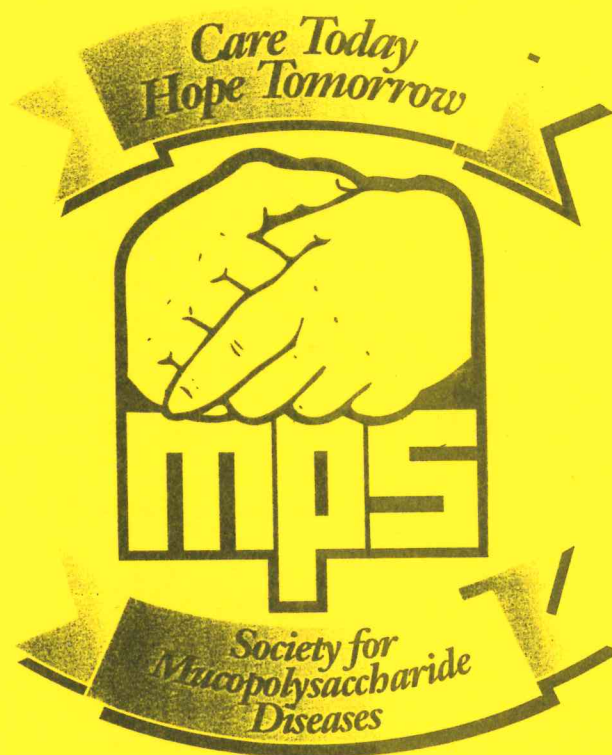


NEWSLETTER

SPRING 1993

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES



National Registered Charity No. 287034

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The Society for Mucopolysaccharide Diseases

55 Hill Avenue, Amersham, Buckinghamshire HP6 5BX
Telephone 0494 434156

The MPS Society is a voluntary support group, founded in 1982, which represents over 500 families in the UK with children or adults suffering from Mucopolysaccharide and related diseases. It is a registered charity, entirely supported by contributions raised by members, and run by the members themselves. Its aims are:

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

The Society operates a network of Area Families throughout the UK and Northern Ireland, who offer support and links to families in their areas. It provides an information service for families and professionals. At the present time it funds a Consultant Paediatric Post and two biochemists, one at Manchester Children's Hospital and one at the Christie Hospital. It encourages and assists contact and co-operation between parents and professionals and maintains links with sister societies in Europe and throughout the world.

There is at present no cure for MPS diseases, but much can be done to improve the treatment and care of sufferers. The slogan of the Society is:

"Care Today, Hope Tomorrow"

Please note new office address, telephone and fax number. Please send all fundraising money and correspondence to the MPS Office: Open 9.00am to 3.00pm, Mon. to Fri.

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**Deadline for Summer Newsletter
Friday 17th July 1993.**

Director's Overview

Although I have only been in full time post for just a few weeks so much is happening. The Society moved into our first proper office at the beginning of March. This is in the centre of Amersham and is a short drive from home.

come and presented a cheque. I hope being in Amersham Town Centre will encourage others to come and see what the Society is about and support us in the future.

Since taking up post Family Support has been uppermost in my mind and I am pleased to say I have already been to visit some of our newly diagnosed families.

By the time you read this Mary Gardiner and I will have made a joint visit to Northern Ireland where we will have met with the Dept. of Health and Social Services, the Northern Medical Board and the Regional Genetics Centre, not to mention the MPS families. I will write more fully about this visit in the next Newsletter.



Fundraising: Kieran and Bernie Houston with their daughter Kiera presenting a cheque to Mary Gardiner from St Ann's School, Strabane.

Our new address is on page one. Setting up the office has been a big task. Thanks to all those who helped with this. I began working full time for the Society from the beginning of April. There are still considerable amounts of

"By the time you read this Mary Gardiner and I will have made a joint visit to Northern Ireland."

paperwork to be seen to but I feel relieved that, with the help of Linda and Ann, much of the urgent backlog has now been dealt with. The Society is now ready for business as usual and hopefully more efficient in our new offices.

Already two mums and three toddlers from Maryland Playschool and St Leonards Toddler Club accompanied by the press have

On the fundraising front may I say a big thank you to all of you who have worked so hard these past months. This is most appreciated and has allowed us to meet in full the grants to Dr Ed Wraith (50% of salary), Lesley Heptinstall (60% of salary) and the whole salary of Ruth McDermott. Lesley is a biochemist working on the MPS DNA at the Willink Biochemical Genetics Unit, Royal Manchester Children's Hospital and Ruth is based at The Christie Hospital, Manchester, working on Gene Therapy for Hurler Syndrome. Thank you to everyone at the Willink and Christie's for their commitment over the past year.

A plea on behalf of our Editor who has the unenviable job of bringing you the Newsletter each quarter. Please please keep sending us your news and views.

Christine Lavery

Family Milestones

New Families

Mr and Mrs Sakina Allana, from Evington in Leicestershire, whose daughter Aasyia, aged three, and son Mohammed, aged one, have been diagnosed with Scheie disease.

Mr and Mrs Armstrong, from Hartlepool, whose son, Michael, aged almost four, has been diagnosed with Hunter disease.

Mr and Mrs Shah, from Wolverhampton, whose daughter Adika Batool, aged two, has been diagnosed with Morquio disease.

Mrs E Considine from near Rochester in Kent, whose brother and sister Tony and Olivia Crowhurst, both now dead, suffered from Sanfilippo disease.

John and Jane Dempster, from Muirkirk in Ayrshire, whose daughter Claire suffers from Hurler disease.

Jean and Terry Hale, from Witney, Oxfordshire, whose daughter Louise age twelve, suffers from Hurler disease.

Tanya and Sean Hookway, from North Bideford in Devon, whose daughter Karrie, aged nine months, has been diagnosed with Hurler disease.

Mrs Jobson, from near Padstow, in Cornwall, whose daughter Marie, aged seven, suffers from Hurler disease.

Anita and David Little, from High Wycombe, Bucks, whose daughter Carrie-Anne, age five months, has been diagnosed with Hurler disease.

Mr and Mrs Mc Cann, from Dublin, whose son John, aged two, has been diagnosed with Hurler disease.

Mr and Mrs Mayhew, from Bungay, in Suffolk, whose son Robert, age two, has been diagnosed with Sanfilippo disease.

Mr and Mrs Parfitt, from Shepton Mallett, in Somerset, whose son Toby, age six has been diagnosed with Hurler/Scheie disease.

Clint and Karen Stevenson, from Harthill Shotts, in Lanarkshire, whose son Martin suffers from Sanfilippo disease.

Mr and Mrs Wali, from Radcliffe, Manchester, whose son Bilal, age three, suffers from Hurler disease.

Births

Congratulations to Jane and Nick Bruce from near Wrexham, on the birth of their daughter Nia Jane on the eight of February 1993. Also to her proud grandparents.

Congratulations to Mr Ravji and Mrs Devbai Varsani on the birth of their daughter Jaya, born on the 30th of November 1992, a sister for Rajesh.

Congratulations to John and Julie Burlison from Oldham in Lancashire on the birth of their daughter Nicolle on the 25th of February 1993. A sister for Billy.

