NEWSLETTER WINTER 1990

# THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES


National Registered Charity No. 287034

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



# The Society for Mucopolysaccharide Diseases

**7 Chessfield Park, Little Chalfont, Buckinghamshire. HP6 6RU**
**Telephone: (0494) 762789**

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

**To act as a parent support group**

**To bring about more public awareness of MPS**

**To promote and support research into MPS**

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

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

**"Care Today, Hope Tomorrow"**

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**SAVE OUR EYES! NEVER MIND THE TREES!**

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The newletter is in A4 size this time round as an experiment. We feel the smaller size is very hard on some people´s eyes. The larger size costs a little more. Please let me know which you prefer.

Charles O´Toole

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**SHANE DIXON**
WITH HIS
MOTHER
ZELDA,
Tucking in
At the UMIST
Conference



## 1990/91 CLINICAL AND RESEARCH GRANTS BY THE SOCIETY

You may recall that in the Autumn Newsletter I wrote about two substantial donations received by the Society and of our plans to fund a biochemist at the Willink Biochemical and Genetics Unit at the Royal Manchester Children's Hospital. At the time of writing I suggested that the legacy from the estate of the late **Mrs Evelyn Annie Page** from Worthing, West Sussex, would be in the region of £20,000. I can now share with you the incredible news that the exact amount was **£27,864.43p.** This money is to be used for the investigation of MPS diseases. The committee is currently considering the most appropriate use of this money and I will report back in the Spring Newsletter.

In November the Committee and Medical Advisors met to determine our 1990/91 budget and to allocate clinical and research grants on behalf of the Society.

1. It was confirmed that we would meet 60% (£10,000) of the cost of employing a biochemist who is experienced in DNA techniques and who will work on the Hunter probe obtained from Dr John Hopwood in Adelaide. This will be a Senior Biochemist post based at the Willink. This is a three year grant and the Society will need to raise a further £24,000 in 1991 for this post.

2. Two grants were awarded to Dr Bryan Winchester, Head of the Enzyme Laboratory, Institute of Child Health, London.

   The first of these was for Mrs Elizabeth Young to develop techniques for accurate detection of Hunter Heterozygotes (carriers) using John Hopwood's DNA probe. Investigations will also be carried out on the biochemistry of MPS and ML, where the GAGS do not match recognised patterns, but the clinical picture suggests MPS or ML.

   The second grant of £1000 is to meet the cost of buying Sanfilippo substrate to enable a summer student to screen urines from children attending development centres around the country, who suffer from develomental delay of unknown cause.

3. The final decision was to confirm the third year funding of 50% (£20,000) for the Consultant Paediatrician at the Royal Manchester Children's Hospital, Dr Ed Wraith, who specializes in MPS and ML diseases. The Society will still need to raise a further £30,00 for the period September 1991 to March 1993. After that the post will be wholly funded by Salford District Health Authority.

**Christine Lavery**
Hon. Director

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## NEW FAMILIES

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We are pleased to welcome **Christine and Thomas O´Neil** from Rutherglen in Scotland, although we are very sad to learn that **John Paul** age twelve and **Brian** age nine have been diagnosed as suffering from Sanfilippo Disease.

**Ian and Allison Russell** of Invergordon in Ross-shire, whose son **Sean** aged almost three has been diagnosed as suffering from MLII.

**Brendan and Mary Hayes**, Co Cork, Ireland, whose four year old daughter **Catherine** suffers from Hurler disease.

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## BIRTHS

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To **Diane and Neil Cliff**, a daughter, **Joy**, born on the 5th of July 1990, weighing just over five pounds, a sister for **Stacey.**

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## DEATHS

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**Misbah Haq** from Rochdale who suffered from Morquio disease died in October aged ten years. Our thoughts are with her sorrowing parents and family.

**Richard Champion** from Cambridge who suffered from Sanfilippo disease died in October aged twenty. Our thoughts are with his sorrowing parents and family.

**Carol Hubbard** from Romford died on the 5th of November while undergoing surgery. Carol suffered from Maroteaux Lamy disease. She was a well known and much loved member of the Society for her courage and cheerfulness. Our thoughts are with her husband Paul and her mother Mrs Gannon, who has now lost both her daughters to MPS.

**Colin Snack,** from Milton Keynes who suffered from Hunter disease died on the 24th of November 1990, aged nine years. Many of you will know Colin and his parents Ron and Linda Snack from their work as an area support family and from Ron´s work as the Society´s fund raising co-ordinator. Our deepest sympathies are with Ron and Linda at this very sad time.

**Thomas Beavan** from Market Harborough in Leicestershire died on the 13th of December aged twelve years. He suffered from Hurler disease. Our sympathies to his parents Alan and Deirdre and to his brothers and sisters at this sad time. Many will know Alan and Deirdre from their role as Area Family and from their talk at the conference in 1989.

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## LEGACIES

As you will all appreciate the Society depends on a steady income to allow it to meet all its aims:

Family Support
Awareness
Research

As the Society has matured, it is nine years old in May, its work has become better known and in recent months we have had several enquiries from people wishing to include the Society as a beneficiary in their will. Two of the people who approached us recently have no direct connection with Mucopolysaccharide Diseases, although indirectly they know of our work. Because our overheads are small and a high proportion of our income directly benefits families to some people the MPS Society has more appeal than the much larger bureaucratic organisations. We are able to accept specific requests, i.e for research, support to MPS families nationally or in a specific area.

No one likes to consider their own demise, but if you, or someone you know is making a will and feels that they would like to make a bequest to the Society we can assure you that your wishes will be both appreciated and honoured.

If you would like to discuss any aspects of legacies further please contact Christine Lavery or Linda Golding on 0494 762789 in the MPS office.

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God moves in a mysterious way

His wonders to perform

He plants his footsteps in the sea

And rides upon the storm

Ye fearful saints fresh courage take

The clouds ye so much dread

Are big with mercy and shall break

In blessings on your head.

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## Christmas Party

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The Christmas Party took place this year within sight of the Royal Mint, at the Perkin Elmer Social Club at Llantrisant in Wales. I was tempted to bring along my pickaxe and spade to try and extract a little extra cash for Christmas, but with the food and the entertainment I didn´t have time.

Tony and Mary Lockyer had brought off an amazing coup in getting this large bright warm and cheerful hall, already lavishly decorated. With the help of their friends the tables were groaning with a buffet lunch, enough to feed a small town.

The younger children were entranced by the Magic of Mr Goldini. (Helen asks me to report that it wasn´t very good for the older children, but some of them seemed to be doing quite well at making their own entertainment.)

The Christmas Raffle was brought to a successful climax by David Briggs, with Christine Lavery drawing the first prize.

An unexpected visitor dropped in from the North Pole, and all the little children crowded round him. While the children were listening round eyed to his stories one boy quietly extracted three presents from his sack!

Asked afterwards about whether she believed in Father Christmas another child told me, "It wasn´t the real Father Christmas, it was that fat man over there with the yellow hat, stuffing his face."

The evening ended with Christmas Carols and a Welsh chorus.

Our thanks to Tony and Mary Lockyer and their family and to all the Welsh families for a warm and agreeable Christmas party.

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### MATCHED FUNDRAISING

Many large Companies these days run a scheme whereby they will match amounts of money raised by their employees for any particular charity. I have only recently found out that Abbey National run such a scheme, so every time Linda and I raise any money for the Society I apply to the Abbey National Charitable Trust for a matched donation.

