

NEWSLETTER

EASTER 1988

**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, where they are children, to their immediate families. It is distributed around the world on subscription. Copies are also sent to those members of the medical profession who are directly concerned with MPS, many of whom make a donation towards our costs, for which we are most grateful.

If you wish to be added to the circulation list, please contact the Newsletter Editor at the above address. Annual subscription charges are £5.00 in Great Britain and £10 Sterling elsewhere.

T.O.T. (TRIUMPH OVER TRAGEDY)

How do people respond to tragedy in their lives? Tragedy is a blow we can't escape from, a problem that cannot be solved, pain that cannot be cured. You feel helpless and even hopeless. We can't escape the tragedy, but it's up to us how we react to it.

Looking at some of the people we meet through the MPS Society, would their lives have been as rich if they hadn't been stopped short in their tracks by MPS Disease? Would they have stirred themselves to do the fundraising they have done, or to offer the help to others that they do? Would they have been as thoughtful or considerate? If they had not been touched by tragedy, how much time and thought would they have given to the distress of others?.

I am not saying that personal distress brings out the good in people, or that MPS has benefits. We are brought up with a jolt. Maybe we planned our life would go a certain way. We thought our children would grow up and do better in the world than we did ourselves.

Being stopped short is an opportunity as well as a danger. Our only way forward is to change our way of thinking.

When magazines or newspapers deal with distress such as ours what they like is a **"Triumph Over Tragedy"**. The miracle operation, the marvellous fundraising that will make things better. The trip to Lourdes for the religious, or to Disneyland for the not so religious. But the miracle operation doesn't cure the child, the funds raised are spent, the trip to Lourdes has a return ticket to where you were before. The magazine moves on to feature some other miracle cure. They have to. It's their business.

What can change and stay changed is your outlook, what you think is important, what you hope to contribute or achieve, or, when the chips are down, why you think it is worthwhile simply to endure.

The Society gives us an opportunity to share this journey with others. Some good can come from the suffering of our children. Some people find a voice to express how they have changed in response to MPS. In this Newsletter **Dena Dutile** sums up in one sentence what it has meant for her. **"Love has no timetable, but when a time is set on a life, I guess the love works overtime."**

The newsletter is here to allow your voice to be heard. One further thought. Do you think we have grown up enough to hear some of the sad and bitter thoughts that are part of our lives as well as the brave and strong thoughts? A poem was submitted for the newsletter. "You can't put that in," I was told, "it's too bitter, it might distress some people." Now where have I heard that sentiment expressed before?

Charles O'Toole

DATES FOR YOUR DIARY

1988

- 16/17th April Area Family Training Weekend, Milton Keynes.
- 8th May North West Leisure Group Outing to Stapeley Water Gardens, Stapeley, Nantwich. Meet at entrance 1.30 - 2.00 pm. Return for light tea to Sylvia and Bill **Blackburn**, 11 Beatty Rd Nantwich. (Contact **Mary Gardiner** 0704 213438)
- 21 May Family Day - Cutteslowe Park, Oxford. 12.00 - 5.00pm Bring picnic, everyone welcome. Contact **Jenny Hardy**, 48 Churchway, Haddenham, Bucks. Tel: 0844 291173 for details and map.
- 12th June Family Barbeque 12.00 - 5.00pm **Sue and Dan Butler**, Spriggs Holly House, Spriggs Holly Lane, Chinnor, Oxon. Tel: Radnage 3185
- 21st June Fundraising Garden Party (Lunch £2.50) 12.00 - 3.00pm Sue Butler (as above)
- 24/26th June Camping Weekend in the Great Malvern area of Worcestershire. Contact **Pat Isaac** (inside front cover) for details. Bring your own tent and have a lazy weekend.
- 16th July Coffee Morning 10.30 - 1.00pm Jenny Hardy (as above)
- 17th July **Dr. Garrow's** Garden Party. 10.00 - 5.00pm Roughwood Farm, Roughwood Lane, Chalfont St Giles, Bucks
- 23/25th Sept Annual Conference. Post House Hotel Heathrow. (Booking form with this newsletter).
- 10th Dec Christmas Party (details to be announced).

CONFERENCE 1988

CONFERENCE 88 CONFERENCE 88 CONFERENCE 88 CONFERENCE

Your booking form for this years' conference comes with this newsletter. **Maggie Archard** is once again taking the bookings and you are asked to return your form and deposit by **May 6th** so that we may have some idea of the numbers coming.

If any family or MPS adult has difficulty finding the money for the conference fee and the cost of travel to Heathrow please let Maggie or your Area Family know. There are organisations which will help with expenses and we don't want anyone to be prevented from coming.

We are hoping to have a relaxed easy going weekend with plenty of opportunity for families to get together. This year we are not having any talks from medical specialists, apart from Dr. Bax who will be reporting on our research project. We thought it was time we devoted a conference to sharing thoughts and ideas on ways to cope with MPS and the effect it has on our lives.

We will be there to welcome you from lunchtime onwards on Friday. We hope to arrange play facilities for children during Friday afternoon. This year the buffet supper is included in the conference fee. Friday evening will follow its normal pattern of informal reception and mini-market.

The children are to go to **Thorpe Park** again on Saturday and possibly to **Windsor Safari Park** on Sunday morning. We are delighted that the Amersham Baptist Fellowship will once again be providing volunteers to take children out. Where possible the children will have the same volunteer as last year. There will be a children's tea party with entertainer on Saturday and a separate programme for the older brothers and sisters during the evening, as well as videos for the older MPS children.

There will as usual be a **dinner dance** on Saturday evening and baby sitters will be available.

The Society has a growing number of adult MPS members (eleven at the last count) and we will be delighted to see them at the conference. Apart from enjoying their company it is so helpful to the parents and younger MPS members to hear what they have to say about how they have coped with MPS.

Management Committee

NEW FAMILIES

Jane Forsey whose brother and sister died from Sanfilippo Disease in the 1970's. Jane lives in Bristol.

David Watts and his family from Merseyside. David is an adult and suffers from Morquio.

Lynn Thompson and her family. Lynn lives in Yorkshire and is an adult suffering from Morquio.

Wendy Ruddom from London is another adult Morquio sufferer.

Vilma and Vanda Vanni are sisters who live in Surrey. They are adults who suffer from Morquio Disease.

Royston and Rosina Westwood from the West Midlands. Their ten month old daughter **Georgina** has Hurler Disease.

Martin and Jill Sutcliffe from Derbyshire. Their ten month old son **Henry** has Morquio Disease.

Martine and John Brennan from Lancaster. **Harry** aged one year suffers from Sanfilippo Disease.

Also welcome back to **Val Spencer** from Oxford. We lost contact with Val and 13 year old **Jamie**, who has Sanfilippo, after they moved house three years ago.

DEATHS

We are very sad to report the deaths of the following members of the Society. Our thoughts go out to their families and friends at this time.

We are very sorry to hear from Iris Turner that her daughter **Jacqueline** died last March. Jacqueline was twelve years old and suffered from Sanfilippo Disease.

Dean Colvin from Bromley, Kent died in January. He was suffering from Hunter's Disease. Our sympathies to his family.

James Hartley, son of Maria Rose, died on March 12th, two days after his tenth birthday. Our thoughts are with his family.

Lee Kelly from Widnes, died on March 11th aged 4. Our sympathies are with his family and with his grandparents Mr and Mrs Goulden.

