NEWSLETTER AUTUMN 1990

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

National Registered Charity No. 287034

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This newsletter is published quarterly and distributed free of charge to sufferers from MPS disorders in Great Britain and to their immediate families. It is distributed around the world on subscription. Copies are also sent to those members of the medical profession who are directly concerned with MPS, many of whom make a donation towards our costs, for which we are most grateful. If you wish to be added to the circulation list, please contact **Christine Lavery** at the above address. Annual subscription charges are £5.00 in Great Britain and £10 Sterling elsewhere.

The Society for Mucopolysaccharide Diseases

30 Westwood Drive, Little Chalfont, Buckinghamshire.
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The MPS Society is a voluntary support group, founded in 1982, which represents over 300 families in the UK with children or adults suffering from mucopolysaccharide and related diseases. It is a registered charity, which is entirely supported by contributions raised by its members and it is run by the members themselves. Its aims are:

To act as a parent support group

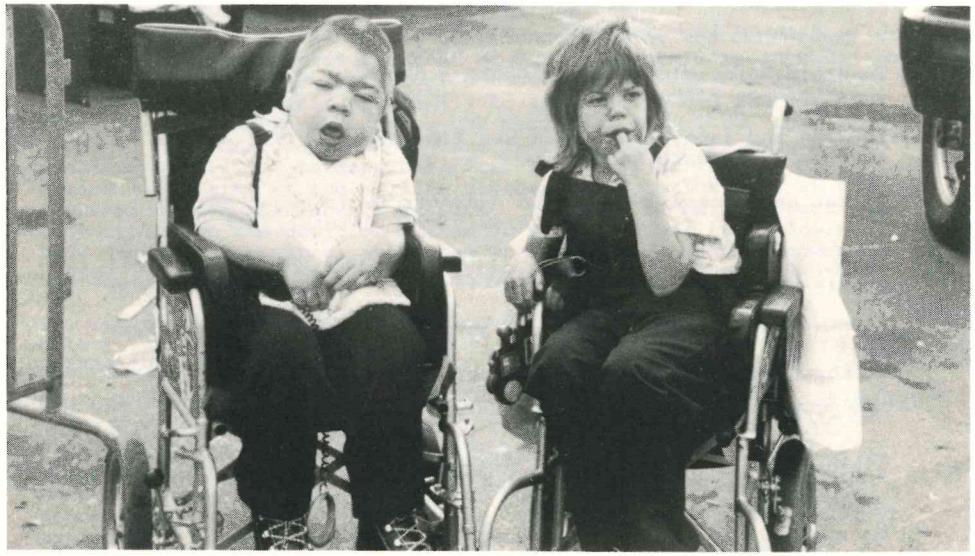
To bring about more public awareness of MPS

To promote and support research into MPS

The Society operates a network of Area Families throughout the UK and Northern Ireland who offer support and links to families in their areas. It provides an information service for families and professionals. At the present time it funds a Consultant Paediatric Post at the Manchester Children's Hospital. It maintains links with sister societies in Europe, North America, South Africa, Australia, New Zealand and Japan.

In most cases there is at present little treatment for MPS diseases but much can be done to improve the care of sufferers. The slogan of the Society is:

"Care Today, Hope Tomorrow"



Colin Snack and Kristina Briggs at Battersea Fun Fair.

NEW FAMILIES

Mr and Mrs Stewart, from Dunoon, Argyll, whose son **David** died aged sixteen years from Hunter Disease.

Mr and Mrs Djialli, from Cardiff, whose sons **Nicholas** and **Marcus** have been diagnosed as suffering from Sanfilippo D, also **Mr and Mrs Evans**, foster parents of Nicholas.

Maria Barnfield and Mark Cook, parents of **Sasha Barnfield**, from Wootton Under Edge, Gloucester. Sasha is four years old and has been diagnosed as suffering from Sanfilippo disease.

Kathy and John Lawrie, from Witham, Essex, whose son **Stuart** has recently been diagnosed as suffering from Sanfillipo disease.

Carol and Ronnie Jones, from Felling, Tyne and Wear, whose four year old son has been diagnosed as suffering from Morquio disease.

Mr and Mrs Stennings, from Pinner, whose son **James**, born in February 1990, has been diagnosed as suffering from Hurler disease.

Mr and Mrs Cooke, from Barnsley, South Yorkshire, whose son **Geoffrey** has been diagnosed as suffering from Hunter disease.

Mr and Mrs Reid,from Dunoon, Argylshire, whose son **Alistair** has been diagnosed as suffering from Hurler Disease.

Mrs Jennifer Mallaney from Dunoon, whose daughter **Andrea** died at the age of four from Hurler disease.

BIRTHS

Congratulations to **John and Julie Burlinson**, on the birth of **Lisa Sian** on 18th September, a sister to **Billy.**

To Maria Barnfield and Mark Cook, a daughter **Jodie Elizabeth**, a sister for **Sasha.**

To John and Kathie Lawrie, a son **Timothy**, born 9th August, a brother for **Stuart and David.**

To Pat and Rosemary Dawson, a daughter **Lucia**, who sadly has been diagnosed as suffering from Hurler disease like her brother **Michael**, who died in 1986.

DEATHS

Matthew Hodges died on the 23rd of July 1990 aged thirteen years. Matthew suffered from Hunter disease. Our thoughts are with his family at this sad time.

Sally Ann Bradford, who suffered from Sanfilippo disease, died, aged twenty five years, on the 25th of August 1990. Our thoughts are with her family at this sad time.

GOOD NEWS

August and September were destined to be busy and exciting months in the 1990 MPS calendar. After over two years of planning, checking, double checking and worry the "International Symposium on Mucopolysaccharidoses and Related Diseases" was upon us. MPS families from all over the world were converging on Britain. Committee Members were endeavouring to combine last minute conference tasks with visits to Windsor Castle and Buckingham Palace and the daily chores of washing and ironing in preparation for our stay in Manchester.

As if this wasn't sufficient 10 days before the Conference we received confirmation from John Hopwood, of Adelaide Children's Hospital in Australia that we could announce that he had after 10 long years found the site of the Hunter gene on the X chromosome and had developed the DNA probe. Exciting news indeed made all the more exciting as two British boys, Robert Culley of Bristol and Christopher Shorthouse of West Midlands had played an important role in this discovery. Both Christopher and Robert have a complete deletion (piece missing) of the X chromosome and this confirmed previous thoughts on the precise site of the Hunter gene.

Dubious of what the tabloid press would make of such a story I invited a larger and trusted journalist, Ann Lloyd. for the "Independent" to write an article. The Society is grateful to the Culley and Shorthouse families for giving the story a human touch and to Dr Ed Wraith and Dr John Hopwood for their professional input allowing Ann to write a sensitive and accurate story which was duly published on the medical page of the Independent for Tuesday 28 August, along with a small piece in the News Section. A press release was then sent to other agencies and a press conference scheduled for Thursday 30 August at the Britannia Hotel. By this time Dr Hopwood had arrived in Manchester and interviews with the BBC World Service and local radio were arranged.

As those of you who were present know the International Conference was a tremendous success and it was decided that a 3rd International Conference organised on similar lines to Manchester will take place in Mainz, West Germany in 1993. More about this in future Newsletters.

Back in the MPS Office, Little Chalfont following the Conference it was hard to imagine that the rest of September could be anything but back to work as usual. This couldn't be further from the truth. Mr and Mrs Nowell a relatively new family to the Society had suggested we write to Mr Mcgreevy describing the Society's activities and financial needs. A telephone call one evening in early September resulted in a donation of £10,000 to meet the first year cost of the new post of Senior Biochemist at the Willink Biochemical Genetics Unit at the Royal Manchester Children's Hospital. The post is being advertised this month and the position filled in early January 1991. One of the main tasks of the person appointed will be using Dr John Hopwood's Hunter probes to study families with a history of Hunter Syndrome.