If any of you work for a Company where you think such a scheme might be in operation just ask your Personnel Department, and they will put you in touch with the relevant person.

This is definitely a useful, and easy, way of adding to the money you raise.

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### UNIVERSITY OF YORK RAG

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Over the last few years our Welsh Area Family, Tony and Mary Lockyer have dedicatedly applied on behalf of the Society, to various University RAG weeks. By and large these applications have been successful.

Pictured is Julian Warren, who suffers from Morquio Syndrome, receiving a cheque for £369, from the President of the University of York RAG.

On behalf of the Society, thank you Julian and thank you to all the students who helped to make this donation possible. Don't forget if you live near to one of Britain's Universities or know someone attending University do pass the details on to Tony and Mary Lockyer, 29 Llanberis Close, Tonteg, Pontypridd, Mid Glamorgan Tel: 0443 203845.

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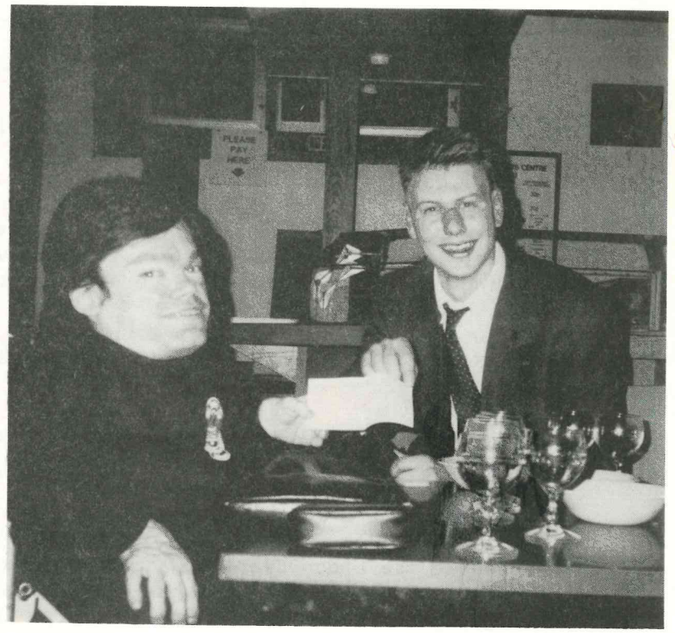
**JULIAN WARREN**(left)

"grips and grins"
as he receives
a cheque from
**Richard Walker**
of the York
University Rag Week



### LONDON MARATHON

With this Newsletter you will find a sponsor form for the London Marathon. I know that we have at least one runner for 1991, and that is Rob Burgess, an MPS dad from Luton. If there are any other runners then please get them sponsored by as many people as you can.

Last year we didn't do too well from the London Marathon, so this year lets do all we can.

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## MPS "ASDA TROLLEY DASH

The 30 October 1990 saw the culmination of almost 5 months slave labour when Mr Charles Dawson of Allerton in Liverpool took part in a 3 Minute Trolley Dash. This is the story of that dash.

It was the middle of May when we were having one of our usual family get-togethers that we said "What can we do to raise money for the Society. The suggestions were bandied about but one stood out. A TROLLEY DASH!!! I said I had recently seen one of these done and what a success it had turned out to be.

After some discussions this is what we decided to do, we got onto a printer who we knew, he helped to design the tickets, we spoke to our local Asda Superstore who were more than willing to help us, so much that they gave 3 weekends in September/October to set a stall up in the food hall to sell tickets. Only one problem remained - how many raffle tickets did we need, we agreed on 5,000 books at a £1 a book or 20p each.

We also at this time arranged where to draw the winning raffle ticket, this was to be on the 20 October at my son's cricket club - Sefton Park CC.

So there it was all set to go, 5,000 tickets and nearly 5 months to sell them.

At the beginning, the family all took books of tickets and sold them to friends, neighbours, workmates and anyone who would buy. Myself, I distributed tickets to all our local shops with posters advertising the sale of tickets. Family who live abroad (Australia, Spain, Israel) sent donations for tickets, also family in this country (Leeds, Manchester), the local pub also sold tickets, one local businessman sold £388 worth of tickets by not giving change when customers bought their goods - he was the local Chinese Take-a-way, his staff did a wonderful job. Tickets were also sold in local factories. In all prior to selling tickets in the Asda Superstore we had raised a total of £782.00.

On the 13 September 1990 we set up our stall for the first time in the Asda Food Hall, Hunts Cross, Liverpool. All the management and staff were very helpful.

During the first weekends at the Asda, we averaged takings of £800, the third weekend was cut short due to myself having to go into hospital on the Thursday for a minor operation, nevertheless we still raised £550 on the weekend. In total over the 5 months we were able to raise £3,500.

Meanwhile the Disco Evening was arranged as said before for the 20 October 1990, where we were going to have the draw, we arranged for the Staff Personnel Manageress of Asda - Mrs E Dykes to draw the winning ticket. Over 80 people attended the evening all had a good time, further raffles took place raising another £150.

My thanks go to all the family, friends, everyone who sold tickets, to Asda Superstores for everything and Sefton Cricket Club for allowing us to hold the Social Evening.

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The culmination of this story ends as it began. On Tuesday 30 October at 8.00 a.m. when we arrived at Asda (8 of the family including David) to meet the winner of the Dash, an eight year old girl named Joy, but it was her father who was to do the dash, also there was her mother, sister and a couple of cousins. We were met by Mrs Dykes and other members of staff who made all the arrangements for the dash to take place at 8.30 prompt.

At 8.30 a.m. the dash began, people were dashing everywhere, throwing articles of food, household goods etc into trollies. At the end of three minutes, 5 trollies were full, it had been hectic, shopping will never seem the same. Staff commented it was one of the best dashes they had seen.

Everyone was delighted that this family had won the dash, as we were told that prior to finding out they had won, they had been burgled so they felt that there was someone looking after them. Asda also presented the children with some toys.

SIDNEY SHIFF

**A car for £99 a year!**

Yes, really, that is what Magna Marketing are offering to some potential customers.

There are snags of course. You have to accept that your vehicle will be covered with advertising slogans and stickers, which actually cover the cost of supplying the vehicle.

Insurance and running costs are the user's responsibility.

Mark Reade, director of Magna, is confident that the offer will attract some disabled drivers and also charities who otherwise could not afford to operate a vehicle.

*Magna Marketing, Weybridge, Surrey, tel: 0932 821800.*


**Sidney Shiff (centre) and family,** presenting a cheque for £3000 to Mary Gardiner at the Disco Evening after the Trolley Dash.

## LIONS TEDDY BEARS

I understand that in some areas the local Lions Clubs are willing to supply a large Teddy Bear to each public house in their district, to be raffled for charity.

The idea is that a sheet of paper is marked off into 200 squares, and all the locals in the pub are invited to buy a square for 50p. When all the squares are filled the draw is arranged, preferably to be held on a night when the pub is busy, and whoever has the winning number goes home with the bear.

Why not contact your local Lions, addresses available at your library, to see if they are operating this fundraising idea.

## Heathfield Agricultural Show 1990

Robin and Mary Gooch with family and friends had a stall again this year at the East Sussex Show Ground on May 26th.

It was a massive show but we were allocated a generous area with a thirty foot frontage. We borrowed two large tents which Robin and one of his friends put up almost single handedly (or is it double handedly?)

