

Newsletter



The Society for Mucopolysaccharide Diseases

National Registered Charity No.287034

Spring 99



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- | | | |
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**The Society for
Mucopolysaccharide Diseases**

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The MPS Society is a voluntary support group founded in 1982, which represents from throughout the UK over 900 children and young adults suffering from Mucopolysaccharide and related Disease their families and professionals. It is a registered charity, entirely supported by voluntary donations and fundraising, and run by the members themselves. Its aims are as follows:-

- To act as a Support Network for those affected by MPS diseases**
- To bring about more public awareness of MPS**
- To promote and support research into MPS**

The Society operates a network of Area Families throughout Great Britain and Northern Ireland, who offer support and links to families in their area. It provides an information service for families and professionals. At the present time it supports two specialists MPS clinics at the Royal Manchester Children's Hospital and at the Hospital for Sick Children, Great Ormond Street, London. The Society also funds research projects at the Christie Hospital, Manchester; Royal Manchester Children's Hospital and the Institute of Child Health, London. 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"

*The photograph on the front page is
of Eleanor Gee (Sanfilippo), along
with her sister at the First East
Anglia MPS clinic.*

CONTENTS

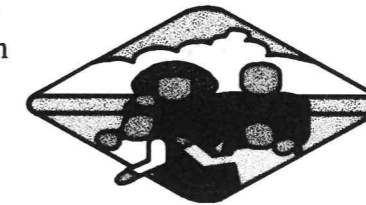
Page 3	Chairman's Report
Page 4	Chairman's Report and Introduction to Regional Development Officer
Page 5	Milestones
Page 6	Area Family Support
Page 7	Family Support – Announcement of First Birmingham MPS Clinic
Page 8	Family Support – First East Anglia MPS Clinic Report
Page 9	Family Support – First East Anglia MPS Clinic Report
Page 10	Family Support – First East Anglia MPS Clinic Report
Page 11	Family Support – Helen House
Page 12	Family News – Poem
Page 13	Family News from Scotland
Page 14	Siblings News
Page 15	MPS Annual Conference
Page 16	Overseas – International Symposium – Austria
Page 17	Overseas – International Symposium – Austria
Page 18	Overseas – German Hospice
Page 19	Overseas – German Hospice
Page 20	Overseas – German Hospice
Page 21	Information – Family experience of gastronomy
Page 22	Information – Family experience of gastronomy
Page 23	Information – Family experience of gastronomy
Page 24	Information – Family experience of gastronomy
Page 25	Information – One Hundred Hours
Page 26	Information – Reduced Council Tax
Page 27	Information – CPAP Mask
Page 28	Information
Page 29	Medical Information – Gene Therapy Trial for Hunter Disease
Page 30	Medical Information – Enzyme Replacement Therapy
Page 31	Bereavement Support – Katie remembered
Page 32	Bereavement Support – Anticipatory Grief
Page 33	Bereavement Support – Poem
Page 34	Fundraising – 3 Peaks Challenge
Page 35	Fundraising
Page 36	Fundraising
Page 37	Fundraising – MPS items for sale
Page 38	Fundraising
Page 39	Donations
Page 40	Area Family Support
Page 41	Area Family Support

**Deadline for the 1999 Summer Newsletter
26th June 1999**

CHAIRMAN'S REPORT

As promised I am using this opportunity to give more detail about the decisions reached by the Trustees in their efforts to enhance support to individuals suffering from MPS and Related Diseases, and their families. These decisions were made after lengthy consultation over many months, and taking into account the findings of the Users Survey carried out in July 1998.

Following discussion with senior staff in their specific work areas, the Management Committee at their meeting on 30th January 1999 voted unanimously in favour of a business plan and the implementation of the following recommendations.



- To address succession planning by appointing an Assistant Director with specific responsibilities in policy and fundraising
- To relocate the Society's advocacy support for Northern England, Scotland and Northern Ireland to the Royal Manchester Children's Hospital
- To relocate all core activities, projects and administration to the Society's Head Office
- To restructure the Society to take into account the changes in responsibility and job descriptions
- To re-evaluate those posts where job descriptions and levels of responsibility were not commensurate with the current levels of remuneration

In reaching these decisions the Trustees were mindful of the Society's total commitment to enhancing support to MPS families and ensuring that the services and activities offered by the

Society are accessible to the increasing number of MPS families seeking the support of the Society,

and must be equitable to all the families. At the same time, the Trustees considered the need to streamline administration and to ensure that costs are kept to a minimum.

With a major commitment to family support and scientific and clinical research the Trustees recognised that more time was needed to secure substantial sums of money to replace the four National Lottery Charities Board Grants achieved three years ago, and which have now ended. It was also necessary to develop strategies to obtain new money to replace several large grants from Trusts which will run out at the end of 1999.

These decisions will enable the Society not only to underpin its current support activities but also to respond to the changing needs of children and young adults suffering from MPS, and their families. In particular the Society is already consulting young adults physically affected by MPS in the planning of an interactive programme for them.

The Trustees are aware that there remains uncertainty among some families over the recent restructure of the MPS Society. The Trustees were disappointed that we had to appoint new staff for the Northern office in Manchester. It is very unfortunate, however, that about 6 bereaved MPS families whose need for the support of the organisation is no longer acute may even be seeking to undermine the work we are doing. In this connection families may have been approached by letters or phone calls asking you to write or attend meetings. We know that this has caused a number of families distress and we are continuing to investigate the possible abuse of the Society's confidential database and to ensure that it stops.

CHAIRMAN'S REPORT

We are continuing to provide a high level of support to MPS families throughout the United Kingdom that includes help with Disability Benefits, Educational Advice, Home Adaptations and Equipment, Medical Management, Carrier Statues, Prenatal Diagnosis, Respite Care, Grant applications and Bereavement support.

I wish to reassure families that we are here for you with practical and emotional support. This has not and will not falter.

Wilma Robins
Chairman



Regional Development Officer

We are pleased to announce the appointment of Ellie Gunary as Regional Development Officer based in Manchester – *Wilma Robins*

I am very pleased to be able to introduce myself Ellie as the Regional Development Officer for the MPS Society. I am already very familiar with the Society having been a member for nine years. Some families already know me, some will know of me. My husband, Paul Gunary had Hunter disease. Paul died in July 1998 at the age of 31. (Our wedding photograph is on the back page of the Hunter information booklet). I also come from a social work background of working with young adults and children with learning disabilities and have a social work qualification.

I have already had the opportunity to introduce myself at two area family days in the north. In April I will be in Northern Ireland to meet families at the clinic and conference and in June I

will be at the Scottish clinic. I look forward to meeting all the families through my work for the Society. Although I will be responsible for family support in Northern England, Scotland and Northern Ireland, I will be working closely with Christine, Hannah, Angela and Sheila from the Amersham office in order to provide a flexible approach to the support offered to all MPS families throughout the United Kingdom.

I am currently part way through my induction. Once this is completed I will be able to provide support unsupervised within the Royal Manchester Children's Hospital and particularly at the clinics. The Society is currently considering three options on an office base in Manchester. I am pleased that I have the opportunity be involved in the decision and that together we can ensure the premises chosen are as accessible as possible and best suited to meet MPS families' needs. In the meantime I have temporary accommodation from which I am able to offer support.

Families in Northern England, Scotland and Northern Ireland may contact me direct by telephone/fax on 0113 2588993 and write to me via the Amersham office. I am really looking forward to all the opportunities this post offers and most of all to becoming part of the MPS support network.

Ellie Gunary
Regional Development Officer



MILESTONES

New Families

Paula and Steve Robjohn live in Rotherham. Their daughter Jordane has recently been diagnosed with Sanfilippo disease and is 3 years old.

Asma and Sharif Seedat live in Leicester. Their daughter Bibi, Aisha who is 1 year old has recently been diagnosed with Morquio disease.

Jack Robinson and his foster mum Fiona Mullins live in Clacton on Sea. Jack has Hunter disease and is 3 years old.

Deaths

Elaine and Stuart Pragnel-White's 8 years old son Liam sadly passed away on the 25th January 1999. Liam suffered from Hurler disease.

Ruth and Barry Simpson's 18 year old son Mark sadly passed away on the 16th February 1999. Mark suffered from Morquio disease.

Susan and Vince Hayward sadly said farewell to their daughter Emily who died on the 1st March 1999. Emily suffered from Hurler disease and was 8 years old.

Claire and Mark Benison's 1 year old daughter Alice recently passed away on the 8th March 1999. Alice suffered from Mucopolidosis Type II.

Mohammed Ismail's 10 year old daughter Rozeena sadly passed away on the 7th April 1999. Rozeena suffered from Maroteaux Lamy disease.

Mr and Mrs Mann's 17 year old daughter Amarjit sadly passed away on the 2 April 1999. Amarjit suffered from Scheie disease.

Tanya and Sean Hookway sadly said farewell to their daughter Kallie who died on the 9th April 1999. Kallie suffered from Hurler disease and was 6 years old.

In Remembrance

Rajesh Varsani who was born on 29 July 1982 and died in May 1997. We all love you and miss you. Mum, Dad, brother, sister and family. (*acknowledging Rajesh whose death was not printed in the newsletter at the time*).

Congratulations

Our congratulations go to Dawn, Mark and Jade Robinson on their new arrival 'Daniel' to the family.

AREA FAMILY SUPPORT

North West Xmas Party

The day started with everyone arriving and settling down in a nicely decorated room around tables. Soon all the families were chatting and the food was served. After the food (that was left out for anyone who wanted more) the children were entertained by Magic Phil, whilst the parents continued to get to know each other. We had a raffle with lots of donated prizes and made a presentation to Bill and Sylvia Blackburn to thank them for all their support help over the years as an Area Support Family. Santa came and the children seemed pleased with their presents. Still not exhausted the children enjoyed more magic and some dancing. The day came to a close at around 5 pm. A good time was had by us all.

