

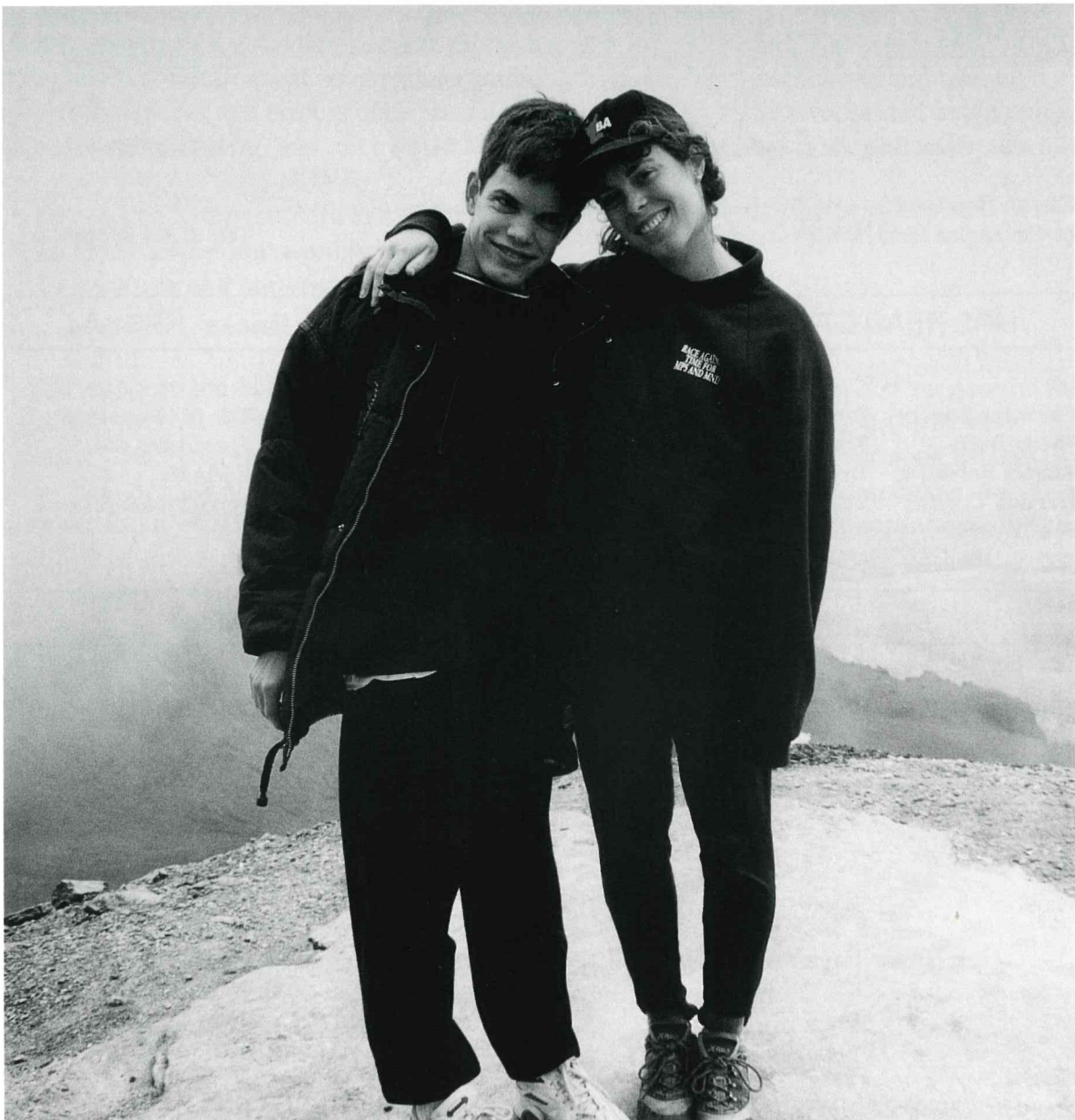
Newsletter



The Society for Mucopolysaccharide Diseases

National Registered Charity No.287034

Summer 99



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The Society for Mucopolysaccharide Diseases

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

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

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

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

"CARE TODAY, HOPE TOMORROW"

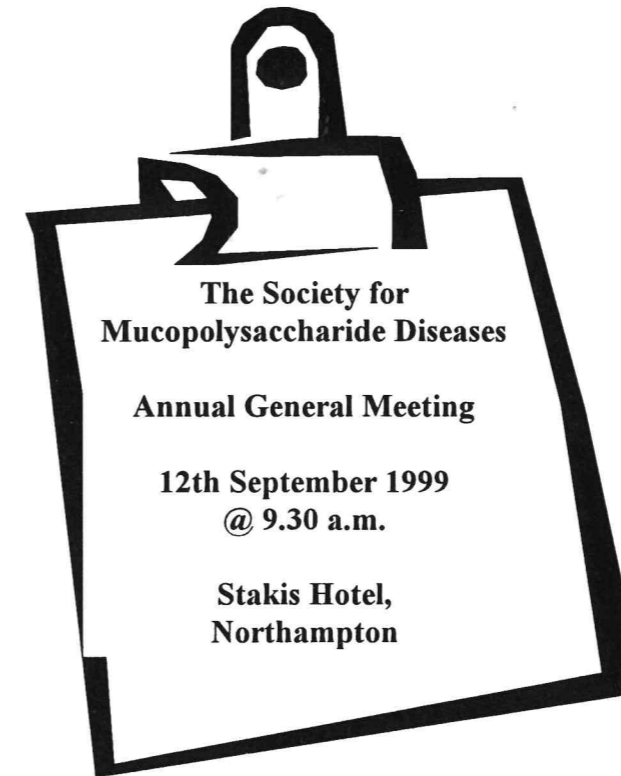
The photograph on the front page is of Andrew Hawkins (Sanfilippo) 16 years old with his sister Tracy on the summit of Mount Snowdon after their successful climb (full article in newsletter).

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Deadline for the 1999 Autumn Newsletter is 24th September 1999

CHAIRMAN'S REPORT



Some of you may have noticed that on the introductory page of the last Newsletter (Spring 1999) where we refer to the Society's aims and objectives, that we changed from saying that we act as a parent support group to a 'Support Network for those affected by MPS Diseases'. This has been necessary because we now have 90 independently minded adults from the age of 18 to 60 with MPS disorders. Representations were made to us that the reference to 'parent support group' did not reflect the Society's growing membership of affected adults. The matter was discussed by the Management Committee which includes Sarah Long, a Trustee and an adult with MPS, and it was unanimously decided that the word should be altered to meet the changing needs of our membership. The new words cater for all our members and contain the same message of support which is our main aim and

objective, and our highest priority and commitment.

On Sunday 2nd July bereaved parents gathered at the Childhood Wood to spend time in the peace and serenity of the forest to reflect, remember and share memories. It was a glorious sunny day just perfect to enjoy the tranquility. Later we met at the Boughton Pumping Station to chat over a buffet lunch. Many thanks to Hannah Crown at the MPS office who organised the day.

The next event is the Conference on the 10th – 12th September. I look forward to meeting many of you there.

Wilma Robins



Yes the time has come around again – Christmas. A new selection of Xmas cards will be available at the Conference this year, so please do come and have a look and then you will save on postage and be able to take them home with you.

MILESTONES

New Families

Alan and Elizabeth Scott live in Scotland. Their son Christopher has recently been diagnosed with Sanfilippo disease and is 13 years old.

Thomas and Janice McDonagh live in North East England. Their 2 year old son Callum has recently been diagnosed with Mucopolidosis III.

Janice and Errol Jones from Wales. Their son Steven who is 3 years old has recently been diagnosed with Sanfilippo disease.

Mark and Debra McAfee and their daughter from Northern Ireland. Jade aged 18 months has recently been diagnosed with Sanfilippo disease.

Tom and Ann-Marie Ward live in Northern Ireland. Their daughter Tiffany has been diagnosed with Hurler disease and is 6 months old.

Julia and John Mongan from Northern Ireland. Their daughter Shannon Mongan has been diagnosed with Hurler disease and is 10 months old.

Mr and Mrs Barlow from Yorkshire whose daughter Jodie has recently been diagnosed with Sanfilippo disease. She is 3 years old.

Elaine Muers son Daniel has recently been diagnosed with Hunter disease. They live in North-East England. Daniel is 3 years old.

James and Julie Hope-Gill from Yorkshire. Their son Timothy has recently been diagnosed with Hurler disease and is 1 year old.

Deaths

Sadly Edward and Holly Nowell's 19 year old son Edward died on the 7 June 1999. Edward from Somerset suffered from Hunter disease.

Marie and Robert Heaphy's 14 year old daughter Sasha, died on the 24 June 1999. Sasha suffered from Sanfilippo and came from Gloucestershire.

Congratulations

Congratulations to Amanda and Michael Heisig on their latest arrival. Nathaniael. He was born on 14 May 1999.

Our congratulations go to the Alison and Neil Pickard on their new arrival Anna on 22 April 1999.

Congratulations to Heather and Mark Browning on the arrival of Chloe to the family.

AREA FAMILY SUPPORT

South West Area Family Day

MPS families from the South West enjoyed a fun packed day at their annual Easter Egg hunt in Trowbridge.

The weather just held out long enough so the children could enjoy finding and eating their Easter eggs outside.

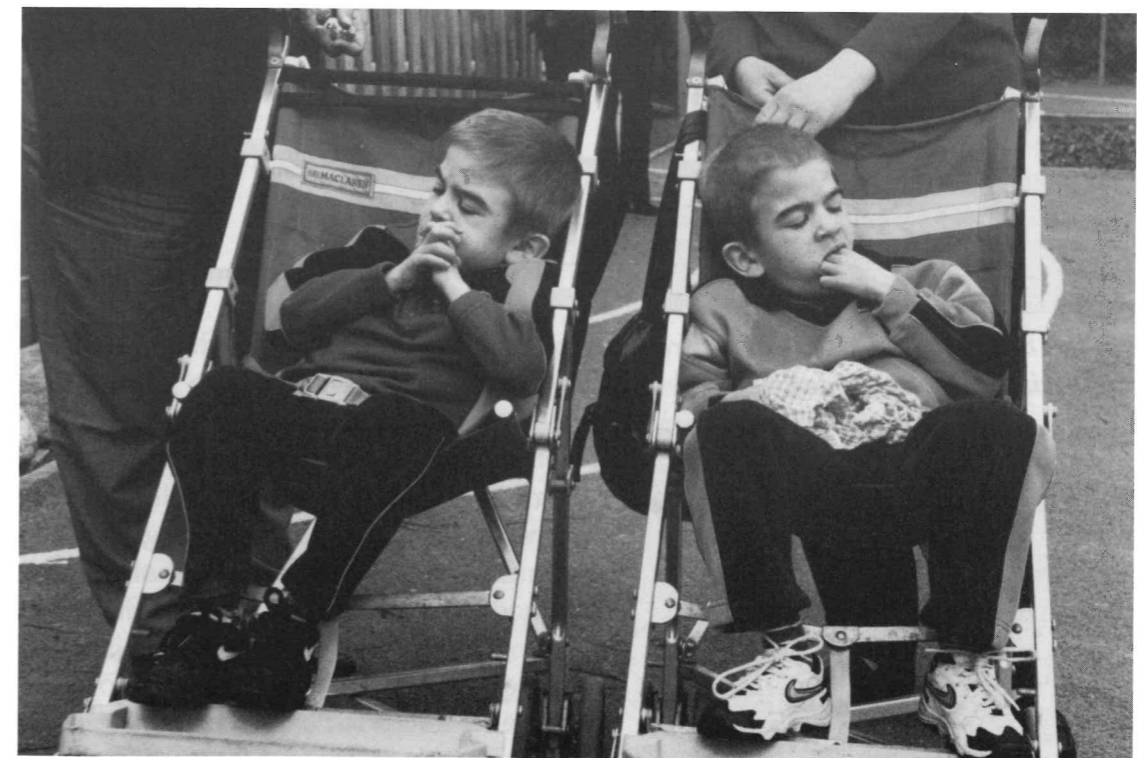
It was a great chance for me to meet new families and to catch up with all of those who I haven't seen for a while.