Congratulations to Sandra and Harry Meadows from Latchford, near Warrington on the birth of their son, Joseph, born on the 28th of December 1992, a brother for Emma and Rebecca.

Congratulations to Michelle Watkinson from Colwyn Bay, on the birth of her daughter, Clare Jane, born on the 19th of January 1993, a sister for Michael and Hayley Marie.

Deaths

Marc Dickson, from near Edinburgh, who died on the third of March 1993, aged just under sixteen. Marc suffered from Hunter disease.

Rebecca Dagnall, from near Bolton in Lancashire, who died on the 24th of March 1993, aged just under seven. She suffered from Hurler disease. Her father Peter, died tragically in a climbing accident in 1991.

Ian Trevor Harvie, from Boars Hill, Oxfordshire, who died on the fifth of March 1993, aged twelve. Ian suffered from Sanfilippo disease.

Robert Mahoney, from near Neath, West Glamorgan who died on the 18th of February 1993 aged nineteen. He suffered from Sanfilippo A disease.

Islam Usman, from Crumswell, Manchester, who was born on 2nd February 1993 and died on the 9th of March 1993. He suffered from I-Cell disease.

Our thoughts are with the grieving parents, relatives and friends of all these children and with all those grieving for children lost through MPS diseases.

"The Childhood Wood"

Bitter sweet memories flooded back when MPS families made a poignant journey to Nottingham on Friday 26th February 1993.

Their mission was to plant oak tree saplings in Sherwood Forest in memory of all their sons, daughters, brothers, sisters and grandchildren who have died from MPS.

Over 100 families from all parts of the United Kingdom made the pilgrimage to Sherwood - more than 150 oak tree saplings were planted to commemorate our MPS children.

A permanent memorial.

Environment Secretary of State, Mr Michael Howard inaugurated "The Childhood Wood" by planting a tree in memory of Simon Lavery who had Hunter Disease.

Mr Howard said: "This wood will not only

provide a permanent memorial to Simon and the other children who have died of this dreadful condition, but by living and growing after their deaths it will become an ever strengthening symbol of hope.

And there is hope. The 157 children each remembered by a tree in this wood all made significant contributions to research into MPS in their short lives, and that is now, like a tree bearing fruit.

It is therefore, fitting that the trees planted in their honour are genetically special.

Disabled Access Funded.

Mr Howard then presented a cheque for £2,500 to Andrew, Benjamin and Lucy Lavery to pay for disabled access facilities to the wood.

Christine Lavery.



The Hon. Michael Howard, Secretary of State for the Environment, talks with Andrew, Ben and Lucy Lavery after planting an oak tree in memory of their brother Simon. Simon died from Hunter disease in 1982 aged seven and a half.



Lord Howe, Minister at the Forestry Commission, planting Lee Tilbury's tree. Lee, from High Wycombe, suffered from Hunter disease and died in 1980, aged 12.

"Just a little note to say how much we enjoyed the weekend. We all applauded the time and consideration you and your team must have put into it to make it so successful."

Peter and Pauline Headland, Horndean, Hampshire, parents of Victoria

"Michael and I are sorry not to have been present at the inaugural planting of the 'Childhood Wood'. We are so pleased that you sent us a photo, for which we thank you. We will ever be grateful to the Society for the way in which it made us feel united with other families who alone know the joys and sorrows which comes with these very special children.

Dean was born twenty nine years ago and I can still remember as if it were only yesterday, how lonely it felt, not knowing anyone, apart from my family, who could begin to understand what it was we were going through. Thaks to your invaluable work, no one need ever feel like that again."

Pauline Hammond, West Yorkshire mother of Dean Elland.

"Thank you for your valient efforts on the 26th, which culminated in a delightful if somewhat emotional and poignant day."

Jean Armsby, Virginia Water Surrey. Mother of Julie.

"We plan to revisit the Childhood Wood in the forest next year so that other members of our family can attend. If the Society ever plan such a revisit, we would be interested to hear."

Janet Bailey, Ross on Wye, sister of Richard Church.

"We were privileged to help George and Jill Evans with the tree planting in memory of Paul and Cheryl. The ceremony was a sad one, poignant but uplifting. It made one's heart glow to think of a forest of mighty oaks as a living memorial, being visited by generations of children to come".

John and Mary Stacey, Little Chalfont, volunteers.

Extracts from letters recieved about the inaugural planting of the Childhood Wood.

"We felt really good, being with so many other families with the same memories that we have."

Terry and Ann Makepeace, West Bromwich, parents of Gareth Makepeace.

"We were thrilled to be part of that very special occasion and it was a great privilege to plant trees for these special children".

Larry Thompson, Helen House Hospice.

"Thank you for sending information and a photograph relating to the planting of Susan's tree. May I congratulate you and the other people who run MPS Society on the imaginative and energetic development of the Society during it's relatively short life."

Richard F Walker, Solihull, grandfather to Susan Beal.

"Both Roger and I found it a very moving occasion and we were extremely impressed by the dignity of the event".

Ann and Roger Green, Lincs., parents of Charles Green.

"Malcolm and I will always remember this weekend and plan to visit the Childhood Wood over the years."

Pam and Malcolm Soutar, Shrewsbury, parents of Christine Soutar.

"I was very pleased to be asked to plant a tree in memory of Paul Stanley. I would be grateful if you could send me the address of his parents so that I can write to them. I know where his tree is and I will keep an eye on it over the years."

Sir Andrew Buchanan, Lord Lieutenant of Notting ham.



Robin Hood, with Maid Marian and his merry men returned to the Forest to honour our tree planting, to the great delight of children and adults. Marian looks a little chilly here.

Austin Brady
 Director, Sherwood Initiative,
 Forestry Commission Workshop, Nottinghamshire.

Dear Austin,

I am writing on behalf of the Society and all the bereaved MPS families to say thank you for all your help in making the "Childhood Wood" a reality.

I hope you would agree that everything went very well on the day and that it was a poignant and dignified occasion. Many families have written to express their gratitude not just to the Society but to the Forestry Commission for all their help in bringing about this wonderful project. I should be grateful if you would pass on our gratitude to all the members of your team who worked so hard to prepare the wood and to support our families on the day.

Once again thank you for everything.

Ms. Jill Turner,
 Nottinghamshire County Council,
 Trent Bridge House, Nottingham

Dear Jill,

I was sorry not to have had the opportunity to say a personal thank you for all your hard work, enthusiasm and support in creating the "Childhood Wood". Appreciating that you are no longer at Trent Bridge House I have asked Kim to forward this on to you.

On behalf of the Society and all the bereaved MPS families, thank you very much for your help over the last few months. As a Forester I feel that the contribution you made to the project is not easily recognised by those who didn't know. I personally have learnt a lot in the few weeks we have collaborated on this project and sincerely trust it won't be too long before your skills in the field are properly recognised.

Once again thank you.

Mr Bill Yeo,
 Education Office, Aylesbury, Bucks.

Dear Mr Yeo,

Following our telephone conversation of last week, I am writing to say thank you very much for agreeing to send in your internal mail, one of the enclosed packages to all the Headteachers in the Aylesbury Vale Area.