Selma Oulton

Dates to Remember

- 9th May North West Family Day
- 30th May South West Crealy Park Outing
* * *
- 11th June Scottish Clinic
- 20th June North West Family Day
- 26th June Nowell's Garden Party-Somerset
* * *
- 4th July Childhood Wood Remembrance Day
- 9th July Birmingham Clinic
- 11th July South West BBQ
* * *
- 10-12 September MPS 17th Annual Conference
* * *
- 8th October Jeans for Genes Day
- 6th October Scottish MPS
Family/Professional Conference
- 21st October Bristol Clinic
- 22nd October Cardiff Clinic
- 29th October Childhood Wood Planting
* * *

MPS Visit to Helen House

The MPS Society is having an open day at Helen House on the 19th May 1999. If any families who are not currently receiving support from the care team at Helen House but would like to visit with a review to using Helen House in the future please do get in touch with Angela in the Amersham office.

East Anglia Families

Coming soon a family barbeque at Paul and Zelda Hilton's. Families in East Anglia will receive invitations in due course.

Does anybody know of shoes that you can get adapted for Hurler children as an equivalent to Pedro boots ?
Write or phone the office with your answers.....

FAMILY SUPPORT

Advance Notice of the First Birmingham MPS Clinic 9th July 1999

I have great pleasure in announcing that for the MPS families living in the West and East Midlands, we have at last finalised a date for the first Birmingham MPS clinic. The clinic will be held at Birmingham Children's Hospital on the 9th July 1999, so please put a note in your diaries. The clinic will benefit those families who live in the following areas;

- Birmingham
- Coventry
- Leicester
- Northampton

Doctor Ed Wraith from Royal Manchester Children's Hospital will be joining Dr Stewart Green from Birmingham Children's Hospital to see the families.

I will be sending out letters with more information to all of the families who live in the above areas in April.

If I do not get to see you before then I look forward to meeting you in July. Please remember that places will be limited so please return your forms as soon as possible.

I also thought it would be helpful to you all to know that I look after the families that live in the following counties. So when you phone the office you will know who will be helping with your problem.

- | | |
|-------------------|--------------------------|
| East Sussex | Hampshire |
| Hereford | Isle of Wight |
| Kent | Leicestershire |
| Midlands | Northants |
| North West Thames | Oxfordshire |
| Staffordshire | South East Thames |
| South West Thames | Surrey |
| Warwickshire | West Sussex |
| Worcestershire | Plus all ethnic families |

Angela Ratcliffe deals with request for support from families in Wales and the following English counties;

- | | |
|----------------|-------------------|
| Berkshire | Buckinghamshire |
| Cambridgeshire | Cornwall |
| Devon | Dorset |
| Essex | Gloucestershire |
| Hertfordshire | North East Thames |
| Norfolk | Somerset |
| Suffolk | Wales |

Hannah Crown – Asst. Development Officer



FAMILY SUPPORT

**East Anglia 1st MPS Clinic
22nd January 1999
The Norfolk and Norwich Hospital
Norwich, Norfolk**

In January the Society held its first MPS clinic in East Anglia.

Christine and I paid a preliminary visit on Thursday 7th January to The Norfolk and Norwich Hospital to meet with Dr Chris Upton, the consultant who had very kindly agreed to host the MPS Clinic.

Dr Upton showed us round and seemed a little bemused at our positive reaction to the setting he was suggesting. We are used to less than perfect hospital rooms, as are most people who work with or in NHS hospitals, so the provisions we were shown at this first meeting seemed tailor made. Lots of space and toys, consulting rooms (other than the ones the doctors were using) for feeding children and talking privately to parents. The nursing staff were all very friendly and enthusiastic which would be helpful in making the clinic a success.



Jade Robinson – Hurler

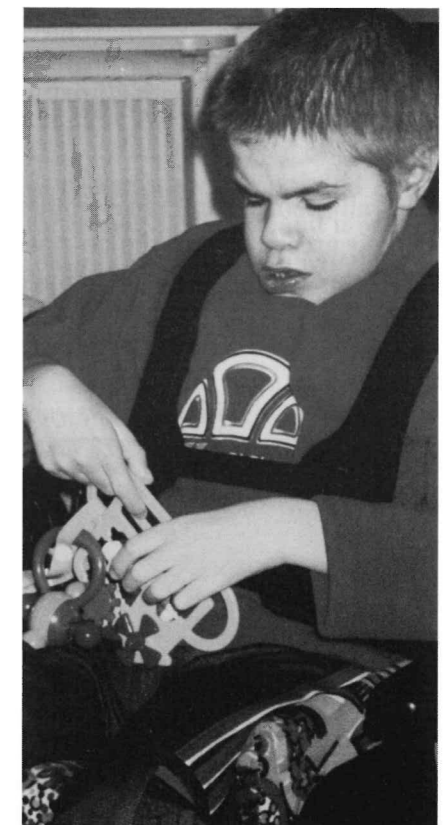


Angela on the left meeting with Robert Mayhew – Sanfilippo and his mum at the clinic

FAMILY SUPPORT

Jeremy Papworth – Sanfilippo

Thomas Thacker – Sanfilippo



I was a little nervous as this was to be my first clinic without Christine to fall back on. If it all went pear shaped I would have to hold my hand up, but after visiting the hospital I felt a little more confident and went back to the office and drafted a letter to the families.

Clinic day soon came round and late on Thursday Sheila and I left work and drove to Norwich. I have a lousy sense of direction and

once behind the steering wheel lose the ability to map read but fortunately it's virtually a straight road all the way so we arrived on schedule. We met up with Dr Ed Wraith, had dinner and stayed the night in a hotel over the road from the hospital as clinic was due to start at 9 am on Friday. Due to the time of year we were worried about weather conditions so as the organisers we did not want to be the last ones to arrive. (Not a very good way to start our first clinic.)

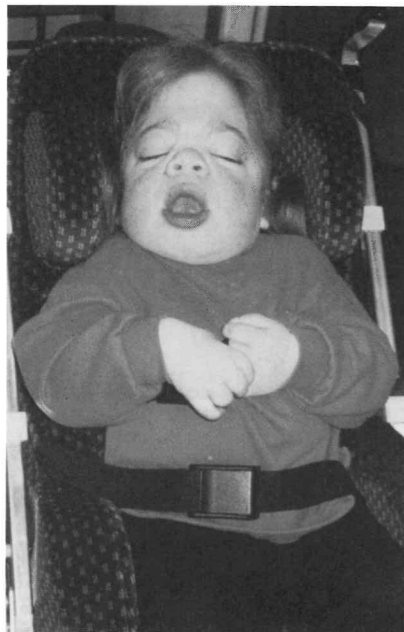
FAMILY SUPPORT

Once families started arriving all our anxieties disappeared and everything went pretty well. We even managed to keep to appointment times (pretty much). It was lovely to meet all the families, some of whom I hadn't spoken to before and some whom I had been introduced to when I visited East Anglia with Christine some months before.

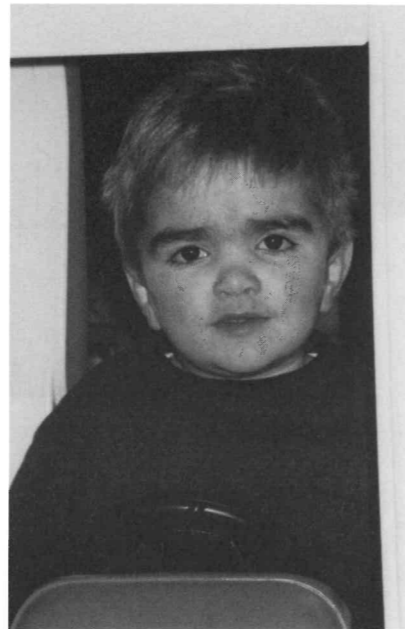
The families all seemed very pleased that we had a clinic in their area and with the co-operation of hospital staff this will become an annual occurrence.

In my opinion our first East Anglia clinic was a great success. We would like to thank all the staff at The Norfolk and Norwich Hospital for making us feel so welcome and we look forward to repeating it again in 2000.

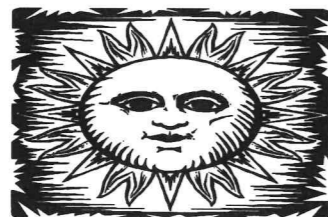
Angela Ratcliffe – Asst. Development Officer



Jessica Stuart – Hurler



Dominic Stimpson – Sanfilippo



FAMILY SUPPORT

Helen House Children's Hospice Oxfordshire

On 23rd March I visited Helen House Children's Hospice in Oxford. Helen House is situated in the centre of Oxford and is set in beautiful surroundings with lovely gardens to walk in and a very happy and friendly black Labrador who loves to be cuddled!!

The hospice offers 6 beds for Palliative or Respite care and 2 emergency beds. It also has two fully equipped family flats that have two double bedrooms. Refurbishment is now taking place in a house opposite the hospice to accommodate two more family flats, the flats will be ready sometime this year.

The hospice has all the usual amenities such as a playroom and multi-sensory room. Helen House also has a beautiful spa pool room that has a mural on the walls of a seaside and it even has a lighthouse with a flashing light.

Helen House accepts referrals from anyone who has the family's consent and where the suitability of the child for hospice care is confirmed by the GP and/or paediatrician.

Mary Thompson is the Head of Care at Helen House and along with her team provides a high level of support to the child and family.

