Newsletter

The Society for Mucopolysaccharide Diseases

National Registered Charity No. 287034

Winter 2002

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Front Cover: Roma Drayne with young members of the Hillside Players presenting a cheque for £100 which was raised at a Players Variety Concert at St Colman's, Lambeg

SOCIETY NEWS

Director's Report

Christine Lavery

Firstly on behalf of the Trustees and the MPS staff team I want to offer a huge thank you for your kind thoughts this Christmas and for all your support throughout 2002. It was lovely to see those of you who could make it to the events throughout the year. Your fundraising efforts too have been much appreciated and are vital to enable us to deliver the services you need from the MPS Society. We provide our advocacy and support services without charge but of course they do cost us. Even the telephone bills and office rent have to be paid. Please don't stop supporting our work. As the Society enters its 21st birthday year it is as important as ever that we have the resources to support an ever increasing number of affected children and adults, their families and carers.

Our advocacy team are always ready to hear from you and hope those of you that have used our advocacy service, help line and information resources have found it a positive experience.

We were pleased to see such a large number of MPS families at our Christmas parties in Scotland and the South East. As you will see from the write-ups in the Newsletter, young and not so young enjoyed the seasonal festivities. On the other hand we were very disappointed that having planned and organised twelve Christmas parties in all corners of the United Kingdom only 37 families booked in total, making 10 Christmas parties not viable and having to be cancelled. Considerable time was expended setting up the Christmas party programme so in 2003 we shall be looking for commitment from you before spending valuable staff time cancelling them. Time that with hindsight could have been better used supporting members in different ways.

Enclosed with this Newsletter is the National Weekend Conference programme for 20-22 June 2003 in Northampton and a booking form. In essence there are three separate symposia on the Saturday. Symposium A is aimed at familes whose children and young adults have Hurler, ML II and the other diseases causing neuro degeneration. Symposium B is most appropriate for individuals living with a physical disability and aiming to live independently, perhaps with Morquio, Hunter, Maroteaux Lamy disease, ML III and those who have had BMT. Symposium C is directed at those suffering from Fabry disease, their families and carers. On Sunday the conference will be joint and reflect on the Society's research activites as well as current and future treatments. We do expect a large number of members to book and advise reserving your places early.

For our members in Northern Ireland and Scotland we are planning day conferences proceeding or following from regional clinics to take place in Edinburgh in May and Belfast in November. It goes without saying all our members will receive a warm welcome at our conference in Northampton.

Finally may I wish you all a happy and peaceful New Year.

Postgraduate Course - Mainz

Ellie Gunary - Assistant Director

One of the things I love about working for the MPS Society is that the work is continually changing and you never stop learning. Each day brings something new. When Christine approached me a few months ago about the possibility of participating in an International Postgraduate Course on Lysosomal Storage Diseases I eagerly accepted this opportunity. I set to work updating my CV and felt very honoured, particularly as a non-medical graduate, to be accepted onto the course. A more in-depth knowledge about cell biology, the laboratory diagnosis and the clinical characteristics and management of children and adults affected by lysosomal storage diseases could only improve my knowledge and therefore my work for the Society.

I set off on Sunday 24th November 2002 for Heathrow Airport to pick up a flight to Frankfurt from where a car would collect me and take me to Mainz. I was a little bit anxious. What had I let myself in for?!

Lectures started the next morning at 8.30am with cell biology and pathology followed by an afternoon addressing laboratory diagnosis and animal models. Throughout the week the twenty students on the course got to know each other as well as leading medical and research professionals in the field of lysosomal storage diseases. I found it very interesting learning more about the experiences of up and coming doctors and laboratory staff in the field and it was reassuring to know of the interest in this field in a new generation of medical and laboratory staff.

Whilst I found the Monday lectures very interesting there were occasions when they became so technical that I wondered what language was being spoken! I have my notes and if needed I will be consulting medical dictionaries over the next few months to ensure I understand them.

The following day, although a long one, beginning again at 8.30am but not ending until 9pm, addressed the clinical characteristics of Fabry disease and Enzyme Replacement Therapy for Fabry disease. Christine gave the last "speaker" presentation for this day jointly with Bettina Wildi, the President of the German MPS Society, on the Role of Patient Support Groups in Lysosomal Storage Diseases. I was definitely back on home ground here!

