NEWSLETTER mps SPRING 1983

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

YOUR COUNCIL OF MANAGEMENT FOR 1982/83

CHAIRMAN	Mr. G.C. Nichols, CBE., DFC. 'Mossville', Cokes Lane, Chalfont St. Giles, 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 OFFICERS	Dr. D. Garrow, BM, FRCP, Dr. B. Neal, MBBS, MRCPG, D. Obst. RCOG.
GENERAL MEMBERS	Mrs. M. Hourigan. Mr. R.J.O. Lavery.

AREA SUPPORT FAMILIES

Mary & Colin Gardiner, 35 Church Rd., Banks, Southport, Merseyside PR9 8BT. 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, Leicestershire.

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

AIMS OF THE SOCIETY

1. To act as a parent support group.
2. To further research into MPS Diseases.
2. To educate the public about Mucopolysaccharide diseases.

A LETTER FROM THE SECRETARY

The Society continues to go from strength to strength. It is so nice that many of our families have chosen to take an active interest, busily fund-raising, writing articles for the newsletter and getting in touch with other MPS families and in some cases meeting to hold coffee mornings. It is always a pleasure to put faces to the voices on the telephone and in the last couple of months we have enjoyed a regular flow of MPS visitors to Little Chalfont. We have also helped several families to hold joint coffee mornings which adds another dimension to the Society's work.

We have been particularly lucky with the attention the Society has received from the Media. Our appearances on Thames TV's Programme 'HELP' was well received and we had many donations and a further 50 letters of enquiry. As a direct result we heard from 5 new MPS families. It is too soon to judge the impact our appearance on the 'LINK' programme of 20th March 1983 had but this sort of publicity can only be to the benefit of MPS children in the long run. Several families have had written questions with regard to treatment of MPS children asked in Parliament which continues to keep the plight of MPS children in the limelight. Many families have forwarded me copies of articles about their children carried in local newspapers and as I type this I learn that the Daily Mirror for Monday 28th March is carrying an article on Elizabeth Peach, the only girl in the world known to suffer from Hunter Syndrome.

At last we have heard from the Charity Commissioners that they have accepted our application for Charity registration and trustees have been nominated. They are Mr. C. Grant, Mr. R. Heath MA (Oxon), Mr. R. Lavery and Mr. G.C. Nichols CBE., DFC. The Committee and Trustees met on Friday 25th March to adopt the Rules of the Society and to sign the Trust Deed. I will be returning the documents to the Charity Commissioners for stamping then we will receive our Charity Registration number.

Plans for the Family Weekend, AGM and Conference continue to progress and we hope to announce final details in early May. In the meantime if any family who hasn't returned their form and wishes to attend, I will need to hear from them urgently as we have to know final numbers. I am happy to say a number of doctors and specialists in MPS have agreed to present papers so it should be a very stimulating and informative week-end.

Finally please keep the articles for the newsletter coming in, we are happy to print photographs along with stories, or if you only have a brief piece of news then we have introduced our News in Brief page expressly for that purpose. To those in the medical profession interested in MPS we would very much like to hear your news and views as well as any relevent articles on MPS.

Christine Lavery

MUCOPOLYSACCHARIDOSES

The Enzyme Laboratory, Institute of Child Health, London, has been involved for a number of years in the investigation of patients thought to be affected with a mucopolysaccharidosis. The investigative procedure has been developed to cause as little trauma as possible to the patient and a minimum of inconvenience to the patient's family. Initially a small volume of urine is required (about a tablespoonful) to estimate the total GAG excreted and subsequently to study the individual GAG types by electrophoresis. Where the excretion 'pattern' indicates a diagnosis of a mucopolysaccharidosis either whole blood (2-3 teaspoonfuls) or a tiny piece of skin (to provide a fibroblast culture) are obtained so that further tests may be performed to confirm the type of mucopolysaccharidosis involved. More than 100 cases have been studied in this way (with another 40 from whom we have been unable to obtain further specimens).

In recent years, we have pioneered the use of the methods developed in this laboratory for urine analysis in the direct examination of GAG content of amniotic fluid in early pregnancy. From about 14 weeks gestation, foetal urine contributes to the amniotic fluid. If the foetus is affected, foetal urine (and therefore amniotic fluid) will show the presence of the same abnormal components as those excreted by a previous affected child. Although these abnormal components are present in very small amounts, only 3ml (less than a teaspoonful) is needed to show whether the excretion 'pattern' is normal or not. Initially this method was used as a back-up test for the enzyme analysis of cultured cells, but it has been found to be so reliable that it can now be used confidently as the sole method of prenatal diagnosis in cases where amniocentesis is late or fails to provide a large enough sample for cell culture, or where the cell culture fails. It can also be used in situations where the exact diagnosis has not been made for the affected child, although whenever possible it is used in conjunction with analysis of the appropriate enzyme. A full range of these enzyme tests is carried out by the Enzyme Laboratory.