We sold a trailer load of plants, some donated by nurseries and some grown by friends. Christine displayed a vast array of childrens clothes, the result of many months of knitting. Our friend Johnny attracted the children with the stock from his former novelty shop in Tunbridge Wells and Christine tempted them out of their last 15p's with her world famous Rice Crispy Fingers.

It was Petticoat Lane style for Robin in bowler hat and bow tie in the afternoon as he sold off most of the remnants. This is our local show and all the family, including James and his brothers Nick and Adam, had an enjoyable and successful day.

Emboldened by our success we are now planning to descend on our local Sainsburys, collecting boxes at the ready!

**Christine Gooch**



## AN IRISH MPS SOCIETY?

Brendan and Mary Hayes from Monkstown in Co Cork have just joined the Society and have expressed an interest in setting up an MPS Society in Ireland.
We hope they will be able to go ahead with this and wish them every success and encouragement.

Their daughter Catherine, born in 1986, had a successful bone marrow transplant in 1988. Perhaps Irish families would like to contact them.

**Brendan and Mary Hayes**
Fairy Hill
Monkstown
Co. Cork
Ph 021 842 067

**Nice one Harry!**

**Mr Harry Green**
of Liverpool
who did a sponsored
bike ride from
Liverpool to
Blackpool in June
last year to raise
money for the Society.

## MENTAL HEALTH FLAG DAY

Another piece of paper you will have found with this newsletter is the booking form for Mental Health Flag Day. In 1990, with only a few families doing the collection, we managed to raise over £800 for the Society. Let's try and beat that in 1991.

It really is very easy - just fill in the form enclosed to let me know where you would like to collect - and I will then ask MHFD to arrange the licence from each separate Local Authority.

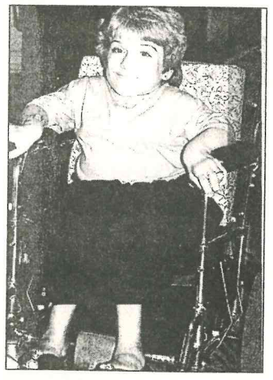
Once that is arranged I will let you know, and you simply fix up to collect the tins, labels, stickers and advertising bumph from a local bank. All that is left is to go and rattle a tin for a few hours on the day.

Money for old rope really!!

# The missing enzyme

**Sanfilippo's syndrome is a rare, genetically inherited disorder caused by single enzyme deficiency. The symptoms are distressing, but therapists can help parents to cope, says Dorothy Penso.**

*Two boys who suffer from Hunter's disease photographed with Dr John Hopwood of Adelaide Children's Hospital, who located the Hunter gene on the X chromosome. Below, an 18 year old girl who suffers from Morquio's disease.*



**THE mucopolysaccharidoses (MPS) are rare disorders of complex carbohydrate metabolism. Single enzyme deficiency results in the abnormal storage of glycosaminoglycans (GAGS).**

**The disorders were biochemically classified in 1969. During the last ten years, bone marrow transplants have successfully replaced the missing enzyme in a number of children.**

IN THE LAST ten years, 86 children with Sanfilippo's syndrome have been born in the UK. The disorder is characterised by the breakdown of mental and somatic functions with severe and distressing behavioural disturbances.

Like all the mucopolysaccharidoses, it is inherited. Prenatal diagnosis is possible, but the disease may not be apparent in the first child before further children are born to the family.

Parents may first seek medical advice because of their child's hyperactive and destructive behaviour. Signs which alert the clinician to the possibility of the syndrome are slow development, severe speech delay, disturbed behaviour, turbulent sleep disturbance, loose stools and recurrent infections, especially otitis.

In the second stage of the disease, behavioural difficulties become more pronounced, with self-destructive activity and indiscriminate chewing of objects.

Intellectual ability deteriorates and language skills which have been acquired are lost. Some children are never toilet trained, others become incontinent.

As the disease progresses, physical activity slows down, and unsteadiness develops with frequent tripping and falling. Eventually, independent mobility is lost.

The time scale of these events varies. Dutch statistics report the earliest death as at six years (type A) and the oldest living sufferer as 48 years old (type B).

Unlike other MPS disorders, growth is not so stunted and the face is less affected by the abnormal storage of glycosaminoglycans (GAGS).

*A 21 year old boy who suffers from Sanfilippo's disease, photographed at a barbecue at this year's International Symposium on the Mucopolysaccharidoses and Related Disorders*

The hair is thick and abnormally coarse. There is more body hair than usual. The eyebrows are bushy and may meet in the middle. The features are coarse with thick lips and flattened nose bridge.

Joint contractions develop, especially in the elbows, knees and tendo-Achilles. The fingers may become clawed due to carpal tunnel syndrome.

Hepatomegaly and splenomegaly are not as severe as in other MPS syndromes.

Some children develop herniae. Both conductive and perceptive hearing loss can occur.

Periods of severe diarrhoea can be distressing both for the child and parents. Later there may be severe constipation when the child becomes less active.

In the later stages, petit and grand mal may develop.

Hyperactivity, aggression and severe sleep disturbance are perhaps the most distressing symptoms. Behavioural programmes are *not* helpful, as the symptoms are due to the progression of the disease, *not* to poor management.

However, therapists can provide support for families and suggest coping strategies.

Modifying at least part of the house will enable the child to play without constant supervision. The area should be free from items with sharp edges. Windows may be fitted with strengthened glass and the floor covered with easy to clean materials.

Television sets and music centres can be placed on high shelves and operated by remote control. Downstairs toilet facilities ease changing and washing.

The child's excess energy can be safely expended in a garden with substantial fencing. Some children are calmed by the movement of a car journey.

Some 66 per cent of girls and 33 per cent of boys are reported to show aggressive behaviour. Typically, this consists of kicking and hitting, seemingly generated at random.

Dr Martin Bax, an authority on the disease, suggests that hitting may be a form of greeting, excitement at seeing a new person or a desire to protect personal space.

One parent has reported that his son has been less aggressive and has had a longer concentration span since he has worn glasses. Another parent reported a similar effect since her child has worn a hearing aid.

Parents who never have an undisturbed night's sleep are ill equipped to deal with a hyperactive child. This is the plight of many parents who care for a child with Sanfilippo's disease.

Though these children behave like very young children, they need only the same amount of sleep as children of their chronological age. Sleep may be less disturbed if bedtime is later while the child rises at the normal time each morning.

A further problem is that the child's sleep is not usually continuous. There may be several phases of wakefulness each night when the child behaves in the same manner as in the day — hyperactively.

Some parents have found their own solutions to these problems.

One parent from the US uses a sleep belt which allows his child to turn but not to get out of bed. Other parents have reported that such a device causes panic in their child.

Many parents feel that their child only wants to see what they are doing, and then will happily return to bed.

One parent advocates using a double sheet on a single bed so that the child is well tucked in and feels secure. For similar reasons, other parents secure a duvet to the corners of the bed or use cot sides.

These suggestions for coping with sleep disturbance in Sanfilippo children were all proffered at the Second International Symposium of Mucopolysaccharide and Allied Disorders at Manchester University in September. Many informative papers were presented concerning the latest developments in diagnosis and treatment.

## Meaningful

Perhaps the most helpful aspect of the conference was the presence of families from many parts of the world. Mixing with affected children and discussing practical problems with their parents made the medical papers more meaningful.

