NEWS

LETTER

mps

THE SOCIETY FOR

MUCOPOLYSACCHARIDE DISEASES

FREE TO MEMBERS

YOUR COUNCIL OF MANAGEMENT FOR 1982/83

CHAIRMAN	Mr. G.C. Nichols, CBE, DFO, 'Mossville' Cokes Lane, Little Chalfont Buckinghamshire.
HON. SECRETARY	Mrs. Christine Lavery, 30 Westwood Drive, Little Chalfont, Buckinghamshire. Tel: Little Chalfont 2789
HON. TREASURER	Mrs. Catherine Grant, 'Roselawn' 43 Woodside Close, Amersham, Buckinghamshire Tel: Amersham 4799
HON. FUND-RAISING OFFICER	Mrs. Susan Heath, 'Prospect House', 133 White Lion Road, Amersham Common, Buckinghamshire Tel: Little Chalfont 2029
MEDICAL ADVISORS	Dr. D. Garrow, BM, FRCP. Dr. B. Neal, MBBS, MRCPG, D. Obst. RCOG.
GENERAL MEMBERS	Mr. R.J.O. Lavery Mrs. M. Hourigan.

AREA SUPPORT FAMILIES

Mary & Colin Gardiner, 35 Church Road, Banks, Southport, Merseyside.
Derek & Pat Kirkman, 63 Higher Shady Lane, Bromley Cross, Bolton, Lancs.
Robin & Christine Lavery, 30 Westwood Drive, Little Chalfont, Bucks.
Neil & Jane Reid, 'Meadowlark', 9 Huddleston Way, Sawston, Cambs.
Robin & Anne Ridley, 2 George Road, Lutterworth, Leics.

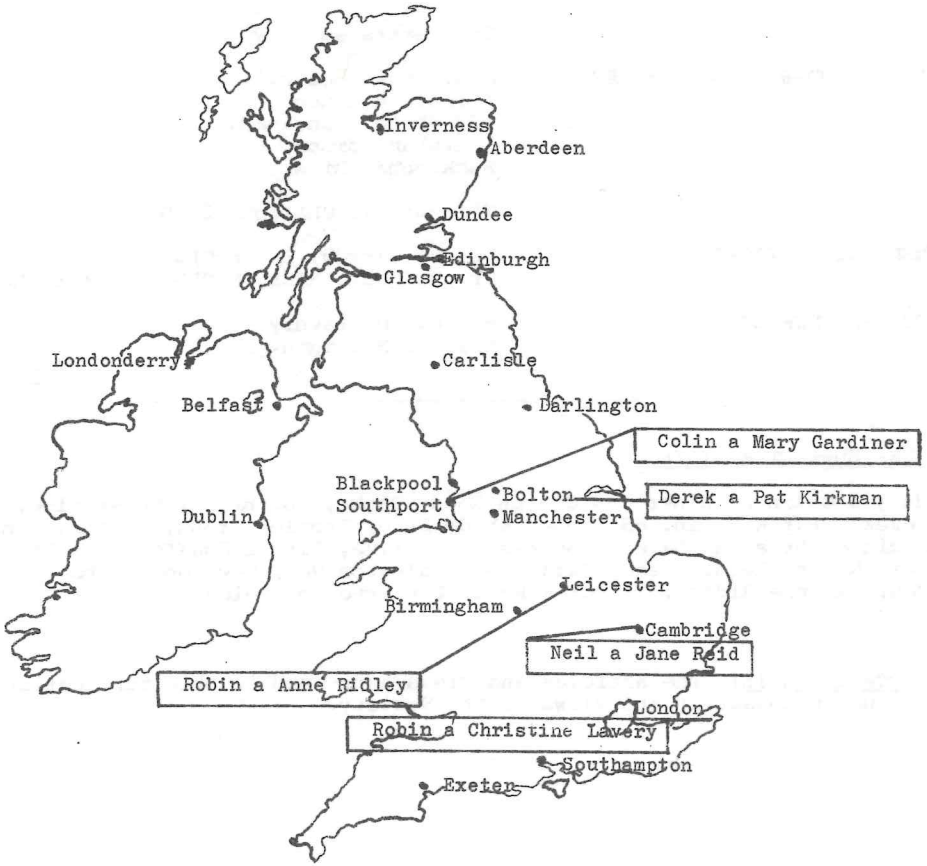
IMPORTANT NOTE: The articles and views expressed in this publication are not necessarily the views of the Society.

