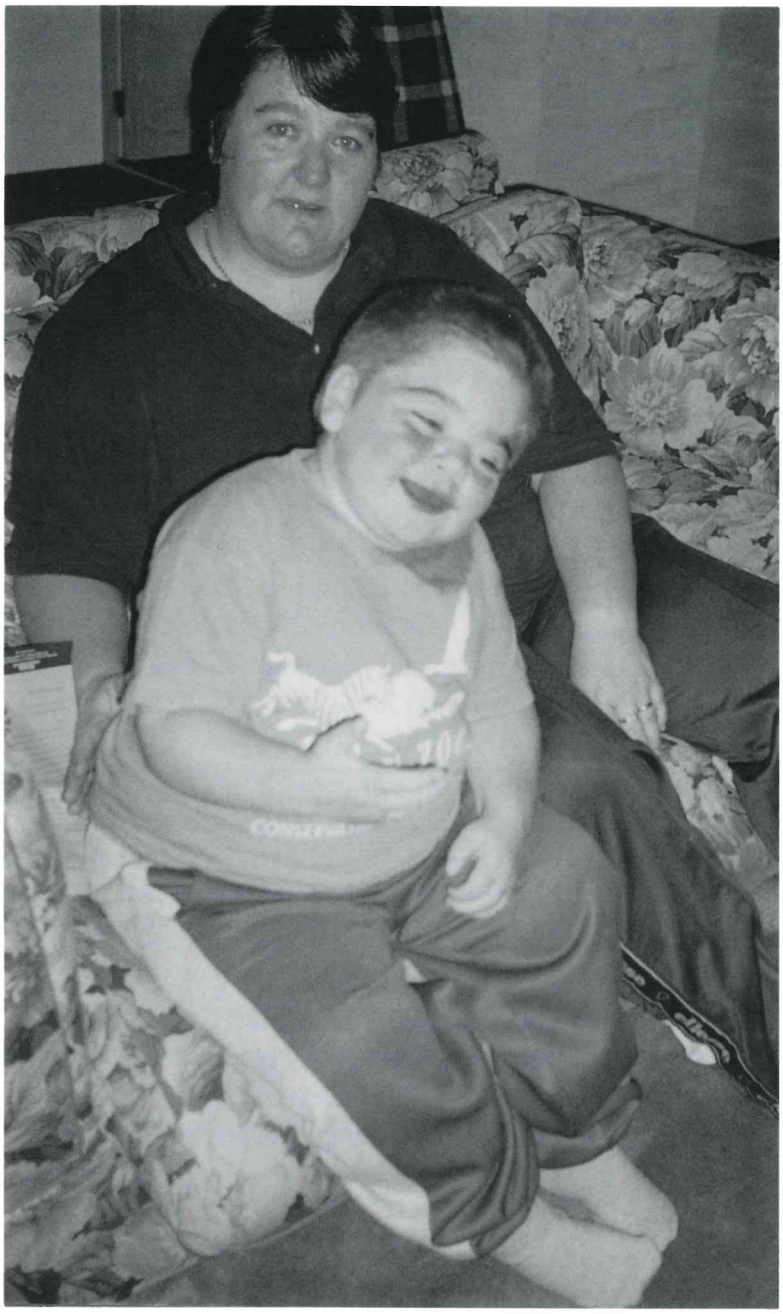
Newsletter

The Society for Mucopolysaccharide Diseases

National Registered Charity No.287034

Autumn 98



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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 over 900 families in the UK with children or adults suffering from Mucopolysaccharide and related diseases. It is a registered charity, entirely suported by voluntary donations and fundraising, and run by the member themselves. Its aims are as follows:-

To act as a Parent Support Group
To bring about more public awareness of MPS
To promote and support research into MPS

The Society operates a network of Area Families throughout 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 specilaist 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; Bristol 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 Disease, 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 Thomas Birch aged 6 years old who suffers from Hunter disease and his Mum at the MPS Family Conference in September 1998

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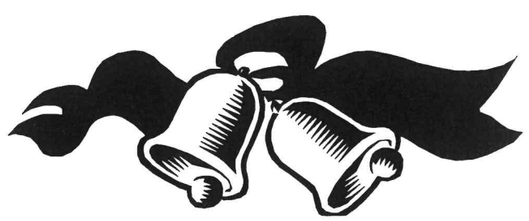
Deadline for the 1998 Winter Newsletter
4th January 1998



On behalf of the all MPS staff
(Christine, Sheila, Angela, Hannah,
Mary, Pam and Anne)
We wish you all a Merry Christmas

CHAIRMAN'S REPORT

presented by Vic Lowry - Vice Chairman in the absence of the Chairman
-Wilma Robins,at the Society's AGM Sunday 20th September 1998

In the past twelve months the Society, through its Amersham and Northern offices has responded to a large number of MPS families in crisis. 38 new MPS families have sought the support of the Society bringing the number of UK MPS children and young adults known to the Society to over 900. 20 families have lost their MPS child or young adult in this past year.

With so many demands on the Society, particularly in the area of family support and advocacy staff resources have been stretched severely. To help meet the increasing workload Anne Leech was appointed as Administrative Assistant in the Northern office. In the Amersham office we said goodbye to Joan Evans who has moved to Germany and Anne Brockfield who left to have a baby. Angela Ratcliffe and Hannah Crown have been appointed as Development Assistants.

The Society continues to have a presence at both the MPS clinics held at the Royal Manchester Children's Hospital (RMCH) and the Hospital for Sick Children, Great Ormond Street(GOSH). Very successful regional MPS clinics have been held in Belfast, Cardiff, Bristol and Glasgow. An annual clinic for East Anglia is planned for the New Year.

In addition to this, the MPS Family Weekend Conference, a day conference for MPS families and professionals was held in Belfast in June and a similar conference will take place in Scotland at the end of this month.

The Society has continued to provide training and support to Area Support Families, many of whom have organised very successful and much appreciated activities in 1997 / 98.

However the Society is carrying out a review of the role of Area Support Families and the possibility of establishing a network of 'befrienders'.

In the third and final year of the National Lottery Charities Board Grant, 17 MPS families enjoyed a one week holiday at Filey in North Yorkshire in July whilst in May, 15 physically disabled MPS youngsters took part in an ActivityWeek at Bendrigg Lodge in the Lake District. Again this week could not have been possible without the practical help of volunteers from the Royal Logistic Corps.

In October 1997, 12 bereaved families planted oak saplings in memory of their MPS children and young adults. We were joined on the day by Sir Andrew Buchanan Lord Lieutenant of Nottinghamshire who delivered a message from Her Majesty the Queen. In July more than 120 bereaved family members met in the 'Childhood Wood' to remember all those who have lost their lives to MPS. Particular thanks go to Ron and Linda Snack who organised the day.

Jeans for Genes Day, 9 October 1997, was a great success and raised MPS nearly £225,000. This money has enabled the Trustees to award a similar amount in Research and support grants. New grants were awarded to Professor John Hopwood to research enzyme replacement for Morquio Disease and to the Royal Manchester Children's Hospital to fund 50 % of a second consultant's post specialising in Mucopolysaccharide Diseases.

CHAIRMAN'S REPORT

Jeans for Genes Day on 10 October 1998 promises to be even more successful than previous years with sponsorship from a majority of all the major Jeans companies and free advertising at London tube stations and bus stop hoardings throughout the UK. The schools Jeans for Genes pack contains specially written science teaching material geared to primary or secondary education.

