

NEWSLETTER

AUTUMN 1996

**THE SOCIETY FOR
MUCOPOLYSACCHARIDE DISEASES**



National Registered Charity No 287034

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The Society for Mucopolysaccharide Diseases

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

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

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

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

"CARE TODAY, HOPE TOMORROW"

Front Cover: Samantha Brockie aged 5 years who suffers from Scheie and Sarah Long who suffers from Morquio Disease

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**Deadline for the Winter Newsletter
6th January 1997**

Please send us lots of photos taken over Christmas

CHAIRMAN'S REPORT

The Chairman of Trustees, Mr A G King, presented the following report to the Annual General Meeting held on Sunday 22nd September at the Stakis Country Court Hotel, Northampton. This was based on a report prepared by the Director.

In the last twelve months we have continued to support over 800 families in the UK including the families of 30 children diagnosed with MPS since the last AGM. Some of these families are with us this Weekend. Visits and contact with newly diagnosed families continues to be a priority area of work nationally.

The Society had responded over the year to many families in crisis, particularly in the areas of education, housing and welfare benefits. However the Trustees recognise that the Society's advocacy service is severely stretched based on our present staff complement.

The Society continues to have a major presence at both the MPS clinics held at the Royal Manchester Children's Hospital and Hospital for Sick Children, Great Ormond Street.

A majority of the Area Support Families participated in a highly stimulating training weekend in Derbyshire. Whilst recognising possible limitations, our volunteer support network is being encouraged to offer increased telephone support. Many Area Family events have taken place including Christmas parties, outings and BBQ's. Yorkshire and Humberside held a very successful Family day at Sherwood Pines, and the North West incorporated a sponsored abseil into their summer programme of events.

In November 1995 the Society organised another successful MPS clinic in Glasgow with Dr Wraith and Dr Vellodi in attendance. A similar clinic for Northern Ireland is promised for later this year.

On the advice of the Forestry Commission the Society changed its timing for future plantings in the 'Childhood Wood'. The next planting is on 25th October 1996 when thirty bereaved families will participate. There has been considerable discussion about the health of a small number of trees; many having made a slow start are now shooting profusely and are very much alive. The few which have died will be replaced before the planting in October.

Eighteen MPS families enjoyed a one week holiday at Filey in North Yorkshire in July whilst physically disabled MPS teenagers took part in an Activity Holiday in the Lake District. Again the holidays could not have been possible without the practical help of volunteers from the Royal Logistics Corp. Hullavington.

As you will see from the display boards Christine and Mary had a very busy and informative visit to Australia for the 'International symposium on MPS and Related Diseases'. They played an active role in the International Working Party Meeting. Christine presented a paper on the 'Incidence of MPS' and both ran workshops, Christine on Palliative Care and Mary providing a forum for young adults with MPS to have a say.

CHAIRMAN'S REPORT

March the 1st was Jeans for Genes Day 1996. Those of us at the sharp end sometimes wondered if we'd ever get there as four charities learnt to live with each other! But we did and now we are heading for a much more energetic Jeans for Genes Day in October 1997. We hope it won't be too long before we can announce the major sponsors.

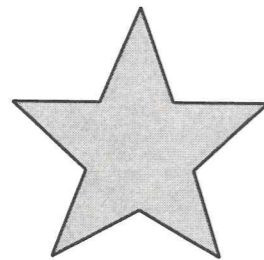
The best news is that the Society has received all its costs back and Jeans for Genes has raised over £150,000 for MPS to invest in research. The Society has established an expert panel of scientists and lay people to peer review the research grant applications received at the at the closing date of 30th August 1996.

As you recall when I addressed you last year the Society was facing up to a significant drop in fundraising receipts and a financial deficit of £48,539. As you will hear from our Treasurer and Assistant Treasurer the Society's position 10 months into this financial year is slightly improved but we still have much to do. Apart from prevailing on all our members, families, friends and relatives to 'think MPS' when it comes to fundraising Christine has been successful in achieving some major grants from the National Lottery under poverty for £64,000 to subsidise the holidays for 3 years. The BBC Children in Need Appeal have given a grant of £9,000 for Area Family Support in 1996/97 and the Department of Health, London and DHSS in Belfast have awarded core grants over 3 years. The Al Fayed Charitable Trust have funded the £17,000 3rd year of the research project 'Gene Therapy for Hurler Disease'. Christine's Jerwood/Guardian Award and sponsorship from Genzyme and Mangar International met the cost of attending the conference in Australia. We have a substantial application currently being considered by the National Lottery to fund a Director of Support Services (North) and National Development Officer for Ethnic Minority Families. In the Meantime we have to keep fundraising.

A G King
Chairman of Trustees
19th September 1996

We would like to extend our thanks to all the volunteers who came to the MPS Conference at Northampton.

We appreciate that you all gave up a whole weekend to care for the children and we cannot thank you enough for all your help.



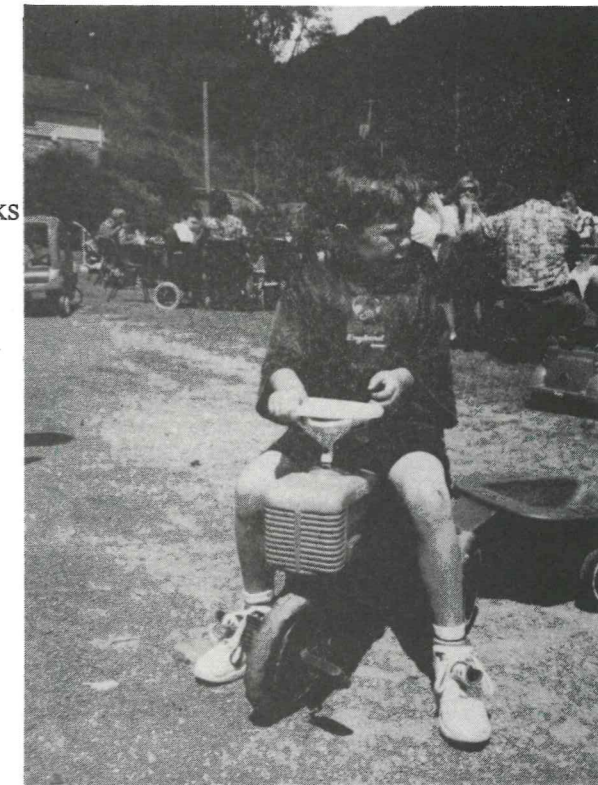
AREA FAMILY SUPPORT

WELSH MPS B.B.Q.

Once again a beautiful sunny for the Welsh MPS BBQ which was held at the home of Rhian and Bob McKnight., Brookhouse Farm.

The food once again was superb thanks to Rhian, her family and friends. We also had a wonderful draw, thanks to all those who gave prizes. Games and face painting for the children with a gift stall for the adults. Many thanks to all the families who were able to attend. Mike and Ann Kilvert.

Pictured below is Joseph Coleman from Cardiff, aged 6 years who suffers from AGU.



Pictured above is Christopher Jones, aged 9 years who suffers from Sanfilippo Disease. He seems to have a strong resemblance to the friendly sheepdog.

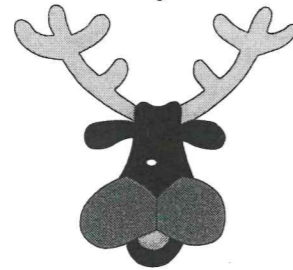


Looking as if they are enjoying themselves are Ann Canton and her husband, Mervyn.