I am also pleased to enclose for your perusal, the literature enclosed in each package which consists of a copy of our letter to Headteachers, a "Jeans for Genes" information sheet and our publication "An Introduction to Mucopolysaccharide Diseases".

Once again thank you very much for your help.

Mrs Kim Kimberley-Hall
 Nottinghamshire County Council
 Trent Bridge House, Nottingham.

Dear Kim,

I am writing on behalf of the Society and all the bereaved MPS families to say thank you for your help in making the "Childhood Wood" a reality.

I hope you would agree that everything went very well on the day and that it was a poignant and dignified occasion. Many families have written to express their gratitude not just to the Society but to you and Nottinghamshire County Council for all their help in bringing about this wonderful project.

I am of course writing personally to the Chairman and his lady as well as Austin. I am sending Jill's letter care of you. Would you be kind enough to forward it to her as I realise Friday was her last day.

We are compiling a record of all the press cuttings and both you and Austin will receive a copy as soon as it is ready.

With best wishes.

Letter from New Zealand

Dear Christine,

Christmas seems to arrive early each year no matter what events are sent to plague us. However, a welcome time to hear from old friends.

Joanne's year has been one of much suffering and weakening, and therefore the same effect on us. Luckily, we now have the support of a woman doctor, Doctor Rosy.....**Ring-a-Rosy** has taken on new meaning for us. However, medical costs have peaked for us too.

My daughter Janis moved to a new job in August. She is Policy Adviser at the new Education and Training Support Agency (ETSA). A complete break from ecology, but a much needed change and salary increase, and she seems to be enjoying it.

Somehow, Ian and I have managed to participate in a very varied social life, even if we do leave before everyone else - Theatre, Art Receptions, Parties, dinners, a ball, and a very special celebration party in May for our Wedding Anniversary.

Ian's sister came to visit from Canberra and her eldest son Scip (now 21) came separately in June. His visit was a joy - the first time Janis and Jo had met a cousin - a special time for them all, and Scip was especially wonderful with Jo.

I am using every opportunity I can to promote MPS. On the afternoon of our anniversary party we took Jo in her wheelchair to see the hall decorated. (She was too exhausted to attend the evening). She got up with Jenny, her care assistant and with every ounce of energy she could drum up she danced to her favourite album, "Simply Red". You can see her joy and she was so happy for us. I thought her photo would be good for her to see in the newsletter next time. She had her drawing framed by a friend and she was thrilled. Her

chest is pretty bad these days and she seems to get lots of pain.

Next November I will be fifty and I intend to celebrate with a Masquerade Ball on the 30th of October 1993. So, if anyone finds themselves in this neck of the woods, come and help celebrate!

Love,
 Marion.



Joanne Freegard, age 24 (Sanfilippo A) dancing with her friend and care assistant Jenny before her mother's anniversary party.

Marion Freegard is an artist, living in Wellington. She is the organiser of the NZ MPS Society.

Ashley Brown

I have been reading the magazine that we get and I think someone should hear about Ashley. Maybe it will help more children to be diagnosed earlier.

Ashley was born at 32 weeks at a London Hospital. He weighed 4lbs 2oz. and he was fine. I was told that he would have to stay in special care until the day when he was supposed to have been born. Ashley did so well that he only stayed a month. However two weeks after he came home he was back in hospital with a chest infection. This was the start.

From then on he was in and out of hospital every other week. On one of his check ups it was found that he had a large liver and a large spleen. At the time we were very worried as he had already had two operations to repair hernias. He was only about nine weeks old then.

They kept Ashley in for a while during tests, then we had to wait a long time for the results. Finally Ashley was diagnosed at six months as having Sanfilippo, type C.

"All the things that Ashley does are so precious to our memories".

We were stunned. We had always wanted a little boy. We already had a little girl so this was our family complete. But now it felt like we were being punished.

Ashley is now eighteen months old. He is walking and talking a little. He is always up to mischief. All the things that Ashley does are so precious to our memories that even our little girl notices it. After all he has been through, with his asthma, he still can give this great big

smile that for some reason everything seems fine.

We still haven't come to terms with Ashley's condition and I don't think we ever will. But we have learned to cope with it.

I hope that as Ashley was diagnosed so early that a lot more children will be also so that people will have a lot more special moments with their children like we do.

**Ann and Kevin Brown
Stacey and Ashley.**

Marathon Sponsorship Forms.

Please return your Marathon Sponsorship Forms to Ron Snack as soon as possible. Ron needs to check the forms against any money that has been collected.

**Ron Snack,
16 Bradwell Common,
Milton Keynes,
Bucks. MK13 8Bt**

Gregory Coles



Joshua and Gregory Coles. Gregory has Sialic Acid Storage Disease.

to over come difficult problems, of which there can be many.

With the help and support of my family and many good friends, I persevere through the months taking each day as it comes. It was not until Gregory was 14 months old that I stopped bottle feeding him and started to tube feed him. If I had known before how much less stressful to all concerned tube feeding would be, and how quickly he would put on weight, I would have started a long time ago.

Dear All,

I am not really sure where or how to start this letter, especially as I need to keep it as brief as possible.

On 30th May 1991 I gave birth to my first son Gregory. Similar to many of you, I had never heard of **Sialic Acid Storage Disease**, so it was a great shock to find out how poorly he was and that we will lose him.

I found it very difficult finding out any detailed information about Gregory's disease and, it was not until July 1992 that I heard of your society through a chance reading by my mother, of an article in a Woman's Own magazine. My mother (**Deirdre Coles**) is now on the mailing list and I regularly read the newsletter with avid interest. It helps a great deal to find out you are not the only one, and I found talking to **Stella Hale** whose daughter also suffered from Sialic Acid Storage Disease a great help, especially for finding new ways

On 20th October 1992, Gregory had a slight surprise, when a brother arrived on the scene. You can see a picture of the two rascals above. They are a lot of work and many have asked if they are twins, as at the moment Joshua is the same size as Gregory.

Before I finish off I would like to thank everyone who has helped over the past two years, especially my mother and family, **Anita Lathem**, Gregory's Godmother and neighbours of ours, **Rev. Norman Edsall** and his congregation, who generously raised money for the society over the Christmas period and are always keen to hear how Gregory is. Their help and support has given me strength on many occasions in times of need. I wish you all well, my thoughts are with you.

Love,
Alison Coles
Stoke D'Abernon
Surrey

Kym and Dwain Taundry



Kym Taundry, age 9. (Sanfilippo A)

My name is Pauline and my husband's name is Kevin. After three years of coming to terms with the the diagnosis of our two children Kym and Dwain, who both suffer from Sanfilippo A disease, I would like to have this article printed in the newsletter.

Kym was born July 23rd 1983 a healthy baby. Before the age of three Kym had been in and out of hospitals with chest problems. Tonsils and adenoids were taken out and grommets were placed in both ears. Her health visitor thought Kym was just a slow child with learning difficulties. Kym enjoyed singing, playing and helping me. Then gradually Kym was starting to forget words to nursery rhymes that we sang together. She did not seem to want to communicate if I asked her anything. From the age of three to the age of six Kym had less speech and communication, her toileting became poorer and her walking became very unsteady. The consultant had no idea what was wrong with her. Tests on her were just starting.

