, we talked, told stories, laughed and cried together. The morning of the fusion June 17th, David was so brave, he did not want the operation but he knew he needed it. We hugged as he went off to sleep, the next three hours were horrendous. We just wanted to see that our son was stable.

I can not describe the feeling when Mr Cowie told us that David was fine and the fusion had been a great success. Onward to the recovery ward. There was my brave son lying on his bed looking washed out. The first thing he said to me was 'Mam I need a cuddle' which I promptly did. The staff were tremendous during the first two crucial days ahead; David never complained once. By the third day he took three steps because he wanted to play with his friends. By day five he was walking unaided and went from strength to strength.

Over sixty cards and some parcels were sent to him. I feel sure that the prayers people said and the cards which were received helped David's recovery tremendously. On the tenth day we were allowed home, the house was covered in bunting, a huge welcome home poster and lots of balloons. Family and friends were there to greet us it was a lovely surprise.

I can not thank Mr Cowie, his team, the ward staff Carole, Michelle, Norman and all the others enough. They were a great support and extremely caring and professional.

For other parents out there who have a child who may need a fusion, I can only say that it does get better. Each day we could see an improvement in David, it is amazing where the strength comes from. He was back to school only three weeks after his operation, he plays with friends and is very mobile. He has a great sense of humour and has not lost his extrovert nature. We are extremely proud of him and are looking forward to mid October when the halo will be removed. Then I can have a proper cuddle, without bars.

Yours

Carole Jones



David Jones with his sister **Victoria** nine days after his cervical fusion. David is age nine and has Morquio disease.



Adam Brown with parents **Denise** and **Gavin** and brother **Neil** at Cotswold Wild LifePark Outing organised by Ron and Linda Snack on the 11th of September. Ron reports that the group enjoyed the Meercats and the Iguana, but missed the penguins. To make up for this they played a frantic game of cricket!



Sue Lowry from Harpenden, whose daughter **Sarah** died in February, **Tetsuya Motamura**, now living in Vienna, **Sarah Long**, studying at Bath University and **Stephen Little**, at an outing to Woburn Safari Park. Sue and Vic Lowry came as helpers to the conference in September and wrote to say how pleased they were with it. "A very rewarding weekend".

Further Adventures of Edward

Edward Nowell and his family are sure they had a miracle granted on February 7th this year when Edward underwent surgery for spinal decompression at Manchester Children's Hospital. Ed Wraith decided that Edward needed an operation for decompression at the top of his spinal cord. Ed masterminded the whole operation with a wonderful team, lead by Mr Cowie and Mr Rothera. This was the first one performed on a Hunter boy. It was a risky operation but it had to be done, otherwise Edward would have become paralysed.

If anyone saw Edward at the conference they witnessed the wonderful result!

Thanks to Christine, Ed, Mr Cowie and Mr Rothera and all the team in Manchester. Words will never express our gratitude.

From Edward, Eddie and Holly and all the family.



Edward and his surgeon, Mr Cowie at RMCH

A Point to Ponder

Having been to three conferences now, each has left a different impact on us.

This year's conference brought home the fact that living with an MPS child, one has to accept that the road is not to recovery, however much one may wish this, but at best it is to remain stable and in time of course to degenerate.

Once one can accept this fact, then all allowances one makes for daily ups and downs make sense, and one realizes that the MPS child is not "trying to get out of doing things", but is genuinely feeling off colour.

A mature MPS young person knows his or her limitations and to work with them on this basis makes life happier for all. This is an understanding that throws a new aspect on life.

Eddie and Holly Nowell.



Fred Gibbons, Town Crier, Tony Eyre, and Edward Nowell, fund-raising in Wells on 3rd of July. They raised over £1,700 which will be matched by a sponsor.

Lynn Pienaar writes from South Africa

P O Box 7643
JOHANNESBURG
2000

8th August 1994.

Dear Mary,

TJ, Marie and I want to thank the following people for the most wonderful holiday we have ever had:

Mary, no words can express how thankful we are for everything you and the MPS Society have done for us. We really enjoyed the MPS-Barbeque on our very first day. We are grateful to you for sharing so much of your time with us. Thank you too for all the kindness, support, presents, great food and most of all your fabulous personality, so full of love and understanding.

To Bob, Rhian, Sara and family in South Wales who offered us their hospitality - Thank you for wonderful accommodation and all your time spent taking us to so many beautiful places. You made a dream come true for me. I have always wanted so much to see a real castle and words cannot express what it meant to me to be there, walking in those precincts. The times that I carried TJ all the way up to see my castles were all worth the backache I endured!. The day we spent in St. David's Cathedral was particularly an experience I will never forget. Thank you Bob for taking care of Sara while we were sightseeing! She is such a lovely little girl with really the cutest smile! It took her only a day to be able to say TJ's name. Thank you Rhian for all your support when TJ was hospitalized; all the hours you spent next to his bed and thank you for your love. I wish you all the best with Sara. She will always be in my prayers.

