

Newsletter

Autumn 1995



# The Society for Mucopolysaccharide Diseases



National Registered Charity No. 287034



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## The Society for Mucopolysaccharide Diseases

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

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

The Society operates a network of Area Families throughout 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 three biochemists, one at Manchester Children's Hospital, one at the Christie Hospital, Manchester, and one at 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 Picture shows Jamie Andrews aged four from Thurmaston, near Leicester at the MPS family holiday at Filey, Yorkshire in July. Jamie and his brother David, aged 6 have Hunter disease. (See Page 14)



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**Deadline for Winter Newsletter**

**21st December 1995**

## Director's Report

*The Chairman of Trustees report to the Annual General Meeting held on the 24th September 1995 at the Stakis Country Court Hotel, Northampton, was based on the director's report as follows:*

Over the past twelve months we have continued to see a significant increase in demand for the Society's support services to both affected and bereaved families. The families of 45 children diagnosed with MPS since the last AGM have contacted the Society seeking information and support. A considerable number of these families are here this weekend. Christine and Mary have responded to many crisis situations in areas of education, housing and welfare benefits. Visits and contact with newly diagnosed families continues to be a priority area of work nationally, with Area Families being encouraged to offer more local support.

Both the Manchester and Great Ormond Street MPS clinics are flourishing, with Christine and Mary providing support and practical help on clinic days.

Many Area Family events have taken place, including Christmas parties, outings and barbecues. On the whole these have been well attended and much appreciated by those who have participated. In April this year the Area Families underwent further training over one weekend. Very useful discussions on how they perceive their role, confidentiality and fund-raising took place.

In October 1994 the Society organised an MPS Clinic in Glasgow with Dr Wraith in attendance. In Northern Ireland a very successful Weekend Family Conference was held with MPS families from all Ireland coming together to hear Ed Wraith and Professor Nevin speak on MPS. Last Wednesday in Belfast the Society organised a day seminar on MPS for families and professionals. Ed Wraith lent his support and travelled with Professor Hopwood and Christine to speak at this meeting.

The third planting of the "Childhood Wood" took place on Friday 24th of February, when nineteen oak saplings were planted in memory of MPS children and young adults who have died. More than 100 family members and guests shared in what was a most dignified occasion, followed by tea at the Clumber Park Hotel.

Seventeen MPS families enjoyed a one week holiday at Filey in North Yorkshire in July, whilst fifteen physically disabled MPS teenagers took part in an Activity Holiday on Exmoor, Devon. Again the holiday could not have been possible without the practical help of volunteers from the Royal Logistics Corps, Hullavington.

In November 1994 the Society was awarded a further considerable grant by CSL to fund the continuing work being undertaken by the Society on the European Database. This work has involved Christine and Mary travelling to several European destinations to meet with professionals and overseas MPS Societies. In December 1994 Christine and Mary participated in the American MPS Conference and undertook meetings with representatives from CSL. It was following these meetings that we learnt that CSL had, with regret, decided that they could not continue alone in developing Enzyme Replacement Therapy for MPS. Committed to finding suitable partners for this project, or independent funding, the British MPS Society co-ordinated two applications for EU



funding from BIOMED 2. Whilst we have learned that neither have been successful, we believe the effort was fully justified.

As you will hear from our Treasurer and Assistant Treasurer, the Society's income has fallen considerably this year, with a marked drop in fundraising receipts. This has meant that staff have had to give more time and thought to applying for hard to come by corporate donations. However, we are grateful to everyone who has supported the Society financially. Without this the work of the Society would be severely hampered.

And, before I go, what of the National Lottery? The Society has applied under the criteria of alleviating poverty for a grant of £81,000 over three years, to fund Family and Activity Holidays. We aren't terribly optimistic but live in hope!

**Christine Lavery**  
Director

Mr & Mrs D Donegani  
37 Tynedale Road  
Loughborough  
Leicestershire  
LE11 3TA

Tel:01509 232400

Mrs Christine Lavery  
The Society for Mucopolysaccharide Diseases  
55 Hill Avenue  
Amersham  
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25th September 1995

Dear Christine

We wanted to write to you to thank you so much for the conference over the weekend which we felt privileged to be able to attend. Please do pass on our appreciation to all those who worked so hard.

We have already benefited much from the help of both yourself and the society and we appreciate it very much. It has certainly 'lightened the burden' over these recent months. Over the weekend our appreciation for the society grew much. The care for the children was first class, the AGM was conducted in a most honouring, interesting and sensitive way, the three talks on Saturday were most stimulating and our 'volunteers' were most delightful. We came away very impressed with the professionalism of all involved and at the same time the very real care and concern for all members of the family.

Yours sincerely,

David

David & Jan Donegani

## Conference a Great Success!

This years weekend conference, from the 22nd to 24th of September at Stakis Country Court Hotel, Northampton, was a great success. Over ninety families attended, of which about a third were new families. A special introductory meeting took place for new families. Professional speakers this year were Dr Ed Wraith, Dr Ashok Vellodi, Professor John Hopwood and Mr Norman Picavance, Clinical Nurse Specialist from Royal Manchester Children's Hospital. The children enjoyed themselves on outings to the American Adventure Park and Woburn Safari Park. On Saturday evening the young people went to the Pizza Hut for dinner and then spent the evening bowling, while their parents relaxed at the dinner and dance, entertained with verve and enthusiasm by Martine Brennan and "Second Chance".

A special thanks to all the volunteers who looked after the children on the outings and at the creche and who did the baby sitting and patrols. Many of the volunteers have been coming for several years now. A particular thank you to **Deirdre Bevan** and **Ann Neal** for running the creche. Very warm thanks to the management and staff of the hotel who again gave us an outstanding service. Many parents have written to congratulate Christine and Mary on how the conference was organised and run.

**Paul Leonard** from Fulham in London was elected to the Committee at the Annual General Meeting. (See article, page 19). **Mary O'Toole** who stood down from the Committee was thanked for her services over the years, particularly for her work on the MPS Leaflets. The meeting also heard about the setback in work on Enzyme Replacement Therapy because the Australian Company, CSL, are unable to proceed on their own. Concerns about fundraising were also discussed. Although the Society balance is in good shape, the gap between what we are spending and what we are raising is widening and a smaller proportion is coming from fundraising by members. In the coming year the Society will need to consider this matter carefully.

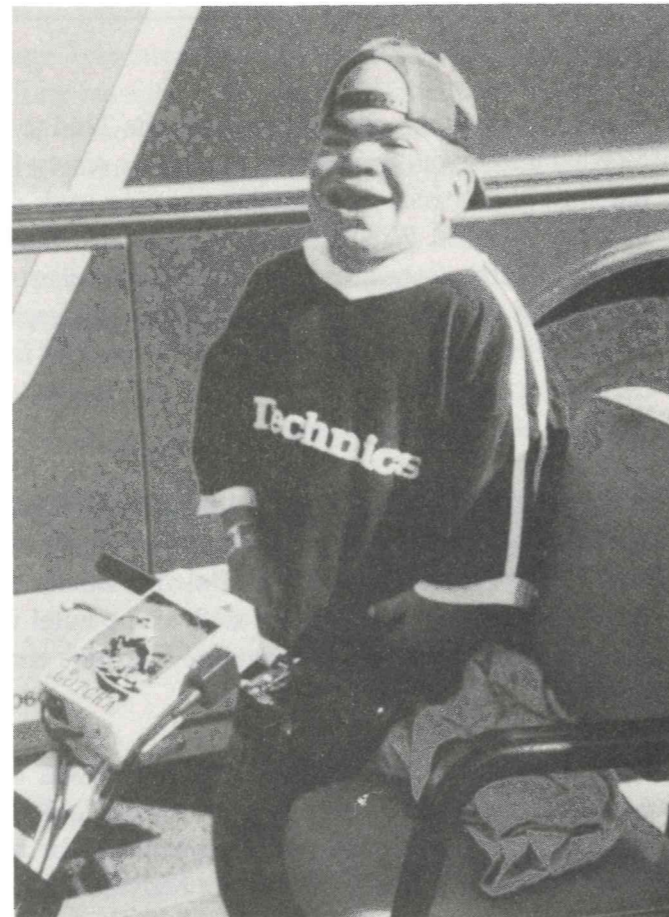
On a more cheerful note, much of the costs of the children's programme and of the volunteers was raised by contacting local charities in the areas where families live.



**Andy Ward**, one of the many volunteers from Amersham Baptist Church who have helped at the conference over many years in succession, seen here with **Faye Rowe** at the American Theme Park. Faye is aged 14 and has MPS III (Sanfilippo). She lives at Erith in Kent.



**Familiar Faces and New Faces**



Top right:

The familiar face of **Edward Nowell** aged fifteen, from Wells in Somerset, ready to take off on his magnificent three wheeler.