Fundraising continues to be one of the Society's largest sources of income. The Trustees take this opportunity to thank all the families for 'thinking MPS' and for giving their time and energy to raise such tremendous amounts year on year. Special thanks, too, to our two student fund raisers who spend their Saturdays in the Amersham office putting together the MPS fund appeal packages to trusts and companies. Their efforts continue to be hugely successful. It is particularly pleasing that more than half the funding received in the current year has been 'new money' but there is no room for complacency. In the present economic climate when we are beginning to see Corporate Donors struggling to maintain their donations to charities. We cannot for a moment relax. We are appealing to you, therefore, to continue your unstinting efforts.

MILESTONES

New Families

Carol and Brian Fisher's daughter Tamale has Sanfilippo disease and they have recently joined the Society. Tamale who was diagnosed only recentlyat the age of 31 lives in Balby, Doncaster.

Deaths

Sadly Shane Dickson died on the 8 September 1998. Shane aged 11 years from Sutton Bridge suffered from Hunter disease.

Bethan Hosking from Tregar, Dyfed sadly died on the 17 July 1998 aged 11 years. Bethan suffered from Sanfilippo disease.

Sadly Ben Coole aged 15 years passed away on the 5 July 1998. Ben suffered from Gangliosidosis disease and came from Exeter.

Remember to circulate your Xmas card flyer to your friends and families and send orders to the Amersham office a.s.a.p.

'Ode to a spell chequer'

I have a spelling chequer,
It cam with my PC,
It plainly marks for my revue,
Miss takes I cannot sea.

I've run this poem threw it,
I'm shore your pleased two no,
It's letter perfect in it's weigh,
My chequer tolled me sew.

MPS CONFERENCE

The 1998 MPS Family Conference

What a wonderful weekend was had by us all. Our first Sibling Conference went very smoothly and the children have asked that there be another one next year. The programme for Saturday and Sunday was a great success and we would like to thank all the speakers, professionals and families who did a brilliant job.Alas, Sunday our last day had to finish with an exciting ending for the children but not the volunteers and parents. Yes, one of the coaches broke down and all the mums and dads were waiting to have their lovely Sunday lunch when alas, the children did not turn up on time. They did eventually arrive and most managed to have something to eat before we all said our goodbyes and returned home.

On behalf of the families we would like to thank all the volunteers for doing such a wonderful job with all the children. They certainly seemed to have enjoyed themselves as you will see from the photographe.

We would also like to thank the staff at Thorpe Park, Pot Bellies Restaurant, Jarman Park and Woburn Safari Park for helping to make the weekend so enjoyable for all the children and volunteers.

Also the MPS families who helped by selling our Xmas cards, promotional goods, and other fund-raising items in the reception area. We could not have done without them. And last but not least all the staff at the Stakis Hotel for their help over the weekend.
They overcame the many problems that we put their way with ease and yet again the service and food was wonderful.
A highlight of Saturday afternoon was a visit from the Towersley Morris Men. Many of the children (and adults) were mesmerised by the colourfull costumes and amazing dancing.

Also a personal thank-you to Mary, Pam, Anne, Christine, and especially Angela and Hannah who help me through my first Conference that I had organised. We hope that you will now be able to put a face to our voices at the other end of the phone in the Amersham office. Yes - we were the three ladies who you saw behind the MPS desk.

Sheila Duffy
Development Officer

MPS CONFERENCE

Our First Conference

Friends and family have been asking us all about the MPS Conference and we have been very happy to tell them all about it. In fact since we drove out of the hotel car park, we have talked of little else; the new friends we have made, the sad bits, the funny bits, the food, the drink (and what do Scotsmen really wear under their kilts !!!) the workshops and seminars, the professional, the children etc. etc. ....

Emma and Jack had such a wonderful time too, Sue and Jeff looked very weary when we said our goodbyes. It was very reassuring to know that our children were in such capable hands.

It is hard though to put into words the feeling of friendship, support and understanding that we shared with so many familes over the weekend. I read a book recently and found this quotation from Henry Miller I think it probably says it all - "Only in sorrow and suffering does man draw close to his fellow man; only then, it seems, does life become beautiful".

Mandy Stuart - Jack has Hunter disease

Sibling Workshops

Two sessions of the siblings workshops took place; the first had nine participants aged between 12 and 16 years, the second included eight children of 11 and 12 years.

Both workshops began with participants introducing themselves and telling others their age and where they had come from. The moderator introduced a booklet produced by the Genetic Interest Group, "Genetics ? What's it got to do with me?", specifically for children who have a sibling with a genetic disorder. The booklet is about Adam, a fourteen year old boy with a sister, Sophie who is affected by a genetic disorder. Adam tells in his own words how he felt left out because his parents spent so much time helping Sophie - and describes how he and the whole family came to terms with his feelings. The moderator asked if anyone wanted to read pages from the booklet. In both sessions, someone volunteered and others read some of the follow-on pages followed by some discussion.

The session with the older children developed into the value of siblings meeting as a group. They felt that it would be best to meet informally and chat about their feelings without adults around as there were many issues they felt they were uncomfortable voicing in front of parents and other adults. The possibility of a newsletter especially for young people / siblings was also discussed.

The session with the younger children developed into a focus on what genes actually were, with children drawing how they visualised genes in their mind. The moderator then explained, using diagrams, how minute each gene was and the fact that they have an impact on our bodies physically.

The booklet proved to be a useful resource in opening up discussion around sensitive issues in a non-intrusive manner, allowing further discussion to develop through cues from the participants. It appeared relevant for both age groups.

As moderator, I felt the sessions had allowed a structured space in which participants were able to begin exploring issues as a group that may, as individuals remain as thoughts.

I also felt that sessions such as these may prove particularly useful if, as in this case, they start from an early age. Children can get to grips with the facts about genetics and its implications, at a time when they are inquisitive but sometimes unable, as yet, to articulate their questions and concerns, without help.

Aamra Darr -Research & Development Officer

MPS CONFERENCE

We thought that it would be useful to publish some of the talks that the parents presented at the MPS Conference and below are three of the talks from the Seminars that took place.

"Managing a post BMT child"

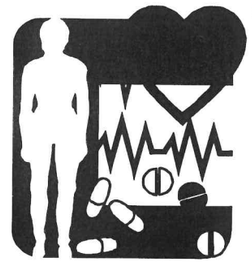
Having returned home after a super weekend at the MPS Conference I felt that I must put pen to paper and say a big WELL DONE to all involved in organising the event. The Conference on Saturday morning was very interesting and in parts very heart moving. The workshop we attended in the afternoon was excellent. Our group was chaired by Dr Charles Penncok with Dr Ashok Vellodi taking the forefront with his presentation of 'Managing a Post BMT child'. Families listened about carpal tunnel syndrome, corneal clouding and various other medical and social matters of interest to everyone. We listened to Bob McKnight speak about Sarah's history. Everyone contributed to the final discussion with some of their own personal experiences. Below is a summary of Bob's talk, Bob's talk should have been entitled 'Why didn't we get a helicopter?

Over the past two years it has become very apparent from the parents talks that although we live in different parts of the country, much of what we thought only happened to us was happening in parallel to other families. That is one of the most important functions of the MPS Conference along with, of course the Professional input.

The main theme of his talk was our daughter Sarah who was diagnosed with MPS 1 in June 1993 at the age of 9 months. Prior to this she had an inguinal hernia reparied at 5 months in our local hospital. Had we have known then what we know now this fairly minor operation would have been approached with a lot more caution by us. At about a year old Sarah had her first bout of bronchiolitis and then after an anxious wait at 15 months old Sarah has her first transplant. I think in hindsight Sarah rejected the bone marrow within the first five minutes, but we waited in hope over the next six weeks that it had taken. Unfortunatly her own bone marrow grew back.