Mike, Debs, Jackie and all the staff at Derian House Hospice - Thank you for taking care of TJ while Marie and I went to London for a break. All the walking to see the historic places of interest was worth it. Back at the hospice, everybody was wonderful. Thank you for making us feel so at home. Thanks for all the care, support, presents and great food, especially our last Sunday lunch with you! TJ was just starting to get to know the place (especially the kitchen where he could find some yoghurt any time of the day) and the people (following Jackie), but we will visit again, good willing, maybe next year.

John, Martine, and Harry - Lancaster - Thank you for taking us to the Brontë Country. That was something very special to me and I will always remember it. Thank you for showing us around and making our day very memorable. Thanks for your time, support and care. I have tried to explain to people here in South Africa just how green it is in England, but I think they have to see for themselves to appreciate such lovely scenery. Thank you for the lovely record you have made for "Harry"; I will always treasure it.

Many Thanks to the staff in Ashby Ward, Royal Manchester Childrens Hospital for taking care of TJ.

Dr. Wraith - Royal Manchester Childrens Hospital - Thank you for being there when TJ needed you. You are the best! Please keep TJ's file to date because he is going to be your patient forever!

Many thanks from all of us!

Love Lynn, Marie & TJ

Andrew Hawkins

Extracts from an article about Andrew which appeared in their local paper last year.

Peter and Jean Hawkins live at Finchhamstead in Berkshire. They have three daughters and a son, who is the youngest. Andrew Hawkins was ten years old when his parents were told that he suffered from Sanfilippo disease, and would undoubtedly die in his late teens from this rare condition.

A few months on, Peter and Jean have mixed emotions on learning the cause of the years of heartache they have suffered.

Jean says, "We would like to have known a lot earlier. We had five bad years with him with the temper tantrums and he had a really hard time."

Peter adds, "People don't understand, that's the trouble. We have had a lot of problems with friends and relatives, big fall outs over the years - we have become reclusive.

"The thing is that Andrew looks so normal", Jean continues. "He has changed our life completely. You can't take him anywhere really. We don't go out or see anyone.

Sanfilippo children have behaviour problems. "Andrew has done things that would make your hair stand on end. And compared to some other children with the condition, he is a mild case. He is obsessive. He goes on and on until he gets what he wants. You can keep trying to

deflect it but you can't for long. We sometimes have to give in, even though we don't like to. If you don't, life isn't worth living."