Their address and telephone is as follows;

Helen House Children's Hospice
37 Leopold Road
Oxford
Oxon
OX4 1QT

Tel: 01865 728251

A Week With the Australian MPS Society Representatives

On the 22nd March 1999 Ros Smith and Teresa Llewelyn-Evans arrived in England to spend a week at the MPS Society.

Teresa has recently been appointed President of the Australian MPS Society and is very interested to learn how the British MPS Society operates. The two ladies spent a day in the office observing the work that we do.

On Tuesday we visited Helen House Children's Hospice which was very interesting for Ros and Teresa as they still only have one children's hospice in the whole of Australia. We then set off for Nottinghamshire and the Childhood Wood. As I manage the Childhood Wood it was a good opportunity to check the trees and I am pleased to say they are all thriving and the wood looks lovely with the spring flowers. Ros has a tree for her daughter in the Wood and Teresa planted one for her son.

On Thursday Angela and I had a clinic at Great Ormond Street Hospital and Ros and Teresa came along with us to see how our fortnightly clinic works.

It has been a very interesting week. I hope that Ros and Teresa have gone back to Australia with some more ideas of how the British MPS Society operates and we wish Teresa all the best as she embarks on her new role.

Hannah Crown
Assistant Development Officer

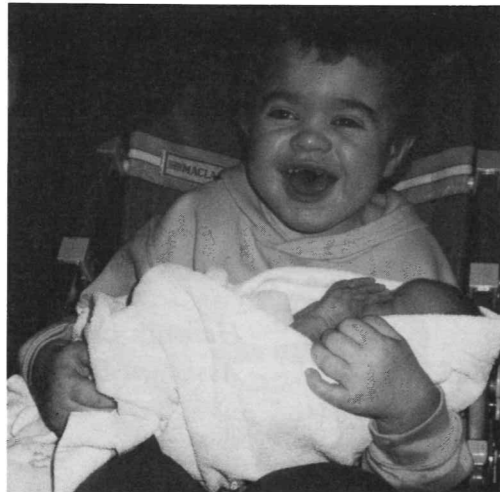
FAMILY NEWS

IT SCARES YOU

Witches and wizards rule the day
When Halloween comes, kids shout 'Hooray!'
It's very weird of me to say,
But Halloween night is really a day!
The sky is black – the leaves are red,
All sorts of scary stuff goes on in your head.
The night wolf howls, the dark dog barks,
People SCREAM, Pumpkins ROAR,
Stuff comes out from behind your door!
People tell you 'It's not that scary'
But there are hundreds of monsters
- some even HAIRY !!!

Look!
There is a rat!
There is a mouse!
There is a cat in that old haunted house!
So don't go to sleep on Halloween night!
That is, you don't want a nasty old fright.
Don't see a black cat!
Or a pale, white dog!
Especially on this night of fog!
It's far too late, I've got to fly
See you soonBye !!!

By
Deborah Boyle Age 9
(Scheie disease)



*Jacob Wragg – Hunter
with his baby brother
George*

FAMILY NEWS

Congratulations to Joanne Evans

*We have recently received this letter from
Provost Nancy Allison JP and thought that you
would all like to read it.*

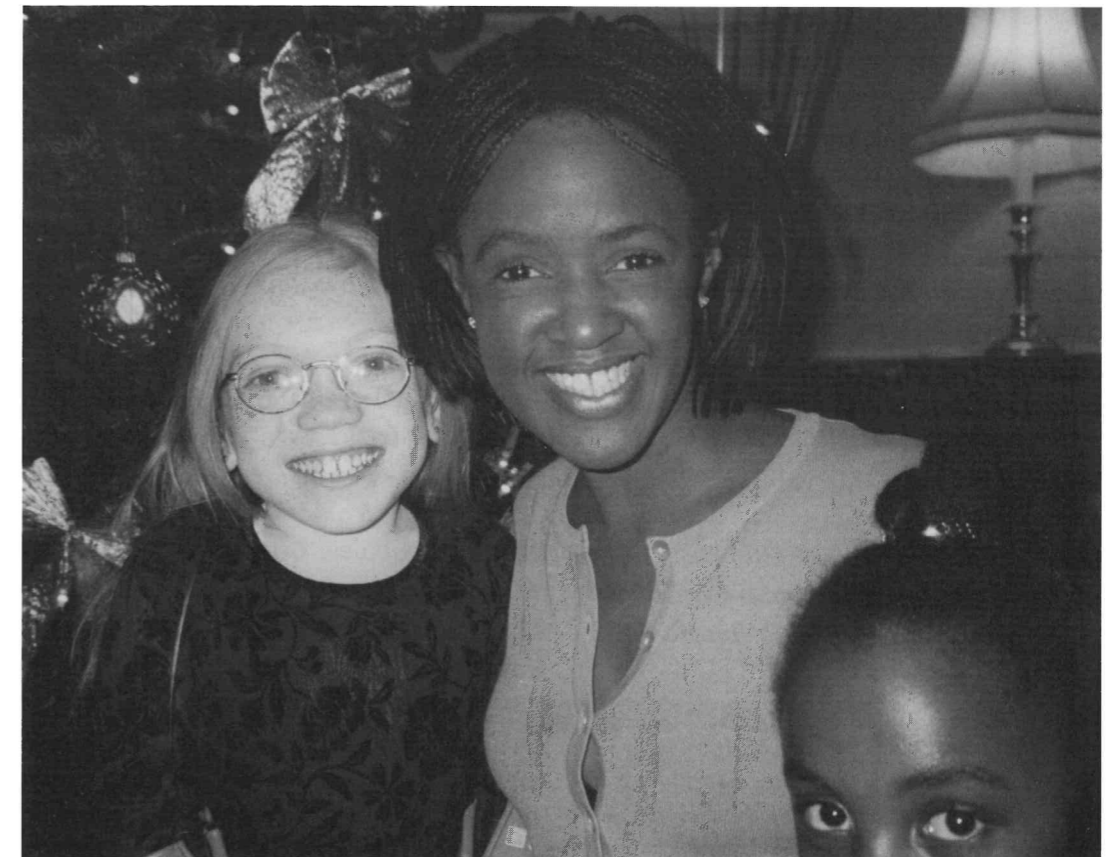
PROVOST COMMUNITY AWARDS 1998/99

As Provost of Renfrewshire I launched the Provost's Community Awards in 1997 and the latest Awards Ceremony took place on Friday 5 January 1999 in Paisley town Hall at which the winners of each award category were announced, after having been short listed by an independent judging panel.

This year Miss Joanne Evans, who resides in the Bridge of Weir, received the award for Special Needs Child.

The winner of each category of award was invited to nominate a charity or organisation to receive a financial contribution from the Provost's Community Award fund and in this instance Joanne choose the Society for Mucopolysaccharide Diseases. Therefore as Provost of Renfrewshire and also as chair of the judging panel, I am delighted to enclose a cheque to the value of £500 which I am sure will be put to the greatest use.

Joanne Evans (Morquio) is pictured below with Diane Louise Jordan at the Downing Street Party at Xmas with Siobhan McLaren-Hall sneaking in.



SIBLINGS NEWS

BROTHERS AND SISTERS I NEED YOUR HELP !!

Yes, I think the time has come for all you brothers and sisters out there to help me put together a siblings' page for future newsletters.

Please write to tell me what you would like in it and send me articles, photos, etc for me to publish.

Anyone good on the puzzles side of things, jokes, individual profiles ???

Anyway I will start the ball rolling and ask any sibling out there to reply to the following questions and then if I get a response from some of you I will go ahead with *your* page.

Sibling Profile:

Name
Age
Nickname if any
Your Pets
Favourite activities; food; bands; videos;
What makes you angry?
What makes you laugh?
Who is your idol?
What funny situation has ever happened to you?
What job what you like to do?
If you could change the world, how would you?
If you won a million pounds what would you do?

*A small photograph of you would
be nice to insert in this space*

COMPETITION TIME

Hello all you budding artists out there, we thought it was about time you sent in some of your wonderful drawings to the office to brighten up our walls.

We have enclosed a sheet for you all to colour and draw on and their will be a small prize for the winners.

To be fair I think that there should be 3 age groups;

Under 5 years old
5 – 11 years old
12 years and over

The winners will be announced in the next newsletter and the closing date will be 31st May.

So get your colouring pencils out and we await to receive all your wonderful posters.

Look forward to hearing from you all -

*Sheila Duffy – Project and Information
Officer*



Please Note

Unfortunately the telephone number that appeared in the last newsletter for you to contact Claire Arrowsmith should have read 0191 292 1234. Claire is very happy to hear from any brother or sister who is feeling down, going through a bad time or who just wants a chat.

MPS ANNUAL CONFERENCE



**The Society for Mucopolysaccharide Diseases
17th Annual Conference
10th – 12th September 1999. Stakis Hotel, Northampton**

There are still a few place left for the MPS Conference at which you can talk to Dr Emil Kakkis and personnel from Biomarin, Genzyme and TKT and learn of the new developments in respect of Enzyme Replacement Therapy as well as hear presentations on many other aspects of caring for children and young adults with an MPS disease.

This year for the first time we have included a satellite seminar on Mucolipidosis. We hope as many families as possible affected by this condition will attend the conference.

If you want to come please book now. The reduced cost of £100 per parent/carer is being held until 20 May 1999. If you have mislaid your conference forms please ring the Amersham office for a replacement.

The Society also welcomes professionals to attend our conference, either for Saturday only or the weekend. If you would like to receive a Conference pack please contact the Amersham office.