Dwain was born on the 1st of April 1986 as a healthy boy. Dwain also up until the age of

three was in and out of hospital with chest problems, tonsils and adenoids. He also was making slow progress. One morning after he had woken up I thought he did not look well, his stomach looked very swollen. He was taken into hospital. He had a swollen spleen and an enlarged liver. My consultant asked if he could do more tests with Dwain. When the tests arrived back we were told that Dwain suffered with Sanfilippo type A. Kym was taken into hospital for the day, for the same tests. She too had Sanfilippo A.

I imagine that most people would say that they were shocked and upset when they got the diagnosis. But with my feelings I cried for



Dwain Taundry, age 7, (Sanfilippo A)

several days for both children, but also I felt relieved because it had answered a lot of problems about Kym and why for three years she had not progressed like a normal child.

I have always loved children and wanted a large family. When Kevin and I first met he already had two children and I had one. We had a little boy, Aaron, who was born in 1990 His test results were clear. Most of all, God has given us two very special children whom we all love so dearly, Kym and Dwain.

Pauline and Kevin Taundry

Carl Rogers

I am writing to the newsletter to introduce myself and my family to you all.

My name is **Debbie Rogers** and I live in Hoddesdon, Herts along with my husband **John**, son **Carl**, aged 3, and daughters **Hayley** aged 4, and **Lawren** aged 11 weeks.

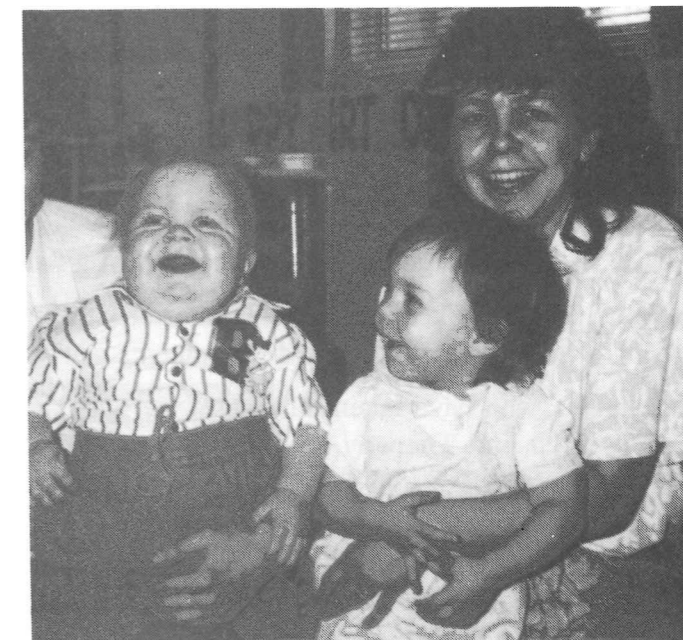
When Carl was seven months old he was diagnosed as having Hunter Syndrome. As members of the MPS society you can imagine the effect this had on us all. The next three months were spent seeing genetic counsellors and doctors at Westminster Children's Hospital with a view to a Bone Marrow Transplant.

After a lot of discussion and deep thought we decided that this was Carl's only chance. We went ahead with the treatment. In January 1991 Carl had his transplant. He was then ten months old. My daughter Hayley was the donor.

Carl eventually came home from hospital in April 1991. He came through the four months in hospital quite well. For three and a half of those months he had been in a sterile unit.

Two years on, Carl is doing very well. Everything is still "wait and see" until he is at least five years old. However he has had very few problems since being home.

To our dismay and that of many others, the Bone Marrow Transplant Unit will not be moving to the new Chelsea and Westminster Hospital when the hospitals are combined, as was previously stated by Riverside Health Authority.



Debbie Rogers with Carl and Hayley

Carl has Hunter disease, and has had a bone marrow transplant.

Surely, something as valuable as this, which gives our people the slightest chance of leading as near to normal a life as possible should not be allowed to be disbanded for the sake of a £?

After speaking to some other parents I decided to start a parent/patient petition to present to the Minister fo Health. Should anybody wish to join this petition, I should be grateful if you would write stating your views on this matter. The letter should be addressed to Virginia

Bottomley, Minister for Health. But please send it to me :

Mrs D Rogers
129 Whitley Rd
Hoddesdon, Herts., EN11 OPS

I look forward to hearing from you,

Jeans for Genes

"Jeans for Genes", is a publicity and fundraising scheme, dreamt up by the ever fruitful mind of Mary Gardiner. Schools are asked to hold a "Jeans for Genes Day". The children (and staff) wear their jeans to school and each makes a donation to the Society. *Mary writes as follows:*

I am writing to congratulate you all on the tremendous response to the Jeans for Genes leaflets. Many families have seen the reward of their efforts as schools are taking up the idea and holding "Jeans for Genes" Days. Please don't feel discouraged if your school has not done a Jeans day yet. Many schools commit themselves to certain charities for either the term or the year. If your school has fixed a date, you could always ask if they would like to do it later in the year. I am happy to write to any school on your behalf, if you ask me to.

At the present time we have written to every family in the Society, and to all schools in Northern Ireland, Nottingham, parts of the Northwest, Blackpool, Liverpool, Manchester and Bolton. We hope to cover all parts of the country where we know there are MPS children. I must say though, that the best way to approach schools is through the personal contact of a family living in the Area.

As we receive updates on research we shall keep the schools informed through a half yearly update sheet. The families will, of course, be informed of new developments as they become known to us.

Another thank you to those families who have taken this appeal to heart and who are busy raising funds in their area for **Gene Research and Therapy**.

Thank you all for being as marvellous as ever and rallying round to help with this appeal.

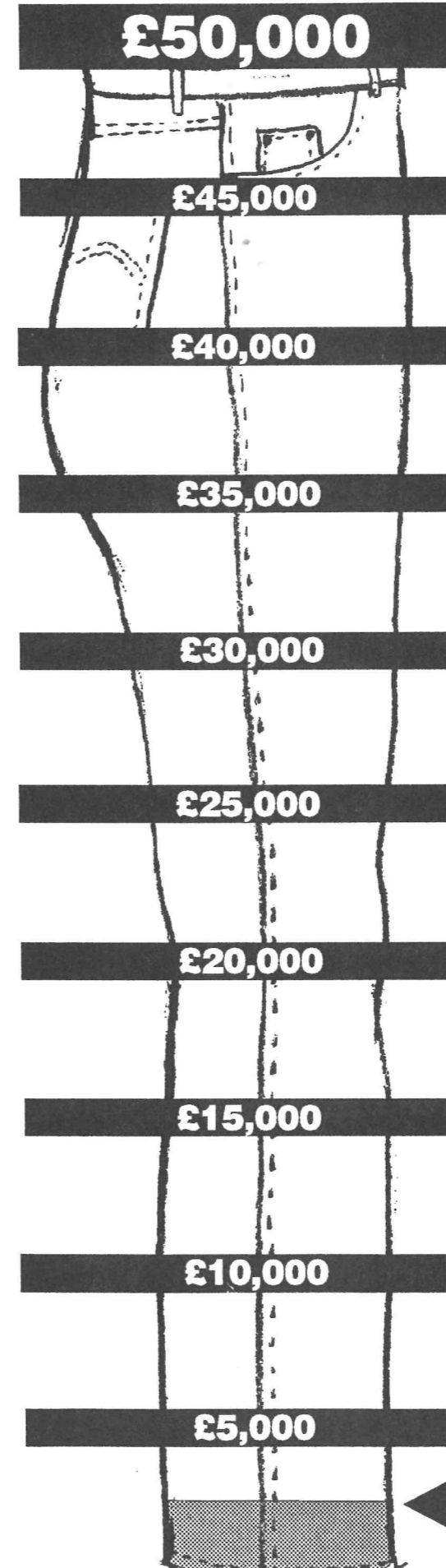
Mary Gardiner. Northern Co-ordinator.