As part of the course each student was asked to make a 5-10 minute presentation on a case study and it was during the evening session that we heard some of these. The case report I gave, about a piece of individual advocacy support work, was very different to the medical and scientific case reports previously heard. My aim in presenting the case I chose was to generate awareness of life outside the clinic room and how decisions made in the clinic room can affect the lives of patients outside. I was pleased to see that my presentation generated discussion and a key medical professional present reinforced the importance of doctors remaining aware that they are also their patient advocates.

Wednesday consisted of lectures on Gaucher disease and after more case reports we were given an afternoon tour of Oppenheim. Oppenheim obtained its town charter back in 1218 and is dominated by half-timber houses and romantic narrow lanes. Whilst visiting St Katherine's church, which is famous for its "Oppenheim Rose" window we listened to a 15 minute organ concerto, then spent a very pleasant evening socialising and enjoying local wines and food.

The final day of lectures promptly began again at 8.30am on Thursday morning with Dr Ed Wraith speaking about MPS and related diseases. Ed was followed by Dr Marie Vanier from France speaking about Neurolipidosis and a further speaker Dr Goebbel on Ceroid Lipofusinosis.

After an afternoon of lectures on Bone Marrow Transplants and Gene Therapy a farewell dinner during which we were given certificates took place. We did have an exam question to answer but luckily these were mostly about our visit to Oppenheim!

Dr Ed Kolodny, Ellie Gunary, Dr Ed Wraith, Dr Nicola Poplawski and Mrs Kolodny enjoying local wines and food

Early the next morning it was back on a plane and back to the UK. I would like to thank everyone involved in organising the course for this wonderful opportunity, particularly Dr Michael Beck for hosting it and making the course such an invaluable and enjoyable experience.

Introducing Alison West - Advocacy Support Team

Hello. For those of you who have had the unrivalled pleasure of meeting me already, you can ignore this part. For the rest of you, my name is Alison West and I am the new member of the Advocacy Support Team at the MPS Society. I started working here in September and have been kept very busy in the past few months with a variety of advocacy support work, regional clinics and a couple of conferences. I come from a varied background, with experience in Dance Therapy and counselling (and much more besides!) and I'm looking forward to meeting and working with you all in the near future.

Goodbye From Helen

Helen Heard, a member of the advocacy support team, left the employment of the Society in January. Helen is moving on and sends her best wishes to all the families she has supported over the past year. On the behalf of the members we send Helen our best wishes.

'The Event Of The Year'

Dr Maureen Cleary is Metabolic consultant at the Hospital for Sick Children Great Ormond Street having spent the last five years working alongside Dr Ed Wraith at the Royal Manchester Children's Hospital. Dr Cleary holds regular MPS Clinics at Great Ormond street and as of March 2003 will hold regular Adult MPS Clinics at the National Hospital, Queen's square, London. Referrals to Dr Cleary come thrugh the GP or local doctor to Great Ormond Street.

Photos courtesy of Dr Ed Wraith

Advocacy Support Events For 2003

January
Birmingham Clinic:- Friday 24th January

February
Newcastle Clinic:- Tuesday 4th February

April
East Anglia Clinic:- Friday 4th April
Cardiff Clinic:- Wednesday 30th April

May
Bristol Clinic:- Thursday 1st May
AGM:- 10th May (proposed)
Scottish Clinic:- 15th May
Scottish Conference:- 16th May
Northern Ireland Clinic:- to be confirmed

June
House of Commons tea party:- 4th June
National Conference – Northampton:- 20th – 22nd June
Birmingham Clinic:- 27th June

July
Remembrance day – Childhood Wood:- 6th July

October
Jeans for Genes:- 3rd October
Tree Planting- Childhood Wood:- 24th October

November
Cardiff Clinic:- Wednesday 5th November
Bristol Clinic:- Thursday 6th November
Northern Ireland Clinic:- to be confirmed
Northern Ireland Conference:- to be confirmed

UK wide information days will take place throughout the year.

The advocacy support team remain committed to establishing a regional clinic in the South East of England.