The Mount
Truemans Way
Haywarden

I enclose a photo showing the only time Victoria has been to any of the society's gatherings, and that includes our own North West ones. She has usually managed to become poorly. Even at the party she was not herself - a handful of blisters, hence the bandage. Anyway I was over the moon that she managed it this time and I have the photos to prove it!

Micheline Johnson

VICTORIA JOHNSON (making her debut)
with **BILLY BURLISON & COLIN SNACK**



THE APPOINTMENT OF DR. ED WRAITH,

PAEDIATRIC CONSULTANT IN MPS DISEASES

As many of you know finding a doctor who has extensive knowledge and a lifetimes interest in MPS is rare. We are fortunate that Dr. Rosemary Stephens at the Hospital for Sick Children, Great Ormond Street has fitted the bill for many years and supported families over and beyond the call of duty. Nevertheless, as sad as it is Dr. Stephens is not getting any younger and we are aware that it will be very difficult to find someone to follow in her footsteps. Also Dr. Richard Watts, CRC, Northwick Park another 'expert' retires in April.

In Dr. Ed Wraith we have found a young energetic consultant who is about to turn down an offer of Head of Metabolic Genetics Unit at the Royal Children's Hospital, Melbourne to become Paediatric Consultant in MPS and related disorders at Manchester Children's Hospital. This is a new post and subject to final discussions with the Regional Health Authority on 4th March this post will become operative from 1st April and be wholly funded in its first year by the Society. (£30,000). We are negotiating with the RHA for them to take over a quarter of the funding in the second year and half in the following two years.

WHAT DOES THIS POST MEAN TO THE SOCIETY?

Yes it means more fundraising! But most important it means we have a Consultant and Genetics Unit based in the middle of the Country, easily accessible by train, plane or car, yes you can park without risk of the dreaded meter lady. He has already had experience of nearly 100 MPS children of all types in this Country and Australia. The Society has a Consultant who is young, innovative and keen to see families get the very best help in the symptomatic treatment of their MPS children.

We are also planning counselling sessions for adolescent siblings of MPS children, study days for interested professionals and to back up the Dr. Martin Bax project full clinical case studies of MPS children. Most important Dr Wraith is happy and willing to accept MPS referrals from anywhere in the UK. His keen interest and experience make him well qualified to develop a special service to our families.

SLEEP IN CHILDREN WITH SANFILIPPO SYNDROME (and their families!)

Many families in Britain and abroad have filled in and returned our questionnaires on sleep in children with Sanfilippo Syndrome (SFS). As well as that, three families have taken part in a structured programme designed to carefully measure and then hopefully change their child's sleeping pattern.

So far 45 completed sleep questionnaires have been returned. The countries they come from are:

Britain	36
Canada	4
United States	3
New Zealand	2

The questionnaires have elicited detailed information concerning

- A. Child's daytime routine
- B. Child's sleeping pattern
- C. Settling to sleep
- D. How family sleeps
- E. Medical information
- F. Desired changes

Parents have carefully filled in all the information and at present we are entering it onto the computer. Throughout the study confidentiality of information is maintained by a secure coding system.

Results are not yet available though when the information is analysed we will be in a better position to offer sound advice and information to parents and to other professionals involved in the care of children with SFS.

The second aspect of this research involves travelling around Britain visiting families whose Sanfilippo child sleeps poorly (unfortunately junkets to the USA or Zealand have not been encouraged!) Three families have taken part so far.

The help and advice offered regarding sleep occurs in two stages:

1. Each family is sent a Sleep Diary for keeping detailed records of their child's current sleep pattern.
2. The family is visited and their child's sleep pattern is discussed in detail. Together with parents we then try to work out some way of trying to alter the sleeping pattern. This is very much a collaborative process where we devise a sleep programme together.

The results are hopeful. One little girl who had eight broken nights every two weeks now has three broken nights every two weeks. Other children have improved by coming off medication, having a more predictable sleeping pattern and appearing to be happier when going to bed and to sleep. Thus the parents and ourselves have not been aiming for a 'cure' but an improvement.

Three children is too small a number on which to come to any firm conclusions. Also we have yet to follow up these children in a few months time. In the near future we hope to see six more families.

What we can say is that a few children have shown some short term response to a structured programme designed to alter their sleeping pattern. Considering the extreme nature of the sleep problems some of the SFS children have, and the consequent exhausting daily routines that their parents may face, we feel that our tentative and modest results are ample reason to continue looking for ways to help these children and especially their families gain more rest and sleep.

Once again thank you for filling in and returning the sleep questionnaires. If anyone has an uncompleted sleep questionnaire and has a spare half hour, please fill it in and return to us. Also if you have not received one and would like to fill one in please phone or write to us and we will send you one.

We will keep you up to date with further results during the summer.

Dr M Bax, MD, MRCP Mrs G. Colville John Watters
Senior Research Fellow Clinical Psychologist Psychologist

Community Paediatric Research Unit
Westminster Children's Hospital
Vincent Square
London SW1 2N2
Tel: 01 828 9811 ext. 243

TIPS WANTED

Many of our Hurler, Hunter, and Sanfilippo children suffer from **diarrhoea**. An American mother recommended what she called **THE BRAT DIET** --- bananas rice apple sauce and toast. I am sure many of you will by trial and error have worked out ways of avoiding too many dirty nappies. It would be helpful to other parents who are newer at the game to hear what you have tried.

A change of diet is sometimes suggested for reducing the problems caused by excessive mucous or for reducing hyperactivity. Have any of you views on this? Please jot down your ideas and send them to me so that we can eventually pass them on in the newsletter. It could help Mary as well who is grappling with the task of drafting leaflets on the various MPS conditions. I look forward to your letters!

The Editor

Lobby of MP's - 19 January 1988.

Over 40 MPS families from all over the Country came to Westminster Hall and on to the House of Commons to Lobby their MP's. By the time the 19th came round 14 other Handicap Charities and Parent Support Groups had joined us making our lobby of over 200 parents quite impressive.

It caught the imagination of the press who turned out in force. BBC London Plus were on my doorstep at 6.30am to film the Lavery's at breakfast before starting their day in Westminster! The exclamation mark is because it must be the first time in history that we have sat down as a family for breakfast.

Mary Gardiner having been in London with Maggie Archard and myself the previous day to film the Kilroy Silk programme only arrived back in Southport in the early hours of the morning to be out by 6.00am and on a coach with 17 other MPS families to travel to London to see their MP's.

Everything went to plan and the coach arrived on cue to be filmed by Granada and BBC for the early evening news.

Inside the House over 40 parents stood up to speak at the Press Conference in the Grand Committee Room. Peter Thurnham MP chaired the meeting and about 50 MP's popped their heads round during the proceedings.

In the Lobby Mary Gardiner with Catherine, Alexandra and Emma Hughes nearly caused a diplomatic incident when Kenneth Hines MP responded to the green card and appeared to see his Constituent 'Harry Gardiner'. On finding it was Mary and three children in tow he made every excuse in the book but as we all know Mary can stand her ground and stand her ground she did.

The Lobby was a good humoured dignified event by parents who know how important it is to keep open the option of choice if successive pregnancies are found to be affected. A tribute to these parents is paid by Jo Richardson during the debate on 22 January and is published in Hansard.

THE COMMITTEE STAGE

Although the high profile the press gave this bill before the second reading has recodedd we can't afford to be complacent and take a back seat.