At 18 months she had her second transplant and this made the first seem like a breeze. Nine day post transplant Sarah caught pneumonia and her weak state was no match for the illness. Her little body lacked the strength to keep going and so she arrested. Luckily she was in theatre at the time and was revived. Isolation out of the window she spent five long days and nights in Intensive Care with us constantly being told if she makes it through the next 2 hours, then 4 hours, then 12 hours and so on. She did and the joy of the Bone Marrow Unit staff was evident. It was only then we realised that they had resigned themselves to not seeing Sarah again.

Slowly Sarah's blood group changed, enzyme activity appeared and she gained strength. 12 weeks on and we headed home. The road from Pendine to Manchester became very familiar to us as the check ups were weekly to begin with, then fortnightly and so on. It's exactly 204 miles each way !



MPS CONFERENCE

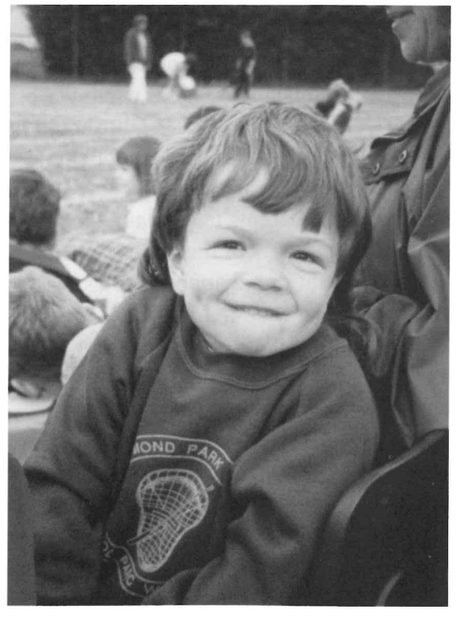
Then the corrective work began in June 1995. Sarah had her first back operation which consisted of doner bone being used to fuse four of her vertebrae together. Just a short stay in hospital this time followed by the next 3 months in a plaster jacket from her shoulders to her thighs. Not the most comfortable of summers for Sarah, yet she endured and came through. Unfortunately the procedure didn't prevent further deterioration and so it was back to the drawing board. In the mean time her neck was checked and we were told that Sarah would need complicated surgery to correct that fault. Back to Manchester in October 1998 for further spinal surgery, this time a vascular rib was taken, Sarah has enough to spare and this was used to scaffold what is now quite a lumpy part of her back. This operation did not correct Sarah's back curvature, rather prevented any further damage. Again, about 17weeks in plaster. Nothing seems to phase Sarah. Now she is in her fourth supporting brace - we have a collection on top of the kitchen dresser, so we can see how she's grown.

Other small things such as a leg brace, one foot two sizes smaller than the other, hearing aids (now no longer needed) are there to be lived with and overcome. Sarah refuses to allow anything to prevent her doing what she want. She is a happy, social and determined little girl- an example to us all. Just now Sarah doesn't know she is different from other children. She even won a medal for running in her school sports. A long way from being told on June 17 1993, her mum's birthday, that our little girl would never be a teenager. Someone should have told Sarah.

I do now feel the way forward is to have more input from transplated families. Having attended the Conference over the past four years, I definitely think that the families of BMT children could give so much and also benefit from each other. A successful transplant so much changes the outlook, and the more feedback families have, the easier it becomes for everyone to have an understanding of what the future might bring. There are many possibilites of us all pulling together: for example - having a mini conference on the Friday afternoon prior to the main weekend; BMT family days or may be a family contact. Knowing each other a little better might help us to cope a little better and give us hope for tommorrow.

Rhian & Bob McKnight - Sarah has Hurler disease

(Bob presented his story at the MPS Conference and everyone thought it was most informative).



MPS CONFERENCE

"Sam is in mainstream School"

We had Sam's diagnosis in November 1994, when he was 4 years old. At that time he was in a playgroup connected to a mainstream school close to his Grandmothers house. Both myself and Mark work full time therefore this seemed the most appropriate pre school placement. The following February we moved too within half a mile of Grandma's house, still in the fog which seems to take months to dissipate after diagnosis. Sam was still attending playgroup and we did not notice that Sam's playmates were gradually disappearing up into the mainstream school whilst Sam was left behind, I think his lack of height hadn't made me aware of the fact that he was surrounded by three year olds. In March realisation dawned. I approached the playgroup supervisor; she looked blank and ultimately embarrassed. Sam's short stature had also not made her realise that he was getting too old for the playgroup. I think he just blended in too well with the new recruits. I wasn't cross with her, but I couldn't stop the feeling of rage inside me. As far as I could see Sam had been forgotten. The ugliness of the diagnosis drowned me again. I felt so upset I immediately stormed across the playground to see the Headmaster. I made up my mind Sam was going to be treated fair.

Typical me, I flair up without knowing the facts. Apparently the Headmaster had written to us three months previously (at our old address) to inform us that we lived outside the catchment area. Sam hadn't got a place and wouldn't be offered one. I explained the situation to him, how we had moved,Sam's disease and the close proximity of his Grandmother etc. The man would not budge. I don't know how I got home that day, I was so upset.
Several glasses of wine later Mark and I knew what we had to do. The solution to our problem was to get Sam a Statement of Special Educational Needs.

One phone call to the County of Berkshire's education department led to a mountain of paperwork, queues of professional waiting to examine, report, prod, poke, interview, evealuate, speculate, intimidate. We knew what we wanted and were prepared to stand our ground. Sam needed to be at a resourced mainstream school and we knew exactly where. By pure chance a small village school located 5 miles away had exactly what we wanted to maximise Sam's schooling potential. It offered the following;

* Full access to the national curriculum and an academically challenging programme.
* A physical environment, which is readily adapted to the needs of pupils with physical disabilities.
* Special support assistance to enable access to materials for learning and when necessary mobility.
* Specialsed equipment, such as lap top computer, to ensure full access to the curriculum.
* A well planned liaison programme that ensure that the parents, school staff, medical specialist and therapists are able to collaborate in the child's best interests.

Too good to be true? No - a school such as this really existed and by pure determination we got what we wanted for Sam. Would another school located nearby have provided Sam with the support and promotion of independence? Maybe, but he would have been the only physically disabled child there. Sam's self esteem needed to be fostered by social success. We didn't want our child to be treated differently by teachers or pupils, for them to show fear, discrimination or exclusion.

MPS CONFERENCE

Lamb's Lane school accepted the disabled children in their wheelchairs. Every child seemed an equal. We spoke to the teachers and Headmistress about Sam's disease and gradual deterioration that would occur. They told us what we wanted to hear. Sam would be treated exactly the same as the other pupils, but would be supported by an occupational therapist, physio and any equipment needed would be made readily available. Independence was promoted and any assistance needed (help with getting dressed was encouraged not by adults but by fellow pupils).

Our application for the school was supported and on the 6 September 1995 Sam started his first day at school. Sam is bright child and very sociable. He has fitted into mainstream school well and has made many friends. Weaknesses have been identified early and objectives set in order to optimise his abilities. For example Sam's handwriting is not so good primarily due too poor wrist control. He has now got a lap top computer and is concentrating on his typing skill. Initially his OT persuaded Sam to use chunky pencils to improve his grip. Those who know Sam know his strong willed character and the refusal to be different, he has proved to be a challenge to all his teachers. No chunky pencils for him! Not when everyboy else were using ordinary pencils. The only solution was for every child in Sam's class to use the same chunky pencils that were assigned to Sam. Great success every child's handwriting improved! The same went for chairs. Sam refused to sit on the chair given to him, because it was different. So all the children had the same type Sam did. Hand splints look like "Power Ranger" gloves, all his mates wanted a pair too. Tony is his helper and best friend; Tony is eight and would do anything for Sam.