WANTED!
ROBIN HOOD
MAID MARIAN
and WHO?



This proud young man looks like he has just decided on his future career as an Outlaw in Sherwood Forest. Please let us know who you are and we will send you the picture!

JEANS for GENES



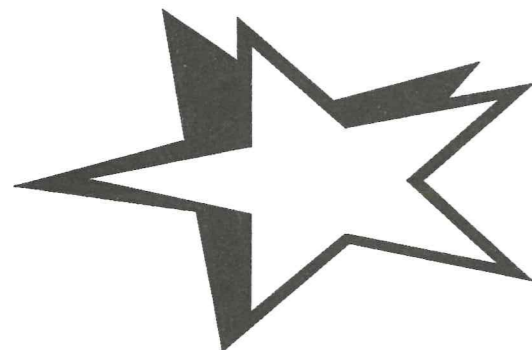
Thank You Schools!

- Wirksworth Junior School, Derbyshire
- St Anne's Primary School, Strabane, Co. Tyrone
- Stainforth Middle School, Doncaster
- Kelvin Grove Primary School, Gateshead
- St Basil's Primary School, Widnes, Cheshire
- Newbridge Primary School, Bath
- The Meden School, Mansfield, Nottingham
- Tarleton High School, Preston
- Coppice First School, Sutton Coldfield
- Weald Centre, Romford
- William Levick Primary School, Sheffield
- Green Park County School, Maghull, Liverpool
- St James' CE Primary School, Warrington
- Spring Cottage Primary School, Hull
- Thomas Barnes School, Tamworth
- Dunluce School, Bushmills, Co. Antrim
- Lowry High School, Salford, Manchester

The amount raised at last count. Lets fill those jeans!

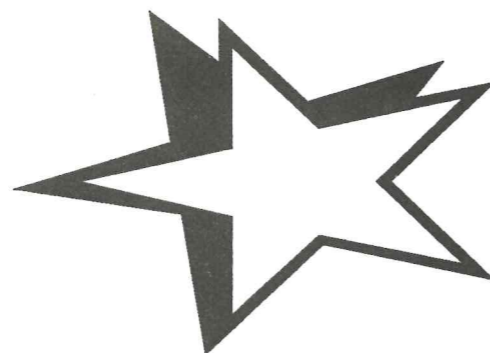
September 1993 Grand MPS Draw

We are back in June!



This years draw will take place in Nottingham, in September. The date will be on the tickets and in the next newsletter.

Tickets for this years draw will go out to all families in June. Further supplies can be obtained from David Briggs.



There are so many large and valuable prizes that they cannot be transported to Stoke-on-Trent to enable the Draw to take place at the Conference!

Promoter: David Briggs, 7 Humber Street, Retford, Notts. DN22 6LZ Tel 07777 00046

Registered under Section 5 of the Lotteries and Amusements Act 1976 with Chiltern D.C. Reg. No. 263.

Deed of Covenant

We are all aware that our economy is still in a very depressed state and this means that the funds reaching the Society are diminishing. To enable the MPS Society to continue to move forward we need all the money we can get and one way at no extra cost to anyone is to ensure that all donations are as tax effective as is possible and the following ways to ensure this spring immediately to mind.

The first is the ordinary Deed of Covenant where a person intends making the same annual donation to the Society for four consecutive years. If you are liable to income tax and make payments under a Deed of Covenant then the benefit to the society increases by a third. For example a Covenant payment of £21 per year for four years costs the donor £84. The Society can claim back from the Inland Revenue £7 a year so the total contribution is effectively £112!

Some people like to give a lump sum and here is where the Deposited Covenant come into play. If a person gives say £60 he can make this one off payment under a Deposited Covenant and again the Society can reclaim the Income Tax which in this example would be a further £20.

For larger sums there is Gift Aid - this can apply to any single gift of £250 or more. On a single gift of £500 the Society can claim back an additional £166.

It is emphasised that anyone who pays Income Tax can benefit the Society greatly by making their donations under one of these schemes at no extra cost to themselves. A simple Deed of Covenant is included along with this Newsletter. If you want any more information on this or the other two suggestions please contact the MPS Office.

Alf King, (Chairman of Management Committee)

This item is repeated from the last newsletter because the Deed of Covenant form was accidentally missed out from the posting.

Grandfather's Fun Day.

My father was coming up to his seventieth birthday and it was proving very difficult to find him a suitable present. Like a lot of people of this age group, he had most of the things he needed.

With this problem still unsolved, he let slip that his birthday would be a good opportunity for a family gathering, combined with a long overdue housewarming party. Good idea, but even better, I thought that all these captive people in a party mood would be ideal to con, ...sorry, sell MPS raffle tickets to.

Well, my father was able to top even that by

generously suggesting that instead of birthday presents he would be delighted to receive donations to the MPS Society. What a great idea.

The party organisation sprang into action. We had a very enjoyable gathering of miscellaneous aunties, uncles, first cousins etc., that hadn't seen each other for a long time. My son Robert was fascinated by all the activity. His presence was of course a reminder of what Hunter syndrome can do. A good time was had by all. What is more to the point £170 was raised for the Society in addition to the raffle tickets sold.

Vivienne Culley

FETE IN AID OF THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

The fete will take place at 2.30pm on

Saturday 22nd May 1993

at the home of **Edward and Holly Nowell "Beryl" Wells, Somerset Tel: 0749 678738.**

Holly Nowell with the help of members of the Wells Ladies Lunch Club will be holding a fete in the grounds of her home on Saturday 22nd May 1993, all proceeds of which will go towards research into MPS Diseases.

The Fete will be opened at 2.30pm by the famous author **John Le'Carre**. There will be various fundraising stalls, music, children's games, tombola, raffle and teas. Edward and Holly would very much like to see as many MPS families as are able to come.

Admission to MPS families - Free

Adults £1.00p. Children and OAPs 50p.

1993 Christmas Cards

Do you run your own Company?
Are you influential in your Company?
Do you have a Company Christmas Card?