The Society is committed to funding 60% of the salary of the post holder for 3 years when it will be absorbed into the Salford Health Authority Budget.

Our second piece of good new has been in the pipeline for some months. The Society subscribes to Smee and Ford who then supply us with details of legacies and wills published. For the last two years at a cost of less than £300, Linda Golding in the MPS office has been responding where appropriate in the hope that the Society might benefit. Some of the sceptics among us wondered if our small charity ever would. Back in July we were notified that the Society were on a short list to benefit from the estate of the late Mrs Evlyn Annie Page, from Worthing, West Sussex whose bequest was that the residue of

her estate be used for the investigation of Incurable Diseases. Certain checks had to be made with regard to our charitable status and we have just heard that MPS is to to receive approximately £20,000 for clinical or biochemical research into the Mucopolysaccharidoses and Related diseases. Good news indeed provoking food for thought on how best it might be used.

As by the time you receive this Newsletter Christmas will be only just around the corner may I wish you seasonal greetings from Robin and I and the children, Andrew, Benjamin and Lucy.

Christine Lavery
Hon. Director

Dear Christine and Robin,

I am happy to say that our return flight to Poland was very pleasant and we arrived home safely. Kamila went through the journey easily.

We are very impressed by England, because there are many differences between our countries. We have sore throats from telling our friends about our visit and about you and your family. We would like to give our warmest thanks in your next newsletter to the British MPS Society , to all the organisers, to the sponsors who made it possible for us to be there and to all the friends we got to know in England, and especially to your family. We like you very much and I do hope we are friends. Thank you for making our stay enjoyable and interesting and for your kindness and helpfullness to the Polish family you didn't know before.

We should be only too pleased if we could do anything in return. God bless you all. I do hope we will be able to meet some of you again, in Poland or some other country.

I am back at work and Joanna is looking after Kamila. She is well and a good girl now, though we live in a very dusty habitat and it is easy to get an infection. Magdalena has started school and she wants to learn English as she liked the visit so much!

At present I am very busy getting ready for a meeting of our management committee. I will write more in my next letter. Please give your children a hug and a kiss from us. Please write to us.

Best wishes,

Marek, Joanna, Kamila and Magda Popek
Oskochanowskiego 4131
43 - 190 Mikolow, Poland

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THE INTERNATIONAL SYMPOSIUM - WHO BENEFITS?
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So the Society organised an International Symposium attended by doctors and researchers from around the world. It took an enormous amount of organising and cost a great deal of money. As you stand in the rain selling your Christmas raffle tickets, you may well ask "What benefits have come out of it, or are likely to come out of it?"

It is not, apparently, the custom to write up the talks given in such gatherings, for the good reason that if researchers have something to publish they like to do it in their own time in the recognised journals. So, although you will be getting a conference report (eventually), it will not have an account of the professional talks. So you will have very little to go on to assess the benefits of getting the gurus together.

However the Society is convinced that there are great benefits from getting professionals together, particularly in combination with the parent's conference.

At a very basic level many people who lead the world in their own area of work do not have an overall knowledge of MPS conditions, how they affect sufferers and what is the difference between the conditions.

A big motivation for medical pioneers is in developing new treatments. Sometimes they will want to try out treatments to find out whether they do any good or not. It may be very difficult for them to see and hear about the effects on families of high risk treatment. If the children and families are there other professionals in the field can be helped to get the balance right between experimentation and patient care.

A very hot topic debated among the professionals concerned the pros and cons of bone marrow transplant. At present different doctors give very conflicting advice to parents about this choice of treatment. If the conference moved the medical profession forward towards a common view on this treatment then this alone would make it worthwhile.

One very obvious reason for getting researchers together is to stimulate their interest in the conditions, by helping them to meet the children and adult sufferers. Normally their only contact will be through samples in a laboratory. Meeting the children will stir their human interest and compassion and recharge their batteries to put greater effort into MPS work.

Because they have personal contact and they see the interest that is being taken in their work they are more likely to give priority to MPS research. There are lots of other problems competing for their attention and if they don't get feedback they may well move on to something else.

Creating personal links between researchers from different parts of the world encourages them to share and collaborate, rather than to work in isolation. Sometimes links will be created that lead to an exciting breakthrough. At the conference in Minneapolis an MPS committee member asked Dr Ed Wraith to introduce her to Dr John Hopwood, from Adelaide, Australia, who had been working on isolating MPS genes for ten years. This conversation led to Drs Wraith and Hopwood agreeing to collaborate, and among the samples sent to Adelaide were some from Christopher Shorthouse and Robert

Culley, which turned out to be completely missing in the gene for iduronate sulphate sulphatase. This enabled Dr Hopwood to prove with certainty that he had isolated the right gene for Hunter disease.

The excitement of international collaboration and the sharing of samples and information creates a momentum which can speed up progress in research.Progress towards identification of carriers may be something that got a boost from the Manchester meeting.

Issues about "Care Today" also benefit. Specialists from Brazil, India, and Italy went away from Manchester intending to work on setting up MPS support groups in their countries.

Readers of the novelist David Lodge may well be sceptical about the image of free loading professionals jet setting round the world to attend International conferences. That image did not fit with the people who came to Manchester. The organisers are confident that investing in professionals in this way pays off both in day to day decisions about the treatment and management of sufferers now, and in making progress, however slow, towards hope for the future.

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Dear Mary and Charles

This is to ask you to thank the organisers for their warm reception and support during the MPS conference, and to congratulate you on a successful conference. For those of you on the organising committee this conference must have taken hours of work from which many of us have gained. I am very grateful to have had the opportunity to have met so many people with knowledge of Morquio disease. I especially appreciate your sharing your experiences and thoughts with me.

Gayle and I will be attending the US conference in Orlando in December. I hope to bring them to the International Conferences in Minneapolis and in Mainz too.

Enclosed is a photo of us with Ian taken this summer, just before his operation.

Regards,

Steve Smith

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THROUGH THE EYES OF A VOLUNTEER

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This was the first time Ken and I and Tracey Dobkin volunteered to help at an MPS conference, and to be honest, we did not really know what was involved. Our friend Bernice Task asked us if we were able to assist as she herself would be there with her nephew David Oulton and his sister Sarah.

We found this to be an extremely well organised event - even the rain which stopped the trip to Lyme Park coulden't the enthusiasm of the organisers who found alternative activities for volunteers and children on the campus.

The feeling which I personally came away with was primarily sadness at the plight of these children, but this did not last long when I thought of the immense love given to each of them by not only their own parents but other parents who obviously were able to relate in a wonderful way to everyone of these children.

This caring attitude of all the people involved in the MPS conference - and I must include the catering staff and the volunteers - can only be to the advantage of MPS sufferers in the future, when hopefully research will be able to alleviate the plight of these special children.

My husband and I are looking forward to helping again next year, hopefully for the whole weekend, when we would enjoy getting more involved with one particular family.

We are going to a 'Hot-Pot' supper in Liverpool during October in aid of funds for MPS and have started selling raffle tickets for the Christmas draw, so you see what an impression the children have made on us.

Betty Shackman

William Holroyd and friends at the Conference.

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THE CHILDRENS OUTINGS

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On Saturday we set off on a two hour coach journey to Alton Towers. Me and Sarah, my helper, went off and started looking round. Then at twelve o'clock we had lunch at the marquee. After that we went off on a cable car over the gardens and the Corkscrew to a different part of the theme park. Over there we looked around and then saw a fountain show, which was lots of different fountains playing to music. Then we went back to the cable car and went on the swan ride. After that we followed Henry's parade and went on the teacup ride. Then we went back to UMIST.

On Sunday we went off to Chester Zoo. Me and Sarah went around with Sarah's family. Sarah's mum had two small children so we hired two buggies. Before lunch we saw the elephants which stood up on the wall. Somebody nearly shook hands with its trunk but couldn't quite reach. Then we saw the monkeys which were really cute. After that we had lunch. Then we went into the aquarium and the nocturnal house. Then we had an ice-cream and looked in the shops and went home.