Sam enjoys school and we are kept closely informed of his progress. We go to annual reviews of his progress and he seems to be keeping up academically with his peers. He has made many friends and we haven't had any report of bullying. We seem to be under the same pressure of others parents, the need for new designer trainers, premiership shirts and trendy haircuts. This is how we want Sam to be. We want him to be academic, a success in his social life - normal.

This is not unrealistic. If Sam can adapt to his physical changes so can others. He will not be treated any different to his brother Ryan. We want Sam to have the same life choices, chances and pressures of the kids. I want him to go onto senior school and do well. This is his right.

Rachel Wheeler - Sam has Morquio disease
(Rachel presentated this talk at the MPS Conference - Well done Rachel.)

"Adam has severe learning difficulties"

Adam has severe learning difficulties and attends a Severe Learning Difficulites school in St Albans. He began his school life at the age of four. At this time he could feed himself, communicate fairly well, was able to count from one to thirteen by rote and knew the alphabet. He would ask us to draw objects for him and would then colour them in himself and he loved to sing and dance. However, he wasn't keen on playing with other children, found it difficult to work alongside them and most of all he hated change. Along with his behavioral problems and his toiletting habits we were worried just how well he would cope with this new way of life.

MPS CONFERENCE

We had met with some resistance from the education authority. During the statementing process we were visited by an educational psychologist who after meeting with Adam for maybe half an hour thought that mainstream nursery provision would be the best option. I recall that Adam threw one of his temper tantrums and I was told it was because I was invading his space. This gave us cause for concern as it appeared that they hadn't quite grasped some of the effects of Adam's condition. With Christine's help we arranged to visit Watling View school. We walked into early years and to our amazement Adam went and joined the group and allowed us to see the rest of the school without him. Normally he wouldn't let us out of his sight. It seemed as though Adam had made up his own mind and having three MPS children already in attendance, so had we. A meeting was held where we aired our opinions and it was finally agreed that Adam should start the following term.

Adam was to be in a group with seven other children with a 1:2 staff ratio. He was to cover the full national curriculum with adaptations to suit his abilities. They were to incorporate 'Makaton' signing into his daily routine which we thought may be an extra method of communication at a later stage in his life. Although difficult at first Adam soon settled in and began to enjoy his new way of life.

Each year, Adam's statement is reviewed and new objectives are set according to his needs and abilites. Also, any other concerns involving equipment at home or maybe respite care can be put forward and relayed to the appropriate parties. Speech therapists and physios are also based in school should there be need in their respective area. Apart from the yearly review, parent involvement is encouraged and various events are held during the year where we are given the opportunity to meet with teachers and other parents.

We also keep a diary to record Adam's antics both at school and home. Adam is now coming up to his fourth year at school and has changed considerably during this time. He now uses photographs to recognise activites he'll be taking part in that day as his verbal communication has become limited. He can recognise some of the 'Makaton' signs and particularly enjoys it when accompanying a song. Adam enjoys school enormously and has advanced through the school with friends he has known since early years and hopefully will continue to do so until school leaving age which is nineteen.

We believe we made the right decision in choosing an S.L.D. school for Adam as it allowed him a short time for being top of the class and he has the long term stability that he needs.

I thought I'd close with some comments from Adam's report - His favourite subject you'll be surprised to hear is Food Technology. Adam enjoys food technology sessions, he is always eager to taste the ingredients. He finds it difficult to work with food and not eat it. He is always given an initial taste but on occasions can get quite frantic trying to reach all the ingredients - And that's Adam on a good day.

Denise Brown - Adam has Sanfilippo disease
(presented by Denise at the MPS Conference - Congratulations for getting thru it)

AREA FAMILY SUPPORT

To facilitate a better standard of care for all MPS families served by the Amersham office the area has been divided between myself and Hannah.

It seems sensible that I take the areas and families which I have already visited and come to know whilst Hannah takes over the remaining areas. We have done this as far as possible by county.

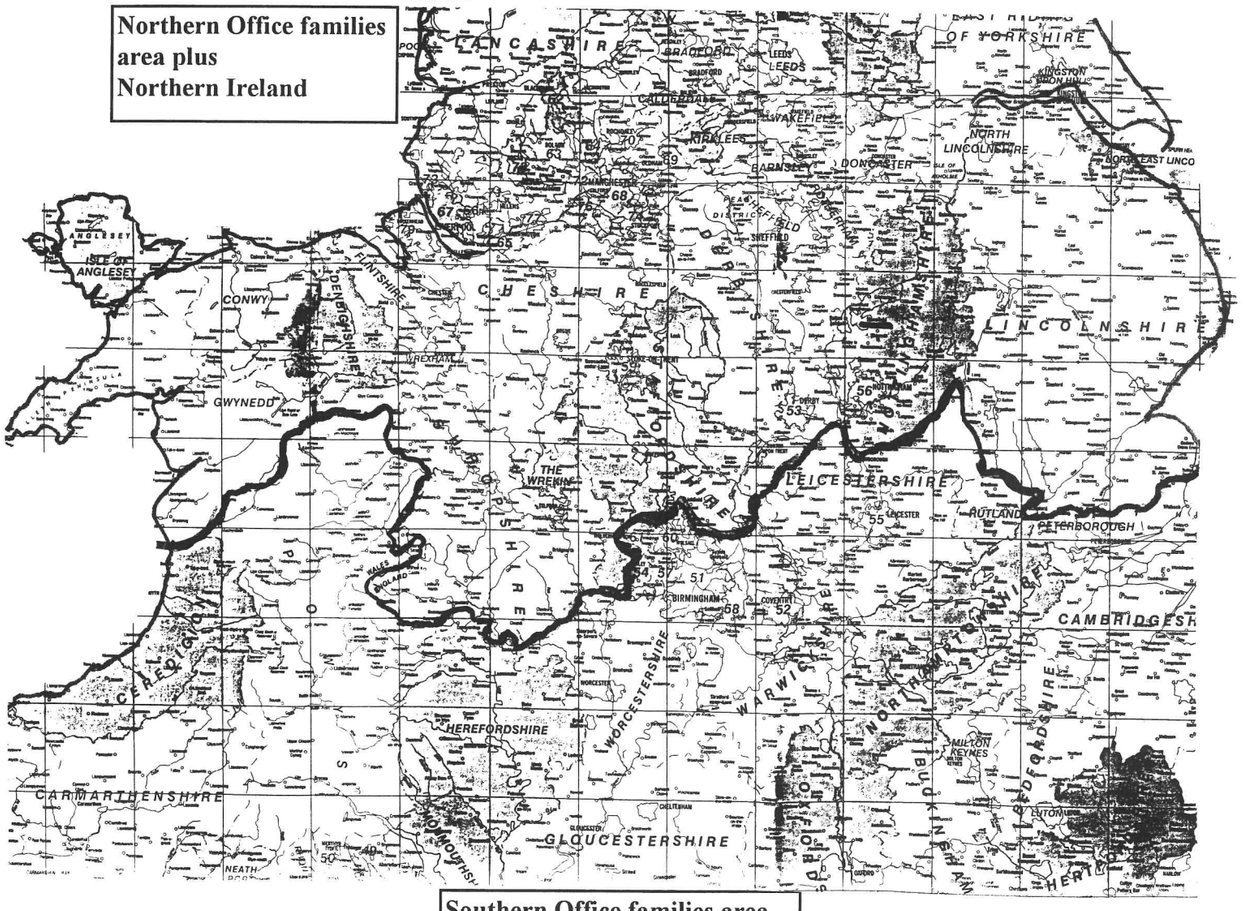
All future calls from families in these areas will initially be dealt with by Hannah or myself. It would be helpful when requesting advice or support if you have important addresses and telephone numbers available and can outline the issues.