AREA FAMILY SUPPORT

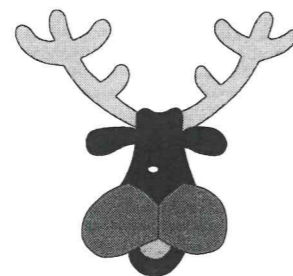


1996 Dates for your Diary



Sunday 6th October 1996	Chester Zoo	Family Day (Blackburn and Brennan - North West)
Sunday 24th November 1996	Christmas Party	North West (Blackburn and Brennan)
Sunday 1st December 1996 Loddon Valley Leisure Centre, Reading	Christmas Party	South East (Mark and Rachel Wheeler)
Sunday ?????December 1996 (to be arranged)	Christmas Party	Briggs and Rollinsons Tweendykes School, Sutton, Hull
Sunday 8th December 1996	Christmas Party	Wales (Ann and Mike Kilvert)
1st week in December 1996	Christmas Party	Bernie and Keiran Houston (Northern Ireland, to be arranged)

If you have not yet received notification of a Christmas Party in your area then please contact your Area Family.



MILESTONES

Births

Congratulations to Peter and Sue Stuart whose daughter Annie Beatrice was born on 1st July 1996.

Congratulations to Jackie, Clive and Hannah Chisling on the early arrival of their daughter Mollie Imogen born on 29th July 1996.

Congratulations to Zelda, Paul and Shane Hilton on the arrival of their daughter Lauren Mary, born on 9th July 1996.

New Families

Mr and Mrs Begum from Birmingham whose son Tariq, born on 13th April 1995 was recently diagnosed as suffering from Morquio Disease.

Mr and Mrs Aylott whose son, Jamie was diagnosed with Aspartylglycosaminuria (AGU) disease. Jamie aged 19 years lives in Colchester.

Mr and Mrs Razaq from Bury whose son, Mohammed was diagnosed with Maroteaux-Lamy. Mohammed is 2 years old.

Mr and Mrs Khan's son, Nasser has been diagnosed as suffering from Morquio Disease. Nasser is 3 years old and comes from Slough.

Mr and Mrs Aijaz whose son Umran was diagnosed with Sanfilippo Disease. Umran from Leicester is 20 years old.

Susan Percival is a newly diagnosed adult sufferer of Scheie. Janice Wilkes is also a newly diagnosed sufferer of Scheie. Janice and Susan are sisters who come from Reddich.

Deaths

Sadly on 16th July 1996 Daniel Anthony, aged 9 years died. Daniel from Ipswich suffered from Hurler Disease.

Judy and Chris Holroyd's son William died on 25th July 1996. William aged 22 years old suffered from Sanfilippo Disease.

Mr Filippo Maresca, father of James, Anthony and Thereza who all suffered from Sanfilippo Disease, died on July 1996 Our thoughts are with his widow Catherine and family.

Sadly Christopher Britton aged 13 years died on 7th July 1996. Christopher, from Bristol suffered from Sanfilippo Disease.

Unexpectedly, Virinder Basra, son of Kamaljit and Jasvir, died on 31st August 1996. Virinder suffered from Hurler/Scheie and was 11 years old.

On 10th September 1996 Graham Johnston sadly died. Graham from Cumnock who was 11 years old suffered from Fucosidosis.

FAMILY NEWS AND INFORMATION



Monica and I would like to thank all those who visited and sent cards while Kristina has been in hospital at Manchester. After three operations, four weeks in Intensive Care and a total of nine weeks in the hospital we know how much the support of the Society and our friends has meant to us. In particular we would like to thank Mary and the Northern office for actions above and beyond the call of duty. We hope to have Kristina home shortly.

Thank you all again

David, Monica, Emma and Kristina Briggs.

DIAL A DREAM

Dial a Dream is a charity started by the
LONDON TAXI DRIVERS

with the intention of helping sick children, especially those who are seriously ill. Hence the motto
LET ME LIVE ANOTHER DAY

We have helped hundreds of children to realise their dreams and new members are always welcome. So if you know of a seriously ill child who needs help to realise a dream, or wish to make a donation telephone:

Dial a Dream - 0181 530 5589

Registered Charity No.1011637

QUESTION

Have any other parents of MPS children been told that their child suffers from a bleeding problem - if so how was this diagnosed? Has any treatment been offered and was a name given to this disorder?

Cathy Flaig, Mum of Thomas(Sanfilippo)

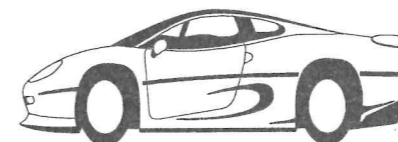
ANSWERS Required Please
Through the Amersham Office



FAMILY NEWS



Pictured above is Alex Butler from Chinnor Hill with his Metro car in which, Alex who suffers from Hunter Disease and is 23 years old acts as the family chauffeur.

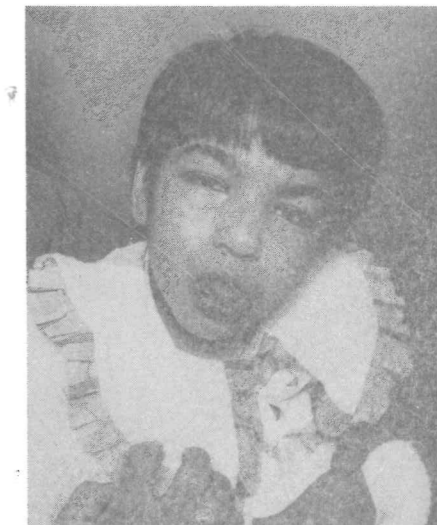


MPS CONFERENCE 1996

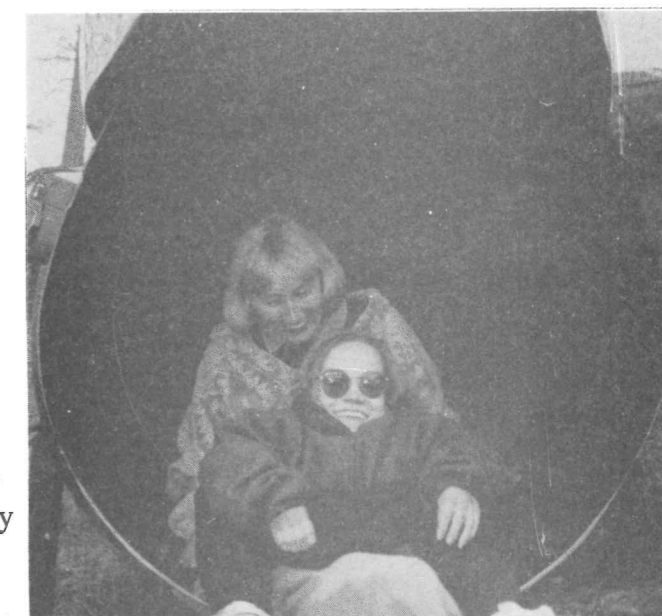
The MPS Conference was held last weekend and hopefully all those who attended went away feeling that they had gained something positive from the weekend.

We will be covering the Conference in more depth in our next newsletter. But we would like to inform members of the changes of Trustees which were decided at the Annual General Meeting. Sadly Alf King resigned along with Pauline and Sean Mahon and Alan Beavan. We are sure that you would agree that we owe them all a big vote of thanks for the continued support and hard work they have given over many years.