Above:

**Amie Oliver** enjoying the sunshine at the American Theme Park. Amie is aged four and a half and has MLII disease.

Left:

**Adika Shah** aged 4 and his brother talk to a friend. Adika has MPS IV (Morquio disease)



**Lauren Wainman** makes friends with **Alex Butler** on the coach. It's good to have a reliable friend in new surroundings. At the conference strong friendships develop between the young people, both those with a condition and those without. They learn from each other how to live with MPS.



**Jason George** aged 6 from Knowle, near Bristol, is clearly having a good time. But what is he doing with his foot? Jason and his twin brother **Jamie** suffer from MPS III (Sanfilippo disease)



### Births

Congratulations to **Julia and Peter Andrews** from East Gostcote, Leics., on the birth of their second son, **Stephen** on the 26th of August 1995, weight 4lbs 14oz., a brother for **David**, who suffers from Hunter disease.

### New Families

**Dawn Watts and Mark Robinson** from Norwich, whose daughter **Jade**, born 2th May 1995 has been diagnosed with MPS I (Hurler disease).

**Anne-Marie Watson** from Glasgow whose daughter **Zara**, born on 4th of August 1989 has been diagnosed with MPS III (Sanfilippo disease).

**Michael and Ann Morrissey-Crouch** from Etchingam, East Sussex, whose son **Patrick**, born 24th August 1994 has been diagnosed with MPS I (Hurler disease).

**Mrs and Mrs Mann** from Handsworth, Birmingham, whose daughters, **Rupinda**, born on the first of March 1966 and **Amarjit**, born on the 15th of October 1981 suffer from MPS VI (Maroteaux Lamy disease).

**Jackie Edwards** from Thornhill, Cardiff, whose son **James**, born on the 9th of August 1992, has been diagnosed with MPS II (Hunter disease).

**Tania and Mark Brown** from Letchworth in Hertfordshire, whose son **Albert**, born on the 20th of August 1994, has been diagnosed with MPS I (Hurler disease).

**Tony and Janet Malone** from Norton, Stockton on Tees, whose son **Joseph**, born on 12th of May 1994 has been diagnosed with MPS I (Hurler disease).

**Errol and Janet Jones** from Drefach, Llanelli, Dyfed, whose son **Christopher**, born on the 9th February 1987, has been diagnosed with MPS III (Sanfilippo disease).

### Deaths

**William Corcoran** from West Ealing, London, died on the 23rd of September 1995 from Hurler disease, aged seven. William's sister **Marian** died from Hurler disease and his sister **Amanda** and brother **David** also suffer from Hurler disease.

**Victoria Johnson** from Hawarden in Clwyd died on the 24th July 1995 aged almost eighteen. Victoria suffered from MPS III (Sanfilippo disease).

**Charlotte Pollard** from Thameside, Manchester, died on the 10th of August 1995 aged two and a half years. Charlotte suffered from MPS I (Hurler disease).

**Sarah Kilvert** from Newtown, Powys, who died on the 27th of September 1995 aged 22. Sarah suffered from MPS IV (Morquio disease) Her brother **Carl** also died from Morquio disease. Sarah shared with her parents the job of Area Family for Wales.

**Winnie Larkin** from Glengormley, Belfast, who died on the 2nd of October 1995. Winnie was the Treasurer for the MPS Organising Committee in Northern Ireland.

*Our thoughts are with the grieving parents, relatives and friends of all who have died recently. We pray that they will find courage, strength and hope in this sad time. Please consider what support you can offer them.*

### MY HOLIDAY IN AMERICA. BY LOUISE HALE.

On Saturday 6th May 1995 I went to Florida with the National Holiday Fund. The flight to America was 9 hours long and we flew with Virgin Airlines on a Jumbo Jet 747. We had dinner on the way and watched 3 films. The landing was very bumpy and I was sick.

I stayed at the Sheraton Hotel and shared a room with a girl called Tanya. The hotel was really nice. It was very big. The weather was very hot. 95 degrees!

We travelled around Florida and went to these places...

Sea World - We watched the Dolphins and Whales swim around their big pool. I got splashed by a whale called Shamu!

Busch Gardens - I went on a ride called the Tidal Wave. I got really soaked!

The Magic Kingdom - I saw Minnie mouse and Mickey mouse. I got their autographs and a big kiss from Mickey! Also all of Mickey friends were there. I went on a ride called Thunder Mountain which is a run-away train ride. It was really scary. I had to hug my helper Kathy!

Universal Studios - I went on lots of rides here like - ET, Ghost-busters, King Kong, Jaws and Earthquake. I went to see Lassie, Mr Ed, Benji and Beethoven. I really liked it there.

M.G.M. Studios - First of all I went to see the Parade where lots of cartoon characters walk around. Then I went to see the Little Mermaid show. Then the Indiana Jones Show, and finally the Beauty and the Beast show.

The Epcot Centre - I went on a really good ride called Spaceship Earth. I saw a show called Journey Into Imagination. I also saw a 3-D show called Honey I Shrunk The Audience. It was amazing!

At night I went to a place called Planet Hollywood. I had dinner there and saw a comedy show. Also we visited the Beach club and there was a disco.

**I also went to the Hard Rock Cafe.**

**I spent a day at one of the state prisons. I had a ride on a big Motor Bike.**

The policemen and women were nice and they put on a barbecue for us.

My helper Kathy was really nice, she helped when I was buying things because I had never spent Dollars and cents before. I bought lots of badges everywhere I went and T-shirts and gifts to bring back.

I had the best time ever and came back with lots of toys, presents and a sun-tan.

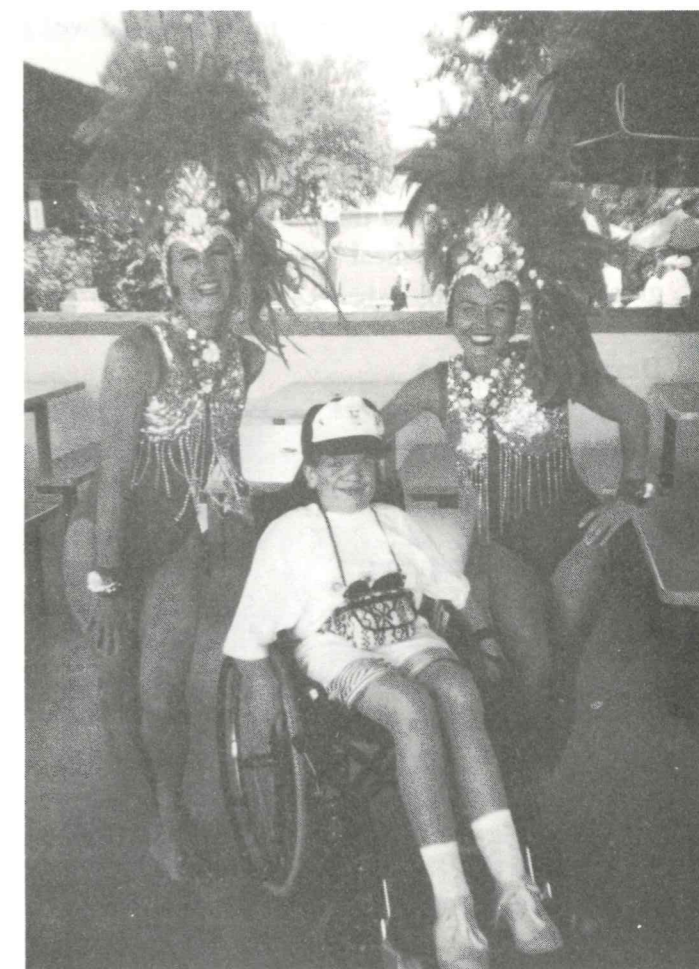
This holiday was great! I really enjoyed it and would love to go again.

I am really grateful to Christine Lavery for putting my name forward for a place on such a wonderful holiday and to the Holiday Fund and its helpers for all of the wonderful memories !!

**Louise Hale.**

**2 Rissington Drive**

**Witney Oxon OX8 5FG**



Louise with feathered friends in Florida



## Another Florida Fan!

Hi! I'm Derek Richardson and I am writing to tell you about my holiday arranged for me with the National Holiday Fund. I went in May and had a wonderful time. When Mum told me I was going to Florida I was speechless (unusual for me). I thought she was having me on.

When the day came to go, mum drove me down to Gatwick airport and we all met at the airport hotel where we stayed overnight. Here we also met Polly from "The Bill" and we had a lovely cake with all our names on. The following day we flew to Orlando and had a short drive to the Sheraton Hotel in Kissimmee where we stayed.

We stayed for two weeks and visited loads of places, including Disney World, Sea World, Busch Gardens, Universal Studios, the Police and the Sheriffs. George was my helper and we had a lot of fun together, we often went swimming at the hotel.

