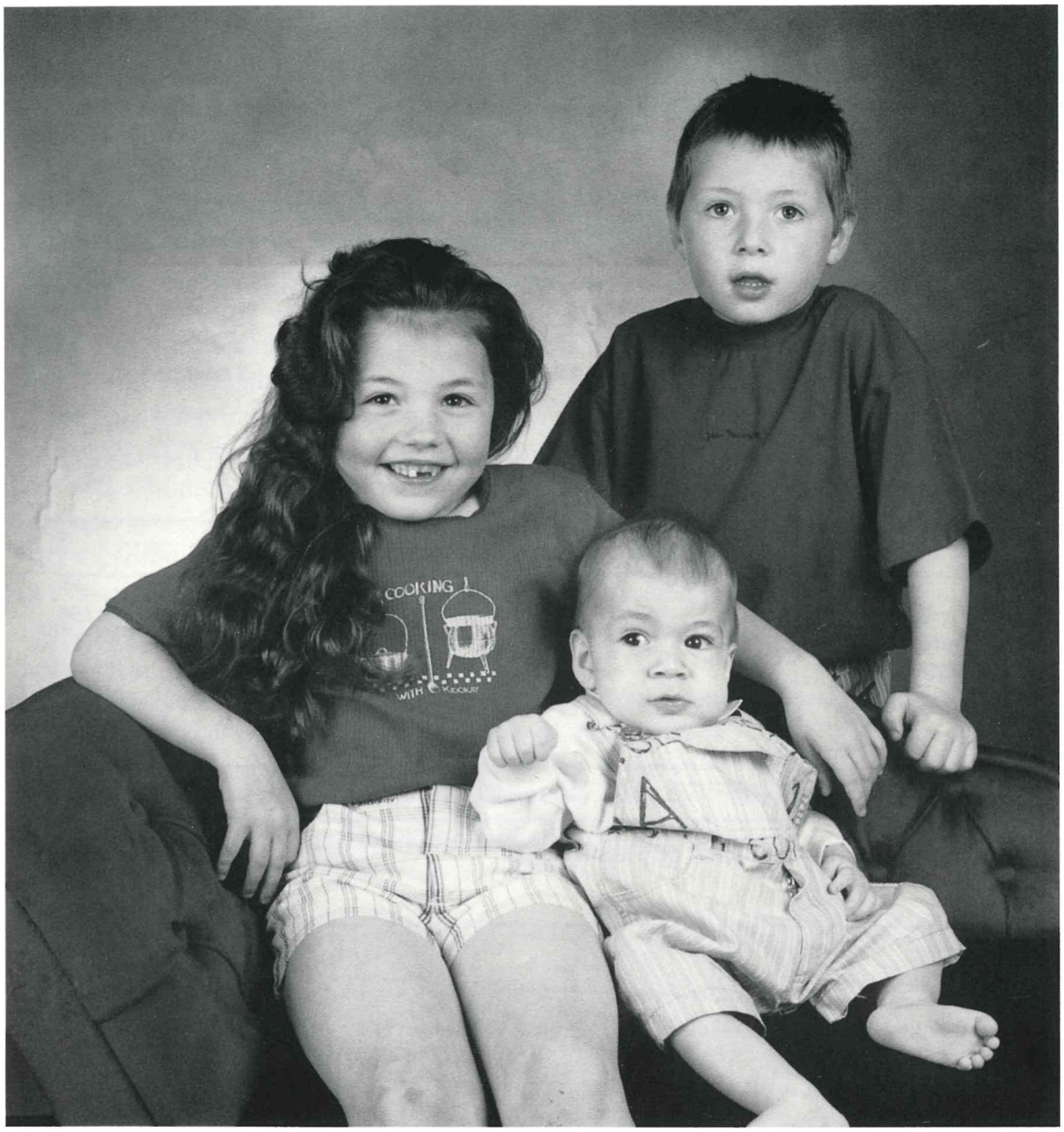
Newsletter

The Society for Mucopolysaccharide Diseases

National Registered Charity No.287034

Autumn 97



MANAGEMENT COMMITTEE

Paul Leonard (Chairman of Trustees)
75 Amyand Park Road, Twickenham, Middlesex TW1 3HG — **Tel: 0181 8923106**

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

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

Jon Lawrie (Vice Chairman)
Flat 7, 75 Avondale Road, Gorleston on Sea, Great Yarmouth NR31 — **Tel: 01493 440429**

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

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

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

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

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

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

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

Dr Claire Garthwaite (co-opted)
'Saddlers' High Street, Bramley, Guildford Surrey GU5 0HP — **Tel: 01483 893502**

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

Christine Lavery (Director)
Joan Evans
Sheila Duffy

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

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

Mary Pagett (Director of Support Services North)
Pam Thomas

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

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

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

The Society for Mucopolysaccharide Diseases

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

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

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

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

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

"CARE TODAY, HOPE TOMORROW"

Front Cover:
The photograph on the Front Cover is of Callum Pollock with his brother and sister. Callum is 1 year old and suffers from Hurler Disease..

CONTENTS

The MPS Staff would like to send their Best wishes to all Families at Christmas

Deadline for the 1997 Winter Newsletter
24th December 1997

Please send us lots of photos

DIRECTOR'S REPORT

Covering the Presentation by Mr P Leonard at the Society's AGM
Sunday the 14th of September 1997

In the last twelve months we have continued to support over 850 families in the UK including the families of 30 children diagnosed with MPS since the last AGM. *This is the same number as in the same period last year*. Some of these families were with us at the Weekend MPS Conference in September. Visits and contact with newly diagnosed families continues to be a priority area of work nationally.

The Society has responded over the year to many families in crisis, particularly in the areas of education, housing, welfare benefits and palliative care. However the Trustees recognise that the Society's advocacy service is severely stretched based on our present staff complement. The Society is actively seeking £210,000 to fund two new development posts to support families from ethnic minority groups and to underpin the work of the area support families, over the next 3 years.

The Society continues to have a major presence at both the MPS clinics held at the Royal Manchester Children's Hospital (RMCH) and Hospital for Sick Children, Great Ormond Street,(GOSH). In July 1997 we saw the world first in gene therapy for Hurler Disease which was funded by the MPS Society. The first two children received their new genes at the RMCH.

A majority of the Area Support Families participated in a highly stimulating training weekend in Lancashire. Whilst recognising possible limitations, our volunteer support network is being encouraged to offer increased telephone support. This year more Area Family events than ever have taken place throughout the UK. These included Christmas parties, outings, BBQ,s and even a day at the beach. In Northern Ireland the first family 'Share Weekend' has taken place.

The Society is proud to have achieved a First MPS clinic for Northern Ireland held in Belfast and a First Welsh MPS clinic held in Cardiff. Scottish MPS families came together for their regular annual clinic this year held at the Royal Alexandra Hospital in Paisley.

On the advice of the Forestry Commission the Society has changed its timing for future plantings in the 'Childhood Wood' to the Autumn. On the 25th of October 1996 thirty bereaved families planted oak saplings in memory of their children and Sir Andrew Buchanan, Lord Lieutenant of Nottinghamshire, unveiled the Childhood Wood Information Board. Many of the trees having made a slow start are now shooting profusely and are very much alive. The few which had died were replaced earlier this year.

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 holiday could not have been possible without the practical help of volunteers from the Royal Logistics Corp. Hullavington and Leamington Spa.

DIRECTOR'S REPORT

As a result of the monies raised from Jeans for Genes Day (1st March 1996) the Society was able to support seven new research projects that may lead to gene therapy or enzyme replacement in the future. Several of these projects are over 3 years and we are now dependent on the success of J4G Day that took place on the 10th October 1997 to fund years 2 and 3 of these projects (£250,000) and to be able to consider new research projects.

After a financial deficit of £48,539 in 1994/95, in 1995/96 we achieved a small surplus of £392.(This does not take into account J4G which is restricted funds). 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 the Society has been successful in achieving three major grants from the National Lottery for Family Support in Scotland, Northern Ireland and Wales in addition to our First National Lottery Grant under poverty to subsidise the holidays for 3 years (ends October 1998). The Department of Health, London and DHSS in Belfast have awarded core grants over 3 years and the John Ellerman Foundation have given a grant of £10,000 per year for 3 years. Unfortunately a substantial application to the National Lottery to fund a National Development Officer for Ethnic Minority Families was unsuccessful. Fundraising continues to be a crucial source of income for the Society.

Trustees

At the Management Committee meeting on the 27th September 1997 Dr Claire Garthwaite was co-opted to the Management Committee. Claire and her husband James have two young sons, Thomas and Louis who both suffer from Hunter Disease.

Jon Lawrie and Vic Lowry were elected as Vice Chairmen. Jon who lives in Norfolk is the father of Stuart who suffers from Sanfilippo Disease. Vic and his wife Sue live in Hertfordshire and lost their youngest daughter, Sarah who suffered from Maroteaux-Lamy when she was 19 years old.

Finally the Society has said good bye to Dr Bryn Neal who has been a Trustee since the Society was founded in 1982. Bryn who is a General Practitioner in Amersham has given the Society so much help and valuable advice and must take considerable credit for where the MPS Society is today. I hardly knew Bryn or his wife Ann when I wrote asking if he would be a founding Trustee all those years ago. I still have Bryn's little note saying he was willing to be a Trustee but didn't have much spare time to offer!

Thank you Bryn for everything.

We are delighted that Bryn is going to stay in touch and remain a member of the MPS Society's Peer Review Committee for research grant applications.

Christine Lavery
Director

MILESTONES

New Families

Mr and Mrs Hendry from East Sussex whose one year old daughter, Victoria has recently been diagnosed as suffering from Hurler Disease.

Mr and Mrs Glover from Burnely whose 3 year old son, Robert was recently diagnosed with Sanfilippo Disease.

Aiysha Hannif has recently been diagnosed with Sanfilippo Disease. Mr and Mrs Hannif live in Shipley, North Yorkshire.

Mr and Mrs Brown from Doncaster whose 5 year old daughter, Natalie was diagnosed last year with Sanfilippo Disease.

Mr and Mrs Khan from London whose daughter, Amina has recently been diagnosed as suffering from MLII.

Joanne and Alex MacGregor's son Alexander aged 1 year has recently been diagnosed as suffering from Morquio Disease. The MacGregor family come from Darvel in Ayrshire.

Vivienne and Ian Von Memerty from Manchester whose daughter Valeska and son Oscar have been diagnosed with Maroteaux Lamy Disease.

Val and Sep Moxon whose 4 year old son, Jamie has been diagnosed as suffering from Hunter Disease. Jamie lives in Deepcar, Sheffield.

Nazareen and Janwgu from Birmingham whose 5 year son, Mohsin has recently been diagnosed as suffering from Sanfilippo Disease.

Congratulations

Congratulations to Nigel and Allison Oliver on the birth of a little brother for Amie. Jacob was born on the 26th July 1997.