For the periodJanuary 1977 to December 1982. 115 pregnancies have been studied in this way (from types I - VII) and to date the predictions have always been correct. Many of these have come from this country, but we have also received specimens from all over Europe, Scandinavia and even Tunisia. The sample can be readily sent by post, and a result is available three working days after receipt of the sample.

Note: GAG (glycosaminoglycan) is the term now used rather than mucopolysaccharide to describe the material excreted in urine by these patients.

Mrs. Jean Mossman
Enzyme Laboratory
Institute of Child Health

TREASURER'S REPORT

We are pleased to report that money - both raised and donated, continues to come in. Sources range from such fund-raising events as a sponsered shave to the kind donations of viewers to the Thames TV 'HELP' programme, earlier in the year.

Whilst our primary aim remains the establishing of our Research fund, our fond ambition this year is to raise enough money for the purchasing and funding of a Holiday Caravan. This would be expressly for the use of MPS families, and would be sited near a safe beach, close to all amenities. Fittings would reflect the needs of a handicapped youngster. Any ideas or contributions gratefully received!

Snowball profits will be split equally between the Research and Caravan Funds. We do, of course, observe the wishes of donors who contribute to a particular "cause" eg., we gratefully acknowledge a cheque for £400 received recently for inclusion in our Caravan Fund. Indeed - many thanks to all of you who have supported us over the past months.

A new venture this month has been the launching of a range of Mabel Lucie Attwell Stationery, personalised with our Able Label stickers. Initial response has been promising; unfortunately postage costs prohibit the sending of stationery to families holding fund - raising events, although any members 'passing our door' so to speak are invited to collect a package of stationery for resale.

We will keep you informed of our progress.

Catherine Grant, Honorary Treasurer.

THE VERSATILE BATH CHAIR

Recently one of our MPS children, Lisa Wilson who is 12 years old and suffers from Sanfilippo Syndrome, became in need of a special bath aid. It had become increasingly difficult for Lisa's mother, Marlene to bath Lisa and wash her very long hair whilst supporting her at the same time. Both the Wilson's and the Society appealed to Social Services to supply this piece of equipment but received a negative response.

We approached the Amersham and Chesham Lions who most generously offered to finance the purchase of the versatile bath chair for the use of our Society. Subsequently members of the committee were invited to a Race Night fund raising event and as a result we were presented with the chair which is greatly appreciated by Lisa and her family.

FUNDRAISING REPORT

By good Friday our initial eight families will have received their coffee snowball packs, and already the snowball account is attracting money. Some people have combined their snowball with a sale which is boosting the account even further. Every coffee morning brings us one step nearer our target of sponsoring research and of purchasing a holiday caravan for MPS children and their families. (This we are intending to purchase and equip to cater for all the needs of MPS children).

At a slower rate, we are now able to offer anyone else a chance of participating in the coffee snowball, but as the event finishes on 21st June, we will need to know promptly if you wish to take part. All you would have to do is to invite 5 people to coffee at a charge of 50p. per head, and in turn those people would have to invite 4, and so on down the line until one person is left inviting one other. At this level (level 5) provided the chain continued to its conclusion, you could raise £160. If you feel you could only cope with a starting number of 4 (level 4) you could still raise £32, so please do ring either Christine Lavery or myself if you are interested so that we can get the papers sent to you - all you have to do is pass them on to your guests, but they give information about MPS and our targets, and this will be another way of helping us spread the word.

Christine and I have spent weeks of working until ungodly hours, stapling and collating 80,000 pieces of paper to get this event going, so do give us your whole hearted support to justify our sore fingers and bleary eyes to our long-suffering husbands.

Susan Heath

A MILE OF TWO-PENNY PIECES?

As summer is approaching, how about seeing if your local schools or youth groups would organise a mile of two-penny pieces? It's fun to do and the money adds up very quickly.

GAS BOARD DEMONSTRATION

As a fund-raising event, see if you can get your local Gas Board to do a Cookery Demonstration in your area with the proceeds to go towards MPS.

Dear Readers,

Our family consists of husband Graham, Jane 10½ years and David 4½ years who has Hurler's Syndrome.

