

Newsletter

The Society for Mucopolysaccharide Diseases

National Registered Charity No.287034



Autumn 99



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Deadline for the 1999 Winter Newsletter is 15th December, 1999

CHAIRMAN'S REPORT

It is customary for the Newsletter following the National Conference to include the Chairman's Report at the Annual General Meeting (AGM)

**Presented by Wilma Robins at the Society's AGM
at the Stakis Hotel, Northampton on
Sunday 12th September 1999**

The past twelve months have proved challenging for the Society. Taking into account the extensive survey of family needs, and recent changes to charity and employment law the Trustees took decisions that included the relocation of the regional office. I wish to record the appreciation of the Trustees of the work undertaken by Mary, Pam and Anne in that office. The Trustees were disappointed that these staff members felt unable to continue their work with the MPS Society. I also wish to report the following assurances that the Society's relocation of the regional office to the Royal Manchester Children's Hospital would be welcomed, this has not been forthcoming despite considerable efforts on our part. Due to the lack of office and present climate the regional Development Officer has been and will continue to work out of the Amersham office for the foreseeable future.

Support to those suffering from MPS, their families and carers remains the prime focus of the Society's work. Two papers are enclosed in your envelope. The first defines the individual support and advocacy available. The second represent a breakdown of all the support requested and delivered to individuals and families since January 1999.

The Society continues to have a presence at both the MPS clinics held at the Royal Manchester's Hospital (RMCH) and the Hospital for Sick Children, Great Ormond Street (GOSH). The regional clinics held in Belfast, Glasgow, Cardiff and Bristol have continued to be very successful. New in 1999 has been the East Anglia and Birmingham MPS clinics. A similar clinic to that held in Belfast will take place in the near future.

In addition to the MPS Family Weekend Conference, a very successful day conference for families, individuals and professionals was held in Belfast in May, and a similar conference will take place in Scotland in October.

During this year the Society has consulted with the ethnic minority families and adult members suffering from MPS in order to identify how their needs can best be met. The results of this consultation are on display. In addition a small team of volunteers comprised of MPS family members are supporting the management of the Childhood Wood.

The Society values greatly the role of volunteers. We have been able to utilise the skills of many of our membership. Some have high profile roles as Trustees, Area Support Families, Annual Draw Co-Ordinator and fundraisers. Many more members and friends continue to provide voluntary support of the Society by being a link family, providing interpreting services, caring for children at clinics and conferences, speaking at a variety of events; and have one parent developing and writing new information resources, including the booklets.

CHAIRMAN'S REPORT

In July the Society held a day in the Childhood Wood for all those who have lost a family member to MPS. Following a brief ceremony of remembrance the families enjoyed a lunch together nearby.

Jeans for Genes Day held on the 9th October 1998 was a great success and raised MPS £390,000. This money, raised in partnership with three other charities, is primarily to fund research that may lead to gene and enzyme replacement therapies. The Trustees awarded two major Jeans for Genes research grants in this financial period. Jeans for Genes day on the 8th October 1999 promises to be as successful as last year.

Fundraising for family support continues to be one of the Society's largest sources of income closely followed by donations and legacies. The Trustees wish to take this opportunity to thank all the families for their time and efforts over the year in helping to raise such tremendous amounts year on year. We cannot for a moment relax and appeal to you, therefore, to continue your unstinting efforts into the new Millennium.

End of Report

Drawing to the end of the Society's business year I take this opportunity to thank the Trustees who have stepped down at varying times during the year; their time and contribution to the development of the business plan is very much appreciated. I wish to thank, too, the Area Families who stepped down during this year. Their contribution to the Area Family Network was invaluable. At the start of our new year, I look forward to working with the new management committee. Many challenges lie ahead but we will do our utmost to serve the Society to the best of our ability.

Wilma Robins – Chairman



SUPPORT FOR THE MPS DATABASE

The MPS database was established in the early 1990's to demonstrate the incidence of MPS and Related Diseases Europe wide. Thanks to initial funding by CSL and a high level of collaboration between the British and European MPS support networks we have been able to clearly show the incidence of MPS in many European countries.

At the MPS Family Weekend in Northampton the MPS Society was presented with a cheque from Biomarin. The Society has also received additional funding from TKT. Combined these funds will enable the MPS Society to develop the database and work more closely with MPS Societies World wide.

On behalf of the MPS Society I would like to thank Biomarin and TKT for their generous support.

Christine Lavery – Director

MILESTONES

New Families

Lorna and Russel Ingram's son Matthew has been diagnosed with Hurler disease. Matthew is 13 months old. The family live in South Yorkshire.

David and Angela Kelsall live in Staffordshire. Their 3 year old son Ryan has been diagnosed with Sanfilippo disease.

Hitiche Cevik, originally from Turkey but now living in London, has been diagnosed with I-Cell disease. Hitiche is 8 months old.

Susan and Mark Miles from Cheshire have a son, Adam, who has been diagnosed with Hurler disease. Adam is 1 year old.

Jonathon and Carol Croft live in Lancashire. Their 6 year old son, Christopher, has been diagnosed with Hunter disease.

Ayseha Ghaffer from Wales has been diagnosed with Sanfilippo disease. She is 3 years old.

Edward and Kate McDonnagh live in the North West. Their daughter Winnie Marie has been diagnosed with Hurler disease. She is 7 months old.

Sailesh and Nita Tailor are from the West Midlands. Their son Pavan has been diagnosed with Multiple Sulphatase Deficiency. Pavan is 2 years old.

Julie Bird from West Yorkshire has a son called Jack who has been diagnosed with Morquio. Jack is 3 years old.

Deaths

Sadly Simon Hoather died on 24th September 1999 aged 12 years. Simon suffered from Hunter disease.

Thomas and Christine O'Neil's 18 year old son Brian, died on 9th September 1999. Brian had Sanfilippo disease.

Stephen and Val Kaye's son Daniel, died on 28th September aged 17 years. Daniel had Hunter disease.

Congratulations

Amanda & Greig Stuart now have a baby daughter, Amelia Jane born on 27th August 1999. A sister for Jack and Emma.

Babita and Haj Afzal have a son called Adam born on 29th September 1999. A brother for Alisha, Azaria and Anika.

FAMILY NEWS



Birthday congratulations to the following MPS children and adults whose birthdays are in October, November and December

- | | | | | |
|-------------------|------------------|----------------------|--------------------|----------------------|
| Shereen Abbess | Carissa Aggett | Maryam Ahmed | Sobia Aksar | Billal Aksar |
| Sujaid Ali | Asayia Allana | Jibrell Arshad | Abdu Awadhi | Pam Bagshaw |
| Sannah Begum | Peter Benbow | Katherine Biddle | Thomas Birch | Paul Blanchard |
| Catherine Boswell | Adam Brown | Sharon Bush | Alex Butler | Edward Butler |
| Terry Butler | Ann Canton | Shyam Chandegra | Luke Chappell | Hannah Chisling |
| Joseph Coleman | Robert Commons | Amy Cooper | Alexander Cosgrove | Jamie Cowan |
| Daniel Croghan | Derek Denham | Katie Devine | Dermott Devlin | Jade Docherty |
| Roma Drayne | Kim Eggleton | Bradley Evans | Tamale Fisher | Mark Fitzgergald |
| Thomas Garthwaite | Louis Garthwaite | Colin Griffin | Azaria Hajiafzal | Nathan Halsall |
| Aiysha Hannif | Jamie Hicks | Nicky Holyroyd | Mathew Home | Christopher Isaac |
| Sadiqual Islam | Jamil Jam | Aaron Jennings | Stephen Jones | Gulnawaz Khan |
| Zafar Khan | Shoaib Khan | Fiona Larkin | Victoria Lawley | Christopher Leask |
| Benjamin Lemon | Keegan Lovick | Alice Marston-Taylor | Richard Matthews | Jade McAfee |
| Maria McCall | Shaun McCawille | Martina McDonagh | Daryl McLachlan | Matthew McLaren-Hall |
| Kimberely Meaker | Jamie Moxon | Samantha Mullen | Lorraine Mullen | Tara Murphy |
| Daniel Newton | John-Paul O'Neil | Victoria Oldaker | David Oulton | Kerry Parker |
| Angela Paton | Nicole Pickard | Natalie Pidden | Grant Pollard | Annette Puddy |
| Hardev Rehal | Derek Richardson | Thomas Rickett | Charlotte Rickett | Miriam Saud |
| Christopher Scott | Aisha Seedat | Mohammed Sherlala | Kyle Shields | Shabana Shoukat |
| Emma Slater | Mark Smith | James Stewart | Kyle Taylor | Michael Thompson |
| William Todd | Mirza Usman | Vilma Vanni | Tiffany Ward | Charlie Welch |
| Emma Whiteley | Joanne Wilson | Jacob Wragg | Christopher Yates | Karen Yeo |
| Asma Yunis | | | | |

In the next newsletter birthdays for January, February and March to be included. Photographs of birthday parties and cakes would also be great

FAMILY NEWS

The Education System versus The Parents

Our daughter, Lauren has Hurler disease and is now six years old. For over two years she attended the local mainstream nursery, which is not attached to either of the local primary schools.