The resourcefulness and devoted care of the parents towards their children was inspiring. The MPS Society is an important element in the lives of these families, allowing members to give and receive support they need to care for their handicapped children.

**Further information**

The Society for Mucopolysaccharide Diseases, 7 Chessfield Park, Little Chalfont, Amersham, Bucks HP6 6RU.

Restricted Growth Association, 103 St Thomas Avenue, Hayling Island, Hampshire PO11 0EU.

ACT (Action for the care of families whose children have life-threatening and terminal conditions), The Institute of Child Health, Royal Hospital for Sick Children, Bristol BS2.

*Dorothy Penso is a senior occupational therapist at the Child Development Centre, York District Hospital, York.*

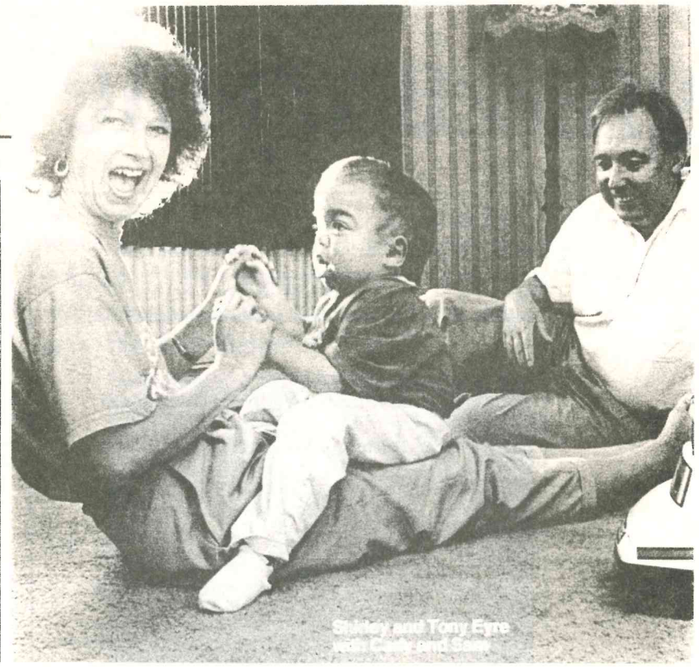
**Classification of MPS**

| | |
|---|---|
| MPS 1 H | Hurler's disease (severe physical and intellectual impairment) |
| MPS 1 S | Scheie's syndrome (normal intellect) |
| MPS 1 H-S | Hurler-Scheie (normal/near normal intellect and severe physical symptoms) |
| MPS 11 | Hunter's syndrome |
| MPS 111 | Sanfilippo's syndrome, types A, B, C and D |
| MPS 1V | Morquio's disease, types A, B and C |
| MPS V1 | Maroteaux-Lamy syndrome |
| MPS V11 | Sly's syndrome |

**Some Effects of Abnormal Storage of GAGS**

**The manifestation and severity of these effects vary according to the disease and between individual sufferers from a disease.**

**Face**
Thick lips
Bushy eyebrows, synophrys
Flattened nose bridge
**Brain**
Convulsions
Behaviour problems: sleep disturbance, aggression, hyperactivity
Intellectual impairment
**Liver/spleen**
Enlargement
**Heart**
Thickened ventricle walls
Valvular incompetence
**Respiratory tract**
Thickening of airway walls resulting in narrowing of lumen.
Pulmonary hypertension
Increased secretions
Sleep apnoea
Enlarged tonsils
**Mouth**
Enlarged tongue
Enlarged gum ridges
Poorly formed teeth
**Eyes**
Corneal clouding
Glaucoma
**Ears**
Conductive or neural deafness
**Bones**
Malformations
Joint stiffness, especially knees and hips
Tight tendo-Achilles
Thickened skull
Kyphosis
**Hands**
Clawing
**Skin**
Thick, lacking elasticity
**Hair**
Thick, abnormally coarse



Shirley and Tony Eyre

# Genetic counselling *explained*

Shirley Eyre smiles with delight as her energetic two-year-old daughter, Carly, races around the house. Carly is Shirley's little miracle, the healthy child she thought she'd never have.

Four years ago, Shirley and her husband Tony discovered that a one in 10,000 chance meant they both carried genes for Hurler's syndrome, a fatal disease in which the body is unable to break down fats.

It had already affected their son Sam, then aged one. This means he'll become progressively handicapped and is unlikely to survive beyond the age of 10.

"It was a devastating blow," says Shirley. "First, to hear that our lovely baby had this terrible condition and, second, to realise that any further children might be affected."

As they wanted another child, the couple sought genetic counselling at their local hospital. The counsellor confirmed they had a one in four chance of producing another Hurler's syndrome child, but explained that it would be possible to do early prenatal tests to discover whether the foetus was affected.

Ten weeks into her next pregnancy, tests showed the foetus had been affected and Shirley decided to have a termination.

When she became pregnant again, doctors were able to give her the news she longed to hear — the baby was healthy.

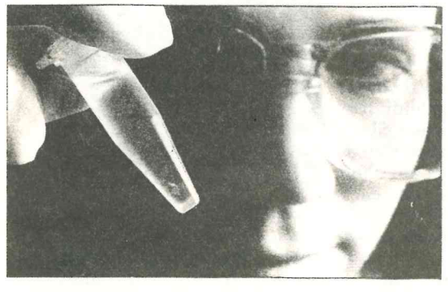
After Carly was born, the couple decided not to have any more children. "We've decided to call it a day. We love Sam and we just thank our lucky stars for our beautiful little girl," says Shirley.

There are over 4,000 genetic disorders which can be passed by parents to their children. In some cases, only one parent needs to carry the faulty gene for there to be a chance of a child being affected.

According to Christine Lavery of the Genetic Interest Group, most couples don't know they have a faulty gene until one of their children is affected. Others may be forewarned because their relatives have a particular disorder, alerting them to the fact they could be carriers.

Every year, genetic counsellors help hundreds of couples who know, or suspect, they carry potentially damaging genes. Their job is made a little easier by recent breakthroughs in locating the precise fault in the genes causing diseases such as cystic fibrosis and Hunter's disease. This means doctors are equipped with much more information about how these disorders are passed on, and about how to identify those people most at risk when having children.

**'There's more we have to offer and more we can do to help'**
**Dr Angela Barnicoat**



**DNA in a test tube — key to creating healthy babies**

"We're seeing more people than ever before, though it doesn't mean problems are on the increase," explains Dr Angela Barnicoat, counsellor at the Genetics Department at Guy's Hospital, London. "There's more we have to offer and more we can do to help them."

## Getting help

If you're concerned about the risks of passing on a genetic disorder to your children, the first step is to see your family doctor, says Dr Barnicoat.

"He may be able to reassure you or put you in touch with someone who can offer expert advice."

If you do need specific genetic counselling, it's usually available at hospital genetic units — most health regions have at least one.

According to Dr Barnicoat, the first stage in the process is to build up as much information about the couple and their families as possible. This requires details of the health of the parents, grandparents, brothers, sisters and even cousins.

Depending on the type of condition and how much is known about it, the next step usually involves taking blood samples from both partners and key members of the affected side of the family. These are used to try to work out the patterns of inheritance, looking particularly at the way the information-carrying substance of the genes — DNA — is passed from generation to generation.

Because it takes weeks, even months, to analyse blood samples, it's best to investigate any possible genetic disorder before trying to become pregnant.

From the results, the medical team is able to work out the likelihood of any child being affected. It might be quite a low risk, or as high as a 50 per cent chance.