David was diagnosed as having this disease at 16 months. It was a terrible shock to all of us, but my husband was marvellous; he said we must pull ourselves together and do the very best for David by giving him a happy and normal life as far as it was possible. We told Jane everything about David's condition straight away and what it would entail. This she accepted quite calmly and now when we visit the hospital, she always comes along and this has made Jane extremely close to her brother.

David has the usual characteristics of a child with Hurler's. He had grommets inserted last September which improved his hearing, and he is now beginning to talk. He is chesty during the winter months, and his breathing at night is loud and uneven. Even though he has all these problems, he is a very happy little boy. The children at the local nursery which David attended until he was 4 years old, still refer to him as "Laughing David Criddle".

David now attends an assesment school "Prestwood House". Here he will stay until he is 7 years old. I put him on a special bus each morning and he returns the same way at 3.30 p.m. He loves every minute of his school day; his work is the standard of a 3 year old, but he is very astute and aware of his surroundings, and has all the normal reactions of a lively 5 year old.

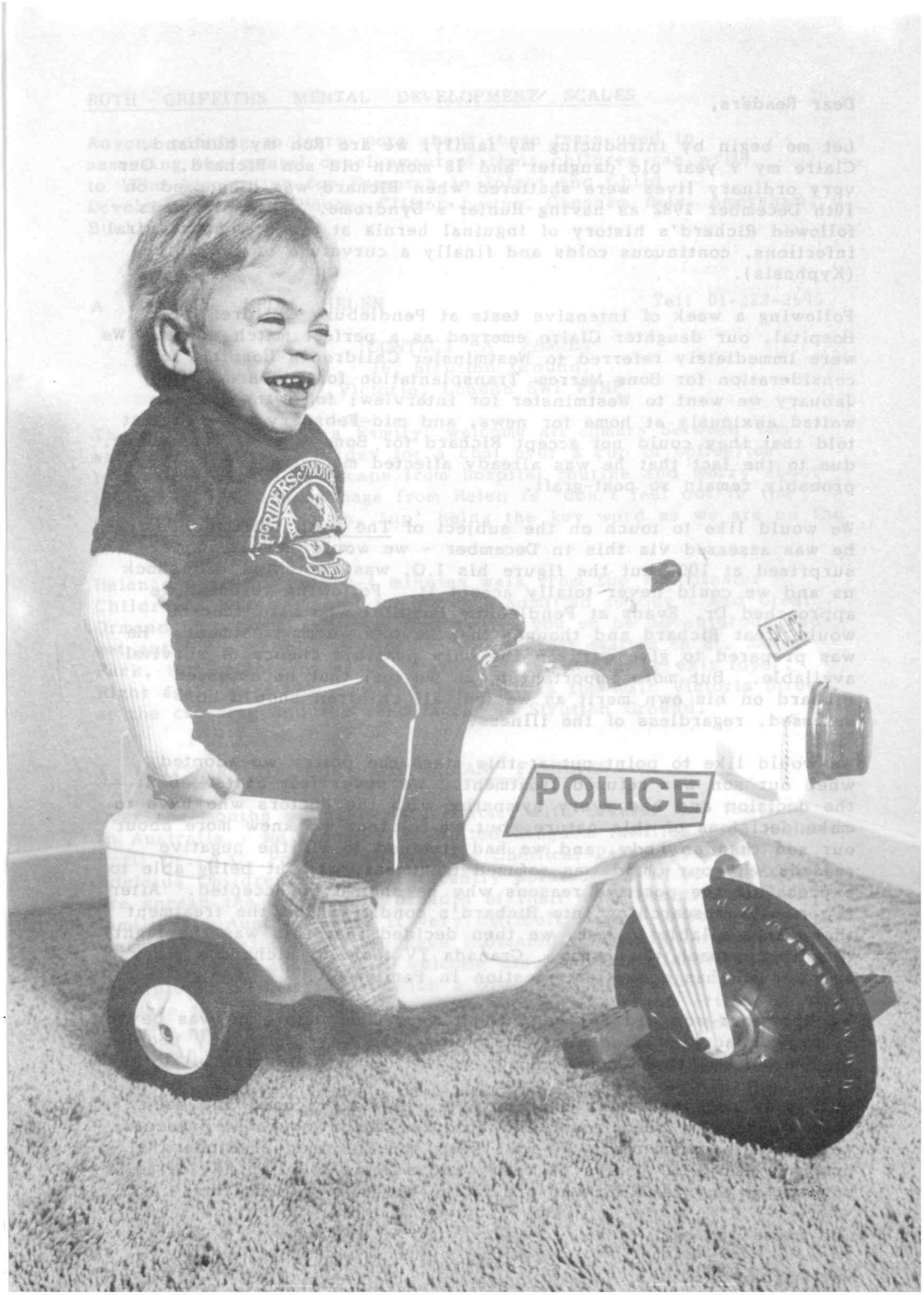
David's condition has never ruled our family life. We all have hobbies including David. He is learning to swim, belongs to a Saturday Club, and after Easter will be having horse riding lessons. Every year we go to Menorca for our holiday. which he greatly enjoys. In a few weeks time we are all going to Holland to stay with a family we met a few years ago in Majorca. David loves to travel which, of course, makes everything much more enjoyable for all of us.