Our thanks go to Jackie Chisling, Fer Pidden and Anne Hill for arranging yet another great event.

Hannah Crown – Development Officer

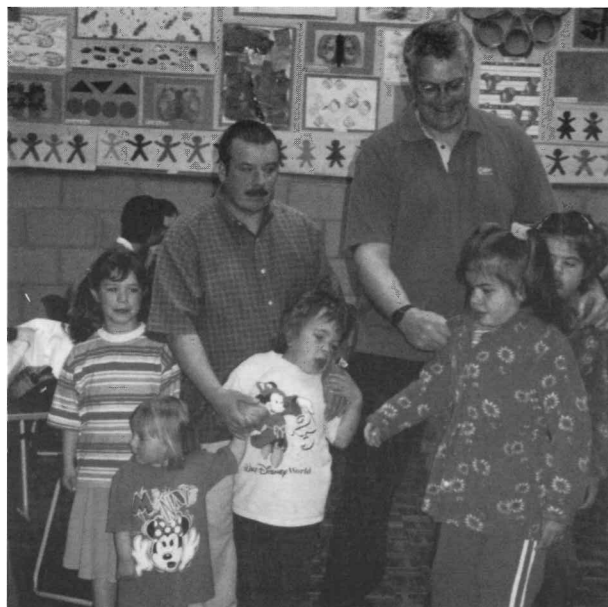
While mums and dads enjoyed lunch and a chat, the children played in the school and in the playground.

Photographs of the event are also on the next page.



Jamie and Jason George – Sanfilippo twins

AREA FAMILY SUPPORT



Hannah Chisling, Josephine and Francesca Kembrey (Sanfilippo) with their Dads' and Hannahs' sister and cousin.



Mathew Home (Hunter) along with his Dad and Hannah Chisling cousins.

Yorkshire and East Coast Area Family Day

A report from the brothers and sisters of Lauren Cawthorne on their Area Family day.

On Sunday 13th June the Yorkshire and East Coast had an area family day at Cannon Hall, near the village of Cawthorne. We did not know what to expect, but when we arrived we soon found there was something for us all to do.

First it was lunch in the picnic area and then off to the farm. Lauren loved everything on the farm rabbits, goats, pigs, horses and cows. She had great fun stroking them. Lauren especially liked the pigs.

At then end of the farm there was the adventure playground, we all like this and took turns looking after Lauren on the slide. The two Davids' and

myself then went off to the gift shop. Mum, Dad and Lauren went back to the farm.

After meeting mum at the picnic area Dad, me and the David's went to the Cannon Hall museum. There were furniture and cut glass figures and on the top floor The War Museum. All of which was very good.

We discovered much more to do at the other end of the Hall grounds but by this time Lauren was tired and it was time to go. Mum and Dad said we will have to go back again.

Thank you all for such at great day out.

Rachel (me), Lauren, David and David Cawthorne

AREA FAMILY SUPPORT

Dates to Remember

- ***
 10-12 September MPS 17th Annual Conference

 30 September Bristol Clinic
 1 October Cardiff Clinic
 8 October Jeans for Genes Day
 9 October Scottish MPS
 Family/Professional Conference
 29 October Childhood Wood Planting

Potteries Area Family Day

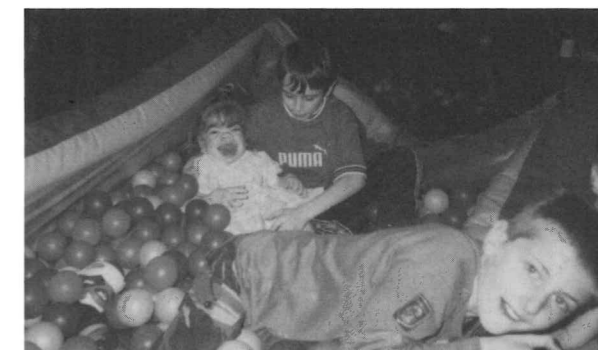
On the 18th April we arranged a visit to Granada Studios for our Area Family Day. The day went really well and the weather was good until 3.30 when the heavens opened. All the families enjoyed themselves and it was lovely for everyone to meet up again.

Lynne and Chris Grandidge

Yorkshire and East Coast Area Family Day

This year we decided to have an indoor get together in April because we have been caught out by the weather in the past. And well ! Yes, the sun decided to come out all day, but not to worry though we all still had a wonderful day. Mums, Dads and relatives were able to chat whilst the children were entertained by a band of youngsters called 'Dads Lads', fun in the ball pool and also a visit from an Easter Bunny and a Teddy Bear who gave everyone Easter eggs. Amy Rollinson organised pass the parcel, colouring competition and Easter hat competition. Wonderful face-paintings was also enjoyed by the children.

Barbara and Trevor Rollinson



Lauren Cawthorne –Hurler in the ball pool – what a lovely giggle.



Daniel Wainman – Sanfilippo with his Grandad.



Lynn Thompson –Morquio, along with her family

FAMILY SUPPORT

**Bristol MPS Clinic
15th April 1999
Children's Centre, Frenchay Hospital**

the room was full because the doctors managed to see 18 patients throughout the day.



Hannah Chisling along with Francesca Kembrey both Sanfilippo with Francescas' mum – Julie.

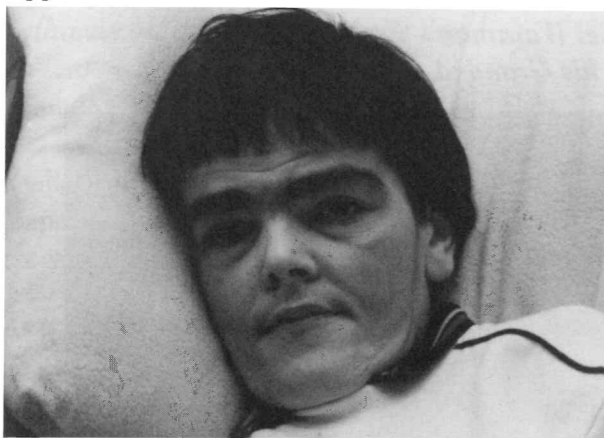


Louise Hill – Sanfilippo with her parents Gordon and Anne.

Richard Skidmore accompanied us on this visit because we wanted to have some photographs of you all and he was completing his 3rd year University course on Photography and volunteered to take the photographs for us. His intention is to create a portfolio of MPS children with differing diseases and at different ages. His sister Helen suffers from Hurler disease and was the first girl to be treated by BMT.

Thank you all for your co-operation in having your photographs taken because I know at times things got rather hectic in our wee small waiting room. But as you can all see it was well worth it and on the following pages you will see some of Richard's work.

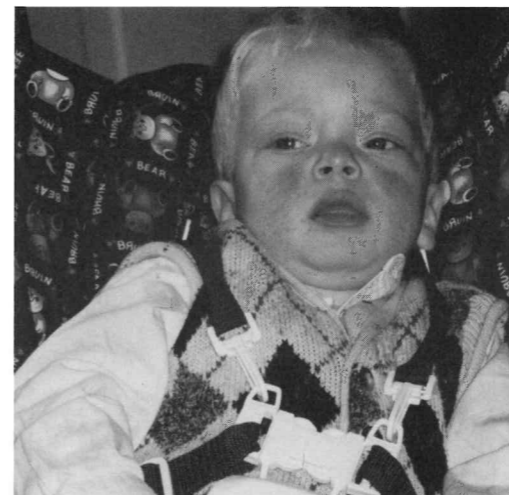
*Sheila Duffy
Project and Information Officer*



Karen Naish – Sanfilippo

It was lovely to meet all the families again. Yes

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Terry Butler – Hurler



Diana Green - Hurler

MPS CARDIFF CLINIC



Sarah and Gavin Hyde –Mucopolidosis III



Steven and Christopher Jones – Sanfilippo

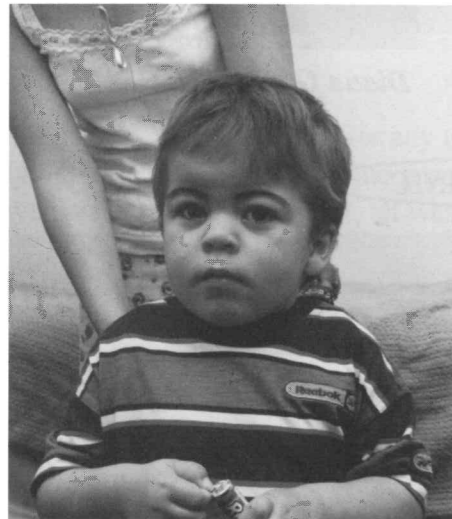


Carissa Aggett – Hurler along with her family at the Cardiff MPS Clinic

FAMILY SUPPORT

**Cardiff MPS Clinic
16th April 1999
University Hospital of Wales**

On Friday 16th April 15 patients attended the MPS clinic at the University Hospital of Wales, Heath Park, Cardiff. Luckily the weather had improved considerably, as the snow had caused havoc the previous day. Everyone arrived safely.



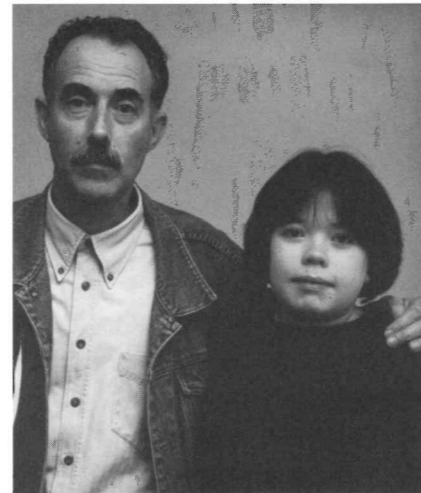
Stephen Young – Hunter

Our thanks goes to Dr Wraith and Dr Shortland for seeing all the MPS patients and we even managed to finish on time, which is some kind of achievement as you all know. Also to Sue – Dr Shortland’s secretary for arranging everything.

Richard Skidmore also accompanied us on this visit with the aim of capturing more of you on camera for his portfolio.