For an increasing number of genetic conditions, prenatal tests are available to determine whether a developing foetus is affected at an early stage of pregnancy. Couples then have the option of having a termination. Where a termination is not an acceptable option, a couple may find the tests are useful in preparing themselves mentally for the arrival of their baby.

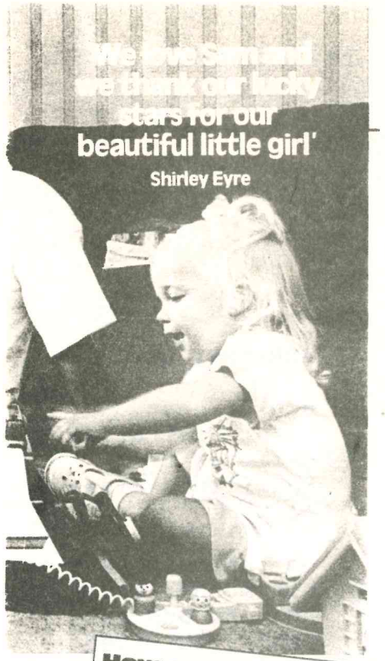
"If there's a problem we know about before birth, we can make sure you have the child in a hospital where there are the best facilities to treat the condition," explains Dr Barnicoat. Parents also make arrangements for any necessary special care.

Eventually, there may be ways to have a healthy child, even if you do carry faulty genes.

Long-term, there's the possibility of in-the-womb operations becoming widely available to correct some genetic conditions, particularly heart or kidney disorders, before birth.

**Joanna Moorhead**

*For more information contact: The Genetic Interest Group, c/o Contact a Family, 16 Strutton Ground, London SW1P 2HP (071-222 2695).*




**How counselling can help you**

Genetic counsellors can:

- Explain how an inherited disease occurs.
- Predict the chances of your child being affected, if there's an indication the disease may be in the family.
- Discuss the outlook for you and the child if you do become pregnant.
- Arrange prenatal testing to see if a baby is affected.
- Explain options available after the birth of an affected child.



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A healthy daughter

-Thanks to Genetic Counselling.

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Fame came our way recently when "Bella" magazine featured us in an article on genetic counselling, explaining how we went ahead and had our lovely daughter Carly.

It was just a small sentence which the magazine picked out which seemed to express everything, " We love Sam and we thank our lucky stars for our lovely little girl". It was just a simple line but it expresses our thanks to the people who helped us to have a daughter we thought we would not have.

Its been a long road after our first daughter Hayley died and Sam was diagnosed as having Hurler Syndrome. It was wonderful to have a perfect little girl.

Perfect! did we say perfect? Sometimes poor Sam must think that a storm has arrived with toys flying in all directions, Carly shooting past him on her bike and running and jumping all over the place. However she never touches him, she seems to know that Sam sometimes isn´t well.

Mothering Sam is Carly´s favourite pastime. She gives him his drinks. She wipes his nose even when he doesn´t need it. She fits his hearing aids, but not necessarily in his ears!

Genetic counselling has given us a future with Carly when we thought all was lost. We know that Sam hasn´t got long to live and that losing him will leave a void. However we know that having Carly will give us strength and direction when the inevitable happens.

Tony and Shirley Eyre

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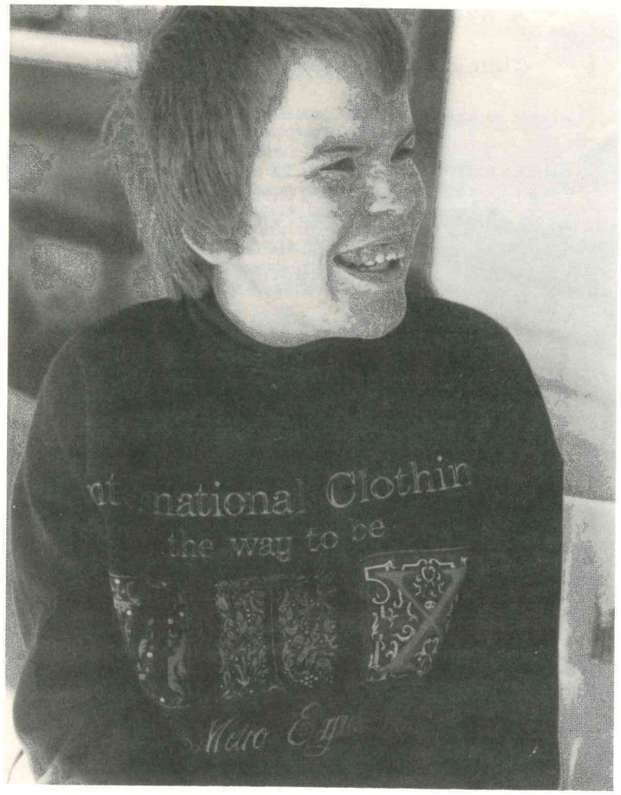
Acknowledgements to "Bella" magazine.



**ADRIENNE SMITH,**

age sixteen,
is an Australian
sufferer from
Sanfilippo Disease.

On the next page
her mother tells
how she and her
family survived
a difficult time
in 1990.

**AMBER OVER THE MOON !**

**Amber Le Page** is a happy three year old, even though she suffers from Hurler disease. She loves to look at pictures of MPS children in the newsletter and she thinks every one is a photo of herself.

Her mother Mrs Teresa Le Page, of Rockneath, Hogue Du Pommier, Castel, Guernsey, C.I. says she will be over the moon to see her picture.

How about sending Amber some more pictures?



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Ros Smith, former President of the Australian MPS Society and currently organiser for an Australian genetics group wrote to Christine Lavery following the UMIST conference. Ros lives with her two daughters, Catherine aged eighteen and Adrienne aged sixteen who suffers from Sanfilippo disease.

Here is an extract from her letter.

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Epping, New South Wales
16th December

Dear Christine,

As you know Adrienne was in respite care while I attended the UMIST conference.

Some days after my departure for the UK, Adrienne fell out of bed sometime during the night and ended up against a heater and severely burned her left leg. What came next is something for conjecture. The leg would not heal and became badly ulcerated. Following the fall which I believe traumatised Adrienne she ceased eating and feeding herself, lost the ability to walk etc. -- so by the time I got off the plane and made contact with the unit Adrienne was considered to be in the final stages. I was somewhat shocked as she had been fit and well (for Adrienne) before I left. Now I was being asked to consider palliative care. The person I was confronted with was a thin wraith like form with a vacant response living on "Sustagen" and barely alive. She had, we believe, pined away following the shock of the burn.

Today, nearly three months afterwards, Adrienne is responsive and eating by herself. She is walking with assistance, although we still make good use of the wheelchair. The leg ulcer has healed.

This has taken constant supervision, twenty four hours a day, from Catherine and myself. Adrienne has not attended school this term for fear of knocks and infections. However she will start the new school year at the end of January.

As if all this was not enough my housing situation became very insecure. However following an extremely emotive meeting (Adrienne´s situation didn´t help) the Committee of Management decided that we can stay even though there was no change in my financial circumstances. A relief, because Adrienne wasn´t fit to make changes at that point. However I feel the situation is tenuous and I wish I could resolve my housing situation without accepting charity.

As you see life has been extremely difficult. However slowly but surely I am surfacing again and steadily attacking the backlog of Society work. Thank you all for allowing me to spend time with you and for broadening my education and knowledge of the UK. We certainly hope to implement a number of the ideas gained during my visit.