It was very hard to choose which was the best bit of the holiday but I think it must have been riding the big four wheel buggies. It was all great!

### Derek Richardson



## Jibreel Arshad

Jibreel was diagnosed with Morquio disease (MPS IV) at the age of one and a half years. At that time he was noticed to have a short neck and deformed chest. Gradually the disease affected his wrists and knees. Regular check ups at the Royal Manchester Children's Hospital have been satisfactory. Following an MRI scan in September 1994 it was decided to perform a cervical spinal fusion.

The operation was performed on 31st of March 1995 at RMCH. He was discharged after seven days. He restarted school on a part time basis one month after the operation. His teacher and colleagues were very sympathetic and helpful.

Jibreel adapted to the jacket and halo remarkably well. We modified some of his shirts by trimming the collar so that it could slide up the jacket easily. Washing his head, face and the lower part of his body was not a problem. Under the jacket we sponged him regularly. Every night we had to clean his pin sites. He had the halo checked at the hospital every fortnight.

It was very difficult to get Jibreel to rest. He is very fond of his bike and with his brother he is always on the move. On three occasions he needed antibiotics for pin site infections. Once he complained of severe headaches. A CT scan revealed that one of the pins had penetrated his skull and the pin needed re-siting. The halo was removed after three months and he needed a soft cervical collar for five days.

The day the halo came off was one of our happiest. We had a party. Jibreel had just started summer holidays and we went to the Cotswolds.

We are proud of Jibreel. He has been very brave. He thoroughly enjoys school and likes to do household chores such as gardening and cooking.

### Pernia and Ali Arshad

Doctors Ali and Pernia Arshad live in Whitefield, Greater Manchester.

Jibreel, aged six years, defending his turf from his brother Ebrahim, proudly displaying his halo and jacket.

\* \* \* \* \*

## News Flash on the 1996 Jeans for Genes Appeal !

### **Three Major Development You Should Know About !**

The first piece of news is that the timing for the Appeal is being altered to *Spring 1996*. Now we need to concentrate on getting the 'Jeans for Genes' message across to the maximum number of people during the next 5 months. You remember that we are hoping that everyone will wear their jeans to work and to school on one day - office, workers, bus conductors, nurses, shop assistants, vicars - everyone and anyone !

The second is that the three charity partners are being joined by a fourth - *the Great Ormond Street Children's Hospital Fund !* This is marvellous news. Great Ormond Street's name is know everywhere, which will be a great boost to our efforts. It also means that we have the opportunity to work with some of their fund-raising team. Their team is tremendously experienced, they have a wealth of contacts and they are extremely enthusiastic about 'Jeans for Genes'.

*The third is that a Major Retail Outlet is adopting the Appeal and is helping to make 'Jeans for Genes' as equally major National Event !*

### How will 'Jeans for Genes' benefit MPS Families ?

1. The money raised from the 'Jeans for Genes' campaign will be divided equally between the four charities.
2. The MPS Society will use the money raised by the 'Jeans for Genes' campaign to fund and promote gene research for Mucopolysaccharide and Related Diseases.

We are all delighted at the way this campaign is coming together, but must add a word of caution. The Society's aim of supporting families is a priority and we must never lose sight of the need to keep fundraising for our support activities. We cannot use 'Jeans for Genes' money for support.

However, you can play an enormously important role in making the campaign a success and encouraging organisations, businesses, schools and individuals to support our 1996 appeal. A full information pack will be sent to you as soon as they are available.

\* \* \* \* \*



### AREA FAMILY SUPPORT AND TRAINING

Being an Area Family means making a commitment, not only to the MPS Society but to the many families who seek our help, not an easy task to be taken lightly. Fortunately, we have a marvellous team of Area Support Families who bring to the Society a wealth of knowledge and understanding of the needs of MPS families. All have experienced the impact of an MPS disease in their own family and all have a willingness and commitment to help and support others.

It's not just a question of planning and organising family gatherings, like Christmas parties/ barbecues etc., it's the practical help and support which goes on behind the scenes. The telephone calls and visits as they help families through the difficult times of diagnosis, illness and sadly death of the child. It's having that special human quality of caring.

Many of our Area Families have their own MPS child to care for, like Allan and Fiona Byrne from Scotland, their daughter Louise suffers from Sanfilippo and over the last year Louise has been extremely poorly, yet Allan and Fiona have continued to support the Scottish families and have organised two specialist MPS clinics.

Allan and Fiona have just recently been joined by Jim and Cath Maclean from Inverness. Jim and Cath have two daughters, Louise and Emma. Emma had a bone marrow transplant some years ago for MPS I. A very warm welcome to them.

Over the years some Area Families have lost their own child, still continuing to offer others support even though their own loss has been painful to cope with. I think you will agree that we in the MPS Society are extremely fortunate to have such people on board with us.

The Society has always acknowledged the need to support these people and to offer training in specific areas of self help and support. These have been wide ranging, from listening skills to budgeting and managing finances.

This year we had a weekend training programme at from 28th to 30th April. We held the weekend at Cwrt-Y-Gollen Army Training Camp in the Brecon Beacons. Our grateful thanks go to Bob and Rhian McKnight from South Wales, who so kindly took over the organisation of the venue and facilities and who, with their friends and colleagues, gave up their own weekend to help us. Bob and Rhian are not an Area Family but like many others work behind the scenes to help in many ways for which we are most grateful.

Some of the topics we dealt with during the weekend were, the history of family support, the current expectations of Area Families, report from each of the Areas, planning managing and financing Area events, strategies for the future, confidentiality, equal opportunities, access to a tertiary centre, research, and balancing the books. Under the guidance of the army we did some exercises outdoors to help us work together with increasing confidence and trust.

After many years as an Area Family, Ron and Linda Snack from Milton Keynes are retiring. I know their decision was not an easy one to make and that they will be greatly missed. Ron and Linda joined the Society when their son Colin was diagnosed as suffering from MPS II (Hunter) and have continued to work tirelessly, even after Colin's death in 1990. They organised the National Raffle for many years and were, until this year, co-ordinators on the MPS family holiday. Ron also served as a trustee as fund-raising officer. The list is long and impressive, so I won't embarrass them any more other than to say on behalf of all the many, many families and friends in the MPS Society " Thank You " for all the years of care, love and support.

On a final note, Ron and Linda do leave an area without that vital link, please do let Christine or myself know your thoughts on the direction for this area.

Mary Paget Director Family Support Services Northern.

## Irish MPS Society

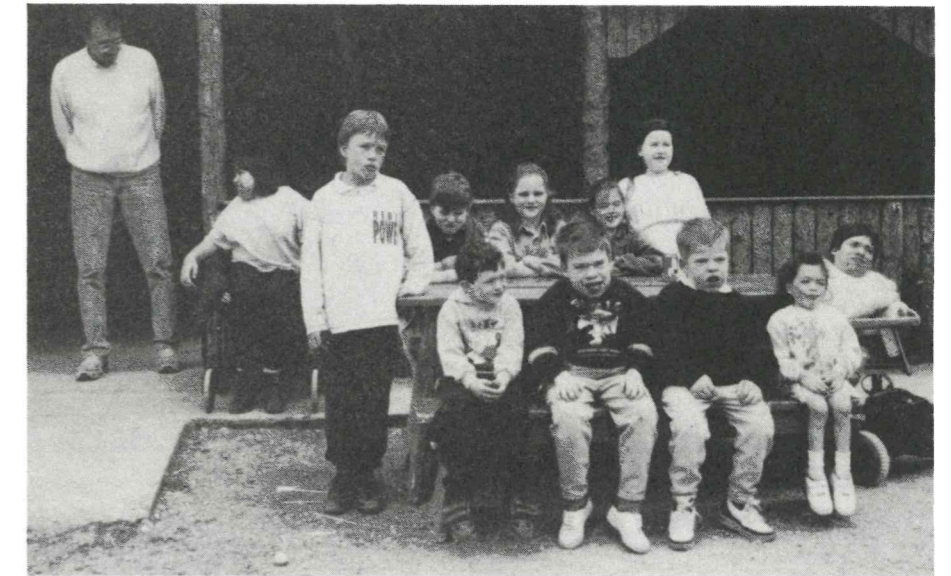
We have recently formed an MPS Society in the Republic of Ireland and would be grateful if you could mention it in the newsletter. I am enclosing a photograph taken at a picnic at Glendeer Farm in Athlone in June. This was the first family day organised by the MPS Society in the Republic of Ireland. It was a great success with some families meeting other MPS families for the first time.

We hope to make contact with more MPS families and plan to arrange further events.