OVERSEAS

5th International Symposium on Mucopolysaccharide and Related Diseases Vienna, March 18th – 21st 1999

On 18 March Sheila Duffy, Hannah Crown and myself accompanied by Sarah Long, Jon and Catherine Lawrie and the McKnight family travelled to Vienna for what was expected to be not just an interesting meeting scientifically but without a doubt the first International Symposium to herald realistic new therapies for the treatment of MPS Diseases. We were not disappointed.

Over four hundred and fifty professionals and parents gathered at the Renaissance Penta Hotel to present papers on best practice in the clinical management of MPS Diseases. The British were there in strength clearly demonstrating their expertise. Mr Richard Cowie spoke on 'Management of Craniovertebral Anomalies in Mucopolysaccharidoses', Mr Robert Walker spoke on 'Anaesthetic Implications for Mucopolysaccharidoses' and Lorraine Burnett spoke on 'Care of MPS 1 following Bone Marrow Transplantation'. As you would expect Dr Ashok Vellodi and Dr Ed Wraith were heavily involved in both the parents conference and the scientific programmes. Dr Alan Cooper and Prof. Bryan Winchester presented papers on the biochemistry of MPS.

There were a number of eminent scientists and doctors from around the world including; Prof. John Hopwood from Adelaide, Australia; Dr Chet Whitley from Minneapolis, USA; Prof. Elizabeth Neufeld from Los Angeles, USA; and Prof. Tadeo Orii from Gifu, Japan. All of whom in their own way have made important contributions to the scientific developments and understanding of MPS Diseases.

So what did we learn that is new for MPS? Firstly it was encouraging to see so many representatives from three major pharmaceutical companies Biomarin, Genzyme and TKT who are de-

veloping Enzyme Replacement Therapy (ERT) for MPS Diseases. Dr Emil Kakkis from the USA, who pioneered the clinical trial for MPS Type I (Hurler/ Hurler Scheie and Scheie Disease) demonstrated his results with a video presentation by the children and young adults who have received ERT on the clinical trial, and their parents. Everyone who saw this presentation could not but be moved.

Whilst appreciating that ERT will not benefit many sufferers of MPS, it is of importance that MPS families in Britain have access to this information and that Dr Emil Kakkis has agreed to speak at the MPS Conference in Northampton, 10-12 September 1999.

As a member of the Advisory Committee for the International Symposium I was invited to suggest speakers for the Parent Conference. I am delighted that not only were my suggestions taken up but that Bob and Rhian McKnight who gave a personal experience of Bone Marrow Transplant for their daughter Sarah (MPS I) and Richard and Elizabeth Volk who told of their experiences of gastrostomy feeding for their 16 year old twins, Hendrik and Emily (MPS III) spoke so well. They were a hard act to follow when it was time for me to present the findings of the European MPS Database.

As a young adult who is physically disabled by Morquio (MPS IV), Sarah Long participated in the MPS Adult workshop. There were a number of young adults suffering from MPS in Vienna but unfortunately it proved very difficult for them to communicate with one another, as there was no one to help interpret when they wanted to meet up socially in the evenings.

OVERSEAS

At the Gala Dinner on Saturday evening the Symposium delegates said goodbye to Marian Kraft, (founder of the Austrian MPS Society) and to Jurgen and Brigitte Zumbro (founders of the German MPS Society) who have retired from their work for MPS. It was my pleasure on behalf of the British MPS Society to acknowledge the work of Marian, Jurgen and Brigitte and present them both with a specially engraved goblet recognising their years of help to MPS families in Austria and Germany.

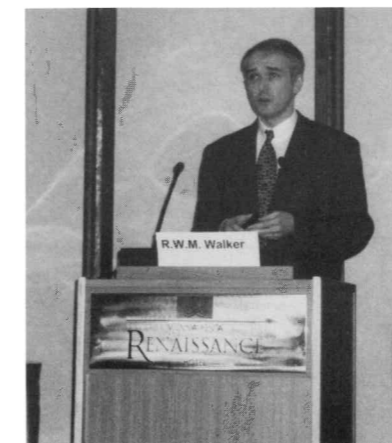
The Conference ended with presentations for the best scientific posters, the announcement that the next International Symposium will be in May, 2000 and not in 3 years time as previously agreed. The British MPS Society accepting the invitation to host the following International Symposium in either Autumn 2001 or Spring 2002.

The Society is grateful to the organisers of the International Symposium and Genzyme for their financial support to members of the British MPS Society attending this Symposium.

Christine Lavery – Director



Sarah Long – Morquio



Rob Walker speaking at the Conference



Richard Cowie speaking at the Conference

OVERSEAS

News from Germany

On a private visit to Germany over Easter, Robin, Benjamin, Lucy and I wee invited to a very special Birthday Party to celebrate the 16th birthdays of Hendrik and Emily Volk who both suffer from Sanfilippo Disease Type B. The eighty guests included many of Hendrik and Emily's MPS friends and their parents as well as carers and family members. Many of you will be able to see this very special birthday celebration on Sky television on the 30th May as part of a documentary about caring for children with MPS. The only problem is you may have to brush up you German !

Some of our time in Germany was spent with Jurgen and Brigitte Zumbro founders of the German MPS Society. After 13 years they have retired and along with their 21 year old daughter, Natalie who suffers from Sanfilippo disease are preparing for a new life in Australia.

Perhaps the highlight of our visit was to the Kinderhospitz (Children's Hospice) at Olpe. Nearly ten years ago we sowed the seed of thought for a Children's Hospice in Germany. We encouraged several MPS parents to visit England and see for themselves Helen House and Martin House. It has taken a long time but in Summer 1998 Kinderhospitz Balthasar opened its doors for the first time. Knowing that the Kinderhospitz was modelled on Helen House we were keen to see the German interpretation. We were not disappointed the architects have done a truly remarkable job combining the best of Helen House with inspired ideas of their own. For anyone at the planning stage of a Children's Hospice a visit to the Kinderhospitz should be high on the agenda.

The address is;

Kinderhospitz Balthasar
Maria-Theresia-Str. 30a
57 462 Olpe
Germany

Tel: 00 49 2761 92 65 41

Below are some photographs that were taken at Kinderhospitz.

Christine Lavery – Director



Open stairway leading from the parent accommodation to the centre of the hospice.

OVERSEAS



Parents entrance to the hospice



Circular landing with parents accommodation leading off

OVERSEAS



Christine Lavery along with Verner Weber, Director of Kinderhospitz.



The hydro therapy swimming pool with patio doors out to the children's playground.

INFORMATION

**Gastrostomy Tubes -
A family experience**

Meal times have always been an emotional event in the Volk household. In earlier years, it was a question of my husband and me trying to defend our own plates and glasses and those of our healthy children from the hands and mouths of our Sanfilippo twins who tended to act at Mach 3 speed. Plates would hurl through the air like frisbees, knives and forks would be stabbed into things other than food, the food itself would regularly have to be removed from walls, chairs, and whatever we were wearing. We had made up a song which we sang as a family at meal times, the refrain being *So everybody look out for your food*. As time went on, Hendrik and Emily became more restricted in their movements and we began to feed our children. This too was an emotional, and often colorful experience at times, but hey MPS parents tend to roll with the punches, right? Then came the stage when the food was pureed into something that always came out rather bland and grey looking, no matter what you had put into the blender before hand. And just when we were beginning to get used to that, the children began to sputter and choke, initially on the liquids and after that, even on the more solid foods, with mealtimes starting to take forever. We began to wonder specifically, how much liquid did I really get into the children, how much food went down, and how much of everything was on the bibs and towels? There was a period of telling ourselves, *It's OK, they're still doing fine so we're still doing fine*. Then came the signals from the schools. (We didn't get much into the children today, you might try feeding them a little more tonight because we had so much to do around here at lunchtime).

Honestly, though, there came a point one day when we realized that the chance of Emily not getting enough to drink or choking and getting food into her lungs was so real that something

would have to be done.

A couple of years ago, feeding tubes were not yet all that common among the affected children. We were great friends with a Tay Sachs child, who had a feeding tube through his nose. It was clear that THAT was out of the question due to the relative activity of our children. But what to do? And what were GASTROSTOMY TUBES, anyhow? I tried to find out about them through the med-line in the United States. Mind you, this was a few years back. I would have been happy if I could have just found a clear definition somewhere which said; *a gastrostomy is a tube inserted into the stomach, by which food and liquid can be directly inserted. Do it*. But what I hit upon was less information about the feeding tubes as an ethical question which ended up costing us a lot of turmoil. Since we today are so happy about the decision we made to have the gastrostomy tubes put in, I would like to bring up this question of ethics, as I think it something all parents need to think about and be at peace with when faced with such a decision. It goes like this. My husband and I have always agreed upon not wanting to do anything which would in any way prolong our children's suffering. But by virtue of the fact that you are able to feed and water your child adequately, your child will probably live longer. And there you have it. Our family solved the dilemma for ourselves by reasoning that we are fortunate to live in a part of the world where everyone has enough to eat and parents are able to feed their children. We feel that as parents, it is our duty to feed our children, and especially to provide them with liquids, as long as possible and for us the gastrostomy tubes are a possibility of doing this. We consider it a right that our children have to be able to receive nourishment as long as they do not tell us expressly that they do not wish to do so, or, in the case of our children, as long as their bodies do not shut down and the tube feeding is rejected.

INFORMATION

At this point, three years down the road with gastrostomy tubes, we are more certain than ever that this was, for us, the correct decision. It has given us valuable time with our children and we even feel that, certainly with respect to eating, it has improved the quality of our twins lives, something which cannot be emphasized enough.