Its quite an experience having a child like David. He's taught us a great deal, most of all about enjoying life. His happiness seems to rub off on everyone he comes into contact with. I would also like to mention all my friends, doctors and health visitors who have supported us during the bad times and pulled us through - we would never have survived without them. So really, what I'm saying is try and make the most of every day, and help your child to enjoy whatever it can. Our reward is that big beaming smile David gives us.

Pat Criddle

Pictured right

DAVID CRIDDLE



Dear Readers,

Let me begin by introducing my family; we are Ron my husband, Claire my 9 year old daughter and 18 month old son Richard. Our very ordinary lives were shattered when Richard was diagnosed on 10th December 1982 as having Hunter's Syndrome. This diagnosis followed Richard's history of inguinal hernia at age 5 months, viral infections, continuous colds and finally a curvature of the spine (Kyphosis).

Following a week of intensive tests at Pendlebury Children's Hospital, our daughter Claire emerged as a perfect match donor. We were immediately referred to Westminster Children's Hospital for consideration for Bone Marrow Transplantation for Richard. In January we went to Westminster for interview; following this we waited anxiously at home for news, and mid-February were in fact told that they could not accept Richard for Bone Marrow Transplant, due to the fact that he was already affected mentally and would probably remain so post-graft.

We would like to touch on the subject of The Ruth Griffiths Test; he was assessed via this in December - we would have been surprised at 100% but the figure his I.Q. was quoted at did shock us and we could never totally accept it. Following refusal, we approached Dr. Evans at Pendlebury Hospital who said that he would treat Richard and thought that he was worth treatment. He was prepared to give our son the only possible chance of survival available. But more important to us we feel that he assessed Richard on his own merit as we feel all children should be assessed, regardless of the illness.

We would like to point out at this stage the policy we adopted when our son was refused treatment. We never felt bitter about the decision and had every sympathy with the doctors who have to make decisions of this nature, but we felt that we knew more about our son than anybody, and we had listened to all the negative reasons why our child was refused treatment, without being able to express all the positive reasons why he should be accepted. After two months researching into Richard's condition and the treatment that was available to him, we then decided that this was the right time to approach the media. Granada TV took up Richard's story and our MP has a written question in Parliament.

We knew our son did not have much more time before he was beyond help; we had a great deal of help along the way from many people. We can not mention them all, but we will always be grateful to them.

Our story does end on a happier note, in that Richard has been reconsidered by Westminster and accepted, and we are at present waiting to be admitted. We will keep you informed of Richard's progress and will always be ready and willing to offer advice and support to any families who are facing the same difficulties.

God bless you all.

Val Turner

RUTH GRIFFITHS MENTAL DEVELOPMENT SCALES

Anyone wishing to learn more about these tests used in assessing the mental development of their children can write to 'The Association for Research in Infant and Child Development, Eden House, Clifton Lawns, Chesham Bois, Amersham, Buckinghamshire.

A MESSAGE FROM HELEN

Tel: 01-222-2695

'CONTACT A FAMILY'
16, Strutton Ground,
Victoria, London SW1 P2HP

The Staff at 'Contact a Family' welcome all comers between 9am and 6pm Monday to Friday for a chat over a cup of coffee/tea. It gives a chance to escape from hospital routine and worry about treatment. So the message from Helen is "don't feel out in the cold pop up and see us, 'up' being the key word as we are on the 5th floor and no lift".

Helen's office is only 3-4 minutes walk from the Westminster Children's Hospital, and for parents admitted to Guy's and Great Ormond Street the same welcome awaits you so be adventurous and get out for a couple of hours. The nearest station is St. James Park, turn right out of the station at the Broadway exit foyer. Right again past New Scotland Yard, cross the main Victoria Street at the crossing and the road facing is Strutton Ground.