We are pleased to tell you that Sarah Long who suffers from Morquio Disease has joined the Trustees. The other new Trustees are Alison Pullin and Vic Lowry and we would like to wish them all good luck.



"I am Sumeya Bhaiyat from Leicester. I was born in 1983 with Fucosidosis which was diagnosed at the Child Development Clinic. I am a happy little girl who enjoys going to my special school. I visit the Rainbows Children's Hospice in Loughborough every few months to give my Mum a break."



Above is pictured Sarah Long with Mary Pagett on the Teenage and Young Adults Holiday.

FAMILY NEWS



Pictured above are Mrs Trudi Deacon and her daughter, Jane Heritage. Mrs Deacon's son, Michael died in 1958, aged 15 years from Hunter Disease.

Trudi, her husband, Albert along with Jane and her husband, John have helped the Society over the last few years by holding fundraising events and raising the awareness of MPS.

Trudi and Jane are pictured on the bench which they donated to the 'Childhood Wood' in memory of Michael.



This lovely bridesmaid is Samantha Brockie.

She was a bridesmaid along with her friends Stacey and Kelly.

As the wedding took place only 3 days before Samantha's fifth birthday, Mum, Victoria, Dad, Jim and sister, Daniella went to EuroDisney to celebrate both the wedding and Samantha's birthday.

We are sure everybody had a great time.

FAMILY SUPPORT



These photographs were sent to us by Mrs Shah who thoroughly enjoyed this year's family holiday at Filey. Mrs Shah was thrilled to make so many new friends and to be in such a caring environment.

Opposite are pictured Adelliah aged 5 years who suffers from Morquio with her family and Mary Pagett.

Below is pictured Adikah Batool aged 5 who suffers from Morquio with his brother Hassan and also Marwan aged 7 who also suffers from Morquio Disease.



If you are interested in learning more about the Holiday Centre below, Please contact : Mary Jardine 01229 773937

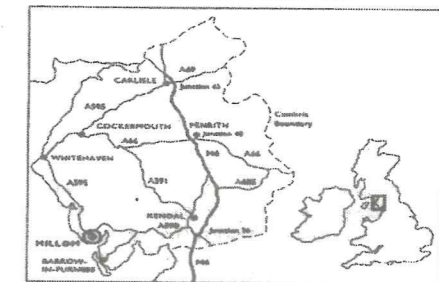
HARRIET HOLIDAY CENTRE

FOR YOUNG PEOPLE



Our Centre offers comfortable bunkhouse accommodation with facilities for disabled youngsters, and a base for adventure on the banks of the Duddon Estuary in South West Cumbria.

HOW TO FIND US



ATTRACTIONS

- Adjacent to the Centre**
The Duddon Estuary, a site of international importance for wildlife, including many wading birds, the rare bee orchid and natterjack toad
- In and around Millom**
- Fishing, walking, horse-riding
 - Beaches at Haverigg and Silcroft
 - Hodbarrow RSPB Nature Reserve
 - Watersports at Port Haverigg
 - Duddon Pilot Hotel - Wheelchair access
 - Folk Museum & RAF Museum
 - Millom Recreation Centre
 - Tennis, Bowling & Putting Greens
- Further afield**
(All within a forty minute drive)
- Muncaster Castle, Owl Centre, etc.
 - Ravenglass & Eskdale Railway
 - Several swimming pools including one with disabled access
 - Steamers on Windermere
 - Gondola on Coniston
 - Many other Lake District attractions

OVERSEAS NEWS

International Symposium on Mucopolysaccharide and Related Diseases**Wollongong, New South Wales, Australia****24-27 May, 1996****ROUND THE WORLD IN 8 DAYS**

After more than 3 years looking forward to this Conference the time had come for Mary Pagett and I to travel half way round the world to Australia. For Mary this was her second visit. The first being in 1988 when the MPS Society in Australia was in its infancy.

This visit wouldn't have been possible without the financial help of Genzyme, Mangar International and the Jerwood Guardian Award. We should also thank the Australian MPS Society who met my registration fees for speaking at the Conference and a very special thank you to Ros Smith (co-founder of the Australian MPS Society) for showing us a little of New South Wales whilst we recovered from jet lag.

The Conference provided a marvellous opportunity to meet families from the South Pacific basin as well as many of our friends who travelled from Europe and the USA. Mary and I were also joined in Wollongong by Paul and Jean Leonard (London) and Keiran and Bernie Houston (Northern Ireland) and their families who timed holidays in Australia to coincide with the Conference.

What follows is a brief synopsis of the presentations. We have requested a set of audio tapes and when they arrive we plan to publish some of the talks in future newsletters.

Denise Law, President, MPS Society, Australia spoke on what it was like to have children with MPS and how it impacts on not only the immediate family, but the extended family and the community. Denise and her husband Ron have lost two daughters to Sanfilippo Disease.

Christine Lavery, Director, MPS Society, United Kingdom was invited to give a report on the incidence of MPS in Europe and the USA. Using the data collected from families and professionals from Russia to the UK we were able to demonstrate that the numbers of affected children and young adults is far higher than previously published figures indicate. In the United Kingdom we have identified nearly 850 individuals biochemically diagnosed with MPS. Using data relating to MPS births between 1974 and 1991 we were able to show the following incidence rates:

MPS Type I	1 : 117,000
MPS Type II	1 : 166,000
MPS Type IIIA,B,C	1 : 87,000
MPS Type IV	1 : 214,000
MPS Type VI	1 : 500,000

The overall incidence of MPS and ML is 1 : 25,000

OVERSEAS NEWS

Dr John Hopwood, Women's and Children's Hospital, Adelaide, South Australia spoke on the relationship between the genotype and phenotype. Several scientists from his laboratory also spoke on results achieved for mutation analysis and their relationships to the clinical development of the patients. It was suggested that in some patients the clinical development can be somewhat predicted but that other genetic factors within the same gene and other genes will possibly help to explain why patients with the same mutation might be clinically different.

At a later point in the Conference Dr Hopwood announced that he had received a letter of intent from a biotechnology company in the United States paving the way for possible enzyme production and clinical trials to begin for one MPS Disease. He indicated that he was not at liberty to disclose the name of the company nor which disorder it might be. It was hoped that within months a contract would be signed and this information made public.

Dr Ed Wraith, Consultant Paediatrician, Royal Manchester Children's Hospital, England reported on the difficulties facing families whose children suffer from MPS. He quoted a passage from an article published in 1948 in the Journal of the Disabled Child "*We know of nothing that will help these children... institutionalisation should be urged for children with the greater degrees of mental deficiency, especially if normal siblings are made to suffer psychologically, financially or in any other ways or if the patient becomes an object of curiosity.*" Dr Wraith explained how far attitudes have moved on in almost 50 years, but that many problems still remain. He spoke about the sometimes differing views of the professional and the parent in how each sees the child and what might be considered successful treatment. He related this to the outcome of bone marrow transplant and the upcoming enzyme or gene replacement therapy. Dr Wraith acknowledged that there is usually a difference in the ways that the parent and scientist see success.