THE SOCIETY'S STRUCTURE

Although, inevitable, the hard grind of setting up the Society has had to be done by one family backed up by a small Core Committee, it is not the Society's aim to be a one man band, but one big family all working to the benefit of children affected by Mucopolysaccharidosis and their families.

Our eight member Core Committee is made up of a chairman, treasurer, secretary, fund-raising officer, two medical advisors and two general members. We will meet quarterly, and at these meetings matters arising and policy decisions will be made.

As an extension of our Core Committee we have incorporated the help of five area support families who have agreed to support families with affected children and to back up our fund-raising efforts. Between these five families we have over 33 years experience of Mucopolysaccharidosis. Each family has borne and coped with the very individual problems that have confronted them and now feel that in the light of their experiences they are ready to offer their support to other families as the need arises.



THE FINANCIAL AIMS OF THE SOCIETY

Initially, our financial aims did not aspire beyond our ability to fund the first quarterly newsletter. Thanks to the many generous offers of help and donations we can now extend our horizons, and, without wishing to appear too ambitious, it is the feeling of a majority of families that if Bone Marrow Transplant is seen to help our children to live a more healthy and fulfilling life with survival into adulthood, then we must be ready to fund a Bone Marrow Transplant Unit, so that any MPS child medically suitable and with an acceptable match may be given the chance of a better quality of life. It will be sometime before we know the outcome of Bone Marrow Transplant and Amniotic Implants on MPS children but, in the meantime, we must fund-raise in earnest so that if and when the time comes, it will not be money that deprives an MPS child of his/her life.

At the same time we must live for today, and have money available for the benefit of our older MPS children for who a 'cure' will come too late. We have several ideas in hand, including a Family Meeting next September/October and also some thought is being given to the idea of a Group Holiday for MPS children and their brothers and sisters. We would hope to have more details on these ideas in the next newsletter.

In the meantime any fund-raising activity is most welcome, as would be your thoughts and comments on the points raised.

Christine Lavery.

We wish to thank the following people for their generous donations:

The Amersham/Chesham MENCAP Society
The Wives Group at Christ Church, Chorleywood, Herts.
Mr. and Mrs. T. Tappenden.
Mrs. Vivienne Culley
Mr. and Mrs. J. Windsor.
Dr. J. Ellison.
Mary and Colin Gardiner
Anne and Robin Ridley.
Mrs. Jean Silvey.
Mr. Les. Leeds.
Alf and Judy King.
Mr. and Mrs. A.P. Southee.
Mary O'Toole.

Our Thanks also go to:

The Amersham Lions for the printing and photocopying facilities they have made available to the Society for the Society for the coming year, at no cost.

The Amersham Round Table for their generous offer to meet the cost of display boards. This will allow us to set up displays in Building Society windows, Libraries and Medical Schools and, therefore, bring about more public awareness of the plight of MPS children.

SECRETARY'S REPORT

Hello and welcome to the Society for Mucopolysaccharide Diseases (MPS for short). Perhaps as this is our first newsletter, readers would allow me a few words about our family. Rather an unorthodox secretary's report I know.

Robin and I were about three weeks off our 11th wedding anniversary when Simon, our eldest son, died from Hunter's Syndrome aged 7½ years, four months ago. Simon's death was very sudden and left us both numbed. When feelings of reality began to return, we were greatly comforted by the knowledge that Simon had, in 7 short years, done as much as some people do in a lifetime, and thoroughly enjoyed himself at that. Eight weeks after the Hunter's diagnosis was made on Simon, at the age of 21 months, we accompanied Robin on the 9,000 mile journey to Tokyo, Japan where he took up his posting at the British Embassy. For us it was a journey into the unknown, foreign country with alien language and culture, but most of all there was the isolation of coping with a potentially sick child. As it turned out Japan proved a most fantastic place to bring up a young family. There was so much going on and so many places to visit, that we are sure it was the constant stimulation that kept Simon so active and alert for so long. Between the ages of two and 5½ years he travelled round the world three times covering four continents and during our darkest periods, memories of Simon meeting his idol Mickey Mouse at Disneyworld can bring a smile to our lips. During this time Simon was joined by his middle brother, Andrew, who after an Amniocentesis in London, Amniotic Diagnosis in Bethesda America, was born at the Bluff Hospital, Yokohama, Japan on midsummer's day 1978. Andrew's appearance was at a time when Simon could enjoy the prestige of being big brother, sadly this wasn't the case when our third son Benjamin, was born 12 months ago.