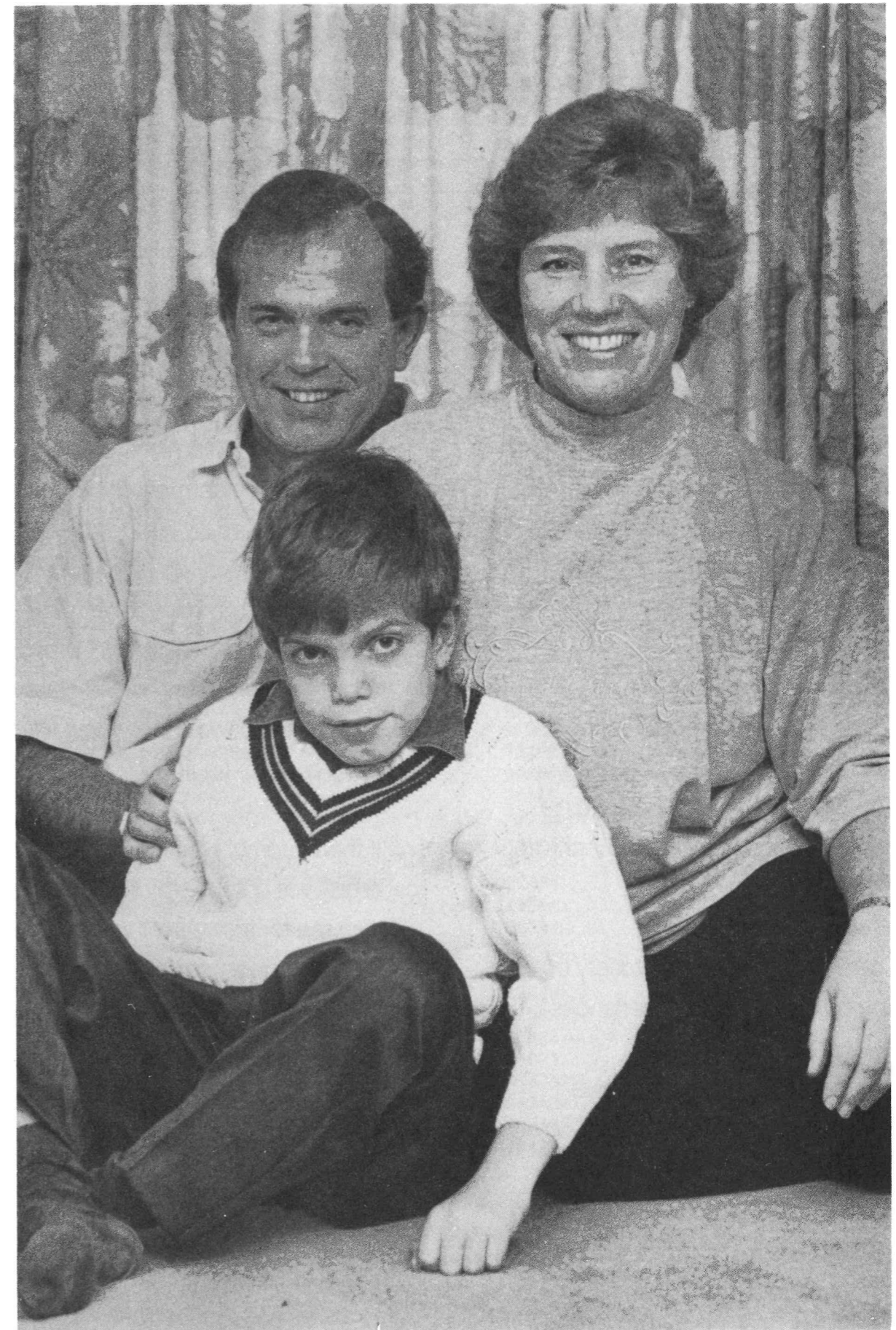
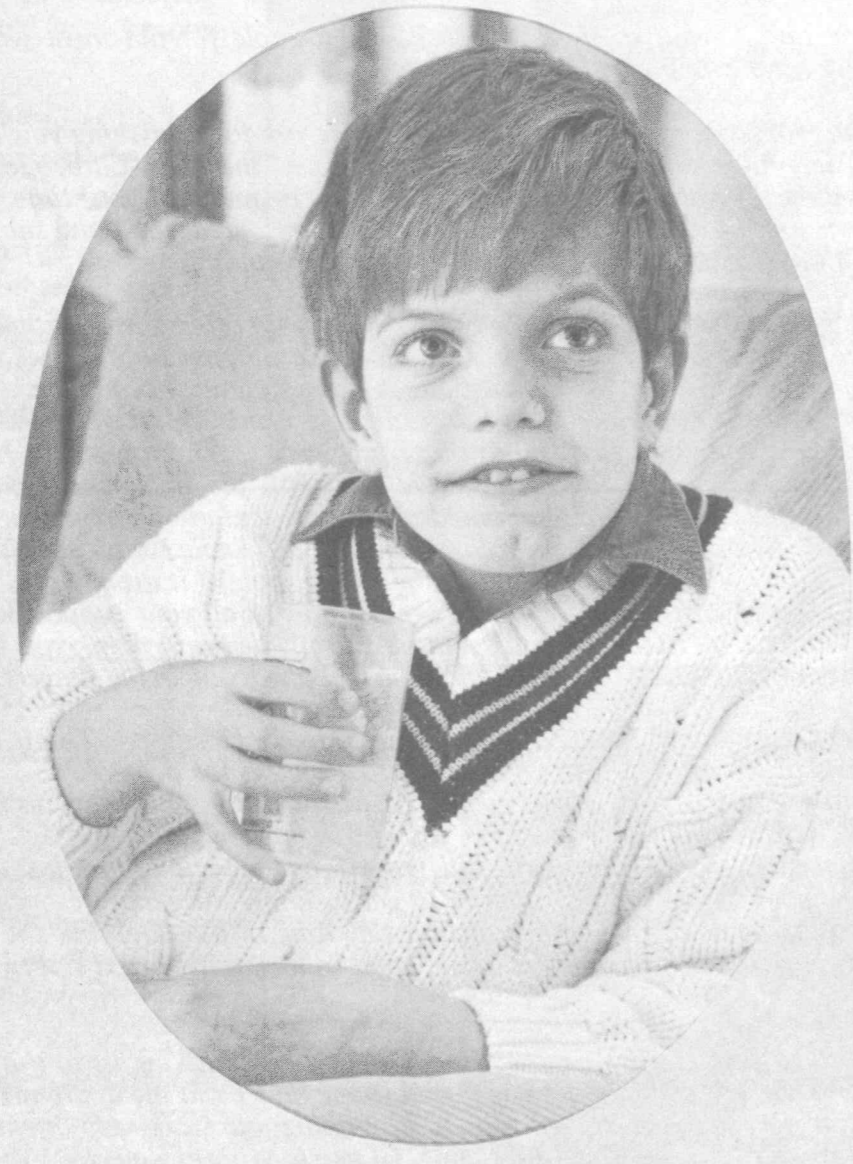
"It was getting to the stage when we were just being beaten. We were physically abused parents," says Jean. "Which is why in the end we badgered the local doctor."