Angela and I enjoyed meeting all the families again, and Ellie for the first time. We all felt that the clinic had gone well and what a pleasant way to finish work on a Friday. All we had now was the drive home on a sunny evening leaving the snow behind us.

*Sheila Duffy
Project and Information Officer*



*Megan Rennoldson – Mannosidosis
along with her Dad*



*Christopher Rees-Mucopolipidosis III
along with his sister*

FAMILY SUPPORT

**Northern Ireland MPS Clinic
Stakis Park Hotel – Templepatrick
29th April 1999**

What a warm welcome we all received in Belfast when we arrived. The sun was shining- (which I believe is not a common occurrence in Northern Ireland) and everyone was so friendly. Christine, Ellie and myself had a full MPS clinic, that this year was held at the Stakis Hotel, Templepatrick, Belfast. A big thank you to all the staff for all their help on the day.

Dr Ed Wraith was joined by Dr Fiona Stewart, Consultant Geneticist, Belfast City Hospital and in total they saw 15 patients.



John McDonna – I Cell

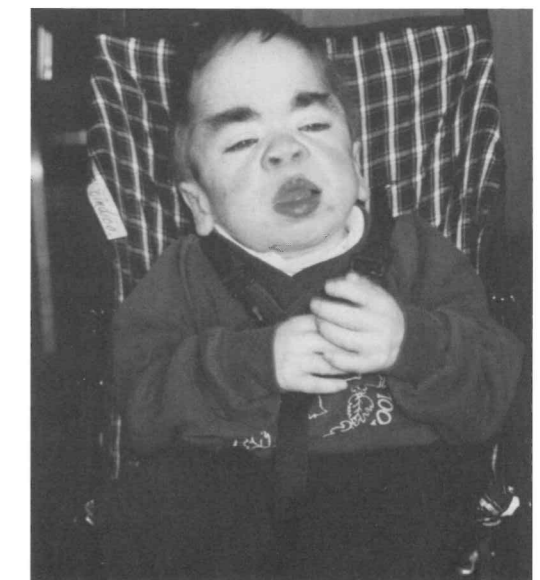
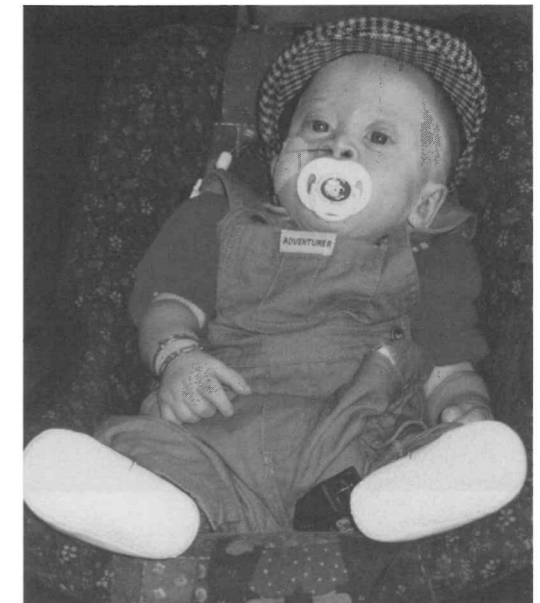
William Todd – Hurler/Scheie

Luckily our clinic rooms opened up onto the grass and near the water fountain where we were taken by hand for several walks by the children. Lucia Dawson was a pickle because not only did she get her Granddad to take her for a walk, but also myself and Ellie. The weather was glorious and with the water nearby the children loved picking up the stones just as if they were at the seaside.

It was lovely to meet up with all the families from Northern Ireland who for Ellie and myself have only ever been a voice over the phone.

As always I had my camera with me so here is a selection of some of the children who were able to come along to the MPS clinic.

Sheila Duffy-Project and Information Officer



Michael Copeland – Hurler

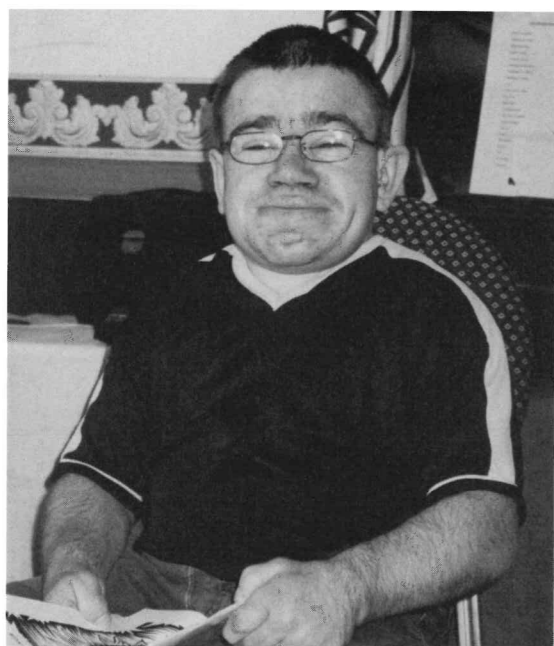
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Roma Drayne – Morquio



Catherine McGratton – Morquio



James Stewart – Hunter

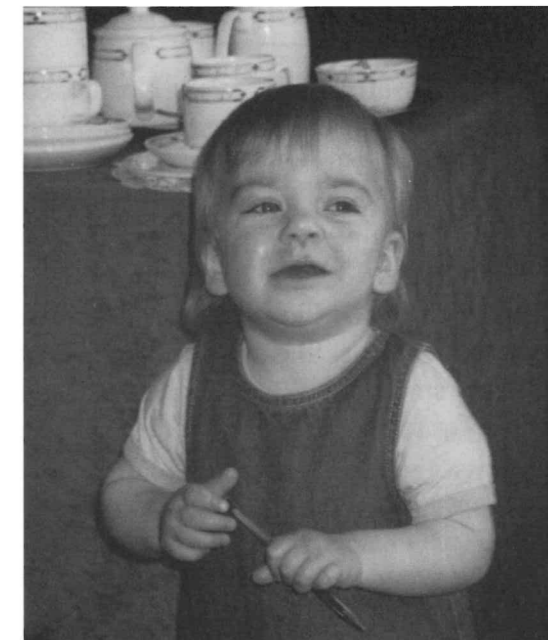


Elizabeth Kirkpatrick – Morquio

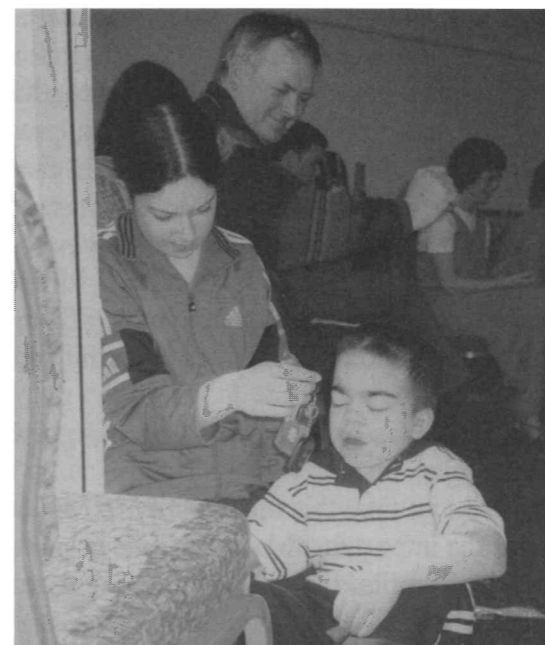
FAMILY SUPPORT



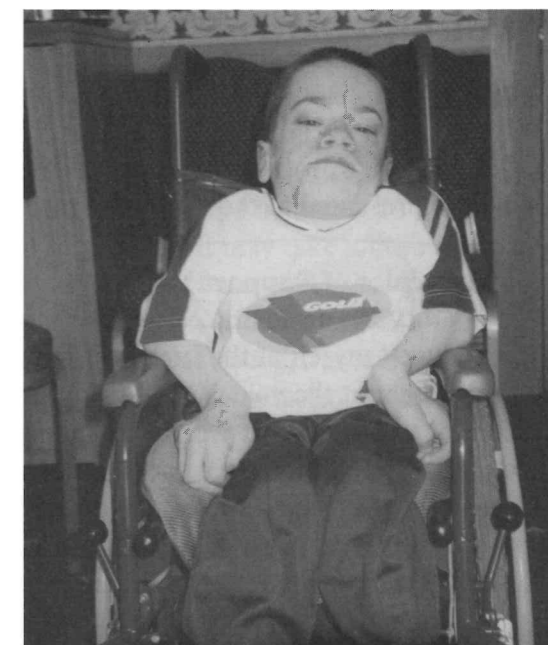
Lucia Dawson – Hurler



Jade McAfee – Sanfilippo



Shaun McCawille – Hunter with his sister and Dad



Niall Devlin – Morquio

FAMILY SUPPORT

Northern Ireland MPS Conference 30th April 1999

What a big turn out we had for our Northern Ireland Conference this year. Several professionals turned up on the day to see if we had any places available and luckily there were still a few seats left.

Our thanks goes to Dr Fiona Stewart for chairing the Conference for us. She did a brilliant job and all went very smoothly. We even managed to finish on time for lunch.

The hotel proved to be a brilliant location for the conference to be held. The facilities were good and certainly everyone enjoyed their lunch whilst enjoying the lovely scenery.

Some very useful information was to be had from the talks and even some handkerchiefs were needed in a couple of them.

As they left everyone said that they had had a very informative day and look forward to returning next year.

On the following pages you will read two of the talks that were presented at the Conference.

Principles of Support Work

When I introduced myself at the Irish MPS conference I talked about the values and principles that are central to the support work with families the Society offers. I will be addressing these issues further at the MPS conference in Northampton, sorry to disappoint those of you who would have liked to hear my experiences of being married to someone with Hunters disease.

As the conference is still a few months away, I thought families might find the content of my

talk and the information I shared useful to read now.

I am really proud to be able to introduce myself as the Regional Development Officer for the MPS Society. I was thrilled to be offered the post, am enjoying the challenges it has presented so far, and look forward to moving on with the society as it embraces the challenges of supporting MPS families into the future. As I was listening to Christine and Fiona introduce me it occurred to me that working with the society has its similarities to living with MPS. I was approached only two days ago about speaking today. I had to think on my feet very much like families have to while caring for their children.

My background is in nursing and social work. I have worked in all the statutory, voluntary and private sectors with a wide range of client groups. The majority of my work has been with children and young adults with disabilities. My particular interests have included the social aspects of disability, advocacy, skills teaching and methods of communication. I have a social work qualification. I have been a member of the MPS Society for nine years, introduced by Paul, my husband. The experience of conferences, family days, and the professional support the society offers, as well as that of being a carer, having cared for Paul during the time he was very ill, have given me a framework of understanding from which I am able to offer families empathy and support.

Individuality

I would like to take this opportunity to outline some of the important values I will be bringing to my work. The first is recognising the unique experience of each family. I would like to stress that all my experience can be is a framework. While important to acknowledge the common factors all families facing the challenges of MPS

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encounter, it is vital to recognise the individuality of each sufferer and each particular family's way of living with the diseases. Support can only be effective if it addresses these. I will be taking the lead from each family in what support to offer and how to offer it in each individual situation.