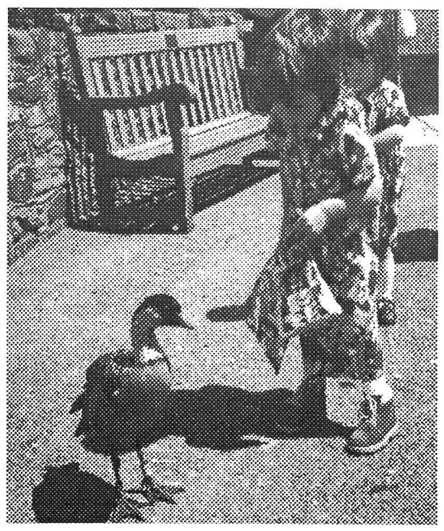
Congratulations to Paula and James Connelly on the birth of a little girl, Alanah who was born in November 1996.

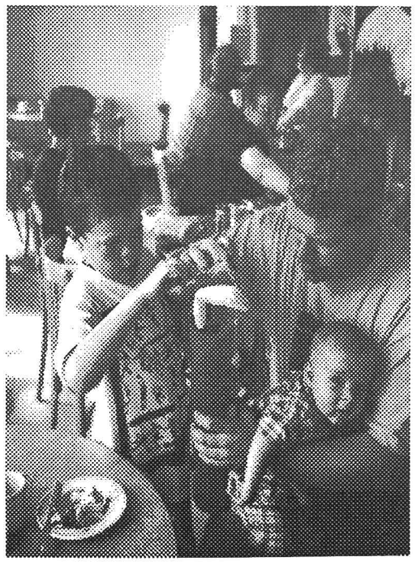
AREA FAMILY SUPPORT

Welsh Family Day - 6th July 1997

Yet again the Welsh Summer get together was blessed with wonderful sunny weather. Thanks to all the families who managed to join us at the Wildfowl and Westlands Trust at Llanelli. We all had a great time, lots of chat, plenty to eat and see, finishing the day with cup of tea and a grand draw. Hope Rhian is taking lots of water with her prize. Many thanks to all families and friends for their generous draw prizes. A special thanks to Sue and Winford for finding us a great venue.

Love and Best Wishes to all families
Anne and Mike Kilvert





AREA FAMILY SUPPORT

South East Family Day - 1st June 1997

A bright summer's day, even though a little breezy, made the perfect start to our first event.

Families began to arrive shortly after 10.30am, we think the Nurse's were tying to make up for the late arrival at last year's BBQ. Soon everyone was relaxing in the garden chairs and cultivating their tans. The children had a tiring day playing on the climing frame and playing footlall.

Michael managed to avoid any cooking even thought he was supposed to be cook for the day. However, his brother served a feast fit for a king and Thomas kept everyone entertained by giving several drum concerts.

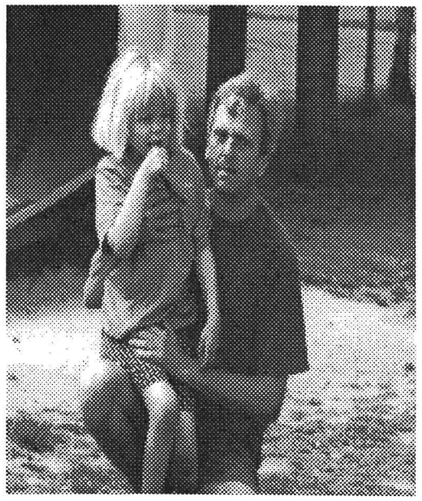
Karen and Mike Wheeler

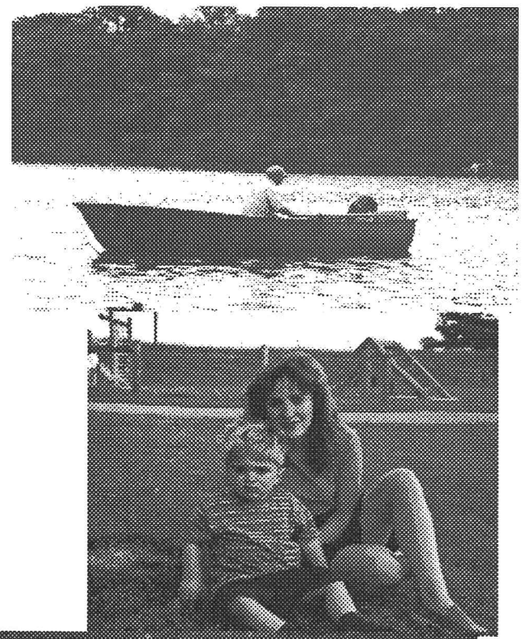
AREA FAMILY SUPPORT

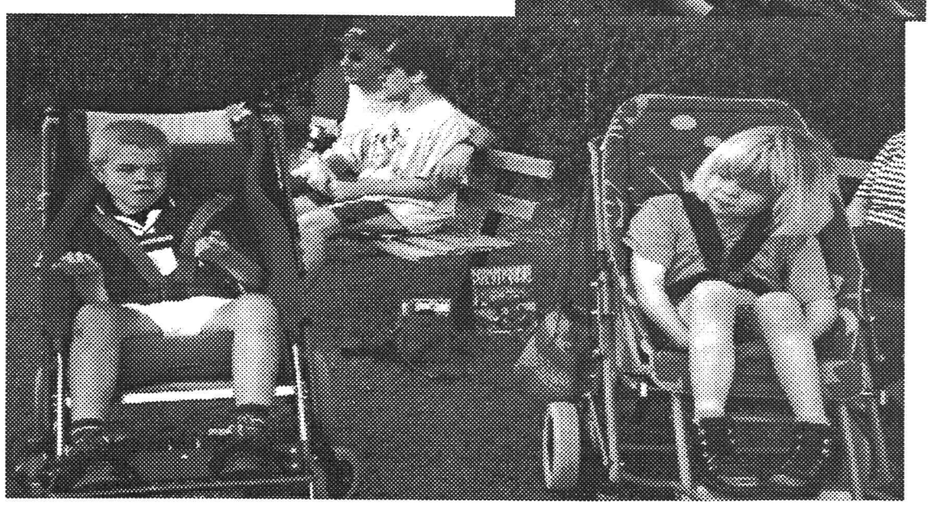
East Anglia Family Day - 13th July 1997

This day was held in Fritton Lake Countryworld where all the families attending had a lovely day despite the downpour after lunch. It was good to meet up with friends and make friends with new families.At Ftitton Countryworld the children enjoyed the many activities including a train ride, fun on the boats and a horse cart ride.

Julie Thacker

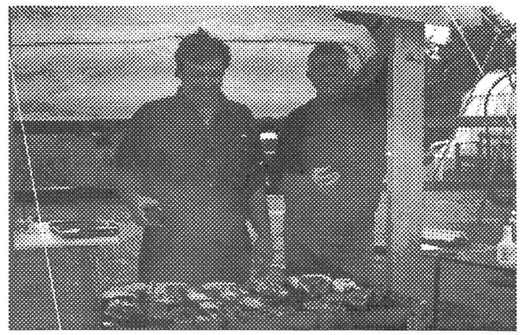






AREA FAMILY SUPPORT

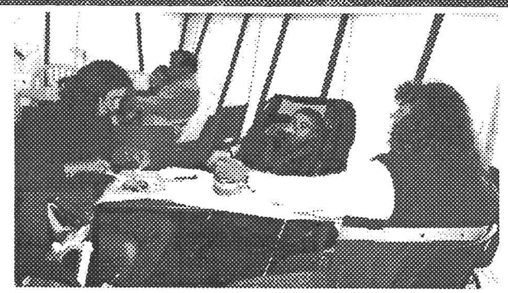
Potteries and North West Family Day - 22nd June 1997



Potteries and North West Area Families had a barbecue on Sunday 22nd June 1997 at Gilfords Dairy, Willaston, Cheshire. I expect most people can remember what a terrible month June was for bad weather and this particular Sunday turned out to be no exception but thanks to all the families who turned up to make the day successful, despite the rain. Thank goodness we had a marquee in which we were able to enjoy the lovely barbecue cooked by Bill, Chris Grandidge and my friend Jean which was cooked under a "makeshift" canopy, so nothing was spoiled. Between the heavy showers the children were able to play and run around and had fun on the bouncy castle.

Thanks to everyone who turned up for your support.

Sylvia and Bill Blackburn



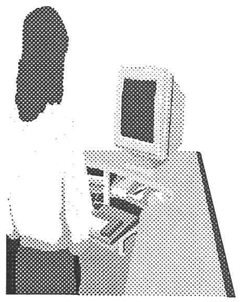
FAMILY SUPPORT

Well here it is : We have already embarrassed the Trustees so now it is the turn of the MPS office staff to be included in the Rogues Gallery.

Above: Mary Pagett

Above: Pam Thomas

Opposite:
Christine Lavery

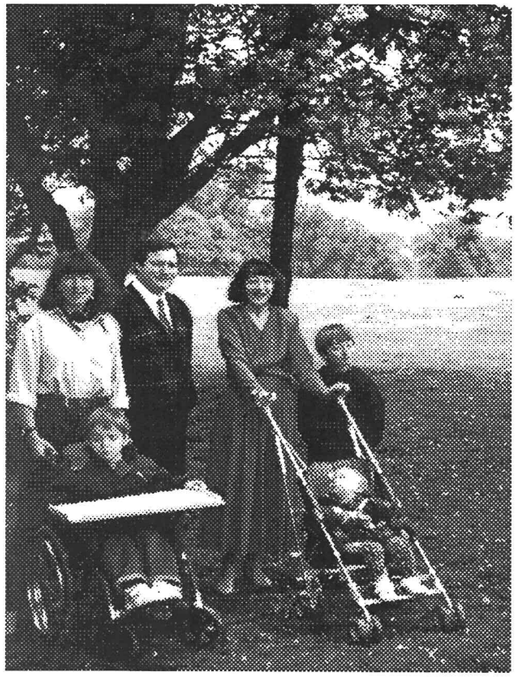


Below: Sheila Duffy

Below: Joan Evans

FAMILY SUPPORT

GETTING TO KNOW YOUR AREA FAMILY



Over the next few issues of the Newsletter we will be printing photographs of the MPS Area Support Families. We hope that if you have not met your Area Family then this will help put a face to the voice.

Pictured opposite are the Stevenson Family from Harthill in Scotland. They are Clint, Karen, Ross, Martin and Rebekah. Martin's aunt, Karen is pushing his wheelchair.

Martin is 9 years old and suffers from Sanfilippo Disease.

Pictured opposite are the Fisher Family from Safron Walden, Essex. They are Caroline, Bob, James, Francesca and Adam.

Dog and Cat.

Twelve year old James has Hunter Disease.