So, the ultimate decision having been made, the Volks set out to find a hospital which would do the operation for the children. The hospital in Bonn, Germany, which had normally taken care of us over the past years, decided that this time they would pass, due to doubts expressed by the anaesthesiologist, though the operation itself would certainly have been simple enough. We were referred to a hospital in Sankt Augustin which had at its disposal the glass-fiber optic intubation method, making for an easier anaesthesia through fairly narrow passageways. What Emily, and 6 months later Hendrik, received was a PEG (Percutaneous Endoscopic Gastrostomy) and the button which is on the outside wall of the children's stomachs, means that we can take off the tube, except for when we are feeding the children. That in turn means that there are no tubes left dangling which could be inadvertently pulled at or swung from by well-meaning siblings. We really like what we have, but let me tell you something. No matter whom I have talked with so far, and I have broached the subject in the meantime with many other parents here in Germany whose children have gastrostomies, each parent thinks THEIR system is the best. And you know what, it probably is. Apparently there are several different possibilities for inserting the tubes, and several different types of feeding tubes. And there are some where you can take the dangling part on the outside off and some where you can't. And there are fat tubes and thin tubes, like the ones we have. When the time comes, you should ask the hospital what they would suggest for your child. Some criteria

which would play a role are, what is my child's general state of health, has the child ever had an operation on his stomach before, is the child's esophagus so narrow that a gastroscopy (the thing the doctors look into the stomach with prior to placing the feeding tube, would not be possible,) etc. Some hospitals use one system of gastrostomy tube and others use another. You just need to know there are different ways of doing things. According to Dr. Bachour, senior surgeon at the Children's Clinic in Sankt Augustin, there is especially one factor of extreme importance. Make absolutely sure that the size of the PEG the doctors will insert into the stomach of your child coincides exactly with the size of the button, if there is going to be one, which will be delivered from an outside distributor not directly affiliated with the hospital, and which will need to be replaced from time to time by you. If these two vital pieces are not the same caliber (and unfortunately, sometimes they are not), then there could be a real problem with leakage and who wants a child with sores around his gastrostomy tube all the time? If you need to know more, there is also the Internet these days where you can go online to gather information, especially plausible as an alternative if your IQ is around 200 and you studied medicine in your life B.C. (before children). Probably the best thing, however, would be if you could corner one of those eternally busy surgeons at the clinic of your choice. I would think that in general, a hospital would suggest the method it knows best and has the most experience with. And at any rate, I would go somewhere else before I would ever try to persuade the hospital to do something they have not previously tried just because you had heard of another child where the procedure had been carried out a bit differently.

After the operation, we used a syringe for a while, injecting the food and liquid very slowly



INFORMATION

into Hendrik and Emily. That was OK but at some point one of the nurses remarked that this was very low-tech and that it certainly would be better to get one of those pumps, which would then consistently pump the food into the stomach at a very slow rate. Well in a hospital surroundings those beepy machines are par for the course, but at home, did we really want to look like a hospital? I'll tell you what shocked me more than anything else. It was the fact that, after the operation, the hospital would even think of releasing such a valuable child with a hole in its stomach and a new piece of equipment besides into the hands of such a mechanically-and medically-inept person like me. Furthermore, horrors, now that I had this piece of hospitalish looking equipment, did we have to live antiseptically at home? Did I have to fumigate? Would I get arrested at some point for poisoning my children? I laugh now but it was scary initially. No, it's true that those pumps really are idiot-proof. I'm so glad we have them.

Back to the feeding tubes, themselves – if your surgeon puts in the kind of tubes our children have, then the button and removeable tubes can only be put on after three months, when everything has sufficiently healed. Until that time, the children have a normal feeding tube, but one which cannot be detached. By the way, as luck would have it, the feeding tubes our twins sport were put in by two different surgeons and there has been ample opportunity for comparison. Emily ended up with an abscess and had to be operated upon twice, but now her tummy button is doing fine. Hendrik had no problems following the operation but his button is more to the side of his stomach, which means that it has to go through more muscle inside and rubs against his clothing sometimes. Both tubes are good, but even though the children have the same type, our experiences with them have been very different. What do you put into the feeding tube once you

have it? Basically, I guess you can put in anything you'd want, probably even gummi bears if you'd thin them with enough liquid. We no longer puree the food we cook for ourselves and put it through the tubes for our twins. We give our children bottled food now. I just feel that I can then assume that what the kids get is a totally balanced diet. This kind of food nowa-days is carefully calculated to make sure a child gets the proper amount of liquid, vitamins, and roughage so that digestion results as optimally as possible. So far, knock on wood, we have never had a problem with constipation. We also know exactly how many calories our children get each day. I must say no one can tell you absolutely before hand how much food your child will need. You just have to try it out as this varies from person to person. Hendrik does well with 1350 calories a day, Emily receives 1200 and still weighs 10 kilos more than her brother! With the feeding pumps, we feed the children 350 - 500 calories over a time span of about an hour and a half for each of



three meals. If you have the feeling that your child feels bloated you can adjust the pump to distribute the food much more slowly. By the way the bottled food is flavored; due to the gases arising from the stomach, the children will certainly know what they are eating children still be able to taste their food. We always flush out the feeding tubes with camomile or fennel tea after feeding. Never forget that children need to drink a lot, more than adults, and that liquids are more important than solid food.

You will probably encounter people every once in a while who themselves feel better if they can stuff a kid with sweets. I have a wonderful photo of Emily with a caregiver at a childrens hospice. Emily is hooked up to her feeding tube, but is being fed ice cream orally at the same time. How nice that is a child is doing particularly well, you can also give meals by way of mouth. But equally comforting to know that you can be sure that

INFORMATION

every bit of medicine you have to give and all the food and liquid your child needs can be given through the feeding tube and will actually arrive where it's supposed to go. Of course, the care of the mouth is more important than ever once you stop feeding a child orally. We brush the kids' teeth and brush out their mouths after each feeding anyhow, just to make sure there is no discomfort from dryness. Concerning the question as to at what stage of a child's life the gastrostomy tube should be inserted, well, that's something each family must decide for itself. Now and then a child will come to the hospital in St. Augustin who has already lost a substantial amount of weight or is severely dehydrated. It may be necessary to feed the child up by IV or nasal tube for a few days in the hospital before the doctors can operate. Again, Dr. Bachour says that if a child is in a stable enough state to be able to get to the hospital, then he can put in the gastrostomy tube, if not always the moment a child arrives. He also points out that in general a gastrostomy tube is a better bet than nasal tube feeding in the long run. First and foremost, a gastrostomy is more comfortable for the child since there is no foreign object in the throat all the time. But also, feeding through the nose is not as clean a procedure as feeding through the stomach—with the non-sterile tubes running past the lungs and through the child's passage-ways, the risk of lung infection is increased. There are, he is careful to point out however, some further things every parent should know prior to having a gastrostomy operation. His statistics show that there are complications at a rate of 20% for gastrostomies. An abscess can form, or there can be a perforation of the bowels/intestines. Even so, 80% of these operations are performed with no complications, and most importantly, Dr. Bachour emphasizes that although they often perform this surgery in Sankt Augustin, a patient has never been lost to the procedure. So there you have it, a gastrostomy is an operation of choice. After three years, I can say,

It was a good choice for the Volks. Showers and baths are no problem. And just imagine, our nearly 16-year-old twins can even go swimming without giving a thought to the little buttons!

Presented by Elizabeth and Richard Volk at the recent Symposium in Vienna.



Emily and Hendrik Volk at their 16th birthday party.

INFORMATION

One Hundred Hours

Who supports the parents?

Our work at One Hundred Hours is based on three basic premises which we know ring true with the vast majority of parents of parents we talk to;

- 1) the suspicion or knowledge that your baby has multiple disabilities and complex needs is a traumatic event.
- 2) parents want immediate services and support for their child
- 3) supporting the parents, as well as the child, benefits their ability to cope and benefits their relationship with their child.

While these premises seem obvious for anyone who has been in this position, support for parents is very rarely forthcoming and the situation is made worse by it taking sometime for services for the child to start. This can leave parents feeling isolated and abandoned once they leave the hospital with their baby or child.

Family support model

We have developed a support system for parents which is currently available for those living in and around West Yorkshire. The system is based on a keyworker (a paid professional attached to the family) who can visit the family in their own homes to offer emotional support and advocacy to help learn about local services, access those services and get the best out of them.

The relationship between the keyworker and the family is based on honesty, trust and confidentiality so providing 'safe' space for the family in which they can discuss whatever they want. The service is entirely parent-led – that is, it is entirely up to the family to decide when they want to see

their keyworker, and how they want to use their time. For example. A parent may simply want to sit down, have a cup of tea and a chat about how things are going, at another time, they may want their keyworker to come along to a meeting about their child to support them in making their case or finding out information, they may want their keyworker to find a specific piece of information about available therapies.

The important thing is that the keyworker provides is entirely independent which can be extremely important for families who are concerned about seeming critical of the services their child is currently receiving. Our work is entirely funded by donations and is managed by a group of trustees who in the main, are parents who have used the services of One Hundred Hours in the past.

Where does the name come from ?

The name One Hundred Hours comes from our practise of offering families two years of intensive support at about two hours a week. Of course, if families want support for longer than this, the keyworker does not simply stop visiting. The door is always left open. Parents can decide to continue using their keyworker, but perhaps less frequently, for example.

A new initiative

We are particularly excited by a new development which is about to take place at One Hundred Hours. We have talked to many parents in West Yorkshire and throughout the UK. One common message is evident – the time when parents really want to know that support is available at the time of the diagnosis or when suspicions are coming to light. To offer this, we are appointing a special keyworker to be placed at Leeds General Infirmary.

This 'Link Worker' will be available in the hospital for any parent who wants an independent person who has the time to talk to them.