Partnership

Working in partnership is the second value. I believe in working with families, not for them. I see my role as one of enabling families to achieve the best for themselves and their children. It is parents and families who live day in and day out with their children and are the experts in their particular children's care and needs. All of us, working for the MPS Society need families to be proactive in asking for our services. Families have to take this responsibility and contact us. We are not mind readers and are not able to help without being approached. The Society's commitment to family support has increased over the last year. There are more resources for family support now, than ever before.

We recognise that in order to reach as many families as possible we need to be able to provide a variety of means for families to approach us. Structured events like the clinics and conferences, and more informal networks like area families and family days, provide a variety of means for contact within the Society and for developing further, support and social networks.

A strong commitment within the Society is to work in partnership, both with each other, and with other professionals. Hannah, Angela and I, the Development Officers, have designated geographical areas within which we offer support. We are however committed to close team working, including work with Christine, the Director, and Sheila, the Projects and Information officer to ensure that all families receive the best advice and support available. In some circumstances

because of our individual strengths and interests, two of us may work jointly with one family.

Likewise, we are committed to working in partnership with other professionals. We may be able to offer expertise in MPS, but will not have the depth of local knowledge and resources that will exist within an individual family's local professional network.

Equal Access

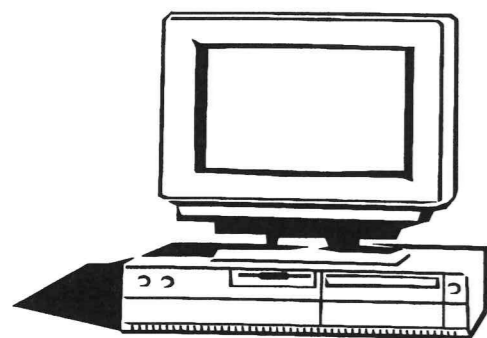
Equality of opportunity is at the forefront of all services offered today. Providing for equal access to the MPS Society's services is a challenge. For us a particular challenge arises because of the large geographical area covered. I have been listening to the views of MPS families, and one area of support that seems to be of particular importance is MPS staff presence at clinics and within the specialist medical centres in Great Britain

We, as yet, have been unable to finalise details of an MPS northern office near or in the RMCH. I am totally committed to the location being within easy reach of the hospital, especially as 64% of MPS patients are seen at this hospital. Equally important is that the facilities are user friendly and accessible. It may take a little while longer to find an office base with these criteria, criteria which when met, will ensure MPS families visiting, will have easy access to and privacy when using our Manchester based facilities.

Promoting better access to our services involves educating other professionals about the areas of expertise we are able to offer. I have had one meeting with a group of staff at RMCH to clarify my role and when it is appropriate to involve the MPS Society's support with a family. I am myself developing new areas of expertise and interest every day. I was already very familiar with

FAMILY SUPPORT

the MPS Society's support with a family. I am myself developing new areas of expertise and interest every day. I was already very familiar with the benefit system, care needs and the roles of different services. I have worked with adaptations and am currently supporting a number of families through the DFG grant procedure. I am in the process of setting up other communication meetings with other support services, including the children's hospices, trust fund organisations and other specialists.



Confidentiality

Another essential element of a good quality service is confidentiality. Families can be assured that information given to us, and which professionals share with us, is not divulged outside the employees of the MPS Society without the family's prior knowledge, and except in extreme circumstances consent. We have no closed files and families have access to their file at any time. The society is registered under the Data Protection Act.

Feedback

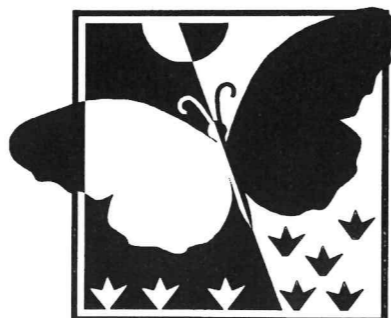
Feedback after any support offered is important. I know from my own experience that the large number of professionals involved in life with an MPS child or adult can be confusing and daunting. Families may feel bewildered by, not only what is happening, but also who is supporting them with what. Quite often whole new languages have to be learnt; those of the medical

and social care professionals. Follow up and feedback, whether by phone or written, helps clarify what was discussed, what was agreed, what arrangements were made and who is responsible for pursuing each different area of support identified. Families often need time to absorb the huge amount of information that can be covered at meetings, particularly multi-disciplinary meetings. New issues may arise after there has been time for reflection. Follow-up further empowers families to take the lead in deciding how to manage their own lives. Ensuring that professional support and families are working to the same goals is important. Many studies have shown that whether a family takes up a service or not, depends on whether or not the service is perceived as relevant. The service has to match each family's expectations and needs to be effective. In order to ensure we meet families' needs we require feedback on the services offered.

Please do contact me and the other MPS staff if you need our support, or have any feedback on the services the Society offers.

I look forward to hearing from you.

Ellie Gunary
Regional Development Officer



FAMILY SUPPORT

My son has Sanfilippo

Let me start by introducing myself. My name is Alison Shields, some of you will know me but for those who don't I'm from the fishing town of Kikeel the beautiful area of Mourne, in County Down where the mountains sweep down to the sea. Beside living in America for two years, while still at school, and in Derbyshire for six the rest of my life has been spent in Killeel.

Andrew and I married in 1987, Craig our eldest was born in 1988, then Scott the following year, Kyle was born in October 1992, and I remember being slightly disappointed when the midwife said. "It's another boy", but that lasted about a few seconds until he was put into my arms. Then I was just thankful that we had another healthy son, or so I thought.

Kyle as a baby was never a great sleeper and always seemed to have colds. When he was ten month old he had had about ten courses of antibiotics and our doctor decided further investigations were needed. This was Kyle's first experience of hospitals. He had to go in to have an antibiotic fed intravenously into the vein. Our Kyle has turned out to be every doctor and anaesthetist worst nightmare, with deep seeded veins. On this occasion the only place they could get a vein was the side of his head, but I believe it looks worst than it actually is. After further tests it was discovered he had a reflux to his right kidney, this was then operated on when he was a year and a half. Kyle's development continued to be slow, his understanding was limited, he only spoke a few words and potty training was turning out to be a complete disaster.

At then end of April 1996, when Kyle was 3 1/2 He was referred to the child development team at Craigavon hospital. Originally his delayed development had been put down to him having major surgery, but now they felt he should have caught up. They examined Kyle and done a number of tests and also needed a urine sample, but as Kyle wouldn't perform I suggested taking one to my local hospital the following week when he had a routine check up. I took the sample with me and the nurse tested it for a urine infection and then discarded it not realising it had to go for genetic testing. I'm sure she wasn't very popular, but as there was no way we were going to get another sample I was sent home with a sample bottle to be left in at my own clinic, with the word written on it 'Test for Mucopolysaccharide disease'.

This was the first time I ever hear of Mucopolysaccharide and curiosity got the better of me and I thought right I'm going to find out what this is. First I got the dictionary out and although I found it, the meaning meant nothing to me at all. Andrew was going to our doctor the following week so I got him to ask. The doctor told him it was a genetic disease, which was extremely rare and we would try not to worry about it at present. If we wanted further information he would get it for us. We left it at that.

Anyone who knows me will know that I enjoy doing competitions, I get the Chat and Take A Break most weeks to do the puzzles and very rarely would I get time to read any of the articles. Towards the end of May though I was flicking through, I think it was the Take A Break when my eyes were drawn to a particular story. The word Mucopolysaccharide appeared to jump out of the page at me, I thought here's this word again. The story was about two wee boys who had the disease, I don't know who the family were, but as I read through the story it told

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about their behavioral problems sleeplessness, hyperactivity and how they had developed. I thought that sounds like our Kyle. Then as I read on about the disease, I read how that it was terminal and there was no cure, I really found it hard not to worry. An Aunt of mine had also read the article and said to my uncle how much the boys resembled Kyle but never told me this until after his diagnosis.

We had an appointment mid November with Dr Magee but she phoned on the last Tuesday in October to say that her clinic had been cancelled on the Thursday because of Halloween and could we come then to get Kyle's results. I was out that Tuesday night with a Mum and Toddlers group. A friend whom I had confided in asked me if I thought Kyle had this disease with the big long name. I said no, but I was really only trying to convince myself because I knew there was something wrong with Kyle and since I had read the article I had always had it at the back of my mind that this was what was wrong with him.

I personally don't believe anything happens by chance and I feel that reading the article had help prepare me for the news we were to receive that day. Being prepared or not as many of you know it still comes as a tremendous shock.

Dr Magee and Dr Bell took Andrew and I into a room while the speech therapist, who knew Kyle took him to play. They informed us that, yes Kyle did have a Mucopolysaccharide disease called Sanfilippo disease and they explained to us all about the disease. We didn't really take much in. We were given leaflets, contact with MPS and an appointment for a week later when we would be more prepared to talk about it and have any questions we had answered.

We left the room in a daze and I remember Kyle coming flying down the corridor his usual,

happy, boisterous self and I just burst into tears, from all the built up emotions. As many of you know it's impossible to put into words how you feel, we were utterly devastated and our world just seemed to fall apart that day. Our wee son had a disease that would eventually kill him and we'd never see him grow up. The worst thing was that there was absolutely nothing we could do nothing about its.



Kyle at the Northern Ireland MPS Clinic.

We read up on all the information we could get on the disease, we also contacted Keiran and the MPS Society and spoke to Christine, every one was of great support to us and I found it helped to talk to people who knew what we were going through.

Once family and friends heard our news our home resembled a wake. We were inundated with people calling to offer their condolence and support. It was just as well Kyle was there showing he was very much alive. Entertaining everyone with all his antics. It was so hard to take

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in that this extremely active, happy child would have such a brief life.

This soon ended though, everyone had there own lives to get on with and we were left to cope pretty much on our own. I am finding though that I do get the strength to cope when I need it and it's just a matter of relying on the Lord and taking one day at a time. It is a great help to have the Society behind us, and also the support from our local disability team.

Having a name for his disease and a reason for his severe behavioral problems has been a relief in some ways Be it a mother's instinct but I knew from about the age of 2 that there was something different about Kyle, in comparison with the other two boys. I had tried to discipline Kyle and tried to encourage good behaviour, without any success. It makes me feel bad now looking back, knowing what I know and realizing that he had little understanding and couldn't be held responsible for his actions. Talking to Christine shortly after his diagnosis, just finding out that a lot of children with Sanfilippo are not potty trained helped. I immediately gave up on it and just this took a great burden from me. Kyle some days would have 4/5 severe bouts of diarrhea, which is one of the side effect of his disease. It's a lot easier controlled in nappies, especially when he has been eating sand and soil you can imagine how pleasant they can be. I had tried potty training Kyle from when he was 2 and wasn't getting anywhere. My worst nightmare was always Doctor's waiting rooms, I don't know why but he always caused havoc, maybe he was just trying to get how own back. He would enjoy the soil in the plant pots, throwing toys, rolling about on the floor, or just taking off down the corridor with me in pursuit. I would get hotter and hotter under the collar as I would notice other parents whispering about him, or watching, knowing they were thinking that he was a spoilt

and undisciplined child. We just can't take Kyle out to people's houses anymore, saying that, he doesn't get invited, except to family who are very understanding and know to have the room cleared of anything valuable before he comes.