FAMILY SUPPORT

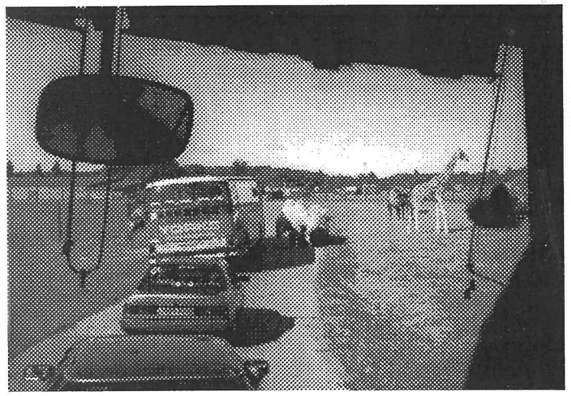
The 1997 MPS Family Conference.
Stakis Country Court Hotel, Northampton.

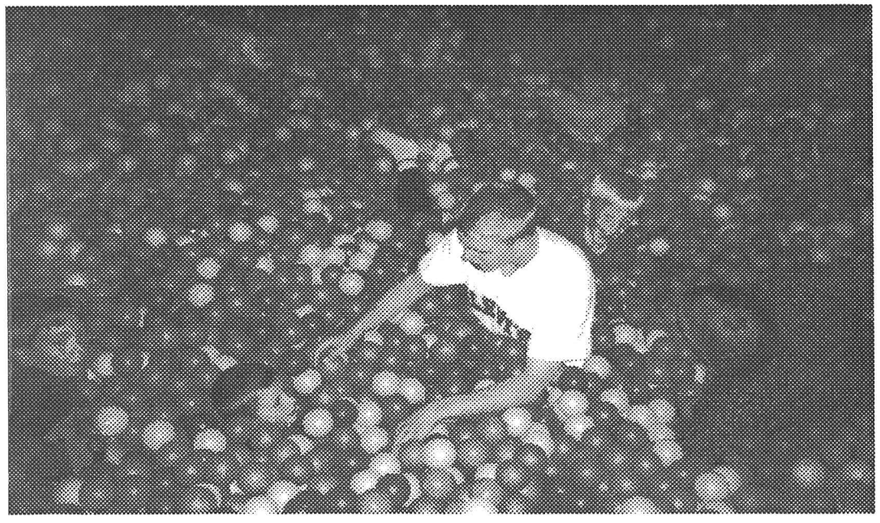
This year's conference was very successful from the staff's point of veiw. We would like to thank all the volunteers and all the families who attended. We were especially pleased by the way everyone worked together and made our job easy by having read instructions and timetables beforehand.

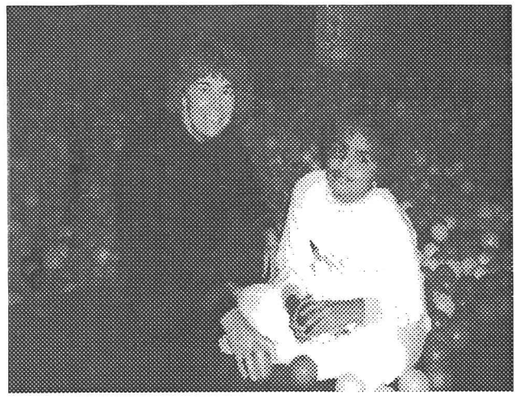
As you will see from the following photographs the children had a wonderful time on the outings and the volunteers seem to be enjoying it too!

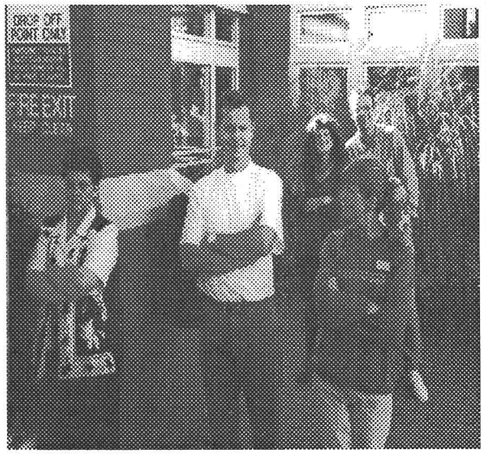
We would also like to thank the staff of Thorpe Park, Pot Bellies Restaurant, Jarman Park Bowling Alley and Woborn Safari Park for helping to make the weekend so enjoyable for the children and volunteers. We would like to thank the Stakis Hotel staff who yet again were helpful and pleasant and inobtrusive and as always were ready to accommodate our various requests.

FAMILY SUPPORT

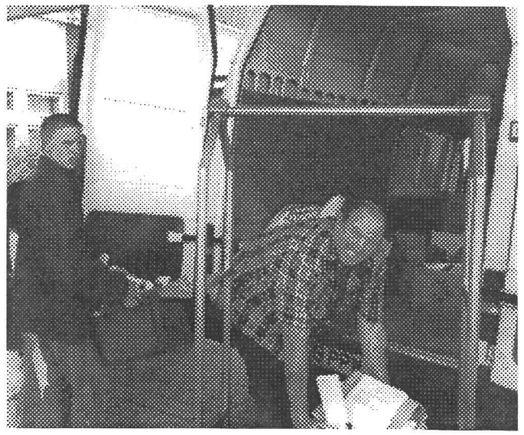






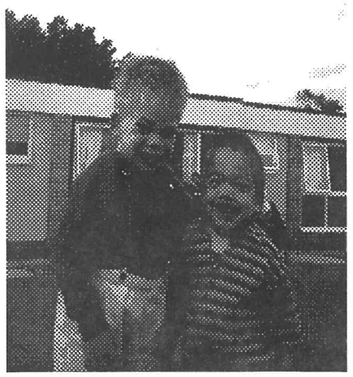


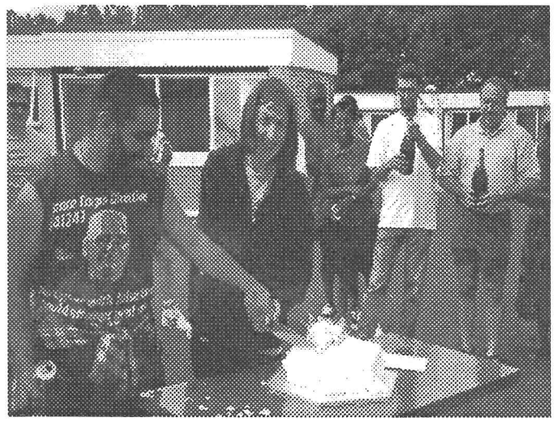
FAMILY SUPPORT

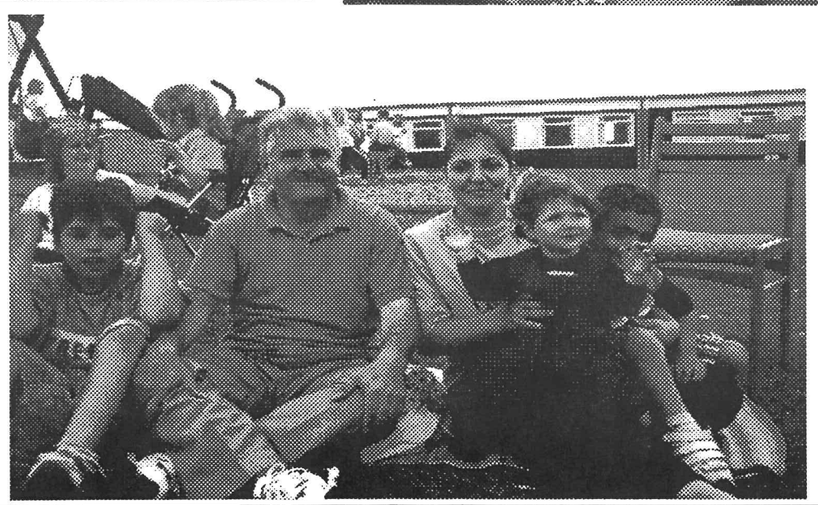


FAMILY SUPPORT

MPS Family Holiday at Haven Holiday Centre, Filey - July 26th - August 2nd.







FAMILY NEWS

'MARA'

HOLIDAY SUPPORT AND RESPITE CARE SERVICE IN WEST CORNWALL

FOR YOUNG PEOPLE & ADULTS WITH A LEARNING AND/OR PHYSICAL DISABILITY. PERSONALISED ARRANGEMENTS, DESIGNED TO SUIT INDIVIDUAL NEEDS

FOR FURTHER INFORMATION TELEPHONE: 01736-787406
OR WRITE TO: TRACY WATKINS, 'MARA', 2 BOSCASWELL TERRACE, PENDEEN, PENZANCE, CORNWALL TR19 7DS

Twenty months ago David and Tracey Watkins left our village in Buckinghamshire to start a new venture just outside Penzance. They had bought two adjoining cottages with a vision of converting them into a support and respite care centre for any one, or any family, who finds it difficult to have a holiday.

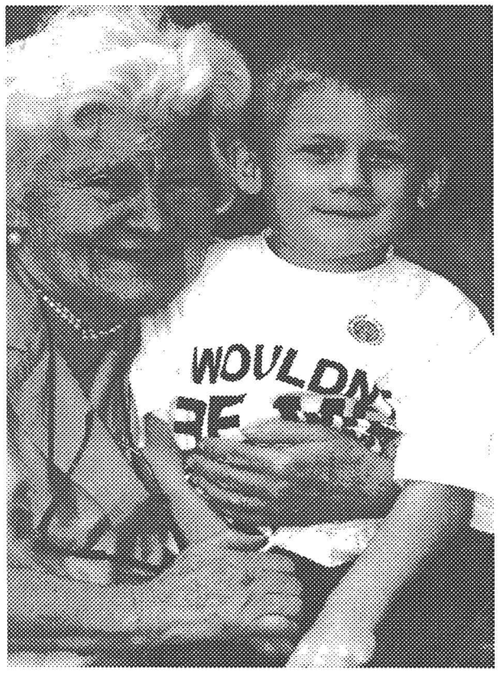
We were lucky enough to visit them this summer and their venture is now fully operational. The ground floor consists of a large bed - sitting room and all mod cons within easy access. This leads off to a modern, purpose built bathroom/toilet designed for people with a disability. Upstairs there are further rooms of varying sizes. All meals are prepared in the kitchen and served in the ground floor dining room. Special diets can be catered for. David is an area beat bobby in St Ives and is, therefore, often around during the day.

Tracey is a former manager of a day centre in High Wycombe and is well qualified to look after disabled people of all ages. She knew our son Matthew, who suffered from Hunter Syndrome, and is therefore well aware of MPS children and their families' needs. So, if you need a break in beautiful West Cornwall at any time please give Tracey a ring. She would love to hear from you.

Jenny and Andy Hardy

FAMILY NEWS

The following is an extract of an article from the TV Times by Jill Todd.