**Mary Boushel**  
Chairperson,  
101 Hillside,  
Dalkey,  
Co. Dublin.  
Phone 01 2856234

**The British MPS Society offers warmest congratulations and best wishes to the newly founded Irish MPS Society and we look forward to working together very fruitfully in the future.**

**Go Neiri an bothar libh!**



### **MPS CONFERENCE - NORTHERN IRELAND**

**FORTE POST HOUSE HOTEL - DUNMURRAY**  
**20 September 1995**

Fourteen MPS families and 21 professionals, plus speakers and invited guests attended a most successful day conference on the 'Mucopolysaccharidoses'. Prof. John Hopwood and Dr Ed Wraith travelled to Belfast with Christine, Mary and Joan to give MPS families and professionals throughout Northern Ireland an opportunity to hear the most up to date thinking on the management and treatment of the MPS Diseases.

Prof. Nevin, Consultant Geneticist, chaired the meeting and Dr Heather Kilgore, Medical Advisor to the DHSS in Northern Ireland, welcomed everyone to the Conference. Prof. Nevin's secretary co-ordinated the crèche which was most appreciated by parents of young MPS children and siblings.

By the time I had arrived in Belfast considerable media interest had been expressed. At 8.15 a.m. on the morning of the Conference a taxi arrived to whisk me away to appear on BBC Ulster. It was a great boost that the journalists then accompanied me back to the Conference to interview parents and professionals for the lunch time news.

The Conference was a great success and the Society acknowledge its appreciation to the Dept. of Health and Social Security in Northern Ireland for their considerable financial support to the Society and for making this Conference possible.



**MPS FAMILY HOLIDAY - FILEY**

**JULY 22ND - 29TH**

Seventeen families enjoyed a week away together at our favourite holiday site - Filey, Yorkshire.

We managed to put a team of volunteers together at the last minute following a cancellation due to illness. Our volunteers make all the difference, as we are able to offer that extra bit of help to families.

After every holiday we receive letters of thanks and here is just one of them.

*Dear Mary,*

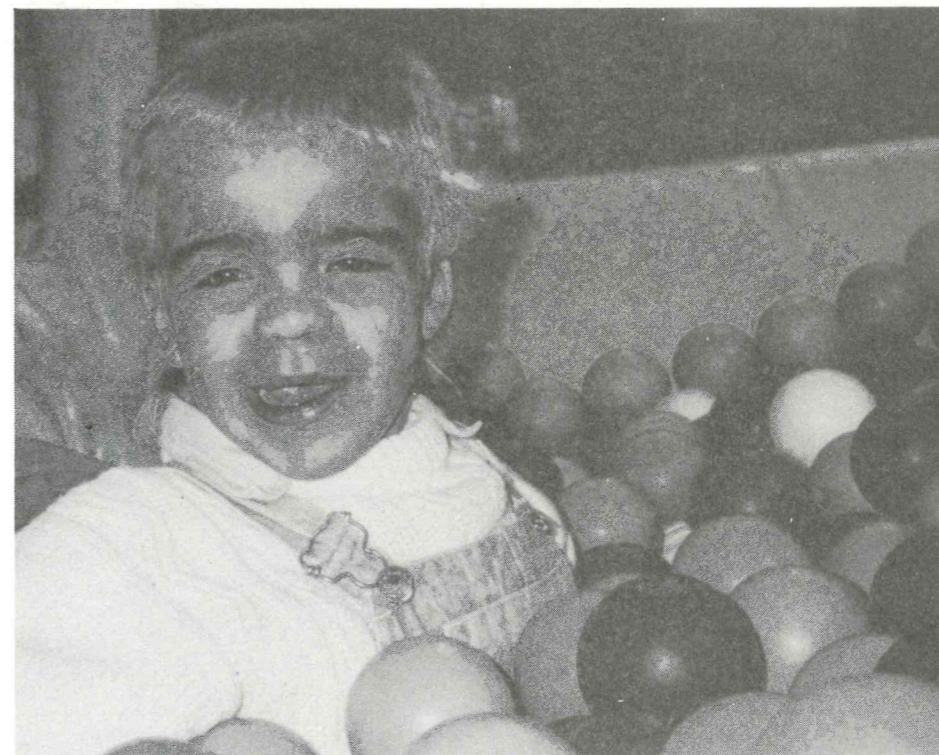
*Now that I am back home and settled in I just had to write and thank you for making our stay at Primrose Valley such a pleasant one. The dedication of you and your team, and the opportunity afforded us to meet other parents were unequalled. Your professionalism and efficiency with the organising of the event were always evident, and I am sure that it served as a great boost of confidence to us all. On Sunday the 13th Rosemary and I went to a car boot sale and raised £100.00, we have decided to donate this to the MPS Society. With our grateful thanks and best wishes to you all.*

*Yours faithfully,*

*Lisa, Rosemary and Harry Nurse.  
2 Russell Grove  
Brixton  
London SW9 6HU*



Adam Brown from Hemel Hemstead relaxes in the glorious sunshine on the beach at Filey.



**Daniel Wainman** plunges into the ball pool at the camp.

**The Brown family** from Hemel Hemstead at Filey, with **Corporal Neil Whitewick**, now a regular helper at MPS events.

Pupils at Whittaker Moss School in Rochdale who raised money by a "Jeans for Genes" day in May. In the middle are **Michael and Simon Hoather** from Denehurst Park, Rochdale who have Hunter disease.







Martine Brennan with four enthusiastic young volunteers at the family holiday in Filey.

### A VOLUNTEER'S EYE VIEW

Abi and myself have been volunteers for the MPS Society for a number of years now, at the conference, family days and on the holidays at Filey, Yorkshire, in which time we have had some great laughs and some unforgettable memories.

I learnt from my time spent with my brother, Richard (Hunter) that these children are very special and need our care, love and devoted attention to help them enjoy their lives to the full. At the same time they make our lives that bit different with the happiness they bring and I admire the children and their families for the courage they have in everyday life.

Over the years I have seen the Society grow into what it is today, which is something quite wonderful. Without the commitment of families, friends, doctors, scientists, fund-raisers and of course volunteers, it would not be possible. I feel proud to be part of something in history which has moved forward in great ways.

This year at the conference Abi and I looked after Daniel and Lauren Wainman who both suffer from Sanfilippo. They kept us on our toes but we liked the challenge and loved seeing their mischievous faces when they had us running after them all over the American Theme Park.

**Catherine Gardiner.**  
**Abi Raine.**

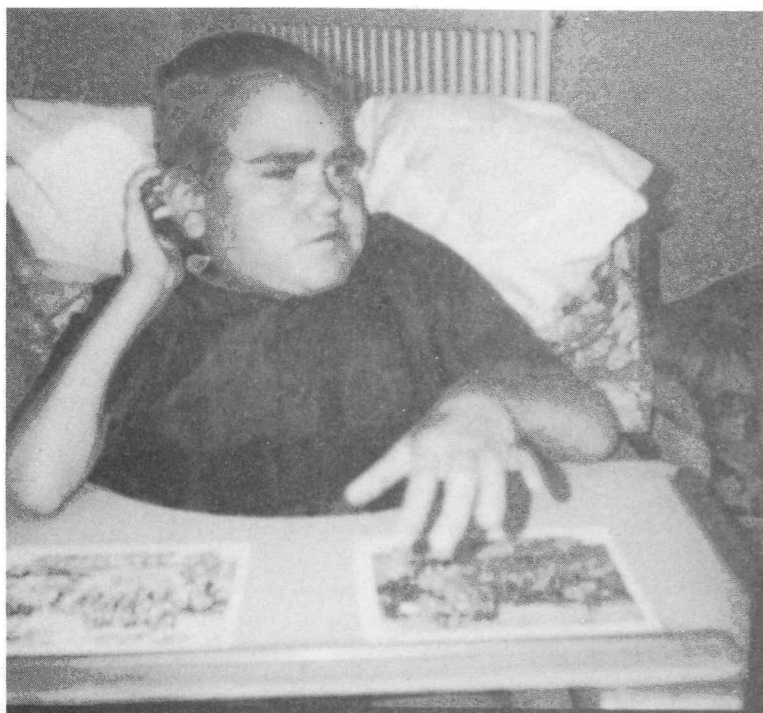


Stacey Cliff age 9 (MPS III) from Maltby, Rotherham and Lynn Thompson (MPS IV) at an outing to White Post Farm in May 1995. What a photo!

Jamie Hicks age 9 (MPS II) and family from near Penzance, at Filey holiday.



## Richard Mort



Eight years ago when our son Richard was six he was diagnosed as having Sanfilippo syndrome. Like all MPS families we were devastated. At the time we were advised to apply for a grant to build a safe room for him and also to apply for Mobility Allowance.

The fight with our local council dragged on and on until eventually I threatened them with the newspapers. A fortnight later we were given permission to build a safe room plus a shower room and also were given a substantial grant. This took nearly three years.

The Mobility Allowance was also a long battle which also took three years. In the end with help from the MPS Society, letters from Ed Wraith and Wilma Robins who represented us at the final tribunal, we succeeded in obtaining Mobility Allowance.