Perhaps it was the isolation we felt, in that for years I was unable to locate another family with a Hunter's Syndrome child that prompted me to start the Society of Mucopolysaccharide Diseases. Anyway the initial response from families with affected children and the various members of the medical profession has been most enthusiastic, and my postbag grows daily.

Finally, I must say a word of thanks to Ann Worthington of 'In Touch' and to Peter and Lesley Greene of 'The Research Trust for Metabolic Diseases in Children' whose support has been invaluable, and to a small nucleus of friends and parents whose enthusiasm has been infectious.

Christine Lavery

THE FAMILY FUND

This is the Joseph Rowntree Memorial Trust, founded with the aim of helping families financially, where there are children who are very severely handicapped, living at home.

Help may take the form of goods, services or a grant of money for some definite purpose related to the care of the handicapped child. The sort of help offered includes, assistance in various ways with transport porblems, equipment for dealing with laundry, help with holidays where a family could not otherwise afford one. If you think the Fund can help you write to: The Family Fund, PO Box 50, York, YO1 1UY.

MAKATON

The Makaton Vocabulary comprises of a specially selected vocabulary considered to be most essential and useful in providing basic communication. It is structured in stages of increasing complexity and follows the normal pattern of language development. The initial stages comprise of the basic vocabulary necessary to express essential needs, the subsequent stages expand them and more complex language concepts are introduced. The aim is to ensure that if limited learning ability and poor retention prevent an individual from progressing beyond the initial stages, then he or she will still have acquired a useful, though limited, communicative language.

The original version of the Makaton Vocabulary was devised to be used as an aid in the teaching of sign language to mentally handicapped deaf people living in a hospital environment. It has since been revised by Mrs. Margaret Walker M.Sc. LCST. to increase its size and scope and is being used successfully in promoting communication with non-communicating SSN hearing children and adults, with some autistic children and with some normal adults presenting specific communication problems following neurological damage as in the case of a 'stroke'.

Only key words are signed, but they should always be accompanied by normal grammatical speech. Signs may be performed with either hand and it is often possible for a physically handicapped person to make the necessary adaption of a sign without losing its meaning. The signs are a way not only of communicating facts, but of expressing emotions. The signs themselves should, where appropriate, be accompanied by suitable facial expression e.g. pleasure, pain, enquiry, surprise and so on.

The Makaton Vocabulary is being used very successfully at Heritage House School with many children and it has, in fact, helped to promote language with some children who had not used language before.

Compiled by Mary Hourigan using facts from the Makaton Information Sheet

Postscript

Many parents may never have heard of Makaton but in reading Mrs. Hourigan's article recognise that they may have developed a very basic form of the technique with their own MPS child. To know that it is used skillfully and successfully in schools suggests that it is worth finding our more.

Further information is available from: MAKATON Vocabulary Development Project, 31 Firwood Drive, Camberley, Surrey.

We wish to extend our deepest sympathies to the families of the following children. Our thoughts are with them.

Richard Gardiner

Simon Lavery

Sarah Ridley.

HURLER'S SYNDROME - OUR FAMILY

To sit helplessly by and watch your little girl die in front of your eyes from this horrible disease is a memory we will carry with us for ever.

My husband Robin 36 and myself, Anne 34, lost our little girl, Sarah, 10 months ago at the age of 4½ years, such a short time yet then it seemed years.

By then, I felt I was 2 people, myself and Sarah, with Sarah gradually taking over my personality as she became more poorly and needed my constant caring and devotion which I was only too glad to give.

Realising at 7 months old that Sarah, far from being a normal healthy child was to become physically and mentally handicapped and eventually would die struck a double blow. Just before Sarah was born my Mum died following a very short traumatic illness. This had a deep effect on me.