Little Sam Wheeler lay on his hospital bed scarcely able to move after a spinal operation. His tiny body was encased in a rigid steel frame, yet nothing could wipe the excitement and pleasure from his face.
Clutched tightly in his right hand lay a gleaming new Power Rangers sword a he had just been given by "Coronation Street", battle-axe, Maud Grimes, played by Liz Bradley, 73. She fell in love with Sam, six, when she met him at the 1995 Children of Courage awards ceremony and has since kept in touch with the little boy who has a rare genetic disease which means he'll never grow bigger than a three year old.
'He is an absolutley delightful child, without a trace of self pity' says Liz. 'He never compains, despite his pain and just chirps on in his cheeky, cheery little way.'

Because of Sam, Liz has become a patron of the Jeans for Genes Appeal which aims to raise £2million for research into genetic disorders. The idea is that on Friday, 10th October 1997, people will abandon their working clothes and wear jeans instead to earn sponsorship. 'Because of Sam, I've become aware of just how many genetic diseases there are,' says Liz. 'One baby in 30 is born with some form of genetic disability.'
Sam's mum Rachel, a midwife recalls the first time she knew something was wrong with her son: 'I always felt uneasy but doctors insisted there was nothing amiss. but when Sam was a toddler I noticed his spine looked strange. After getting out of bed he'd be stiff and hobble along like an old man. When Sam was two Rachel and husband, Mark, a flooring contractor, noticed Sam had stopped growing.
'We were devastated to learn Sam had the genetic disease, Morquio' says Rachel. Only one in 500,000 people has the rare disorder. Rachel, 30 and Mark, 33 both carry the recessive gene. 'It was just desperate bad luck', she says. 'But it is not something you think about when you fall in love and get married, is it?'
Sam's brother Ryan, 4 years old is also a carrier but it won't affect his children unless he marries another carrier. Sufferers of the disease tend to have a shorter life and can have both severe mental and physical disability.
Sam is only physically affected.
'Sam won't grow any more' Rachel explains. 'His internal organs will try to grow but his bones have stopped so he will become more and more disabled and his rib cage will be pushed out. His spine operation two years ago was to slow the advance of the disease. He can walk at the moment but not far because his joints hurt. He doesn't like a wheelchair because he wants to be like other boys so we use a big buggy. We have never wrapped Sam in cottonwool and we have been truthful with him form the word go.' adds his mum.
Sam goes to a normal school near his Reading home. 'When the school wanted Sam to have a special chair to help support his back he wouldn't have it. Instead all the children were given a similar chair and that made him happy. He desperately wants to be normal.
He once reduced me to tears when he said

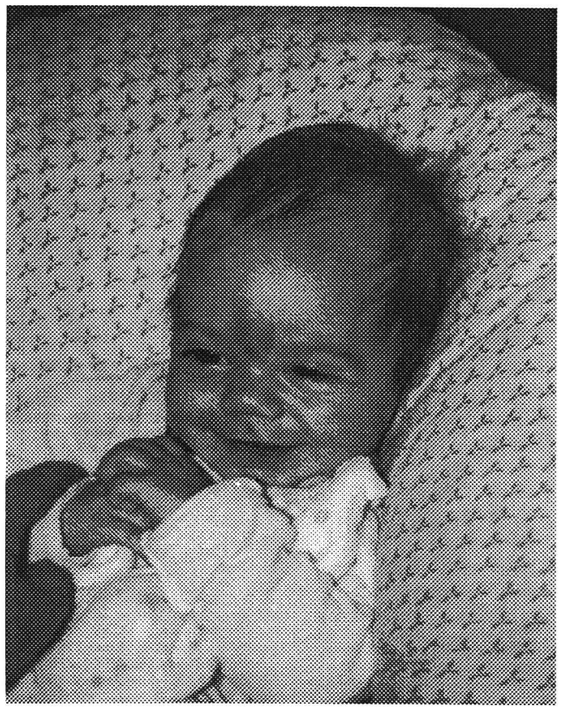
"Mum, I may be small in my body but I'm big in my heart".

FAMILY NEWS

Pictured above are 8 year old Katie Martin (ML2) and her sister Lisa who is 5 years old. The girls are pictured with their cousins, Chantell aged 7 years and Nicola aged 5 years old.

Above are Lisa and Katie.

Sandra Martin (proud Mum) sent us these photographs of the girls who were all bridesmaids at her sister's wedding in July 1997.



This beautiful baby is Nathan Menker who was born on the 2nd April 1997 and was nearly delivered in Daddy's car. Alison and Klaus are very pleased that brother, Joshua loves him to bits and is very impatient for him to start playing football.
The girls in the office would love a cuddle. So anytime you are passing Alison!!!!!!

FAMILY NEWS

XMAS PARTY
HOME COUNTIES

The Home Counties Christmas Party will be held on the 7th December 1997. Further details will be sent out to families when the venue has been confirmed.

XMAS PARTY
WALES

The Welsh Christmas Party will be held on the 23rd November 1997. Please contact Anne and Mike Kilvert for further details.

BARBIE

The latest Barbie doll in America, called 'Share a Smile' Becky, is in a wheelchair but she will not be able to visit other Barbie friends as her wheelchair cannot get through the front door of a Barbie House

Pretty Realistic Then!

Something happened recently which I thought you would find interesting. My 18 year old daughter, Natasha suffers from Sanfilippo B and lost her speech many years ago. Karen, Natasha's care assistant who comes twice a week was having trouble feeding Natasha. Natasha's grandparents were on a welcome visit and Nan sat Natasha between her legs so Karen could feed her the scrambled eggs easier. Natasha choked a little and coughed the egg out. Karen said "Oh dear, Natasha - all over Nanny's arm" At this point Natasha replied clearly "All over Nanny's arm!!!!

As you can imagine we were all amazed. I was not , much to my regret in the room but both Karen and Nan witnessed it.

I thought you would be interested because it proves the reason we are always careful about the things we say about Natasha in front of her. It also highlights the fact that because someone has lost the power of speech and verbal communication it does not mean that they are not aware.

Has anyone else had this experience, when a child who has not spoken for years suddenly repeats a sentence?

Julie MacIntyre

FAMILY NEWS

Helen House Children's Hospice celebrates it's fifteenth birthday in Novenber 1997. fifteen years which the care and needs of children with life limiting conditions and the support of their families have been more widely recognised.

In 1980-81, as a result of her friendship with a little girl called Helen, Sister Frances Dominica, then Mother Superior of the Anglican Society of All Saints in Oxford, spearheaded an appeal to open the world's first Children's Hospice.

In November 1982 Helen House first opened it's doors to children and their families. This purpose built house is equipped to care for up to eight children in a "home from home" environment. Here parent bring their sick child, brothers and sisters, and share or set down the burden of caring for a short time. The multiskilled team look after the sick child as the parents wish, so that they rest, have a holiday, take their other children for special activities, without having to worry about the daily chores. Here families can find friendship and practical help and above all - time.

In those early days, children came from all over the UK; then, as happens with good ideas, others started appeals for children's hospices around the country. Helen House was followed by Martin House in 1987, by Cambridge and Acoms in 1988 and the children's hospice movement was on the way. In 1995 the Association of Children's Hospices was launched with membership expanding in 1996 to include proposed children's hospices.

The Associaion meets regularly and looks at all aspects of care, administration, policy and fund raising. A national awareness week is planned in 1998. Paediatric Palliative Care is a field in which there is a growing interest and Children's Hospices have considerable experience.

The Children's Hospices now operating around the UK are all individual, charitably funded organisations, with their own particular knowledge, expertise and management structures. All are staffed by multi-skilled teams whose common interest stems from one concem, the same concern which inspired Sister Frances Dominica to found Helen House - that is the desire to be alongside the sick children and their families as friends along what can be a long and lonely road.

Names and Addresses of the Childrens Hospices in the U.K.

Acorns Children's Hospice, 103 Oak free Lane, Selly Oak, Binningham 829 6HZ

Demelza House, Demelzehouse Children's Hospice, The Old Priory, Mill Road, Findsbury, Rochester, Kent ME2 3BT

Derian House, Chancery Road, Astley Village, Chorley, Lancashire PR7 1DH
Francis House, 390 Parrswood Road, Didsbury, Manchester M20 5NA

Helen House, 37 Leopold Street, Oxford OX4 1QT

Hope House 12, Nant Lane, Morda, Oswestry, Shropshire SY10 9BX

FAMILY NEWS

Little Bridge House, Redlands Road, Fremington, Barnstaple, North Devon EX31 2PZ

Little Haven Children's Hospice, 126Chalkwell Avenue, Westcliffe-on-Sea, Essex SSO 8HN

Martin House, Grove Road, Clifford, West Yorkshire LS23 6TX

Naomi House, Stockbridge Road, Sutton Scotney, Winchester, Hampshire S021 3JE.

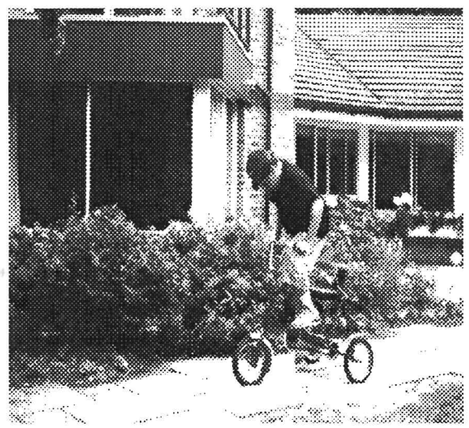
Quidenham Children's Hospice, Quiden ham, Norwich, Norfolk NR16 2PH
Rachel House, Avenue Road, Kinross KY13 7EP
Rainbows Children's Hospice, Lark Rise, Off Hazel Road, Loughborough LE11 2TLS

The Children's Hospice for the Eastern Region, Milton, Cambridgeshire C84 6AB S021 3DA

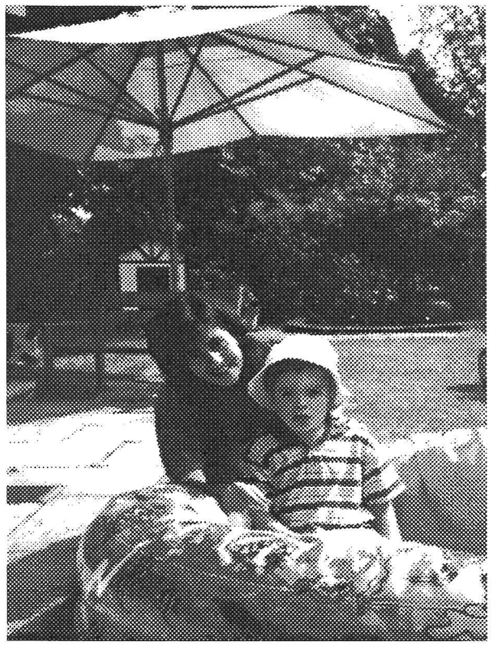
Ty Hafan, The Children's Hospice in Wales, Hamard House, Cardiff Road, Barry, Vale of Glamorgan CF63 2BE

Further information from ACH Secretary, Graham Collins, General Manager, Quidenham Children's Hospice.