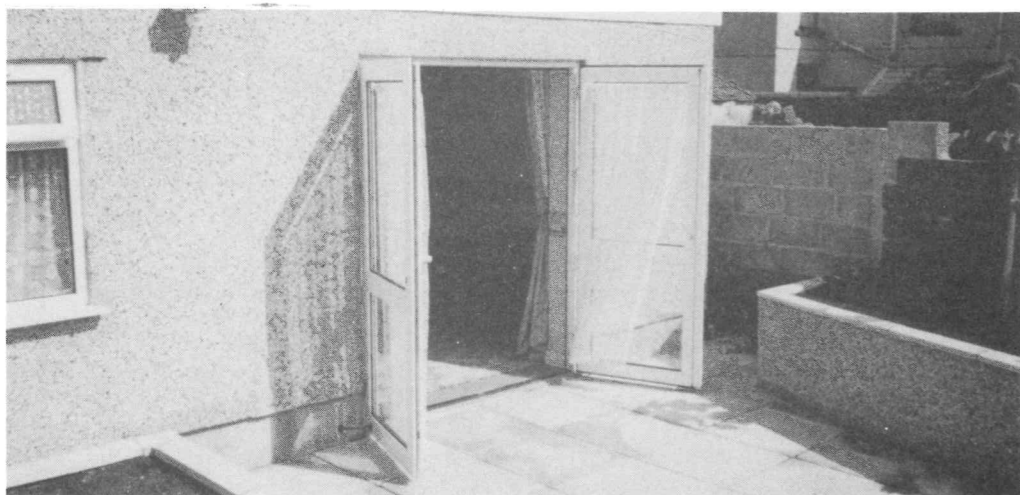
Two and a half years ago I wrote to Christine asking her what equipment we would be needing in the future, as I had a meeting with social services. Christine telephoned me and said that she would attend the meeting. She first called to see the extension that had already been built and told us that it was totally inappropriate to meet Richards needs. Since then Christine has been down to South Wales on many occasions to meeting after meeting. It was a real battle but I had total faith in Christine, she really worked hard for us.

The first six months of this year Richard has been very ill in hospital. He has also had a gastrostomy tube fitted as he was unable to take anything orally, but now he looks really well and is putting on weight. While he was in hospital his room was altered. We now have a beautiful room for him with ceiling hoist and whirlpool bath and a patio, so we can take him out into the garden.

We would like to say to Christine thank you very much for all you have done for us, we really appreciate your hard work. Also thank you to Dr Ed Wraith, Mary Pagett, Daffydd Wigley, and also to our local MP, Mr Gareth Wardell.

We advise any family with an MPS child to approach the MPS Society for advice first and don't make the mistake that we did. Without the Society we would have nothing.

**Dennis and Valerie Mort and Richard, 2 Belgrave Rd., Lougha, Swansea, SA4 6RF**



## Our Child's Post-Mortem - A Parents' Decision

Jean & Paul Leonard

We have been asked to share our thoughts and actions in requesting a detailed post-mortem or autopsy to be carried out on our son who died in October 1994. We have had a complete range of reactions from other parents, friends and relations but we are both satisfied that this was something we felt was right.

### Early Days

To give a summary of early events, our happy, loving but rather slow older son, John of 3½ years, and his baby brother, Christopher, of 6 months, were diagnosed with the rare metabolic Mucopolysaccharide disorder, Fucosidosis (less than 20 diagnosed cases in the UK). In the most severe form, a child with Fucosidosis may only live to 5 years and suffer increasing physical and mental handicap. As John's condition worsened during 1993, his whole body became gradually more wasted. Talking to our GP and other people in the medical profession we realised how little was known about Fucosidosis. Not a great deal is understood about what actually happens to the brain and the rest of the central nervous system. Also questions were arising as to the quality of the myelin sheath around the nerves, and the odd types of joints in these children. We decided a post-mortem would help improve medical knowledge.

### Trying to be positive

After the early stages of anguish, despair and anger we were encouraged by the love, support and prayers of family and friends, and we moved into a more constructive attitude. We joined the Mucopolysaccharide Society and the Research Trust for Metabolic Diseases and decided to do all that is possible towards research and to improving other people's health. We carry organ donor cards and have registered with the Anthony Nolan Register and so have many of our friends and family.

### Dealing with the Post - Mortem

We discussed the likely personal trauma of having our son sent for a post-mortem but decided that if the post-mortem would increase medical knowledge by helping our other son and similar sufferers of MPS disorders, it would be worth while. We discussed our decision with our GP and Consultant. It was suggested that the best place for the proposed post-mortem should be at the Great Ormond Street Children's Hospital.

Several factors were concerning us at this stage. We realised that we had to clarify in advance all items of paperwork, transport (which was done by the local undertakers) and that whatever the time and place of John's death, the mortuary at Great Ormond St would know precisely why this special PM was being carried out and which tissues and organs the pathologist wanted to test or examine microscopically. We knew we would be too upset at the time of John's death to 'think straight' and it might be far too late to set up complicated arrangements if this happened for example on a Friday night.

We both agreed that it would also be reasonable to change our minds at any stage.



One troubling thought was the feeling we might be abandoning John on the day of his death. During a stay at the Cambridge Children's Hospice John unexpectedly died peacefully in his sleep at dawn, on a Sunday in October. He had a bad asthmatic spell the previous evening and died of heart failure. The staff of the Hospice were wonderful and we stayed with John for several hours, wept, held and kissed him. Eventually we were ready to say our good-bye and we drove home. Later that day Cambridge undertakers took John's body down to Great Ormond Street Hospital.

#### The Funeral Arrangements

John was brought to our local undertaker's chapel of rest, two days after he had died and the post-mortem had been completed. We sorted out some of his special clothes for John to be dressed in, plus his favourite toys and story books and took these to the undertakers. The rest of the day was spent sorting out John's nursing equipment. Jean and John's nanny, Hayley, who had cared for him since he was six weeks old, decided to see John at the Chapel of Rest. We were both concerned that John might seem damaged because of the post-mortem. The undertaker's receptionist was a very kind woman and we asked her if John looked disrupted or whether we would see any incision marks. She was very reassuring and told us that she was not even aware that an extensive post-mortem had been carried out and that he looked a beautiful lovely boy lying dressed in his coffin. We decided we did not want to spend the rest of our lives regretting not seeing him again and went into the chapel. He did look lovely and not disarranged. The only difference seemed that he seemed more dead but this may be because we had had three days to come to terms with the event.

#### The Funeral Service

John's funeral service was held 8 days after he died. The service was beautiful and the church was full. We asked friends to bring a small posy of flowers from their garden to the graveside and thus any money they might have spent on flowers could be donated to the charities that had helped John while he was alive i.e. the Children's Hospice for the Eastern Region, the MPS Society or the RTMDC. The total sums were gift aided which meant that the charities could claim a further 25% from the Inland Revenue.

It was very painful to sit and write this article but we never regret our decision to have the post-mortem carried out. We have been told that the professionals have gained a great deal of knowledge about the disorder. This may directly help our other son who has undergone a bone marrow transplant, as well as others. Please think carefully if your child has a rare disorder and has not long to live....Could a post-mortem help research for the benefit of others?

Jean and Paul Leonard

## WHAT IS THE POINT OF LEARNING TO TALK?

- and is it worth the trouble?

Einar (MPS II, 8 1/2 years old) and his family think so ..

Growing up without being able to communicate with other people is one of the most frightening things that can happen to a child. It is like living in a glass bubble: you see others addressing each other, you understand that they are doing something important together, from which you are shut out.

It is worth thinking about exactly what they are shut out from. In my view, the job that language does, and which cannot be replaced, is *communicating about that which is not present*; i.e. the past, the future, everything beyond vision, and all that we imagine. The child without language can communicate body sensations, mood, and attitudes to what is around him or her. But talk about what happened at school, the visit to granny tomorrow, the playground round the corner, or stories and jokes, are beyond reach. The child without language cannot understand how the rest of us organize and master our lives.

Mastering language is a very difficult task for normal children, it takes them years of practice to become fluent, and mother tongue teaching goes on all the way through school. We can imagine then how hard it is for children with communication problems; try as they will, their condition stops them from taking part in something that looks as natural as breathing to others. And often it seems to the child that nobody cares, or can help.

It is easy to understand, once you think about it, that children who cannot communicate as a consequence may become angry, disruptive, aimless and hyperactive, or depressed and remote, all depending on how they respond to their isolation. I am not saying, though, that communication skills alone can improve behaviour. Rather, we need them to get started.

I am mother of a Hunter boy, but I am also a linguist. What follows here, is a (brief) review of how Einar's communication

handicap was handled, and what results we think we got (hard to say exactly, without another, untrained Einar to compare with!).