Thankfully Kyle's doctor is extremely understanding, he's always at the other end of the phone and will see him at any time, slotting him in-between patients avoiding him having to wait. His dentists will likewise come back from lunch early and fit Kyle in first. It helps to have such understanding people behind you.

We are at present having great difficulty in adapting our home, it's turning out to be a real nightmare. To be honest if it was just for myself I'd have given up ages ago, but because it's for Kyle we plan to fight for what he needs and the other boys. We have been able to adapt a room in our home for Kyle in the meantime, with padded walls, floor and safety glass in the window. The radiator is mounted high up on the wall and the television likewise, as he has no sense of danger. There is a split door of the kitchen into Kyle's room, so we can have the bottom half closed and still be able to see into him. A friend's daughter painted a mural of Postman Pat and Barney on the walls as part of her school art project and it has really brightened his room up. We also had to fit childproof locks onto our kitchen cupboards and drawers, as he would just throw cutlery, plates, cups and doesn't know the danger of knives. It wasn't so bad when he was smaller as I could have placed things at the back of the worktop and he couldn't reach them. Now he is six and a half, he has got taller and the dangers have increased twofold, He can reach everything now. After finding him chewing on the lead of my kettle one day, when it was switched on, I've had to remove everything from the worktops. Kyle absolutely adores balls of any kind and loves to play with them, so after finding him

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trying to bounce eggs off the floor we have had to put a chain on the door of the fridge to keep him out. Our microwave has had to be closed in because Kyle has a thing about switches, he would press the button, opening the door then slam it shut again. It was a constant press, slam, press, slam. Likewise the light switches were on, off, on, off, now we have them operated by a key, which is then hung up out of reach. The television was the same and it is now mounted on the wall. I still have the problem with my hob and oven to sort out though, as he turns on the gas, and has a thing about banging the oven door open and shut, that's when he isn't trying to climb on it. I've had to take all the rings off my hob and put them together when I need to use it. We also have to keep all the doors locked in the house, sometime you feel like you are in a prison. We have our back garden pretty secure for him but the older boys have on a couple of occasions left the gate open and he's got out and given me a real fright. He has no road sense and had on one occasion ventured onto the main road where thankfully a neighbour found him, just as I was going frantic looking for him. It doesn't half give you a scare and I'm constantly on the boy's backs about gates.

Kyle never slept a complete night, (until he was put onto melatonin by Dr Wraith), for which I am extremely grateful. Now everyone is amazed at how well he is sleeping. I don't want to chance fate but he is going down about 9.00 pm and sleeping until around 6.00 am. Unless he is having problems with his ears, he now sleeps most nights. The worst thing is that he can't tell you if he is in pain, or if anything is annoying him. He is usually such a happy child we now know if he is upset or crying that there is something wrong. In most cases a visit to the doctor usually proves it is his ears. He has had vents in

which have helped him a lot. A few months back though when the doctor couldn't find anything and he was still screaming the place down on the Saturday I phoned the dentist who kindly opened up for us and saw Kyle and sure enough there was a bad tooth. He put in a terrible weekend before he was able to get an anaesthetist to get it out on the Tuesday. He won't let anyone nurse him so we had no way to comfort him. Once the pain relief wore off he just run around aimlessly crying constantly. Now we have him checked over regularly by both the doctor and dentist to try and avoid him any unnecessary suffering.

Another time he was quite upset when he arrived home in the taxi from school. Neither the driver nor I knew what was annoying him, but we soon discovered the next day. When I looked into the back of the taxi another boy had Kyle by the hair and was pulling as hard as he could pull. Now they come in a mini bus and all the boys are in their own corners, well away from each other.

Kyle is still into everything, taps are a favourite, we have avoided any major flood thus far, but he did flood my mum's bathroom. He loves to chew, clothes, tea towels, socks, anything and everything goes into his mouth, sand soil, stones and flowers are some of his favourite. We usually keep a supply of tea towels and we let him chew on these as they are tastier than soggy socks or sand and stones. Needless to say Kyle enjoys his food and will eat almost everything. He would just have difficulty chewing meat. He has his own high chair and we tend to let him feed himself while he is still able, regardless of the mess he makes. He has to use a bay's feeding cup with a non-spill lid as he would turn it upside down or just throw it. Kyle used to say a few words but sadly he has lost that ability now. He loves you to sing and play with him though and his whole



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face will lighten up as he giggles and laughs. A happy smile is always a gift that Kyle shares freely.

Kyle is at present attending Rathfriland Hill Special School in Newry and seems to really enjoy it. When the bus comes in the morning he doesn't know whether to stand at the window and laugh at it or go out and get on it. He is collected at about 7.50 am in the morning so he is away early, then he gets a taxi home and is in around 2.00 pm.

We also get respite for Kyle one weekend a month when he stays at Orana in Newry. To start with I had real difficulty with letting him go, but I've worked through that now, and the fact that he enjoys it so much and they are all so good to him helps. I started by letting him stay for about an hour while I went shopping and gradually worked it up to longer and longer. The first overnight stay I couldn't even bear to take him. His Daddy and Nanny went and I sat at home crying my eyes out and feeling really guilty about it but I had to think of our other two boys. Craig who is almost 11 and Scott who is 9. This gives us opportunities to spend a bit of time with them and take them places, which we just can't take Kyle.

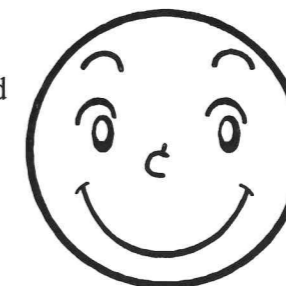
It can get very difficult for them with Kyle being so hyperactive and even getting homework done was a real nightmare until we got the room adapted for Kyle. He was always lifting books or pencils and did once scribble on Craig's homework. Craig told me that he just told the teacher that his wee brother did it and it wasn't his fault as he is disabled and doesn't understand. The teacher thankfully told him that it was okay and gave him an A. We don't want them to feel that Kyle is ruining their lives. Many times in our

home the pair of them would be fighting as boys do, and I hear one say to the other "I wish I hadn't got you for a brother, I wish I'd only got Kyle". Never have they said we wish we didn't have Kyle, they both love him very much despite his often difficult nature and the fact that his behaviour and disabilities restricts many family pursuits.

The shock has worn of now but the pain will always be there. My attitude to life has been changed. I'm not sure if it has made me a different person, but I worry less about trivial things and try to make more time for my family. Of course we have some anxieties about the future, but we're determined to enjoy the present. Kyle remains our great joy and we wouldn't swap him for anything. Knowing that we will not always have Kyle helps us find that last centimetre of patience to cope with many trying situations. When he is causing havoc I can be thankful that he is still able to, as he is already starting to slow down and he will eventually go off his feet and not be able to do anything for himself.

Kyle thankfully is oblivious of his problems and is usually a very happy child and I don't know how we will face the future without him. I do know though that when that time comes our Lord will give us the strength we need, and in the meantime we count every moment with him as precious.

I just want to end by reading a poem which I had on a tape which was given to me just a few days after we got Kyle's diagnosis, it's been a real blessing to me.....



FAMILY SUPPORT

Heavens Very Special Child

A meeting was held quite far from earth
 It's time again for another birth,
 Said the angels to the Lord above
 This special child will need much love.
 His progress may seem very slow
 And he'll require extra care
 From the folk he meets down there.
 He may not run or laugh or play
 His thoughts may seem quite far away
 In many ways he won't adapt
 And he'll be known as handicapped.
 So let's be careful where he's sent
 We want his life to be content
 Please Lord find the parents who
 Will do this special job for you.
 They may not realise right away
 This leading roll they're asked to play
 But with this child sent from above
 Comes stronger faith and richer love.
 And soon they'll know the privilege given
 In caring for this child from Heaven
 Their precious child so meek, so mild
 Is Heavens Very Special Child

SIBLINGS NEWS



Name: Kirsten Macintyre

Age: 17

Pets: Four goldfish

Favourite Activity: Basketball, going to the gym and playing pool at my local pub.

Favourite food: Chocolate, most defiantly !!!

Favourite band: I haven't really got a favourite band but I enjoy all types of music mainly R n'B and swing.

Favourite video: Austin Powers

What makes me angry: When we all go shopping or for a walk and Natasha is in her chair and people really stare. They just don't seem to stop to think that we can feel and see them staring.

Funny situation: A large group of us went to our local theatre to see the stage version of the film "The Full Monty". Near the end of the show the actors had to pick five women out of the audience to have on stage where they did a sort of striptease. I got picked and carried on to the stage where to my amusement my mum was sitting very red and embarrassed next to me on a stall.

What job I would like to do: When I finish my college course I would like to be involved in the retail or graphic design business.

If I could change the world how would I: I would find an instant cure for Mucopolysaccharide diseases.

If I won a million pounds I would: Buy myself a T reg Subaru Impretzer rally car and my boyfriend one too.

(thank you Kirsten for my first reply. I now hope that after reading this lovely profile that some more siblings our there will be putting pen to paper and replying.....).

COMPETITION RESULTS

Many thanks to all the lovely drawings that we have received in the office. Our walls certainly look a lot brighter now.

The decision was a very difficult one to make but after a long discussion in the office Christine, Angela, Hannah, Sue and myself all came to the same decision. Yes we could not make up our minds and have sent you all a prize that we hope you will all enjoy.