On Monday morning we were supposed to go to Lyme Park but it was pouring with rain so we stayed at UMIST and watched films. Then we played rounders for the rest of the morning.

Helen O'Toole

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Sunday outing from the UMIST conference to Chester Zoo
The sun shone for children and volunteers

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IAN MAGUIRE

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Ian was born on the 24th of August 1969. His birth was normal, although his haemoglobin was very low. He was slow in talking and in becoming toilet trained and in learning. When he was about four years he was refused normal education and was sent to an ESN school. He was extremely hyperactive, uncontrollable and anti-social. He was considered to be a very "naughty" boy. It was recommended that he be sent to boarding school so that he would be disciplined correctly!

He did go to boarding school. When he came home again about five months later he was completely wild and had lost sensible speech. He was doubly incontinent and his behaviour was agressive. He was even more hyperactive and he laughed incessantly. He broke windows and threw things - total disruptiveness. At this stage he was referred back to the psychologist who had monitored him for five years, to find an explanation for all this.
Ian was admitted to hospital but after two hours there was a request to remove him as he pushed beds down the ward with the brakes on. He had smashed the toy cupboard and some lockers and had thrown every book out of the window. They had to engage two extra nurses to look after him!

There was no chance I would take him home at that point. I had had enough. This "naughty" boy was not coming home until they proved he had a normal brain.

After four weeks of tests, eg, lumbar puncture (after twenty five minutes Ian was riding a bicycle up and down the ward!) The last test was an EEG where a bubble of air is inserted into the spine which is then x-rayed for defects. Ian was in theatre all afternoon and at 7.30pm we had a phone call to say that he had been transferred to a life support machine in intensive care and could not be revived. We were counselled by the anaesthetist and the doctor about the possibility of brain damage due to lack of oxygen to the brain. We had to return home at 12.30am to our two daughters and rang up at 6.00am to enquire about Ian's condition.

"IAN MAGUIRE SAT UP AT 3.00am, pulled out all the tubes and ran down the ward shouting "Where's my breakfast!"

On the fifth week he was pronounced fit and healthy and we were advised to take him home. We could not envisage the turmoil and problems ahead. There was no backup system or help available then. Instead of coming home Ian was admitted to a locked ward in a mental hospital where he lived for seven years. We were able to visit every day between six and eight in the evening. His time there was too horrendous to describe. We requested further tests at the age of ten and a half and we were told these too were negative as to diagnosing his condition. It took years of hard work by his social worker to arrange for a transfer to a suitable unit in Preston called Beech Tree, run by the Spastics society. The unit's aim was to give Ian the opportunity to regain skills he once had. Most of his peers were cases of self inflicted injury and had behavioural and social problems. There were visitors of all nationalities interested in the treatment and in the success of this venture.

A Canadian came one day and asked about Ian's history. Had he been tested for MPS? Yes, at seven and a half, he was told from the records. He persuaded the unit to re-test and the outcome was that Ian was diagnosed at the age of sixteen years as suffering from Sanfilippo 'C'.

The unit could not continue Ian's programme of intensive training and he was referred to Dr Barnardo's in Yorkshire. We went to see his new home in trepidation. It was a large mansion which was the ideal home to offer Ian long term care. We visit every weekend and cannot express enough our pleasure and gratitude to the staff (each and everyone) for Ian's overall happiness and well being over the past three years. We do feel that once diagnosis has been confirmed it is essential that the right environment is found for Sanfilippo sufferers, so that space, safety, stimulation and maintainance of skills is achieved.

Sylvia and Les Maguire
11A Irby Rd
Liverpool 4
Merseyside L4 7XA

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Robert Culley and Christopher Shorthouse with Dr John Hopwood
A winning combination to find the Hunter gene.
(see facing page)

A discovery that came too late

TWO British boys suffering from Hunter's disease, a rare metabolic disorder which usually kills children before they reach their teens, have been instrumental in the discovery of a gene defect which causes their condition.

This means it should be possible to treat children with the disease, according to Dr John Hopwood, Head of the Lysosomal Diseases Research Unit at the Adelaide Children's Hospital, Australia.

While he describes the discovery as "a real milestone", he is careful to emphasise that it will be four or five years before it is possible to help sufferers by injecting them with the gene they either lack or possess in a damaged form.

A lot of work has yet to be done to find the safest and most effective way of introducing the gene into the patient. The earlier it is done the better it will be for children because, as far as it is known, damage already caused is unlikely to be reversed.

'We were happy for the parents and the children who will benefit in the future'

The official announcement of the breakthrough will be made at an international symposium of mucopolysaccharide (MPS) diseases for professionals and families, which will be held in Manchester this weekend. For two of the families at the conference, the development is not news. The Culleys, from Bristol, and the Shorthouses, from the West Midlands, have known of it for some time. It was their sons who played a crucial role in the discovery.

But for 11-year-old Robert Culley and eight-year-old Christopher Shorthouse, the breakthrough has come too late for them to benefit. Andrew and Vivienne Culley's feelings are understandably mixed. "We were happy for the parents and the children who will benefit in the future," says Mrs Culley, "but there was sadness, because it's too late for Robert."

Mr Culley adds: "We're glad though that Robert has been able to help other people. Everybody feels they want to make a contribution to the common good of humanity. It's nice to know that Robert has achieved that."

Hunter's disease takes its name from the doctor who first described the condition. Mucopolysaccharides are long chains of sugar molecules used in the building of connective tissue in the body. The body continuously replaces used materials and breaks them down for disposal. Children with Hunter's disease are missing an enzyme called iduronate sulphate sulphatase which is essential in cutting up the two mucopolysaccharides, dermatan and heparan sulphate, when they have been used.

When the gene responsible for producing this enzyme, the one which was isolated by Dr Hopwood, is either missing completely, as in the cases of Robert and Christopher, or is defective, the disease occurs.

The symptoms occur because the mucopolysaccharides remain stored in cells, causing progressive damage as the waste cellular tissue builds up in the body.

Babies may show no sign of the disease, but as more and more cells become damaged symptoms start to appear. Some sufferers may be only mildly affected, but for many there is progressive mental and physical handicap, leading to death in childhood.

Children with Hunter's disease may learn to walk and to say a few words. They may achieve daytime and even night-time continence, but from around two to two-and-a-half years old, deterioration begins and they regress towards

babyhood. They lose their ability to walk, speak and digest whole foods. They have difficulty swallowing and are at risk of choking. They have severe breathing difficulties and great internal discomfort as the heart, lungs, stomach and intestines are gradually squeezed because of abnormal tissue build up. As babies, the children tend to cry a lot then, as toddlers, they are hyperactive. However, this phase fades gradually until the final stage in which the children are placid.

It was when Robert was three – and in his "extremely" hyperactive stage – that Mrs Culley wrote to the Mencap magazine, *Patients' Voice*, hoping to get in touch with other parents of children with a mucopolysaccharide disease.

Her letter appeared in the same issue as one from Mrs Christine Lavery whose son Simon had recently died, aged seven, from Hunter's disease. Mrs Lavery's letter announced her intention of setting up a support group for parents of MPS chidren.

The group was called the Society for Mucopolysaccharide Diseases and Mr and Mrs Culley joined straight away. At present there are 517 member-families. The society estimates there are at any given time about 400 MPS sufferers in the UK, of which around 70 will suffer from Hunter's disease.

'Christopher and Robert provided the proof that we had isolated the right gene'

It was at the MPS society's annual conference in 1988 that the Culleys and the Shorthouses, along with the other families, were asked for blood samples for research from their children.