INFORMATION

They must just want a listening ear at a time of great stress or they may want information about referral onto other services, including a long-term One Hundred Hours keyworker. We are hoping that this will be a model of support which can be replicated throughout the country.

Wherever you are

Our local family support is not our only concern. We are very keen to generate further debate and discussion about support parents throughout the country. We know that the support a parent receives should not be dependent on where they happen to live. We want to encourage other services to take on support parents as an important part of their work.

Footprints – is a further initiative – it is designed to support groups of parents anywhere in the UK to influence local service providers anonymously and effectively. A One Hundred Hours worker visits the local group of parents to talk about local services and the impact these had on the family and helps the group pass this information on to those involved in providing or designing those services. The idea is that this information can be used to develop services for new families coming along in the future.

If you would like to know more about One Hundred Hours, please do not hesitate to contact me:

Godrun Spencer
One Hundred Hours
83 Silver Street
Kings Heath
Birmingham B14 7QT Tel: 0121 441 1580

How we managed to get our Council Tax reduced !

Angela Seymour having in the last newsletter read the article on reducing Council Tax has sent me this letter that I thought you would all like to read.

Two years ago we approached the local council about a reduction in Council Tax because of David who has Sanfilippo disease.

They arranged for an assessor to call, we had to prove that the home has been adapted to meet David's needs. We don't have an extension, but we have a hoist and the bathroom door is wider than average to allow wheelchair access. They are the only things we have in the home for David. Two week after assessment we were given a reduction from Band C to Band B, which is a difference of £110 a year. Once a year we sign a declaration that we still have a disabled person living with us. On receipt of that letter they continue with that reduction.



INFORMATION

CPAP Mask

I would like to relate our experiences with the CPAP mask and machine. Two weeks ago Joseph (6 years, MPS I) and myself had a brief hospital stay at Princess Margaret Children's Hospital. It did not have the best of starts, as we arrived after school at 3.30 pm. Despite knowing that we booked in for CPAP trial, the Respiratory Technician left at 4.30 pm without fitting Joe for his mask or providing the machine. We sat in our room until 6.30 pm, when finally we were told that she had gone home, so we were also sent home to return the following day. I was very upset because I had geared myself up for what was almost certainly going to be a harrowing experience for us both! We duly returned the next day, this time things went smoothly and the technician arrived at 4 pm with the dreaded apparatus. Joseph was not impressed and let us all know about it! The technician explained how to use the machine and the "ramp button", which increases pressure gradually over 10 minutes and makes the first experience easier to cope with. Now Joseph isn't so fond of hospitals or doctors for that matter and we automatically presumed that the mask fitting and use would be a disaster!! We were wrong, the technician suggested just trying to get him used to the mask first.

I waited until he was very tired and put the mask straight on, no messing about, I pinned down his arms, to stop him from pulling off the mask, turned on the pressure and laid down on the bed with him. He moaned and groaned and winged for about half an hour, but he made no attempt to pull off the mask! He drifted off to sleep and slept the whole night through without waking up once!

The nurse checked his oxygen levels every hour and they were perfect. He slept so quietly I didn't get a wink of sleep all night because I kept having to check that he was still alive!! Things had gone so well that the doctor agreed that we could

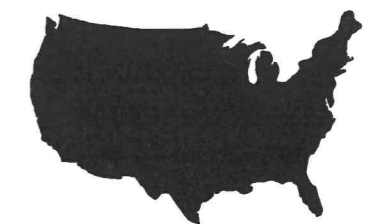
go home that morning and off we went, CPAP machine and mask in hand.

The next night at home was better, Joe only winged for 10 minutes then went straight off to sleep and slept silently all night, no snoring, no coughing. On the other hand I didn't get a wink again, as I was scared stiff the mask would come off during the night but all was well. The mask is very tight fitting and stays put even with changing positions. It is now more than two weeks since our stay and Joe makes no attempt to take the mask off, he sleeps beautifully, however this does not mean that he likes it. He still hates it and he gets worried about it as bedtime approaches but he does accept it and I'm sure it is good for him. Of course I would love not to have to use it but this is a far safer alternative to surgery, which may have limited success.

Unfortunately, poor old Joe still has to endure another sleep study next week as the doctors, in their wisdom need solid technical proof that the mask works for him. This also means another sleepless night for me but I am confident it has been worthwhile. I would encourage any parents in the same position to try the CPAP, it really isn't as bad as it seems (but of course it's not me that has to wear it!)

Barbara Rendell

Taken from the USA MPS newsletter.



INFORMATION

GIG – Genetic Interest Group

Please remember that GIG has moved and their new address is;

Unit 4D
436 Essex Road
London N1 3QP

Tel No: 0171 704 3141
Fax No: 0171 359 1447

Email: mail@gig.org.uk



Orange Badge

Please remember that you can still apply for an Orange Badge even if you are unable to drive and do not own a motor car. If you have a permanent and substantial disability which causes an inability to walk or have a very considerable difficulty in walking. eg. Your relatives or friends can take you about in their motor car. They can use your orange badge as long as the badge holder is a passenger in the car at the time. Contact your local council for details.

HOME ENERGY EFFICIENCY SCHEME

Grants are available to owners and tenants of property in England, Scotland and Wales to have homes more energy efficient.

To obtain information ring: 0800 072 0150

Or write to;
The Energy Action Agency,
PO Box 1NG
Newcastle-upon-Tyne
NE99 2RP

GENETICS: WHAT'S IT GOT TO DO WITH ME
A resource pack for the parents, brothers and sisters of people with a genetic disorder.

This pack has been well received by families and professionals and orders are coming in. If you would like a pack please contact GIG on Tel No: 0171 704 3141, remember single copies are free of charge.

Rates

Individuals	Single copies	FREE
families	Single copies	FREE
Support Groups	Multiple copies	£6.95
Institutions		£6.95

MEDICAL INFORMATION

First Hunter Gene Therapy Trial In the U.S.A.

Earlier this year researchers at the University of Minnesota's Institute of Human Genetics completed Minnesota's first clinical trial of gene therapy to treat Hunter syndrome. Dr Chet Whitley, director of the trial looked for patients to serve as research subjects among Hunter patients whose disease was diagnosed when they were adults. The Food and Drug Administration ruled that the experiment could not be tried on anyone under 18. The patient received his final infusion on January 9th.

The gene therapy approach involves extracting, genetically correcting and re-injecting a patient's white blood cells. During the experiment the patient would go to the university one week-end a month for 12 months to receive treatments with white blood cells carrying the healthy genes. Because white blood cells live for only a few weeks the treatment had to be repeated at least once a month. It is the first of its kind in the world for patients with Hunter syndrome, a rare inherited disorder caused by the lack of an enzyme necessary to break down complex carbohydrates in cells. In its severe form, it can cause progressive brain damage and death before age 20. The patients, who was the first patient to enter this trial, has a relatively mild form of this condition.

The patient donated white blood cells in October 1996 at the University. Monthly throughout 1997, a small portion of his cells were thawed and mixed with the gene therapy 'vector' - a harmless virus engineered to transfer a copy of the normal gene into the patient's cells. The cells then begin to manufacture the normal enzyme. After these cells were genetically corrected, they were administered to the patient intravenously, much like a conventional blood transfusion. The

process was repeated monthly for approximately one year because white cells have a short life span.

'This week's infusion completes the treatment phase of this study and had demonstrated that the procedure is technically feasible and appears to be safe', said Dr Chet Whitley, the trial director. 'Whether or not the gene therapy procedure will be effective remains to be determined and will be determined by on going monitoring of the patient'. The trial is funded in part by the National Institutes of Health.



The patient, a 47 year old elementary school principal, said that although the monthly flight schedule had been a challenge, he would gladly participate if the Institute conducted further research. He referred to his part in the trial 'as being just a drop in the ocean'. He will return to the university periodically for tests to show if he still has some of the healthy, genetically engineered cells in his blood, and if the treatment affected his syndrome.

Mr Whitley also plans to experiment with someone with Hurler syndrome this year. In this case instead of correcting white blood cells, they will correct stem cells, the seed for bone marrow.

Taken from the Canadian MPS Newsletter

MEDICAL INFORMATION

Enzyme Replacement Therapy for MPS 1

In late autumn 1998 Genzyme General and BioMarin Pharmaceutical Inc. reported substantial improvement patients treated in a clinical trial using -L-iduronidase. The results were presented at the American Society of Human Genetics annual meeting. The trial culminates thirty years of research and marks the first time enzyme replacement therapy has been used effectively with MPS 1 patients. It involved ten patients in a twenty six week treatment protocol after establishment of a clinical baseline. Over time the treatment reduced live size, with most patients having normal liver size by twenty weeks. There was also evidence that the enzyme successfully broke down the complex carbohydrate materials which accumulate in an MPS 1 patient. There was significant improvement in physical ability and quality of life and stamina with eradication of symptoms such as headache and vomiting after a few weeks of therapy.

All trial patients will continue to receive therapy with evaluations at twelve and eighteen months. The US FDA has designated -L- idurondidase a "fast-track" product. BioMarin received ORPHAN DRUG designation for the enzyme in September 1997, potentially giving the product market exclusively for seven years following FDA approval.

Copied from the RTMDC newsletter with their permission.



A Pen Pal Wanted

We have received this letter from Húlya Akkaya from Denmark and she is hoping that someone would like to write to her.