Desperately wanting a normal child to give us something to live for we went into our 2nd pregnancy with our eyes wide open. Knowing our chance of having a normal child was only 1:4. We were prepared for the worst. The Amniocentesis showed I was carrying another Hurler's child. One copes with a termination the same way as with any other overwhelming problem confronting you - you just dig your heels in and follow your sense of reasoning. We never had to justify it to ourselves. We know all the suffering and heartache there was with Sarah both for her and us and no way was I going to subject a baby knowingly to this kind of suffering, no matter what anyone said. So when I did have my termination I never allowed myself to dwell on it, and even now I know we did the right thing.

We now have a very normal boy, Mark, who is 2½ years old. We feel we are very lucky. Robin has been sterilized now because neither of us want to go through any of it again, knowing we might never be so lucky again.

Needless to say, this has had a profound effect on us and our marriage Robin having to sit by and watch me go to pieces when times were rough, but we did get over all those rough patches and now have a deeper bond than ever. Whatever happens now can never touch what we have already been through. In our experience you need each other but the tendency is to fight each other when things get difficult. You learn that by experience. I am slowly coming back to normal tho' I still have my moments.

Like all our Hurler's children, Sarah was so very special and made friends wherever we went so she has left a huge gap in all our lives which will never be completely filled.

Now, we have had the experience and well understand many of the varied problems that occur, we would hope that through the group we can put it all to good use.

We want to help, so please let us.

Anne, Robin and Mark Ridley

HOW LIFE BEGAN FOR LEE AT FIVE

Many of you may have read the article in the 'Sunday Times' dated 20th June 1982, and wonder is Lee Brown is continuing to make good progress after his Amniotic Implant at Guy's Hospital 10 months ago. For those of you who missed the write-up, Lee is five years old and has Hunter's Syndrome. He is of normal mentallity, but is partially deaf and portrays most of the other characteristics of the disease. We are very grateful to Trevor and Shirley Brown for this progress report.

> "When we were first approached by Dr. Benson and Dr. Adinolfi about the Amniotic Implant, we decided that so long as there was no immediate danger to Lee, he had nothing to lose by having the operation. If there was to be any rejection of the tissue it could be easily removed so there was no great risk. After the operation Lee was a bit sore for a couple of days but he soon recovered. Some months later when Lee had his second implant, to top up the cells, the technique had been improved and this was by injection. As for the benefits of the implants, starting from the top down, Lee's hair is much softer, his fingers are more supple and most recently we have noticed that he can expand his toes. We feel that if the implant can arrest the disease at a certain stage, then as Lee is now he could lead a normal life, but we also feel that as he is still only five the next couple of years will be vital".

Postscript: If anyone wishes to read the 'Sunday Times' article in full on Lee Brown and Amniotic Implant then write to me and I will get you a copy. Christine Lavery

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FROM THE FUND-RAISING OFFICER

Our fund-raising is getting off to a good start. At a Bring and Buy Sale cum Coffee Morning at Christine Lavery's we raised £135.00.

Our main 'Behind the Scenes' fund-raising effort is a sale of Christmas cards and other Christmas items and gifts through a fund-raising service from which we get 25% profit. We have had sticky labels printed to put on the back of the cards saying 'Sold in Aid of The Society for Mucopolysaccharide Diseases'. If anyone is interested in becoming an agent for their area please contact either Christine Lavery or myself as soon as possible. This particular effort is not just seasonal as the catalogues provide general selections for after the festive season.

In the next issue we will be announcing our grand fund-raising scheme for 1983. It is very exciting and will involve all our members. So watch this space.

SUSAN HEATH

HYPER-ACTIVITY IN MPS CHILDREN

Hyper-activity can be quite a common feature in the young MPS child. In children with no-known cause for hyper-activity ie. no brain damage or other illness, symptoms include being poor sleepers, speech may be a problem and often balance is poor with extreme clumsiness. Their behaviour is unpredictable and disruptive both at home and at achool. They are excitable, cry easily, and are unable to sit still for more than a few minutes. Eyes and hands do not always co-ordinate properly. As babies they are prone to cot rocking and head banging. There is sometimes a history of head-aches, catarrh, asthma, hayfever and other respiratory complaints, tummy problems, rashes, bedwetting and often an abnormal thirst.