Not speaking directly to Christine will not reduce the quality of care that you receive. If it is something which we have been involved in we may very well be able to help you ourselves but if we are unable to do so we will refer the matter on and if you tell us what is happening we will be able to push urgent issues to the top of Christine's ever increasing pile of work.

We are here to support you so don't hesitate to telephone, e.mail, fax or write if you need help or want a listening ear.

Angela Ratcliffe - Development Assistant

Northern Office families area plus Northern Ireland



Southern Office families area

AREA FAMILY SUPPORT

South West Area Family Day

On the 14 June families from the South West area gathered for a day out at Crealy Park, near Exeter, Devon. Seven familes joined us, some with aunts, uncles and cousins and we were pleased to see so many grandparents as well.

The weather was kind and we were able to base ourselves outside at a group of tables and chatted, swapping news and ideas.There was plenty to see and do. Various indoor and outdoor facilites and lots of animals to see in the farm section.

We were pleased to meet several familes we have not met before and hope to see you all again soon.

Anne & Gordon Hill

Kimberley Meaker - Sanfilippo sharing her granny and grandad with Louise Hill - Sanfilippo

Welsh Area Family Day

Christopher Rees - M3

On the 12 July we held our Barbeque at Bob and Rhian McKnight's farm. The weather was reasonably kind to us so the children wondered around the farm seeing the new kittens and enjoying the other animals. A great time was had by us all and it was lovely to see Angela from the Amersham, so we could all put a face to her voice.

A big thank you to to Bob and Rhian and their friends and family for letting us use the farm.

Mike and Anne Kilvert

AREA FAMILY SUPPORT

London & Home Counties - Xmas Party

They will be having their Xmas Party at the Loddon Vally Sports Centre, Lower Early, Reading on Sunday 13 December from 2.00 - 6.00 pm. Please reply to their invitation a.s.a.p. so that we can reserve you a place.

North-West & Potteries Xmas Party

Sunday 29 November from 12.30 to 5.00 pm at the Devonshire House Hotel. For further information contact Selma Oulton.

Wales - Xmas Party

Sunday 6 December at Clydach Hall, Swansea. Please contact Anne and Mike Kilvert for further details.

South-East Xmas Party

Sunday 6 December at the Wheel Inn, Burwash Weald. Please contact Robin and Mary Gooch for more information.

South West - Xmas Party

Please contact Jackie Chisling Tel: 01225 764851 if you would like to go to Wookey Hole, Wells on Sunday 6 December 12-4 pm for the Xmas Party.

North East - Xmas Party

Ann Thompson and Barbara Arrowsmith have booked St Thomas Aquinas church hall, Darlington on Sunday 29 November from 12.30 to 4.00 pm for their Area Family Xmas Party. Please contact them to reserve a place.

Yorkshire - Xmas party

David Briggs and Barbara Rollinson will be having their Xmas Party on Sunday 29 November at the Paces High Green Centre, pack House Lane, High Green, Sheffield. Please contact them to reserve a place.

FAMILY NEWS

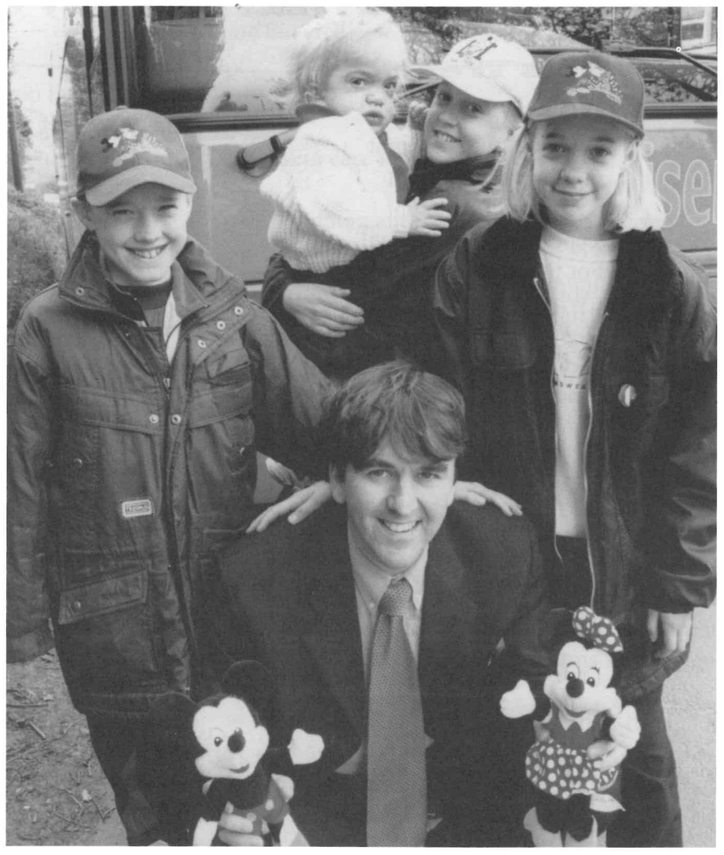


Photo of Katie (Hurler) with her brothers Gary and Andrew and sister Laura.

Katies' visit to DisneyLand - Paris

Last December our local newspaper did a beautiful article on Katie. This was noticed by Robert Shaw who runs Harry Shaw Travel based in Coventry. He wrote offering us a free holiday in Disneyland - Paris.
We has been going through a bad 'downer' when he wrote and it was wonderful to have something so brilliant to look forward to. It seemed like a turning point for us all. It was lovely to meet such a warm and generous man and we cannot thank him enough for the wonderful holiday and for putting us back on track.The children especially had a wonderful time after a very exciting build up. Katie turned out to be scared of the Disney characters but loved the rides we took her on, especially 'It's a Small World'. We remembered to get the disabled pass which ensured we went to the front of the long queues - so we almost 'did Disney in one day'.

Lindsey Devine - Katie's mum

FAMILY NEWS

Life's Weather

The future is bright
But you just might
Awake in the night
Deepest feelings you will
For the pain and the ill
When it's all up hill
Worst is the fear
So you find top gear
And good will appear

That storm passed by
In the wink of an eye
Please tell me why
We needed to cry
Like the clouds in the day
They're black, white and grey
If I could only
Have my own say
I'd get up there
And blow them away

Life's like the weather
It changes you know
Rain in the air
Down comes the snow
The sun comes out
Then the birds sing
There's no doubt about
We've done the right thing

Sometimes it's warm
Sometimes it's cold
Now you've been told
About our life
I am what I am
Still the man's wife
And our little girl's MAM.

by
Sarah's Mum -
Rhian McKnight

(Sarah suffers from Hurler disease)

INFORMATION

The Lifetime Service

The Lifetime Service was set up in 1993 as a research project to consider the particular needs of children with non-malignant life threatening illness and their families. The Service is now established in the Bath Clinical Area, providing nursing and psychological care to children and their families.