Hi, My name is Húlya and I am 16 years old. I am living in Denmark and my parents come from Turkey. My disease is Hurler Scheie mucopolysaccharidose. I am looking for a girl having the same disease to by my friend. I would very much like you to write to me on my E Mail:

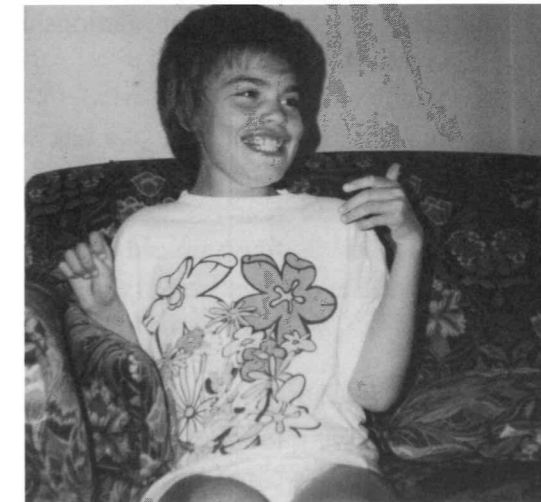
Húlya.Akkaya@Tovshoejskolen.dk.

My home address is:

Húlya Akkaya
Vester Ringgade 188, 3 tv
8000 Arhus C.
DK - Denmark



BEREAVEMENT SUPPORT



Katie

Patient, Katie sits and listens,
Watching eyes wide,
With pupils that glisten.
And then I see, the faintest smiles,
Her lips spread thin,
For the shortest while.
Life is short, as we all know.
And, from time to time,
We all must go.
To this world, you bid farewell,
As now in eyes,
Salt waters swell.
Yet I'm happy all the while,
I recall, the time I saw,
Young Katie smile.

Katie Vivier suffered from Sanfilippo disease and passed away last May. Her escort on the school bus Julian wrote this poem about her.

BEREAVEMENT SUPPORT

Bereavement – Anticipatory Grief

Anticipatory grief is the grief that begins before death, which the news of a fatal diagnosis, whether for oneself or for a beloved person. A dying person is a grieving person; the family and friends are grieving persons. Anticipatory grief is experienced much as grief is experienced after death, with denial giving way to disorganization and acceptance. But there are differences, and usually denial lasts much longer than it does in the news of a death.

People have often interpreted Kubler-Ross (on death and dying 1986) to mean that persons move or ought to move through the stages of dying, from denial through anger, bargaining and depression, to finally acceptance of death, but professional have observed that a 'smooth', progression doesn't actually happen for their patients. Instead, denial operating as optimism and hope for a cure alternates with periods of despair and depression; acceptance of terminality comes and goes. If a person looks healthy, denial is easily maintained and is useful as long as reasonable hope can be retained. Denial then is appropriate until the end, for some people. However, when denial has been maintained until death, the first reaction for the survivors is shock. In short, knowledge about an impending death does not necessarily mean acceptance has been reached by the time the death occurs.

In any grief process the dying person or loved one must detach emotionally from significant relationships, for acceptance to follow. If the dying person detaches from friends and family before death, wishing so spend last days in solitude, wishes should be honoured and not viewed by survivors as rejection of them.

But when the converse happens: When family and friends complete their 'psychological burial'

of the patient before he dies, as can happen in a long decline, then it is the patient who is truly bereaved. He or she has been deprived of several important relationships; the survivors have only lost one.

If a family can talk with a dying patient about the illness, grieve together about expected loss, can reach some agreement for meaningful ritual, can finish up old business (I'm glad we had this life together – I'm sorry I said ...) there may be little grief work to do after the death and little sorrow remaining. Speedy second marriages are sometimes misunderstood by outsiders and seem callous acts when in fact; all concerned may have cared enough about each other to have opened the subject. 'Permission' may have been given to the family by the dying person for an emotional re-investment to be made and expressed.



What makes it difficult to grieve ?

We live in mobile, uprooted society in which frequent moving and changing

shrinks a person's circle of personal, intimate and supporting relationships.

Society puts pressure on us to heal quickly – like two weeks after the funeral. Usually this is because people are uncomfortable around those who grieve.

Many people have grown up in an environment in which grieving was unacceptable. At the time of major loss it is easy to keep the accompanying feelings inside.

Some losses are socially unmentionable. This means that some people never share their loss with anybody. The most common inhibitor of

BEREAVEMENT SUPPORT

Grief does not know what to expect. What are normal reactions to a loss?

How should you feel ?

Article taken from the Australian MPSnewsletter



The following poems taken from 'The Compassionate Friends'

You Know You're Making Progress When

- You can remember your child with a smile.
- You realise the painful comments others make are made in ignorance.
- You can reach out to help someone else.
- You stop dreading holidays.
- You can sit through a church service without crying.
- You can concentrate on something besides your child.
- You can find something to thank God for.
- You can be alone in your house without it bothering you.
- You can talk about what happened to your child without falling apart.
- You no longer feel you have to go to the cemetery every day or every week.
- You can tolerate the sound of a baby crying.
- You don't have to turn off the radio when his or her favourite song comes on.
- You can find something to laugh about.
- You can drive past the hospital or that intersection without screaming.
- You no longer feel exhausted all the time.
- You can appreciate a sunset, the smell of newly mown grass and the pattern of a butterfly's wing.

Tears... ..

There is sacredness in tears.

They are not the mark of weakness but of power.

They speak more eloquently than ten thousand tongues.

They are messengers of overwhelming grief, of deep contribution and of unspeakable love.

FUNDRAISING

'Racing Against Time' - 3 Peaks Challenge in aid of the MPS Society 11th - 12th June 1999

Sister Tracy and 3 of her not the fittest of friends have decided to try to raise monies for MPS. This will involve climbing the 3 highest peaks in the British Isles; Ben Nevis, Scafell Pike and Snowdon - within 24 hours! This will take place over the 11th and 12th June 1999.

Training has begun!

At first they appeared to think this should take place in the local pub! However pangs of conscience, panic and pressure from brother Andrew and father Peter, have now resulted in some serious, if somewhat painful training!

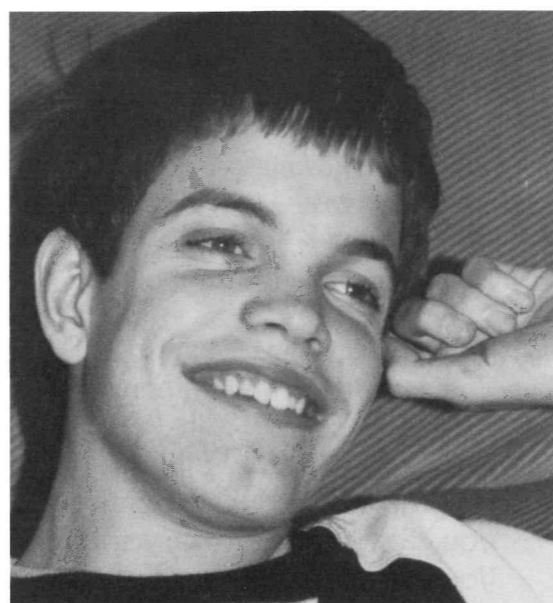
The 'gang of four' attempting the challenge are Tracy Hawkins (sister of Andrew Hawkins who suffers from Sanfilippo disease), Jonathan Goldsmith, Stuart Pond and Clive Baughan.

Three of the four went skiing in February. Stuart returned with a dislocated shoulder and Jonathan with pulled knee tendons. However, unperturbed, Jonathan and Tracy returned to the slopes at Easter whilst Stuart stayed at home to continue his good rate of recovery.

To achieve their goal a considerable amount of organisation, practise and training will be required. Anyone willing to help with driving, organising, marshalling, orienteering training, equipment, sponsorship and back up teams should contact Tracey on the numbers provided below.

The Challenge hopes to raise much needed funds for causes dear to our hearts. Please help in any way you can.

The team aim to complete the Challenge mid



afternoon on Saturday 12th June at the summit of Mount Snowdon, Wales. Supporters are most welcomed to join in the celebrations there and later that evening at a local pub with function suite and accommodation.

Tracy can be contacted on:

0118 966 6112 (home)
01344 727458 (work)
0468 551457 (mobile)

or alternatively write to her at 26 Maiden Lane Centre, Lower Earley, Reading, Berks RG6 3HD

Hawkins Family

Enclosed in this newsletter is a sponsor form to enable all our families to collect sponsors in support of the '3 Peaks Challenge'. All the money raised on these sponsor forms will go to support MPS children and young adults, and their families.

FUNDRAISING

Tracey and her team have secured considerable commercial support for this event however they would welcome help from anyone who would like to act as marshalls or who would like to be in the welcoming party on the top of Mount Snowdon. (There is a train that goes to the top!!) Please try and support Tracey and her team as well as the Society by collecting sponsors for this event as you can.

The Summer newsletter will tell you of how Tracey, Stuart, Clive and Jon's 'Race Against Time' went.

Please send all money and sponsor forms to the Amersham office.



David and Monica Briggs receiving a cheque for £960 for funds raised at a Pie & Pea Supper dance in Scunthrope organised by Gemma's Aunty, Susan Mansfield (right of photo) from Mark Nicklin of Rock this Town Band.

CHARITY FLOWERS DIRECT

The MPS Society receive 15% commission from
Charity Flowers Direct.
Please remember to quote the
Charity Source code MPS
when placing your order.
Tel: 0990 300 600
(leaflet enclosed with the newsletter)

FUNDRAISING

I thought I'd share with you a lovely way our Family managed to fund-raise.

Our daughter Katie was diagnosed as having Hurler in November 1996. About January 1997 we started having bright new £1 coins in our change. They were 1996 £1 coins so we decided to collect them for 'Katie'.

By the end of the year we had about £94 collected in a jam jar and handed them over to Peter Stuart (a Trustee) when we went to see his family.