The badgering finally paid off, but not without a measure of persistence. The family saw dozens of specialists and finally a neurologist identified the symptoms.

They had been searching for an answer since Andrew was a toddler. He seemed a normal child until he was two years old. Then he became hyperactive. When he started school, he would not learn, he needed a speech therapist and he became disruptive.

Jean says, "We had ten years to get used to the idea that he was going to be around, then all of a sudden you realize that he won't be." And Peter adds, "It came as a terrible shock to know that it is incurable. When we didn't know what was wrong, we always had hope, this way you haven't".

"He is a very loving child. He is difficult and you need to be with him all the time, but we get a lot of pleasure from him." They know the future will not be easy and only hope that they are prepared for the hardship that is to come.



Rainbows Children's Hospice

Lark Rise, off Hazel Rd, Loughborough, Leics. LE11 2HS

Tel: 0150 9230800

WHAT IS RAINBOWS?

Rainbows is a dedicated children's hospice serving families throughout the East Midlands area (Leicestershire, Lincolnshire, Nottinghamshire, Derbyshire and Northamptonshire), who have a child with a life-limiting / threatening illness.

WHAT IS OUR AIM?

We aim to give respite care to the whole family who need a break from the constant day to day pressures of life at home, caring for a child / children with a life threatening illness.

The care team are from a variety of caring professions and experiences and will give support and understanding. The team will give the physical care if the families wish us to, but in a manner which reflects their wishes.

HOW CAN WE GET REFERRED?

A child can be referred to Rainbows by anyone. However, a medical report will be obtained from the child's G.P. and Consultant (and anyone else who can give relevant information). Each child will be assessed by the Head Nurse and Medical Adviser at Rainbows before a decision is reached. Once we feel that the hospice will provide a suitable environment for the child and family we plan with them how we can contribute to the family's welfare.

If then a family would prefer to arrange a day visit or short stay so that they can see for themselves whether or not Rainbows meets their needs, this can be arranged.

The Rainbows accommodation is very spacious, homely and relaxed to give a home from home feeling, with a kitchen, dining room and lounge for all to use.