Mary Thompson
Head Nurse, Helen House.



Pictured above: Simon Mansfield Sanfilippo



Pictured above: Adam Brown aged 6 years. Sanfilippo

FAMILY NEWS

I am a mother of two boys who both suffer from Mannosidosis. Mark is 15 and his brother Philip is 13.
The diagnosis was made through a routine urine test when the boys were 6 and 4. Prior to the diagnosis being made there were few symptoms to indicate that anything was wrong, apart from a slowness to crawl and walk and Mark's delayed speech, there were no visible indications that anything was wrong.

Mark attended a day nursery and it was while in attendance that the teaching staff and school nurse noticed problems with speech, hearing and learning difficulties. This resulted in him having a weekly speech therapy session. Following nursery Mark was statemented into an MLD junior school.

Philip followed Mark first into the nursery and then he was also statemented into the MLD junior school .

Once the enzyme deficiency was detected and the urine sample sent to the Royal anchester Children's Hospital, Willink Unit, it was confirmed that both boys had a mucopolysaccaride disease.

After being told this prognosis and the devastating consequences of the condition they were admitted to RMCH for numerous tests. During this time and for a long time after I found the diagnosis very hard to accept and went into a long period of denial.

The following few years went by without any major health problems and both boys seemed to be developing well.

At the age of 11 Mark started to complain about pain in his right leg. This would flare up from time to time and particularly after a lot of walking or sporting activity. This was investigated and discovered that on his right side the head of the femur and the socket had not developed properly. It was agreed that because Mark's symptoms were not affecting him too often that treatment would be left until a later date.

Over the next 3 years Mark's pain was steadily getting worse until he was suffering on a daily basis so it was decided that Mark needed treatment. So in October last year he had an operation. The operation was expected to involve a femoral osteotomy and reforming of the socket. Unfortunately the operation did not go as planned and only one part of the operation was performed, the femoral osteotomy, breaking of the fema and realigning it with the socket and putting in metal work to hold the bone in place until healing had taken place.

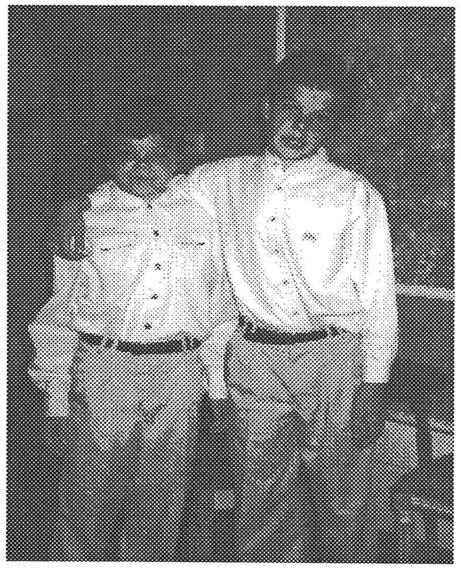
Mark was in hospital for 10 days and then allowed home. One week later Mark's wound began to swell .

It swelled so much that Mark was readmitted to hospital to undergo another operation to open the wound and to wash out the area.

Two weeks later the swelling occurred again and it was suggested that the wires holding the metal work in place may be causing an irritation. So on 7.11.97 Mark was readmitted to hospital to have the wires removed. It was also decided to dress the area with a pressure dressing and this eventually solved the problem.

Over the following months on visits to the outpatients department it was becoming clear from x-rays that the bone which had been broken and plated was not healing. On 1.3.97 Mark was admitted once again to hospital where an operation to remove bone marrow from his hip and inject it into the break of the bone to encourage the bone to start healing. This failed and 6 weeks later Mark was admitted into hospital to have the whole process redone (5th operation).

FAMILY NEWS



I was devastated to find on our next visit to hospital that no more healing had taken place so the two previous operations had been futile, another operation was suggested.

Mark had an appointment with another consultant to see if he had any other suggestions. It appeared that the metal work in Marks leg had been moving, due to the fact that it had now been in place for some eight months, this was preventing the bone from making a connection and healing. So here we are again in hospital with Mark being immobilised into a hipspiker in the hope that this will give the bone a chance to heal. Mark is now having to face being immobilised for the next seven weeks.

Throughout this 8 month ordeal Mark has managed to remain cheerful even though he has not been able to bear weight since the original operation back in October.

Mark's brother Philip has a problem with his ankles which have been causing him some pain, this has been relieved be inserting specially made insoles into his shoes. He is able to lead a near normal life as possible at the moment, attending school and participating in all activities

Throughout this treatment there has been no suggestion that this problem of healing, both wound and bone, have anything to do with Mannosidosis. After speaking to the experts involved in Mark's case it appears that no other MPS child has, as far as they are aware, ever experienced this problem. If anybody reading this article has a child with Mannosidosis or a child who has experienced anything similar to Mark I would love to hear from you via MPS Society. This obviously is also directed to anybody in the medical professions who could shed any light on this subject, I would be very grateful for any information.

UPDATE 19.8.97

Success! Mark has just had the hipspiker removed and ex-rays show that his bone has healed at last 'yes'

Mark is now undergoing regular hydrotherapy and physiotherapy sessions to build up his weak muscles, he has started to walk with some support and hopefully it will not be long before Mark is walking independently.

Jayne Weir Wirral, Merseyside
email address: Jaynew@netcomuk.co.uk

OVERSEAS NEWS

Frank Patrick Augustus Zimmerman -A Precious Star

I re-launched a hibernating organisation in New Zealand, renaming it the New Zealand M.P.S. and M.L. Family Society because I knew that other families are feeling the same lonelieness with their sorrow and frustration in their lack of knowledge that my family has felt since Frank's diagnosis.

Frank is now 8-years-old. He was diagnosed with Hunter Syndrome (MPS II) when he was 2½ years-old after I had pursued what can only be described as "Mother's Intuition."

As Frank is the youngest of my four children (Claire, 14; Rachel 13; Ria 1I) the only boy and the only boy, in my husband Mike's family, his birth was greeted with special joy. He was named for all three grandparents not yet represented in our children's names - Frank (my Dad) Patrick (my Mom) Augustus (Mike's Father) Zimmerman.

I was awestruck by the radiant smile, complete with dimples, which lit up his tiny face on his first day of life. I always keep my babies with me from birth, I feed them and hold them while they sleep as much as possible. Whenever he slept, from day one, Frankie would smile this full, toothless smile. A joyful smile has always been a gift Frank shares freely.

As an experienced and doting Mum, however, I began to notice "peculiarities" about my precious boy by the time he was about 6 months old. He had some respiratory and ear infections which none of the girls had experienced so young. I noticed when bathing him at about 8 months old that his head didn't seem to have properly closed and seemed larger at the front. When I bathed his back, it seemed unusually curved. I brought up these concerns at visits to my G.P. He replied that "some babies have lumpy heads" and that "Frankie is just a bonny round boy.'' As to his snoring and the fact that when Frank had a cold his nose ran thick and profusely - "he'll outgrow it."

Frank was late to walk compared to the girls. When at 14 months he finally took unassisted steps, we were delighted. He toddled along with small steps that we thought were ever so cute. But when Frank was 2-years-old, my sister-in-law one day referred to it differently, "What a funny way he has of walking," she undiplomatically declared.

I realised, however, that she was right. I had raised this issue too with my G.P., as well as Frank's not yet speaking intelligibly "as though he was repeating sounds heard underwater."

"He's a boy with three sisters to do his bidding," the doctor had replied.

Now, I realised that although such reassurances were what I hoped most to hear, the doctor never really examined any of the issues I'd raised.

I insisted Frank have a proper hearing test. The results? A severe hearing loss.

I visited another doctor in the practice asking that she examine his back, his distended stomach and the way he walked. She had him walk 4m down a hallway and simply proclaimed, "He has a curve in his spine, I'll refer you to an orthopaedic surgeon right away."

OVERSEAS NEWS

The orthopaedic surgeon examined Frank two weeks later saying he'd do corrective surgery on the kyphosis when Frank was 6-years-old **and** he'd like to refer Frank to a paedicatric specialist as "we may be dealing with more of a syndrome here."

On the ride home that day I felt immense sadness, thinking my son will never be able to play rugby and knowing it was one of his Dad's dearest dreams to cheer his only son across the try line.
But, two weeks later, the paediatric specialist told me that my baby boy "probably" had Hunter Syndrome a form of M.P.S. that it was degenerative intellectually and physically and fatal.
I cried unrelentingly while restraining him for a complete set of skeletal x-rays and then the urine test, which would tell for certain. Then I drove home and phoned his father at work simply saying "Come home." He registered the severity of the situation by the tone of my voice and burst into tears for one of the rare occassions in his life.
We asked the G.P. for any information he might have on Hunter Syndrome.
"Well 1 am absolutely certain that he doesn't have this rare, devastating disease," he replied. But he obliged by photocopying a page from his medical book. It had a very outdated photograph of a boy unclothed but for knee-high socks wrinkled about the child's feet. It was harsh, but, the boy looked so much like our son, right down to the bushy eyebrows. The text described Hunter as "gargoylism." We were absolutely despondent.
Well, you all know how difficult it was to rise that morning one week later to receive the test results, dress the children, make breakfast, make lunches for the girls, try to smile as we kissed them at the school gate and carry on to the paediatrician's office.

He had a pamphlet with a bit more information and a contact for the M.P.S. Society. A hair root test (a shocking dash of one' s dignity' later confirmed that I was the carrier, a one in a million mutation as I have 38 cousins on my mother's side, she has four sisters and never before or since has Hunter Syndrome appeared.
As an American, all my family are in the U.S. There are many, many times when I feel like the loneliest person on the planet. I strive to acquire all the information I can about Hunter Syndrome so that I can do all that is possible to enhance my son's precious, brief and painful life.
Once Frank had tubes inserted in each ear to drain fluids, his hearing became near normal. He's had the tubes replaced twice He had adnoids removed and stopped snoring At 5-years-old, however, he was snoring loudly again - he had tonsils plus regrown adnoids removed. He endured major corrective spine surgery last year, which although a profound ordeal has been wonderfully successful.

He remains our great joy, of course. His sisters love him despite his often difficult nature and the fact that his behaviour and disabilities restrict many family and individual pursuits. Knowing we will not always have him, helps us find that last centimeter of patience to cope with trying situations.

I have named the newsletter for our New Zealand society "The Star" because every night of his life, his father or I have sung "Twinkle Twinkle Litte Star" as part ofhis bedtime lullabies. One night in reflective mood, his father emerged from Frank's room saying "Whenever I sing that to him, I always think - ***"He is the Star."***

Patricia and Mike Zimmerman.