A WELCOME TO OUR AUSTRALIAN FAMILIES

Over the months we have made contact with several MPS families in Australia. We thought our United Kingdom families were isolated until Dr. A.C. Pollard, Director of Chemical Pathology, The Adelaide Children's Hospital recently pointed out to us that as they are spread the length and breadth of their vast country, MPS families in Australia find it very difficult indeed to form their own mutual support group. We have indicated to Dr. Pollard that the MPS Society in the UK will welcome his Australian families and if possible help them to establish a branch in Australia. So a message to our friends down under is "let's have an article or two for the newsletter" and if any family wishes to be in touch with a UK family in similar circumstances I will be happy to pass on your letters. That also applies to UK families wishing to hear personally from Australian families.

Christine Lavery

HELEN HOUSE

We first heard about your Society because we were privileged to help care for little Rachel Huxted in the last weeks of her life. As many of you will know, she had Hurler's Syndrome and she died just after Christmas, aged ten. She first stayed with us for a few days before Christmas and, like everyone else she knew, we loved her from the moment we met her. She went home for Christmas and had a wonderfully happy time with her family and then returned to us for the last few days of her life. Her parents stayed here too and we feel that her family are special friends of ours.

The idea of Helen House came about through the illness of one little girl. Helen was a lively, loving, healthy child of two and a half when suddenly she became ill and was found to have a very large brain tumour. Despite skilled surgery, she is now at the age of seven in the same condition as she was soon after her operation - totally helpless, unable even to turn herself over in bed, unable to communicate with us in any way and scarcely aware of her surroundings. Having got to know Helen and her parents well during her six months in hospital and realising something of the strain they were under once Helen was at home, I asked them if they would trust me enough to "lend" her to me sometimes. This has happened and she has come to stay in my room at the Convent on many occasions, for short visits, so enabling her parents to have some unbroken nights sleep, the opportunity to take her little sisters to visit friends or relatives, or the chance to have a holiday. On several occasions Helen's mother has been unwell and Helen has come to stay with us then. Helen House is quite simply the idea of our very special friendship with Helen and her family extended to other gravely ill children and their families.

We have built the house in our garden in East Oxford and it is designed to be as much like home as possible. We want the children to feel that they are coming to stay with friends when they come here. Our nurses don't wear uniforms and we have tried to create an informal family atmosphere. We have room for eight children at any one time and we welcome their parents to stay here too, if they wish to do so.

We believe that once it is recognised that a child cannot benefit from hospital treatment aimed at recovery, the ideal place for that child is usually his or her own home, but we recognise the tremendous strain this puts on any family. We are here to offer as much help and support as we can to such families. Helen House opened in November 1982. Some of our children come at regular intervals, for example one week in every six, two weeks in every two months; others just when a particular need arises at home. Where it is at all possible, we like to know a child and the family before the final stage of illness, so that there is a chance to build up a loving relationship. We accept referrals from any source, but of course we must have the full agreement of parents and General Practitioner or Consultant before we agree to have a child to stay. If anyone would like to know more about us, please do not hesitate to get in touch with us. The address is: Helen House, 37 Leopold Street, Oxford, OX4 1QT - Telephone Oxford 728251.

S.R.N.; R.S.C.N.

COMMERCIAL FOR HELEN HOUSE

The following letter was sent to the Society from Sue and Peter Bramford, following the stay of their daughter Toni at Helen House:

"Toni was at Helen House for a week and was very well looked after - she didn't lack for anything and was given all the love and attention that any parent could give.

Helen House is very well equipped; it has separate bedrooms for the children but if they became friends they could open the adjoining doors for them to play together or to watch television.

It is fully carpeted with central heating - they even have a hydrotherapy pool which Toni thoroughly enjoyed. They have plenty of toys for them to play with.

But what we liked about Helen House was that the staff are known by their Christian names and when you talk to them it is as if you have known them for years.

When we arrived on Sunday, January 23rd we met Jamie who is a S.F. sufferer. He is ten years old and unfortunately can no longer walk unaided, but when he saw Pete push Toni through the corridor (we were laiden with luggage) he soon pushed Pete out of the way and started to push Toni to her room. We had to take Toni's clothes and also her disposable nappies, and a few of her favourite toys.

As their beds are higher than Toni's divan at home, we asked if it were possible to have a mattress on the floor, as she would have tried to climb out of the bed, even with the cotsides.

All I can say is that Toni will be going there again as I know I have no worries about leaving her there - in fact she is booked in for the end of March as we are having building work done then. To anybody who is thinking of letting their child stay at Helen House, you couldn't pick a better place".