The Society for Mucopolysaccharide Diseases

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

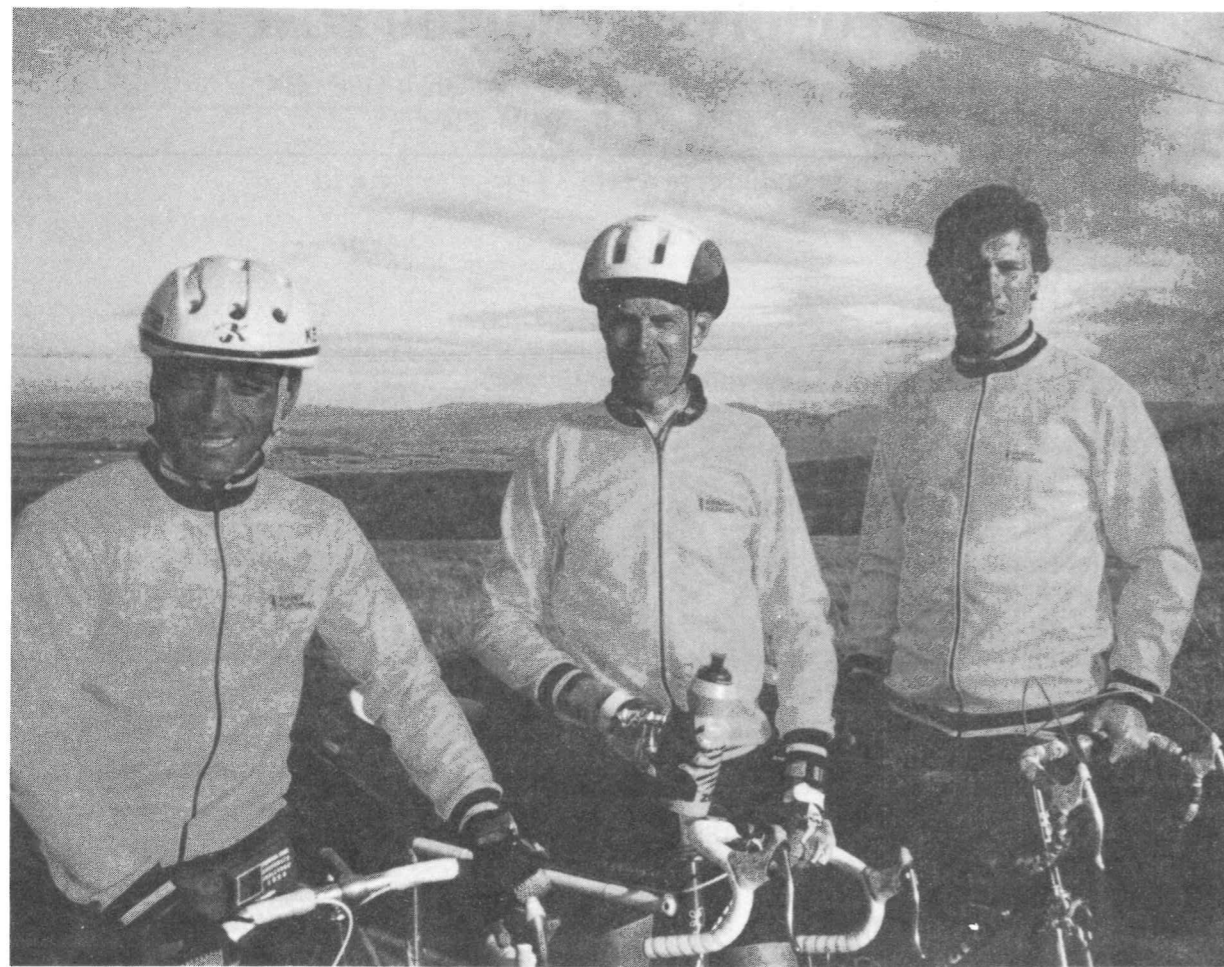
1994 GRAND MPS DRAW

05/11/94

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Fundraising Photos



Tony Natale, Mike Willoughby and Ray Sutton who work with **Ron Snack** in Abbey National, Milton Keynes, on their epic fundraising ride from top to bottom. (See page 25)



Gemma Thompson and friends from **Whinfield Junior School, Darlington** with an elegant display of legs on their "**Jeans for Genes**" at their school. Gemma's brother **Michael** suffers from Hunter disease and is aged 7. Has your school had a **Jeans for Genes** Day yet? Contact **Mary Gardiner** and she will tell you how it's done.

JOHN-O-GROATS TO LANDS END SPONSORED CYCLE RELAY

The idea for this particular fundraising event was spawned in the strange mind of Mike Willoughby, a colleague of mine at Abbey National. The name may sound familiar because Mike has run the London Marathon for us a couple of times.

Anyway Mike said, back at the end of 1993, that he and three of his friends at work, thought it would be a good idea to do a sponsored relay cycle ride from one end of the Country to the other for MPS. Like a fool I offered to go along and do some of the driving, and we started putting together a few tentative plans.

We had to get hold of a mini bus, to use as a support vehicle, we had to obtain some funding for accommodation, fuel, food etc, we had to find some bright cycling clothing, we had to get someone to let us have some spares for the bikes and we had to settle a route. The planning went along quite successfully until one of the riders had to drop out. In order to obtain the maximum amount of matched funding from the Abbey National Charitable Trust a team of four is the smallest number. Ron appears, in his size fifteen boots, and offers to do some of the cycling - as soon as I had said it I knew I had done wrong, but there was no turning back.

Getting nearer the time for the off, about four weeks away in fact, and we were finally given the use of a large diesel mini bus by BMG Motor Group in Bletchley. The MK Social Committee of Abbey National voted to give us £500.00 towards our expenses and we had the clothing, courtesy of the Purchasing Department of Abbey National so we were ready to go.

We left Milton Keynes late on the evening of Friday 2nd September and began the long haul North. It really is a long way to John-o-Groats, and we finally reached there in the early afternoon of Saturday - having had very little sleep overnight. Never mind, we enjoyed the local sights and had an early night. Mike and Tony Natale, the AN gym instructor shared one room and had a good night sleep while Ray Sutton and myself shared another room. Apparently Ray had a disturbed night due to my snoring.