If any of these apply to your child, and you feel that these symptoms may be more than you would expect from a MPS child, it might be well worth trying the elimination diet which is used with great success on a lot of hyper-active children.

The late Dr. Ben Feingold MD., an American allergist has spent many years researching the possibility of chemical food additives being linked to hyperactivity and behavioural disturbances. He has formulated a 'food programme' basically cutting out all foodstuffs with artificial colouring, artificial flavourings and preservatives. This involves reading labels of everything you buy, but to make life easier, the diet has been adapted for English food tastes, and must be adhered to 100% A single bite or sip of 'forbidden' food can lead to a reaction that may last for 72 hours. Also it may take up to 5 weeks before any improvement is noticed as the toxins have to be removed from the system.

If your child has been prescribed behaviour modifying drugs and some types of antibiotics on a long term basis, as many of these contain artificial colour and flavouring, it may be advisable to discuss with your doctor the possibility of prescribing an alternative medicine without these additives or to prescribe non-coloured/flavoured medicines.

One particular problem area is tap water as although it is biologically clean, it does contain a lot of chemicals which may cause hyper-activity in children, particularly chlorine. Therefore, it is a good idea to use a Brita Water Filter (cost about £7.95 from any good health food store).. It is simple to use. The water tastes very good and the whole family would benefit from using it.

The FOOD PROGRAMME is available from: Sally Bunday, 59 Meadowside, Angmering, Nr. Littlehampton, West Sussex.

If you just want information about the Hyper-Active Children's Support Group, then please send a stamped addressed envelope. If you would like to receive the diet, list of safe foods by manufacturers, plus lots of additional information, the cost is £5.00 payable to H.A.C.S.G. and is well worth every penny.

Susan Heath

As from the middle of October we will be able to supply people wishing to undertake fund-raising events with information sheets on MPS and the Society and also Name Cards. These could boost your fund-raising efforts and spread awareness of the Society.

TIME WILL TELL

Our family consists of husband Neil, Daniel born 28.10.77, Laura born 2.6.79 and myself, Jane. Daniel developed at quite a normal pace but did not walk until 15 months. He had an inguinal hernia at 13 months and crawled healthily everywhere following an operation to rectify the hernia. Speech was our main concern as this was slow and we thought he could be suffering from deafness, as amongst other things he did not always acknowledge our entry into his room. He had an enlarged abdomen but the Health Visitor said he had a very healthy appetite. As neither Neil or myself had ever dealt with babies or toddlers we did not know what to expect in development other than what the text books told us etc. However, the slowness in speech did concern us rather. Eventually after being referred from one specialist to another to be told nothing was wrong with Daniel we met a paediatrician at Addenbrooke's Hospital, Cambridge who suspected Daniel had Hunter's Syndrome. After intensive tests, Hunter's Syndrome was diagnosed one week before Christmas 1980. We were immediately referred to Dr. Philip Benson at Guy's Hospital who, after more tests, agreed with the diagnosis. More tests followed, culminating in a visit to Peter Harper at Cardiff University Hospital, where we were informed that I am a carrier so future male foetus could be affected. It came as a dreadful shock as there had been nothing in either of our families. As I am a carrier we were told Laura stands a 50% chance of being a carrier to any of her future male offspring.

In January of this year, Daniel had an Amniotic Implant, being one of the first operations of this type carried out at Guy's (or indeed anywhere in the world) which involved him having an incision made across the tummy and implanting membranes from a recently performed caesarian section. It was hoped these would feed into his system the enzymes which his body lacked and multiply. We were both in hospital for just under one week. More tests followed to discover if this implant had had any effect. After a few weeks we were told it had had little if any effect but they had meanwhile implanted some other children using slightly different techniques and were getting good results on their enzyme levels. We were asked if we would object to Daniel being implanted again - we were willing to try anything and only to pleased they were willing to 'try again'. At the end of June we went again to Guy's and were in less than 24 hours while they operated - this time a small cut was made and a tube inserted through which the membranes were dispersed. I should mention Daniel had also undergone several ear operations, including the fluid drained and grommets inserted - now he has more effective gud (pron. good) tubes which have greatly improved his hearing. We were told at first diagnosis we would never get any speech from Daniel but he can now talk, not always clearly due to his enlarged tongue but he does keep persevering. He is now attending a small assessment unit in Cambridge and is progressing well in many aspects.