We fought with the education system term by term to keep Lauren there, as she was extremely happy. She fitted in wonderfully with the other children, and all of the parents and staff supported this. Unfortunately, the headmistress was very prejudiced, and was constantly looking for any problems. She was unable to find any difficulties until Lauren reached the aged of four and a half, the age at which the other children were moving onto one of the primary schools. The headmistress wanted Lauren to do the same, but we felt that Lauren was not ready for this move, and so the fight began – *The Education System versus The Parents*.

We had meeting after meeting, but we were not able to agree on any course, so we were all at stalemate for one and a half years. They just didn't seem to understand our point of view. The Educational Psychologist seemed to lose the plot, as he was issuing reports about Lauren based on word of mouth from the headmistress, and without even seeing Lauren. He even expressed his concern that Lauren would still be in the nursery when she was ten years old. Crazy or what!

The nursery's Chair of Governors was brought into a review meeting and after comparing Lauren to his autistic son and trying to make us feel that we were depriving her of a future, he ended by saying 'What is this Hurlers, anyway?'. He was left looking quite stupid.

January of this year arrived and we were talked into viewing some of the Special Schools in the area, which are all between thirty minutes to one hour away. We visited four of these schools, three of which we did not like. The fourth school seemed okay, so we went back for another visit with Lauren. Everything seemed fine, but the Headmistress of the Special School announced that she did not want Lauren's teacher's aide to be with Lauren at the school, as she felt Lauren did not need her. If the teacher's aide did go, she would be placed with sixteen years olds, as she was adamant that Lauren would be left to her own devices, as she had no problems. So, it was back to the drawing board.



In the end, we followed our instincts and believed that Lauren could cope with being in a mainstream school, but with right attitude and support from the staff.

So the search was on. Many schools refused to take her without even discussing Lauren's needs, usually giving lame excuses which we knew we could appeal against, but we wanted to find a school which *wanted* to give Lauren a chance.

After what seemed like a losing battle, we found a small village school nearby, which has a nursery, an infant and a junior department all on the same grounds. The school was bright, cheerful and welcoming, with what seemed to be positive attitude. The headmaster stated that he "would be proud to have Lauren in the school", so the appropriate arrangements were made. After all of the frustration, rejection and desperation, we finally felt on top of the world.

Lauren's teacher's aide of three years was happy to go with her. We realised how lucky we were to have found a school that would be as flexible as Lauren needed.

FAMILY NEWS

But, had we done the right thing? Would Lauren cope with the transition? This had to work out okay.

When Wednesday 9th June, Lauren's first day at her new school arrived, I felt many conflicting emotions but for Lauren's sake we got on with the routine of feeding, washing and dressing whilst watching a 'Barney' video. In her new school uniform she looked so wonderful and suddenly so grown up.

When the taxi arrived with the teacher's aide, Lauren toddled down the drive with her school bag and with a big kiss for Mum & Dad got in the car, gave a big wave and off she went to school.

Lauren loves her new school and the school loves her. So far, everything has gone exactly to plan, much to the disapproval of some professionals (presumably because they were proven wrong). I think that this is another example of a situation where the parents knows best. If you believe that something is right for your child, then listen to your instincts, and do not be pushed into decisions which you feel are wrong for your child – The System Can Be Beaten.

Dawn Cawthorne – Lauren's mum

Roma Drayne – Children of Courage Award

Roma Drayne was presented with The Children of Courage Award on behalf of the William Keown Trust, at the Stakis Hotel, Temple Patrick, Northern Ireland on the 29th June. The photograph shown right is Roma with her certificate.

Roma was nominated for this award by the Musgrave Park Hospital who looked after Roma when she wore her halo following her cervical fusion operation 2 years ago.

Despite being uncomfortable and in considerable pain after having an accident wearing the halo (the front pins actually dislodged when she bumped into a wall). She carried on as usual. It was a strange sight to see her running around on the beach wearing this halo, playing, watering the plants in the garden. She was very brave and cheerful for most of the time. Her first day at school was a big event for her and everyone else in the class, I'm sure there's not many children who start school wearing a halo!

But the award which Roma received was really to highlight that disability does not mean inability and Roma certainly showed that with her courage and determination to get on with things, live life to the full and enjoy it.

Bernie Drayne – Roma's mum



FAMILY NEWS

Starting School

Our oldest son Tom is 5 years old and has Hunter disease. He started in September 98 at mainstream school with an assistant. We started seeing a child psychologist when he was four to get advice on how to talk about Hunter disease with him and to answer questions he was beginning to ask about himself. Like all parents we were very nervous about him starting at school.

The psychologist advised us that shortly after Tom started school his teacher should explain about Hunter disease to the class in simple terms in order to prevent teasing later. When he started school aged 4 3/4 we didn't feel that Tom was quite ready himself for such a talk as his understanding of Hunter disease was so limited. In addition all the children were just getting used to school and hadn't really noticed he was different.

However, by the last term of his first year, Tom had begun to tell his friends about 'Hunters' when he couldn't do something that they could do (like sitting cross legged, running as fast or when he was incontinent). One day he came home and told me that a little boy in the class had been trying to help straighten out his fingers for him. We asked Tom what he thought about telling the whole of the class about Hunters and were rather surprised when he said he thought it was a very good idea. That convinced us the time was right.

We approached his teacher but she was very nervous about giving such a talk and also wondered, since he had not been teased, whether it was really necessary. We then discussed it with the school doctor. Together we devised a talk that the school doctor and the school nurse

would give to the children. The talk would be about how we are all different and would mention a few particular ways we are different such as wearing glasses, asthma, eczema and 'Hunters'. In this way Tom would not be singled out. We also agreed that each child should take a letter home to their parents mentioning what had been discussed. Tom had met the school doctor on a couple of occasions and liked her. We had told him what she would say so he wasn't surprised by anything.

The talk itself went very well. All the children and Tom really enjoyed it. We also had very positive comments back from some of the parents who had asked their children about the talk. Tom is much happier now his friends have some understanding when he says "It's not my fault, it's just the Hunters".

Claire Garthwaite – Tom's mum

Below is the talk that took place and we feel would be useful for you to read.

Some of you have met me before. Can anyone remember who I am ?

I am Doctor _____
Why do we have Doctors?
People are ill, parts of our bodies get sore and do not work properly.

How many of you have seen a Doctor when you have not been well?

How many of you have had operations?

Have many of you had your tonsils out?

Does anyone need to use one of these (holds up an inhaler for asthmatics) ?

Some people have asthma and they need this

FAMILY NEWS

Medicine to help them breathe more easily. Some children find that they get a bit short of puff if they are running around.

But asthma is something you can't catch from other people.

Some people need to wear glasses. (Who wears glasses here ?) Does anyone in your family wear glasses? We wear glasses to help us to see better.

I see that Tom (Hunter disease sufferer) is sitting on a special chair. Does anyone know why?

Maybe Tom can tell us?

Its because his legs get sore when he sits on the floor for a long time. Now Tom doesn't have asthma and he doesn't have eczema. He has something else with a special name - 'Hunters'.

Hunters is something Tom has been born with and it makes it hard for Tom to run as fast as some of you. It also make it harder for him to sit on the floor for a long time. Tom's fingers are a bit bent and can't straighten which makes it more difficult to write and so he is going to use the computer more to write with. But Hunter disease is not like catching a cold.

When our body doesn't work as well, it's not our fault - that is just the way that we are all made.

Does anyone else have a bit of their body that needs special looking after?

Does anyone have eczema where their skin is very itchy?

Whatever might be wrong with us we must all look after each other and never be unkind to each other because, its just the way we are made and is nobody's fault.

This was the letter that was sent home to the parents after the talk.

Dear Parents

As part of learning about their bodies the children have had a visit from the school doctor and nurse. They have been talking about what happens when the body doesn't work as well as normal.

The class have discussed asthma, eczema, wearing glasses and a condition called Hunter disease, which affects one of the children in the class. The children have been told that none of these conditions are catching but that we are all made differently.

If you have any queries, please discuss these with Miss xxxx who can put you in contact with the school doctor.



FAMILY NEWS

Sharing Resources

On our visit to meet with families in the South West of England, back in June, Christine and I went to see Fer Pidden. In the course of the conversation Fer mentioned that she had a buggy in the garage which Natalie had outgrown but which was in perfect working order. She asked if we knew of anyone who we might be able to help by donating this to them. We were sure that we could and took the buggy with us.

When we got back to the office I telephoned a community nurse who I had recently been in contact with and asked her if she thought the family that I had in mind would like the buggy (which was now tucked, not very discretely, behind Sheila's desk). She agreed that they would be ideal and we went about arranging a suitable time to deliver it.