Mr Culley smiles. "We're always being asked for something – usually it's a urine sample, sometimes a tiny skin sample. We always say yes because we hope it might help. This time it was blood that was wanted, but to us it wasn't any different from the other requests for samples. We didn't know that this was going to be it, as it were."

"Robert was very good," recalls Mrs Culley, "in fact while the nurse was taking the blood – not an easy job because Hunter's disease children tend to have thickened skin and the veins are hard to find – he actually fell asleep."

The blood samples were processed by consulant paediatrician, Dr Ed Wraith, and his team at the Willink Biochemical Genetics Unit at the Royal Manchester Children's Hospital, the major clinical and diagnostic centre for metabolic diseases in the north of England.

The Willink team extracted the deoxyribonucleic acid (DNA) from the blood samples provided by the society and from others provided by their own patients, and sent them to Dr Hopwood, who has been working on isolating MPS genes for 10 years.

What the analysis showed was that both Robert and Christopher had a complete deletion of the gene Dr Hopwood was targeting as the "Hunter gene": everything else was fine, but that gene was missing.

"In order to prove we had isolated the right gene, we had to demonstrate that a patient with the clinical condition had total deletion of that particular candidate gene. Until you have that you can't really call it the Hunter gene," Dr Hopwood says. "This was what we found with Christopher and Robert. They provided our final proof."

For further information, contact the MPS Society, 30 Westwood Drive, Little Chalfont, Buckinghamshire.

Why only boys are sufferers

IN Hunter's disease the gene responsible is on the X-chromosome, which is inherited from a mother who is a carrier. Only boys develop symptoms while girls carry the disease. Invariably women will not know they are carriers until they have an affected child.

Girls inherit two X-chromosomes, one from each of their parents, while boys get one X-chromosome from their mother and one Y-chromosome from their father. This means that when the mother is a carrier there is a 50-50 chance of a girl being born a carrier and a boy being born with the disease.

At present, parents who already have an affected child and wish to have more children can arrange for prenatal diagnosis to discover, through an enzyme test, whether a foetus is affected and have the option of terminating the pregnancy.

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DEPARTMENT OF PEDIATRICS
Director : prof. T. ORII

September 28, 1990

Mr. Charles O'Toole
8 Elmhurst Ave
London N2 OLT

Dear Mr. O'Toole:

Thank you very much for your kind hospitality during the 2nd international meeting on the mucopolysaccharidosis and related diseases dated August 30 - September 3. All of the information about the active MPS society and advanced progress on MPS was very beneficial to us.

At that meeting I talked with some members of your society, and I promised to write a letter to introduce the Japanese MPS society to them. Although I myself am a pediatrician and a biochemist working at Gifu University School of Medicine which functions as a center for MPS in Japan, I'm also one of the members of the Japanese MPS society.

Firstly, let me explain that the Japanese MPS society is a convenient name which I have used following the British MPS society. Japanese name is ムコ多糖代謝異常症患者および親の会 (Muko tatō taisha ijō shō kanja oyobi oya no kai). There isn't a formal English-translated name yet. If I try to translated it into English faithfully, it's MPS patients and parents society.

The Japanese MPS society started in June 1986 as a small group. The society sent the first newsletter to 8 families involved with MPS children in June 1987. The first meeting was held in May 1988 in Gifu city where 6 families and a few professionals gathered. After that, the newsletter was printed and sent yearly and the annual meeting, which promotes the communication among the families and the professionals, was held in Gifu city. This year's meeting was held on July 27 - 28 and nearly 30 families attended. The present society consists of 44 families and some professionals. The aims of the Japanese MPS society are:

1. moral support to the families,
2. investigation into the actual circumstances of MPS patients,
3. increase of the member of the society,
4. co-operation with research institutes,
5. education of professionals and the public.

The symbolic mark of the Japanese MPS society was designed by Kōichi Asakusa, the president of the society, in August 1988. The silhouette is of a characteristic MPS patient. S/he is looking at the sky, and on the chest there is a symbol of life, a heart. S/he is gazing with much hope.

Although the Japanese MPS society is now a small group, each member is very active and ambitious to expand and enhance the society. In the near future we hope to be able to communicate internationally.

sincerely yours,

Toshiya Sasaki

Toshiya Sasaki

The symbolic mark of the Japanese MPS society

Meeting of the
Japanese MPS Society
Gifu city - July 1990
'Gazing with much hope'

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RICHARD : LIFE AFTER BONE MARROW TRANSPLANT

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Monday 3rd of September saw the final day of the MPS International Symposium at UMIST. The lectures on this last morning were of particular interest to me because they were about bone marrow transplantation in the MPS child. The speakers were from Minneapolis, where many of the American transplants have been done, and from the Westminster Children's Hospital, London, which has pioneered transplants for MPS children in the UK.

As I left the lecture theatre deep in thought and with plenty of food for it, Charles very unexpectedly approached me and asked if I would like to write an article for the Autumn newsletter. I was pleased to do this and felt the privelege was mine.

My son Richard is almost nine years old and at the age of fifteen months was diagnosed at Pendlebury Children's Hospital, Manchester, as having Hunter syndrome, the severe type. Further tests confirmed that our ten year old daughter Claire, our only other child was an 100|| match donor. My husband urged the team at the Westminster to consider Richard. Despite his severe hydrocephalus and obvious mental retardation, Richard received his bone marrow transplantation on 7/5/83 at the age of twenty months.

We were in the hospital for a total of eight weeks and the transplant, we thought, was the perfect setting for a success story. Richard suffered no 'Graft versus Host' disease problems, there were no infections, not even a raised temperature. I will never forget my little boy's tolerance and unfailing patience during the bombardment of drugs into his body. He was so very ill, but I can't remember him ever crying.

The decision at that time was I feel the right one, Claire being a perfect match - we didn't really have a choice - we had to give him a chance. With hindsight now I know that the decision was very wrong.

I will firstly summarize the improvements which were made. Within six months Richard's hepatosplenomegaly was gone, he became stronger physically and he began to acquire certain skills which he had never had before. He learned to drink independently, he learned how to walk and he became a bit more aware of life around him. Sadly though, seven years later, we have not in any great way moved on from this level of progress and the problems I live with far outweigh the improvements.

As far back as I can remember all Richards "Ruth Griffiths" tests have indicated exactly the same level of IQ. I suspected it through the years but certainly know it now that mentally Richard is not making progress. This is because, as medically confirmed, the graft does not cross the blood brain barrier. This is apparently chiefly the case in Hunter children. The Hurler children seem to have a better success rate in this respect.

We had, therefore, to accept the fact that Richard would not make any great progress. He continues to be doubly incontinent. There never was and still is no meaningful language, only screaming, shouting and some garbled babbling. As he is getting older his behaviour is becoming a big problem. He displays aggression, he can be disruptive, he is noisy and he can be hard to get through to. He also has dramatic mood swings. This behaviour goes on all the time, as anyone who met him at the Symposium will tell you.

Three years ago saw the end of my fifteen year marriage. Richard's father could no longer cope with our life with Richard. We were beset with many personal problems related to stress and strain and Ronnie left us. My whole way of life as I had known it was ripped wide open and I have had to very slowly and with a lot of strength, faith and hard work rebuild my life.

I have continued to care for Richard as a single parent. Although I love my son very much, honesty must prevail. My life is very isolated, lonely, stressful, and sheer hard work. I am still faced with residual problems and some ongoing deterioration with Richard's health, the main ones being ENT problems and hernia repairs.

The conference revealed that, quite likely, the new enzyme from Claire may not be able to penetrate through the cartilage to the bone structure. Richard therefore may suffer skeletal problems in the future. This was, I must admit the biggest shock at UMIST, although I knew from his orthopaedic consultant that his kyphosis - spinal curve - is still malformed. Richard is also due to have his hands examined by Dr. Ed Wraith for carpal tunnel syndrome.