Outpatient Clinics At Great Ormond Street

Christine Lavery - Director

Feedback from Children and Parents Wanted

Professor Leonard is currently reviewing the organisation of Outpatients for metabolic medicine at the Hospital for Sick Children, Great Ormond Street and would be very interested to hear of your ideas as to how the clinics you attend might be improved. He would be grateful for your comments on any aspect of the organisation of outpatent clinics. This might include

1. The timing of clinics
2. The arrangements for checking in
3. Duration of consultation
4. Facilities available whilst waiting
5. The arrangemnets for blood tests and other investigations
6. The need for joint clinics with other specialities

These are only some of the suggestions and any other thoughts or ideas you might have would be very welcome.

Please let me have your comments, thoughts, ideas as soon as possible as we need to feedback. You can e-mail me at c.lavery@mpssociety.co.uk, telephone, fax or write to me at the MPS Society.

Roma The Globetrotter

Roma Drayne

I was in London two weeks ago with my Dad. We had to get up at 5.30. It was freezing. When we were going to France for our summer holidays I got up at 3.00. We left the house at 5.50 with only 15 minutes to get to the airport. We got on the plane at 6.30. Drat, there was a half an hour delay or SO WE THOUGHT, then at the time at 8.30, the pilot said "the fog has cleared but we are still waiting for a slot." We finally took off at 9.20am.

When we got there we waited for Auntie Shealgh to pick up our luggage, so we could head up to London. We then went to the London Eye. It was great, we could see Buckingham Palace and the Houses of Parliament. After we got down we went to the Imperial War Museum which was great.

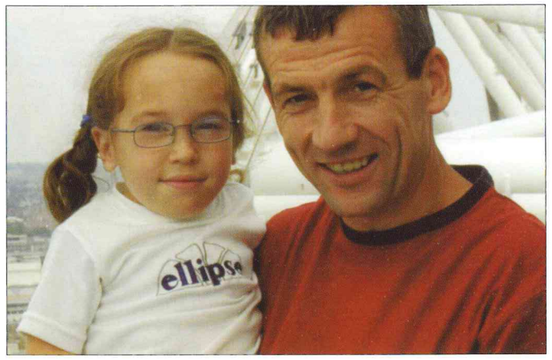
The next day we went to the Tower of London and saw the Crown Jewels and the white castle (top tip, go there early to avoid the queues). When we left, Dad and I wandered around St. Catherine's dock and saw loads of skateboarders all sponsored by Silversurf.

After Dad had a coffee, we went on a boat cruise along the River Thames, after that we walked passed the houses of Parliament and Downing Street, where we were with the MPS Society at Christmas.

The next day Sunday, we were meant to go to Brighton I was sick with a cold sweat so we had to stay home. I was fretting, our flight was that day! So I stayed in and watched the Lord of the Rings - the fellowship of the ring. I was okay by the time we got down to Gatwick. I was all excited to get there, who wouldn't be? I would see my family soon. We boarded the flight more excited than ever I couldn't wait or contain myself much longer. When I saw my family at last! Kilian had wrote on the tarmac, 'Roma and Dad welcome home'. Peter asked, 'Where is my toy car?'

This Summer I have been a Globetrotter. Dad says next year is Rome!

p.s. Manchester United stink!



Day In Lapland

Gina Page - Finance Office

One morning in late November Karen Wheeler of Indigo Holidays telephoned the Society to offer the opportunity for two children with MPS and two parents to spend a Day in Lapland. Keen for everyone to have an equal chance I entered all the affected children from the MPS membership in a hat. Well actually a large box and asked Angela to draw the names. First out was a family from the Midlands with two affected Children. In great anticipation I phoned with news that they had won a trip to Lapland only to find the family had already booked a trip for themselves for the day before. Delving back into the box Angela drew out Ashleigh and Jack's names and needless to say they jumped at the chance.

Dear Gina

I am writing to you just to let you know how much my daughter Ashleigh enjoyed her recent trip to Lapland. As we live in Devon we dont tend to see a great deal of snow and Ashleigh has only seen a few flakes so to arrive in Rovaniemi and see 2-3 feet of snow really amazed her. The whole day was unbelievable and we managed to do all the excursions aranged the Husky Drive theReindeer Ride the visit to Santa Park and not to forget meeting Father Christmas. When we arrived at the village of Narkaus we were taken from our coach to the centre of the village by Skidoo and our driver then took us from one activity to another and even took us for a Skidoo ride into the woods.