The family who are now the proud new owners of the buggy have passed on a thank you letter to the Pidden's and very kindly sent us a photo to illustrate how much happier and more comfortable Edward is in the new buggy than he was in his wheelchair. (see the front page).

Angela Ratcliffe- Development Officer

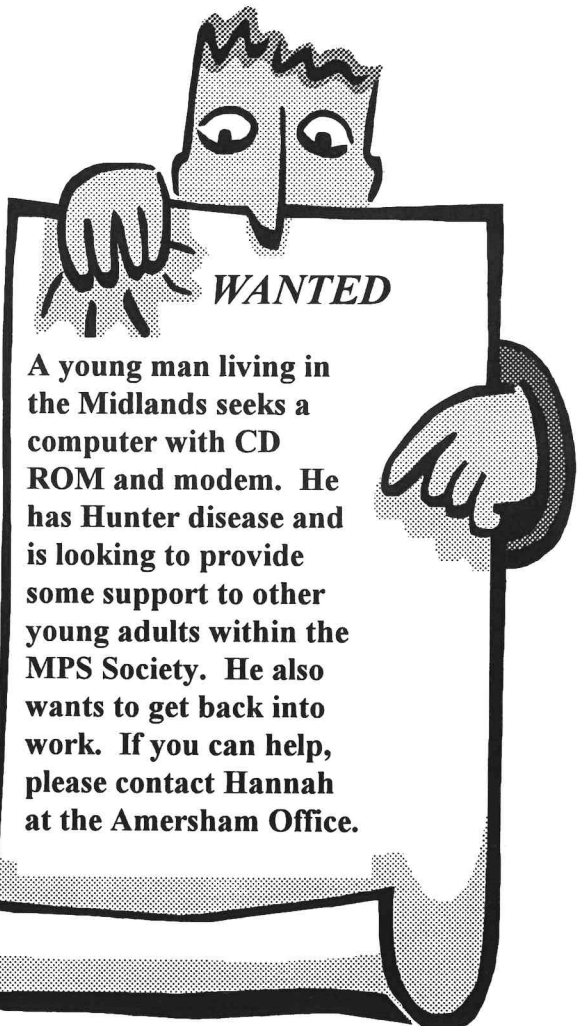


So please take note that if there are any other parents out there who also have specialised equipment that has been outgrown or is unwanted send a letter into the MPS office and we will gladly either identify a family in need or put a note in the next newsletter.

Sheila Duffy-Project and Information Officer

FOR SALE
Wall and floor padding worth £4,000 no longer needed. Good condition

Telephone Denise Brown 01442 395907 for more details. Any reasonable offer considered.



SUPPORT TO MPS ADULTS

Results from Activity Questionnaire

This questionnaire was sent out to all MPS adults aged over 18 years who are independently minded. The results are as follows:

Weekend break – Hullavington	15	List of other young adults to get in touch with	1
Mid Week break – Hullavington	13	Long weekend Christmas shopping spree in New York	1
Shopping trip to France	11	Euro Disney	1
Weekend at Alton Towers Hotel and Theme Park	13	Ten pin bowling	1
Weekend at Centre Parc in Nottingham	13	Adventure holiday	1
Mid Week break at Centre Parc in Nottingham	12	Light water valley	1
Group day out in London	9	Thank you for returning the Activity Questionnaire that I sent out to you in the summer.	
Group day out (other)		The most popular activity offered at the time was the weekend and midweek break at Hullavington. Unfortunately, at the present time this is not an option due to the regiment being involved in active service.	
Twickenham	1	One of your requests has already taken place as you will read in this newsletter. The shopping trip to France is in the planning stage and we will contact you as soon as I have managed to finalise the arrangements.	
York	2		
London	1		
Mini Conference	9		
Other ideas:			
Pakistan	3	<i>Angela Ratcliffe – Development Officer</i>	
Rent somewhere in France for weekend/mid-week break	1		
Christmas shopping – big indoor shopping mall	1		
Theatre trip to London	1		



SUPPORT TO MPS ADULTS

Lorraine's Visit to the Home of English Rugby

Lorraine has sent me the article that appeared in the RFU Touchline newspaper written by herself after her visit to Twickenham – the home of English Rugby, that was arranged by Angela Ratcliffe – Development Officer.

I am 24 years of age and I've experienced a lot of happy events in my life such as touring the United States, Canada, Holland and Jersey. I had the pleasure of meeting Terry Waite, Jimmy Saville and Larry Grayson and some of the Leicester Tigers players. Also I've been to shows in the West End of London – Cats, Les Miserables, Miss Saigon, Starlight Express and Joseph and the Amazing Technicolor Dream Coat.

I love rugby, especially supporting Leicester Tigers, but I also enjoy cross-stitching, stamp collecting, collecting pin badges and listening to tapes & CDs of the 60s and 70s.

I have Morquio disease which comes under the heading of Mucopolysaccharide which is split up into separate disorders all connected to each other. My brother and I have Morquio disease, which affects the growth of the bones, and causes problems with the spine, heart and lungs. Resulting in many health problems and surgery over the years. Last March my brother Christopher passed away suddenly, he was aged 20. This affected me very deeply.

The Mucopolysaccharide Society (MPS for short) sent a questionnaire to me asking if I would like to go on any of the selected trips. None of these really appealed to me, so I asked if it would be possible for me to visit

'Twickenham – the home of English Rugby' and to my surprise and delight, they arranged a tour around Twickenham and for me to meet the president of the RFU, Peter Trunkfield and have lunch with him.

The whole stadium was much larger than I had imagined and the amount of places suitable for wheelchair users was unbelievable. I was well pleased that a national stadium had thought about the disabled and the facilities they needed.

On my tour around I was shown the England changing room. If only I could have been a fly on the wall on a match day! The room also retained the original cast iron baths which are 7 feet long and 2 feet deep and still being used by my heroes.

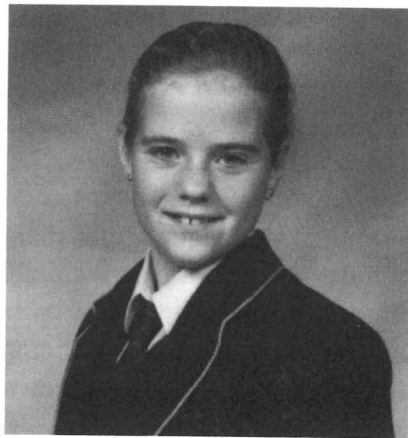
The museum was very well laid out and the film clips showing the pre 1914 matches were very interesting indeed, especially the early matches of the Leicester Tigers.

It was a great honour to meet the president of the RFU and to have lunch with him and I would like to thank all those who made my day out at Twickenham possible. It was a great day, and I will always remember it.

Lorraine Rock at Twickenham in the photograph below.



SIBLINGS NEWS



If I won a million pounds I would:

Give some to a charity, some to my family and I would keep some for myself.

Thank you Sophie for replying and I hope to receive some more replies for our next Newsletter.....

Sheila Duffy
Project and Information Officer



Name: Sophie Longley

Age: 11

Favourite Activity: I enjoy playing the piano and I like the sport. I especially enjoy swimming.

Favourite band: Five and Boyzone.

Favourite video: Dumb and Dumber because its really funny.

What makes me angry: It makes me angry when people say nasty things about my sister.

Funny situation: In a shop I smacked my dads bottom and when he turned round I realised it wasn't my dad.

My friends make me laugh, especially Lauren, Michelle and Lucy. My family make me laugh too.

What job I would like to do: When I am older I would like to be a Paediatric Physiotherapist.

If I could change the world I would make sure everyone had a home and make sure there were no wars.

MPS FAMILY CONFERENCE

The 1999 MPS Family Conference

We hope that everyone had a safe journey home on the Sunday after the Conference. We were so lucky with the weather again this year and I know that the children had a wonderful day at Thorpe Park and Woburn Safari Park, as you will see from the photographs.

On behalf of the families we would like to thank all the volunteers, old and new, for doing such a wonderful job caring for all the children.

We would also like to thank the staff at Thorpe Park, Flexible Catering, Jarman Park, Woburn Safari Park, Stakis Hotel and Souls coaches for all their help in making the weekend run so smoothly.

A special thank you to Mickey and Minnie for making a special trip from Disneyland Paris to meet all the children after their tea on Saturday. It was a delight to see all their faces when they got close to the real thing.

For all the families that were unable to attend we hope that by hearing and reading what took place at the Conference maybe we will see you next year. Book early because we were full this year, and places will be on first come basis. The programme and booking form will be coming out with the next newsletter after Christmas.

Last but not least I would like to also thank all the speakers that gave their time to present their talks, especially Dr Kakkis from BioMarin who travelled from USA to attend. His talks were most interesting and good news to some parents.