When Einar was 2 1/2 years old (summer 1989) and still had not learnt to speak, we took him to see an ENT specialist who suspected reduced hearing. This led to extensive testing, also a functional hearing test at a special nursery school for children with hearing deficiencies. One of the teachers there had had a Hunter boy in her group earlier, and recognized the symptoms. The diagnosis of MPS II was confirmed some months later, in the spring of 1990.

Einar's lack of language was essential in finding out what was wrong with him: Teaching him to communicate as best he can became an essential aim in the years that followed. Professionally, I felt that this was a challenge not to be refused, although I had never before worked on language deficiencies. However, we know something about how language skills are acquired, and this is where I started:

- Everyone understands a lot more than he or she can express, and knows the meaning of many times as many words as those we use.

- Language is a general sign system. We use a sign (a word) to represent the concept, or idea, of an object. For instance, the word *chair* can refer to all chairs, not only the one I am sitting in at the moment.

- The breakthrough in language learning happens when the child realizes this. Most children will have made this discovery by the time they are 18 months old, many understand it long before.

- Language has to be learnt at the right time and in the right sequence, give or take a couple of years. The more handicapped a child is, the more trouble will it have in



catching up, and the delay tolerance is smaller than in the non-handicapped.

- Since hearing disorders almost always are diagnosed when the child fails to start speaking, the child will have lost months and years of exposure to language.

Normally, children spend the first year or so sorting out the sound flow of speech, and learning to recognize the word unit. Children who are hard of hearing often master a few easily recognizable and often used words (like *mum* and *dad*), but often they have missed too much to grasp the system. This means that an important precondition for discovering the link between word and concept is not fulfilled.

In one respect, we had an advantage; We knew that Einar didn't understand Norwegian when he came to us from Korea at one year of age. So we spent a lot of time establishing (eye) contact, talking, teaching him to recognize the first words etc. On the other hand, Einar had to swap one sound system for another, and that obviously set him back.

With all this in mind, this is what we did:

First, we arranged for Einar to go to the above-mentioned nursery school for children with hearing deficiencies. Einar was already in an excellent mainstream school. But his lack of language made independent group playing impossible. We could see that he was getting lonely in the crowd - he needed a teacher next to him all the time. He didn't understand the pretence games his peers were busy with (at three years). When he tried to take part, he ruined something and got pushed away.

At the new school, he was taught sign language to follow spoken Norwegian - or signed Norwegian as it is often called. The method was teaching through play on a one-to-one basis, so he was brought into the group right away. (This system has continued with subsequent school changes.)

My husband and I had to go and learn signed Norwegian as well (a precondition for a place!). Einar's grandparents also came along.

This sort of sign language follows ordinary spoken language. You omit most of the little words and concentrate on the important words in the sentence. For instance, in the sentence: *would you like an apple?* only the words in bold would be signed, while your expression would signify that this is a question.

We also learnt some rules for making communication easier. Here they are, in order of importance:

- 1 Eye contact and closeness is essential. If necessary, hold the child's head still to secure attention.
- 2 Start with a few words/signs and repeat them again and again. A child with normal skills will practice through endless repetition while it is learning to speak. Your MPS child needs this even more, only the repetition falls on you.
- 3 Start with words which are important in your daily routine and that convey something pleasurable - like *food*, *bath*, or the like. Arrange with the school that you practice the same words/signs (Einar had a little report book which told us what to work on every day).
- 4 Start as early as possible. We talk to our babies from the day they are born, and babies to deaf parents have been known to use simple signs at eight months (easier to do than speaking!).
- 5 If you can, show the object (or the action) while you say the word and use the sign. Name (with word + sign) the important objects in the child's room, show the sign for *wash* and then wash hands etc. You won't have to do this forever with the initial words, but it helps the child fit meaning and word/sign together, and hopefully, "crack the code".

6 Turn yourself into a talking machine! Conversation with small children can be repetitious and boring, so if the child is silent, parents can be excused for sending up thanks and being quiet themselves. Still - make sure that your time with the child - whether in work (feeding, nappy changing etc) or play - also is talking time. I used to put Einar on the kitchen bench and talk my way through preparing meals, by showing and naming all I used and did. And he became a very interested little cook!

7 Spend a few minutes every day going over yesterday's and today's schedule, and plans for the near future. It is a good idea to use the child's school report book, or photographs, together with signs/words. We spent a film on photographs of the local shop, tram stop, teachers, the postbox, his buggy, etc and put them into a little pocket album which stayed by his bed, and was brought out for these conversations. Later on, we used the family albums, or pictures in his report book.

We have also made great use of children's songs, rhymes etc, accompanied by signs. I'll never forget Einar's delighted laughter when we first did *Humpty Dumpty* with him. Communication need not - indeed should not - be entirely utilitarian. There must be a large area for fun and games. Songs and rhymes are also excellent accompaniment to unpleasant tasks (tooth brushing) or exercise games, because they give these activities a shape - the child learns what to expect.

The big question then is: has Einar mastered language? And if so, has this skill improved his and our lives? In fact, is the result worth the effort?

Einar could say at most some 20 stable words, and quite a few more which depended on context (he remembered the word when he saw the object). (He cannot articulate well enough now to utter recognizable words.) He used a few signs, but preferred

pointing/reaching, eye movement or action.

He shows through action that he understands a lot of what is said directly to him. Yesterday he was invited to a birthday party, and when I told him (word/sign), he turned his head and looked for his own birthday crown which sits on a tall shelf. He also clearly understood that it is to happen in a week, and that he is to buy and bring a present.

He masters turn-taking in dialogue, and concentrates on understanding when he is addressed. He will also start conversations, try to tell us what he wants or direct our attention to outside objects that interest him, and that he wants to hear about.

He seems to us to understand a great deal more than he has ever been able to express, not only practical, factual things, but jokes and metaphors. When I bathed him last night I said I couldn't lift him - "you're as slippery as a piece of soap!" He reached for the soap and patted his tummy and laughed.

Einar had his period of hyperactivity, before he became too stiff and and unstable to run around. But he was never unmanageable, and he could always be led to play constructively for short periods. He was and is cheerful, affectionate and cooperative. He understands that some unpleasant items on his agenda have to be endured, and take less time if he helps to do them (exercises, cutting hair and nails, examination by various professionals etc).

Einar has learnt to understand that life is organized through language. He cannot read, but he knows what books, posters and labels are for, and allows us time to read them. He asks by pointing out or reaching for what interests him. He could never read music, but wanted notes in front of him when he played the piano. And so on.

He now enjoys being read to (it took some training). This can be difficult to organize as he needs to see the book and the reader at the same time, and he should ideally have the story told in signed language. We manage



this sometimes but not always.

As you see, Einar is and has always been a long way from normal mastery of language. He has nevertheless made good use of the communication skill and understanding that he has developed. We feel that his own and our quality of life is much improved through this. At least there is always something we can do together!

We also see that Einar has the self-confidence needed to make friends wherever he goes, and cope with new surroundings and experiences (We take him everywhere, and we have never had problems). The communication skills he has, have secured him some independence and freedom in contact with other people, and made his life - we think - a lot easier.

I have at times met the view that communication is something for the schools to teach, and that we, as parents, don't know enough about it. But the most important learning place when it comes to communication, is the home. We all know more than anyone outside about our children, they trust us and they want to stay close to us. What better starting point can you have?

Oddrun Grønvik Bachke  
Oslo



## LITTLE BRIDGE HOUSE

"Little Bridge House aims to help and support families who face the emotional and physical strain of caring for children who, sadly, are not expected to live into adulthood. This does not have to make Little Bridge House a sad place, although sadness' are faced together, Little Bridge House is a place of love, happiness and friendship."

Little Bridge House is the newest, it only opened on 25th September of this year, of the few children's hospices in the country and the only one to cover the vast area of the south-west of England. I am writing to tell you of our first impressions.

During the hottest part of a very hot summer we travelled as a family down to Barnstaple from our home in Frome for a visit. This had been instigated by Christine (Lavery) after she had visited us shortly before and obviously felt we were in need of some respite - but that's another story! I should perhaps mention at this point, for those of you who do not know us, that we have four children; two sets of twins: Amelia and Sarah who are nine and Emily and Thomas who are four and a half. Emily has Hurlers Syndrome.

I have an old school friend who now lives in Barnstaple and after lunch we all went along to Little Bridge House which is set in a small village called Fremington, two miles outside Barnstaple in North Devon. Although a new building, we were all immediately struck by its character for it is built in a beautiful golden coloured stone and the extensive gardens seemed already to be well established. Mandy Robbins, the head nurse, came out to greet us and although a little subdued at first; apart from Emily, of course, who is never shy, the children soon became excited as they began to realise that this could be a good place to come and stay!