My daughter now has some wonderful memories and some fantastic photos of the trip she also has a certificate to say she has crossed the Arctic Circle. We also met the other MPS family and Ashleigh has made a new friend in Jack. When we arrived at Stanstead on the Thursday morning we found that on our flight we had a film crew and comedian Frank Carson. He was filming for a TV programme about the trip to Lapland which will be transmitted on New Years Eve. Frank was very down to earth and posed for photos and took intrest in all the children, Ashleigh had her picture taken with Frank and got his autograph.

Finally I would like to thank you for giving my daughter the chance to experience Lapland and I have no doubt that Ashleigh will never forget the day.

Please find a few photos of the trip.

Many Thanks Ricky & Ashleigh Montgomery

Ricky Ashleigh aged 11

Jack's Trip To Lapland

On 12th December, Dad and I went to Lapland for the day and it was brilliant. We had to get up really early at 3 am and then we drove to Stanstead Airport. It was quite busy at the airport as lots of other children were going to see Santa as well. There was also a funny man called Frank Carson going, he was with his grand-children and they were being filmed.

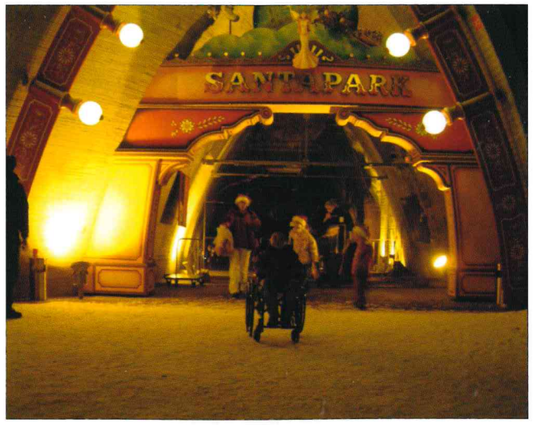
When we arrived at Lapland it was really dark and very cold. A nice man pulled us on a sledge behind a skidoo and took us to a place to get some warm clothes and boots, we were very cosy after that. We then had a reindeer ride which was good fun, all I could hear was the sound of the reindeer's bell. My favourite bit of the day was meeting Father Christmas, he is over 100 years old and has a very, very long beard. He gave me a reindeer bell as a present. (I also asked him for a pool table and I must have been good because he brought me one.)

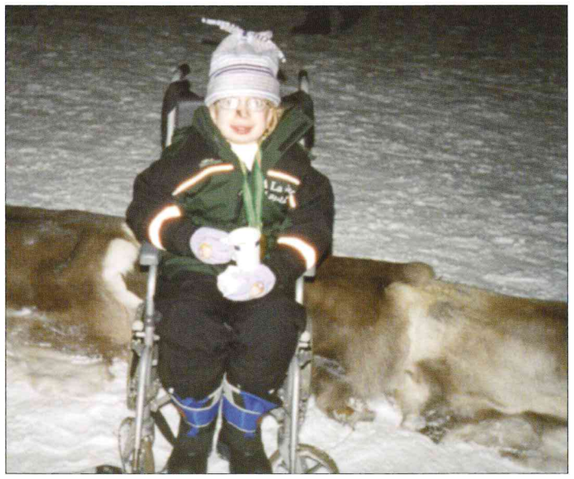
There was a ceremony for crossing the Arctic Circle where we had black stuff put on our noses. I wasn't too keen on that but I got a nice certificate to bring home. We had some nice hot chocolate to warm us up and then we went to Santa Park. We went on some rides and saw the Post Office where all the letters to Father Christmas are sent. There was also a big shop full of Christmassy things. Dad and I bought 3 big stockings, one for me and one for Emma and one for Milly.

I was very tired on the flight home, but I enjoyed the food. We got home very late and I had a day off school the next day. Thank you very much to the people who made my dream come true,

Love from Jack Stuart xxxxxxxxxxxxxxx

Clockwise: Angela and Gina drawing the lucky tickets to Lapland, Ashleigh Montgomery MPS IHS in Lapland, Jack Stuart MPS II and his Dad Greg visit Father Christmas at the North Pole.





A Special Friendship

Kate Lowry

Just recently I was lucky enough to finish a business trip to the States with a few days R&R with the Motomuras in New York.