If the answer is yes to any of the above questions, perhaps we can help you and you can help the Society. We are in the process of choosing MPS Christmas cards for 1993. We have access to an excellent selection of cards with a wide range of designs. If you would like to consider using one of the designs for your Company card please contact me as soon as possible.

Sue Butler

Spriggs Holly House
Spriggs Holly Lane
Chinnor Hill, Oxon. OX9 4BY
0494 483185

MPS

It's a Knockout

5th of September 1993

The Fun Day and "Its's a Knockout " Competition is now in it's third year. It is held near Clacton on Sea in Essex. This year looks like being the best ever. The local Radio Station Road Show will be there.

There will be sideshows, stalls and Arena events - leading up to the main event. This will be six local pubs doing battle to win the coveted Knockout Trophy.

This year's hosts, Edward and Judy Spall at the Black Boy Public House in Weeley have been working hard with us to organise the events. Local farmer, Frank Lumber, is loaning us his field. We have welcome assistance from local families June, Barry, Karen and Tony Bradley, Mike Francis, Mike and Tracey. Not to forget my husband Tom and the hard work and time he has given. We hope to make this a day to remember, while at the same time raising funds for MPS.

All are invited to attend. The more the merrier! Hope to see you all on the day.

Maureen and Tom Fryer

Goosander, Pillcox Hall Lane, Tendring, Clacton on Sea, Essex.

Phone: 0255 830984

Special Offer

Pale Pink Sweatshirts with logo on left breast. Large and Extra Large.

Special Price while stocks last!

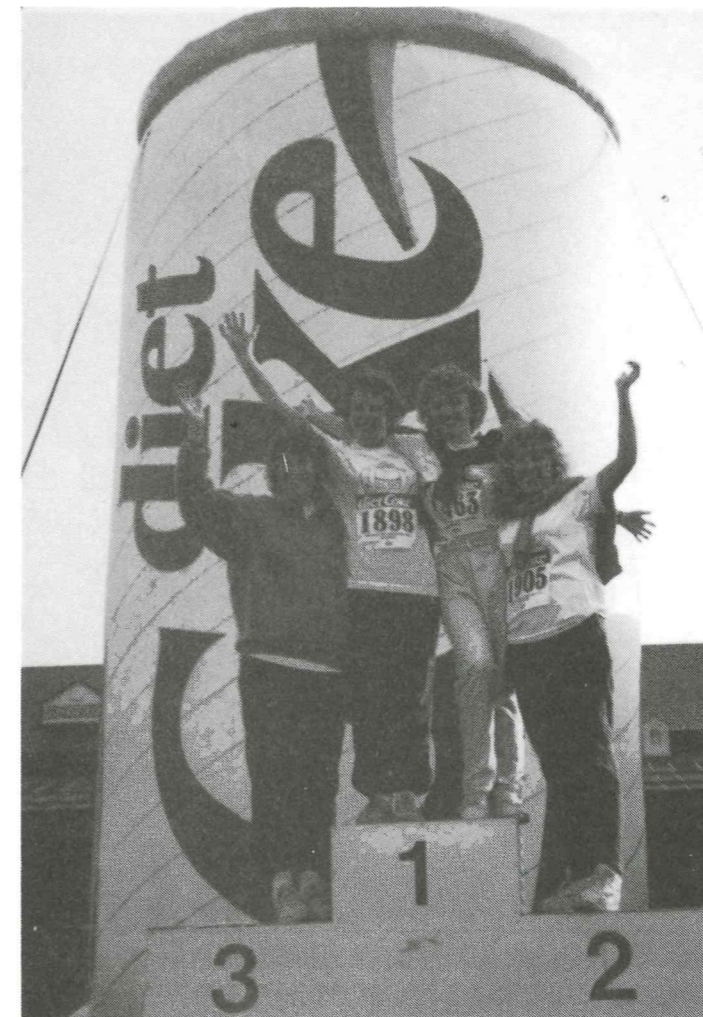
£6.50 including post and packing.

Orders to Sue Butler by 10th May.

Thats the way to do it!

Ann Kilvert from Newtown in Powys, with friends Pam, Nicci and Jane Shrimpton at the Diet Coke London Run in October.

They raised £250 in sponsorship for the Society. They look as if they enjoyed it too. Our thanks to them and to all their sponsors!



Three year old George does thirty laps.

On February 24th, at Fairmile Montessori School, Cobham, Surrey, my little boy George did a sponsored walk. He nominated MPS as his special charity because he has a little friend, **Gregory Coles** who suffers from the disease. George did a valiant thirty laps of the cricket pitch, as did several other children. They raised the magnificent sum of £150 - more than a third of which will be coming to the Society.

George slept well that night, that's for sure!

Helen Dean, Stoke D'Abernon, Surrey.





Becky Dagnall with Mum and Nana, being greeted by Ken Dodd at the turf cutting for Derian House Hospice in 1992. Becky died on the 24th of March 1993, aged seven. She suffered from Hurler disease. Our thoughts are with her mother, family and friends.



Christmas Party at Milton Keynes in 1992. Mrs Chou and son. Susan and Jonathan Fine with baby Gila, Leanne Woods, Rebecca Hardy and others.

Remember

*Remember me when I am gone away,
Gone away into the silent land;
When you can no more hold me by the hand,
Nor can I half turn to go/yet turning stay.*

*Remember me when no more day by day,
You tell me of our future that you planned;
Only remember me; you understand
It will be too late to counsel then or pray.*

*Yet if you should forget me for a while
And afterwards remember, /do not grieve;
For if the darkness and corruption leave
A vintage of the thoughts/that once I had,
Better by far you should forget and smile
Than that you should remember and be sad.*

Christina Rosetti

This is the poem of remembrance read by Catherine Gardiner at the inauguration of the Childhood Wood at Sherwood Forest, Nottingham on Saturday 26th February 1993 in the presence of representatives from over one hundred families who had gathered to commemorate the lives of children who died from MPS diseases.

Are you claiming everything to which you are entitled?

DISABILITY LIVING ALLOWANCE

This combined allowance replaced the former Attendance and Mobility Allowances. It can be paid at four different rates.

- Help with getting around

Your child will qualify if:-

- * over 5 and
- * having difficulty walking.

- Help with personal care

If you are doing more for your child than you would for a child of the same age - e.g. giving medication or regular physiotherapy - you should claim. If your child needs attention during the night as well you may qualify for the higher rate.

You can claim Disability Living Allowance whether you are working or receiving Income Support. Savings are not taken into account.

To apply: Phone Freephone 0800 882 200 and ask for a claim pack.

INVALID CARE ALLOWANCE

If you are caring for someone who receives Disability Living Allowance and if you earn less than £50 per week, you should claim Invalid Care Allowance. It does not matter how much your partner earns. If you receive Income Support, the amount given in Invalid Care Allowance will be deducted but you will still be better off (see under Income Support below.) ICA counts as taxable income.

INCOME SUPPORT

If you receive Income Support, you should find your allowance is increased when you start to receive Disability Living Allowance and Invalid Care Allowance. Income Support is made up of personal allowances and premiums. Check that you receive the following:-

- Child getting Disability Living Allowance - Disabled Child Premium
- Receiving Invalid Care Allowance - Carers Premium

If you are not clear that you receive the correct premiums, ask the Benefits Agency to write to you telling you how your allowance is calculated.