OVERSEAS NEWS

Dear Joan and MPS Families
Hello, my name is Lori Di Ilio from Ontario. My husband Rob and I have two children Matthew aged 6 and Kaitlyn aged 4. Matthew was diagnosed at the age of 4 with Sanfilippo Type B. Kaitlyn is unaffected. We recently went "On Line" and discovered that the UK had an MPS web site. Joan suggested we write a letter to the members to introduce ourselves, which we are happy to do.
It has been a rather difficult time these last few years with Matthew's difficult behaviours, ear infections, hyperactivity, etc....thus leading to his eventual diagnosis. As most of you know this news ripped our hearts out. The shock has worn off but the pain will always be there. We try to be positive, live for the day and not dwell to much on the future.
When Matthew was four years old he was at the peak of his hyperactivity and aggression. He could sing many songs, knew his alphabet and could say one or two word sentences. I am not sure when it happened but he no longer sings or speaks. But somehow he communicates his needs, usually through a hit, a kiss, or a laugh. Most of the time he is looking to fill his tummy. If he is really hungry, he runs all over the place becoming very anxious. We try to anticipate his needs before things escalate.
Physically, Matthew is still very mobile. He walks well but tends to tire easily and will sit for longer periods. He struggles to get up if he has been sitting on the floor and will look for something to help himself get up. Matthew always enjoyed going to the park but no longer climbs the slides or any of the apparatus's. As we have such long winters he forgets what to do from one summer to the next.
Matthew's sleeping pattern, like most Sanfilippo children has always been difficult We have tried quite a few medications. The most successful so far has been Amitriptilyne. This is quite a safe drug, causing very few side effects and is not addictive. He was on Nitrazipam, this worked quite well and we will go back to this if we find the Amitriptilyne no longer works. I have spoken to some Sanfilippo parents and we have come to the conclusion that for some reason these drugs seem to lose their effectiveness after a while.
Matthew was on 900mg's of Tegretol for his aggression. After 18 months we decided to take him off this. He had been falling a lot and having little catnaps throughout the day. This corrected itself after a few weeks. Matthew attended a fully integrated regular grade 1 class with 15 other children. He has a one to one worker who is a child and youth worker having extensive training in behaviour management. She is wonderful. The teacher and the worker have been able to foster friendships between Matthew and the other children. In fact, Matthew was invited to a couple of birthday parties this year. So far the school that Matthew attends has been extremely supportive. The have held cupcake sales from which all proceeds have been donated to the Canadian Society for MPS and Related Diseases Inc.
Overall Matthew is still into everything, throwing foods, taking juice out of the fridge, turning cups upside down, stuffing everything and anything into his mouth, in fact, I found an entire package of Trident gum in his mouth the other day. The Heimlick manoeuvre is becoming a common occurrence around this house. As he gets taller the danger has increased twofold. We had a very bad accident of the 14th February. I was cooking Rob's Birthday/ Valentine dinner when I turned to drain something at the sink Matthew put his hand on the still hot back burner. He sustained second degree burns. It was horrible and since then I immediately fill the used pots with a little water and put them on the still hot burners. We also had gates built and the most important one is blocking the entrance to the kitchen, however, sometimes Kaitlyn accidentally leaves it open.

OVERSEAS NEWS

Matthew still favours his right hand and has forgotten how to bounce a ball with it. An Occupational Therapist suggested that we should rub and massage his hand in order to desensitize it. ***Now, if only I could get him to sit still to do that.***
Kaitlyn and Matthew have a pretty good relationship now. It was very difficult when she was a toddler. Matthew looks for his little sister and she mother's him most of the time. I suppose life has become easier now that Kaitlyn is older and more independent.
The Canadian Society for Mucopolysaccaride and Related Diseases' national officer will be moving from Alberta to Ontario, where I will be the new Executive Director. I imagine it will be as big a challenge as anything I have ever encountered. Fortunately, there are a small group of parents who want to see the Society continue and are willing to contribute what they can, to at least keep the parent support and our Newsletter going. **Wish us luck**.
We would certainly welcome a note of support and encouragement from the UK families. I am continually looking for suggestions, words of inspiration, ideas on how to cope with a Sanfilippo child.
All our best to you and your beautiful children.
Lori and Rob Di Ilio

Pictured here are Matthew and his sister, Kaitlyn.

I am sure that all our members would like to join us in wishing Lori and Rob good luck in their new endeavour and I am sure they would appreciate letters or newsletter articles from any families in UK.

The address of the Canadian MPS Society is:
Mrs Lori Di Ilio
P.O. Box 64714
Markham
Ontario L3R 0M9
Canada

INFORMATION

The following was kindly written for the MPS Newsletter by Dr Liz Fairbairn of the Paterson Institute, Christie Hospital, Manchester.

On Thursday the 24th of July 1997, the world's first gene therapy treatment for Mucopolysaccharidosis type I (MPSIH, Hurler syndrome) was begun by doctors and scientists in Manchester. Bone marrow, taken from a 16 month old girl was transferred from The Royal Manchester Children's Hospital, to the laboratories at the Paterson Institute for Cancer Research for insertion of a gene producing functional α-L-iduronidase, the lysosomal enzyme which is defective in individuals with Hurler syndrome. One week later, the bone marrow was reinfused into the girl.

The principle of the gene therapy approach being taken by the Manchester group is based on the mechanism by which bone marrow from an appropriate donor can correct the enzyme deficiency in patients who have received a bone marrow transplantation. That is, blood cells produced by the gene-corrected bone marrow of the patient will spread out around the body and secrete enzyme which can then correct the effects of Hurler syndrome in other organs of the body.

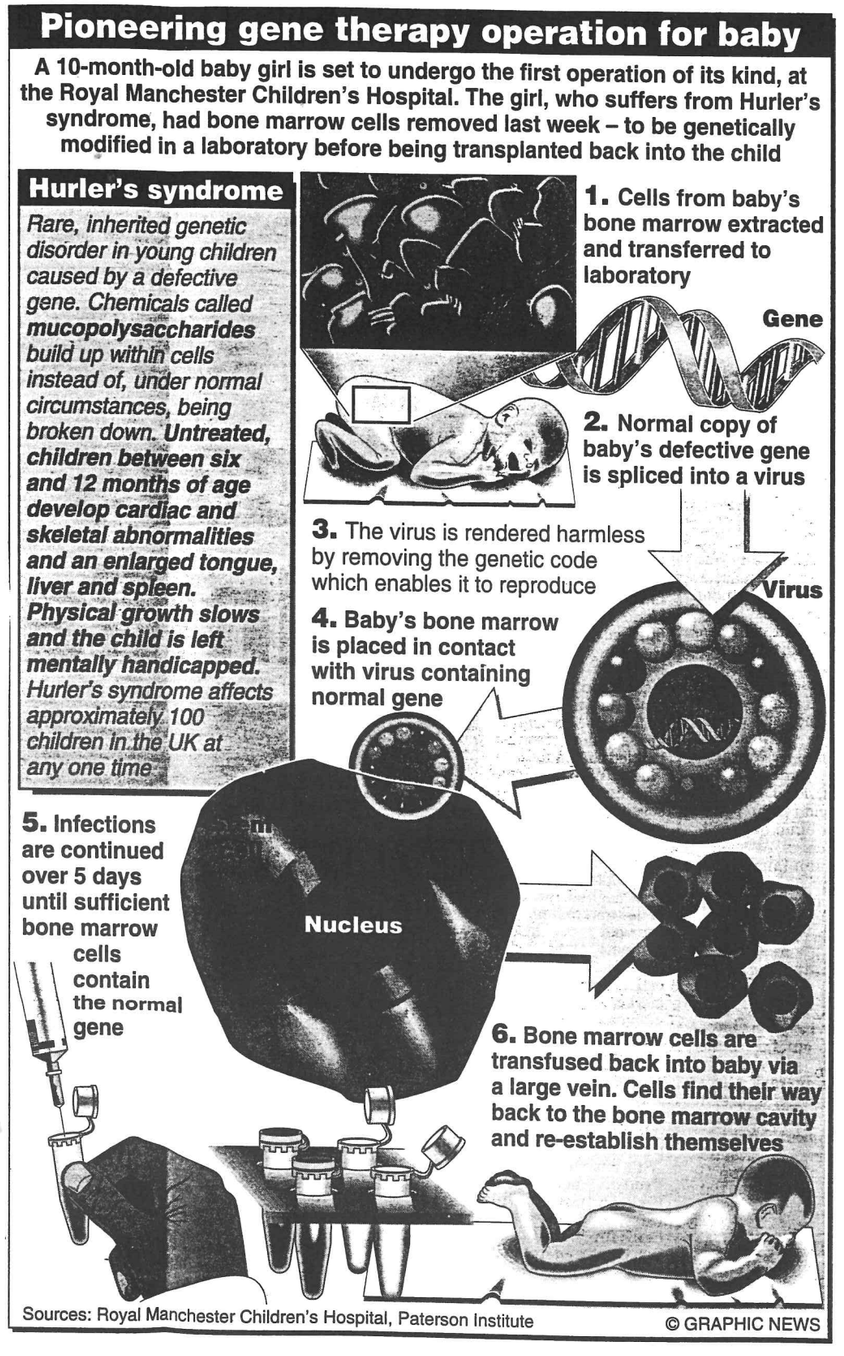
In order to achieve gene transfer into the cells of the bone marrow, the scientists have made use of a virus which under normal circumstances is very efficient at infecting blood cells. Once it infects cells, this virus normally inserts it's DNA into the DNA of the infected cells and then reproduces thousands of copies of itself, which can go on to infect other cells. Scientists have modified this virus so that it does not contain any of it's own genes. This has two effects: firstly, whilst the virus can still infect cells and insert it's DNA into that of the infected cells, it cannot reproduce copies of itself and this means that the virus cannot produce a widespread infection within the patient - this is a safety measure to avoid the virus causing any illness. Secondly, the room made within the virus by removing the viral genes means that it is possible to insert other genes which can be used to correct the defect in the cells of a patient - in this case the gene for α-L-iduronidase was inserted into the virus.

For the current gene therapy application, the bone marrow was placed into a special liquid growth medium, which supports and stimulates the growth of bone marrow and which also contained the virus. The bone marrow was kept under sterile and warm conditions with further additions of virus over the following four days. Meanwhile, the patient was given drugs which had the effect of destroying some of the bone marrow cells which had been left in her body. This was done to make room for the gene-corrected marrow cells and one week after it was taken from the child, the bone marrow was reinfused.

It will be several months before it is known to what extent the operation has been successful. Meanwhile, two further young children will receive treatment during September. Careful analysis of the effects of treatment will be important in order to assess the efficacy of the gene therapy procedure.

INFORMATION

We are sorry for the quality of this diagram but we had to copy it from a photocopy. Hopefully you will find it interesting.