Tetsuya Motomura & I have been friends since 1994 when we originally met at the annual MPS conference. We shared some jokes and have been sharing them ever since. If you ever get the chance to meet him, get him to tell you the one about Fritz. It's sure to get you both laughing and then you'll also get to hear & see Tetsuya's wonderful chuckle - he shakes up & down whilst exhaling a wonderful 'hee, hee' that sounds as musical as if The Three Tenors were warming up! Even without the joke, Tetsuya's laugh is enough to make you smile inside & out.

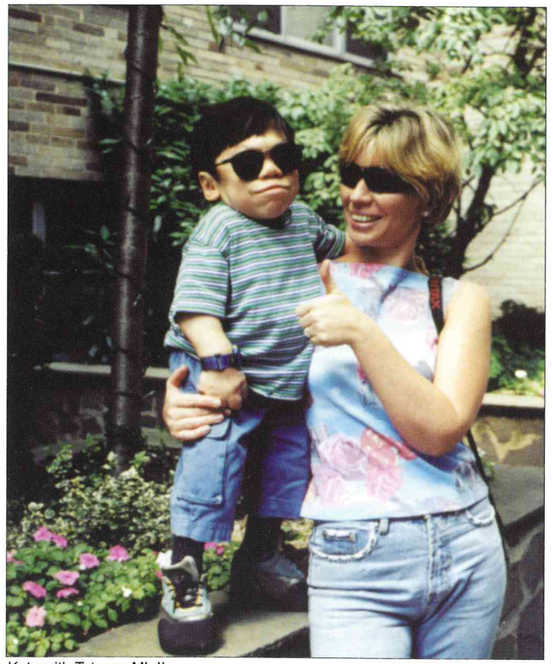
Spending time with Tetsuya is always a privilege. He makes you feel very special and treats you like his best friend. He doesn't want to end the day because he doesn't want to part with you (even for sleep!) and he can't wait to see you in the morning as soon as he wakes in order to chat.

Tetsuya is one of those amazing people who is 100% awake as soon as he wakes (unlike me!) This could be in part due to the oxygen mask he now sleeps with. Although his eyes are a bit dry in the morning from the increased air passing over his face, his throat seems to suffer no consequences and he is chatty & questioning from the first moment.

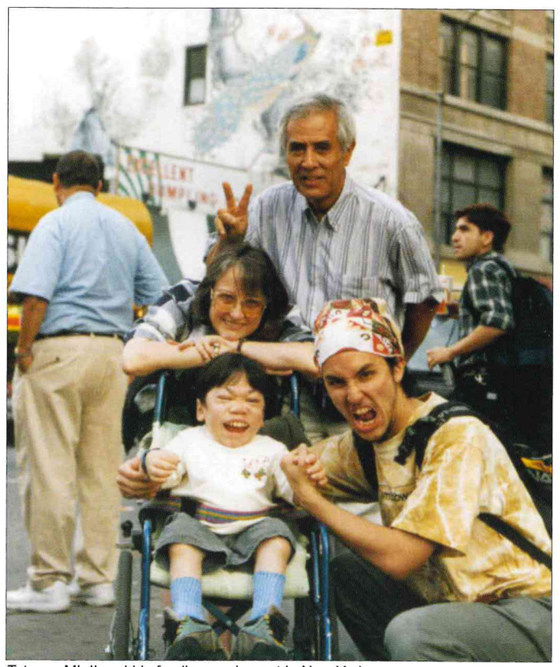
One of the reasons I love Tetsuya's friendship is that he is so interesting & interested in all that is around him. He can talk knowledgeably about any subject. Admittedly some subjects, like Harry Potter, he can talk about 'ad infinitum'! He really grilled me on the details of each book & the movie. Make sure you've buffed up on your Harry revision notes before you visit Tetsuya! However, we also talked on a variety of subjects such as school, computers, New York, Japan, religion, aftershave, cooking oh, and did I mention Harry Potter?!

Tetsuya is a great guide to have in The Big Apple. He knows every landmark and how to get home from them! One afternoon we strolled out in search of a new computer game (Platoon Commando or something similarly boyish! Tetsuya tried vainly to convince me of its prowess as a game - I was not persuaded. But I was impressed at how quickly he mastered it!). Anyway, on each street corner as we strolled along, Tetsuya was able to point out every landmark. After 4 trips to NY I can still only name Macys and Bloomingdales.