If you have any problems or queries about allowances, ask for help from your local CAB, or ring the **Benefit Enquiry Line** on Freephone 0800 882200. Wilma Robins, MPS Welfare Rights Adviser, is also happy to advise or help. (address on front cover).

The SSBP Intersyndrome Study

What is the SSBP?

The Society for the study of behavioural phenotypes (SSBP) is a group of professionals, doctors, psychologists, geneticists, researchers - who are trying to find out more about how children with different rare syndrome disorders behave.

How did it start?

For many of us this interest began when individual parent support groups approached us asking if we could do some research into their children's behaviour. When we compared our findings it seemed obvious that although some behaviours occurred in several syndromes, some seemed very symptom specific. An example would be the way many Sanfilippo children just seem to crash into anything which is in their way rather than go round it.

We think that many behaviours are part of the syndromes.

We found that although standard textbooks contained descriptions of the physical characteristics of syndromes, they rarely mentioned how the children behaved. For this reason most hands on workers in the field - teachers, social workers, doctors, health visitors, psychologists - knew nothing about these specific behaviours. They assumed they were caused by the "mental handicap" or were the result of poor parental management. Our view is that many of the behaviours are as much part and parcel of individual syndromes as are the well known physical characteristics.

Our aims

We therefore have two aims. We are trying to find effective ways of passing on information about specific behaviours to workers in the field. This is very important in day to day

practice because the educational and management needs of the children with different syndromes are very different. We are also trying to "prove" our point to the wider scientific community.

Differences seem obvious to parents.

Of course it seems obvious to parents and to those of us who are interested in these behaviours that specific behaviours do exist. Children with Sanfilippo seem as different as chalk and cheese to those with tuberous sclerosis even though they have similar IQ and most are very active and sleep very badly. The problem is that most researchers have used different methods to investigate the behaviours so we cannot do direct research comparisons between syndromes. Hence the sceptics say - "the differences aren't real, it is just that you investigated the problems in different ways".

A pilot study.

We now hope to answer this question once and for all by doing a nationwide study of 500 children, fifty from each of ten different syndromes. We are developing a special interview for the study and we will use the same method for all 500 children. We have a Medical Research Council grant to carry out the first part of the study, a pilot project which will last for eighteen months. If that goes well we will then have to get further funding to see all 500 children throughout the UK.

Sanfilippo Volunteers wanted.

We would like to include children with MPS disorders, and particularly those with Sanfilippo in the study and we hope that you may be able to help us. We will concentrate on children age 6 - 12 years. We won't be looking for the fifty children we need until about 1995.

We need some families to talk to.

What we do need at the moment is a few "friendly families" whose children we can get to know, who we can turn to for advice, and who would be prepared to act as guinea pigs for us to try out early versions of the interview - with the parents, not with the child.

If you have a child now aged 6 - 12 and would be prepared to help and live within a reasonable distance of Oxford, London or Brighton, please get in touch with :-

The SSBP Intersyndrome Study Office
Community Paediatric Research Unit
Academic Department of Child Health
Chelsea and Westminster Hospital
369 Fulham Rd., London SW10 9NH.
 Tel: 081 746 8626

If you would like more information about the SSBP please contact:-

The SSBP Office
The Park Hospital for Children
Oxford. OX3 7LQ.
 Tel: 0865 226322.

Dr Jennifer Dennis, Project Director.

If you would like to talk to someone in the Society before contacting the project, more details can be had from Christine, Ann or Linda at the MPS Office.

Genetics Interest Group (GIG)

The meeting advertised on the next page has a very relevant programme. It may be of interest to some families or professionals.

Further details, application form and map from:

Patricia Van Aardt
 Genetic Interest Group,
 c/o Institute of Molecular Medicine
 John Radcliffe Hospital,
 Oxford, OX3 9DU
 Tel: 0865 744002



Jill Sutcliffe presenting a cheque to Mary Gardiner at Nottingham on the 26th of February on behalf of Wirksworth School.



GIG HELPLINE 0865 744002

FAX 0865 222501

GIG IS AN UMBRELLA GROUP OF VOLUNTARY ORGANISATIONS CONCERNED WITH GENETIC DISORDERS
 REGISTERED CHARITY NUMBER 803424

FIFTH INTERFACE MEETING

FAMILY LIFE AND GENETIC CONDITIONS

FRIDAY, 25 JUNE 1993
 11:00 - 4:00
 FRIENDS HOUSE
 173/177 EUSTON ROAD, LONDON NW1 2BJ

CHAIRMAN: DR MICHAEL PATTON
St George's Hospital Medical School, London

(This meeting will be preceded by the Annual Meeting of GIG at 9:30 am.)

- | | | |
|-------------|--------------------------------|--|
| 10:30 | Registration and Coffee | |
| 11:15 | Family Defences | Dr David Craufurd
St Mary's Hospital, Manchester |
| 11:45 | Living with a Genetic Disorder | Vic Midgeley
Von Hippel Lindau Support Group |
| 12:05 | A Sister's View | Barbara Carmichael
Fragile X Society |
| 12:25 | Should Children be Tested? | Lauren Kerzin-Storrar
St Mary's Hospital, Manchester |
| 12:45 | Discussion | |
| 1:00 - 2:00 | Lunch | |
| 2:00 | A Parent's Concerns | Lesley Greene
Research Trust for
Metabolic Diseases in Children |
| 2:20 | Being at Risk | Nicola Paddison
Alzheimer's Disease Society |
| 2:40 | Family Care Work | Shirley Dalby
ATAXIA |
| 3:00 - 4:00 | General Discussion | |
| 4:00 | Coffee/Tea | |

Dates for your diary

- Saturday 22nd of May Fete at Wells, Somerset (page 19)
 Saturday 22nd of May Visit to Kew Gardens (Contact Ron Snack, see back cover).
 28th to 31st May International MPS Conference Essen, Germany.
 5th September Visit to Burford Wild Life Park. (contact Ron Snack).
 5th September "It's a Knockout" Clacton, Essex. (see page 18).
 17 -19th September Annual Conference, Stoke-on-Trent, Staffs.
 12th December Christmas Party, Milton Keynes. (Ron Snack)

Please let me know well in advance about any events that are planned so that they can be publicised in the Newsletter.

I watch you move, I hear you talk.

I watch you move, I hear you talk	I shout and rage to make it clear,
And yet my limbs don't want to walk	But it often falls on stone deaf ears.
I move my mouth to let you know	
Any yet somehow the words don't flow.	I want so much to be like you,
	To laugh and talk and play the fool,
I watch your face to test your mood,	To understand and be understood
Perhaps you think me very rude;	Like everyone in this world should.
But I have thoughts and feelings too,	
If only I could talk to you:	But perhaps I'm trapped in this poor frame
	To teach mankind a simple game,
To tell you, oh so many things,	That love and patience, strength and trust
The joy I feel when I hear you sing,	You all can learn by helping us.
And then, if only I could explain	
The pains and headaches I contain.	