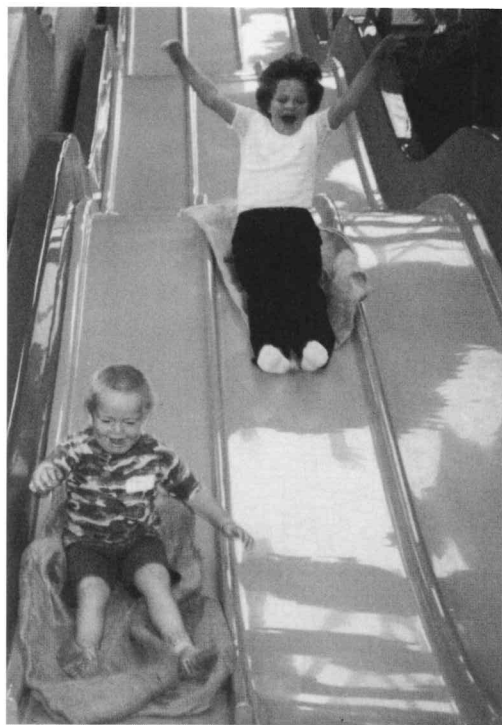
For the first time we are investigating putting together a conference video. Further details will be available in the Winter 99 Newsletter.

Sheila Duffy
Project and Information Officer



MPS FAMILY CONFERENCE

A selection of photographs of Volunteers and children taken at Wooburn Safari Park



MPS FAMILY CONFERENCE

Benjamin has Sanfilippo Disease

On the 11th May 1989 our lives were changed forever with the birth of our first child Ben. We were the proudest, happiest new parents you could imagine. He was a big blond beautiful placid easy baby. So pleased were we that we decided to have another baby almost straight away.

I was heavily pregnant when my first realization of Ben's problems became apparent. We had gone to the clinic for his 18 month assessment and he had spent the whole time trying to make his escape from the room and showed a total lack of co-operation. More worryingly I complained to Gary when we returned home that he was unlike the other children there. I put it out of my mind.

The new baby was born, a girl and things went from bad to worse. Ben's behaviour was dreadful. Gone was the placid baby and in return we had a totally uncontrollable toddler – they were dark days – and I couldn't cope. We moved house and I began to look for reasons why Ben was like he was. My health visitor was convinced that he was fine, I really think she thought that the problems were mostly mine. I read about syndromes like Fragile X and convinced myself that Ben had this. I also thought he may have brain damage from his difficult delivery. Our local community paediatrician checked Ben for fragile chromosome sites and eliminated this and checked my hospital notes with regard to his delivery and again drew a blank.

He had had an operation for grommets as he had loads of ENT problems and a short while later was diagnosed with a sensory neural hearing loss. He was fitted with hearing aids

and started a special nursery for hearing impaired children. It was here that his hyperactivity reached its peak to quote the nursery teacher 'he wrecked the joint'.

At this time also we were referred to Royal Manchester Children Hospital, which is very local for us to see Doctor Super. We had had so many appointments that I didn't think too much about it except when he said that he thought he knew what was wrong with Ben and later rang to say that they had found something in his tests. I was actually excited because I genuinely thought that at last Ben would be treated.

So we set off for the hospital on a cold December morning with great hope, but we returned home a devastated and broken family, Ben had Sanfilippo. I had no idea that things like MPS existed, and never imagined that it was so untreatable. When people asked I had to revert to the piece of paper to remember MPS. I never thought that it would roll of the tongue like it does today.

The weeks and months after the diagnosis are all a bit of a blur. Being 'a want to know kind of person', I couldn't wait to receive information from the MPS Society. I contacted the then Mary Gardiner who talked to us for hours and I will always be grateful for her absolute honesty. Family and friends coped and helped all in their different ways.

We arranged school, respite care, help around the house and developed various coping strategies. During the hyperactive stage we adapted the house really by just moving any ornaments and valuables – those we had left !

MPS FAMILY CONFERENCE



And keeping Ben out of the kitchen and in bed became my life's work !

We put settees against the windows that he banged on in delight! We kept old carpets longer than anyone would think possible – as his favourite thing was running around at the speed of light with a feeder cup full of Ribena tipped upside down!

Its funny though because as I was writing this I had to really think about what it was like in those hyper-active days, now that they have passed. What I will say to anyone who has a child at this stage is that it does pass honestly!

I think the turning point came for us when we stopped trying to make Ben change. Before this maybe we had not accepted it. I was trying to teach Ben to talk, be toilet trained, be good, be still, not to chew, not to hit the TV!

My best bit of advice is to change what can be changed and just to accept what cannot. Even throughout his most anti social days, Ben has always made friends. He and I know that Sanfilippo children in general are the most loving charismatic individuals and everyone falls in love with him.

My theory is that Sanfilippo children are hyperactive because they know their lives are short, so they pack everything into a short space of time therefore they have no time for sleep. So if you are a Sanfilippo parent next time your child wakes just as you are about to go to bed, remember this and pop the telly on for yet another episode of Thomas the Tank Engine – just like we did!

These days Ben is very quiet, he is tube fed and we have epilepsy and immobility to cope with instead and I know that there is worse to come.

Sanfilippo changed our lives. At the time of diagnosis, I genuinely thought our lives were ruined. I know now that they were not.

We have made ourselves a family life. It has at times been very hard. We were both determined that ours and our children's lives would be normal or not just normal but really good! We had a third and healthy baby and I know now that we have been very lucky. We are blessed with all our children. We do have a good family life – it is just a different one.

Jo-Anne Adshead – Ben's mum



MPS FAMILY CONFERENCE



I am a carrier for Hunter Disease

Hello, my name is Claire Arrowsmith. I am 17 years old and live in Newcastle. I am currently attending college doing a pre-nursing course plus A levels. I am hoping to go to university next year to do childrens' nursing.

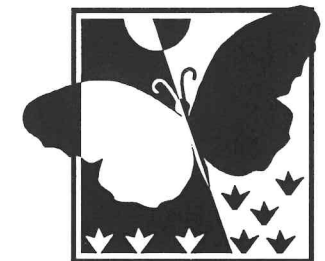
I live at home with my mother and father and my brother Colin. Colin is 19 years old and suffers from Mucopolysaccharide II – Hunter disease (mild). My family and I have been a part of the MPS Society for 15 years and my parents are the Area Family for the North East.

For those of you who do not know much about being a carrier, I will briefly explain. All of the other diseases in the Society take both parents to carry the recessive gene, Hunter disease is different. With Hunter disease the fault is X-linked and is therefore only carried by the women. No matter who the woman chooses as a partner there is a one in four chance of her having an affected boy. If the mother of an affected boy is not a carrier then the fault has occurred in the male sperm during conception.

When I was younger I asked Dr Ed Wraith to carrier test me, but he wanted to wait until I was old enough to fully understand. When I eventually was tested, I was 12 years old. My Nana and my Aunty were tested at the same time. Waiting for the results seemed to take a lifetime. In fact it was only a week. I felt anxious and scared but I still had hope.

We all got the results back together. We are all carriers of Hunter disease.

At first the implications did not really sink in. I would tell people that I was a carrier and explain what this meant, but statistics do not portray the whole picture. They do not tell the whole story, the reality of it or the pain. One thing that really helped was that my parents had always brought me up with the fact that I probably was a carrier. So it did not come as such a shock.



When I first started to really think about it I was around 14 years old. I started to think about the future and having children. I think this is when it really hit me, the problems that lay ahead and the decisions that I would have to make. It was scary. At first I felt I had no one to talk to, no one who understood. I struggled to come to terms with being a carrier. Some of the questions that went through my head were;

- Will it happen to me?
- What will I do if it does?
- Will I get prenatal diagnosis?
- Could I face getting the results?
- What would I do?

I felt guilty for feeling this way. My brother might have had 16 operations, but he is happy. Colin once said to me "I hope you have a Hunter son Claire, because then I will have nephew just like me". This comment made me feel really guilty for ever even considering a termination.



MPS FAMILY CONFERENCE

At the stage that I am at now, I really do not know what I would do, but I do know that what ever decision I do make, it will be well informed and very well thought out. I will not rush into anything. At least I have the privilege of knowing, unlike my parents, and no doubt most of you. Finding out that I am a carrier has really made me re-evaluate my personal beliefs.

Over the years I have heard lots of different points of view. Some people think that if you knowingly keep an MPS child, then you are selfish and cruel and that you are just thinking of yourself and not the child. There are also people who think the opposite. They think that no one has the right to take a life away.

I realise that not all siblings or carriers for that matter feel the same way I do. A lot of people do not realise how hard it can be living as a sister and a possible parent. I have now come to terms with the fact that I am a carrier and there is nothing I can do about it. It's like carrying a time bomb around which can be passed on into the future.

Somebody asked me a while ago if I thought carrier testing was important in childhood, or should you wait until adulthood. In my opinion this question is simple – Yes, it is very important and no you should not wait until adulthood. If you already have MPS in the family then carrier testing is essential.