The added attraction of visiting Tetsuya is the opportunity to spend time with his fabulous family. Kazuma (big brother) dances his way round the streets of New York, interspersing rehearsals for his own show in a NY drama & dance festival with choreographed Kung Fu fighting with Tetsuya! Yuki (father) manages to balance a busy corporate schedule with what appears to be an even busier family schedule involving a full understanding of all computer games on the market! And Sally (mother) is able to return from a gruelling flight & busy 2 weeks with family in Zimbabwe to bring an oasis of calm to the apartment.



Kate with Tetsuya ML II



Tetsuya ML II and his family one day out in New York

New Members

The Society has recently been contacted by Richard Shimmin who has Fabry Disease. He lives in the Midlands.

The Society has recently been contacted by David Craig who has Fabry Disease. He lives in the Midlands.

The Society has recently been contacted by David Camfield who has Fabry Disease. He lives in North Yorkshire.

The Society has recently been contacted by David Laffin who has Fabry Disease. He lives in the Midlands.

The Society has recently been contacted by Tom Parrott who has Fabry Disease. He lives in the Midlands.

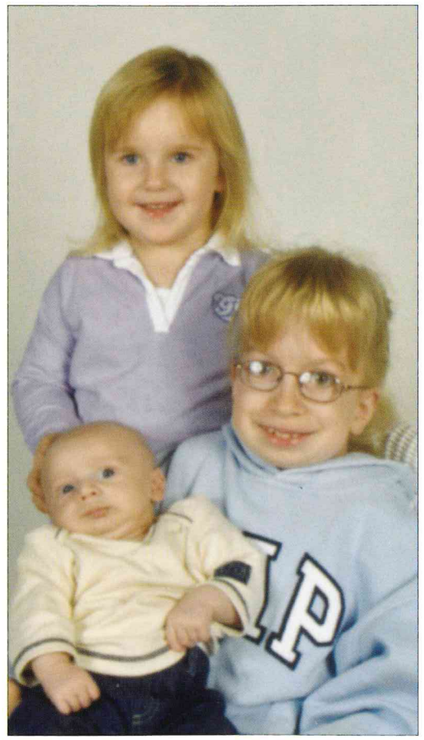
Rachel and Bob's son, Ryan, has recently been diagnosed with Hunter Disease. Ryan is three and a half years old. The family lives in the Yorkshire area.

Claire and Ken's son, Piers, has been diagnosed with MPS I Scheie Disease. Piers is eleven years old. The family live in the South of England.

Bob and Claire Stevens have recently had both their sons diagnosed with Hunter Disease. Oliver is two and three quarter years and Samuel is nine months. The family live in the South East.

The Society has recently been in contact with Mr and Mrs Chapman whose son, Luke has been diagnosed with Sanfilippo A Disease. Luke is two years old and lives in the North East of England

Births



Harris Ricky John Montgomery was born on August 21st 2002 at 11.14am and weighed 7lb 1oz. He is pictured with his big sisters Ashleigh & Charley.

Stuart Lawrie has a new half brother and sister, Elizabeth Mary Lawrie weighed 5lb 15oz and Alexander Robertson Lawrie weighed 6lb 11oz. The twins were born on 23rd October.

The photo is of Emily Otway and Jordane Robjohn of Rotherham at a donkey sanctury on Emily's sixth birthday

An Apology

We would like to apologise to Peter, Sue, Hollie and Annie for mis-spelling Jessica's name in the last newsletter. The tribute should have read Jessica Rose Stuart.

South East Christmas Party

Alison West - Advocacy Support Team

On a freezing Sunday in December, somewhere near Dartford, a festive group of families gathered for the MPS South East Christmas Party.

The room had been decorated beautifully in green and red, although some of the pictures did have to be removed from the walls as the children's excitement got the better of them. Lunch was served shortly after arrival and everyone managed to get at least a short time to eat a hearty meal before the rigours of the afternoon.