During Committee MP's will discuss and decide amendments to the bill. It is now vital that we keep all Committee Members well briefed on how this bill will affect individuals. If it comes to it I and others will sit night and day through Committee to provide the correct brief on the handicap issue.

HOW YOU CAN HELP

Please send a case history (family story) saying exactly how this bill will affect your family. This will be submitted with others to the Committee as a briefing. Even if your pre-natal resulted in a healthy baby, your story with the implications of what might have been if unhappily the result had been different is just as important.

Please put pen to paper now and send to Christine Lavery. Remember we are wanting to keep open the option of CHOICE for MPS families. The Society does not take a view on the rights and wrongs of termination for severe handicap and some of our members would not wish to consider such a course. Their views are respected and the Society will continue to support and press for better facilities for all MPS children now and in the future.

Mr & Mrs W.Griggs
25 Napier Gardens
Hythe Kent
CT21 6DD

"THAT UNPRONOUNCEABLE SOCIETY"

Last year a good friend who has a lovely garden said, "We would like to have a Garden Party for that unpronounceable society this year." So thankfully, we teamed efforts and decided to call it "July Jinx". I think the name had something to do with it, as there was a jinx on it! The date was July the 18th (the day before Dr.Garrow's Garden Party). The weather was identical! We had taurpaulins out on the patio to spread the load a bit, but most of the water and the mud was tramped indoors! However we managed to raise over £400. Nobody had much of a chance to view the garden - Percy and Queenie had worked for weeks to get it looking beautiful. Nothing daunted they said that anybody could visit the garden anytime during the year, providing they put something in the MPS box. People did too!

Come December 25th Father Christmas (looking suspiciously like Percy) was ringing his bell and visiting all the houses in his road. Full of Christmas spirit everybody wanted to give Father Christmas something for a change, so he made another collection! I think it is a happy thought that Father Christmas supports MPS----dont you?

Molly Griggs



Reg. Charity No. 290069

Disabled Living Foundation

380/384 Harrow Road
London W9 2HU
Telephone: (01) 289 6111

CLOTHING & FOOTWEAR ADVISORY SERVICE

CLOTHING WORKSHOPS

Clothing workshops have been established in various parts of the United Kingdom. Most are in the North of England and we are as yet unaware of any in Wales.

These workshops make clothes for people who, as a result of their disability, have found it impossible to buy the clothes they want from ordinary sources (including specialist mail order). Most workshops will also undertake to alter or modify ready to wear clothing to meet an individual need. Where possible customers should visit the workshop to discuss style, fabric requirements and to be measured and fitted. Some workshops will visit customers in their own homes while others will undertake a postal service.

Most workshops will try and make any garment a customer needs but men's tailored suits and women's foundation garments are outside the scope of some.

All the workshops on this list have been set up with the help of the Manpower Services Commission. This enables the workshop to charge a price for their clothes which is comparable to a similar garment in a chain store.

Under MSC regulations most workshops are restricted to covering a limited geographical area, usually either the town or county in which they are situated. However, some will make clothes for people who live outside their official boundaries particularly if you can arrange to visit the workshop. It is worthwhile phoning to enquire. Those who operate a postal scheme will usually consider enquiries from anywhere in the country.

Although many workshops are called Fashion Services or Fashion for the Disabled, each workshop is independent.

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*   The DLF Clothing & Footwear Advisory Service has
*   resource papers, leaflets and books on all aspects
*   of clothing, footwear and dressing for people with
*   disabilities. A full list stating prices and
*   including an order form is available on request.
*
*   The Clothing & Footwear Advisors at the Disabled
*   Living Foundation, 380-384 Harrow Road, London
*   W9 2HU.
*
*   tel: (01) 289 6111 will answer any clothing or
*   dressing queries (please send s.a.e.).
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VIDEO STARS

If you want a happy souvenir of the children enjoying themselves, next time you come to a major MPS event why don't you pack a blank VHS video tape in the car? The chances are there will be a video camera around, for you to use or for someone to use for you. Colin Gardiner, Dan Butler, Pat Isaac and I have experience of the two video cameras which the Society has acquired over the last two years and Colin and I have come up with this new wheeze to get more recorded tapes to more families.

The Society now has quite a library of videos of past Conferences, Christmas Parties and the odd Area Family Day and from time to time we make copies on request for families. There are many happy and hilarious moments to be treasured, but also lots and lots of time taken up when YOUR STAR is not in focus, so, at future events (between "official" filming) we've decided that the Person-In-Charge Of T' Camera (PICOT) will loan it out for 5-10 minutes, on a first come first served basis to responsible and sober persons to take their own video of their own child, with their own video film, which they bring and take away. If you are not too sure about using the camera, then PICOT will film for you.

If you don't own a VHS Video Recorder, bring a blank tape anyway. Your friends and relations are sure to have a recorder and who knows, you may win the pools at the next MPS Christmas Raffle?

Bring the same tape to future events and build yourselves a soap opera library classic (you can get alot of 5-10 minute scenes on a VHS 180 type).

Meanwhile, if you think the Society already has a video of some recent treasured moments of your children ask us at Westwood Drive. We are happy to make recordings for £5.00 to cover cost of tape and postage.

Robin Lavery

My Name

My name, a word which belongs to me,
or do I belong to it?

It's a curse to which I answer

Enslaved by its command.

Do I follow this word,
or does it follow me?

I obey when this word is uttered,

I am this word, my name;
my name is me

Or am I it?

Sarah Long

CHRISTMAS GREETINGS!

Congratulations to Gillian Colville and her husband on their daughter Susannah who was born on Christmas day 1987. Many will have met Gillian through the survey which she helped to carry out.

OVERSEAS PEN-PALS

I am pleased to report our first success of a young lady in the UK writing to a pen pal in America. I now have a young man aged 15 who would like to write to a pen pal in the UK who has a brother or sister with Hurler Syndrome. His sister who is 13 would also like to contact a friend here. They live in Texas USA. There is also a girl aged twelve who would like to write to a pen pal in the UK. She has a brother with Sanfilippo. She would like a friend with a brother or sister with the same condition. This young lady lives in Illinois. If you would like to contact any of the above or to find other pen-pals in the USA please let me know. We now have a contact in Mr Bill Sellmeyer who is helping find them.

Sue Butler
Spriggs Holly House
Spriggs Holly Lane
Chinnor Hill
Oxon.

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FOR ALL PARENTS

"I'll lend you for a little time, a child of mine",
He said,
"For you to love while he lives, and mourn when he is
dead.
It may be six or seven years, or twenty two or three,
But will you till I call him back, take care of him
for me?
He'll bring his charms to gladden you, and should his
stay be brief,
You'll have his lovely memories as solace for your
grief.
I cannot promise he will stay, since all from earth
return,
But there are lessons taught down there I want this
child to learn.
I've looked the wide world over in my search for
teachers true,
And from the throngs that crowd lifes lanes I have
selected you.
Now will you give him all your love, nor think the
labour vain
Nor hate me when I come to call, to take him back
again.
I fancied that I heard them say, Dear Lord, Thy will
be done.
For all the joy Thy child shall bring, the risk of
grief we'll run.
We'll shelter him with tenderness, we'll love him
while we may,
And for the happiness we've known, we'll ever
grateful stay.
But shall the angels call for him much sooner than we
planned,
We'll brave the bitter grief that comes and try to
understand."

Anon

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HALO NEWS

Lorraine Dymond of Harlow, Essex has at last come out of her halo five long months after her cervical fusion. You may remember Lorraine was shown on the Children of Courage broadcast in November last year. Congratulations to Lorraine and her family.