The decision of when to have it done should be up to the child and not the parents. This is for two reasons;

1) the parents might push the child into having the test done too young when he or she is not

ready to handle the results or they may not understand.

2) the parents might stop the child having the test when he or she might be ready and wants to know.

These days children should be told early on because of young pregnancies. I remember when I was about 14 my Mam sat me down and said that I had to be so careful because unlike most teenagers, I had so much more to lose. This really made me think and I knew then that I would not make the same mistakes that a lot of my friends were making. In my last couple of years at school girls up to two years younger than me were getting pregnant and luckily for them they had healthy children. Just because the legal age of consent is 16

does not mean that anyone sticks to it. There definitely should not be a set age for carrier testing.

In my opinion carrier testing should be done when you reach puberty. I feel that this gives plenty of time to come to terms with the result before you consider having a family.

Just before I finish I would like to thank the MPS Society for supporting my family over the years and I hope that the Society will remain strong in it's support for the future generation.

Claire Arrowsmith



MPS FAMILY CONFERENCE

Siblings Workshop

What can parents do to support siblings?

I've just come in from taking my daughters to school. Not the usual experience this morning as we witnessed a cat being killed by a car. I feel helpless as we watch it dying on the roadside. There's nothing to do but try to find the owner. I'm aware that the girls are asking about the blood and I find myself explaining in a detached sort of way, feeling shocked by the experience and having a desire to protect them from it. By the time we get to school my older child starts to cry and my legs feel a bit shaky. I am reminded that helping children deal with their feelings is not easy when you have to deal with yours.....

I ran a Sibshop for a group of brothers and sisters at the recent MPS conference in Northampton. This was a two hour session for siblings to have some fun and games together as well as an opportunity to express some of their feelings about being the sibling of a child with an MPS disease. I feel that the Sibshop is just one small way of supporting siblings. Parents have a far greater influence on how their children deal with the prospect of losing a brother or sister. Some things can make a real difference.

Siblings want time with parents

One of the hardest things for siblings is not getting enough time and special attention from parents. This happens because of hospital stays, lack of parental energy through caring, and of course because parents want to spend as much time with their child when he/she is alive. It is so difficult to meet all the demands. Although there will be more time for siblings in

later years, siblings really want and need time with parents now. Find a way to give each sibling some special time with you on a regular basis.

Parents are role models

As the parent you are going through the 'unthinkable', living with the reality of having a child with a life limiting condition. At different stages you may feel shock, anger, grief, depression, guilt, isolation, complete exhaustion, hopelessness, fear.....these emotions take their toll on energy and ability to cope. You are doing the best you can in very difficult circumstances.

Siblings will notice how you deal with it all and are likely to take a similar approach. Siblings will cope better if you:

... Talk openly about how you feel. It's OK to cry in front of the children.

Then they know that there's nothing 'wrong' with being upset.

... Take care of yourself - then you are better equipped to look after others. Siblings will see that taking care of yourself is still important.

... Ask for information and get things explained when you want it. Siblings get the message that its OK to ask if you don't understand.

... Seek help if you are overwhelmed by your feelings and feel you cannot cope.

MPS FAMILY CONFERENCE

Photographs of The Siblings Workshop at the MPS Conference in action



MPS FAMILY CONFERENCE

Helping siblings cope

Children usually grow up believing that it is old people who die. When a child is going to die this goes against their expectations of the world. They may even feel that this will happen to them too.

Keep routines going. This provides security and a structure for siblings.

It can be easy not to bother about rules and just give in to things but children benefit from knowing what their boundaries are.

... Celebrate their achievements and events like birthdays - siblings need to feel that their life is very special to you too and that there are still things in life that are a cause for celebration and enjoyment. Take a photo of a sibling's first day at school or their first time riding a bike - this way you can also talk about it again later during a more relaxed time.

... Let them know that they do not have MPS.

Siblings feel included and valued when parents talk to them about what is happening.

... Provide information in small bits and you may need to give the same information many times over - children need time to take things in and make sense of them. Make sure that children find out about serious illness and that their brother or sister is going to die from you - not from an overheard phone call, or from another child at school. Secrets cause anxiety and stress, and can damage the trust your child has in you. Give hope, but not false expectations.

... Ask siblings how they are; ask what it is like for them at the moment; let them know that all their feelings are OK and normal at a time like this and it may help to talk about them. Don't be too surprised if they shrug their shoulders and say everything's fine - children want to protect their parents from any more worry or grief. Show by your own example that sharing what we feel is healthier than letting it build up inside.

The relationship between a sibling and his/her brother or sister who has MPS

... Siblings will want to know that their brother or sister is still the same person as their condition progresses. Explain changes in physical appearance, skills, and behaviour.

When siblings ask if their brother or sister is going to die soon, let them know what you know - false reassurances will spoil their trust in you.

... Siblings will want to spend time with their brother or sister - for companionship; to contribute to helping him/her feel comfortable; to build up a store of memories for the future; and to say their goodbyes when the time comes.



MPS FAMILY CONFERENCE

... Many children like to make a memory box with all sorts of little things to remind them of their brother/sister in the future - photos, a video of them together, a special toy or item of clothing, etc. Each sibling has their own. By doing this the sibling feels that he/she can still stay close to their brother/sister and also gets the message that children do not get forgotten about when they die.

Life outside the home

Siblings may have taken on more responsibilities due to circumstances at home. It is normal for siblings to want to support their parents and want to help care for their brother or sister. However too much responsibility can affect a sibling's health, social life and schoolwork.

... Encourage siblings to have a life of their own - playing with friends, clubs, sports activities.

... Inform teachers, club leaders, and friends about what is happening so that they can be supportive - let them know how they can help.

... Children thrive on fun; humour and enjoyable activities relieve tension and help siblings feel good about themselves - make use of any opportunities you have for this.

If you can only do two things the most important are these;

Find some time to spend with siblings doing something they enjoy.
and

Keep the communication between you going.

Monica McCaffrey - Sibworkshop

Useful resources

How To Talk So Kids Will Listen & How To Listen So Kids Will Talk

By Adele Faber & Elaine Mazlish
Avon 1982. This book has a really excellent chapter on helping children deal with their feelings.

Available from Smallwood Publishing,
01304 226800.

A Child's Grief

This booklet advises parents on helping children before and after a bereavement.

Winston's Wish

Gloucestershire Royal Hospital, Great Western Road,
Gloucester.
GL1 3NN,
01452 394377.

Winston's Wish runs a national programme of bereavement services for children and has produced these booklets:

Helping Children Understand About Serious Illness. This booklet gives examples of how to explain things to children.

The ACT (Association for Children with Life-Threatening or Terminal Conditions and their Families) are holding a one day conference entitled 'Children's Palliative Care: Working in Partnership'. The conference is being held on 15th November at the Royal College of Physicians and will present examples of successful partnerships between agencies providing children's palliative care.

For more information contact 0117 9304707.

MPS CLINICS

Birmingham Clinic

On Friday 9th July the MPS Birmingham Clinic took place at Birmingham Children's Hospital.

The day was facilitated by Dr. Stuart Green, Consultant Paediatrician at Birmingham and each patient was seen jointly by Dr. Green and Dr. Ed Wraith.

Christine, Ellie and myself were also present on the day to deal with any non medical matters.

15 MPS Children were seen at the clinic which was held in the day unit between 9.00am and 4.30pm.

The next clinic is being arranged for Friday 10th December, letters will be going out to all of the families living within the catchment area. A clinic is also planned for June 2000.

**Hannah Crown
Development Officer**

Dublin Clinic 24 - 25 June 1999

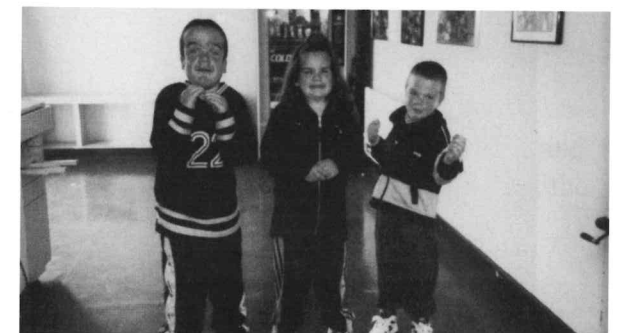
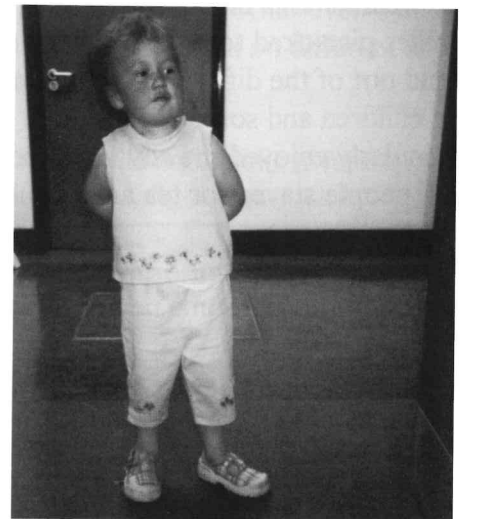
I was very pleased to be invited to provide support to Irish MPS families at their two day clinic and conference held in the Summer.