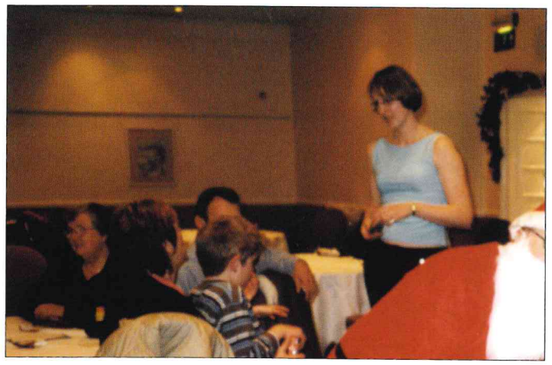
After the food had been cleared away the games began, with spirited participation from everyone in the rounds of musical chairs, musical bumps and pass the parcel. There were lots of winners and the prizes were collected with glee before being thrown around the room or used as weapons.

Following the games, the entertainer amazed everyone with his jokes, juggling, plate spinning and magic tricks. The highlight came when he asked for volunteers from the audience and taught them how to spin plates themselves. Watch out for that fancy china at home!

Finally, as everyone was beginning to get tired, Santa Claus appeared. Actually it was Harry Nurse in a very fetching Santa outfit, but he looked fabulous, and the children excitedly collected their gifts from him.

Before we knew it the party was over and as the adults wearily gathered their belongings together, the children excitedly led them out to their car, eager to get home and eat their present from Santa.

To coin a phrase, a wonderful time was had by all!



Clockwise from top left: Alison West at the Christmas Party, Faye and mum with Santa's Present, Sam and his Mum Wendy getting a present from Father Christmas, Thomas receiving his present from Father Christmas.

Scottish Christmas Party

Gordon, Norma & Lewis Broadley

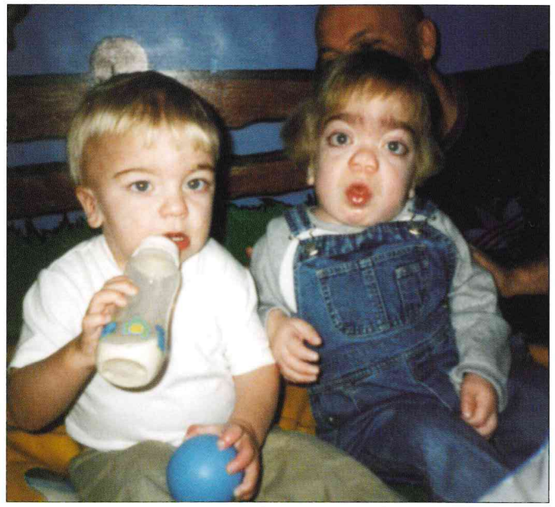
We recently attended the MPS Christmas Party in Livingston.

This was our first MPS outing as a family since our son Lewis was diagnosed with Sanfilippo in March. The prospect was a little daunting as you don't really know what to expect. What we got was a great, positive and uplifting day out.

The venue was great. Lewis loved the ballpit and all of the farm animals. He loved the cakes and sausage rolls. He is still not sure about this Santa Claus fella though! We were surprised there were so many families at the party and I have to say I don't think I've met a nicer group of adults and kids in my life. Everyone was very friendly and it was so nice to talk to people who know what you are going through. It's very easy to feel alone out there.

The kids were great, both MPS and non-MPS and I think it's fair to say they all had a great day out. I have NEVER known Lewis to sleep so well!! Must say a big thank you to Barry Wilson for all the work put in. Where do you get the energy? Can I also thank everyone who was there for helping to make it a very special day for us and we look forward to the next chance to meet everyone.

If anyone wants to get in touch please e-mail us at gordon-broadley@hotmail.com or through the Society .



Bristol Clinic

Alison West - Advocacy Support Team

31st October 2002

On 31st October, the Bristol clinic took place at the Frenchay hospital. There was a steady stream of people coming to see the doctors and we were kept busy all day, introducing ourselves to new families and catching up with familiar faces. It was good to see so many of you.

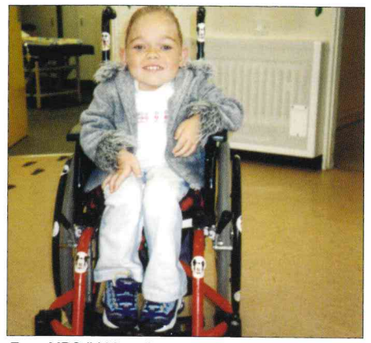
We have been gratified to hear how much you value the Bristol clinic although many of you have expressed a concern at the size of the consultancy room. As you know, there are often a few doctors plus nurses and the family plus any equipment that also needs to be in there. Unfortunately we are limited as to which room we can use but, while it is rather small, I hope that this does not detract from the opportunity to meet with and talk to the doctors in person.