Come morning and Ray was ready to leave at 8 am for his first two hour stint in the saddle. The rest of us saw him off and then went back into the hotel and ate a leisurely breakfast. We left around 9 am and caught up with Ray somewhere south of Wick.

The pattern for the first day was quickly established - the mini bus would pass the cyclist, drive on for about five miles, then park and wait for the bike to go by. Every two hours there was a change of cyclist, and we found the time really flying by.

The route took us down the East coast almost to Inverness and then along the Caledonian Canal towards Fort William. We had arranged to meet the Macleans, an MPS family, at Dingwall where they were waiting for us with cooked pasta, salad, bread and a wonderful bottle of pale brown liquid.

The first night saw us climbing through Glen Coe, which I am sure is a

wonderful sight, but not when you are driving behind a bike at about ten miles an hour. We had decided it would be safest for the mini bus to stay with the bike during the nights, and it was just as well that we had as up in the mountains of Central Scotland we had our only run in with the police. We were pulled over and asked why we were going so slowly - the cyclist at the time, Tony, did not appreciate the question as he thought he was doing very well. Anyway the police let us go and we plodded on towards Glasgow.

We crossed the Clyde at Erskine Bridge and disaster almost befell us here. Ray was on the bike at the time and, due to roadworks on the bridge, cyclists were re routed down a dark tunnel. Ray hit a manhole and came off - fortunately no lasting damage and we were able to continue after a few choice words about Scottish Bridge officials.

By the time we reached Kilmarnock we had been on the road for almost 24 hours continuously and we decided that, to be able to finish the ride, we would have to have a stop for a meal, and then a stop of about two hours at night for a sleep. The idea of being able to sleep in the mini bus may have worked if we had been driving along motorways at seventy, but not when you are following a bike at ten to 15 miles an hour, and constantly changing gear.

After a quick breakfast at the Little Chef we continued on our way and slipped quite out of Scotland late Monday afternoon. We were all excited as we passed Penrith as we knew that Kendal, the next major town was the half way point. We struggled into Lancaster at about nine on Monday evening where John and Martine Brennan fed us more pasta and let us use their beds for a couple of hours.

Up again at around midnight and off, looking forward to the delights of Preston, Wigan and Warrington - at least we cleared those places before the traffic built up. On through Nantwich and Newport, a quick stop at Shifnal for food, get through Worcester and Gloucester and then the long ride down the A38 towards Bristol.

It was as we neared Bristol that Ray decided he had found a good way to cut short his spell of cycling. We normally tooted when it was time for a change of bikers but this time Ray was quite adamant that he had heard a car horn when he still had a quarter of an hour to go. Suffice it to say that no-one else heard it.

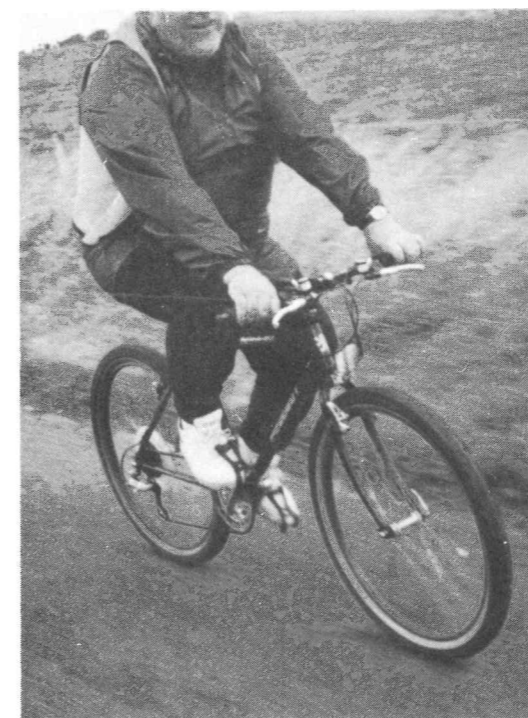
By 10 pm on Monday we had reached another milestone as Mike led us over the Clifton Suspension Bridge and on past it to Congresbury. Time now for another couple of hours sleep, sat up or scrunched up in the mini bus, before we began the final assault - less than 200 miles to go now - the end was definitely in sight.

Ever onward along the A38 to Bridgewater and Taunton. Sadly, although we had arranged to call at Dave and Michelle Brooks Daws in Taunton, we were rather earlier than we had anticipated and it would have been a shame to wake them - sorry folks. We had crossed into Devon by now and passed Tiverton and Crediton, a quick stop in Okehampton for some food and off again towards Tavistock and Liskeard.