A LETTER FROM THE RYAN FAMILY

May we introduce ourselves to everyone involved in MPS? My wife Sheila and I have been married for 4 years and our son Paul is aged two years and two months and suffers from Hunters Syndrome. It was diagnosed last September when he was 22 months old and we have been referred to Westminster for a possible BMT. We have not been contacted yet so you will all appreciate it has been a nerve-wracking time. However we have coped by fund-raising for the BMT unit which has turned into a full-time job. On a more personal note, I myself am unemployed, a plight not uncommon at the moment, and Sheila works three nights a week at the local pub. Paul himself is fit and well at the moment except for his hearing which is very bad - he still has to say his first word and shows no signs as yet but then he is still young. He was first in hospital for a hernia op. at 12 weeks old, then he had grommets inserted at the age of one. We were still not satisfied with his general development and asked for him to be tested further in September '82 when we discovered the heartbreaking news.

May I congratulate the MPS Society for the help and security it gives people who find themselves in this unenviable position, and give special thanks to our area family, the Gardiners, who have been tremendous.

Dougie Ryan

A LETTER FROM CAROL HUBBARD

I have suffered with MPS type VI for 32 years now. I am 4 feet 4 inches tall and have arthritis in my neck, shoulder and hip joints. I had an operation on my hips when I was 16 years old, which has been a big success and I walk unaided. I had an operation on my heart last year which again has made a terrific difference to me. My eye sight is poor and I am slightly deaf in one ear.

Despite all this I have lived a fairly normal life. I went to nursery school at the age of 4 years and continued my education in a normal school. I might add that I was always the shortest person in the class and that always upset me and still continues to worry me.

I cope with life very well and am happily married. I gave up work about three years ago because of my heart condition, until then and since I left school I was employed as a machinist and enjoyed this very much.

Six years ago I became pregnant, but on the advice of my doctors I had the pregnancy terminated. Suffering from MPS does not worry me at all, I am very happy and enjoy what I have in life. I would much rather be normal but I know that will never be, so I make the best of what I can manage.

I certainly hope this gives some encouragement to you although I know other MPS diseases are different, and I am relatively lucky in comparison.

My best wishes to everybody.

Carol

POSTSCRIPT

Carol contacted us as a result of my appearance on the Thames TV's 'HELP' programme. Until she saw the programme Carol and her sister Linda believed that they were the only two people in the United Kingdom suffering from MPS. Linda is slightly younger than Carol and not quite as fortunate in that she is more handicapped and wheelchair bound.

Originally Carol and Linda were diagnosed as suffering from Morquio Syndrome but more recently it was changed to Marateaux-Lamy.

ELISABETH

On March 21st 1979 our daughter Elisabeth was born and my husband Dave and myself, Sue, felt that our family was complete - we already had two sons, Matthew who was born in 1975 and Timothy born in 1977. Elisabeth developed quite normally although she had an enlarged abdomen and an umbilical hernia which was repaired in October 1981. She was slower to walk and talk than the boys but we felt that this was because she was a third child and consequently didn't need to move or talk as her adoring brothers did everything for her.

She continued to develop normally and we were not at all worried about her although she did seem to suffer from a lot of colds and coughs. When she was $2\frac{1}{2}$ years old we moved from Northampton to Rugby. Just three months later, after a routine visit to our GP., we were told by the local hospital that they suspected that Elisabeth was suffering from a 'syndrome'. We didn't believe that it could be serious as she was such a happy, healthy little girl; we were sadly mistaken. After many tests at St. Cross in Rugby and Great Ormond Street, Elisabeth was diagnosed as having Hunter's Syndrome and was in fact the only girl in the world known to have the disease. The fact that she was a girl made the diagnosis more difficult and is possibly the reason that it wasn't spotted earlier. We now realise that she showed the classic symptoms from an early age. However, we were devastated. Why our little girl? I went to Cardiff for enzyme tests and it was discovered that I am not a carrier. Elisabeth's enzyme deficiency is a complete freak due to a damaged chromosome.

Once the diagnosis was confirmed we were referred to Westminster Hospital to discuss a possible Bone Marrow Transplant. The usual tests were carried out and our eldest son, Matthew, is considered to be a possible donor, although the match is not as good as the doctors would like. Four potential donors from outside the family are being tested as I write and we are anxiously awaiting the results. We are also waiting to hear whether Elisabeth is considered to be a severe case of Hunters as obviously Westminster is concentrating on those children most at risk. A recent assessment shows that she has a substantial hearing loss, stiffness in all her joints and her general development is below her chronological age but still within the range of normality. She is a very happy, loving little girl, but she is also very stubborn, difficult to reason with and quite a handful at times.