Prof. Chet Whitley, University of Minnesota, USA gave a report on the results of bone marrow transplants for MPS that have taken place in the United States. Prof. Whitley stated that there are clinical improvements in some of the patients that have been transplanted but that no improvement in the central nervous system has been detected. He spoke briefly on the impending gene transfer clinical trials for Hunter disease on two adult men due to take place this Autumn.

Lesley & Mick Waite, Parents of a child with Morquio, Australia spoke about their decision for their son to have a bone marrow transplant (BMT). They described the issues they dealt with including making the decision to go ahead and their feelings after the transplant was carried out. They suggested that even at 2 years of age it was not early enough to reduce the skeletal problems seen in Morquio disease. The family felt the overall benefits of BMT included improvement of breathing and sleeping, reduction in the size of liver, no deterioration in the heart and very slight gains in height.

Paul & Jean Leonard, Parents of John and Christopher with Fucosidosis, England described life with John who was diagnosed at the age of 3 years and died at the age of six. They spoke of the help and support they received in caring for John at home and the role of the Children's hospice. By the time John was diagnosed the family already had a second son who was asymptomatic but shown to have Fucosidosis biochemically. Christopher had a bone marrow transplant at the age of nine months. He is now nearly 5 years old and interacts well with his peers at his mainstream nursery school where he has

OVERSEAS NEWS

additional support. Christopher's speech continues to be very limited and psychological tests place his ability at 2 years.

Dr William Sly, University of St. Louis, USA talked about his research with mice. He indicated that in mice, and possibly in humans, there are very small windows of opportunity to get enzyme into the brain before the blood-brain barrier goes up. In mice Dr Sly found he could get enzyme into the brain immediately after birth and that by day 7 this no longer applied. He also found that corneal clouding improved after a bone marrow transplant but did not following enzyme replacement therapy.

Dr Donald Anson, Australia updated and reviewed gene replacement therapy. He explained that the basic difference between gene replacement therapy (GRT) and enzyme replacement therapy (ERT) is that in ERT the enzyme is produced outside the body whereas in GRT the enzyme is produced inside the body. He felt that the best method to introduce GRT would be through a bone marrow transplant with the possibility that the gene would get into the stem cells.

Dr Elizabeth Neufeld, University of California and Los Angeles, USA spoke about her work with MPS I dogs. The major problem her with her ERT trial was that antibodies are formed in the animal. Several speakers addressed this problem and there is clear agreement that more work needs to be carried out to help eliminate this problem while at the same time continuing to work on ERT and GRT. Dr Neufeld described different methods of introducing the enzyme into the dogs and is also studying low dose versus high dose.

Dr Roscoe Brady, National Institute of Health, Bethesda, USA described his work with Gaucher disease and the success of ERT in certain patients. Several studies are being carried out to determine the level and frequency of doses of enzyme needed to continue to achieve positive results. He indicated that it is very individualised and what is best for one patient might not be the same course of action for another. He also spoke of his present work of trying to introduce enzyme directly into the brain of animals.

Ros Matthews, parent of two daughters with Gaucher disease, Australia spoke of how ERT has improved the quality of life for her girls. She spoke of her struggle to achieve funding for the high cost of treatment.

Dr Linda Lashford, Manchester Children's Hospital, England spoke about the anticipated clinical trials of gene replacement therapy (GRT) in MPS I patients. The programme is now in place and they are presently waiting to find suitable patients for the trials. The study is designed to "evaluate whether genetically manipulated bone marrow successfully engrafts following sub-ablative conditioning and if so whether useful levels of enzyme production can be achieved and sustained."

Dr John Wolfe, University of Pennsylvania, USA spoke about GRT in MPS VII. He is working with animal models to develop different ways of introducing enzyme into the body and to establish which appears the most affective.

OVERSEAS NEWS

Sylvia Webb, parent of four children with MLII, Australia told about how the diagnosis has affected her family's emotional, financial and social needs.

Catherine Smith, sister of Adrienne who died from Sanfilippo Disease, Australia described what it was like to be a sibling and that even though her sister has passed away, how MPS still and will always effect her life. She spoke of her feelings regarding carrier status and the professionals attitude to carriers of autosomal recessive MPS diseases. She stressed that statistics have no meaning when you are the person facing the risk.

Dr Preeti Joshi, Westmead Children's Hospital, Australia talked about the impact of chronic illness in adolescence. She indicated that while adolescence is tough enough, it is much more difficult for children with MPS. She discussed the concerns that patients have about self-esteem, career opportunities and relationships.

Living with MPS

Vaughn Glasson, Hunter Disease (20yrs) spoke about his experiences growing up, how things have changed for him, his choice of accounting as his major in school not because he truly loves it but because he feels it is something he can do based on his condition.

Katherine Mitchell, Scheie Disease (young adult) talked about what tricks she has developed to help her with daily task, her dealings with professionals and her feelings about how they treated her, her independence and dependence. (Katie's story follows)

Colin Thompson, Hunter Disease (young adult) spoke about his becoming a solicitor and how he can not find a job in his chosen profession, but that he is now trying to become a professional writer and is looking for a wife. He spoke about his wanting to network with people at the conference and his plans to travel outside Australia.

Heather Anderson, Morquio Disease (12yrs) spoke about what it is like for her in school and with her peers. (Heather's story follows)

Catherine Harcher, Maroteaux Lamy Disease (38yrs) told of her long battle to find the correct diagnosis, her several surgeries, the death of her fiancée and her career changes that finally brought her to being a psychologist.

These presentations by young people affected by MPS were in my mind undoubtedly the highlight of the conference. The speakers demonstrated a wonderful sense of humour in sharing with the audience how they coped with all the sorrow and pain they have been through. Their courage and the way they shared their feelings was an inspiration to us all.

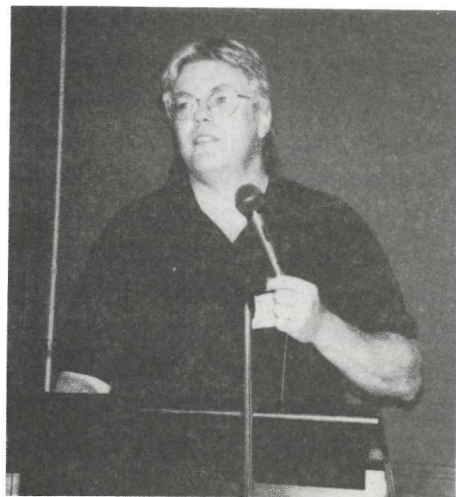
There were many other presentations and family workshops. Mary ran a very successful discussion group for adults affected by MPS and, John Rogers (Melbourne, Australia) and I ran a workshop on palliative care. Mary and I learnt so much from the conference and I hope in turn helped others with our experience of supporting MPS families and advocating the needs of their children.

Finally may we say a big thank you to Denise and Ron Law and their supporters who made this conference the success it was.

Christine Lavery
Director

OVERSEAS

Pictured below at the Australian Conference are Mary Pagett with Kelly Dobson, Dr Ed Wraith, Dr John Hopwood and Jean Leonard.



OVERSEAS FAMILY NEWS

PICTURED AT THE AUSTRALIAN CONFERENCE ARE PAUL AND JEAN LEONARD AND THEIR SON, CHRISTOPHER.



NEWS OF THE MPS CONFERENCE IN AUSTRALIA

Paul Leonard

My wife, Jean and I had not been to an MPS International Conference or visited Australia before but the lure of meeting other MPS families from different parts of the world and sharing their experiences was a major factor in persuading us that we should go.