Avon Health Authority has now purchased this service for their area, and so from October 1998, a team of nurses and psychologists will be establishing a service in the Avon Health Authority area.

The Avon Lifetime Service will offer a needs led, community based service for children with life threatening or life limiting illness that is metabolic, neurological or genetic in origin. (Life limiting is defined as premature death befor the age of 40 years and childhood as 0-19 years).

It will work closely with primary health care teams, and other professionals to enable the child and family to live as normal a life as possible and to care for the child at home or in the place of their choice.

The impact of a life threatening illness on all family members is recognised and the Service is committed to enabling families to cope to the best of their abilities.

The Service aims to achieve this by assessing both nursing and psychological needs, and planning care with the family to provide for their needs. This is reviewed regularly and changes as needs arise.

Nursing care includes:

- Planning and implementing care needs
- Co-ordinating care at home to bridge the gap between hospital and community care
- Training parents/carers to carry out specific nursing care
- Discharge planning and review meetings of care packages
- Support and advice for parents
- Terminal and bereavement care

Psychological care includes:

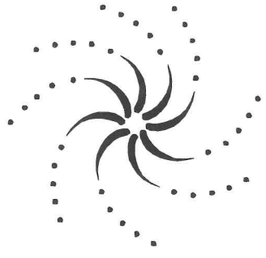
- Helping children and families communicate
- Preparation for hospital or medical procedure
- Helping families come to terms with diagnosis and prognosis
- Bereavement work in preparation for and after death
- Groups for siblings, parents and the ill children.

Their address is;

The Lifetime Service
Child Health Department
Newbridge Hill
Bath BA1 3 QE

Tel: 01255 420785

Mary Lewis
Comminity Paediatric Nurse



INFORMATION

Invalid Care Allowance (ICA)

This is a weekly benefit payable to parents who look after a child who gets the Disability Living Allowance care component at the middle or higher rate. You may be able to get ICA, currently worth £38.70 a week if;

- You look after your child for at least 35 hours a week. *You do not have to be doing anything special, just being with your child for company and support is enough. You can easily meet this condition in the evening or at week ends if your child is at school.*
- You do not earn over £50 a week, after taking off work related expenses, which can include tax, National Insurance, half of any pension contributions and some childminding costs. *It does not matter how much your partner earns, neither do your savings count, nor your partner's savings.*
- You are aged at least sixteen but under sixty-five. *It does not matter how old your child is.*
- You are not studying for more than twenty-one hours a week. *It does not matter if your child is at school.*

Many parents do not realise that they could get ICA. It does not matter if you have never worked - you do not have to have paid National Insurance contributions and you do not have to have left a job to claim. You can claim even if you were at home with your children anyway.

Some common questions that are often asked;

Q What if my family is on Income Support?

A If your family is on Income Support, you will not get to keep the whole £38.70 ICA. This will be taken away from your Income Support, but then the Benefits Agency will add back £13.65 a week. This £13.65 is called the carer premium. Almost all families will be better off by climbing Invalid Care Allowance.

Q What if my family is not on Income Support, but we do get Housing Benefit or Council Tax Benefit (Rate Rebate in Northern Ireland) ?

A Your Housing Benefit and Council Tax Benefit (Rate Rebate in Northern Ireland) will usually go down when you are awarded ICA. However the carer premium is used in the recalculation of these benefits, so you will not lose as much as you might think. Almost all familes will be better off overall with ICA.

Q What if we are on other benefits ?

A If the person who is applying for ICA is already getting another sort of benefit, eg. Widowed Mothers Allowance, they cannot also be paid ICA. However it may still be worth applying because applying means that any Income Support, Housing or Council Tax Benefit (Rate Rebate in Northern Ireland) that you get is increased by the carer's premium.

Q Why did no one tell us about this ?

A ICA is a well kept secret. The good news is that you have the right to up to three months backdated benefit, as long as you met all the conditions during those three months. If for example, you are a full time, mum, whose son has been geting the Disability Living Allowance care component at the middle rate for the last three months, you could get over £500 in arrears of

INFORMATION

ICA. A family on Income Support would not get the arrears of ICA, but could get over £170 of carer premium.

Q How do we claim ?

A Invalid Care Allowance claim pack DS700 is available from Carers National Association, at most local Benefits Agency Officces or from the Invalid Care Allowance Unit, Tel 01253 856123 (England, Wales, Scotland) or Tel 01232 336000 (Northern Ireland).

Carers National Assocation runs an advice line for carers every weekday between 10-12 and 2-4pm Tel 0345 573369 (at local call rates). If you would like to discuss whether you should apply and what the effect will be on your other benefits, do given them a call, or write to;
20-25 Glasshouse Yard, London EC1A 4JT.

TRAVEL FREEDOM

They offer a free travel information and advice service for people with disabilites and their carers from their base in S.Wales and clients from any part of the UK will be assisted

They provide a research service concerning accommodation and access, insurance, attractions, route plans, and tailor made packages to suit all needs.

Please contact:
Keith Hackwood-Development Officer
Travel Freedom
Unit 2B
St David's Industrial Estate
Pengham NP2 1SW
Tel : 01443 83100 Fax : 01443 839800

'Home Unfit for Children, Housing, Disabled Children and their Families
by Christine Oldman & Bryony Benesford
published by The Policy Press (ISBN 1-86134-116-4) £13.95

From nearly 16 years of experience working with families whose children are physically and/or mentally disabled, Mary Pagett and I know only too well how much harder unsuitable housing makes life for families of disabled children.

For this reason the MPS Society was only too pleased to support the authors Christine Oldman and Bryony Beresford in the research of their book 'Homes Unfit for Children'.

The book focuses strongly on the parent/carers perspective of coping with the needs of a severly disabled child and a home unfit for the job. The most poignant statements came from the children themselves.

"I would prefer my mum and dad not to help me in the toilet 'cos I'm getting older. it's nerve wracking and stuff. Even though it is me mum and dad I still don't like it".

For the first time these researchers have put in writing the problems that most MPS families face. Identifying that adaptations are not just about wheelchairs and access but about providing a safe environment for a child and recognising that the needs of disabled children are totally different from disabled adults.

Mary and I commend this book to all professionals working in the community. Well done Bryony and Christine.

Christine Lavery - Director

INFORMATION

Little Haven Children's Hospice
Essex

The Litte Haven Children's Hospice opened its doors for the very first time in March of this year to care for children and families who are affected by life-limiting and life-threatening illnesses across the county of Essex, outer London and north Kent. It is the thirteenth children's hospice to open in the UK and is the first in the south east of the country. Little Haven is part of the South East Essex Christian Hospice organisation which started the Fair Havens adult hospice in Westcliff in 1983.

Little Haven is situated in beautiful woodlands, part of which has been leased to the Essex Wildlife Trust and is being maintained as a local nature reserve. The woodland theme has been carried through out the building, including naming the nine children's rooms and eight family bedrooms after woodland animals and trees, and the bereavement suite is called 'The Woodland Suite'.

The building was architecturally designed to create a home-from-home for the children and their families and to provide a friendly and informal atmosphere. It is child orientated with plenty to do for the whole family, including a messy play area, a computer room and a wonderful hydrotherapy pool and spa bath.

They also have a multi-sensory room, a music therapy area and a TV and games room. For those seeking privacy, there are quiet areas in the garden, a chapel and two lounges upstairs away from all the activity.

The multi-disciplinary team at the hospice have a wide range of knowledge and skills and consists of a Head of Care, trained nurses, nursey nurses, teachers, an occupational therapist, a social worker and a play specialist. They also have a support services team including maintenance, housekeeping, cooks, voluntary helpers and chaplaincy.