Lyndsey Devine

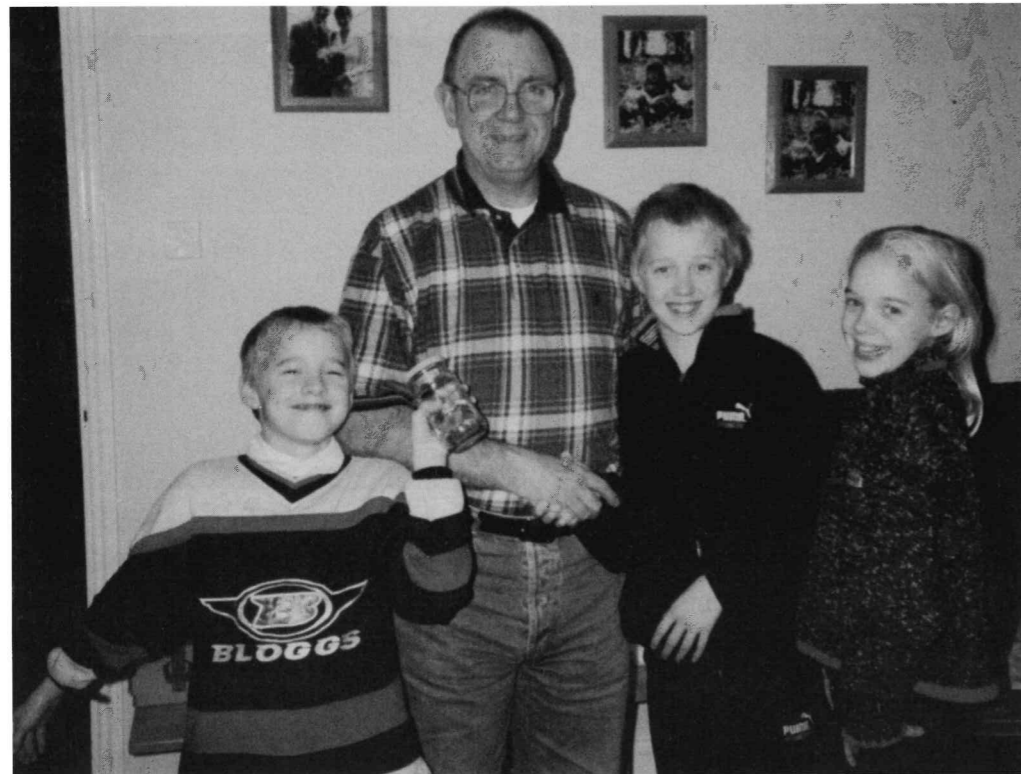


Photo above of Peter Stuart receiving the money jar from Katie's brothers and sister. Gary, Andrew and Laura.



FUNDRAISING

MPS GOODS FOR SALE

Please remember that The Society has a wide range of very good quality polo shirts, sweatshirts, rugby shirts etc in various colours, with an embroidered MPS logo. If you would like to place an order please contact Sue Taylor at the Amersham office who will be able to help you.

Adult Sweatshirts	£13.50	Adult Rugby Shirts	£20.00
Adult Polo Shirts	£12.50	Cotswold Jackets	£ 30.00
Adult t-shirts	£ 8.00	Children Sweatshirts	£ 8.00
Children Polo shirts	£ 8.00	Children t-shirts	£ 4.00
White caps	£ 0.75	Car Sticker	£ 0.50
Blue Pencil cases	£ 1.20	Key Fobs	£ 0.65
MPS pens	£ 0.30	Hologram Pens	£ 0.35
Blue plastic badges	£ 0.25	MPS Enamel Badges	£ 1.95
Pencils	£ 0.25	Rulers	£ 0.80
Bookmarks	£ 0.80	Erasers	£ 0.40
Ties	£ 5.00	Umbrellas	£ 4.00



FUNDRAISING

FUNDRAISING EVENTS

The Society is grateful to the following who held fundraising events

Flixton Infants School - Fun Run
 Pam and Ken Ballard - Sale of Sherry
 Stephen Eddy - Collection in lieu of leaving present
 Chris and Julie Kembrey/Marina and Dave - Car Boot Sale
 Des Pidden - Saving Pennies
 Marianne Stimpson - Charity Catalogue
 Margaret Byworth - Holding a Luncheon
 Thames and Solent - Charity Events
 90 (HQ) Squadron - Christmas Function
 Mrs Gibbons - Selling Marmalade and Fudge
 Ken Ballard - Christmas Stocking/Foreign Coins
 Abercorn Bar - Charity Nights
 Swindon Village Primary School - Fundraising
 White Lion Inn - Loose Change Bottle
 Alan Byrne - Dance and Raffle
 Carol and John Westland - Woodley Winter Extravaganza
 Stewart family - Copper Collection
 Toni Hall - Bungee Jump
 Oddballs Golfing Society Charity - One Day Fundraising

IN MEMORY

Gary Windsor's Grandad
 Olivia Bailey
 James Fisher
 Nanna of John-Peter Hodgetts

COLLECTION BOXES

Focus and Fitness
 Hamilton Wright
 Sid and Betty Shiff
 Pat Lomas
 Emily Hayward

STAMPS

Kilkeel Primary School
 DVLA
 Mr and Mrs Simmons
 Karen and Andrew Weedall
 Mrs Henderson

DONATIONS

The Society is grateful to the following who made donations

Fitton Trust
 C.M.L. Jones
 Jenny Hardy
 Miss Weston
 Mrs Cavill
 Rev. Ian Friars
 Mrs Callaghan
 Mrs Iles
 Marion Ellwood
 Briars Hall
 Independent Insurance
 Margaret Byworth
 Unisys
 First Manchester
 Doreen Small
 Patients at A Mellor & Associates
 Millers Wine Bar
 Target Newspaper
 Jack Stuart Fund
 Mr and Mrs Meaker
 Clydebridge Steelworks
 South Birmingham Ladies Bowling League
 Highland Distillers
 Westminster Abbey Choir
 M J McTiffin
 June Phillips
 St Mary Haxby
 Karen Weedall
 Guardian Royal Exchange
 Margaret Broughton
 Lodge of Silent Temple
 Atlantic Foundation
 Bakers World Travel
 Finchley Reform Synagogue
 Sovereign Healthcare
 Renfrewshire County Council
 St Joseph's Church, Lancaster
 Blair Foundation
 Book Club Associates
 Helen Parry - Children's Charity
 Nycomed -Amersham

AREA SUPPORT FAMILIES

EAST ANGLIA

Julie Thacker
20 Herolf Way, Harleston, Norfolk IP20 9QA
Tel: 01379 854204

Zelda and Paul Hilton
17 Stanley Drive, Sutton Bridge, Nr Spalding, Lincolnshire PE12 9XQ
Tel: 01406 351524

HOME COUNTIES

Rachel and Mark Wheeler
26 Tamarisk Avenue, Reading, Berkshire RG2 8JB
Tel: 0118 9541293

MIDLANDS

Sue and Jeffrey Hodgetts
6 Godolphin, Tamworth, Staffordshire B79 7UF
Tel: 01827 56363

Zerina and Sajjad Shah
37 Lowe Street, Wolverhampton, West Midlands
Tel: 01902 656147

Doreen and Monty Russell
71 Templemore Drive, Great Barr, Birmingham, West Midlands B43 5HF
Tel: 0121 6864779

NORTH EAST OF ENGLAND

Barbara and John Arrowsmith
11 Penfold Close, Fairways Estate, Benton, Newcastle on Tyne NE7 7UQ
Tel: 0191 280 1368

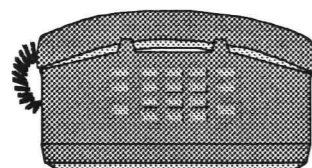
Ann Thompson
7 Sunningdale Green, Darlington, County Durham DL1 3SB
Tel: 01325 254985

Elizabeth and William Armstrong
7 The Crescent, Hartlepool, Cleveland TS26 8LY
Tel: 01429 273703

NORTH WEST OF ENGLAND

Joanne and Gary Adshead
10 Church Lane, West Houghton, Nr. Bolton, Gt Manchester BL5 3PP
Tel: 01942 810109

Selma and Geoffrey Oulton
37 Saville Road, Liverpool 13, Merseyside
Tel: 01514 752941



AREA SUPPORT FAMILIES

NORTHERN IRELAND

Kieran Houston (Chairman)
21 Cavanalee Road, Strabane, County Tyrone BT82 8HB
Tel: 01504 884168

POTTERIES

Lynn and Chris Grandidge .
41 The Boulevard, Broughton, Chester CH4 0SN
Tel: 01244 531163

SCOTLAND

Angela and John Brown
91 Bankton Park West, Livingston, Edinburgh EH54 9BS
Tel: 01506 495434

SOUTH-EAST

We would like to hear from any families who would be interested in knowing what is involved in being an Area Family to contact the Amersham office a.s.a.p.

Until further notice any families requiring support usually given by the support family for this area may contact any family listed on these 2 pages.

SOUTH-WEST

Fer and Bill Pidden
5 Westbury Leigh, Westbury, Wiltshire BA13 3SE
Tel: 01373 865117

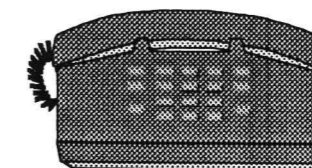
Anne and Gordon Hill
Bowhayes Farm, Venn Ottery, Ottery, St Mary, Devon EX11 1RX
Tel: 01404 813823**

WALES

Ann and Michael Kilvert
Windy Waye, Nantoer, Newtown, Powys SY16 1HH
Tel: 01686 624387

YORKSHIRE & EAST COAST

Barbara and Trevor Rollinson
43 Crosby Avenue, Scunthorpe, Humberside DN15 8PA
Tel: 01724 864115



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