We also decided to write a talk on 'Family Care of Two Children with an MPS Disease'. Having been told to speak for twenty minutes, we were left with the dilemma of what to put in and what to leave out. We compromised and were left with the difficult task of selecting photographs which we both felt would be meaningful and helpful. Fortunately, the talk was well received and given during the first afternoon of the Conference, which meant we had lots of opportunities to enjoy talking to other parents.

The MPS Director (South), Christine Lavery gave a talk on the European MPS database and I thought that there is now a need to expand the database to other countries outside Europe. Both Christine and Mary Pagett, the MPS Director (North) were constantly busy at the MPS (UK) stand providing information on a wide range of issues. It was very noticeable that the UK MPS Society was held in high esteem by the other MPS countries representatives. Many parents wished to read a copy of our booklet on their MPS disease.

Kieran Houston and I represented Trustees' interests. Kieran had brought his wife, Bernie and we all circulated as widely as possible. My son, Christopher, who was diagnosed with Fucosidosis, was well looked after by several carers, all of whom said they were privileged to help. This was particularly noticeable for the outings which included visits to a Theme Park, riding and a playground. A huge room was set aside for a crèche which was sufficiently staffed to cope with babies and toddlers. The highlight for the children was an afternoon at a sports field where we all enjoyed a barbecue, live music and generally letting off steam.

The Conference was structured in a similar way to the UK version. There were group discussions and sessions for the medical professionals, including, from the UK, Dr Ashok Velodi. Also, Dr Ed Wraith gave a particularly useful talk on 'Disorders of the alimentary tract' which many parents found helpful. Lots of time was allowed in the coffee breaks to meet delegates and the opportunity to visit the poster displays, all of which I found interesting. Many of the sessions were recorded and Christine Lavery is exploring the possibility of buying a copy of the tapes for UK MPS families.

All too soon, the Conference was drawing to a close. I have many happy memories and was particularly moved by the session involving some of the young MPS adults, all of whom wanted to think positively and get on with their lives, whatever their disability.

OVERSEAS

{The following are talks given at the Australian Symposium by two young MPS sufferers.}

KATIE'S STORY

Good afternoon, my name is Katherine Mitchell or Katie to my friends. I have been asked to talk to you about living with MPS 1 which is Hurler/Scheie. What it was like growing up with my disability? how it has affected my life? the restrictions placed on doing things, meeting people and the relationships I have with doctors. Some people call it a disease, and try to keep away from you, others call it a disability which it is, I only call it a hindrance because I have always had it, and I don't know what it would be like without it.

It all started twenty three and a half years ago, when I was born. I don't remember much about that day, in fact, I don't recall anything when I was a baby. The earliest I recollect is when I was five living in the blue mountains. I consider my childhood to have been the same as any normal child, I was active, played T-ball, and other sports and could move around without too much trouble.

My education started off just the same as any other child going to school. I went to a normal infants school, where I mixed with the other children without any problems. When I entered primary school, I started having problems keeping up with other students. The teacher would write a board full of information and I would only be at the third line before it would be rubbed off. The main problem was my eye sight, also the fact that I couldn't understand what was being taught, and they wouldn't take time to explain it to me as it would hold the rest of the class up.

On leaving primary school I went to special education where they had teachers aids who could help me. With this special attention I constantly came top on reading spelling and mathematics. I attended this school until the age of 19. From 15 years of age onwards we did work experience for 2 days a week. My first experience of working was in a sheltered workshop, packing goods for companies. My only memory of this job, was being bashed up by one of the workers. I didn't like working there because of the people, and I asked if they could find me a normal job.

Initially the teachers felt that I would not be able to function in a normal job, because people I would be working with may pick on me. After constant begging they found a job at Coles packing shelves and bags. I proved the teachers wrong because I could do the work, and became good friends with the staff there. Unfortunately this job only lasted for ten weeks. After Coles I was given a work experience job in an office. This consisted of typing and answering the phone. I was working two days a week, attending tech two days and school one day.

When I was eight I would ask my parents about my disability, and they would just tell me that I had a blood disorder. At the age of fourteen, I started asking more questions, and was informed, that I would be crippled by the age of eighteen, and deceased by the age of twenty. And as all children, I'm glad to be able to prove my parents wrong, as I'm now twenty three. Only when I was eighteen, and became involved with the MPS society did I learn about my disability.

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It was only after my 16th birthday that I started having problems looking after myself. It began with not being able to put my socks and shoes on. I avoided this by not wearing socks and shoes without laces. I loved having walks along the beach, but found I could not keep doing this because I would become short of breath, and I started having back pains.

You learn some good little tricks in life when you can't do things like other people. Everyone takes washing your hair as an easy task, but if you can't put your hands on your head, it makes for an interesting challenge. I used to put the shampoo on the brush and then wash my hair by brushing it.

Doctors, to be honest, and to the doctors here today, please don't take offence, but I don't really like them. It is not the person that I dislike, most of the doctors that I have known as people are really nice, but it is the tests which I keep being put through. I hate needles, although I don't know of many people who actually like the thought of an injection, but it doesn't do much for me. When something is wrong, they seem to have problems bringing the explanation down to my level so I can understand what is happening to me.

In the last few years, I have been visiting the doctor with someone, this person helps explain what is happening to me at my level. The doctors seem to talk at me, not to me. Also, if you have to be there all day, they are someone to keep you company.

You know how we are all supposed to go to the dentist twice a year, well I also see twice a year; a genetic counsellor, back specialist, optometrist, gynaecologist, breathing specialist, a heart specialist every two to three months, and to top it all off, a see a General Practitioner once a month, nice guy, but is always hassling me about my weight along with some other close friends.

When I wake up in the morning, I swallow half a drug store. I take the following medication, lasex, which is for fluid and makes me run to the toilet for up to six hours, cordizen, emdur and aldactone which are all for my heart. Losec for my ulcer, and finally half an aspirin to thin the blood.

The biggest problem I have when seeing the doctors when they want to take a sample of blood or give me an injection. It takes the doctors a long time to find a vein for the needle.

The part that I hate most about my physical disability is not being able to travel. The problem with travelling is that I need someone to rely on. And that's what I detest most. Even though I have my disability, I am not tied down to one location, and can move about on day trips, visiting friends and going out for dinner. Another part I dislike about my disability is my size. Although, one major advantage is that I have never had to pay full fare on a bus or train.

I had an older brother and sister who both had MPS, my sister died just before her second birthday, whilst my brother made it to twenty two. After my brother died, three years ago, it made me look at life in a different light.

OVERSEAS

A special message to the doctors, when you are dealing with someone with this disability, please talk to the patient. We are just like anyone else. It may take a little longer, but it means so much to us. For our carers, the ones who wash and look after us, thanks, without you life would be impossible. Well not quiet, but I think it would be a little bit on the nose.

MPS Autumn Newsletter

Page ?

HEATHER'S STORY

Hello my name is Heather Anderson and I would like to talk to you about what living with Morquio Syndrome is like for me. I am 12 years old and live in Tasmania. I have two brothers, Michael is 14 Craig is 9 and they are considered normal - but sometimes I doubt it!

MEDICAL - I wasn't diagnosed until I was about 3 years old.

Although when I was 6 months old it was thought I had dislocated hips and so had lots of different plasters to help my hips develop. This didn't work and by the time I was 3, my growing was starting to slow down and my chest and spine weren't looking quite right.