Elena McGauran from Sligo Ireland has had a cervical fusion performed by a surgeon in Dublin. She is now at home in her halo. Best wishes Elena!

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Brave Alex on TV at victims' party

by
Simon Ashberry

HANDICAPPED teenager Alex Butler had the thrill of a lifetime when BBC cameramen captured his very special birthday celebrations on film.

Now the cheerful 14-year-old is looking forward to reliving his party moments in a television documentary being screened on Thursday night to coincide with the 1987 Children in Need appeal.

Alex lives in Spriggs Holly Lane, Chinnor Hill, with parents Sue and Dan and 11-year-old sister Lucinda. A happy-go-lucky pupil at the Icknield School in Watlington, he was diagnosed at the age of six as suffering from Hunter's Syndrome, one of seven rare diseases in the incurable mucopolysaccharide group (MPS).

For three long years his parents were left to cope alone with the realities of the little-known enzyme disorder, which can have a devastating effect on muscle development and life expectancy, stunting growth and leaving sufferers often little more than three feet in height.

Society

"Doctors are often reluctant to give out the names of other sufferers and because there are so few MPS children scattered around the country we were in isolation," said Sue.

Then in 1982 Sue and Dan met Christine Lavery, of Westwood Drive, Little Chalfont,



Happy family: from left, Sue, Alex, Lucinda and Dan Butler, with Suki the cat.

whose own son Simon had been an MPS victim. Christine was in the process of setting up the Society for MPS Diseases to bring together the handful of affected families and for the first time the Butlers were able to share their problems with others.

"We had three years of not knowing anybody at all," Sue explained. "All we knew was that Alexander was a special case and we had nothing to compare him with, so it was a relief to meet Christine."

The MPS Society has gone from strength to strength over the last five years and held its latest annual conference in September at Heathrow, when 250 families gathered to learn from each other and ease the burden of the disease.

Highlights of that weekend were an adventure trip to Thorpe Park and Alex's 14th birthday party at the Posthouse Hotel. Both were chosen to be featured in Thursday's special film report drawing attention to MPS and the society's need for cash to fund an international meeting planned for Munich in 1989.

The following night the BBC makes its annual appeal for money from viewers in a Children in Need programme, hosted by Terry Wogan, Philip Schofield and Joanna Lumley.

It is not the first time the Chinnor Hill youngster has been the focus of attention. Last autumn he won a top Scouting merit award and warm tributes for

his activities at 1st Radnage Scouts, and four years ago Fran Morrison brought BBC news cameras to his home for a report on MPS.

Alex's condition is mild and he is able to lead a full life, joining in with schoolfriends in the playground and proudly displaying the certificates he won for hiking on a school trip to Switzerland earlier this year.

Presented

A keen Liverpool supporter, he is still enthusing about England's soccer victory over Yugoslavia and played for several years in his Cub Scouts side until lack of height became too much of a handicap. Alex is mentally unaffected by his condition but like any kid with

GCSEs looming on the horizon, he groans at the thought of exams. "I've got no chance, there too many subjects," he moans, with a sparkle in his eye.

The signed certificate by England football manager Bobby Robson he was presented with after an FA coaching course last year is a far more important paper qualification to such keen soccer fan.

"It was quite traumatic when we first found out about Alex's condition, but life's got to go on," said his mum. "You can't just sit you've got to make up your mind to swim. He's mentally normal and we're trying to do the same with him: any other teenager would

Next week he won't be just any teenager, but the envy of his classmates.

SUPPORT THE LIVERPOOL 100 !

27 Edna Avenue
Fazakerley
Liverpool 100 AN

Dear Mary,

I have started a knitting circle up, making toys. It is coming along great. We are selling some and using some for raffles. I have spoken to Mary Gardiner who is sending me a paying in book for the MPS Society. Can you put a notice in the newsletter asking for oddments of **unwanted knitting wool**, any colour, any amount. I have had a fantastic response in the hospital where I work. Can you also mention a few names of the main helpers because honestly they have been great. Without their help I couldn't have started the idea up.

Knitters * Ellen, Pat, Betty, Renee, Pauline and Lily. *

Wool collector * Nurse Phil Hughes *

Special Thanks to the day and night nurses at **The Women's Hospital Liverpool.**

Just to see their names mentioned in print will put sparks to their knitting needles. We are hoping to raise quite a bit for the MPS children. Wish us luck. Anthony is just fine.

Diane Bayliss

FOREIGN COIN COLLECTION

We have had the first sale of foreign coins and banknotes and this has raised nearly £103 for the Society. Included were coins that obviously came from collections and these, along with a number of older coins, particularly those with a silver content, helped to produce a reasonable cheque. Over a third of the amount came from collections in the crew room at Heathrow. **Have we any contacts who could organise similar collections at other airports?**

A lot was learnt from the sorting and listing on this occasion. We believe we have found a reasonable dealer for coin, and we are able to sell notes at their full exchange rate. So keep all foreign currency rolling in!

The postage stamp collection is also doing well. Many thanks to Carol and Paul Hubbard for their many hours spent sorting and bundling. Last week's cheque was for £17.50.

Many thanks,

Ken Ballard (Christine's dad)

DISABLED PERSONS RAILCARD

There are substantial savings on train fares to be got with a Disabled Persons Railcard. In many cases fares are reduced to half price. You qualify for the Railcard if you are entitled to Attendance Allowance, Mobility Allowance, or Severe Disablement Allowance. Most MPS children would therefore qualify.

If someone is accompanying the disabled person they can also qualify for reduced fares.

Applying isn't difficult. Ask for an application leaflet from any British Rail Station and take it with your allowance book to any Post Office, who will stamp your application. Then send it to British Rail, Dept XX, PO Box 28, York YO1 1FB. The cost is £12.00, and the card is valid for a year. You will save more than the cost on one long journey. The leaflet also tells about other facilities for disabled people travelling by train.

Be sure to apply more than three weeks before you intend to travel. The Disabled Persons Railcard is good news for families with disabled children. The age of the train need not just be the train of the aged!

"POEMS ARE MADE BY FOOLS LIKE ME"

My neighbour was the Editor of Labour Weekly until it bit the dust a few months ago. When I told him I was going to edit a newsletter he said, "Let me give you only one piece of advice, **never publish poetry!** If you do people will send you reams of it, and it's impossible to tell whether its terribly good or terribly bad. Steer clear of it!" I never take advice. Please send me your poems. If you don't I threaten to print my own.

Poetry is terrific for filling up those little gaps at the end of the page. You get the message? Short poems.

By the way not many of you sent me any photographs. Be seen and recognised on five continents. **Send photographs.** Pencil in on the back the names of the people in the photograph. You may not be famous, yet...All photos will be returned in good condition.

The Editor

Carol and Paul Hubbard
71 Preston Road
Harold Hill
Romford RM3 7YU

We still continue to work hard at the stamps, so keep saving and sending them to us. We recently raised approximately £40. So you can see that it certainly helps our funds. If you want to save postage, remember you can bring your stamps to the conference.

Best wishes to you all

Carol Hubbard

DARREN HORSLEY
(Christmas Party 1987)



Giant sense of humour of man trapped in baby's body

IS 21 AND STILL ONLY 30" TALL!

When I grow up I might go out and get a job—as a hod carrier for Lego!