Life is not always easy. Daniel is very strong and this causes many 'violent' fights with Laura. His concentration span is limited to a few minutes at a time and he needs a lot of supervision. This presents problems with babysitters. However, generally, for now, we cope and make the most of this time. Daniel is a happy little boy with a very affectionate nature and we all have many laughs and sad moments together as a family.

We are hoping the latest operation has done some good but time will prove to be the greatest judge of that.

Jane Reid

AN INTRODUCTION TO OUR AREA FAMILY IN BOLTON, LANCASHIRE

Dear Readers,

My name is Pat Kirkman and my husband is Derek, we are the parents of Simon aged 14 years and Anna who is 9.

Simon is our MPS child, he has Sanfillippo Syndrome. Since his birth and to date we have faced many problems and changes in Simon which we have overcome and accepted. We have had the experience of a happy mischievious child, full of fun and life, then the slow deterioration up to the present time, when now we have to do everything for him. This we do quite willingly and with love, and when we are repaid with a smile it all seems worthwhile.

We have been asked by Christine to become a support family for our area, this we are very happy to do and if we can help anyone with a problem or just the need for a chat, our phone is available at anytime so please don't hesitate to call or write.

About ourselves; as far as hobbies are concerned Derek, who is an Engineer, loves to tinkle about with cars and is very interested in motor sports. I don't have any particular hobbies, although I must confess I enjoy reading. Most of my time just lately has been spent looking after Simon. Anna is a lively boisterous nine year old who really enjoys everything she does. Although she is young over the past couple of years she has really become quite good help to me with Simon. We have never yet heard her complain about him or raise her voice to him.

Derek and myself have decided to start fund-raising for a Bone Marrow Unit, so that newly diagnosed MPS children might live a more fruitful life. This is going to need lots of support from other families, and I hope we can go all out to see what can be achieved.

We wish Christine success with the newsletter and feel certain it will bring both help and hope to parents and children of Mucopolysaccharide Diseases.

MUCOPOLYSACCHARIDOSIS IN THE REPUBLIC OF SOUTH AFRICA

Our contact in South Africa is an MPS mum, Angela Kemp, who has had a long standing pen-friendship with one of our Area families, Robin and Anne Ridley.

Angela lives in Port Elizabeth with her son Simon who is 3 years old and suffers from Hurler's Syndrome. Simon is very poorly physically and takes up all his mother's time. Despite this Angela is in regular communication with six other families with an affected MPS child. One of her mums had twins, both affected with Hurlers, sadly one has died and the other is very poorly. The twins were their parents only children. On a slightly more optimistic note another family have two sons both affected with Hunter's Syndrome and at the beginning of October the boys are going to be South Africa's first MPS Bone Marrow Transplant recipients, their father being the donor for both of them.

If anyone would like to correspond with a Hurler or Hunter Syndrome family in South Africa please let me know.

Christine Lavery

We would like to welcome these families to our Society:

Mr. and Mrs. Bennett and their son Anthony from Blackpool. Anthony has Sanfillippo Syndrome.

Mr. and Mrs. Culley whose son Robert has Hunter's Syndrome. Robert is 3 years old and they live in Southampton.

Jean and Terry Hale whose daughter Louise was affected by Hurler Syndrome. Louise underwent a perfect match bone marrow transplant four months ago. Her sister Lisa became the youngest bone marrow donor in British Medical history at the age of 4 months.

Mr. and Mrs. Hartland and their son Stephen from Birmingham. Stephen has Sanfillippo Syndrome.

Angela Kemp and her son Simon who live in South Africa. Simon is aged 3 years and has Hurler Syndrome.

Linda Matthews and her husband from Staffordshire, their 8 year old son Richard has Sanfillippo Type A Syndrome.

Mr. and Mrs. O'Toole and their daughters Kate and Helen. Helen is 5 years old and has Morquio Syndrome. They live in Sussex.

Tom and Dorothy Tappenden who son Robert, aged 23 years was diagnosed as having Hurler Syndrome. They live in Sussex.