Sheila Duffy
Project and Information Officer

FAMILY NEWS



Birthday congratulations to the following MPS children/adults whose birthdays are in July, August and September

- | | | | |
|--------------------------------|---------------------------|--------------------------------|------------------------------|
| <i>Aijaz Umran</i> | <i>David Andrews</i> | <i>Jamie Andrews</i> | <i>Jamie Aylott</i> |
| <i>Adika Batool</i> | <i>Surinder Bhogal</i> | <i>Kristina Briggs</i> | <i>Dean Brown</i> |
| <i>Albert Brown</i> | <i>Alex Butler</i> | <i>Donald Carpenter-Massey</i> | |
| <i>Lauren Cawthorne</i> | | <i>Suhil Chowdhury</i> | <i>Ruhil Chowdhury</i> |
| <i>Stacey Cliff</i> | <i>Kelly Dacey</i> | <i>Lorren Damen</i> | <i>Marcus Djalli</i> |
| <i>Daniel Donegani</i> | | <i>Daniel Ellis</i> | <i>Megan Fasey</i> |
| <i>Aaron Fitts</i> | <i>Michael Fitzgerald</i> | <i>Paul Franklin</i> | <i>Naomi French</i> |
| <i>Eleanor Gee</i> | <i>Jamie George</i> | <i>Jason George</i> | <i>Andrew Graham</i> |
| <i>Alisha Hajifazal</i> | <i>Dominic Hall</i> | <i>Shabnum Haq</i> | <i>Emma Hartley</i> |
| <i>Sam Hitchin</i> | <i>Michael Hoather</i> | <i>Mohsin Hussain</i> | <i>Sarah Hyde</i> |
| <i>Sharma Jam</i> | <i>Francesca Kembrey</i> | | <i>Josephine Kembrey</i> |
| <i>Rachael Kermode</i> | | <i>Sobiya Khan</i> | <i>Elizabeth Kirkpatrick</i> |
| <i>Christopher Leonard</i> | | <i>Sophie Lowe</i> | <i>Ian Maguire</i> |
| <i>Simon Mansfield</i> | <i>Martin McDonagh</i> | | <i>Kevin McKenna</i> |
| <i>Sarah McKnight</i> | <i>Andrew Millar</i> | <i>Shannon Mongan</i> | <i>Edward Morley</i> |
| <i>Patrick Morrisey-Crouch</i> | | <i>Tessa Nelson</i> | <i>Lisa Nurse</i> |
| <i>Brian O'Neil</i> | <i>Helen O'Toole</i> | <i>Lois Pack</i> | <i>Toby Parfitt</i> |
| <i>Alfie Parker</i> | <i>Jimmy Penfold</i> | <i>Susan Percival</i> | <i>Ben Perfect</i> |
| <i>Callum Pollock</i> | <i>Craig Pope</i> | <i>Esan Rafiq</i> | <i>Michaela Rasen</i> |
| <i>Christopher Reade</i> | | <i>Taieyyib Riaz</i> | <i>Lorraine Rock</i> |
| <i>Faye Rowe</i> | <i>David Seymour</i> | <i>Faiza Shaikh</i> | <i>Jake Shaw</i> |
| <i>Ian Shead</i> | <i>Jack Stuart</i> | <i>Darren Tailford</i> | <i>Kim Taundry</i> |
| <i>Debra Thorburn</i> | <i>Jack Trafford</i> | <i>Richard Turner</i> | <i>Asma Ullah</i> |
| <i>Brain Ward</i> | <i>Michael Watkinson</i> | | <i>Zara Watson</i> |
| <i>Robyn Watterson</i> | | <i>Phillip Weir</i> | <i>Jeanette Whiteside</i> |

In the next newsletter birthdays for October, November and December to be included. – Photographs of birthday parties/cakes would also be great

INFORMATION

The Orpheus Centre

The *Orpheus* Centre is a place where physically disabled and non-disabled young people can try out and develop their talents in all aspects of the performing arts – from box-office to dance, from marketing to musicals. These are provided by running short courses from April to September.

The *Orpheus* Centre is set in Godstone, Surrey and has been designed specifically to host courses for disabled and non-disabled people.

There is a Georgian farmhouse and out-buildings that include accommodation, rehearsal rooms, a recording studio and a theatre in their beautiful barn. The gardens have marvellous views, exciting sculptures and a swimming pool. It is supported by the Arts Council of England National Lottery Fund and many others.

Orpheus is designed primarily for young people (18-40) with physical and/or sensory impairment. They do not ask for any proof of musical or dramatic skills– enthusiasm is all that is necessary.

They operate an apprenticeship scheme that is open to people between the ages of 19-25 who wish to achieve their artistic aims and achieve greater independence. The apprentices are fully involved in the management of the Centre so there is an emphasis on everyone, staff and residents, working together to achieve a sense of belonging and achievement.

They have spaces for 10 young disabled students and if you want to know more about the Apprenticeship scheme and how to apply please write to the Administrator at the Centre.

The Centre is home to the apprentices who stay from one to three years and for students with their 'enablers' who come for a week at a time on residential courses.

Each apprentice is allocated a Key Worker who is responsible for co-ordinating his/her agreed individual care plan. Residents attending short courses will be allocated an 'enabler'.

The centre is a registered residential care home with Surrey County Council and is regularly inspected. It is not a nursing home and nursing care is not provided.



All students attending courses should secure their own funding to pay for the fees. However they do operate a bursary fund and details can be sent.

Courses in 1999 include;

3 day event in July-Songwriting with Richard Stilgoe

6 day events include a Song week and a Dance week and on the 25th July their Open Day.

For further information contact;

Centre Director
The Orpheus Centre
North Park Lane
Godstone
Surrey RH9 8ND

Tel: 01883 744664 Fax: 01883 744994
E mail: staff@orpheus.org.uk
Website: www.orpheus.org.uk

The Orpheus Centre is a project of the Orpheus Trust and is a registered charity.

INFORMATION

The Search is over !!!!!

My daughter Jessica (Hurler) suffers from ice cold feet. I have tried everything to keep them warm but to no avail. I have searched high and low for some form of footwear that would keep Jessica's feet cosy. People I have asked have given me that 'I don't know what you are talking about, go and ask elsewhere look'. Well I've finally tracked down a company which makes footwear to measure using sheepskin products.

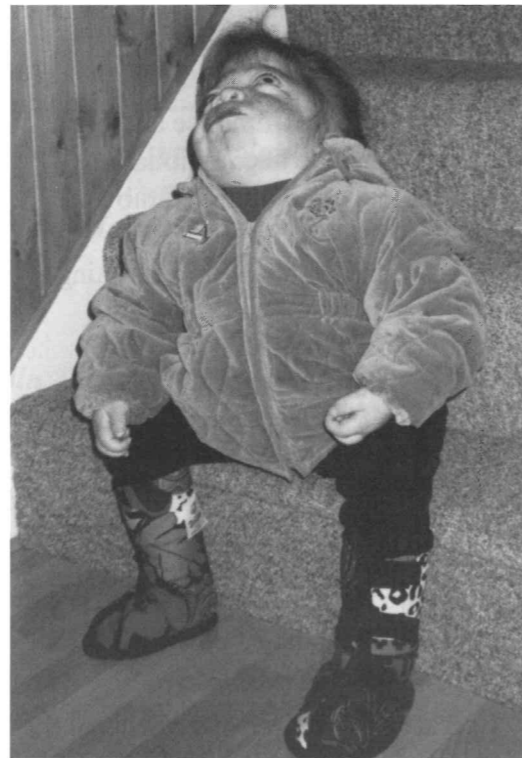
The company is called WARM & WELL and is based in Northern Ireland. It has a staff of five and the managing director, Gisela Schulz couldn't have been nicer, when I explained what I wanted.

I gave them Jessica's measurements, foot length, around knee, calf and ankle, and the length between knee and heel. Just to be on the safe side, I also gave them Jessica's footprints. I chose the material (washable) and type of fastening I wanted. Within a week I had the 'boots' which fitted Jessica beautifully.



There are several different materials, fastenings,

and designs, whether you want boots to the knee or ankle boots. The boots are made with walk on soles but are not suitable to wear in the wet. I had a second pair of boots made slightly bigger with Velcro, so that I could tuck Jessica's trousers into them, as this was more comfortable for her. The boots keep her feet very warm and allow them to breathe so they don't sweat! I will be ordering a pair of 'ankle' boots for Jessica for the summer as her feet are cold whatever the weather.



Jessica modelling the boots in the photographs.

Their address is;
 WARM & WELL
 48 Seagoe Industrial Estate
 Portadown
 Co. Armagh
 Northern Ireland BT 63 5QE
 Tel: 017623 335060 Fax: 01762 361885
 I could not be happier with WARM & WELL and recommend them to you all.

Sue Stuart

INFORMATION

An ideal bed for our Sanfilippo daughter

My name is Alison and my daughter Faye is 17 years old with Sanfilippo 'A'; and weighs 11 stone.

Due to the fact that we were getting back trouble, because of nappy changing, cleaning etc. we decided to get a bed that moved up and down for easier handling of Faye.

We (my husband Gordon and myself) decided that a 4 foot wide bed would be better, due to her restlessness while sleeping. I would also sleep beside her when her night fits are happening.

Most of the normal bed shops could not help, unless we had a standard single 3 feet wide hospital bed, or a double bed with 2 feet by 2 feet 6 inches, individual beds joined together. But we wanted a 4 foot single bed and were having lots of trouble in finding one.

I then went onto the internet and got in touch with companies in Germany, Canada, America etc. Prices went from £7,000 down to £4,000. These beds would take 1 year to build and when completed no real guarantee was with them.

One month later whilst driving through London and still looking for the right bed, I noticed a company selling beds. I went in and had a look. The one that looked good and had the quietest motor I decided to follow up on.

The actual bed was called a 'Comfacto' and the company owner was called John. This person was very helpful and whatever he didn't do, he made arrangements with other people who could help us. This firm was only interested in getting things right and was honest and up front and he

eventually got everything sorted for us.

We now have a 4 foot single bed that rises up and down approximately 14 inches, strengthened to take over 20 stone in weight, headboard, baseboard, cot sides, mattress to the firmness we wanted for under £3,000.

The company is called;
 Design Strength Ltd.
 106 Belgrade Road
 London E11 3QP

Tel No: 0181 925 4477

Having this bed, has made dealing with Faye a lot easier and Faye herself seems relaxed on it, as she will put herself to bed.

I hope this information might be of some use to other MPS parents/carers. I have sent pictures of the bed and information about it to the MPS office. If you would like a copy please contact them and they will send you a copy.

If anyone would like to see the bed I would have no objections to anyone calling at my house. My telephone number is 01322 439 229.

Alison Rowe



INFORMATION

First of the Diana Nursing Teams begin their work

The Department of Health has announced the first of the Diana, Princess of Wales nursing teams. There are to be eight of them in England and another in North Wales. They began work in April. In England the teams will be located in Coventry and Warwickshire, North Cumbria, Cambridge and Huntingdon, Newham, Leicester, Salford, Cornwall and the Isles of Scilly and west Kent. Scotland intends to use the money available to provide community children's nursing courses.

The Diana nursing teams are being established as a memorial to Diana Princess of Wales.

Announcing the scheme in March, the Health Minister Baroness Hayman said, "I was delighted to see such a high level of interest in setting up these pioneering teams to give specialist nursing care and practical help for very sick children and their families, and there was such a good choice of scheme from which to make our first decisions. It has been a difficult process, but the projects finally chosen all have in common a clear focus on working with all relevant agencies and voluntary organisations to ensure that children and their families receive a full range of services they need."

The eight projects in England account for £1,400,000 of the available money in the first year.

Coventry and Warwickshire

This scheme brings together a wide range of disciplines to co-ordinate and deliver care to an estimated 200 families across two health authorities. It has full backing from principal officers in the Health Authorities and Social Services and from key nurses and paediatricians. The team will con-

sist of a nurse practitioner as team leader, community children's nurses, respite care staff, a social worker, a clinical psychologist, a clerical assistant and sessions from a community paediatrician. Their prime objective will be to plan care packages in partnership with families and provide a key worker to co-ordinate and liaise with services. They also plan to develop a register to include families from the time of diagnosis.

North Cumbria

North Cumbria's proposal also has the full support of the Health Authority, Social Services, Health Trusts, primary care groups and the local voluntary sector. The scheme anticipated to care for some 100 families, will provide a 24 hour key worker to co-ordinate care for each family and will incorporate children's nurses, therapists, health care assistants, a psychologist, an educationalist, volunteers and clerical assistance. Local existing social workers will be closely involved in the team's work.