This poem was composed by a Care Assistant and sent to me by Ann Makepeace, mother of Gareth Makepeace, who died on the 5th of August 1991.

The Shaw Trust

The Shaw Trust is a charity which finds employment for people with disabilities. This charity was conceived during the International Year for Disabled Persons in the village of Shaw, specifically to meet known needs of a small group of individuals living in that part of Wiltshire. All were found jobs with employers throughout the county. The individuals thrived and their skills and self-confidence grew quickly.

The host employers found an added quality in their workforce - a greater understanding and a recognition that people with a very wide range of disabilities had much to offer to their colleagues in the workplace. The trust was encouraged to extend its activities throughout England and Wales and into Southern Scotland.

In 1992, Shaw Trust is by far the largest voluntary sector sponsor under the Sheltered Placement scheme. It runs work preparation and job search schemes in **Hereford, High Wycombe and Spalding**. It has eight projects for people recovering from a mental illness

who are ready to make their way back into paid employment.

For all the employees, the Trust offers continuing support both at work, in seeking additional leisure pursuits and holiday opportunities. Advice, guidance and training is available for companies as well.

Throughout the full age range from 16 to 65, the whole spectrum of disabilities, and a very wide spread of skills, the accent is on ability rather than than disability, on achievement and upon social and economic independence.

The Shaw Trust is working in partnership with nearly 3,000 people with disabilities and some 1,800 host companies. If you want to learn more about Shaw Trust's work in your part of the United Kingdom, then please contact:

The Shaw Trust,
Caithness House, Western Way, Melksham,
Wiltshire SN12 8DZ, Tel: 0225 790860.

Spiffing Stationery !

Two of our volunteer helpers, John and Mary Stacey, with their friend Ruth Wood, have formed 'Spiffing Stationery', an enterprise producing and selling a range of beautiful personal stationery for the benefit of the Society. Those of you who were at Nottingham at the end of February will have seen their stand in the hotel foyer and the high quality of their products.

All Spiffing stationery (unlike some similar commercial products), is available in small handy packs which make ideal presents. Larger quantities can of course, also be made on request.

The Notelets can be completely personalised in any way required, with your own special message, text and name of recipient in addition to the address and telephone number.

Spiffing Stationery will be on display at the Conference at Stoke on Trent in September. Meanwhile, enclosed with this Newsletter is a comprehensive descriptive sheet and order form which you may like to use. Spiffing Stationery has undertaken to give to the Society all profits made from sales on our behalf. Please help the Society: place your order today!

Fundraising Events

Men in Charitable Endeavour, Hull.	Evening of Entertainment
Mrs Finch, Bridgewater.	Tupperware Party
Mr and Mrs Lee, Tunbridge Wells.	Collecting 20ps
Jonathan Jones, Heathfield.	Sponsored Anthem Sing
Robin and Mary Gooch.	Book and Make up Party
Peter Stanley, Milton Keynes.	Lunchtime Guitar Recital.
Staff of Group Property, Abbey National.	Christmas Card Collection.
Billy Ingham, Northern Ireland.	Collecting box.
Abbey National.	Matched Funding.
Gateshead Community Health.	Christmas Collection.
Mike Willoughby, Milton Keynes.	Sale of used printer cartridges.
Jackie Rowlands, Nantwich.	Tupperware Party.
Sid Shiff, family and friends.	Sales and Collection
Barbara Watt, Yorkshire.	Sale of Cards.
Ann Kirkpatrick, Northern Ireland.	Collecting boxes.
Mrs T. Pidden.	Collected Copper.
Boots the Chemist, Chester.	"Bosses sponsored walk".
Ann Kilvert.	Diet Coke London Run.
A and P Shrimpton.	Diet Coke London Run.
C J Dean.	Sponsored Road Race.
Amanda Butler.	Sponsored Parachute Jump.
K and P Ballard.	Sold Brooke Bond Tea.
Pam Croghan.	Car Boot Sale.
Mr and Mrs Grandidge.	Collecting tin.
Fairmile Montessori School.	Sponsored Walk.
London Borough of Hammersmith.	Subscription.
M Webb.	Subscription.
J and M Flynn.	Publications.
M Craggs.	Publications.
E Wicket.	Donation
Little Chalfont PO.	Collecting tin.
Lawrence Sherrif School.	Collection.
Heather and Roger Jenkins	Barn Dance.
Carol Westland	Bits and Pieces Sale.
Maryland Playschool and St Leonard's Toddler Club	50/50 Sale
Anglia TV Telethon Trust Ltd.	Fundraised.

Sheila Adams, Ludlow.
BHL Hospitals.
University of Buckingham.
HTV Telethon Trust.
Clifford and Lella Fountaine
P Butler
Nicola Graham/Lynne Kerr.
Burwash C of E School.
Northern Constabulary.
B and D Symonds.
U Timpson.
South Essex Post Graduate
Medical Centre.
R and M Denn.
Dr Lakhsman.
M Naish.
Lindesfarne Primary School,
Gateshead.
Donna Lowther, Gateshead.

*Grateful thanks to all
those listed who raised
money towards the work
of the Society and to the
many others who
contributed.*

*Without your efforts
the work of the Society
would not be possible.*

Area Support Families

Neil and Jane ReidTel: 0223 834570
19 Hillside, Sawston, Cambs. CB2 4BL

Robert and Caroline FisherTel: 0799 86631
The Horrells, Great Samford, Saffron Walden, Essex, CB10 2RL

Alan and Deirdre BeavanTel: 0858 62182
"Tumbleweed", West Gate Lane, Lubenham, Market Harborough, Leics. LE16 9TS

Suzanne and Jeffrey HodgettsTel: 0827 56363
6, Godolphin, Tamworth, Staffs. B79 7UF

John and Barbara ArrowsmithTel: 091 2662999
11 Penfold Close, Fairways Est. Benton, Newcastle on Tyne.

Sean and Pauline Mahon.Tel: 0742 304069
41 Stumperlowe Crescent Rd, Sheffield 10, South Yorkshire S10 3PR.

Mary and Robin Gooch.Tel: 0435 883329
Highbank House, Swifehill, Broadoak, Nr Heathfield, East Sussex, TW21 8XG

Bill and Sylvia Blackburn.Tel: 0270 626809
11 Beatty Rd, Nantwich, Cheshire, CW5 5JP.

Ron and Linda SnackTel: 0908 666819
16 Wandsworth Place, Bradwell Common, Milton Keynes, Bucks. MK13 8BT

Tony and Shirley EyreTel: 0934 834537
6 Westway Park, Yatton, Near Bristol, Avon. BS19 4JU.

Contact for Scottish Families:-

Alan and Fiona Byrne.Tel: 041 6430034
3 Jedburgh Ave, Rutherglen, Glasgow, G7 3EN.

Northern Ireland Co-ordinating Committee:-

Kieran Houston (Chairman)Tel: 0508 884168
15 Barrack Street, Strabane, Co. Tyrone, BT82 8HB.

Margaret Kearney (Secretary)Tel: 026 57 62073
12 Coleraine Rd, Ballycastle, Co. Antrim, BT54 6DU.