So I had to go to the Royal Children's Hospital in Melbourne. After spending all day there having x-rays, photos, tissue and urine samples and lots and lots of doctors looking at me it was decided that I had Morquio Syndrome. Other than having to go to Melbourne yearly for x-rays to keep an eye on my neck life was pretty normal and school life was a breeze. In those days Dr Rogers (who wears fabulous bow ties) used to visit Tasmania every 6 months or so. All the local doctors and others would sit in on the visit - I felt like an experiment gone wrong! Mum had a talk to Dr Rogers and now we usually just see him, which I find is much better.

I just want to say that life is and always has been fabulous, except, when I was five. I was devastated when I was asked to leave my gumnut guide unit because Mum had been honest and told them all about my condition. They said that because of my possible unstable neck I would not be covered by their insurance. This made me feel different to everyone else. Good news about this later....

I got to know the Royal Children's Hospital quite well when I was six years old. I had been playing around and did a forward roll on mum and dad's bed. I went tingly all over and when I tried to sit up I just fell back down. So off to Melbourne for a cat scan and MRI. Good news from the MRI was that it showed my second vertebrae was putting pressure onto my spinal cord - and yes it was time for me to have a neck fusion. I had my top four vertebrae fused together with bone from my hip. They have also been wired together. Straight after the operation I have lots more strength in my arms. I hadn't realised how weak I was until I got a lot stronger. I had to wear a special brace for 3 months. The brace didn't worry me as I could still go to school and found that I could do most things. That year we had five trips to Melbourne - my friends thought I was lucky - they had no idea!

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Good news. the Girl Guides Association of Tasmania had changed their minds. I was normal again (but what's "normal"?) and allowed to become a Brownie as I was too old for Gumnut Guides. YES!!!!!!!

Eighteen months later when I was seven, it was off to hospital again. This time it was for an osteotomy on my legs. I had become knock kneed and finding it hard to walk. I wasn't looking forward to it all, but I knew it had to be done. My neck fusion hadn't worried me because I knew I had no real choice. The osteotomy took 3-4 hours. I was cut just above my knees and straightened. If the surgeons had left me like that I would be walking like a duck. So they also cut me above my ankle. Both legs were in full plaster for 10 weeks. But it was all through the summer school holidays. It took me a long time to learn to walk again. I had to do exercises several times a day, at home, school and in the hydrotherapy pool. When my legs were strong and I learnt to balance I used a walking frame and later on elbow crutches. Which I still use.

Now I'm back to yearly visits to Melbourne, but I always dread bad news.

SCHOOL- At school the furniture is too big for me so I have a custom made swivel hydraulic chair. The kids give me a hard time because they are taller than me.

Instead of getting upset with them (which, is hard to do) I say things like 'you may be 20cm taller but I bet I'm 20cm smarter', then walk away. This is extremely hard at the start of the year with all the new kids at the school. They also don't believe I'm in grade 6, they'll get a shock at the end of the year when the principal calls up the senior students to come and collect their graduation certificates. I am lucky that I find school work a breeze. I am good in the creative writing area and as a result of this, last year I was a zone finalist in the Nestle 'Write Around Australia Competition. As I find physical education and related activities difficult, my school applied for a grant to employ a teacher's aide to extend myself and three other kids in the creative writing area. This to compensate for missing Physical Education. Even though I am pleased by all this I would give anything to run the 75m sprints at the school athletic carnival, even if I came last.

Next year I go to high school - a school with lots of stairs, high desks and walking. More problems - but we are working on them now, so that the school will be ready for me!

HOME - As we live in an older style house I can't reach door handles and light switches. So we've tied cord onto some of the handles. I need help with the shower taps and find it difficult to use the stove as I just can't reach controls because I'm not tall enough. I have a librarian stool to use in the kitchen. It has wheels and when I stand on it the wheels lock. 'Without it I would die of starvation and thirst. Just recently I have been using my elbow crutches around the house because I have found that my ankles were getting sore more often.

OUT AND ABOUT - In the car I sit on a booster seat so that I can see out the window. I always use my crutches at school and my wheelchair for shopping or going for walks as I can't walk comfortably for more than 50m without a rest. I can ride a two wheeler bike and like going around the local bike track about 3km is my limit. I

OVERSEAS

can swim and I have developed my own style which is a cross between back stroke and freestyle.

ORTHOTICS- I have been wearing Orthotics in my shoes for many years. They help my ankles to be more stable and not get as sore as often.

MASSAGE- For the last 18 months I've been having reflexology and massage on my feet and legs every 2 weeks. It has been great to relieve the aches and pains I get in my body, plus it helps me relax and handle daily living.

HEALTH - I really am quite lucky in that I hardly ever get sick. Although h sometimes it get really tired, so I have a lazy day off school to recharge my batteries.

I suppose you've noticed that I haven't talked about all the negative things because when I talk about them it gets me down. To be honest I HATE going to doctors, I HATE going to hospital and I really don't care if people call me names or stare. If they want to waste their time worrying about me, I really wouldn't care less. If I really worried about what people thought of me I probably wouldn't set ,foot outside my bedroom door! It isn't always easy but I'm definitely going to make the most of my life.



Pictured above are some of the young adult MPS sufferers at the Australian Symposium with Mary Pagett. (*Katie Mitchell, Scheie, Catherine Harcher, Maroteaux Lamy and Colin Thompson, Hunter Disease.*)

We were very pleased to receive the two stories from Australia and we would be very happy to publish stories from teenagers and young adults who suffer from MPS in the UK.

FUNDRAISING

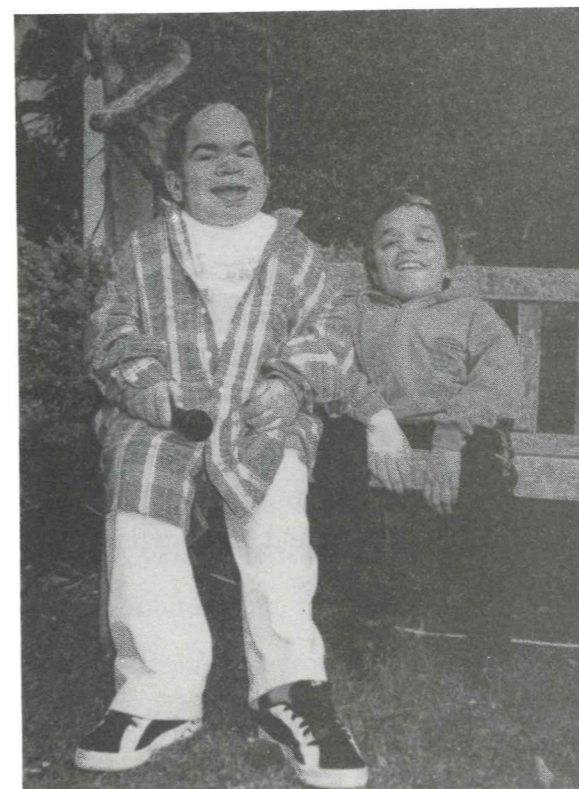
GARDEN PARTY



Pictured here are Edward Nowell and Christopher Isaac with Christine Lavery at the Garden Party held by Edward and his Mum and Dad, Edward and Holly Nowell.

Everyone had a lovely day and lots of funds were raised for the MPS Society.