Leicestershire

The joint proposal from Leicestershire Health Authority, Fosse NHS Trust and Leicester Children's Hospital builds on an existing community service. They estimate some 600 children with life-limiting conditions require specialised care. They intend to increase the number of community children's nurses, and provide a cultural link worker, a psychologist, and designated sessions from a physiotherapist, occupational therapist and dietician.

West Kent and Cornwall

West Kent will be developing two children's community nursing teams managed by a specialist nurse at a District Hospital while Cornwall plan two separately managed community teams utilising some existing posts. They will add on a children's community nurse each and share a psychologist, physiotherapist and are therapist.

INFORMATION

Self-Operated Care Schemes

Newham

The scheme brings together the Community Health Trust, Newham Social Services, East London and City Health Authority and Richard House Children's Hospice in a unique partnership to deliver care to an estimated 650 children and their families. Their team will consist of a co-ordinator, a team of community children's nurses, nursing assistants, part-time occupational and physiotherapists and administrative staff.

They will draw on existing health visitors, school nurse, paediatricians, social workers and educationalists. They plan to adopt the key worker approach and will offer home-based respite and psychological support to families. Interpreting is also included as a necessary component.

Cambridge and Huntingdon

The proposal from Cambridge and Huntingdon Health Authority aims to improve accessibility, co-ordination and liaison between all disciplines by delivering a key worker function for approximately 86 families. The team will act as a resource to health and other professionals and will consist of a community nurse team leader, community children's nurses, community paediatrician sessions, social worker, psychologist, play specialist, educationalist and secretarial staff. The discrete 'core' team will be able to co-ordinate a highly flexible service and will develop relationships with other teams, organisations and individuals involved with families.

Salford

The Salford proposal similarly will enhance existing provision by enabling 24 hour contact, providing respite care and incorporating play therapists and psychologists. They intend to manage a flexible service to encompass the full range of needs of the child and family.

The Community Care (Direct Payments) Act 1996 has made it possible for Social Services Departments to pay money to you if you are willing and able to buy in your own care services for meeting your assessed needs rather than Social Services and others by direct payments. It came into force in April 1997. There are various limitations:-

- The Act does not require local authorities to make direct payments but simply allows them to do so. Some authorities may not run a scheme. If you want a direct payment and there is no scheme in your area you can use the complaints procedure.
- Regulations limit direct payments to particular categories of people and at present only include disabled people under 65 years of age, although if you were getting a direct payment before 65 years it will continue. There is a commitment to review this in April 1998.
- Certain other people cannot receive direct payments, in particular those who have a mental illness and are still subject to conditions under the Mental Health Act (i.e. on leave of absence or supervision after discharge).
- The level of payment may be linked to your local authority's discretionary charging policy and paid net of any charge.
- It can only be used for care at home, or short periods in respite care up to a maximum of 4 weeks in any one-year. Separate periods in Respite care of less than 4 weeks are added together towards the maximum only if you are home for 28 days or less in between.

INFORMATION

- Direct payments cannot be used to pay for services from a spouse or partner, or a close relative living in the same household or else-where (Except in exceptional circumstances).

If the money is not spent on the care that the local authority has assessed you as needing (ie. What they would have been prepared to provide)- then they may ask for it to be paid back. How it will work in practice will vary from area to area.

The local authorities have been given a monitoring task to ensure both that the services you buy meet your assessed needs and for audit purposes to ensure the money is actually spent of the care.

Guidance suggests that local authorities discuss with people at an early stage whether they wish to have a direct payment. There is discretion to refuse direct payments to anyone the judge would not be able to manage, although they are told to avoid blanket assumptions. The person can have assistance in managing but has the final responsibility of how the money is spent.

The Act required local authorities to make direct payments at the rate which would be equal to their estimate of the reasonable cost of the service.

If you are dissatisfied with any aspect of the direct payment, including being refused a payment, you should use the complaints procedure.

If you are considering applying for Direct Payments from your local Social Services Department, you should be well motivated, you must want to operate the scheme and you must want to control your own life. A support worker may be provided to offer you assistance to set up and run the scheme, but the ultimate responsibility is yours.

Operating your own care scheme with Direct Payments enables you to decide who works for you. You will then advertise, recruit, interview, employ and pay for your own staff.

Whilst this does give you freedom and control it also puts certain responsibilities on you:-

- You are expected to recruit and pay for your own staff.
- You are expected to manage the money you are given.
- You are expected to be a responsible employer. You must provide your employees with a Job Description and a Contract of Employment. These tell your employee what you expect them to do and what rules you expect them to operate under.
- You are expected to inform the local tax office that you are employing someone.
- If you pay anyone less than £61 per week, you would not normally have to deduct National Insurance. If your employee is paid more than £72.48 per week (this includes pay from other jobs) you will be expected to deduct tax which you will subsequently pay to the Inland Revenue.
- You will need to amend your household contents insurance to include employer's liability insurance cover. This is to protect yourself from claims should your staff injure themselves whilst working for you. The insurance should include tasks performed in and outside the home (including driving).
- You must ensure the people who work for you are not put at risk of being injured through inadequate health and safety procedures. Training courses are available (i.e. lifting techniques etc). Ask your support worker for further details.
- You will be expected to treat your employees reasonably.

RESEARCH UPDATE

MPS along with a number of UK rare diseases support groups including the Research Trust for Metabolic Diseases in Children (RTMDC) is a member of Eurodis. Eurodis is the umbrella organisation for rare diseases lobbying for and providing information and advice on rare diseases to the European parliament. In early March the Orphan Medical Product Regulation completed another important phase of its progress toward the statute book.

This legislation is important to MPS and for all other rare diseases. It is viewed as a vital tool in improving the health situation of thousands of Europeans affected by rare diseases. MPS is already seeing the results of this pending legislation with a number of biotech companies committing significant funds to the research and development of potential therapies for MPS. We have already seen clinical trials using Enzyme Replacement Therapy (ERT) in the United States for MPS Type I and expect ERT to be introduced into Europe by the end of 1999.

For some MPS disorders we recognise that progress is frustratingly slow. However, the high profile of the MPS Society and its European database is a poignant reminder to pharmaceutical companies of the need for ongoing research.



The money that the MPS Society has received from Jeans for Genes and money raised by families specifically for research has allowed the Trustees following Peer Review to award the following grants in 1998/99.

Dr Robert Coffin
University College London, Medical School
Grant awarded £78,175

This is a two year grant to research Gene Ther-

apy for the Mucopolysaccharide Disease using Herpes Simples Virus Vectors.

As yet there is no treatment for the neurological complications associated with the Mucopolysaccharide diseases. It is our aim to explore the use of a novel 'gene therapy' procedure in animal models as a potential treatment for these neurological complications. Gene therapy involves the treatment of disease by delivery of a gene encoding the deficient protein to the affected area of the body, where that gene would replace the otherwise defective gene into the appropriate area of the body – in this case the brain – which here will be provided by the use of a herpes virus, disabled such that it can no longer cause disease, but which has been engineered to contain the genes deficient in the MPS diseases under study. We will test a mouse model of the MPS disease whether introduction into the brain of this vector engineered to also contain the gene deficient in the MPS disease results in a reduction in the build up of lysosomal lesions.

Dr Guy Besley
Willink Biochemical Genetics Unit, RMCH
Grant awarded £121,202

This is a three grant to research gene mutation analysis in Mucopolysaccharide disease.

During the last five years there have been major advances in identifying mutations in various lysosomal disorders we have recognised the importance of molecular analysis not only to complete the diagnostic investigation but also to assist in predicting phenotype and in providing a reliable means of carrier protection. However these investigations are usually time consuming, and in a busy diagnostic laboratory it is not possible to provide as comprehensive service as we and the patients would like. Some mutation analyses are beset with potential difficulties. It is important that a reliable and robust method

RESEARCH UPDATE

is used to identify in particular MPS I patients with the gene mutation W42OX, especially since those with this mutation are candidates for gene therapy. We are anxious to offer a more effective response to requests for carrier testing in MPS II. Offers of prenatal diagnosis can therefore be better targeted to at risk and confirmed carriers. This grant will fund dedicated member of staff to undertake these investigations.



Dr Maureen Cleary
Royal Manchester Children Hospital
Grant awarded £85,000

This is 50% of a three year grant to establish a third consultant post specialising in Mucopolysaccharide Disease at the Royal Manchester Children's Hospital.

Since 1988 Dr Ed Wraith at the Willink Biochemical Genetics Unit has single handily clinically managed a population of over 400 MPS patients developing an expertise that is recognised throughout the world. Due to his increasing workload and despite the fact that Dr Ashok Vellodi was appointed in a similar position at the Hospital for Sick Children, Great Ormond Street, it is important to provide additional support for the growing number of children and young adults suffering from MPS and to provide an educational environment for a new generation of Consultant Paediatricians specialising in metabolic disease.

Mary Lewis
Avon Lifetime Services
Grant awarded £3,000

This is a project grant to enable the Avon Lifetime Services to develop the following that would be available to all MPS families:

CARE PLAN MODELS FOR HURLER AND SANFILIPPO CHILDREN

These would be outline care needs protocols, to cover different illness stages, and include 'tips' and ideas about how to work through particular problems. They would be developed as 'Core Plans' which would then be available for adaptation to a particular child's needs. It is proposed that a small working party of parents would be used to inform this process, as they are the real 'experts' in what care is needed.

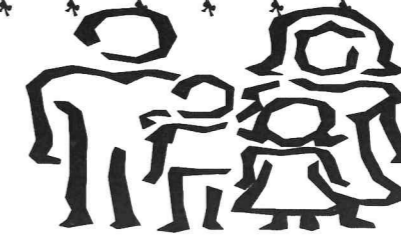
EMERGENCY INFORMATION PACK

A skeleton format of an information pack that would always be carried with a child is proposed. This would cover condition information, emergency procedures, contact numbers, parental specific wishes for treatment. It would have very clear instructions for individualisation and the need for someone to work with the parents to make decisions about information to be included.

GASTROSTOMY INFORMATION PACK

This would give information about different types of gastrostomies, with advantages and disadvantages; as new products come onto the market a regular review would be needed. A care plan following insertion of gastrostomy, and long term care based on evidence and practice which will need regular review. An information section on feeding Sanfilippo children specifically will also be developed in collaboration with a dietician.

BEREAVEMENT SUPPORT



When I've Lost my Child Please

- ♦ Don't say it was for the best – it wasn't
- ♦ Say you are sorry and mean it!
- ♦ Give me some time and space but remember I might need to talk months later.
- ♦ Ask me how I am feeling.
- ♦ Be there when I need you.
- ♦ Ask if you can help in a practical way – is there anything I can do ? eg. shopping, looking after the children.
- ♦ Mention my child – I need to talk about him/her.
- ♦ Don't change the subject if I begin to cry – I need to talk it out.
- ♦ Don't hide your children from me.
- ♦ Don't say I know how you feel.
- ♦ Remember to ask husband/wife how he/she is feeling –he/she is hurting too.
- ♦ Be aware that birthdays and the anniversary of my child's death will always be hard for me.
- ♦ If you haven't been in touch for a while – don't say I've been too busy. If you haven't known what to say I'd rather hear that.
- ♦ Don't tell me about someone else's tragedy and how that was worse than mine.