Charles asked me, as do many people on my travels through life..."How do you cope?" My reply is always the same..."I really don't know!" I suppose God is good and he is supplying me on a daily basis sufficient strength and faith to cope single handedly. WHEN I get the time to sit with my thoughts, I do get fearful about the future because we are actually walking a very lonely road. Nobody can predict the future, nobody can answer my questions about my son. It is like slipping more and more into no-mans-land!

Richard is one of the two surviving Hunters in Britain with a transplant. The other little boy is Ross Lockyer. Tony, Mary and Sally are very close to my heart as they have the same story to tell about their life with Ross. Their donor match was so very different from Richard's; it was not as good. So really it seems to make no difference how good the match is. In my opinion Hunter boys are unsuitable for transplant.

My only hope for the future is that no more families, Hunters in particular, (as this syndrome is closest to my heart) suffer prolonged misery as a result of bone marrow transplant in the way that I am suffering.

May God bless all our families and children.

Val Turner
50 Kingsmead Rd, Fallowfield,
Manchester M14 6RX, Ph 061 256 2641

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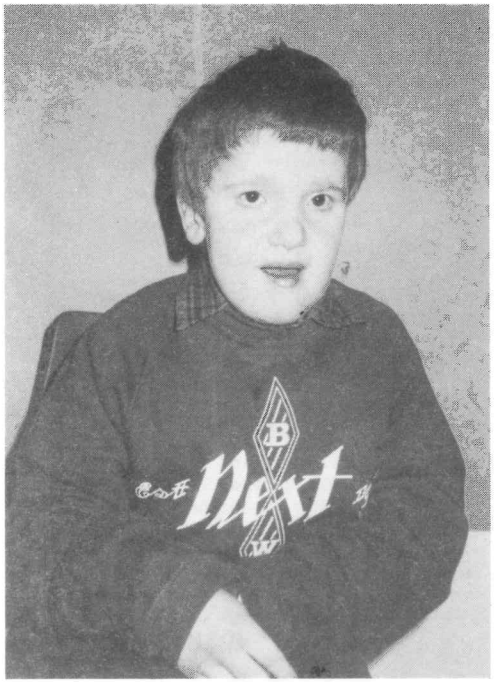
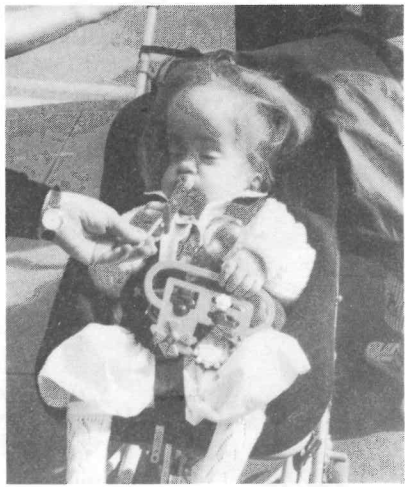
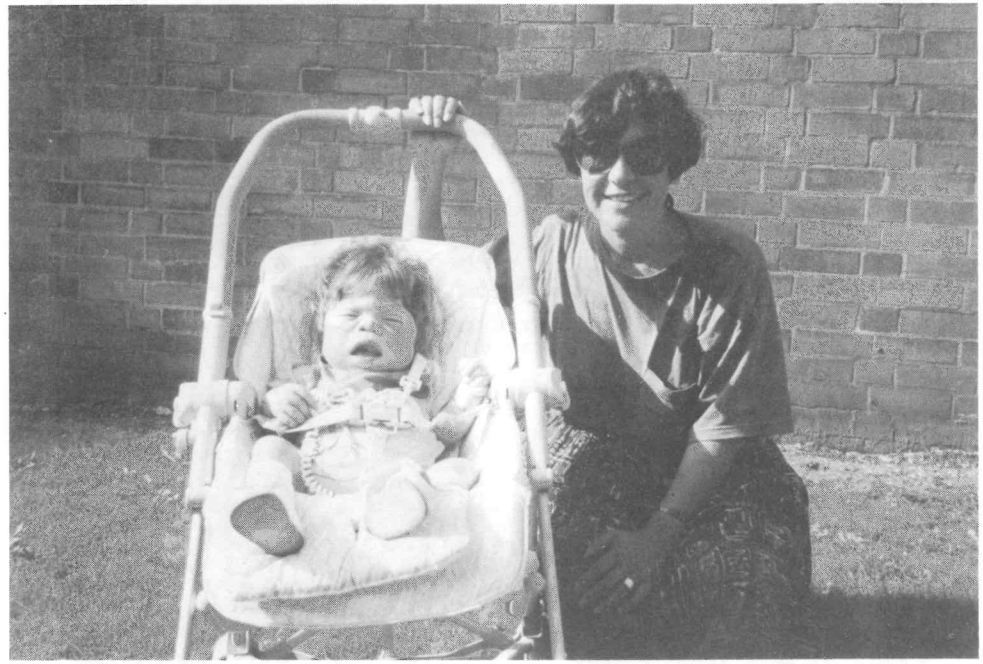


Richard Turner
Age Nine
(Hunter - transplanted)

Leanne Woods
Age Five (Hurler)





Timothy Bryans, age 5 (ML11) with Volunteer **Christine Edwards** at the UMIST conference.

MPS Summer Holiday
Primrose Valley 1990

Are we ready or what!

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AND THEN THERE WAS HARRY
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And then there was Harry, he was lovely, everything we had longed for to make our marriage complete. Having got an older son by a previous marriage both John and I wanted a child of our own.

After a traumatic birth Harry had to spent two weeks in a special care baby unit. After which time, when we were finally allowed to take him home, we were overjoyed, we thought the worst was over and that now everything was going to be allright. How wrong we were. When he was six weeks old he started with a continuous cold, or so we thought at the time! After so many trips to the doctors my doctor suggested we should go to see an ear nose and throat specialist. Harry was then admitted to a local hospital for routine tests - that's when it all started.

They took urine samples, asked a lot of strange questions, and then someone came to take photographs of his hands, face and spine. When I asked the doctor why all this was being done that's when we got the first bombshell. The doctor told me she thought he was suffering from a serious disease, but it was so rare she was hoping she was wrong. We weren't told any more at this point. Tests were sent away and we were told it would be six weeks before we would get the results. But we didn't have to wait that long. After three weeks we were asked to go to the hospital to see the doctor.

As we sat outside the doctor's office I knew the news was not going to be good - I was right. It was the worst day of our lives. We were told that our son was suffering from a rare genetic disease called Mucopolysaccharidosis. They said it was a storage disease, that Harry was missing an enzyme, and eventually he would become mentally retarded and possibly physically handicapped. They said he would be hard to handle and that his behaviour was likely to become socially unacceptable. The whole family was traumatised. We all felt so helpless.

The disease is terminal and there is no cure. MPS is so rare, not many people have heard of it, so this makes it more difficult to live with. We joined the MPS support group and found a lot of comfort from their help. I wanted to do something for my son as well as help the Society and the only thing I could think of was the song "Harry", by Catherine Howe. Harry was named after that song. I kept hearing it when I was pregnant and the words were so lovely - now they mean even more.

If MPS were more widely known about then maybe more could be done in terms of research and finding a cure for this cruel disease that robs our children of their lives.

When you have a terminally ill child, it doesn't mean you can't have dreams - they are just different dreams. I would like to change the MPS slogan from "Care Today, Hope Tomorrow", to "Care Today, Cure Tomorrow".

I wrote this letter to Catherine Howe, who wrote and first recorded "Harry's song", and sent her a copy of my tape.

She loved it and was moved by what I was trying to do and told her boss, Mr Kip Trevor of Carlin Music Publishers. I was invited down to see him in London last February. He loved my version also and said there and then that they would get a thousand records pressed so we could approach radio stations. All of the work has been done for free, from recording the song to getting the record cut and pressed. We had a video and a poster made as well.

With all our love,

Martine Brennan
7 Alexandra Rd
Skirton, Lancaster.