Mr. and Mrs. Wilson and their daughter Lisa. Lisa is 12 and has Sanfillippo Syndrome. They live in Hertfordshire.

Lyn Windsor and her husband from Sussex. They have an 11-month old son, Gary who has Hurler Syndrome.

Trevor and Shirley Brown whose son Lee has Hunter's Syndrome. Lee is 5 years old and they live in the London area.

Mr. and Mrs. King whose son Michael has Hunter's Syndrome. He is nearly 8 and they live in Sussex.

Mr. and Mrs. McCarthy and their son Scott who has Hurler/ Scheie Syndrome. Scott is 9 years old and lives in Scotland.

Mrs. Jean Silvey and her daughter Treena. Treena has Sanfillippo Syndrome and lives in Essex.

Richard and Audrey Hodges and their son Matthew. Matthew is 5 years old, has Hunters Syndrome and lives in Leicestershire.

RATING (Disabled Persons) ACT, 1978

Rate relief for disabled persons (this includes children) under the above Act may be allowed for facilities specially provided or required to meet the needs of a disabled person.

eg. If you are required to heat your house at a higher temperature or more often than a normal family, relief can be given on central heating.

If your child isn't very mobile and you rely on the use of a car then you can claim rate relief on the garage.

If you have a second bathroom and toilet to meet the needs of your handicapped child you can claim relief on the extra facilities.

LISA GOES TO IBIZA

I am the parent of a physically and mentally handicapped daughter. Lisa is 12 years old and has Sanfillippo Syndrome. At the present time she cannot walk, talk, feed herself, is totally incontinent and cannot swallow solid foods. In fact she is just like a baby but much bigger.

We have always had a holiday each year, taking Lisa with us. For the last few years we have had terrible weather in Britain so this year we toyed with the idea of taking Lisa abroad for some sunshine. The more I thought about it the more I worried. My main worries were her food, as I have to liquidize everything and how would we manage with the wheelchair - to mention just a couple. I got as far as the travel agents and brought home the brochures. The more I looked at them the more determined I was to take her. We decided to go to Ibiza as it looked so pretty and quiet, Portinatx to be exact, which is a small, away from it all, town.

I went back to the travel agents and explained our situation and they took over from there. They booked us with Thompsons and Brittania Airways. I couldn't fault either of them. I had a letter from the manager of the hotel giving me the size of the doors and lifts for the wheelchair and a letter from Gatwick Airport to say we were expected with a child and a wheelchair, so everything started to fall into place.

I still had the nagging worry about the food. I didn't want Lisa to get any tummy bugs. When we have a meal at home that I can't liquidize I give her Heinz baby jars. I decided as we had only booked for a week she could have these. Lisa will only have Weetabix or porridge for breakfast and loves custard, rice pudding etc. So my shopping list looked like this:

28 Heinz dinners, 7 Heinz yoghurt, 7 pkts. instant custard
4 tins rice, 1 large bottle of orange juice, 1 pkt. Weetabix
1 pkt porridge - plus dozens of paddi pads.

As we were only going for a week, and it is a warm climate, we didn't need too many clothes, so our baggage weight was alright even with all the jars. I also took a small gas cooking stove and a saucepan. If they had opened my case at the airport I don't know what they would have thought.

At last we were ready, we got to the airport. They had reserved the front three seats for us and took us out to the aircraft by ambulance. We had a lovely flight and Lisa was as good as gold. We were met in Ibiza by another ambulance which took us straight to our coach for our drive to the hotel.

We had a lovely week. The hotel was very nice and supplied me with hot milk every morning for Lisa's cereals. We heated her jars for lunch and took them with us in the flask and fed her wherever we were and went back at tea-time in time to change and feed Lisa before we went downstairs for our dinner and she sat at the table quite happily because she had eaten. Lisa liked the music in the hotel. We took her in the swimming pool and in the sea and it was worth every penny to see her laugh.

The journey home went just as smoothly and if Lisa does not deteriorate too much we shall certainly be going next year.

I'm writing this hoping that for some of you who have thought of the idea but haven't carried it out - Go on have a go and I hope you enjoy yourself as we did.

Mr. and Mrs. G. Wilson and Lisa