FUNDRAISING

'3 Peaks Lament'



It was 5pm on Ben Nevis
All glistening and white in it's glow
Only 1340 metres above sea level
'What ? How far do we have to go ?'

But once up into the mountains
With the ice, the wind and the snow
Suddenly there's thought of summer
Then 'Oh God, I've stubbed me toe!'

They clambered up Ben Nevis
Resulting in injury for Clive
His leg, it hurt like crazy
As if attacked by bees from a hive.

Down came our intrepid heroes
Tracy, Stuart, Clive and Jon too
Back to their cars and their helpers;
Harry, Frank, Lorna and Sue.

They all tore off to Scafell
Deep in the dead of night
It was 3.15 in the morning -
'What ? That cannot be right !'

There was not time for sleeping
Or dreaming of places afar
Just 'Get up, Get out & Get at 'em
And no you can't stay and sleep in the car !'

Back down came our gallant troop
Certainly with no fear
Just with thoughts of words of comfort
Like 'Landlord, gimme a beer'

Now wait—we've still got Snowdon
Just one more mountain to come
Steel yourself for just one last time –
Then you can ease your aching bum!

Now back to the hills for the last time
No time to slumber or pause
Remember the reason for this torment
Don't forget the worthy cause.

So finally it's the top of Snowdon
And still inside the bell
'You've made it, Congratulations !
NOW DIDN'T THEY ALL DO WELL?

*('Shakespearean Brummie' rides again –
Patent as always pending)*

*Anyone reading this who would still like to contribute to the Society for
Mucopolysaccharide Diseases research can send a cheque to the MPS office
with a note to say '3 Peaks Challenge' donation.*

FUNDRAISING



Tracy, Stuart, Clive & Jon
'Racing Against Time'
3 Peaks Challenge June 1999

The story - 11th/12th June 1999

Yes they did it! The intrepid quartet of Tracy, Stuart, Jonathan and Clive climbed the peaks of Ben Nevis, Scafell Pike and Snowdon in 22 hours 54 minutes. No mean feat as they are nearly 500 miles apart.

To accomplish this remarkable achievement they needed a sound and dedicated back-up team to help prepare for each climb and drive the cars kindly provided by Volvo. This support was ably provided by Stuart fiancée Lorna, his parents Sue and Frank and Lorna's father, Harry.

The clock started ticking at 5 pm on Friday 11 June. Ben Nevis is over 1,300 metres high and unfortunately the climb starts from very nearly sea level. This was also the only one of the peaks none of the team had ever experienced before. Half way up, near disaster struck when Clive badly injured the outer tendons of his left knee. Made of strong stuff he strapped the leg and pressed on, but the pace inevitably slowed. Four and a half hours later, as they got down from the snow capped Ben Nevis there was considerable concern for Clive. He was however, determined to go on.

At 3.15 am they started the ascent of Scafell Pike. A very steep and tricky mountain not easily scaled in the dead of night. They were equipped with 'miners headlamps' to enable night vision.

They could see just one other party way in the

distance whose lights bobbed unerringly against the night sky. Despite freezing temperatures, low cloud and driving rain, the gang of four walked up, over and down the other side of Scafell to their awaiting cars, and more importantly – hot bacon sandwiches. The time was now 8.30 am and concern was growing at the possibility of not completing the challenge within the specified 24 hours. By now Clive had developed severe 2-inch diameter blisters behind the strapping on his knee worsened by misplaced treatment with Ralgex!

By lunchtime they commenced the ascent of Snowdon. In the meantime Tracy's mother and father, Jean and Peter, had reached Snowdon independently. As they could not contact the team, due to mobile phone signals being eradicated by Snowdonia mountain ranges, they decided, perhaps somewhat recklessly, to start the ascent of Snowdon themselves. 'So what ?' you may think. They were accompanied by Tracy's 16 years old Mucopolysaccharide – Sanfilippo brother, Andrew !. He is almost unique in that he can still walk and talk, albeit with the equivalent age of a three year old. So, not without trepidation, they set off.

After an hour, Tracy and her team caught up with her family although the problems for Clive were all too apparent as the assault team pressed on for the top. Shortly afterwards, Stuart's mother and support team member, Sue caught up with Jean, Peter and Andrew. Sue agreed to

FUNDRAISING

*The team of four at the summit of Snowdon – and the end of the 3 Peaks Challenge
Jonathan Goldsmith, Clive Baughan, Stuart Pond and Tracy Hawkins*



accompany Jean whilst Peter and Andrew pushed on at a faster pace toward the summit. Andrew was determined not only to catch up with his sister, but also to get a ride on the last train back down the mountain. This he achieved, to be joined by his mother – but only just in time!

So all's well that ends well. The team did a superb job, a degree of effort epitomised by Clive's sheer determination to overcome adversity. *The icing of the cake was Andrew's almost unbelievable achievement of probably being the only known Sanfilippo ever to climb to the summit of Snowdon.* Quite remarkable for someone whose normal life expectancy is just 15.

This was all done to raise funds to continue research into finding cures for Mucopolysaccharide Disease. Regrettably, Corporate responses

have so far proved derisory but at least individual support has been more encouraging. Those involved in this challenge expended not only many hundreds of pounds of their own money, but quite unstintingly a considerable amount of time and effort.

Tracy Hawkins – Andrews' sister



Congratulations to Jonathan, Clive, Stuart, Tracy and especially Andrew on their brilliant achievement from all of The MPS Society. NB. Also the team of helpers of course deserve a big thank you as well.

PLEASE REMEMBER TO RETURN YOUR SPONSOR FORMS AND MONEY ASAP TO THE MPS OFFICE AND THEN WE WILL LET YOU KNOW THE TOTAL RECEIVED IN THE NEXT NEWSLETTER.

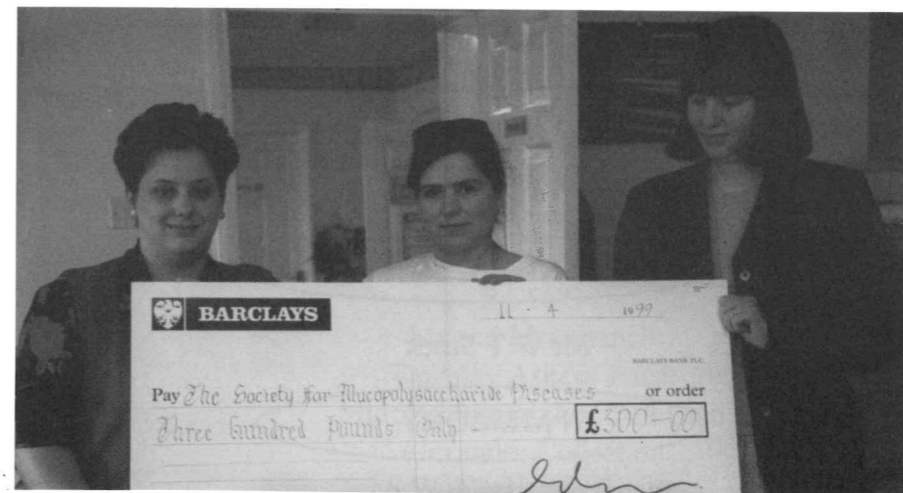
FUNDRAISING

Rocky Horror Charity Night



A cheque for £288 was sent to the MPS Society following a very successful Rocky Horror Charity night held at the Crosby Hotel, Scunthorpe. A fun and 'weird' night was had by all. Five bands played for free and Trevor and myself made a collection and had a tombola stall.

**Barbara Rollinson
Yorkshire and E Coast Area Family**



Over the last 2 years Anne Marie Watson whose daughter Zara suffers from Sanfilippo disease, has written to 100's of celebrities seeking personalised items to auction in aid of the MPS Society. The auction took place in Sleaford one 11th April. A total £3,068 was raised and above is a photograph of Anne Marie Watson and Ellie Gunary receiving a cheque from Sue Green from the Auction rooms. We would like to thank Anne Marie and her family for their wonderful effort in this fundraising idea.

A cheque for £526 was presented to Trevor and Barbara Rollinson from the Harrogate & District Ladies Darts League.

The photograph below shows Mrs Pat Wilson and friend presenting the cheque to Trevor and Barbara Rollinson.



FUNDRAISING

FUNDRAISING EVENTS

The Society is grateful to the following who held fundraising events

Mr and Mrs Firth – Coffee mornings at Stockbridge Library
 Mr and Mrs Firth – Loose change collected by children at local church
 Marine and Dave Foster – Car Boot Sales
 London & Edinburgh Insurance Group – Casual Dress Day
 Gryffe High School – Ceilidh
 Anne-Marie Watson – Charity Auction
 Janice Rigley – Sponsored “Give Up Smoking for 1 month”
 Andrew, Laura and Gary Devine – Fundraising Catalogue
 S M Woodhouse – Relative Brian – ‘Moustache shaved off’
 Wells Blue School – Local Charity Evening
 S Mossman – Sale of car boot items via shop
 Mr W T Stock – Jigsaw and Bric-a-Brac Sale
 Haddenham Morris Men – Annual Tour of Haddenham
 Barbara Rollinson – Rocky Horror Show Charity Night
 Marianne Stimpson – Fundraising Catalogue
 Jackie Chisling – Easter Egg Raffle
 Jasmine McLaren – Sponsored Slim
 Barbara Elliot – Sponsored Womens 10K Run
 First Trust – Staff Draw
 Spiffing Stationery – Sale and printing of stationery

COLLECTION BOXES

Oversley Mill Service Station
 Mrs Glad Hughes

STAMPS

Mr W T Stock

IN MEMORY

Greg Rice
 Emily Hayward
 Edward Nowell
 Olivia Bailey



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The Society is grateful to the following who made donations

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Tel: 01406 351524

HOME COUNTIES

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Tel: 0118 9541293

MIDLANDS

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Tel: 01827 56363

Zerina and Sajjad Shah
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Tel: 01902 656147

Doreen and Monty Russell
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Tel: 0121 6864779

NORTH EAST OF ENGLAND

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11 Penfold Close, Fairways Estate, Benton, Newcastle on Tyne NE7 7UQ
Tel: 0191 2921234

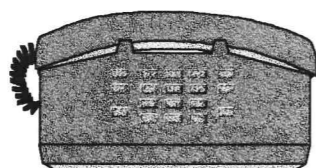
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Tel: 01325 254985

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

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Tel: 01942 810109

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



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

POTTERIES

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Tel: 01244 531163

SCOTLAND

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"Woodlee" 47 Oakdene Court, Culloden, Inverness, Highland IV1 2XL
Tel: 01463 791816

Karen and Clint Stevenson
6 Viewfield Street, Harthill, Shotts, Lanarkshire ML7 5SN
Tel: 01501 751760**

SOUTH-EAST

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

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

SOUTH-WEST

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

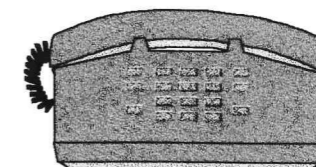
Anne and Gordon Hill
Bowhayes Farm, Venn Ottery, Ottery, St Mary, Devon EX11 1RX
Tel: 01404 813823**

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