The hospice has a philisophy of care stating that 'children with life-limiting and life threatening illnesses will be enabled to live life to the full.' A homely atmosphere, along with a high standard of care, working in partnership with the families of the children, is what the care team staff aim to provide. They will respond to all their physical, emotional, educational and social needs. They will value each family's own needs and give them ongoing support which includes bereavement counselling.

For further information, please contact:

The Care Team
Tel: (01702) 552200

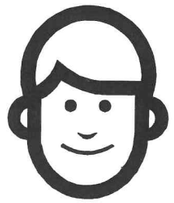
INFORMATION

Glaucoma in MPS children
by
Dr P Ferreira
MBBS, FRCPC, FCCMG

In all MPS Diseases, the basic problem is accumulation of mucopolysaccharides in many organs and tissues of the body, and the eye is no exception. This causes clouding of the cornea (the transparent part of the front of the eye) which is usual in many, but not all MPS disorders: vision maybe also affected in several other ways. One of these is glaucoma, which in MPS diseases is caused by increased pressure resulting from blockage of the filter that normally removes fluid from the eye, because of accumulation of mucopolysaccharides. Glaucoma has been reported in Hurler, Scheie, Hunter, Morquio and Maroteaus-Lamy syndromes, but it is difficult to know how frequent this is in any particular disease because most of the studies report one or two people with this complication and to my knowledge no one has published a long term systmatic ophthalmic study of many MPS patients.

Unfortunatley diagnosis may be difficult. In some other situation where glaucoma occurs it can be quite sudden, causing pain, decreased vision, aversion to bright light and haziness of the cornea. In very young children (under 2 years) there may even be noticeable enlargement of the eye. Although acute glaucoma like this can occur in MPS diseases, the development of increased pressure is more likely to be gradual and could be easily missed by both the patient and family. Also, it maybe difficult for physicians to diagnose because of the lack of symptoms and since it can be difficult to examine the eye properly through a cloudy cornea. Glaucoma can cause permanent visual problems, but can be treated medically (with drugs) and/or surgically. Therefore it is important to be aware of this possibility and try to diagnose it as early as possible. For these and other reasons, I think it is a good idea for all MPS patients to be examined by a specialist ophthalmologist, with repeat visits as necessary. This would be especially important if there are any symptoms suggestive of an eye problem.

copied from the Australian MPS newsletter

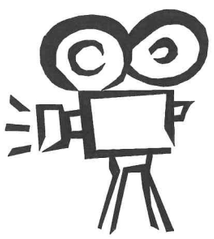


"The Mighty"

a film to be released in December about the relationship between a child with Morquio and a child with learning difficulties.

Based on a 1993 novel by Rodman Philbrick, the film moves along crisply with quick and witty lines from Culkin (the brother of Macaulay). His character, Keven persuades the hulking Maxwell to pretend they are King Arthur's Knight of the Roundtable in working-class neighbourhood of Cincinnati.

Kevin's mother is played by Sharon Stone and also stars Gena Rowlands, Harry Dean Stanton and Meat Loaf, Kieran Culkin plays Kevin a victim of Morquio disease.



JEANS FOR GENES

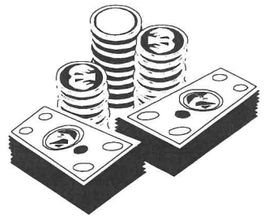
The Institute of Child Health at Great Ormond Street Hospital
explains how they have spent their J4G money

With your support through the Jeans for Genes campaign, the laboratory at the Institute of Child Health at Great Ormond Street Hospital has been trying to discover the underlying defects in the genes that cause Sanfilippo Disease, Type A and B. A report of this work by Dr Clare Beesley is described elsewhere in the Newsletter. These diseases like all the MPS, except Hunter disease, are termed autosomal recessive inheritied diseases. That is, the affected child inherits one abnormal gene (mutant) from the mother and another from the father. The mutations in the 2 genes may be the same, in which case the patient is said to be a homozygote or if a different mutation is inherited from mother and father the patient is said to be a compound heterozygote. The parents each have one copy of the normal gene and one of the mutant gene and are carriers (heterozygotes)of the disease. They are unaffected because the enzyme activity provided by the normal gene compensates for the mutant gene. There is a 1 in 4 chance that the parents will pass on the two mutant genes to a child, who will thus be affected. However, there is a 1 in 2 chance that a child will receive one mutant gene from one or the other of the parents to be a carrier of the disease, like the parents. Such carrier children will not be clinically affected but will, on average, pass on the mutant gene to half of their children.

The incidence of carriers in the general population is very low, ranging from 1 in 150 to 1 in more that 300, depending on the type of MPS. Therefore, the chances of two unrelated carriers meeting and having an affected child is very remote. However, if a carrier marries a blood relative the risk is much higher.

DNA analysis is now becoming part of the full investigation of an affected child. It may help in predicting the course of the disease and suitability of a patient for a particular type of treatment. Once the mutations are known in the affectecd child carrier detection withing that particular family can be carried out reliably by DNA analysis. This information may be important and relevant to adults thinking of having children.

Before a family request prenatal diagnosis it is important to establish that both parents are carriers. Enzyme assay is still the preferred method for diagnosing an affected fetus, but if both mutations are known in the parents, DNA analysis can also be used.



The situation with regard to testing children for their carrier status for the MPS disorder is complicated.The Guidelines produced by a Working Party of the Clinical Genetics Society of the United Kingdom in 1994 recommended against testing children for thier carrier status if the reason is concern about reproduction in the future. It is suggested that children should not be tested 'as a routine'. However, if knowledge of the carrier status of children could help in counselling other members of the family it could be justified. Each case should be considered on its merits. In general, carrier testing of children should be deferred until the children can understand the issues involved and actually request the testing themselves. The decision should be made by consultation between the child's family and his/her GP or genetic counsellor.

JEANS FOR GENES

Little research has been carried out to see what effect carrier testing might have on a child and its family. It is very important that this is done so that future policy on carrier testing of children for autosomal recessive disorders is based on facts rather than guesses or anecdotes. The MPS Society could play an important role in setting up and evaluating such research.

If say a brother of sister of a patient is not tested in childhood then it is important that the test is offered when he or she start a family. Conversely, if a child is tested, it is important that this information and appropriate genetic counselling is available when the result of such a test has practical importance.

In summary, carrier testing of children may be justified after discussion between a family and their clinical and/or genetic counsellors. However, the impact of the result of such testing on the child and its family have not been fully evaluated yet and great care should be excercised before such a decision is taken.

REPORT
Mutation analysis in patients with Sanfilippo syndrome type B (MPS IIIB) by Dr Claire Beesley, sponsored by the Society for Mucopolysaccharide Diseases through the Jeans for Genes campaign.

Mutation analysis has been carried out on samples from 17 patients with Sanfilippo syndrome type B. Two putative mutations have been found in all of the patients: 10 patients have the same mutation in each copy of the gene i.e. are homozygotes and 7 have two different mutations. 19 of the mutations have been found in more than one family, but the remaining 15 mutations appear to be unique to a particular family. Ten of the mutations change a single amino acid in the enzyme and need to be investigated further before they can be classified unequivocally as disease-causing This work will be started in the near future. A further 18 Sanfililppo B patients samples are currently being analysed. These preliminary results show that MPS IIIB is very heterogeneous. Usually, unique tests will have to be developed to detect carrier of the mutations in each family. We have also started mutational analysis for Sanfilippo A patients and this will be followed by analysis of Hurler-Scheie (MPS1) patients.