INFORMATION

Isolation of the Sanfilippo Genes Dr John Hopwood
Women and Children's Hospital, North Adelaide, Australia

There has been a lot of work that's happened since Silvio Sanfilippo first recognised the syndrome named for him. I know progress, to families, has been very, very slow but there is a lot of work being carried out.

In Minneapolis (1988) the group from Adelaide reported the isolation of the Sanfilippo-D gene. In Manchester (1990) we were not able to report any further isolations of the remaining Sanfilippos that's A,B, and C. At the next Symposium in Essen (1993) we had no further reports. So it has taken us till 1996 in Woollongong to be able to announce that the genes coding for Sanfilippo A and B have been isolated. It seems very unfair that it's taken so long when the Sanfilippo parents have seen such progress with the other MPS. But we're now catching up, in the sense that the genes are isolated and I'm hoping that by 1999 we will finish off the C gene.

We are putting so much effort into isolating these genes and mutation analysis because of the mutation's relationship to the clinical appearance and the development of the disorder in the patients (genotype to phenotype). We also believe that knowing the mutation would certainly improve the accuracy of the diagnosis and we should be able to do it faster. Also, without the gene, therapies that we are currently considering for patients are not possible.

So with the genes now isolated for three of the four Sanfilippo types, at least conceptually gene and enzyme therapy are now possible.

From the American and European data we know that the incidence of MPS III seems to vary from country to country and from investigator to investigator. This "1 in 20,000" or "1 in 50,000" depending on where you come from really doesn't matter if you are the "1" but it gives us some idea of the incidence in a sense that they are, from the point of view of the common MPS disorders, major contributors.

The Sanfilippo A gene is located on chromosome 17. Over the last year a number of mutations have been identified. Either what we call 'missense' mutation of deletions. Now it is very important because it enables us to identify patients and families where these mutations flow. This will be applied more generally world-wide now that we have these tools. When we have common mutations this makes diagnosis a little easier. The Sanfilippo B Gene has been isolated in two different labs, in Elizabeth Neufeld's lab and in our lab in Adelaide. Again this work is still not published. It's still very early in the scheme of things but there's still a lot of work going on. The important thing though is that the gene is isolated and there are now five or six mutations that have been identified. This again is important from the point of view of making accurate and rapid diagnosis. We have gone from Manchester to Essen to Woollongong and I'm very hopeful that in the next three years we'll be working on the Sanfilippo genes at the research level and that the diagnostic level will give us the same rapid progress that we've seen with MPS I, MPS II and MPS IVA particularity. So I want to give heart to those families out there with the Sanfilippo issues in mind that things will start to happen now with Sanfilippo and we will see rapid progress in this area.

FUNDRAISING

Pictured opposite is Debbie Topkins, Sam Wheeler's cousin.

Debbie ran the Reading Half Marathon and raised a total of £1,227 for the MPS Society.

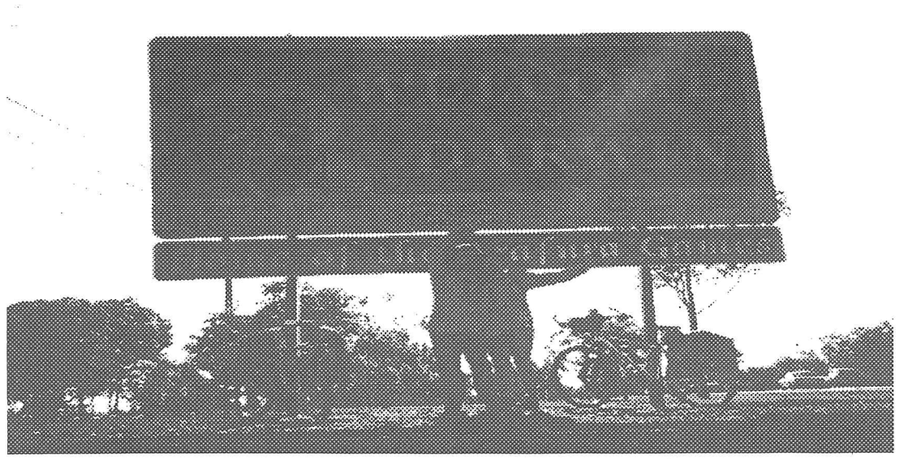
Well done Debbie!

I am enclosing a cheque for £420 from Amy's fund. This was raised by having a raffle. The prize was a print of an original painting donated by a local teacher-artist - Alan Dodds. The draw was made by Amy at a local DASH Group Luncheon.

Moira Bray

Pictured above is Amy Bray aged 6 years old who suffers from ML III.

FUNDRAISING



Adelaide to Darwin

Starting out on the 20th March 1997 we headed out of Adelaide with 2,000 miles to go with only 26 days to complete our journey. The first few days we established a comfortable speed, saddle position and distance between rests (which if Gordon had had his way would have Zero) Days 1 to 4 gave us rain, a steady uphill climb and a head wind.

Day 2 we spent the night at Hazel and Graham Brooks home (Australian support family) who treated us like Royalty, we even managed to do a local newspaper interview for them. Graham and Hazel have five children (young adults), fun loving Daryl, 27 years, Sanfilippo, shy Sandra, 29 years, Sanfilippo and Steve 28 years who is a qualified chef and was previously in the Army. They also foster two young adults with Multiple Surosce, Rayjen and Kyle, who are simply amazing and very cheerful young ladies.

Later as we unloaded our bikes Daryl watched eagerly, there was nothing for it but to let him have a go and the smile on his face said it all. I wll never forget leaving that next morning, it was like leaving home for the first time and the sun rising to our right just made it all the more emotional.

Day 7 was our worst day as you will see. We started our day from a bush camp, with a German couple we had met at Port Augusta who were to stay with us for another eight days, (Anja and Helmut's average day was 43 miles, their longest being 60 miles with a rest day every fourth day). The wind steadily got worse, taking us down to less them 9 mph and as a result we each drank the extra 2 litres of water we had been carrying from the day before, we had started with 8 and a half litres each (each litre weighs a kilo) as there was nowhere available on this stretch to pick up water. This was meant to be a short day of only 60 miles, in before lunch! Eight hours later we arrived in Cooper Pedy - our first rest day followed. From Cooper Pedy it was straight through to Alice - 7 days. Two days off spent driving back to Ayres Rock - Amazing- and ridding myself of a nasty little tummy bug.

FUNDRAISING

From Alice it was down hill psychologically, in reality hilly! At last no wind. The terrain seemed to be changing every 60-100 miles,

sometimes like the Prairies of America and other times like the rock scapes in the western movies you watched as a child. Having reached Mataranka, we'd been in the Northern Territory for 8 days and it wasn't too hot (34 degrees Centigrade), my stomach bug had gone and I was able to get back to drinking chocolate milk again; yummy!

Arriving in Katherine after 9 days, as you can imagine, we started to get excited. We were so close, only 197 miles to go and we had a dilemma. Do we do it in 2 or 3 days? We knew we could do it 2 but it would mean 90 miles to Hayes Creek (Road House) and 107 miles straight through to Darwin and a Double bed - no more tent!

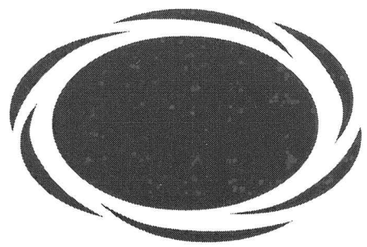
Two days later we were in Darwin and a real bed. the going was undulating to hilly, though we had been told by the local car drivers that it was "undulating to flat". The road also narrowed making it difficult for the 50m long Road Trains to pass us: we would often get off the road before being blown or pushed off! It was quite fun really, you could chase the cloud shadows to get out of the heat of the sun and when it rained cycle hard to keep warm because it was freezing thus keeping the brain amused!

Our last day has to be the best; after 11 days of non-stop cycling I had a blow-out. You know, it is one of those sounds you had spent the whole journey waiting for, hiss....hiss...hiss..and then just when I thought to myself "I know that noise" there was a sharp bang and I was off that bike like the clappers. I looked at Gordon and we both laughed, or we did until we noticed that Gordon's tyre was also about to burst!! So it was the spare tyre for me, which we had carried for the entire journey and a change of front tyre to back wheel for Gordon as we headed for Darwin.

Darwin felt so wonderful, it felt like home. It had taken us 12 cycling days from Adelaide to Alice and 11 non-stop cycling days from Alice to Darwin.

Tracey and Gordon Stewart.

We would like to thank Tracey and Gordon from Cardiff for this magnificent effort in raising £725 for the MPS Society. We hope they had a wonderful time and we are sure they will never forget such an experience!

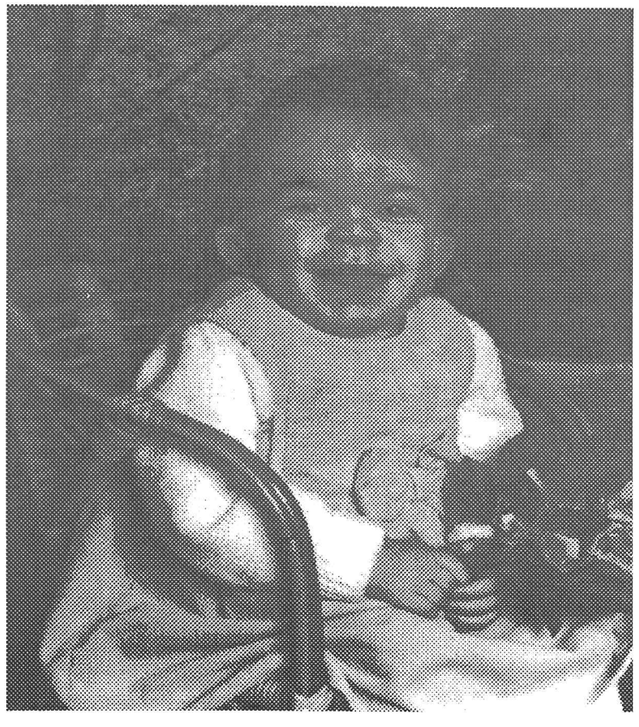


FUNDRAISING

The Annual Biker's Bash held at Scunthorpe's Crosby Hotel raised £650 for the MPS Society.

Above is pictured Barbara Rollison collecting the cheque for £650 on behalf of the MPS Society.

Below is pictured Gemma Rollinson as a toddler. Sadly Gemma who suffered from Hurler Disease died in 1994 aged 7 years old.



Twelve local pop bands entertained hundreds of visitors during a nine and a half hour show. There were various events throughout the day including a feat of strength to see who could lift a full 36 gallon barrel of beer in the fastest time.

Other events held were judging of the best motor-cycle, a karaoke sing-along, a pool flier, tom-bola, bouncy castle and barbecue.

FUNDRAISING

Well done girls in raising £133 for MPS.