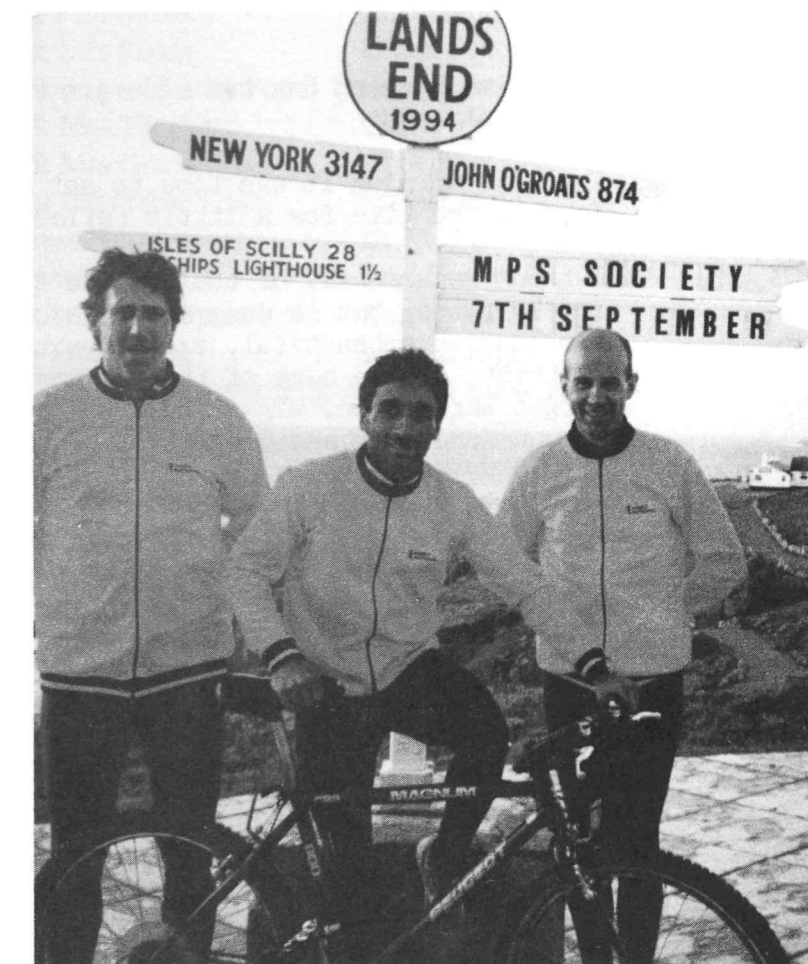
It was on this stretch that we had the only mechanical failure of the whole trip. Ray was on the bike, again, and his back wheel suddenly started wobbling madly, a spoke had gone. This meant that Ray's bike



Mike and Tony with Jim, Cath and Emma Mc Clean and family at Inverness.



Have you heard of "Fat Man on a Bicycle?"
Ron got so carried away that he lost his head.



was relegated to the back of the rack and Ray set off on the mountain bike - a little too small for one as tall as Ray but he managed. At this point, and taking into account the steepness of the hills in this part of Devon, it was decided that everyone would ride the mountain bike. This also meant that we could go to swapping over every half hour without any time being lost by taking bikes off and putting other bikes on the carrier.

Past Bodmin now and on to the A30 for what seemed like a never ending run to Redruth. I think that the gods had saved the worst of the rain for this part of the ride as the heavens were really opening now. Never mind, there's the sign for Penzance and we know it's only ten miles to Lands End from there.

Tony had the honour of riding the final stretch and we reached our goal at 6.25 pm on Wednesday 7 September. Everyone shook hands with everyone else and we were all really pleased to have achieved what we had set out to do. A quick look around Lands End, and the obligatory photograph, and it was everyone in the van and off to Sennen Cove to the hotel for the night. Although we were all very tired we just had to pop off to the pub for a couple of pints before falling exhausted into bed.

This time Ron and Ray had separate rooms so Ray could get a good nights sleep.

The next morning it was time to set off for the drive home to Milton Keynes, and time for a little reflection on what we had done.

I think we were all of the opinion that John-o-Groats may sound like a lovely place, but it does not live up to its name. Other parts of Scotland were beautiful, except perhaps the Erskine Bridge. The Lake District, or the edge of it, was magnificent. We could all happily forget Warrington, Wigan and Preston and remember instead the area around Worcester and Gloucester. Then the West Country of course with its wonderful scenery and steep, long hills.

The lasting feeling about the trip is the feeling of pride that we achieved what we planned to do and the fact that, as a team, we overcame the obstacles that we found along the way, and pulled together for each other.