The clinics were very well organised by Mary Boushell who directs the Irish MPS Society.

A majority of the children seen in clinic had received bone marrow transplants for Hurler disease, many with a very encouraging outcome. I would like to thank Mary Boushell, her

committee and all the MPS families for making me so welcome.
**Christine Lavery
Director**

Five of the children are featured in the photos below.



AREA FAMILY SUPPORT

South West Area Family

MPS Family Picnic



June and July saw two get together for families in the South West. In June we visited Crealy Park a lovely family park near Exeter.

The weather was fine despite a cold wind and families picnicked together, chatted and dipped in and out of the different activities available.

The children and some of the adults particularly enjoyed the adventure zone and most people stayed for tea and donuts until the park closed.

good response to the invite. In July we had a barbeque at our home. The day was a scorcher and at one point we moved indoors for shade – rare in this country! However, we had a lovely barbeque, cooked mainly by Rick Montgomery – thanks Rick!

It was good to meet old friends, folk we haven't seen for quite a while. We hope they keep in touch and thank you to them for coming to see us.

It was good to see some new faces and such a **Ann Hill – Area Support Family**



Parfitt family in the foreground, Fer and Natalie Pidden and Ann Hill background

INFORMATION

Support provided by the MPS Development Officers

We thought that it would be useful to remind all our members of the support offered by us all. So please have a read and if we can help you in any way please contact us.

Clinic Support

Attendance at the regional and main centre clinics to offer non-medical support.

Information/Advice on

- Education – Statement of special needs
- Disabled Facilities Grants
- Grants for holidays and equipment
- Equipment
- Wheelchairs
- Independent Living
- Respite Care
- Benefits
- Relevant voluntary and statutory services

Area Family Support Network

Supporting the Area Families in their role of being a link for families and organising events. Providing mutually requested links between families in similar circumstances.

Developing Services

Continually reviewing and developing the services offered by the Society in consultation with the members.

Health/Medical Issues – Specific medical advice cannot be given, but support in addressing and considering different issues like medical management, carrier status, and prenatal diagnosis is offered.

Sharing Information

Through articles in the newsletter, presentation at the annual conference or other events and the writing of information packs on different aspects of living with an MPS child.

Telephone Listening Service

Enabling families to talk about and think through any concern or issues.

Increasing the profile and public awareness of MPS families.

Principles underpinning the support work

Advocacy Service

Advocating a families needs in meetings or by letter to service providers/other professional workers.

Confidentiality

Families have a right to confidentiality at all times. Any personal information shared with an employee of the Society will not be shared outside the society's support workers unless permission is given or in exceptional circumstances such as abuse.

Family Visits

When support by letter or telephone is not appropriate or adequate to meet a family's needs.

Bereavement Support

Listening service and attendance at funerals when requested. Management of the Childhood Wood and events.

All information and advice given to families and others will be given within the boundaries of the MPS Society's Confidentiality policy.

INFORMATION

Equality

All families will be treated equally by the Society. A service offered to one family will be available to all other families in the same situation of need. All services will be culturally sensitive.

All families requesting support from the Society will be offered it or a written explanation as to why the support requested cannot be offered.

Family Led

Families are responsible for making contact with the Society in order to receive it's support services. The aim of the support is not to do for families but to enable families to help themselves. No information or advice will be given by the Development Officer unless the family request it or in the staff member's professional judgement it is absolutely necessary to give.

Ellie Gunary, Hannah Crown and Angela Ratcliffe

Information, Advice and Advocacy January – September 1999

The Development Team has provided direct, individual support to 254 individual families since 1st January 1999. The support can be broken down as follows

	<u>Method of Support</u>			Professional meetings
	Telephone	Written letters/reports	Family Visits	
Education	18	14	13	21
Equipment and Clothing	6	8	4	
Genetic Counselling Carrier Testing	3			
Rehousing	11	12	10	6
Home Adaptations and DFG Grants	22	14	18	14
Incontinence Supplies	5	6		
Independent Living	12	7		
Medical/Healthcare Issues	56	9	33	12
Prenatal Testing	15			
Research and Treatment	13	1		
Residential Care	1	2	1	
Respite/Hospice Care	11	6	3	
Terminal Care Plans	3	3	8	4
Welfare Benefits	7	32	1	2
Wheelchair Provision	8	15	3	2
Mobility	5	3	1	
Pre Bereavement	5			
Bereavement Support	19		1	
Mental Health Issues	8		2	
<u>Other support</u>				
Professionals referrals, Specific Sibling, Support complaints, Legal support	5	9		1

Since 1st January the Development Team has: Achieved 24 grants for individual families from other organisations and Supported 29 New Families and 11 Bereaved Families who have lost an MPS family members within this time.

INFORMATION

Shoes

Many families have approached the Society asking for information on manufacturers who produce fashionable, small and wide fitting shoes. The Restricted Growth Association (RGA) has gives the following contacts:

CONTACT FOR SHOES

British Footwear Association

5 Portland Place
London

W1N 3AA

They produce a list of manufacturers of footwear for Special Needs.

Small and Tall Association

York Street
London

W1A 2BJ Tel: 0171 723 5321

MANUFACTURE SHOES

Bill Bird Shoes

49 Northwick Business Centre

Blockley

Gloucestershire

GL56 9RF Tel 01386 700855

Cosyfeet

The Tan Yard

Leigh Road

Street

Somerset. BA16 OHR

It would be useful to hear how families get on contacting any of these organisations.

Ellie Gunary

Regional Development Officer

Paediatric Exhibition Kid-E-Quip

On the 11th November at the Reebok stadium Bolton is the UK's largest ever Paediatric Exhibition Kid-E-Quip taking place.

It will be an ideal opportunity to view products from companies who supply specialist Paediatric equipment and services. It will concentrate of the needs of children aged 0-18 years, from seating and mobility aid to educational and play equipment, vehicle adaptations, musical instruments and lots more.

Attractions also include Santa's Grotto, (with free entry and a gift for each child), free play sensory room, test rack area, games and give-aways. The day will be most informative with the Disabled Living team offering help and advice at their desk and various seminars on related subjects. In addition, enjoyable experiences such as 'make overs for busy mums'.

For further details or for your free tickets please contact;

PROMEX Tel No. 01282 455528

or

Disabled Living Tel No. 0161 832 3678.



INFORMATION

Children's Hospices Places for Living

Most people think that children's hospices care mainly for children with cancer, in the last stages of their lives, and that they must be very depressing places.

In fact, children's hospices provide care and support for children with a wide range of life-limiting, or life-threatening conditions, and their families, from the moment of diagnosis onwards if necessary. They are bright, homely places, often filled with fun and laughter, dedicated to improving the quality of life for all family members.

Children hospices welcome the whole family for a break together, also giving parents and siblings time to themselves. They provide expert respite, emergency, palliative and terminal care; practical advice and assistance; and bereavement support for as long as it is needed.

Children's hospices support many families caring for children with an MPS condition. Susan and Vince Hayward's daughter, Emily had Hurler disease. They used Little Bridge House in Devon, together with Emily's brother Thomas and her elder twin sister from February 1996 to March 1999, when Emily died suddenly at home, just before her 8th birthday.

Sue talks about the help and support that she got from the children's hospice.....

Mandy Robins – Head of Care, has asked me to put into words what Little Bridge House has meant to us as a family over the past four years. I agreed, thinking it would be an easy task; but in attempting to write this article I have discovered that there are no words to describe the love we

have received, the memories that remain nor the thanks we give for the care and understanding shown to our children, ourselves and most importantly, Emily, It can be nothing other than a very personal account of our experiences.

When we were about to visit Little Bridge House for the very first time in October 1995, we were very unsure; unsure of what to expect, unsure about how we would cope, unsure of how our children would deal with being with others who needed so much care, unsure if this was right for us. But one thing that we were certain of; we needed some help, we needed a break, someone to talk to, someone to share things with – we were in the right place.

From the moment we first walked through the doors we were made to feel welcome. Emily, who had Hurler disease, was given one of the beautifully decorated children's rooms and Thomas her twin brother, decided he wanted to sleep with her, so a bed was made up for him in the window where this is especially designed for this purpose.

Our older girls were given a room of their own upstairs in one of the two wings that accommodate the parents' bedrooms. During that first visit we took our time discovering all the marvelous facilities Little Bridge House has to offer. A jacuzzi, a teenage room with a snooker table and computer games, a 'messy-play' room of arts and crafts, a huge soft play room with a ball pool, a physiotherapy room and a fantastic multi-sensory room. The children were in seventh heaven! There is also a large garden for all the children to play in with bikes to ride and swings and a huge wooden boat to climb on. It is really beautiful.