Pictured below is Annette Puddy and her father, Kevin. Annette aged 13 years suffers from Sanfilippo Disease



FUNDRAISING

SPONSORED ABSEIL

On Sunday the 9th of June several Northwest Families got together for a family day and BBQ. The weather was fine and the site chosen was lovely, a quiet quarry with plenty of greenery to sit in the for the children to play amongst. The only draw back was that someone had had the bright idea of combining this pleasant day out with a sponsored abseil.

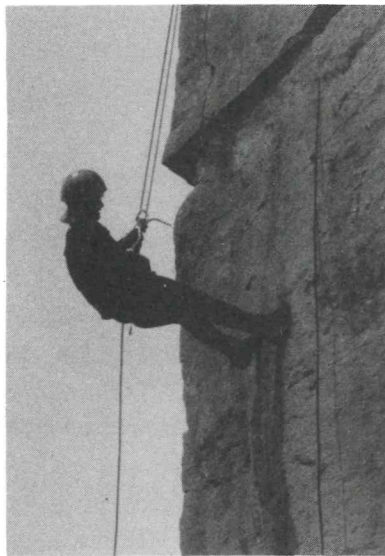
In a moment of madness I agreed to do the abseil, (*This is the woman who got stuck at the top of a children's climbing frame in the park!*) After watching several children float down the 80 foot quarry face I began to gain in resolve, if not confidence.

Eventually my time was up and I must say I did feel a great sense of achievement on safely reaching the ground.

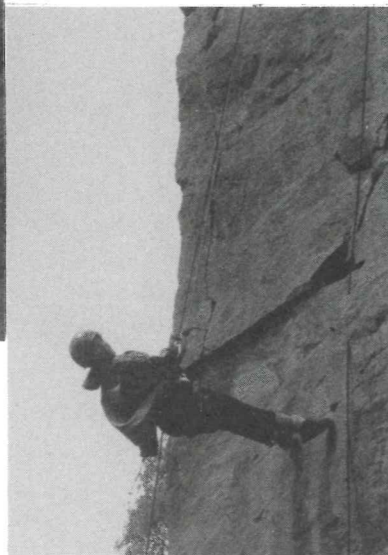
Martine Brennan and June (Matthew Blackburn's Aunt) made it look easy and even managed to smile on the way down. Tom Fuzzard-Tucker's family were well represented and several of them completed the abseil.

Everyone had a good day and all deserve to feel well pleased with themselves.

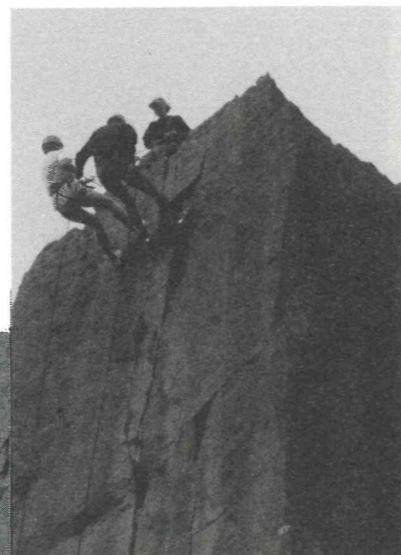
Pam Thomas
Northern MPS Office.



Above is pictured Matthew Blackburn's Aunt June who had time to smile on her way down.



Martine Brennan makes it look easy.



Pam Thomas bravely starting her abseil with Mary helping and encouraging.

FUNDRAISING

Fundraising the Hard Way?

Fire-fighter, Steve Mullen and his friend Dr Simon Worsley attempted to canoe from Devizes to Westminster in under 24 hours - a journey of 125 miles with 70 locks as a further obstacle.

Steve achieved his goal and completed the course last Easter in a time of 23 hours 5 minutes, raising a total of £130 for the MPS Society with special thanks to Fire crews and friends living in the East Suffolk area.



Opposite is Sandra, Rash and Daniel Singh with Sandra's sister, Sue who raised £216.00 for the MPS Society by running the Shakespeare Half Marathon.

As you can see this picture was taken before the run as they are all still smiling.

Cycle Ride from Lands' End to John O'Groats

John Bolton, Stephen Bolton, Philip Bolton, Graham Armitage and Mike Greatbatch, from West Yorkshire all cycled the 866 miles from Lands' End to John O'Groats. It took them eight days from the 22nd July until the 30th July.

It was hard work but they all had an enjoyable time.
Well done Boys.

FUNDRAISING



Pictured above are Emma McLean aged 13 years who suffers from Hurler Disease and her sister, Louise.

“Summer Happening”

This took place at Nairn Academy when Emma asked her Rector if he could organise to raise funds for the MPS Society. This took place on the 13th of June 1996. It was a lovely musical evening followed by a delicious buffet. A great deal of work went into organising this event by teachers and pupils and there was also a “Guess the rabbits birthday”. The rabbit’s jumper was knitted by a parent who cleverly knitted the MPS Logo on the front. This successful evening raised £310.00 for the MPS Society.

Nigel Partington, pictured opposite would like to thank all the people who supported him in his sponsored walk from Wrexham to Llangollen which was 16 miles. Nigel would like a special thanks to go to British Aerospace, Chester and Brymbo Community, Wrexham.



Andy Silcocks from the RS Owners Club in Bristol collected £400 from their special charity rides which they held on the 20th of July. Most of the vehicles were supplied by the Severn Valley Motorsports. Everyone had a thrilling time.

FUNDRAISING



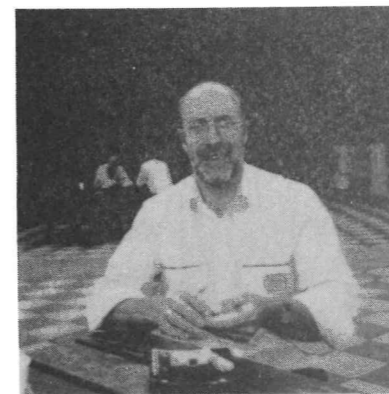
Riding for MPS

The Manchester to Blackpool 10th Annual Bike Ride took place on the 7th of July 1996. About 1,000 riders participated, ages ranging from 12 years to 70 years. It was cloudy with a slight drizzle at the start which cleared by the afternoon. Temperatures were around 16-18 degrees. We set off at 8.30am from Albert Square. It was mainly flat with some nice patches of the Lancashire countryside. The organisation was very good with marshals all along the route. There were refreshment stops, mechanics and ambulances (hopefully not used) at various intervals. I would like to thank my colleagues at Salford Community Care NHS, staff of Heaton Park County Primary School, neighbours and relatives who sponsored me.

For those interested in bike events, write to Bike Events, P.O. Box 75, Bath BA1 1BX, for details.

Ali Arshad Ali, whose 6 year old son, Jibreel suffers from Morquio Disease raised £113 for MPS.

BEFORE AND AFTER - TREVOR'S NEW LOOK FOR MPS



My husband Trevor who has had a beard and moustache for the past 25 years recently decided to shave it off. When this was mentioned to his work colleague's they thought it would be a good idea to sponsor such an



event for a good cause and as our 19 year old son, Lee has Hunter's Disease, MPS was the choice we made.

So the Royal Mail Nine Elms Branch organised the setting up of sponsorship sheets and rapidly gathered many signatures.

It is our great pleasure to enclose cheques for monies raised amounting to a massive £364.60 such a wonderful effort from all Trevor's work colleagues.