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Irene, Harry Brennan and **Colin Snack** with **Mary Gardiner** at the **MPS** Summer Holiday.

Richard Volk with twins Hendrick and Emily (Sanfilippo) with Eamon, Mary and Elena Mc Gauran (Morquio) at UMIST

Dear Christine,

Nigel and I are at last coming to terms with Michaela's disease and would like you to print our story in the Newsletter.

Michaela was born in July 1982, she was a normal healthy baby girl weighing 6Ib 8ozs. She developed as a normal child would.

When Michaela was 2 years old her dad died. I was then left on my own to bring up Michaela. My mum was very good and I went to live with her and my stepfather. I have a brother who is mentally handicapped, he was born like this because the oxygen wasn't getting to his brain after birth. He nearly died at birth, so believe me I know what it is like to look after a handicapped child.

We were brought up by my dad a big supportive family. My mum was one of 14! So imagine the support we had from my Aunts.

I met Nigel when Michaela was 3 years old. He had a daughter Kerry of his own and the girls got on really well. Everything was fine. After 3 years of being together Nigel and I planned another baby. With not having one that was "ours" we were delighted when baby Nigel came along on 30 August 1987. The girls love him.

Then finally on January 9th 1988 we were married. This was the happiest day of my life.

Michaela started school at 4 years old. She could not write her name and didn't make any progress in the first year at school. She was seen by the psychologist and transferred to the London School for children with slight learning problems.

At about this time Dr Nanarakka and Dr Foster, the school doctor suggested some tests. First it was good news then further investigations showed Sanfilippo disease.

We were shocked, we had never heard of it in our lives. That's when we wrote to you. I know I will have to tell her sister, and brother soon, but how do you make a 3 year old understand? Kerry is 7 years old and very grown up for her age. She knows Michaela is different but she is very good and sits with Michaela trying to teach her to count, read and write.

I would like to say to anyone who is going through what we did a year ago. Don't give up hope, they might find a cure before it is too late.

Yours sincerely
Tracey Raven

Michaela Raven age 5 (Sanfilippo) with Kerry,4 and Nigil, two weeks.

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TRIALS AND TRIBULATIONS OF A DRAW CO-ORDINATOR

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Dec 1st to Jan 2nd	Collect addresses of anyone who might donate.
Early Feb	Find out what the Society is doing this year.
Rest of Feb	Compose letters to companies who have donated or who might donate. Go through last years list, discard no hopers, add new possibles.
March	Print out letters and addresses. Go deaf in the process as the printer clatters away for hours. Reprint the letters that Kristina has pulled out of the printer and half eaten. Bribe Monica and our eldest daughter Emma to fold, stuff and stick. Post letters. Arrange surgical removal of tongues from roofs of mouths. (On second thoughts cancel that. Its quieter this way!)
April	Panic at lack of replies. Go to library for more addresses. Repeat the process as for March. Start thinking of suitable top prizes and where to get them.
May	Continue panicking.
June	Panic, but not as much. Still not enough prizes. Collect prizes donated.
July	Beg the treasurer for money to buy the top prizes. Beg, grovel and plead for big discounts. Find out where and when the Christmas Party is. Get a quote from the printers.
August	Get the tickets printed and collect them from the printers. Arrange treatment for backache from carrying too many boxes.
Sept	Fill the car with suitcases, wheelchairs, boxes of tickets, family and other paraphernalia and go to the conference. Have a good time. Distribute tickets to save on postage. Come to an arrangement with Postman Pat about the remainder.
Oct	Send out lists of prizes. Send out more tickets. Put out more flags!
Early Nov	Send out more tickets. Wait.
Late Nov	Beg, con, cajole, arm twist, plead and grovel and collect as many bodies as possible to separate and fold tickets.

X-mas party	Pack prizes, ticket stubs and family into car. Go to the party. Arrange the draw. Get other people to deliver as many prizes as possible so we may have a little comfort on the ride home.
After	Post the last of the prizes. Bank the last of the money. (Resist temptation to fly to South America). Sent details to treasurer. Make peace with family. Have Christmas day off.
Jan 2nd	Start again!

David Briggs

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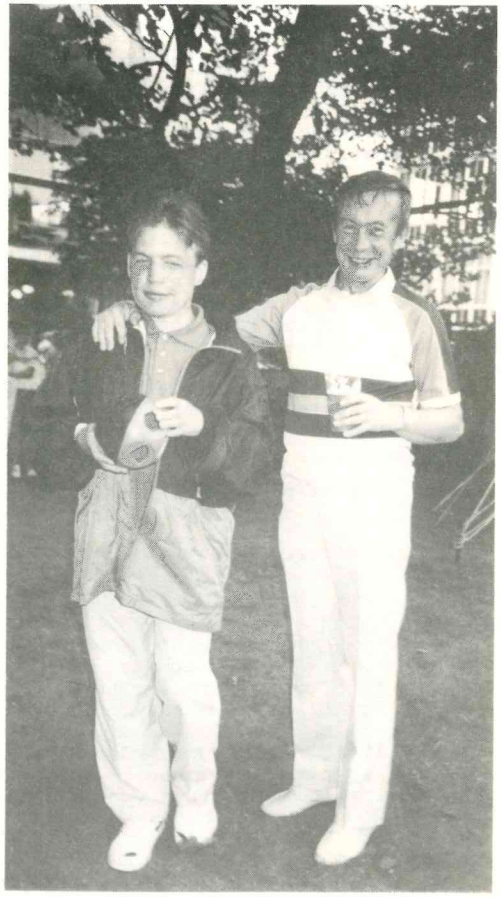

Enjoying the Conference!

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CONFERENCE IMPRESSIONS - By our own correspondent

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Saturday night

Mary Gardiner and Margaret Leask determined to make a night of it. They Shanghai'd a few reluctant men and tottered down into the bowels of the Brittania Hotel to a fearsome hell-hole purporting to be a night club called "Kicks". In this noxious cavity the bodies of tough looking Mancunian persons of several sexes were stacked three deep, marinating in a mixture of sweat, cigarette smoke and inferior alcohol. As Dan and Sue Butler got on down to the dance floor the melee of bodies opened miraculously before them. It was like Moses going through the Red Sea.

I took one look at the wriggling heaving mass, considered that genocide might have a great deal to commend it, but contented myself with creeping off wimpishly to bed.

From the Chandos Tower on Sunday morning the trees and fields on the distant Pennines stood out in the clear air. Down below trains rattled back and forth like Hornbys on the elevated line that ran through the campus into Picadilly station.

No hitches with the coaches. Weather warm and cloudy but bright later on.
As I passed the statue of Archimedes in the bath under the arches, I saw that some wag had put the butt end of a fag in his mouth and an empty beer can by his hand. He looked more like a punter who had just discovered a dead cert for the 3.30 at Kempton Park than a philosopher who had grasped the principle of specific gravity.

We were greatly flattered when one American doctor went on at great length about how pleased he was to be with us in Manchester. It was a disappointment to hear later that he had only just avoided being sent to Saudi Arabia instead.

Dr Reed Pyritz told the UMIST joke - again. (Didn't you hear that one? I sorry UMIST it.)

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KEEP IT ROLLING IN

The fundraising is still going very well, although we are finding it harder and harder to prise money out of Companies we write to. Don't forget that whatever amount you raise, be it five pounds or five hundred, it all helps our Society function.

If there are any new families who would like to become more involved in fundraising then please give me a ring and have a chat. I know that there were quite a few of you who went away from the Conference with very definite ideas about raising money for us.

Thank you all for all the help in raising money over the past year, and let's try to make the next twelve months even better.

(This little piece is in place of a speech at the Conference and believe me it was a lot easier on the nerves)

Ron Snack

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Dear Editor,

I have just received the Summer MPS newsletter which has some excellent articles in it. I particularly enjoyed the American teachers point of view. I read the article about adult sufferers from Sanfilippo with interest.