We have been very lucky in that we have found some very good friends in Rugby; everybody is willing to help us in any way they can and this has made everything so much easier for us. The local press have also been extremely kind and have publicised not only the plight of Elisabeth but have also highlighted the problems of all MPS children and the appalling lack of resources for treating them. We believe that publicity is most important, and if our little Elisabeth can encourage people to sit up and take notice, then we feel that something good has come out of our sorrow.

Sue and Dave Peach

NEW FAMILIES

We would like to welcome these families to our Society.

Mrs. Ahmed whose daughter Funda is 6 years old and suffers from Hurler Syndrome. They live in London.

Peter and Maggie Archard and their son Christopher from Hertfordshire. Christopher is 3 years old and suffers from Hunter Syndrome.

Mr and Mrs Bennett whose 18 year old daughter Theresa suffers from Sanfilippo Syndrome. They live in Essex.

Mr. & Mrs Bradford from the West Midlands. Their 4 year old son John suffers from Hunter Syndrome.

Sue and Dan Butler whose 10 year old son Alexander has Mild Hunter Syndrome. They live in Oxfordshire.

Geoff and Bridget Butler from Derbyshire. Andrew their 16 year old son suffers from Mild Hunter Syndrome.

Val Corfield whose daughter Shelley aged 10 years suffers from Sanfilippo Syndrome. They live in Lancashire.

Graham and Pat Criddle from Wales. Their four year old son David has Hurler Syndrome.

Mr and Mrs Dickson whose 5 year old son Marc suffers from Hunter Syndrome. Marc and his family live in Aberdeenshire.

Alan and Sheila Commons from Yorkshire. Their son Robert aged 5 years has Morquio Syndrome.

Mr and Mrs Donahy from County Down whose 4 year old son Alan has MPS. We extend an especially warm welcome to our first family from Northern Ireland.

Mr and Mrs Edema whose son Elliot has MPS. Elliot is 12 years old and lives in Buckinghamshire.

Barbara and Dave Farrington from Lancashire. Sadly their 1 year old son Mark died after Bone Marrow Transplant treatment last year, but they wish to support the Society.

Ann and Ray Franklin whose son Paul has Hurler Syndrome. They live in Surrey. Paul who is 3 years old was the very first MPS child to have Bone Marrow Transplant.

Mr and Mrs Harris and their son Stephen from Kent. Stephen is 7 years old and suffers from Mild Hunters Syndrome.

Mr and Mrs Holroyd whose two eldest children, Nicky 10 years and Megan 14 years suffer from Mannosidosis. The Holroyds live between West Germany and London.

Mrs Carol Hubbard from Essex. Carol is 33 years old and suffers from Marateaux-Lamy.

Mr and Mrs Hughes from North Wales. Two of their children, Daryll 12 year and Marcus 7 years suffer from Hunter Syndrome.

Mr and Mrs Love whose son Gary suffers from Mucolipidosis. They live in Cumbria.

Mr and Mrs Robbins whose only son suffers from Hurler Syndrome. He is 3 years old and lives in Essex.

Peter and Marlene Sanderson from Gloucestershire. Their daughter Joanne died aged 16 years from Sanfilippo Syndrome last November. Nevertheless Marlene and Peter wish to support the Society.

Mr and Mrs Swiderski and their four children, Matthew 7 years, James 5½ years and twins Helen and Maria aged 3 years, all of whom suffer from Sanfilippo Syndrome. Helen and Maria underwent Bone Marrow Transplants last summer. They live in Nottinghamshire.

Brian and Ann Tilbury from Buckinghamshire. Sadly their son Lee died from Hunter Syndrome two years ago, but recently they have offered to help MPS.

Shirley Twigger, whose 6 year old son has recently been diagnosed as having Sanfilippo Syndrome. They come from Yorkshire.

Valerie and Ron Turner and their son Richard. Richard is 18 months old and has just recently been diagnosed as having Hunter Syndrome. They live in Manchester.

Gerald and Desma Vanderwent whose 22 month old daughter Laura has Hurler Syndrome. They are our first family from Mainland, Australia.

Mr and Mrs Walsh also from Australia, have a 2 year old son Benjamin. Ben suffers from Hurler Syndrome.

Mr and Mrs Whittington and their son Stephen from Herefordshire. Stephen is 2½ years old and suffers from Hurler Syndrome.