Mandy showed us the large, sunny kitchen with its deep blue Aga and the adjoining dining area with a huge hand-crafted table with its exquisite 'Goldilock' style chairs and we were simply stunned. We continued our tour. The eight single bedrooms for the children each contain a window bed should a parent, brother or sister or a friend wish to stay with your child in the room. Amelia and Sarah thought this an excellent idea and immediately began to bicker as to whom should stay with Emily first! The rooms are beautifully decorated in bright fashionable colours and each has its own television, radio, wash basin etc. There are also six equally attractive spacious family rooms for parents and brothers and sisters and although Little Bridge House is keen to create a 'family' atmosphere there are separate cooking and eating facilities should one want to have complete privacy at any time. We went on to discover a Jacuzzi, a teenage room with a snooker table and computer games, a 'messy-play' room for arts and crafts, the most amazing multi-sensory room I had ever seen and rooms and rooms full of toys. Meanwhile Emily had disappeared on a sit and ride car!

We found her in the large garden exploring a little wooden playhouse and Mandy told us of further plans to extend the play area to include a range of climbing activities for the more able child. They have their own bicycles on which families can explore the surrounding area; there is a disused railway line along the road which has been made into a cycle track into nearby Bideford, and, of course, the beach is only two miles away!

Any pre-conceived ideas of what we expected Little Bridge House to be like were washed away and I felt that if I could feel as comfortable here now before the Care Team arrived and before the children and their families began to make full use of the facilities how much more



relaxing it would be once opened. A regular break from the stress of everyday coping could help us as a family. The goal of Little Bridge House is to provide the support that each individual family needs. They will provide respite for the whole family or, once you feel you have got to know them, you could leave your child and take advantage of a holiday elsewhere or, as in our case, spend the time restoring the inside of your house!

This seems extremely naive now, but before we had Emily and she was diagnosed we had no idea that there were children's illnesses for which there is no cure, we had no knowledge of children's hospices but more importantly, we had no conception of the kind of people that give and care so much for others. This knowledge we owe to Emily - she has opened our eyes. It has been hard to accept that we sometimes need help, its hard to take help offered but as the years and months pass and the emotional as well as physical stresses and the tiredness begin to wear us down we feel comforted by this knowledge and are grateful that someone cares. Accepting that you are that family who needs help is, perhaps, the greatest difficulty.

If anyone feels they would like to make contact with Mandy Robbins or visit Little Bridge House for themselves they can be contacted on - 01271 321999.

We are due for our first official stay at Little Bridge House in two weeks time, during the school half-term, and I will go armed with my camera and report back on what I hope to be a 'fun' week. I'll leave you as I began with a quote from the little booklet provided by the hospice which sums up their intentions:

"We hope to provide a haven, a place where children and their families can be nurtured and cosseted, returning home with renewed vigour and a sense of anticipation for the next visit."

Susan Hayward  
Frome, Somerset.

Little Bridge House, Redlands Road, Fremington, Barnstaple., North Devon, EX31 2PZ  
Tel: Barnstaple (01271) 321999 Head Nurse: Mandy Robbins



#### CHILDREN'S HOSPICE ASSOCIATION SCOTLAND

### SCOTLAND'S 1ST CHILDREN'S HOSPICE OPENS IN FEBRUARY 1996

Andrea Cail, Head of Care at Rachel House, Scotland's 1st Children's Hospice, tells The Society for Mucopolysaccharide Diseases about the exciting new support service soon to open for families with children with a life-limiting condition.

"Rachel House is Scotland's 1st children's hospice. Based in Kinross in the central belt of Scotland Rachel House is purpose built to provide care, support and friendship for families with a child or children whose life expectancy is limited by their condition. Many children with Mucopolysaccharide diseases have been helped by the children's hospices in England. I am looking forward to extending the service for families in Scotland when Rachel House opens in February 1996."

So what will Rachel House offer?

- planned and emergency care for the whole family or for the child alone
- support throughout the course of a child's condition
- a qualified and experienced staff team
- a relaxed homely atmosphere where children and families come first

Rachel house can accommodate 8 families at any one time. There are 8 individual childrens bedrooms with accommodation for brothers and sisters. Parents will have the use of separate en-suite bedrooms and whilst they will be welcome to use the main dining room and lounge, a separate lounge, kitchen, smoking room and sun



### CHILDREN'S HOSPICE ASSOCIATION SCOTLAND

lounge are available. This will allow parents to actively participate in their child's care, but allow for privacy and a good night's sleep!

There is ample provision for play, both in house and outside in the garden. A Jacuzzi and multi sensory room allow for rest and relaxation for children, parents and staff. A quiet room and a small library is provided for peace and quiet.

Enquiries and referrals are welcome **NOW**. Any family with a child aged 0 – 18 with a life limiting condition is eligible. All applications will be considered individually.

For information please contact:

Andrea Cail

Head of Care

Children's Hospice Association Scotland

18 Hanover Street

Edinburgh EH2 2EN

Tel: 0131 226 4933



CHILDREN'S HOSPICE ASSOCIATION SCOTLAND  
Registered Office 18 Hanover Street  
Edinburgh EH2 2EN

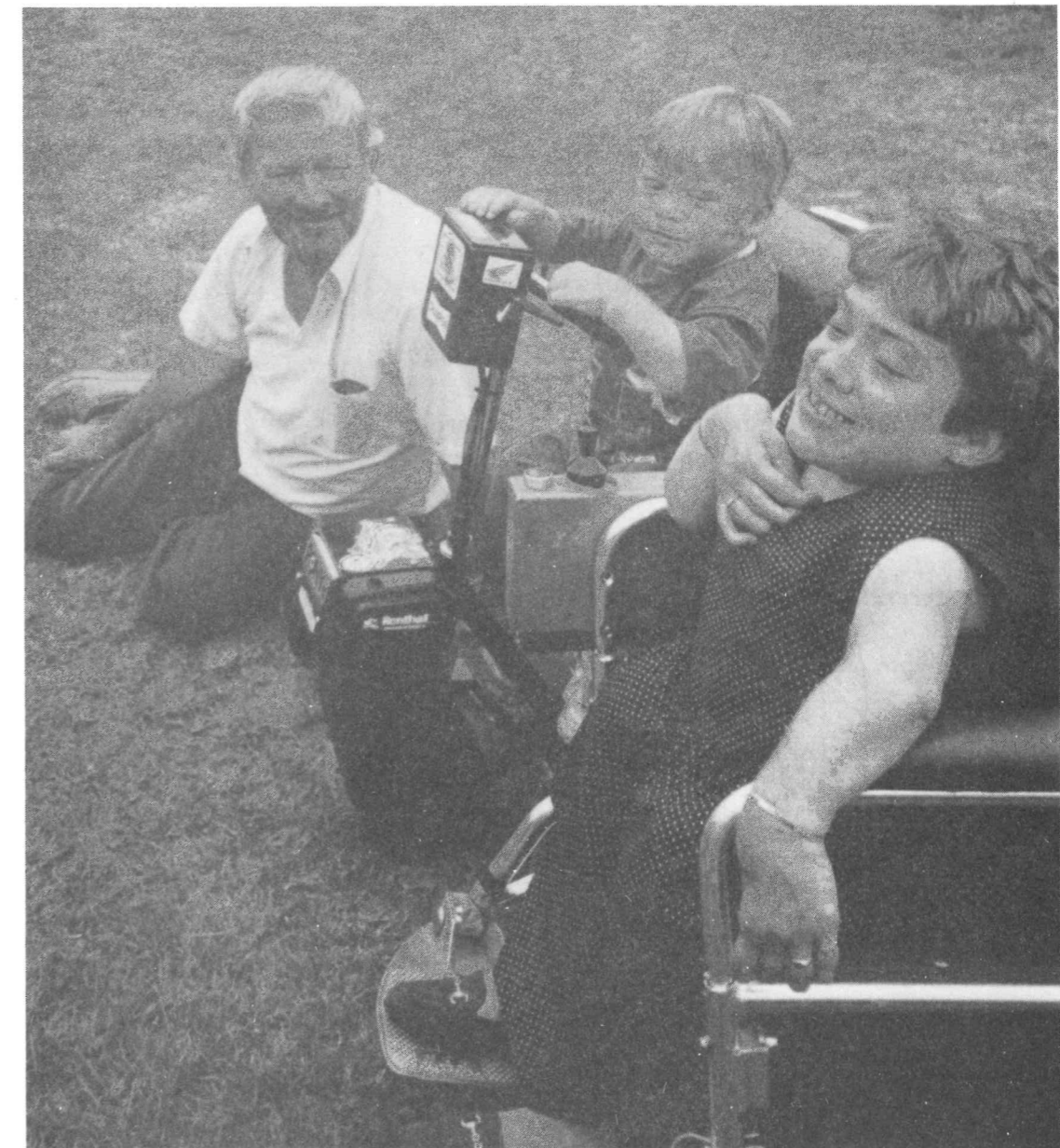
## Sarah Kilvert

It is with great shock and sadness that we heard at the conference of the sudden death after a short illness of Sarah Kilvert. Sarah died on the 27th of September aged 22. Only a short while before Anne and Mike had written to the newsletter about the very successful Area Family barbecue they had at Brookhouse Farm, Lougharne, near Pendine on the 30th of July.