MOTHER'S help: Patrick gets up to the chores

"By the time Patrick was about four he just couldn't keep up with the other kids. He wasn't strong enough."
"We were told that he probably wouldn't see his fifth birthday."

Lucky to be alive

PATRICK beat the doctors' predictions to gain a string of CSE passes at school.

"I went to a special school in Swiss Cottage," he said.

"Then I went to college and night classes and studied computing."

"I enjoy playing with my computer. It's one of the few things I can do on my own."

"Other than that it's watching TV, reading or listening to music."

"I can feed myself if someone cuts up the food first."

"And I can walk a little way with sticks, but not as far as I used to."

"I know I'm deteriorating. But I'm very lucky to be alive now."

"I had an operation in March which stopped me from becoming paralysed and really gave me a new lease of life."

"They took bones

from my leg and put them into my neck to protect my spinal cord."

"For 17½ weeks I had to wear a plaster cast jacket, with steel supports up the side of my head connected to a metal halo screwed into my skull."

"It was really painful at first, but I got used to it."

"Mind you, it was a great relief when it came off. The operation wasn't a cure but it has helped."

"Sometimes people can be cruel. I don't go out much and I've never had a girlfriend."

"It's tough on my family and friends because I can't even go to the bathroom without help."

"But I think it's important to keep a sense of humour. I just take things day by day."

"My big ambition is to go to Disneyworld in America."

"When I see it on TV or in magazines it just looks like so much fun."

"That would be a dream come true."

Patrick is one of only 250 MPS sufferers in Britain.

And his strain of the disease, called Morquio syndrome, affects fewer than 100 people.

They are luckier than

most because the brain is rarely affected and they tend to live longer than other victims.

The disease is caused by an abnormality in the same gene in both parents.

Any child born to them has a one in four chance of being affected.

Hunt for a cure

AN organisation called the MPS Society provides support for sufferers and their families, and helps pay for research into the disease.

Its founder Christine Lavery, who lost her first son to MPS, said:

"My big ambition is to go to Disneyworld in America."

"When I see it on TV or in magazines it just looks like so much fun."

"That would be a dream come true."

"I know I'm deteriorating. But I'm very lucky to be alive now."

"I had an operation in March which stopped me from becoming paralysed and really gave me a new lease of life."

"They took bones



MOTHER LOVE: Theresa and her tiny son. 'I couldn't manage without her,' he says.

Picture by DAVID THORP

CHRISTMAS CARDS

Well done to all those people who sold MPS Christmas cards. This year to date we have received payment for 2040 packets of Christmas cards - that means up to 10200 MPS Christmas cards have been sent.

There are still a few people who have not paid for their Christmas cards - if this is YOU please send the money for all cards sold plus a note of how many you are still holding IMMEDIATELY!!!

MPS GOODS AND FUNDRAISING

Sue Butler has now taken over the job of SALES ORGANISER -i.e. sending out parcels of pens, cookbooks, key fobs etc. as well as T-shirts, which she has been doing for some time. If you would like any items to sell for a profit for MPS, please contact Sue Butler in future. If you have any unsold stock or money for items which you received from Pat Isaac, please return the money for these to Pat as you are on her list of money owing. Pat still remains fundraising co-ordinator so for any advice on fundraising events, publicity materials etc. Please continue to contact Pat. She would be delighted to hear any of your good ideas for fundraising.

DONATIONS

Wilma Robins has become our Welfare Rights Officer and will not be doing the job of Donations Secretary any longer. To keep money matters as simple as possible, the Management Committee request that you send **all raised or donated money** to Pat Isaac (Fundraising Co-ordinator) or Stella Hale (Treasurer) and request either a personal letter of thanks or a receipt. (Letters obviously take a little longer). Don't forget to include details of the event so that it can be listed in the newsletter and the name and address of the person to whom the receipt or letter is to be sent. An s.a.e. is a help to speed things up - though not absolutely necessary.

MARATHON SPONSORSHIP

Enclosed with this newsletter is an MPS sponsor form with a typed sheet containing details of marathon runners for MPS. We are asking all MPS families if they would try to get at least a few sponsors for the runner of their choice.

There are 2 runners for the London Marathon on Sunday 17th April or you may prefer to sponsor Trevor Rollinson and friends who are doing a relay marathon across the Pennines in May.

When you have selected the runner and marathon of your choice, please fill in individual details in the blank spaces on the sponsor form.

Please read the separate sheet and sponsor form for all details.

A PERSONAL HISTORY

(Ann Canton has kindly allowed us to print some notes she prepared to help towards a booklet on Scheie Syndrome which the Society is working on. Ann is aged forty two and lives with her husband Mervin at Pembroke Dock in Wales.)

At birth I appeared normal in every way. When I reached the age of two and a half I was dropping things and not able to grasp objects. From this age I used to cry at night with pains in my arms and hands. I made repeated visits to the doctor who used to say the pains were growing pains. He said I should be kept warm and should stay in bed if I felt unwell.

At the age of five I had whooping cough. After this I had umbilical hernia - the doctor at this point was of the opinion that the muscles in my stomach were very weak. This hernia was repaired when I was twelve years old. I was told that as I grew older the muscles in my stomach should strengthen.

My eyesight deteriorated and from the age of six I have worn glasses. As I was unwell so frequently my mother asked whether any further investigations should be carried out. I was again admitted to the local hospital and had many tests and investigations. The conclusion was that there was something wrong with me but it could not be diagnosed.

At the age of twelve I was referred to a Paediatrician at Morriston Hospital, Swansea. They concluded after many tests that I had "Stills Disease". I was transferred to Llandrugh Hospital Cardiff for further investigations. Wax baths and night splints for my hands were recommended. This treatment continued nightly until I was sixteen years of age.

At this stage I stopped going for check ups. My GP was of the opinion that I had arthritis and that I should learn to live with it. I took pain killers and some anti-inflammatory drugs, fortunately no steroids were prescribed. I would sometimes stay in bed and generally take things easy when I was feeling unwell. This carried on until I was nearly thirty two. Then I went to my GP and in rather strong terms demanded that something should be done. He reluctantly agreed to write to a Rheumatologist at the University Hospital of Wales, Cardiff. Within six weeks I was admitted to UCW under Dr George Nuki.

After many more tests "Scheie Syndrome" was diagnosed. This was in July 1977. I underwent Carpal Tunnel operations on both my hands to try and improve feeling in them. For a time it did help a little. I was told by the eye specialist that corneal graft operations could be done if my sight deteriorated so as to prevent me from working. My sight has deteriorated and I have a great deal of pain.

During my childhood I was able to attend normal school. I loved it so much that sometimes I had to be carried to and from school when I found it too painful to walk. On occasions I was too ill to eat breakfast but insisted on going to school. Mam would bring my breakfast to school during break time! I attended the local comprehensive and obtained three 'O' levels. My ambition was to become a nurse, but unfortunately I couldn't pass the medical.

An understanding Careers Officer suggested that I should go away to College and obtain some sort of qualification. As my hands were clawed and at the time electric typewriters were not widely used he thought perhaps a Clerical and Commercial Course was the most suitable. I attended Portland Training College for the Disabled at Mansfield. It was a lovely place and I have very happy memories of the place and of the time I spent there. I obtained a College Diploma and RSA in bookkeeping and also learned some typing. On completing the course I obtained a post at the college administrative block, but unfortunately due to ill health I had to return home.