Best wishes for a Happy Christmas and a bright and prosperous New Year.

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Mikolow,
Poland
16th Oct 1990

**Dear Fiona and Alan,**

What a surprise to get a letter from you, the more so as it was in Polish! We have memories of our visit to England which we will never forget.... I only hope that sometime we shall be able to entertain you all in Poland similarly.

However nice days and lovely times go past very quickly and we have to come back to our everyday but difficult life.

The present situation in Poland is very complicated. We are living through great political changes and an economic crisis where the poorest are paying the highest price. Among them are the families of handicapped children. We would like to do any job to earn some money ourselves for all the things needed by MPS families. For the present we get quite a few letters (sometimes desperate) from parents of MPS children all over Poland. They cannot get things which they really need for their children. The list is long, from nappies, high calorie food and medicines, to clothing, which as you know the children very quickly wear away. Anyway, you know well yourselves what are the needs of MPS children.

I keep hoping that as the need arises we will find sponsors to help us, but in fact we have to manage without any help. So any form of assistance will be helpful and always welcome.

For all that, I think that one of the greatest comforts which we can give our children is love and that is something which no political situation can control. Love our children as much as we can, accept them for who they are, make beautiful memories with these children, gain strength from them to face what is ahead. Always keep in mind how happy they are in spite of the pain and difficulties they have to face daily. These children are gifted with such peace and happiness they are a blessing to be around and to know.

With good wishes from us all.

Kiss the children from us.

**Marek and Joanna Popek**

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From a letter to Alan and Fiona Byrne (address and phone number on back page). Please contact them if you feel you can assist the Polish MPS Society.

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Verona,
**ITALY**
7th Nov. 1990

Dear Friends,

We are the parents of Elisa, a seven year old girl unfortunately suffering from MPS III, Sanfilippo B.

We could only begin to fully understand the seriousness of her illness last May when we attended the Austrian conference at Pertisau. In fact Elisa is still nimble in her movements even though her mental delay is manifest.

After the Austrian conference we got futher information and literature about MPS from Mr and Mrs Zumbro of the German MPS Society who gave us the address of the British Society. Mrs Lavery kindly mailed us most of your publications and put us in touch with Dr Wraith. Finally we were able to have a complete picture of the situation but this happened two years after we suspected about the disease. The final diagnosis was confirmed for us by a German doctor only last June.

We have also a younger son who is now three years old. Everything in his behaviour makes us think he is sound. However we have also met with many difficulties in getting a quick and certain diagnostic test for him. We hope to have it finalized in the next few weeks.

Also the news that we gathered here in Italy about bone marrow transplantation was very contradictory and put us in confusion. The clear explanation from Dr Wraith and the advice of the Italian doctors that we spoke with after being briefed by Mrs Lavery, made us understand that BMT was useless and risky for our daughter´s case, but what stress we suffered in the meantime!

We realized from our own experience and from what we saw at Pertisau that an Society can bring about more public awareness and convince people to co-operate, so we felt we must do our utmost to try and create a Society in Italy too. We could in this way break the isolation that accompanies a rare disease and join the efforts of other countries.

Last May our appeal to get in touch with other MPS families in Italy and people interested in the disease was published in a magazine and this brought us in contact with nine other families. On the 15th and 16th of September five of them joined us in our home town Verona where the first friendly meeting was held.

Through these families and with the help of Mrs Lavery we also discovered that in our country there are good professional resources and kind doctors interested in MPS. A society could better co-ordinate these resources and help other families avoid our bitter experience.

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(continued on next page)

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The other MPS families, in spite of the problems connected with life with a MPS child (Most of them are Sanfilippo), have a tremendous desire to defeat the loneliness and ignorance that surrounds this disease and to get a better life for their children.

Therefore we ask here to take profit again in the future from your experience in order to put another ring in the international chain of solidarity.

We heartily thank you all on our own behalf and on behalf of the other Italian families.

**Angela e Luigi Montemezzi**
Via Carli 23
37131 VERONA (Italy)

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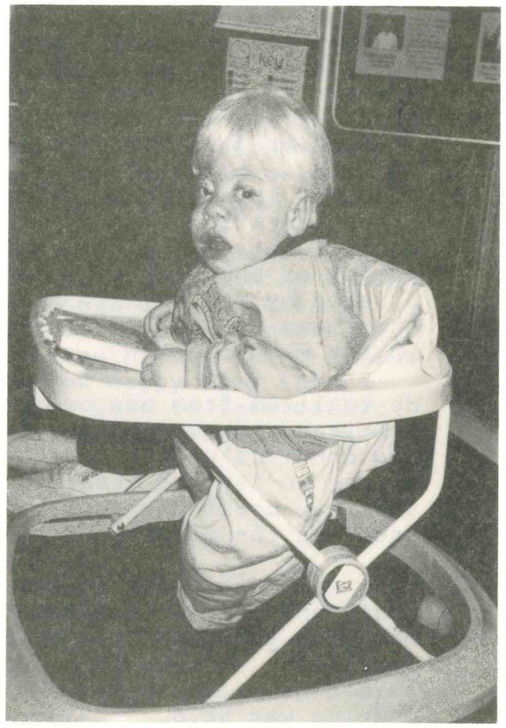
**KAMILA POPEK**
at the Lavery home
in August 1990

**NICE DAYS AND LOVELY TIMES**
give way to
our everyday difficult life.



**Aneka Hoffman**
aged five,
came from
Germany
to attend
the UMIST
conference.
She suffers
from Hurler
disease.



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## FLORIDA HOLIDAY

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Again this year Two MPS children have been selected by the National Holiday Fund to be taken on a two week trip to Florida at Easter. The lucky children are **Emma Mc Clean** from Inverness, and **Victoria Oldaker** from Devon. Congratulations to you both and hope you enjoy your trip!

Here I must make a special mention of **Carol Hubbard,** who introduced the Holiday Fund to the Society, and who died recently. This year one of the holidays was donated to Society in her honour.

The trip is for children only and they travel with a convoy of organisers, helpers and medical staff, staying in fancy hotels and seeing all the sights including Disneyland and the Kennedy Space Centre. (See article Summer 1990). Children need to be between eight and sixteen years, able to travel without their family and able to benefit from the trip.

If you wish to nominate a child for the 1992 trip please contact Christine Lavery at some point. The Society would of course give priority to children whose parents could not afford to take them on holidays abroad. Sue Butler would be happy to advise any family about Alexander´s experience with this group.

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**A GOLDEN OLDIE FROM OUR ALBUM.**

**NO FOG ON THE TYNE FOR COLIN !**

**Colin Arrowsmith** from Newcastle on Tyne being met by the Princess of York three years ago when he returned from a ´once in a lifetime´ trip to sunny Florida. Colin suffers from Hunter disease. His parents, John and Barbara are Area Family for the North East.

## Appeal against refusal of Mobility Allowance

**Richard Mort** is aged nine and suffers from Sanfilippo disease. Some children are described as hyperactive but Wilma says Richard is turbo-boosted active. Richard has to be harnessed to take him walking and even then he is difficult to manage.

Last summer Wilma Robins accompanied the Mort family to a medical appeal tribunal in Swansea about his Mobility Allowance. The parents had been applying since Richard was five but had been turned down every time. This time they were also supported by Swansea Social Services and they had a letter from Ed Wraith.