INFORMATION

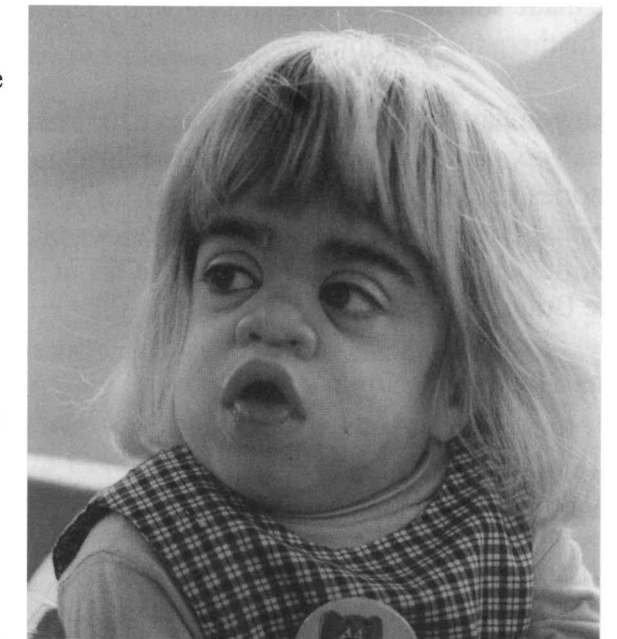
But Little Bridge house is more than a beautiful building; it is a network made up of very special people, who care. They care not only for your child who is ill but for all the family – they will take time and effort to get to know you and to talk to you and gradually you realised you can relax here and, if you wish, there is someone to talk to – someone to listen. This is what makes Little Bridge House so special.

We visited Little Bridge House as a family several times before we thought that, perhaps, Emily could stay occasionally by herself. This would give us the opportunity to have some time in our own home with the other children just doing 'normal' everyday things. A pattern was then set up that Emily would visit every other month for a weekend and we would go as a family for a 'holiday' for a few days once or twice a year. This worked very well, we needed our 'Emily free' times at home and Emily loved her visits. She would always show off dreadfully for a few days when she returned, refusing to eat anything other than ice cream or fromage frais and not wanting to go to bed at her usual time! We had also by this time formed extremely close bonds with several of the care team who would ring on a regular basis to check all was okay and who had the uncanny knack of never forgetting a birthday or important appointment. We could of course, and often did, telephone for a chat if we were worried about something or just going through a difficult time.

Little Bridge House is there to help families in whichever way they wish and to look after your child as you would look after him/her at home. When the end of a child's life is near Little Bridge House will be there to support you; helping you to do things the way you want in whatever way that may be with a quiet and dignified reverence. Many children have died at Little Bridge House, some of these have been expected others were more sudden. Some

children have died elsewhere and been taken to Little Bridge House before the funeral enabling the care team to support the family and help with any arrangements.

When Emily died, unexpectedly, on 1st March this year it was Little Bridge House I telephoned with the news first – I needed them. It wasn't questioned or debated just understood and within three hours Catherine and Liz arrived at our home.



Although we were beginning to be surrounded by friends and family members who love us it was Catherine and Liz who intuitively understood and despite their own sadness, for they loved Emily very much, were able to begin to guide us through the processes and decisions that had to be made. Catherine stayed with us that night and we planned Emily's service – a goodbye celebration that has become one of the most beautiful and poignant memories of Emily that we have. Little Bridge House printed the service sheets and Catherine came back on the Saturday not only to talk about Emily at the funeral but to be with the five of us as we put her into her coffin.

INFORMATION

We have been back to Little Bridge House since Emily has died. There has been a special weekend for bereaved families where we were all able to explore our feelings and think about Emily in a new way – a way that wasn't connected with illness and the anticipation of her death. Then during the summer we have been down for a few days holiday which gave the children a chance to enjoy the facilities again and for us to say our goodbyes. Little Bridge House will be there for as long as we need them and we have made some very special friends who I know will be there for a lot longer.

When you have a child diagnosed with a terminal illness you start to build – you build and develop memories for a time when that child will no longer be there. We have many very precious memories of Emily – a lot of them are of her at Little Bridge House.

Susan Hayward – Emily's mum



There are 20 children's hospices across the UK, with many more at the building or planning stages. Care is free for the families who need it. If you would like a list of children's hospices, or would like to find out more about what we do, please contact:

The Association of Children's Hospices
151 Whiteladies Road
Bristol
BS8 2RA
Tel/Fax No. 0117 9737299

We would love to hear from other families who have experience of other children's Hospices around the UK.

Information Society (dis)Abilities Challenge (ISdAC)

This is a newly formed European organisation who mission is "To instantiate an organisation of people with disabilities (PwD) to:

provide information to the PwD constituencies concerning Information Society (IS)

Develop a clear mandate for actions towards inclusion of PwD in IS

Stimulate and steer the proposed actions under the ISdAC mission"

The European web site is at:

<http://www.isdac.org>

The aim is to broadcast the ISdAC name as far and wide as possible in order to reach interested groups, individuals and influential bodies.

Orange Badge Update

A new leaflet is available outlining how to use the Orange Badge Scheme correctly. The leaflet, which is also available in audio and large print, can be obtained free from:

DETR Free Literature
PO Box 236, Wetherby
West Yorkshire, LS3 7NB.
Tel: 0870 1226236
Fax: 0870 1226237

From January 2000 Orange Badges will be replaced with blue ones which will be recognised throughout Europe allowing disabled people to access local parking concessions. Your badge will be replaced automatically when it comes up for renewal, but if you are going abroad before then ask to have it changed first.

OVERSEAS NEWS



Jordana Kilgour – Hurler disease

She may be silent in the picture but believe me, in real life, she is Miss "Baby-Talk a Lot". If she is not telling us some grand story, she is shaking her finger and telling our dogs to behave themselves. Her favourite TV programmes are Teletubbies and Barney. Her favourite foods are toast and anything with cheese on it. She loves to give hugs and hates to say "Bye" to anyone, it makes her cry.

Belated birthday wishes from all her family especially; Mommy, Daddy, Bandit & Puppy.

Her parents Wendy Taylor and Jeff Kilgour have asked that this birthday entry be put in our newsletter. Jordana obtained a Placenta-Cord blood transplant in September 1998 and we hope that she is doing well. Jordana and her family live in the United States.

Dear Friends,

My name is Magdelene Popek. I'm 17 years old. I attend to Private Female School. I learn foreign languages there; English, German and Latin. I find my future with English language and I command English some. I would like to speak English very well. I think, that the best way to studying this language is staying in England, with English people and speaking with them. I have thought many times about departure to language schools in England, but it's very expensive. I'm not going to burden my parents because they pay enough for my education. I think the best chance for me could be departure to England. I would like to work during Summer holidays (July, August) to earn some money for my stay in England. I can work for example, as a baby-sitter for children will with MPS. I know this illness well because my 18 year old sister is ill with Sanfilippo disease. I would like you to think about request of my departure. Thanks for your interest.

If you think you can help Magdelene, please write to: Magdelene Popek, OS Kochanowskiego 9/31,



RESEARCH

The following note was sent to the MPS Office by Dr. Martin Bax, Senior Lecturer in Child Health in the Paediatric Research Unit at Chelsea & Westminster Hospital, for inclusion in the newsletter.

Dr. Martin Bax
 Community Paediatric Research Unit
 Chelsea & Westminster Hospital
 369 Fulham Road
 London SW10 9NH.

Sanfilippo Questionnaire

“Many thanks to those of you who replied to the questionnaire about sleeping difficulties. The information obtained is extremely valuable. We are still in need of a larger sample of replies, so I would be most grateful if anybody willing to complete the simple form would contact *Angela Ratcliffe* at the Society as soon as possible”

**Development Officer
 Research and Treatment**

As you will have seen from the Chairman’s Report the Society has received a grant to continue and expand the European MPS database globally.

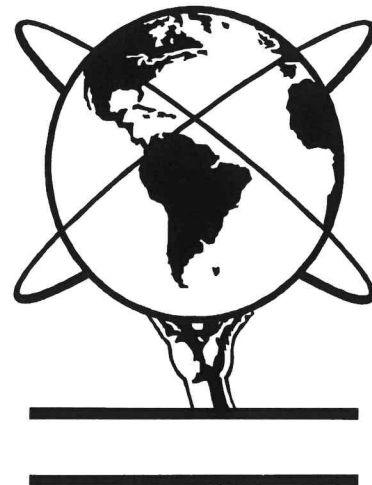
As of 1st November, Angela Ratcliffe will be undertaking this work as well as liaising with the international MPS Societies and co-ordinating information on research and treatment.

Any families who would normally contact Angela for family support should now contact Hannah.

DID YOU KNOW?