Mind you I have been very fortunate ever since my return home, for I have never been unemployed. I worked full time for accountants until I was married. Now I have a part time job as a Book-Keeper for a firm of solicitors. I am able to do most household duties. Some tasks I find a little difficult but I can usually manage in my own way.

Ann Canton



Bob and Bill Sellmeyer

They like parties!

FINAL INSTALLMENT

Bill Sellmeyer's own story.

(In the last issue Bill told us of his work in Education, and how he had to leave his job as a teacher. Here he reflects on his life.)

Life for me is sometimes like a marathon. I run along and then stumble and fall. I get back up to start again and notice that I can't run so fast, then I fall again. I start again and in my attempt to keep up I take a terrible fall. Now I am afraid to get back in the race. A friend extends a helping hand. I cry to see the others move along so fast, but my friend tells me to slow down and enjoy the passing of each day's journey. Gradually I see things in a different light.

After I lost my job I was so frightened to go on with life that I felt shackled in the chains of this problem. One Sunday morning a terrific light entered my room. Even though my wife was there she didn't see it. At once I felt a surge of peace. Then internally I heard a voice saying, "I am with you through all times. Do not fear to share your story." I believe that the Holy Spirit touched me that day, to give me the courage to change, and to do not what I want, but what God wants. God allows us to be human because that is all that we are. That is why when things go wrong the most precious gifts are other people. That is why the MPS Society is so important.

I have struggled in finding peace within myself. I am constantly wondering about the new directions that my life will encounter. I do know that God called me on that September day, and I want to help in any way possible. I am very grateful that my articles were printed for others to see that older adults like myself can slip through and find their true identity later in life. I am a very weak person and this illness pointed out my many weaknesses. When I attend conferences and see most of the children I feel ashamed to complain. Yet each person must express his or her feelings, but in a constructive manner.

Today my wife and I have celebrated ten years of marriage. My sons are six and three and are adjusting nicely. I have entered the hospital three times and I have had numerous infections, but I am functioning nicely as a househusband. Of course there are bad times when I am so depressed and start crying alone in my room. I still notice behaviour changes before any infections when I hate myself and experience so much head pressure that I have to let out this internal feeling.

As for my brother Bob, he is now twenty seven years old and working full time as a groundkeeper. He graduated from a special education hearing impaired class in 1981 and is living at home. He has had a very difficult year with heart surgery and a hernia.

Bill Sellmeyer

KRISTINA

"I think there is something wrong with Kristina" said father.

"What exactly do you mean?" said Health Visitor. "Her speech seems to be deteriorating, I think she is going deaf", said father.

Two hours later.

"I dont think you've anything to worry about, she will grow out of it". Exit Health Visitor. Must ring the doctor first thing, thinks father.

How many others start off with a similar beginning, a worry that she is not the totally perfect two year old you first thought, never mind though, the doctors will cure all. The doctor listened to what we had to say and sent Kristina for a hearing test. This showed that Kristina was already virtually deaf.

"We will put grommets in" said the specialist. "Great", we said. "When?"

Kristina had the grommets in just after her third birthday. The joy we felt at Kristina's immediate improvement overcame our anger at it taking over twelve months to get it done.

Then Kristina had recurrent ear infections. After months of this our GP suggested referring Kristina to a Paediatrician to see if there was any underlying cause. "Great", we said. "How long this time?"

Three months later.

When we got to the Paediatrician she went over Kristina from head to foot. Nothing wrong, but could we bring Kristina in for the morning so they could get some urine samples. This was no problem for Kristina who has the ability to drink a litre and pass two. After waiting another ten weeks we recieved a letter. Nothing found. We were still not happy as Kristina was not developing normally.

Enter new Health Visitor.

"How about a conference between interested parties?" "O.K." we said.

"By the way, can we have her eyes tested?" asked both parents at once.

"Dont worry about it, she can see these pictures alright, leave it to me", said Health Visitor.

Weeks later some of us turn up for the conference. The others have been given the wrong date.

After one and a half hours talking we agreed that Kristina had a problem; but what it was we didn't know. Would we mind if Kristina came into hospital for three days for tests? **YES! ANYTHING SO LONG AS IT WILL HELP KRISTINA.**

KRISTINA(continued)

A month before her fourth birthday we go into hospital. We had to look after Kristina all the time as she would scream and cry if one of us was not there. After height and weight checks we took Kristina down for x-rays. Every so often a passing nurse would pop her head round the door to see what all the noise was about, smile and depart quickly deciding they didn't fancy permanent ear damage as Kristina voiced her displeasure.

Back to the ward. By mid afternoon we began to wonder if we were using the right deodorant. Why were all the staff avoiding our corner of the ward? By the end of the third day I was checking the end of the bed for notices warning of the Plague. No one would admit to knowing what they were were looking for. Everybody had suddenly been struck dumb. The ward sister we only saw twice, once when we came in, and again when we left to go to the other hospital for an eye test. This proved that Kristina was shortsighted and needed glasses.

When we got home we discussed the past three days. We were both worried by the the attitude of the staff. Nobody would impart any information. The next day the hospital rang. Could Kristina come back for more blood tests as they couldn't use the others.

We had to wait for the Consultant Haematologist to take the samples. I managed to get from him that they were testing for Aldo-Reilly bodies. As Monica is a nurse and midwife we had a few medical books. Out they came but we could find nothing. I checked with my boss who is the Board's Area Medical Officer, and we rang everyone we knew with a medical background until we found that they had something to do with detecting mucopolysaccharides. Muco what? So we checked up on those Mucopoly thingymajigs.

Of course we knew that they were wasting their time. Kristina wasn't that ill. As soon as they found the real cause they would cure it. The doctor said it would take four to six weeks for the test results. So we waited. Kristina improved again with her new glasses.

After six weeks, nothing. On a Monday early in November we went to see our GP and told him how we felt. Our doctor said he would get a letter in the post that night. On Tuesday afternoon the hospital rang. "Could we go across on Thursday at 5pm?"

Thursday 5pm we met the Paediatrician. She apologised for the way we had been kept in the dark and said she should have realized that we needed to be better informed. Then she explained what it was she was sure Kristina had. But we still had to wait for the test results to come through.

KRISTINA (continued)

After three hours of discussion we left. I can't remember much about the next couple of days, except that there was a small hope that they were wrong. The results were delayed until the end of January as there were problems with the isotopes used for the tests.

We had contacted the Society at the end of November, and they supplied a load of literature that was very informative and pleasant. Mary O'Toole wrote and asked us to ring her. I thought the number was wrong as it wasn't a London number. It turned out to be a local number in a village eight miles away.

Mary was staying with some friends as she had come up for the Christmas party. When Mary told me exactly where she was staying it came as a shock. She was staying next door to my father whom we had decided not to tell until the test results had come through. We went to the Christmas party and we were impressed by the warmth and trust of the children and by the understanding of the parents we talked to.

Now, twelve months later we have accepted Kristina's illness as well as I assume anyone can accept what we now know. We have been to the conference and to one or two other get togethers and thoroughly enjoyed them.

We have the Society to thank for their support, our Health Liaison Officer, Betty Stone, for her unending help and support. We thank doctors Boden and Foster, our family and friends for being there when needed, and Dr. Rosemary Stephens for explaining it all and patiently answering our numerous questions. We would also like to thank the staff at St. Giles School who have done so much for Kristina in the short time she has been there and for treating her like a human being. Last but by no means least we would like to thank Emma, Kristina's sister who has put up with us all in the past year and helped as well.