When Wilma arrived Richard had been sitting in his buggy for a long time. When the door opened he flew in and ran around the room. He rushed up to the table in front of the doctors and swept all the papers from the table.

The doctors then asked for the child to be taken out. Wilma pointed out to them that they were required to examine the child and observe him walking outside and climbing stairs. When one doctor said to her, "My dear do you want to see the child under a car?" a little green light flashed on for Wilma. I think we may have won this one, she thought to herself.

**"I THINK WE MAY HAVE WON THIS ONE ! "**

Richard was awarded mobility allowance backdated to January 1989.

For the benefit of other parents Wilma reminded me of the key conditions for Mobility Allowance. The person must be "unable to walk or virtually unable to walk,"or "if walking independently causes danger to self or others".

Have you had problems with Attendance Allowance or Mobility Allowance, or other benefits? Wilma will be pleased to hear from you and to advise you. Whether you are winning or losing information on your case will help Wilma build up a picture which may be of help to MPS families generally.
(Wilma's address is on the front page.)

For those who take any notice of deadlines, the one for the **Spring Newsletter** is **Good Friday, 29th of March.** Happy New Year!



## GRANTS FOR ADAPTATIONS AND EXTENSIONS

Until last Spring grants from the local authority for House Extensions or for adaptations such as bathrooms or stairlifts were not means tested. Since then the Government has advised all councils to use a standard formula to assess what the family must contribute. What's wrong with that you may say --- surely it is right that the Government should make sure that scarce money is spent on those who need it most?

However what the Society has been finding is

That the level of income where a large contribution is required is low,

That all allowances such as Attendance Allowance and Invalid Care Allowance are taken into account.

For example one family of four with an income of £11,000 plus allowances was asked to contribute £5,000 before a grant would be agreed.

Virginia Bottomley has assured professionals that the grants will not be administered in such a way as to cause hardship to families. **Christine Lavery would like to hear from you about** your experience in relation to such grants, whether good or bad.

## LOANS FOR ADAPTATIONS AND EXTENSIONS

A related worry for some families is whether to take the risk of mortgaging their home to finance an extension needed for their child. Repayments on the loan could be partially covered by Allowances, sadly, these cannot be relied on if the child's life expectancy is poor. Also, what if a parent has to give up work because of a child's illness?

There is provision for the Local Authority to make loans for this purpose, in circumstances where commercial lenders are unable to take the risk. (Three refusals are required as evidence). The loan has to be paid back in exactly the same way, but there is less risk of the Local Authority taking extreme measures to enforce recovery. Again Christine Lavery would like to hear from anyone who has tried to use this provision.

## CALLING ALL GRANDPARENTS

Some of the Society's most active supporters are Grandparents. Just a reminder that you too can receive your very own copy of the quarterly newsletter and annual report and conference report at a cost of only £5.00 per year to cover postage. See details inside front cover.

## MANAGING MEALTIMES

What sort of worries do MPS parents have about feeding their children? At last year´s conference Kay Coombes reported back on a survey of over one hundred children carried out on behalf of the Society. Here is a list of some of problems parents were concerned about.

Babies who suck slowly
Coughing and choking
Falling asleep while eating
Gums large
Teeth difficult to see
Tooth decay
Soft diet contributing to tooth decay
Inability to chew
Refusing food
Overeating
Fussy eaters

Kay went on to talk about some of the distortions caused by MPS which lead to feeding problems.

Large tongue
Stiff neck
Stiff tissues in the mouth and throat
Accumulation of mucous.

The stiffness in the tissues can contribute to poor co-ordination of the closing off of the airway and the passage of the food into the oesophagus so that the food goes down the wrong way. This can lead to choking and coughing.

Choking is more worrying than coughing. Coughing is safely ejecting the food before it goes down the wrong way.

Sneezing tended to be a problem for some children who also coughed and choked on their food. This is likely to be caused by food going to the back of the mouth and getting up behind the soft palate.

There isn´t a lot of professional advice about how to manage these problems. Every child is different and the parents will know best what works for their child. Here are some tips which you may like to consider for yourself.

1 Encourage self feeding early. This will help them to get to biting and chewing as quickly as possible. MPS children develop more slowly. If you can get these skills well established the child may hang onto them longer.

2 As far as possible encourage chewing and grinding of food.

3 The consistency of the food needs to be matched to the child´s ability to chew and to swallow.

4 Try offering the child a lot of small meals at frequent intervals.



5 Get the child in a position where they can see the food and feel it, even if they can´t feed themselves. Sitting up and leaning forward, with eyes hands and mouth focussed on the food.

6 Try to avoid tucking the hands away. (this is especially difficult with some Sanfilippo children, because their hands - and the food - can go everywhere).

7 Encourage the child to pick things up and take them to the mouth. Feeling the food, picking up, carrying to the mouth, biting, chewing and swallowing are all linked in together. If you can get the sequence started it is more likely to work automatically.

8 When you have to spoon feed try to touch the child´s lips and stimulate their mouth as you put the food in. This will help trigger their swallowing mechanism.

9 Avoid pushing the food to the back of the throat.

10 Don´t tip the child´s head back. If necessary take the shoulders and head back together so that the throat opens properly.

11 Give some stimulation round the mouth and inside the mouth before the meal. (Some of the children didn´t like the inside of their mouth being touched. Practice tends to overcome this.)

12 For children who have problems with drinking you can sometimes help by gently massaging underneath the chin to stimulate the movement of the tongue inside. Once the tissues have become very stiff it is very hard to do that.

13 Tipping liquid into the back of the mouth can be unsafe.

14 Some children who tended to cough drank better with cold liquid than with hot liquid. Probably the cold stimulated the muscles and made something happen.

15 Lastly, if you have the child sitting up and leaning forward --- if something does go wrong you can more easily tip them forward and give them a smart tap on the back.

16 If you lie them on their back and put your hand in to remove the obstruction you risk pushing the food further down the airway.

17 Many people mentioned problems of mucous in the throat causing a lot of regurgitation and vomiting at the start of a meal. Perhaps postural drainage or physiotheraphy could help with this as well as with respiratory problems.

**Charles O´Toole**

## IN MEMORY

Many thanks to those who sent donations to the Society in memory of **Carol Hubbard, Colin Snack and Thomas Beavan.**

Donations in lieu of flowers for Colin Snack go to Furze House Hospice at Milton Keynes and for Thomas Beavan to the Cambridge Children´s Hospice.

## IN MEMORY OF CAROL HUBBARD

I am writing to thank all the members of the Society and friends and work mates for their messages of sympathy and floral tributes. Donations of £64.00 were sent to the Society in lieu of flowers and £54.00 was collected by our friends at the post office. It is nice to know so many people care out there.

**Paul Hubbard**
71 Preston Rd
Harold Hill
Romford, Essex.

## The "SEGUFIXE" Night Safety Belt

The "Segufixe" is a harness which can be attached to any bed and which is used to restrain a child. It is designed to help children who are very unsettled at night. The child is free to sit up, stretch and roll over at will. It does not chafe and so far as we know it is entirely safe and in no way interferes with the child´s comfort.

It was demonstrated at the 1989 conference and there is a road test report by David and Barbara Watt on it in the Spring 1990 newsletter. Since then six further belts have been distributed through the Society and all have been found to be helpful in settling the young person so that both the young person and the carers got a better night´s sleep.