United Kingdom – The shortest mature human ever recorded in Britain was Joyce Carpenter born 21st December 1929 of Charford, now Hereford and Worcester, who stood 74 cm 29 in tall and weighed 13.6 kg 30 lb. She suffered from Morquio’s disease which causes deformities of the spine and shortening of the neck and trunk. She died on 7th August 1973 aged 43.

Taken from the Guinness Book of Records.



FUNDRAISING

Nowell Family Garden Fete

The fete was held in August in the gardens of Edward and Holly Nowell’s. It was attended by the following MPS families Gunary, Chisling, Pidden and Morley as well as friends of the Nowells. Everyone had a great day. Morris Dancers and face painting were just a few of the attractions.

Thank you to Edward and his family for the many thousands of pounds they have raised for the MPS Society in recent years.



In the photograph is Jackie Chisling along with Bill Pidden enjoying their ice creams. Hannah Chisling and her friend Natalie Pidden are also having a good time.

Holly and Edward Nowell who arranged this fete said that they had had a word with Edward about the weather, to make sure that the rain kept away. (Edward passed away recently but the family still wanted the fete to be held). On the day it stayed fine and the family felt that Edward was keeping a watchfull eye on them all.

Holly Nowell with the Mayor and Mayoress.



Bill and Natalie Pidden along with Jackie and Hannah Chisling

FUNDRAISING

The MPS Quilt

My name is Shirley Hawkins and my grand-daughter Carissa Aggett who has Hurler disease lives with her family in Bridgend, Glamorgan. Carissa is in the photograph below with the quilt.



A few years ago six ladies, who regularly attended local patchwork and quilting classes decided to form a group call *Homestead Quilters*. Meeting in each others houses we decided to make full size quilts to donate to various charities for fund raising. We agreed to take it in turns to nominate a charity on a yearly basis. This year was my turn and I nominated the MPS Society as my choice.

As a family we have been very grateful for the help and support so freely given over the years. Back in the days when everyone went to the Manchester Children's Hospital clinic we were so impressed by the friendly welcome shown to us. We were treated like long lost friends, which helped us no end. I felt that the idea of making a quilt was a means of repaying all the help and kindness that the everyone in the MPS Society has given.

The biggest decision was making our minds up which design to use. So searching through countless books and magazines we settled on an American pattern called Martha Washington Star. The fun really started then with the choosing of the materials to use. We all set off to Birmingham to The Cotton Patch, a shop specializing in quilting materials and spent an enjoyable few hours deciding what to use. This particular shop is well used to groups of ladies descending on them with vague ideas of what they wanted. Having made our purchases and making a good day out of it we returned home.

It was then a question of working out exactly how many pieces of the various colours would be needed and getting the rotary cutters out. In all it took about 8 months to complete. After assembling all the pieces that make up the pattern, the wadding and the calico backing were added. The actual quilting was then done on the sewing machine. Many hours of pleasure and companionship went into making the quilt with the hope that someone would have as much pleasure using it as did those who made it.

We then bought the quilt up to the office and gave it to Angela and Sheila to take to the MPS Conference to raffle.

Shirley Hawkins

FUNDRAISING



Above is a photograph of some of the people involved in the making of the quilt

We have held off drawing the raffle as we thought that it was such a beautiful quilt and that people who did not attend the MPS Conference might like to have the opportunity of winning it. Therefore if you would like to donate £5 a ticket for the quilt, write your name and address on the back of each cheque for £5 and we will draw the lucky cheque at the Southwest Christmas Party on 5th December 1999. The lucky winner will have an early Christmas present and the Homestead quilters will have helped the MPS Society.

Sheila Duffy – Project and Development Officer

You will all have received the MPS Diary and Xmas Card Flyer with this newsletter

Please pass the order form around friends and families so that they may also purchase the MPS Xmas cards.

Please then send the order form into the MPS office and we will post them out to you as soon as possible.

FUNDRAISING

FUNDRAISING EVENTS

The Society is grateful to the following who held fundraising events

Justin Hancock – Chester half Marathon
 Clare Woods – Womens 10K Race
 Marina and Dave – Car Boot Sales
 R & S Enoch, P Claridge, R Fleming, D Foster – Sponsored Bike Ride
 Barbara Rollinson – Monsters & Mummies night
 Mrs Brockie – Sale of Promotional Goods
 Mrs Cockman – Monies collected from bags and cans
 Caversham Charity Folk Festival
 Mrs Mossman – Car boot sale via. Shop
 A R Mellor – Surgery waiting room collection
 Alison Pickard – Loose change collection
 Lyn Longhorn – Fundraising Luncheon
 Andy Hastie – Police Band Fundraising Evening
 Francesca Messina and Gemma – Blackpool & Flyde Casino Night
 Edward & Holly Nowell – Garden Fete
 Jaguar Release Dept – Office Collection
 Pistons are Broken Lodge 10613 – Charity Night
 Ladies of Coombe Hill Golf Club
 Status – Raffle
 Edgebarrow School – Year 8 pupils
 Rockwell Automation – MPS Conference

CHARITY BOXES

Pat and John Lomas
 CML Jones & Partners
 Mrs Todd
 Edward and Holly Nowell
 Status
 Mrs Hughes

DONATIONS

The Society is grateful to the following who made donations

Sobell Foundation
 Charity Flowers
 Mrs Booty
 Louise Croghan/Dawn Rushby
 Mrs Heritage
 Helen and Alan Hall
 Elf Atochem
 Trull C.E. V.A. Primary School
 Hamish Husband
 Fyffes plc
 The Woodcote Trust
 Mrs Fasey
 Kirkhill Golf Club
 Bentley Productions Ltd
 Inner Wheel Club of High Wycombe
 Eastern Electricity
 Cytogenetic Services
 Mr and Mrs Lynch
 Amersham and Chesham Lions Club
 FMCG Field Marketing
 Mrs Wanda Lloyd
 DeClermont Charitable Co. Ltd
 Mark Wheeler
 Marianne Ryan
 Lucy Evans
 Marsh (Charities Fund)Ltd
 Lorna Fairhead (Young Enterprise)
 FRS Charity Commission
 Dawn Nelson

IN MEMORY

Edward Nowell
 Arthur Jobson
 Dr Stuart Phillips
 Alice Ruth Beniston
 Olivia Bailey

AREA SUPPORT FAMILIES

EAST ANGLIA

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

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

HOME COUNTIES

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

MIDLANDS

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

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

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

NORTH EAST OF ENGLAND

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

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

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

NORTH WEST OF ENGLAND

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



AREA SUPPORT FAMILIES

POTTERIES

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

SCOTLAND

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

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 MPS families requiring support usually given by the support family for this area may contact any family listed on these 2 pages or the MPS Office.

SOUTH-WEST

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

Anne and Gordon Hill Tel: 01404 813023**
Bowhayes Farm, Venn Ottery, Ottery, St Mary, Devon EX11 1RX.

WALES

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

YORKSHIRE & EAST COAST

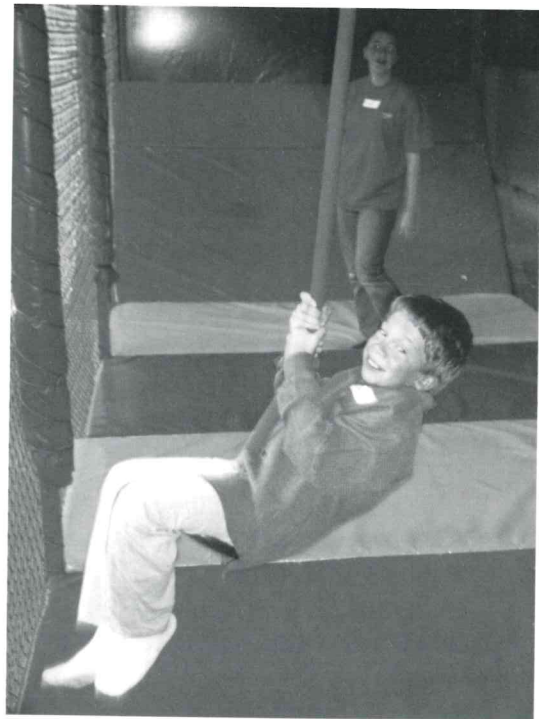
Barbara and Trevor Rollinson Tel: 01724 341534**
43 Crosby Avenue, Scunthorpe, Humberside DN15 8PA

NORTHERN IRELAND ORGANISING

Margaret Kearney Tel: 01265 769565
7 Leyland Heights, Ballycastle, Co. Antrim, Northern Ireland

Joan Christie, Bernie Drayne, Kieran Houston, John Larkin, Martina Larkin, Debbie McAfee, Michael McCawille, Andrew Sheilds, Alison Shields, Dr. Fiona Stewart.





The Society for Mucopolysaccharide Diseases

46 Woodside Road, Amersham, Bucks HP6 6AJ Tel: 01494 434156 Fax 01494 434252
Registered Charity No. 287034