My daughter Kate (Catherine Mary) suffers from Sanfilippo Syndrome and will be twenty nine in May, so she should qualify as the oldest living sufferer from Sanfilippo. We brought her to the conference at Harrogate and we ourselves attended the two conferences at Heathrow. I am therefore surprised and disapointed that she does not appear on your records.

Unfortunately we are unable to attend the Manchester conference but wish you all every success and look forward to the report in the Autumn newsletter.

I enclose a photograph of Kate taken in July at a tea party held in our garden after our son's wedding. She has just started to use a wheelchair.

Yours sincerely,

Susan Scott
Grove Farm, Hunton, Near Maidstone, Kent ME15 0SE
Ph 06272 369

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Editors Note: The Society does have a record of Kate, and I must apologise that incorrect information was given in the last newsletter.

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Catherine Mary Scott (Kate) age 29 (Sanfilippo)

MPS CHRISTMAS PARTY

Saturday 1st December 1990 - 1pm until 5pm

Perkin Elmer Social Club

Llantrisant, Mid Glamorgan

The party will commence at 1pm, with a buffet lunch, childrens entertainment and a visit from Father Christmas. Our Grand Raffle will also be drawn during the party. We hope as many MPS families/Grandparents etc will join us for what is always a very relaxed and enjoyable occasion.

The charge will be £2.00 per Adult - all children free!

If you have any queries please contact:-

Tony and Mary Lockyer
29 Llanberis Close
Tonteg
Pontypridd
Mid Glamorgan
Tel: 0443 203845

PLEASE LET THE LOCKYER'S KNOW IF YOU ARE COMING SO THEY KNOW HOW MANY TO CATER FOR.

HOW TO GET THERE.

Leave the M4 at **Junction 34** and take A4119 towards Rhonnda.

Go straight on at the traffic lights at the Castell Mynach Pub. At the first roundabout go straight on. At the second roundabout turn right into the Industrial Park.

The Perkin Elmer Social Club is immediately on your left before the Royal Mint.

(NB: Don't anybody dare talk to Mary Lockyer about the hole with the Mint in it. She's very fond of LLantrisant).

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If you should need overnight accomodation there is a hotel opposite called the Black Prince. Approximate prices as follows.

Single room £22. Double £34. Family room £54. All bedrooms have bathroom en suite. Tel: 0443 227723

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Win trolley dash and help poorly children

Win a three minute supermarket trolley dash and help terminally ill children in the process!

The dash — in Asda, Hunts Cross — can be won in a raffle currently being held by the local branch of a society for rare genetic disorders.

Mucopolysaccharide Diseases affect hundreds of children throughout the country.

Most die before they reach adulthood; all of them develop physical and mental disabilities during early childhood, although at birth they appear normal.

At present there is no cure for the range of diseases, which are caused by a genetic fault meaning the body cannot produce certain vital enzymes needed for chemical changes.

The grandparents of a local toddler with one variation of the illness have organised the raffle to raise much-needed funds for the society — funds which will be used for family support, to make the public more aware of the diseases and to aid research into a cure.

More than £300 was recently collected for the fund through a sponsored cycle ride from Liverpool to Blackpool, undertaken by Harry Green of Liverpool 17.

Tickets for the raffle will be on sale in Asda, Hunts Cross, during three weekends in September and October.

The draw takes place on Saturday October 20th during a special fundraising evening at Sefton Cricket Club.

The event, tickets for which are £2.50, includes a hot pot supper and a disco.

Tickets for the evening and for the raffle are available from E J Shiff, 37 Laxton Road, Hunts Cross, Liverpool L25 0PG (tel: 486-2746).

Once again Sid Shiff is coming up trumps with the fundraising. He is organising a "Trolley Dash" around his local ASDA store at Hunts Cross in Liverpool, and by the end of September he had sold over £1700 worth of tickets. The winning ticket will be drawn on 20th October and the "Dash" will take place on 30th October.

If anyone is thinking of doing a similar thing I am sure Sid would be quite willing to give any necessary advice.

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THE GOOD DISABLED LOO GUIDE

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When you go into a disabled loo there is always something wrong with it. Either the loo roll is too high or the alarm button is too far away to reach. What I do is give each loo a score of points out of ten. For everything that is wrong with the loo I take away one point. So, say the loo roll is too high and the taps are stiff then that loo would get eight points out of ten.

It is nice to see that people have gone to the trouble to provide a disabled loo but they don't always get it right. Disabled people come in all shapes and sizes. OK, some things can't be designed to suit a very large person and a very small person, for instance the toilet seat. But if a lot of things were designed for a very small person they would do for a large person as well. The alarm should have a cord that goes almost to the floor, then small people could reach it as well as tall. If the toilet roll is very near the loo then it is easy for both small and big people to get it.

If you are building a disabled loo I am ready to test it for you. The amount of money I will charge is very small.

Helen O'Toole

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RETURN TO PRIMROSE VALLEY

To sit and write about a holiday spent with other MPS families does not come easily when I have never written anything before, but I want to share it with those who were not with us.

We arrived at Primrose Valley to be met by Mary Gardiner who had worked so hard to organise the holiday and the planned events. She gave me the key to our six berth chalet which was well equipped, clean and comfy. This was a good start to the week.

Primrose Valley has everything, shops - including a good chippie, pubs, family bars and plenty for the children. My boys Nathan, aged six and his younger brother Dominic aged two, really enjoyed the fun pools and the adventure playgrounds. Most of the time was spent doing what we as a family wanted to do. The beach was a favourite of Dominic's though Nathan found this boring after a couple of hours and wanted to go swimming every day.

There were some planned events and we choose to take part in them all. There was a barbeque on Sunday with John Brennan doing the cooking. Ron and Linda Snack worked hard keeping him supplied with things to cook. Tuesday brought a a day trip to nearby Flamingo Land Fun Park and Zoo. This was a great day and the enjoyment was highlighted when our group was picked to take part in the Dolphin Show. Wednesday was the parents night out - the children were cared for by trained child minders. My good lady Bernie missed this after getting a touch of sunburn at Flamingo Land. We all had a good night, but Ron and Mary had to stay sober as they were driving the mini-buses. On Friday we had a birthday party which carried on to become a farewell party.

It was the hottest week on record so we could not complain about the weather, in fact we would have been hard pressed to find anything to complain about! Thanks to all for a really good holiday.

Eddie Hall
16 Printers Fold
Hollingsworth, Via Hyde, Cheshire

The following items were handed in found at the International Symposium on the Mucopolysaccharidoses and Related Diseases, 31 August - 3 September 1990.

Small Blue Purse

Mothercare Baby's Bib with picture of Micky Mouse going down a slide on front of bib.

If you recognise either of these items please contact:-

Linda Golding
The MPS Society
7 Chessfield Park
Little Chalfont
Bucks HP6 6RU
Tel: 0494 762789

1990 CHRISTMAS DRAW

First I would like to say a big thank you to all those who sold tickets last year. We made just over £6000.

This year we have again received many good prizes. Companies like Matchbox, P&O, Caithness Crystal, TWA, Singapore Airlines, Tonka, News International, Abbey Life and many others have been generous. Unfortunately we have not yet been able to cover the cost of the tickets and some of the postage. So I would like you to sell as many tickets as possible so that we exceed last year's total. Even if you are able to sell only one book then sell it! All I ask is that you justify the effort that has been put into this event and the generosity of those who have supported it. Once I have distributed the tickets, I can do no more, the rest is up to you.

Merry Christmas and a Happy New Year to all.

David Briggs
Christmas Draw Co-Ordinator
7 Humber St. Retford, Notts.
Ph 0777 700046

CLOTHES FOR POLAND

You may have read in the last newsletter that Marek and Joanna Popek have just formed an MPS Society in Poland. Fiona and I met the Popek family at the conference in Manchester - their daughter Kamila has Sanfilippo disease. There are now approximately twenty five families in the Polish Society.