Ron Snack

END TO END - THE BIG BIKE RIDE

As you will see, from the write-up elsewhere in this newsletter, we completed the bike ride from John-o-Groats to Lands End in fine style and I would be grateful if anyone who managed to get sponsors for us could now collect the money as soon as possible and let me have it, so that we can collect our matched funding from Abbey National.

Thank you very much to all those families who did get sponsors for us.

Ron Snack

The Society is grateful to the following who held Fundraising Events:

Spiffing Stationery	Royal Logistics Corps - Hullavington	Mary Tubb
Mr S Roberts	Ron & Linda Snack	Trudie Deacon
Mr & Mrs J Maclean	Trull School of Dancing	Pam Croghan
Greeves Riders Association	Andy, Jenny and Rebecca Hardy	Jane Bruce
Rotary Club - Wirral	St Mary's RC School	Gordano School
Mr & Mrs Johnson	2nd Haddenham Brownie Pack	Dolphin Coins
Eddie & Linda Tailsford	Strathearn School, Belfast	UK Trucks plc
Bob & Caroline Fisher	Bill & Fer Pidden	
Strabane & District YFC	Crazy Craft & Static Stationery	
Rob & Linda Burgess	Hillside Primary School	

The Society is grateful to those who have made Donations:

Babcock International	Mr & Mrs Wylie	W & M Martin
Mrs S Timms	Mr & Mrs Benbow	Agfa
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Methodist Lunch Ladies, Harpenden		
Ealing Ex Servicemen's Club		

DONATIONS IN MEMORY

The Society is most grateful to the friends and relatives of:

Sheila Dean's Mother	Mr B Singleton	Doreen Hedges
Matthew Hardy	Gemma Rollinson	Sarah Lowry
Bobby Davis' Mother	Mr C Grandidge	Norman Duckett
Mrs G Cunningham	Christelle Voumard	Robert Culley

SPONSORED EVENTS & APPEALS

The Society wishes to thank all those who supported:

Chris Bennett's 1157 Miles Marathon Walk
 MPS Runner in the Great North Run
 The Edward Nowell Appeal
 'Be Still Tape' by Catherine Rush
 The Gooch Family Cycle Ride
 MPS Runner in the Wycombe Half Marathon
 Toby Parfitt's MPS Appeal
 Alan Astbury - Potteries Marathon
 Manley Park Infants School Pram Push
 Jeans for Genes
 Mr R Rugman's 50th Birthday Appeal
 Hullavington Challenge
 Liam Houston Golf Challenge Cup
 (Tony Eyre, Nick Pullin & Kevin Puddy)
 Northern Ireland Christmas Raffle
 North West Barbeque & Fayre
 London Marathon - Mike Kilvert
 Big Bike Ride - Ron Snack
 Elinor Bennett Concert
 Sponsored Slim - Ann Makepeace
 Sponsored Diet - Maria Millar

CHARITY BOXES

Wilma & Peter Robins	Pam Croghan	Holly Nowell
Abbey National Staff, CBX, MK	Jon & Kathie Lawrie	A Merry

An Appeal to Members

On the 5 November the Management Committee (Trustees) met to decide the Society's budget for the financial year commencing 1 November, 1994. Before them were a number of Research Projects to consider. Regrettably the Society does not have sufficient money to fund two very worthwhile areas of research.

Please can you help by organising a fund-raising event, making a donation or putting the Society in touch with potential donors. If we can increase our 1993/94 income by £45,000 in this financial year this would enable the Society to increase the Research budget whilst maintaining a very high level of Family Support.

Area Support Families

Martine and John Brennan Tel: 0524 382164
 105 Barley Cop Lane, Lancaster, Lancs. LA1 2PP

Robert and Caroline Fisher Tel: 0799 586631
 The Horrells, Great Samford, Saffron Walden, Essex, CB10 2RL

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

John and Barbara Arrowsmith Tel: 091 2662999
 11 Penfold Close, Fairways Est. Benton, Newcastle on Tyne. NE7 7UQ

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

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

David and Monica Briggs Tel: 0777 700046
 7 Humber St. Retford, Notts. DN22 6LZ

Bill and Sylvia Blackburn Tel: 0270 626809
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Ron and Linda Snack Tel: 0908 666819
 16 Wandsworth Place, Bradwell Common, Milton Keynes, Bucks. MK13 8BT

Tony and Shirley Eyre Tel: 0666 825215
 7 Elmer Close, Malmesbury, Wilts. SN16 9UE

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

Contact for Scottish Families:-

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

Northern Ireland Co-ordinating Committee:-

Kieran Houston (Chairman) Tel: 0504 884168
 15 Barrack Street, Strabane, Co. Tyrone, BT82 8HB.

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