As guides we had to walk six and a half miles for a badge. We decided to combine another badge with this one, and raise some money for a good cause as well.

We walked the "Tame Valley Circular, Waterside Walk" along with our families and best friend. We were all exhauseted after that long day, but we enjoyed it thoroughly.

Gemma Russell and Liesa Martin

(Gemma's brother Mathew, who suffered from Hurler Disease died recently aged 12 years old.)

Pictured below are members of 30 Signal Regiment L.A.D. REME from Bramcote, Nuneaton who on the 1st of July 1997 volunteered to abseil down a building in Birmingham city centre. The task was to deliver the building in the foreground to a group of business men at the foot of the building as part of a promotion to further development in the area. After the event a cheque for £350 was presented by Ian Bone of Balloon Mad to members of the L.A.D. who gratefully accepted it and then donated it to the MPS Society.

Richard Millward

(Father of Abigail who suffered from ML2 and sadly died in 1994)

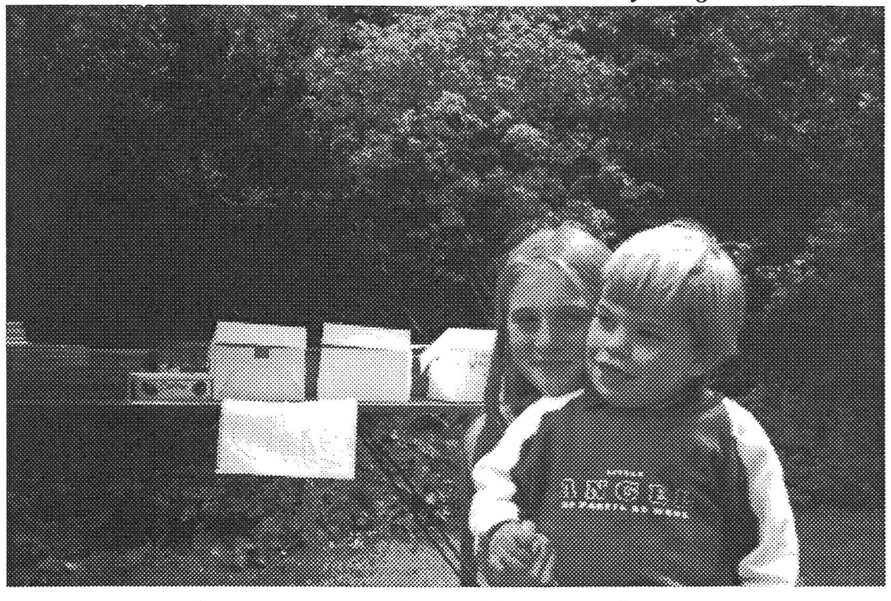
Pictured above are, Top Row: Cpl. Dean Brookfield, Capt. Richard Garbutt, CFN Richie Dowling, Cpl Shadespear
Bottom Row: Sgt. Paul Bolton, Sgt. Andy Lennox, Cpl. Rab Skene,CFN Scouse Jones, WO2 Nick Nicolson.

FUNDRAISING

Please find a cheque for £117.82. This money was raised and donated by my 10 year old niece, Alice Eastwood. Alice held a summer fair in the back garden of her home in Broadstairs, Kent. She organsied stalls, games, a raffle and face painting. All who attended had a great day.

The idea for the event was entirely Alice's own as she wanted to raise money for children like her cousin, Thomas Flaig, my son who is three and half years old and has Sanfilippo and also Muscular Dystrophy.

Thanks Cathy Flaig



Pictured above are Alice with her cousin Thomas

FUNDRAISING

DONATIONS

The Society is grateful to the following who made donations.

Candis Magazine
DUC Handicrafts
Trez Penhaligan
Sky News
John and Marjory Taylor
Mr Birmingham
Mrs Gibbs
J.G Tregoning
Jean Cockman
Eunan and Nuala Conway
Gilgrove Bingo Club Pensioners
Crafts Club, Pitsea
Jean Lloyd
Anne-Marie Watson
Jane Shrimpton
Mr and Mrs Nelson
Carol and John Westland
Carol Tomlins
Mr and Mrs Hendry
Mr and Mrs Heritage
R R Wheeler
Caversham Folk Festival
Wheeler Best Plumbing and Heating
Lucy Evans
Val Evans
Mrs Rosemary Vere
Mr Wensely
Alice Eastwood
Mrs Phillips
Mr and Mrs R Leonard
Mr and Mrs Jackson
Mr and Mrs Zeilstra
Department of Health
Mr Stimpson
IPC Magazines Ltd.
Mr and Mrs Richardson
Mr and Mrs Berriman
Miss Richardson
Lindsey Oil Refinery Ltd.
Barry Mullins
The Racal Electronics plc.
Andrew and Sandra Hunt
Loanends Post Office
Karen and Andrew Weedall
Ann Fraser and friends
Ruth, Barry, Mark and Clare Simpson
Peter and Tanya Steenhoven
Betram Books Ltd.
Noreen and Bernard Fasey
Mr and Mrs Hall
Coutts and Co.
Jardine Lloyd Thompson Group
The Sobell Foundation
Radborough Tabernacle U.R.C.
Jenny and Andy Hardy
Tomkins plc
Invesco Ltd.
CJ&JB Howland-Harris
Mary and Charles O'Toole
The Woodcote Trust
Mr Brown
F P Carpenter
Barclays Bank
The D'Orly Carte Charitable Trust
Norweb
Haselmere Estate Charitable Trust
Probus Club of Thame
Argos
Wessex Water
Peter and Wilma Robins
Brian and Mary Lovick
Dr Douglas Gunary
T J Harrison and Son
Paul and Jean Leonard
The Maurice Wohl Charitable Trust
Lilly Industries Ltd.
Gavin and Denise Brown
Sir Jules Thorn Trust
Mrs Moss
The British Alcan Co.
Mrs B Battersby
Lavender Family
The Eleanor Hamilton Charitable Trust
A G Parfett and Sons Ltd.

FUNDRAISING

Donations Continued……..

Coutts & Co.
The Lady Hind Trust
Muriel Hall
David and Charlotte Steele

FUNDRAISING EVENTS

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

June Timms, Penn Village - Craft Evening
Thelma Pidden, Westbury -Collection of Coppers
Pauline Mahon, Sheffield - MPS Dinner
Pam and Ken Ballard - Sale of Items at MPS Conference
John and Mary Stacey - Spiffing Stationery
Leisa Martin and Gemma Russell - "Thame Valley Circular Waterside Walk"
Harry and Rosemary Nurse, Brixton - Car Boot Sale
30 Sig. Regt. L.A.D. REME - Abseil a building in Birmingham
Lynne Grandidge - Sale of Plants
Moria Bray, Chapeltown - Knitted Coat Hangers
Carole and John Westland, Reading - Garden Party
Peggy Darper, Cavesham - Stall at Garden Party
Michael Parikh, St Albans - St Albans Review Half Marathon
Gillie and Roy Plummer, Cardiff - Auction, Raffle/Disco held on James's 5th birthday
Carol Parfitt, Shepton Mallet - Sale of Bric a Brac and Cakes
Marine Foster & Brian Baker, Bristol - Car Boot Sale
Nat. West Insurance Services, Bristol - Team of 5 riders in Bristol's Biggest Bike Ride
William Armstrong, Nick Bellerby, Lee Morley, Harlepool - Cycle Ride of 140 miles
Roger Hawkings, Blandford Forum - London Marathon
Bernie and Kieran Houston, Belfast - Annual Golf Tournament
Trudie Deacon and Jane Heritage, Sandhurst - Sale of Marmalade and Sweet Peas
Mrs I Wicks, Leeds - Alcan Collection
Alan and Fiona Byrne, Glasgow - Kirkhill Golf Club Day
Alun Jones, Chippenham - Chauffeur at a wedding using a vintage car
Chris Hughes and work colleagues - Held a 'Race Night'
Mr Dobner - Bungee Jump
Peter Hake, Petersfield - Bike Ride
Scunthorpe Bikers - Held a Motorcycle Day at the Crosby Hotel
Mary and Robin Gooch, Sussex - Agricultural Show and Raffle
Emma Saul and Dave Peters, Newtown - London Marathon
Tracey and Gordon Stewart, Cardiff - Adelaide to Darwin Bike Ride
Sue Butler, David and Charlotte Steel, Chinnor - MPS Lunch
Debbie Hopkins, Reading - Reading Half Marathon
R Fleming, Brislington - Bike Ride
Mrs Gibbs, Swanage - Coffee Morning and Bring and Buy Sale
Anita James, Ammanford - London Marathon
Armley Prison - Collection of Alcan
Marina Foster and Brian Baker - Car Boot Sale
Ellacot Family, Bristol - Collection of loose change
Bray Family, Sheffield - Raffle of Original Print

FUNDRAISING

CHARITY BOXES

David and Monica Briggs - Retford
Ron and Linda Snack - Milton Keynes
Pam Croghan - Stockport
Jackie Chisling - Trowbridge
Pat and John Lomas - Pinxton
Sid Shiff and friends and family - Liverpool
Oversley Mill Services - Alcester
Cawthorne Family - Hedon

DONATIONS IN MEMORY

The Society is grateful to the friends and relatives of

Sarah Weedall's Grandfather **Princess Diana**
Herbett Wragg (Jacob's grandfather) **Matthew Russell**
Alan Bates (Sam Wheeler's grandfather) **Gemma Rollison** **Alice Pope**
Ross Lockyer **Leslie Britton (Ian Maguire's grandfather)**

STAMPS and FOREIGN COINS

Rosemary and Harry Nurse **Tesco, Cambridge** **Mrs Wicks**
Marianne and Adrian Stimpson **Safley Champness** **T A Centre, Coventry**
Jean Cockman **Andy and Jenny Hardy** **Mrs McConnell**
Debby Rhead and Colleagues at Brittany Ferries **Ken and Pam Ballard**

SPECIAL OCCASION

Peter Sue and Annie Stuart gave a donation in lieu of Annie's birthday presents

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

Area Support Families

East Anglia

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

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

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

South East

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

Potteries

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

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

South West

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

Gordon and Anne Hill — Tel: 01404 813823
Bowhayes Farm, Venn Ottery, Ottery, St Mary, Devon EX11 1RX

Home Counties

Mark and Rachel Wheeler
26 Tamarisk Avenue, Reading, Berkshire RG2 8JB — Tel: 0118 9541293

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

Wales

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

Area Support Families

Midlands

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

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

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

Yorkshire and East Coast

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

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

North West of England

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

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

North East of England

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

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

Elizabeth and William Armstrong — Tel: 01429 273703
7 The Crescent, Hartlepool, Cleveland TS26 8LY

Scotland

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

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

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

Northern Ireland

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

The Society for
Mucopolysaccharide Diseases

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

Registered Charity No. 287034