Dafydd and Elinor Wigley from Gwynedd, Wales. Their two eldest sons suffer from Sanfilippo Syndrome.

IBRAHIM TIRIOL

We wish to extend our deepest sympathy to Sebera Tiriol and her husband on the death of their youngest son Ibrahim who was four years old. He died in February, three weeks after becoming South Africa's first MPS Bone Marrow Transplant patient. Ibrahims older brother, Muhhamed, has not undergone Bone Marrow Transplant although he too suffers from Hunter Syndrome.

NEWS IN BRIEF

CONGRATULATIONS

Congratulatioins to Dave and Barbara Farrington on the birth of their daughter Emma Jane, born March 5th 1983. Some of you may remember Mark from the programme 'Chance of a Lifetime'. Sadly Mark who suffered from Hurler Syndrome didn't recover from his Bone Marrow Transplant.

LONDON MARATHON

Mr. Peter Glyn-Jones, a London Solicitor who lives in Chesham Bois is running in the London Marathon on Sunday April 17th. All sponsership money is to be donated to The Society for Mucopolysaccharide Diseases.

THE VICKERS WORTHING MARATHON

We have two runners in the Vickers Worthing Marathon to be held on Sunday 8th May. Anyone wishing to sponsor either runner please let me know how much a mile you are prepared to pledge, bearing in mind the Marathon is 26 miles.

A JAPANESE EVENING OF ART AND CULTURE

This has been arranged by the MPS committee and is to be held on Friday 15th April 1983 at Amersham Community Centre. It will include demonstrations in tea ceremony, Ikebana and Kendo. Former British Ambassador to Japan, Sir Michael Wilford has agreed to make the introduction to the evening. All proceeds to MPS.

THE MPS CARAVAN FUND

We are very grateful to Colin and Mary Gardiner who presented the Society with a cheque for £400 to launch the MPS Holiday Fund. This donation was in memory of their own son Richard who died last year after Bone Marrow Transplant treatment.

A GIFT FOR HELEN HOUSE

We have been given a beautiful hand crocheted blanket which we felt would be more appreciated by the children being cared for at Helen House, so we are having a label embroidered accordingly and will present it to Mother Frances on behalf of the Society.

We wish to thank the following people for their generous donations

The Worthing members of the National Housewives Register.

The work colleagues of John Windsor at ECX561 Croydon TSUC.

Worthing Lions Club. Mr and Mrs Randall. Friends of Lisa Wilson. The Young Wives, Worthing. The Young Wives, Bitterne. Mr and Mrs Whittington. Mrs C. Furze. Mrs E. Perfect. Mrs. M. Sweasey. Peter and Maggie Archard. Mr and Mrs Ballard. Mr and Mrs C. Stanley. Mrs Y. Davies. Mrs E. Sharpe. Mrs DLM Golding. Mrs I.J. Glover. Mrs M.E. Salt. Mrs R. Sale. D.O. James. Mrs Joan Sidders. P.P. Jones. C.M. Forde. Mr and Mrs Moran. Mr and Mrs R.E. Stratton. Miss S. Hambury. Mr and Mrs J. Windsor. Mrs E. Budd and Family. Mrs G.E. McKay. Kit & Co Office Acct. Maria Bondi. D.J. Calverley. Mrs A.C. King. E.T. Dixon. Rhona McDonald. Mr H. Leaky. J.A. Skelton. Mrs B. Adams. G.W. Divers. Miss Fox. Mr and Mrs Bennett. The Eva Reckett Trust. Mrs A. Nunn. Mr amd Mrs C. Akle. Blackpool Toy Library Ass.

Our thanks also go to:

Mrs. R. Jones, members of The Worthing Institute and West Durrington Residents Association who went Carol Singing on behalf of the Society.

Mrs Jean Silvey and Glen, and the Staff of Martin Ltd who held raffles.

The Staff and pupils of Davison School who held a Cake stall and participated in a sponsered walk.

Sue Bennett of Blackpool and Lorraine Stanson of Welwyn Garden City who held Coffee mornings in aid of MPS.

Jane and Neil Reid who held a garage sale at their home in Sawston, Cambs.

The pupils of Thomas a' Beckett School who donated the proceeds of their Christmas Carol Service.

The members of Offington Park Methodist Church who held a Children's Christmas Party in aid of the Society.

The fellows at Worthing Treasurer's dept., who on Christmas Eve held a sponsored shave.

Mr Philip Riley who was sponsored on his walk from Warrington to Crewe.

Mrs Skidmore who held a Tupperware Party.