Sarah was a lovely young woman who endured her disability with great courage and good humour and who lived life very fully. The love and affection shared between her and her parents was most marked. They will be devastated by this sudden and unexpected loss. Our thoughts are with them at this time.

Ann and Mike intend to continue with their work as an Area Family and they feel that this helps them to cope with their grief.

Below: Sarah with Christopher Rees (MLIII) aged eight and a half, from Clydach, Swansea and her father Mike at the barbecue in July.





# The Guardian Jerwood Award '95

20 September 1995

The Chief Executive  
The Society for Mucopolysaccharide Diseases  
55 Hill Avenue  
Amersham  
Buckinghamshire  
HP65 5BX

Dear Sir/Madam

I am happy to inform you that Christine Lavery has been shortlisted for The Guardian Jerwood Award 1995 for individual excellence in the charity field.

The attached letter has been sent to her home address.

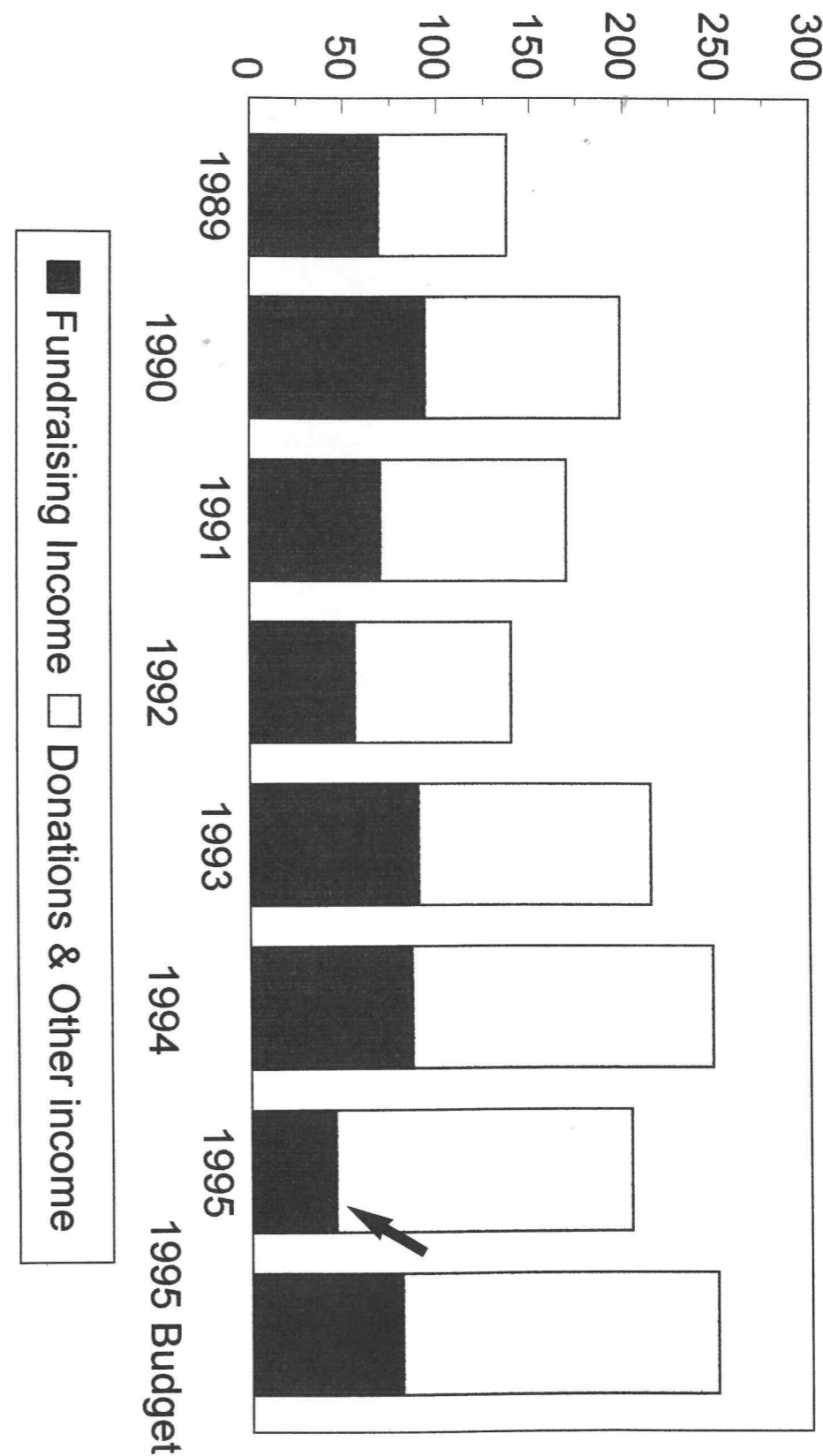
If you would like more information about the award please call me on 0171-611-9151 or my secretary Karen Burbidge on 0171-611-9000 ext 821.

Kind regards.

Yours sincerely

  
Anne Waterson  
Classified Supplements and Sponsorship Manager

## The Society for Mucopolysaccharide Diseases



As you can see from this chart, overall income is down quite a lot this year from last year.

Fundraising is seriously down.

Income this year is a lot less than we have planned to spend.



## ACCOUNTING PROCEDURES

Sounds daunting doesn't it ! But we are simply asking that to make our Treasurer's life and that of the Office Staff, a bit easier please:-

When you send money, cheques or postal orders to MPS, we need to know how it was raised, or where it comes from ?

Has it been for some fundraising that you or someone has done on behalf of MPS?

Is it a straight forward donation from you or some group ?

Or in memory of a loved one?

Is it a donation from a company ?

Is it from a collecting box ?

This information also helps in the compilation of lists of donors for the newsletter.

## 1995 MPS Christmas Parties

<u>Date</u>	<u>Area Family</u>	<u>Location</u>
3 December 1995	Brennan & Blackburn	Southport
10 December 1995	Kilvert	Swansea
17 December 1995	Snack & Hodgetts	Gaydon, Warwick
10 December 1995	Mahon	Sutton On Hull

Further details contact John & Kathy Lawrie. Tel: 0142-786902

Ron and Linda Snack have written to extend a special invitation to the Christmas Party at Gaydon, near Banbury, Oxfordshire at 2pm on 17th of December. This will be the last get together that they will be arranging because they are resigning as Area Family from the end of the year. They are hoping to see as many of their MPS friends as possible. A good time is guaranteed. The party is jointly organised by Sargeant Richard Millward who lost a daughter to MPS just over a year ago.

## Area Support Families

<b>Martine and John Brennan</b> 105 Barley Cop Lane, Lancaster, Lancashire LA1 2PP	Tel: 01524 382164
<b>Robert and Caroline Fisher</b> The Horrells, Great Samford, Saffron Walden, Essex, CB10 2 RL	Tel: 01799 586631
<b>Suzanne and Jeffrey Hodgetts</b> 6, Godolphin, Tamworth, Staffordshire B79 7UF	Tel: 01827 56363
<b>John and Barbara Arrowsmith</b> 11 Penfold Close, Fairways Est. Benton, Newcastle on Tyne NE7 7UQ	Tel: 0191 2662999
<b>Sean and Pauline Mahon</b> 41 Stumperlowe Crescent Rd, Sheffield, South Yorkshire S10 3PR	Tel: 01142 304069
<b>Mary and Robin Gooch</b> Highbank House, Swifehill, Broadoak, Nr Healthfield, East Sussex TW21 8XG	Tel: 01435 883329
<b>David and Monica Briggs</b> 7 Humber Street, Retford, Nottinghamshire DN22 6LZ	Tel: 01777 700046
<b>Bill and Sylvia Blackburn</b> 11 Beatty Road, Nantwich, Cheshire CW5 5JP	Tel: 01270 626809
<b>Ron and Linda Snack</b> 16 Wandsworth Place, Bradwell Common, Milton Keynes, Bucks MK13 8BT	Tel: 01908 666819
<b>Tony and Shirley Eyre</b> 7 Elmer Close, Malmesbury, Wiltshire SN16 9UE	Tel: 01666 825215
<b>Anne, Michael and Sarah Kilvert</b> Windy Way, Nantoer, Newtown, Powys, SY16 1HH	Tel: 01686 624387

### Contact for Scottish Families:-

**Alan and Fiona Byrne** Tel:0141 6430034  
3 Jedburgh Avenue, Rutherglen, Glasgow G7 3EN

### Northern Ireland Co-ordinating Committee:-

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