I'm sure that very few people would consider MPS families in Britain to be lucky, but it does seem that in comparison with most MPS families in Poland this would appear to be the case. Almost all the families are extremely poor, they have no proper health services, no buggies, no nappies, shortage of basic clothing, anoraks, jumpers, tights, shoes, etc.

Fiona and I have started a small venture in Scotland. We are asking all friends and relations to collect good quality second hand children's clothing and shoes, mainly winter goods, and we hope to send off parcels to Poland twice a year. The Society is going to pay for transport, but at the price of 95p per kilo we are going to have to be selective.

Christine has suggested that the next breakthrough in Eastern Europe may be in Romania; perhaps when this happens another family may be able to operate a similar project.

Alan and Fiona Byrne

BANGERS BARBECUED IN BEAUTIFUL BUCKS

The first Sunday of the Summer holidays saw forty people from the Home Counties (North) travel to the umbilicus of the United Kingdom - Milton Keynes - for an MPS barbeque.

Jeff the Chef did a wonderful job with sausages, chicken legs and salad. Linda worked wonders with the kettle and Ron made sure that none of the gateaux went to waste.

The cabaret was first class - Steve made things disappear without the usual props of top hat, wand or even sleeves. He juggled Indian clubs, involved members of the audience and did some incredible things with fire, despite the dry grass and the stiff cross breeze.

It was good to chat with friends, old and new; and once again Ron and Linda came up trumps, doing an excellent job as our area support family. We have to thank them a great deal for all their sustaining strength.

Andy Hardy

MUSIC, PICNICS AND SUNSHINE

What could be better than a picnic in the picturesque grounds of Stowe School, Buckingham, followed by a musical soiree in the Queens Temple? Fifty people spent a lovely sunny evening over cucumber sandwiches and endless bottles of wine before a most enjoyable musical experience in the beautiful hall.

Three talented young men, all ex Stowe boys, entertained us all evening. Stuart Thompson and Nigil Hurley on piano, Jonathan Humbert (voice) played, sang and smiled their way through such diverse numbers as "Patricia the Stripper", the Warsaw Concerto, and for me the highlight of the evening, Michand's "Scaramouche".

£185.00 was taken in a retiring collection. What a marvellous way to raise money. All you need is the right setting, three good musicians and fifty invited guests. Why not try it in your area?

Andy Hardy

IN MEMORY

Many thanks to all those who made donations to the Society in memory of Paul Evans, WH Mullin (Sarah Weedall's great grandfather), Jemma Corbett, Mrs Gregory and Michele Brooks-Daw's grandmother.

GOLF FOR FUN - AND FUNDRAISING

Back in the balmy days of July - do you remember them - Keiran and Bernadette Houston, of Strabane, N.Ireland, organised the MPS Open Charity Golf Tournament in their home town. Would you believe it, in the middle of summer it rained all day, that's English weather for you, or should it be Irish.

Undaunted by this a great time was had by all, even going so far as a play off in the putting competition. As can be seen from the press cutting this was a well organised and well attended event, likely to become an Annual Classic.

Kieran and Bernadette are to be congratulated on raising over £1,000 for the Society.

Sunday's excellent event was the Mucopolysaccharide Charity Open. Despite incessant rain which threatened to cause the competition to be abandoned an incredible 158 players took to the course — one of the best entries in any recent event. Newcomer Declan McColgan, a young man who undoubtedly will make his mark at the game, held off the strong challenge of another father and son combination to take the top prize with an excellent 63 nett (off 21). He was followed closely by Charlie and Francie Patton who both returned scpres of 64 nett to finish second and third respectively. Considering they were playing off handicaps of 7 and 8, neither was conceding much to par. Experienced Willie Christy was fourth with 65 nett, while yet another Patton — this time Liam — finished fifth

(66 nett). Paul McGill posted a 67 nett to be sixth. The gross prize went to Brian Patton who recorded a one over par 70.

Other awards went to: Category One, Sean Devenney 67 nett; Category Two, Liam McDevitt, 70 nett; Category Three, Jim McDaid, Jnr. 67 nett.

Pat O'Gorman's ball ended 4 feet from the flag at the 18th and he took the 'Nearest the Pin" prize.

One of the highlights of what proved to be a superbly organised and efficiently run affair was the putting competition which was finally decided by play-off. Declan McDonnell and Liam Curry were tied on 15 putts apiece after normal play and were required to confront one another in a 9 hole head to head. Again they could not be separated and, to the delight of the crowd which numbered some eighty or so, the combatants entered the Sudden Death stage. By now dusk had descended upon the proceedings to such an extent that several in the assembled throng complained that they could not see the holes. Anyway Declan McDonnell rifled in a 30 foot putt at the first tie-hole to win.

POSTMAN DELIVERS MORE THAN LETTERS

Harry Green, a 59 year-old postman from Liverpool, took on a 215 mile sponsored bike ride for the Society on a sunny Sunday in June - and completed the course. In doing so he raised over £300 for us. Well done Harry.

The route took Harry from Liverpool through Southport, Hesketh Bank (where I'm sure the Gardiners were hanging out of the windows and cheering), Preston and on to Blackpool. After a stop for a photocall and refueling Harry returned by way of Burnley, Manchester and Widnes before getting home to Liverpool.

Many thanks to Sid Shiff for all the organising and to Harry for the leg work.

FUND RAISING EVENTS

Another assortment of fund raising events has again helped to keep the Society going. Thanks to everyone who participated and to all who gave money.

Mrs Todd, Glasgow	Collecting box
Spittal Primary School, Glasgow	General Fundraising
Alan and Amy Bottrell, Glasgow	Collecting 20ps
Victoria Geriatric Staff, Glasgow	Fundraising
All who collected for the Mental Health Flag Day in Runcorn, Carlisle Reading, London and Milton Keynes	Street Collections
David Briggs, Retford	Sponsored Slim
John Hobson, Mansfield	Sponsored Slim
J Humbert, S Thompson & N Hurley	Musical Evening at Stowe
Ellen Robinson, Milton Keynes	Jumble Sale
S Dopierala & M Karczewski, Cheshire	Sponsored Parachute Jump
J Dagnall, Bolton	School Fundraising
H Green, Liverpool	Sponsored Bike Ride
Susan Hughes, N.Wales	Collecting Box
N Ireland Housing Executive	Sponsored Walk & Cricket Match
K & B Houston, Strabane	Golf Tournament
The Gooch Family, Sussex	Heathfield Show and other events
K & A Weedall, Cheshire	Sale of Webb Ivory
Mrs Todd, Glasgow	Collecting Box
G Potter & J Brownlie, Glasgow	Ran across Scotland - the West Highland Way
K & A Weedall, Cheshire	Collecting Box
Alan & Amy Bottrell, Glasgow	Collecting 20ps
Chivas Bros, Glasgow	Office Quiz
Vat International, London	Collecting Box
Becky Evans & Kathy Price	Sponsored Walk across Wales
P Date & H Chorley	Fundraising
P Croghan	Car Boot Sale
Sheffield High School	Home Economics Food Sale
Mr Gardiner, Southport	Collecting Box
B & M Grant	Fundraising
Stafford Garden House Kindergarten	Summer Fayre and Raffle
Mary Gardiner	Car Boot Sale
G & L Bagshaw	Barn Dance
Donogue	Barn Dance
A & J Price	Auction of Jack Hamill painting
Trull School of Dancing	Dancing at Fetes
Mr Coathup	Barn Dance
C, J & JF Norsworthy	Fundraising
Lockyers	Aberystwyth Rag
Pat Criddle	Collecting Box
J Macintyre	Collecting Box
M B Beamond	Dance
S Cully	Fun Run

AREA SUPPORT FAMILIES

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