Although Trevor looked a bit funny at first it has been worth the sacrifice.

Shirley Brown

(Dear Shirley, We agree with you that the After is better and follicley challenged is a lovely expression.)

FUNDRAISING



Above is Margaret Fitzgerald from Luton receiving a cheque for £527 on behalf of the MPS Society from Claire, Wayne and Mrs O'Bryne, headteacher of St Martins de Porress Junior School.

Margaret is the mother of Mark aged 19 years and Michael aged 15 years who both suffer from Hunter Disease.



Pictured above is David Oulton aged 8 years (Hunter) from Liverpool with his Aunt Selma and a local Rock Group called "Exposure".

Selma and her friends worked very hard in raising a total of £661 from two events which they organised. The first was a Kareoke evening in a local pub and the second was a rock band gig where 7 local groups gave their performances free.

It looks as if everybody had a great time.

FUNDRAISING



Last New Year's Day members and friends of the Littlehampton Diving Club leapt into the freezing cold waters of the river at Littlehampton to raise funds for MPS. Some dived in to the water in full gear whilst others braved the elements completely wearing the briefest of bathing costumes. They leapt from a bridge which is some 26ft above the river - this is like leaping of the roof of your house.

This sponsored leap raised £1,800 and in the photograph below Geoff Springett is presenting a cheque for this to myself at Worthing Aquarena where the members train - the presentation was earlier this summer when the weather was certainly much warmer!

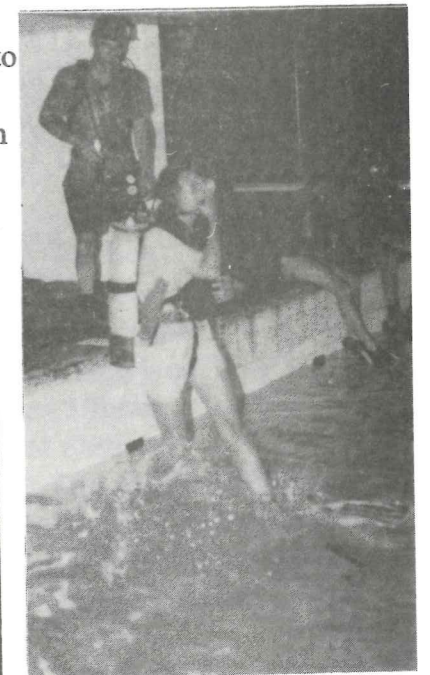
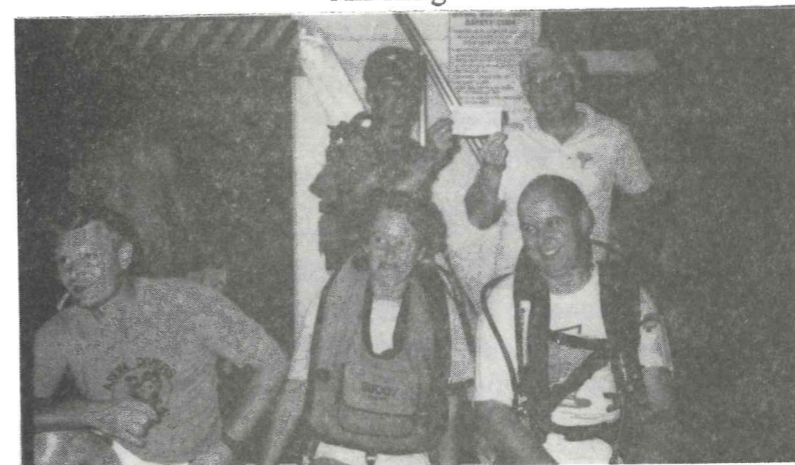
The event was organised by Geoff Springett and Terry Kerry who is the uncle of Jacob, the son of Mary and Andy Wragg.

The other photographs show the Chairman of the Diving Club, Ray Lee and a new member entering the water.

If you are at Littlehampton at the start of 1997 it is an event not to missed - you can even join in! There is fortunately a very good Pub adjacent where everyone goes for lunch and liquid refreshments after the leap.

We are very grateful to people like Geoff and Terry who go to so much effort to raise funds for MPS and I always find it a great delight to meet such people whose hearts are very much in the right place.

Alf King



FUNDRAISING

CHARITY BOXES

Mrs K Lawrie, Hull

Mr and Mrs Cawthorne, Hull

Mrs S Loftus, Post Office, Bensham

DONATIONS IN MEMORY

The Society is grateful to the friends and relatives of:

Mr Peter Powell (Emily Hayward's Grandfather)

Katie Headland

William Holroyd

Louise Byrne

Violet E Rendle (Timothy Norworthy's Grandmother)

SPECIAL OCCASIONS

The Society would like to thank the people who gave donations on the following special occasions.

The Ruby Wedding of Mr and Mrs Pirie - Liam Taylor's Grandparents
Peter Stuart's Birthday (21st?) - Jessica Stuart's Dad
Graduation of Nitika Silhi - Rajesh and Pritika's sister

STAMPS

Barbara Rollison
Rhian McKnight

Ken and Pam Ballard

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

DEED OF COVENANT

Mrs Marlene Hermans

AREA SUPPORT FAMILIES

Robert and Caroline Fisher
The Horrells, Great Samford, Saffron Walden, Essex CB10 2 RL

Tel: 01799 586631

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

Tel: 01435 883329

Bill and Sylvia Blackburn
11 Beatty Road, Nantwich, Cheshire CW5 5JP

Tel: 01270 626809

Tony and Shirley Eyre
7 Elmer Close, Malmesbury, Wiltshire SN16 9UE

Tel: 01666 825215

Mark and Rachel Wheeler
26 Tamarisk Avenue, Reading, Berkshire RG2 8JB

Tel: 01734 861063

Ann and Michael Kilvert
Windy Way, Nantoer, Newtown, Powys SY16 1HH

Tel: 01686 624387

Support Families for the West Midlands

Sue and Jeffrey Hodgetts
6 Godolphin, Tamworth, Staffordshire B79 7UF

Tel: 01827 56363

Zerina and Sajjad Shah
37 Lowe Street, Wolverhampton, West Midlands

Tel: 01902 656147

Support Families for the Yorkshire and Humberside

David and Monica Briggs
7 Humber Street Retford, Nottinghamshire DN22 6LZ

Tel: 01777 700046

Barbara and Trevor Rollinson
43 Crosby Avenue, Scunthorpe, Humberside

Tel: 01724 864115

Support Families for the North West of England

Martine and John Brennan.
105 Barley Cop Lane, Lancaster, Lancashire LA1 2PP

Tel: 01524 382164

Joanne and Gary Adshead
10 Church Lane, West Houghton, Nr. Bolton, Gt Manchester BL5 3PP

Tel: 01942 810109

Support Families for the North East of England

John and Barbara Arrowsmith
11 Penfold Close, Fairways Estate, Benton, Newcastle on Tyne NE7 7UQ

Tel: 0191 2921234

Ann and Ron Thompson
7 Sunningdale Green, Darlington, County Durham DL1 3SB

Tel: 01325 489920

Contact for Scottish Families

Alan and Fiona Byrne
3 Jedburgh Avenue, Rutherglen, Glasgow G7 3EN

Tel: 0141 5695376

Cath and Jim McLean
5 Tern Avenue, Inverness, Highland IV2 3YN

Tel: 01463 224615

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