David and Monica Briggs



**KRISTINA
AND
EMMA
BRIGGS**

TO OUR FELLOW MPS FAMILIES AND FRIENDS

Dear People,

My name is **Dena Dutile**. I live in a small town called St. Martinville in the state of Louisiana, USA. I am writing to you to share my experience with my MPS children and with the hope that I may also learn from others in my situation. It has been one and a half years since I wrote the notes below. As you can see it was a terrific blow to our hearts.

This is a summary of our twin sons affected with **Hunter's Disease** and how we as parents felt in the early stages of a terminal diagnosis.

At four months pregnant my gynaecologist suggested we take an ultrasound to detect if I was further along since he thought I was growing rather rapidly.

I cannot explain the feeling when those two little bodies, facing each other, appeared on the screen. It was like I had just won a lottery, yet a little fear was mixed up in there. Before leaving town for our home in the country I stopped at the first grocery store and used a payphone to call my husband Donnie. "Is this a joke?", he asked excitedly? What a joy!

How lucky we felt! Phone call after phone call came after the news spread. We really felt special.

When our healthy looking seven pound one ounce and six pound six ounce boys were born on schedule we were ecstatic. Giving birth to my daughter Jennifer two years earlier and now my twin sons Lance and Blake were the most wonderful days of my life.

Soon the twins gave us the most tiring experiences of our lives. I returned to work at a local printing shop about a year after they were born. The boys seemed to stay with colds and sleepless nights. Going in and out of doctors offices for two years we finally ended with an ear specialist who suggested a tonsillectomy, adenoid and tube operation. He later suggested a geneticist because of abnormalities in their ears and hearing loss. I can remember driving home from his office that day crying because our future football players would probably have a hearing handicap and I didn't know how to tell their daddy.

A few weeks later we saw the geneticist, a very compassionate lady. She examined the boys and then called me into a room.

After briefing me on her findings she told me she was 95% positive our sons were dying of a storage disease. That was by far the worst day of our lives. In a matter of one conversation our normal sons, --our dreams and hopes for them--working beside their daddy on our farm-- were shattered.

Feeling empty and heartbroken we left the office with our sons.

Dena Dutile (continued)

At this time I must comment on my wonderful mother in law Bootsie who helped us in every way she possibly could. After about a month's crying and hoping for a mistake we started searching for material concerning their condition (MPS I II or III). We learned that it was a hereditary disease which consisted of a missing enzyme needed to speed up the breaking down of certain complex carbohydrates that make up our cells. Since the body cannot break them down they are stored in the organs, bones and brain (severity depending on which disease). The result is heavy damage and inevitable death. We also heard that a bone marrow may be considered in some MPS cases.

After further bloodwork and urinalysis, the geneticist called and told my husband that unfortunately they had an MPS disease that affected the brain and could not be helped. Devastated by this call we again fell apart for some time. We were called to a clinic shortly after and the doctor explained to us that our twins were probably in the San Filippo range (MPS III). She said there would probably not be as much storage in the bones and organs, but there would definitely be storage in the brain. She suggested taking a fibroblast sample to determine which type. This procedure consisted of lifting up the skin and cutting a small sample through all the layers without anaesthetic. Just the thought of hurting them made us very sad.

We were told their lives would be shortened; they might live anywhere from their first decade possibly to their teens. Everything seemed so hopeless. The doctor said to enjoy them now because further down the road it would be very hard for us. It seemed that every time we communicate with the doctors it was like scratching a sore wound. We found the further we stayed away from doctors the better we were, until we were strong enough to start researching on the disease. We then gathered information from Houston to Sweden.

Another clinic came up and a new doctor came to take over our case. When this doctor walked into the waiting room to get his next patient he glanced over at me with the twins and gave a rather peculiar expression. Later he came out for another patient. At this point he called one of the boys to him and shook his hand. He walked over to me and said that the boys did not have San Filippo, but either Hunters (MPS II) or Hurlers (MPS I and the most severe) disease. He examined the boys and I found him most admirable. After further tests we found it was Hunters disease.

Dena Dutile (continued)

This affects only males, and in some cases can spare the brain. There is severe Hunters (average life span 4-14 years) and Mild Hunters (life span teens to adulthood). There is no test to distinguish between the two. Early onset of symptoms usually means it is the severe condition; with the mild variety the symptoms start later. The doctor gave us some hope about a bone marrow transplant.

We tried impatiently to speak with this doctor again by phone, but were only told that he would see us in about two months.

It had been eight months since this ordeal started and I am not quite sure if at this point we knew what to anticipate. Could they be saved? With the diagnosis turnover, and feeling confused and desperate I called my MPS support group in New York. She gave me the name of a specialist in Minnesota who so graciously assisted us. We knew that a young age was an important factor in bone marrow transplant on MPS children. The specialist asked me to order 21 mls. of blood on our three children for a bone marrow match up. We later received a call regretting that they were a mismatch. He discouraged any attempts to match with non siblings. Our sons are doing as well as can be expected although they have most of the symptoms. I wrote this when they were thirty six months. They were then 42" tall and weighed 50 pounds each. They spoke in three to four word sentences and mumbled longer sentences. They attended all day developmental school.

Lance and Blake are in pre-school now. They love football, basketball, and Pee Wee Herman. They are very sensitive, mischievous, and frustrated at times. They will defend each other to the end. They have learned to identify their colors, say their numbers up to ten, and a few teens, identify animals, ride a bike, and many other things that were not expected of them. Any little accomplishment they make pleases us so. We truly love them, and they have touched many people's lives.

Our beautiful sons have taught us a lot, mostly how precious life itself really is.

Love has no timetable, but when a time is set on a life I guess the love works overtime.

If anyone would like to communicate with us, please feel free to write. Also I would like to know could I receive your newsletter. My husbands name is Donnie and my six year old daughter's name is Jennifer. Please write soon.

Dena Dutile

Route 2
Box 2188
Broussard
Louisiana 70518
USA

THE WORLD WIDE LINK BETWEEN MPS FAMILIES GROWS CLOSER.

My name is **Helen Griffiths**, formerly the Secretary of the MPS Society in Australia. I am writing this from Sinzig, West Germany. What am I doing here? Well I guess my story goes back many years.

My mother gave birth to five children, the first and last (both boys) died in infancy. The next is my sister Diane and then my brother Neil who died aged eleven years nine months from **Hunter's Disease**. And then comes me. I have a seventeen year old son who is studying in Australia. My second child Graeme died in 1983 from Hunter's Disease also aged eleven years nine months. My sister's son Greg died from Hunter's Disease aged six years.

I first learned of the Volk family when an advertisement appeared in your newsletter (Autumn 1987) for an au-pair to help them care for their twins Hendrik and Emily, who are affected by Sanfilippo syndrome. Two months after seeing this message I found myself on a jet landing at Frankfurt airport. Until then it seemed inconceivable that I would want to take on the burthen of caring for another MPS child, let alone twins!

From the age of eight my son Graeme was placed in respite care to allow me some time to catch up on sleep and to allow my husband Jamie and I to spend some time together without the constant demands placed on us by Graeme's hyperactivity and need for attention. Graeme needed at first part time care and then full time nursing care as he became more affected. **The decision to accept residential care for Graeme was the most difficult one that I had ever been forced to make.** I would have done anything to enable me to continue to care for Graeme myself. At one time I even considered leaving my husband and other son Jamie so that they could have a life together without the stresses and strains placed on our family by Graeme. I thought I could care for Graeme myself if we were alone. I would have been crazy to have made that move. Some flash of sanity must have broken through to stop me from doing something so disastrous.