Professor Bryan Winchester
Institute of Child Health

Sam Wheeler(Morquio) with Cornation Street star Elizabeth Bradley raising money for J4G.

FUNDRAISING

The photograph above shows Bill Pidden (South-West Area Family) receiving a cheque on behalf of MPS for £132.22 from the pupils of Whitstone Community School, Shepton Mallet, Y8. The pupils came along every Thursday lunchtime and gave up their free time in the holidays to tend the flowers. Perhaps the pupils' efforts might just tempt others to consider trying the same thing next year and have alot of fun as well.

Christine Lavery and Shirley Eyre accepting a cheque from Graham Barton from his wonderful fundrainsing event that raised £5,599-02

FUNDRAISING

£326.27 was raised for the MPS Society from some warm hearted Council staff from King's Lyn and West Norfolk borough council because one of their colleagues had a Hunter boy. The idea was first suggested by girls in the Revenues division of the Council who were fed up with constantaly having to listen to men droning on about their footballing prowess ! The main objective of the event was to raise awareness and money for the MPS along with participants and spectators having fun as well. Thank you to all who took part and by looking at the photograph you all look in good spirits.

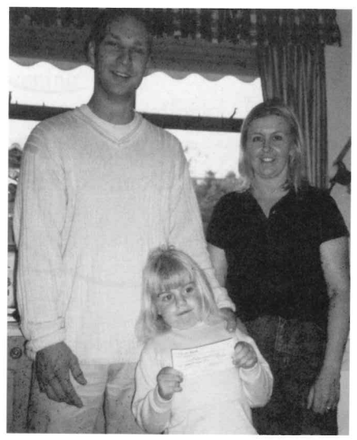


Photo of Lorren Damen with her parent Tina and Stuart presenting the cheque to the MPS Soceity raised by Portsmouth Fire Brigade family and friends.

FUNDRAISING

DONATIONS

Axa Equity & Law
Thorntons
D M Charitable Trust
Tamarind Ltd
Sir Jules Thorn C.T.
Murray Vernon
Gordon Fraser Charitable Trust
Tungscarb
Willow Farm Trust
Morgan Crucible Company
A G Pargett & Sons Ltd
F R S Charity Committee
K P M G
Cliff Richard Charitable Trust
Helen & Alan Hall
Mrs Troop
Mr Cawley
Wessex Water plc
Paul Southworth Charitable Trust
Gaze Buruill Ltd
Harrison & Group plc
Tibbett & Britten Group plc
The Goldsmith Co.
Mr & Mrs Hall
Mrs Sharp
Mr Venton
Tibbett & Britten Group plc
Glynwed Charitable Trust
Avalon Rotary Club
J Allen
Jackie Chisling
Mrs D Coles
Mr Edwards
Mrs Hagye
Mr Holroyd
Ms Milne
Ms Nuttall
M Roze
Jo-Anne Adshead
Hilda Lever
REACT
The Christopher Laing Foundation
Joyce Wilson
Alison Stewart
Sobell Foundation
Scunthorpe Masonic Building
The John & Lucille Van Geest Foundation
Bull Information Systems Ltd
Lt.Col T.C. O'Brian
Mr Lardy
M & S plc
Notts County Council
Hedon Methodist Friendship Circle

STAMPS

DVLA Wimbledon
Dominic Stimpson family
Brighton County Court
Sue Vivier

CHARITY BOXES

Mary Ellen Nowell
T W Coulter
Mr & Mrs Lomas

FUNDRAISING

FUNDRAISING EVENTS

The Society is grateful to the following who held fundraising events.

Focus on Fitness - Sponsored Treadmill Walkathon
Tim & Sue Belben - Valuation event
Carolyn Roddick - Sponsored Step Aerobics
Hemel Hempstead Lions Club - Charity Walk
Maureen Bradford - Paris Marathon
Barbara Rollinson - Charity Bike Day
Mr & Mrs Taylor - Sherry/Coffee morning
Zelda Hilton - Work colleagues event
Bob Fleming - Sponsored Bike Ride
Michelle Lowe - Sponsored Parachute Jump
Pam & Ken Ballard - Sale of Bric a Brac
Adrian Stimpson - Raffle by Bertram books
Adshead Family - Family Day Raffle and Face Painting
Janet & Errol Jones - Pool Tournament
John & Mary Stacey - Proceeds from Spiffing Stationary
Deborah Tomsett - Sponsored Parachute Jump
Harry Bowness - Fun Run
Carol Westland - Local sale
Jonathon Armstrong - Sale of Conkers
Jenny Hardy - Sale of marmalade
Haddenham Cricket Club - Fundraising Tournament
Towersey Morris Men - Performance and play
Rebecca Hardy - Selling stationary
Barbara & Paul Harriss - Sale of Steven's toys
Mr Stock - Sale of Bric a Brac
Whitstone Community School - School event
Heather Wilkinson - Sponsored Parachute Jump
Mary Ellen Nowell - Garden evening
Mr & Mrs Culley's Golden Wedding Anniversary celebrations
Evelyn's 40th Birthday celebrations
Robert & Nikki Best's wedding celebrations

IN MEMORY

Paul Gunary
Ronald Rock
Joan Doyle's Aunty

AREA SUPPORT FAMILIES

EAST ANGLIA

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

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

SOUTH-EAST

Mary and Robin Gooch — **Tel: 01435 883329**
High Bank House, Swifehill, Broadoak, Nr Heathfield, East Sussex TW21 8XG

POTTERIES

Sylvia and Bill Blackburn — **Tel: 01270 668431****
1 Ashlea Drive, Nantwich, Cheshire CW5 7HZ

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

SOUTH-WEST

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

Anne and Gordon Hill — **Tel: 01404 812229**
Bowhayes Farm, Venn Ottery, Ottery, St Mary, Devon EX11 1RX

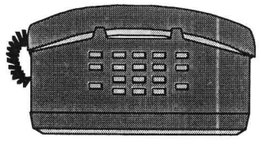
HOME COUNTIES

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

Denise and Gavin Brown — **Tel: 01442 395907**
32 Ellingham Road, Adeyfield, Hemel Hempstead, Herts HP2 5LE

WALES

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



PLEASE NOTE THAT BILL AND SYLVIA BLACKBURN HAVE MOVED AND CHANGED THEIR TELEPHONE NUMBER

AREA SUPPORT FAMILIES

MIDLANDS

Sue and Jeffrey Hodgetts — **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

YORKSHIRE & EAST COAST

Monica and Davin Briggs — **Tel: 01777 700046**
7 Humber Street, Retford, Nottinghamshire DN22 6LZ

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

NORTH WEST OF ENGLAND

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

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

NORTH EAST OF ENGLAND

Barbara and John Arrowsmith — **Tel: 0191 2921234**
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

SCOTLAND

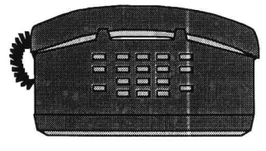
Cath and Jim McLean — **Tel: 01463 791816**
"Woodlee" 47 Oakdene Court, Culloden, Inverness, Highland IV1 2XL

Karen and Clint Stevenson — **Tel: 01501 752712**
6 Viewfield Street, Harthill, Shotts, Lanarkshire ML7 5SN

Fiona and Alan Byrne (*Telephone contact only*) — **Tel:0141 5695376**
3 Jedburgh Avenue, Rutherglen, Glasgow G7 3EN

NORTHERN IRELAND

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



The Society for Mucopolysaccharide Diseases

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