Many people may feel worried about using any mechanical restraint on on a child. The Society would not publicize this product if it just made life easier for the carers. Our experience is that it is of benefit to the young handicapped person for themselves.

The belt is made in Hambourg, Germany and costs about £90.

Christine Lavery has two belts in stock which members can borrow to try out. Please contact Linda at the office.




# The Society for Mucopolysaccharide Diseases

7 Chessfield Park, Little Chalfont, Buckinghamshire.
Telephone: (024 04) 2789


## R E S U L T S.

| | | | |
|---|---|---|---|
| 1 | FERGUSON 'C' CAM-CORDER KIT | 009006. | J. LANCET. |
| 2 | P & O FERRY TICKETS for 2 PEOPLE AND CAR +£100 CASH. | 050966. | M. SHARPE. |
| 3 | SET OF ELECTRIC DIY EQUIPMENT +++ | 066789. | T. LAMB. |
| 4 | CAITHNESS CRYSTAL VASE | 076108. | ALISON WILLIAMS. |
| 5 | EUROPEAN ROAD ATLAS | 030151. | A. ALEXANDER. |
| 6 | LEGO BRICKS SET | 001789. | P. HOWARD-DALE. |
| 7 | BELLS SPEC RESERVE WHISKY | 088484. | BETTY DONNELLY. |
| 8 | PORTABLE RADIO/CASSETTE | 042137. | P. A. DAVIES. |
| 9 | MATCHBOX PLAYMAT AND BRIO. TOYS( X 2) | 072020. | G. CALTER. |
| 10 | BUSHMILLS IRISH WHISKY | 040286. | C. HEARN. |
| 11 | MONSTER SOFT TOY | 003720. | R. ROBINSON. |
| 12 | BOOKS X 3 | 014795. | HUTTAN. |
| 13 | MATCHBOX GARAGE | 014388. | B. ARROWSMITH. |
| 14 | WINE VOUCHER | 009917. | J. DAVIES. |
| 15 | CARS & CARRYCASE | 073311. | USMAN. |
| 16 | MOTORCITY PLAYPACK | 080366. | W. CARROLL. |
| 17 | " CITY CARRYCASE | 051084. | G. STOREY. |
| 18 | MATCHBOX BIG TRUCK | 015064. | W. LTTLER. |
| 19 | YEARS SUBSCRIPTION(SHE) | 069281. | M. BISSET. |
| 20 | " " (GOOD HOUSEKEEPING) | 080400. | MEGAN. |
| 21 | GHOSTBUSTERS TOYS X 3 | 008352. | K. ROWE. |
| 22 | KEEPER TOY | 016286. | J. OWENS. |
| 23 | SOFT TOYS X 2 | 009210. | D. TOWNSEND. |
| 24 | JIGSAWS X2+ MODEL KITS X3 | 052010. | R. CAMPBELL. |
| 25 | TONKA CAR | 009480. | E. BARNES. |
| 26 | £10 ASDA VOUCHERS. | 026331. | K. MOULD. |
| 27 | £10 EMI VOUCHERS | 018920. | B. CRUIKSHANK. |
| 28 | £10 M&S VOUCHERS | 017852. | T. FAIRHURST. |
| 29 | CHILDRENS BOOKS X 2 | 096285. | S. HALLIDAY. |
| 30 | SET CARS CORGI. | 045090. | P. BRANNAN. |
| 31 | TWA FLIGHT BAG +KODAK DISPOSABLE CAMERA | 019731. | B. ROWE. |
| 32 | BERTIE BASSETT(SOFT TOY)+BERTIE BOOK | 039376. | D. HAIGH. |
| 33 | LADIES HANDBAG & PERFUME | 032712. | A. AVERY. |
| 34 | MUSICAL TEDDYBEAR & CLOCK SORTER | 017538. | B. CAMPBELL. |
| 35 | TRAVEL BAG SET. (3) | 071778. | KNIGHTS. |
| 36 | SPONGE BAG SET(INC AFTRESHAVE) | 015317. | D. M. LOMAS. |
| 37 | FRAMED FLOWER PRINTS | 017770. | P. JACKSON. |
| 38 | PRIMA UMBRELLAS X2 | 050291. | J. MCDONALD. |
| 39 | 2FT. TEDDY BEAR. | 080023. | M. ABELL. |
| 40 | P. CARDIN PEN+TWIX PEN. | 060766. | D. FRY. |
| 41 | £30 KIETH PROWSE VOUCHERS | 059594. | A. PALMER. |
| 42 | £30 " " " | 085757. | c/o. WILMA. |
| 43 | HAMPER | 009914. | J. DAVIES. |
| 44 | TABLE & CHAIR | 018391. | H. CRAIG. |
| 45 | BRICK SET. | 045750. | REEVES. |

CONGRATULATIONS TO THE WINNERS AND THANK YOU TO ALL WHO BOUGHT TICKETS.

Registered Charity No. 287034

## FUND RAISING EVENTS

Our selection this quarter includes old favourites like the Collection Box and Car Boot Sales to rather rare items such as Charity Football Matches. Please don't forget - it does not matter how much you raise, every little helps. My sincere thanks to you all for another super year of fundraising.

| | |
|---|---|
| Daniel Croghan's Grandparents | Collecting Box |
| Howard Ringland | Great North Run |
| Fulwell Ceiling Contractors | " " " |
| T Scrafton and Sons Ltd | " " " |
| Colmic Building Contractors | " " " |
| G Finch, Somerset | Bridgwater School Staff "Weigh In" |
| Swansea University Rag | Various Events |
| N & C Rock | Raised |
| C & J Norsworth | Collecting Tin |
| Penygloddfa Primary School | Harvest Thanksgiving Service |
| K & Y Puddy, Somerset | Charity Football Match |
| Mrs M Harvey | Sponsored Slim |
| James and Richard Mellor | Raised |
| Mrs P Croghan | Car Boot Sale |
| Ampleforth College | Raised |
| Paul Butler | Reading Marathon |
| Halifax Building Society | " " |
| C Norcliffe | " " |
| Thameside Business Systems | " " |
| I & H Coleman | " " |
| J E Henehan | " " |
| D Hughes | " " |
| North Wilts Holiday Club | Various Fundraising Events |
| Sid Shiff, Liverpool | Trolley Push Raffle |
| J Dagnall, Horwich | Sale of Dried Flowers |
| Abbey National, Milton Keynes | Matched Fundraising Scheme |
| S Dopierola & M Kawcherski | Sponsored Parachute Jump |
| Mr & Mrs Leask, Shrewsbury | Coffee and Cake Stall |
| Ladybridge Club, Stockport | Collecting Box |
| Pam Croghan, Stockport | Penny Collection |
| T & S Eyre, Avon | Skittle Evening |
| HMP Springhill, Bucks | Raised |
| Child Health Clinic, Edinburgh | Sale of Books |
| E & G Robinson, Milton Keynes | Jumble Sale |
| Annie Gallimore, Milton Keynes | Jumble Sale |
| Jovan Liquer Ltd, Harrogate | Collecting Box |
| L & R Snack, Milton Keynes | Tombola |
| B Ingham, N Ireland | Collecting Box |
| VAT International, London | Collecting Box |
| D Ives, London | Collecting Box |
| B Rollinson | Sponsored Cycle Ride |
| G & L Bagshaw | Raised |
| Julie McIntyre | Collecting Box |
| A & M Lockyer, Wales | Fun Run |

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