Since Graeme's death in 1983, the formation of the Australian Society, and my involvement as Secretary, there have been many changes in my life. My marriage has ended and I have returned to full time work as a single parent. Things have been really rough at times. The society has demanded a lot of my life and my time, which until recently I have been prepared to give.

In 1987 I decided that I should move away from MPS somewhat, to seek other interests and start a new life for myself and Jamie. By September, about the time of the second Australian conference I decided that I would undertake a University course in Sociology and also try to squeeze in a bereavement counselling course. A lot of my work with families had been bereavement counselling, and I was always concerned that I would cause problems because I was relying only on my instincts in talking to parents. Things did not go according to plan and I delayed making the formal application for the courses. In November I read the Volk family's letter, and at the end of February here I am in West Germany.

As for the Society in Australia, it will now be organised with new ideas and enthusiasm and I'm sure it will continue to grow. I have no qualms about dropping my involvement with the Society. I have never seen the Society as a memorial to Graeme or to any other MPS child. The Society in my mind is there to provide support to any family who seeks it.

We in Australia were informed last year of a planned European conference and families are saving money in the hope of being able to travel to Germany to participate in what what could be a truly world wide gathering concerned with MPS disease. We are also considering sending representatives to the US for their first International Congress. Nevertheless it is to a European Congress in 1989 that a large number of families and children want to come. I am prepared to assist in any way to see such a conference get off the ground. If I can be of any publicity value (world wide MPS families help each other) I would be happy to do this. I am also preparing some articles on the management of Sanfilippo children. Now that I am no longer so closely connected on a personal and emotional level I hope to look at methods of assisting families and to consider what has or has not been found to to be helpful.

Helen Griffiths

c/o Beethoven Strasse 6
5485 Sinzig
West Germany

FUNDRAISING EVENTS

Our apologies for the fact that the last 2 newsletters either omitted or did not contain the fundraising events which have been taking place all over the country - due to a changeover in editorship (? correct word?). The following list hopefully represents the events from Summer 1987 onwards. Please remember that newsletter items are written at least 6 - 8 weeks before you receive your newsletter so any recent events will not be included.

Ann Canton Collection boxes and publicity for MPS during Fishguard week

Ron and Linda Snack and friends
Flag day in Milton Keynes

Premier Archers Sponsored shoot

Katie Bottom Clothes party

Andy & Jenny Hardy & friends coffee morning

Janet Flint & friends " "

Mrs. Pierce & friends " "

Mrs. Thorne Bridge party

Joanna Beavan & Claire Harrison
mini summer sale

David & Michelle Brooks-Daw guess the weight of the baby competition

Emma Hill, Louise Scarr, Michael Knowles, Vanessa Howling & Sharon Pollard
Sponsored swim

Mr Gilbert Sponsored swim

Mr. Paul Butler Sponsored diet

Alex Butler's school Fundraising charity week - various events

Premier Brands U.K.- employees Moreton Branch - raffle

J.C. Henderson Commission from Miller fundraising catalogue

British sub aqua club Sponsored swim

H & J Donovan Hyde Park Fun Run

Calor Gas Staff Coffee vending money

E. Lamb High Wycombe half marathon

C & M O'Toole Filming with B.B.C.

Mrs. Roy and friends, General Hybrids, Jarrow
Sponsored diet & raffle

Eton College Chapel Service Collection

Mrs. Gregory made & sold soft toys

Bill & Sylvia Blackburn Christmas cheers

Maggie Archard Baked potato lunches

D.N. Beasley Hartley Wintney Fun Run

Crowborough Evening Townswomen's Guild
Dance & collection of coppers

Privilege Branch HMC & EHQ collection of coppers

Tree House Nursery, Gloucester teddy bear raffle

Lisa Allen mini bazaar

Gordon Fox Glasgow Marathon

Wetherby & district Ladies Circle
Disco in Collingham

P. Barfield Pop Music Quiz

A. Flynn Fundraiser Catalogue Commission

Ian B. Williamson, Collingham
Sponsored walk in the Scottish Highlands

David Watt Use of computer services for local marathons

Barbara Watt Children's clothes party
& friends Pontefract half marathon

Alison Glassford, Bridgwater Fun Bazaar
Scout & Guide Disco

4th Old Catten Brownies sponsored obstacle cycle ride

Sue Hodgetts Coffee Evening

Wembdon Brownies, Bridgwater Coffee Evening

Taunton Branch of J. Sainsbury's
Supermarket dash

D. Kelly Raffle

K. Obeney Various raised events

M. Leask Coffee Morning

P. Isaac Book & Toy Sale

S. Randall & P. Isaac Christmas cheers

G. Finch, Bridgwater held an Autumn term weigh-in

Tonbridge Wells Operatic and Amateur Dramatic Society (TWOADS) and C. Gooch : Concert, carol singing and collections

Bridgwater Cycling Club and Opportunity Playgroup
100 mile sponsored cycle ride

P. de Pass Sponsored climb of Mount Kilimanjaro

Sainsbury's Staff Association South-West Area
Various raised events at Christmas

Downend Baptist Church Bristol Women's Federation
Tiddler jar and stalls

Peterborough Barclay's Bank staff
Sponsored silence

Alex Deacon Sponsored 10 km race Glasgow

Margaret Horsley Linen party, raffle

The Harford family and D. Brimfield & friends
Various sponsored events and carnival over several months at the "Brown Jug", Cheltenham

Wembdon Beavers, Bridgwater Raffle

Julie Burlison Under 4s creche, Oldham, sponsored walk
Raffles, toy parties and football cards

F. Egan Pub Raffle (after reading Daily Mail letter)

Wendy McGinn { Jumble Sale
Christmas Carol Float collection (Stanground Community Assn.)

Trowbridge N.H.R. Summer Conference Collection proceeds

J.G. Smith, London Sponsored climb Mount Kilimanjaro

J. Sweeney Formation Furniture, Caerphilly
Collections and Webb Ivory Commission

Micheline Johnson Pub Raffle

Doreen Russell Various collections

Anthony & Shirley Eyre
Marathon Sponsorship

FUNDRAISING EVENTS (continued)

Westbury Keep Fit Class	Stall at Christmas Bazaar
Crowlands School Romford	Collection at Carol Service
Sarah Lowry and friends	Carol Singing
Daniel & Michelle Brooks-Daw	Sale of oddments from ballet school
Crendon Morris Men	Morris Dancing
Annette Summerskill	Coffee Morning
Dulwich College Prep School	Evensong Collection
Highfield Grove Middle School Stafford	Christmas Activities
Sister Gilbert, Amersham Hosp	Sponsored swim at Dr. Garrow's Garden party
G. and C. Amer	Jewellery Party
Ian Oldacre	Obtaining pledges for money at National sales conference dinner.
Mrs Mansfield & Mrs Holdsworth	Toy Sale
Doreen Gregson & Bill Taylor Newcastle	Held an evening of clairvoyants
News of the World Readers (Patrick Scanlon's story)	Sent money
BBC viewers	Sent money after seeing Children in Need Appeal
British Telecom Social Club Tonbridge Wells	Held a series of events
Donations	In memory of Louisa Dawson (Julia & Louise Broome's grandmother)
Donations	In memory of Christopher and Lorraine Rock's great grandmother

Thanks for other donations too numerous to mention and for MPS charity box collections