We would like to express our thanks to everyone who bought items from our Christmas stall. Everything sold very well, especially the Christmas cards, which had nearly run out by the end of the day.

Our thanks go to Dr Wraith, Dr Jardine, and Dr Stewart who, as ever, give their time so generously and Deirdre and all the staff at the Children's unit who make this clinic happen.

Terry MPS I Hurler

Jasmine MPS III Sanfilippo



Faye MPS IV Morquio

Cardiff Clinic

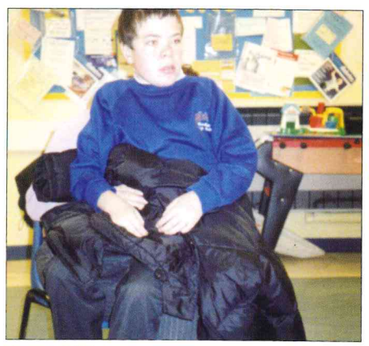
Alison West - Advocacy Support Team

1st November 2002

And so to Cardiff (no rest for the wicked!). This clinic was a little more chaotic than Bristol had been, with so many people we practically took over the waiting area. It was good to meet so many of you.

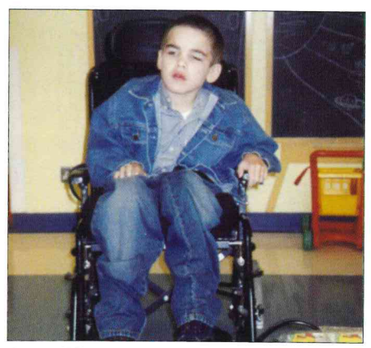
We took our severely depleted stock of Christmas cards to Cardiff and, like Bristol, they were far and away the most popular item. Many thanks to all of you who purchased something from us.

Once again your comments telling us that you value the Cardiff clinic are much appreciated. We would like to express our thanks to Dr Wraith, Dr Shortland and Sue and all the staff at University Hospital who made this clinic possible.



Joseph AGU

Sarah MLIII



Craig MPS III Sanfilippo

Belfast Clinic

Advocacy Support Team

November 2002

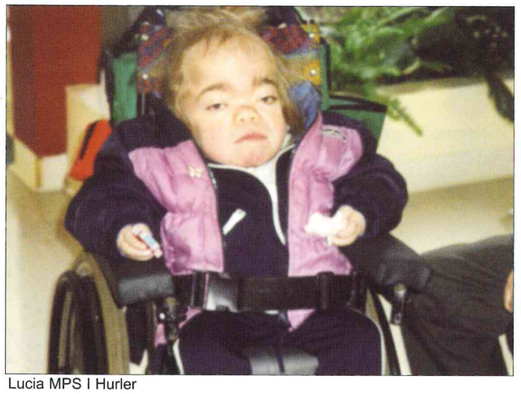
The clinic this winter enjoyed a new location. We were welcomed to the Tower Block Outpatients Department at the Belfast City Hospital. There was an added nuance to the day as the BBC requested permission to film part of the clinic.

Interviews were held with Christine Lavery, Dr. Wraith and Dr. Stewart but the real stars were little John McDonagh and Lucia Dawson, who were quite unphased by the experience. An item went out that evening on the Northern Ireland News.

The clinic was well attended and time was afforded to all members to discuss any issues they had brought. Fog proved the only problem in the day as it had delayed Dr. Wraith's flight in Manchester, but he arrived smiling and still saw all his patients.

John MLII

Chloe MPSIII Sanfilippo



Lucia MPS I Hurler

Dr Fiona Stewart, Dr Ed Wraith, Dr Alex McGee and staff team

Brooke Fucosidosis

Childhood Wood Remembrance Day

Sue Peach - Trustee

Sunday morning, July 7th, 9.30am. A small but dedicated group of people stood outside the Crown Hotel in Bawtry looking nervously at the sky. Yes, it was overcast but the forecast was for dry, warm weather. Yes, it had been lovely the day before but we all remembered "last October". Yes, we were going to the Childhood Wood and yes we did have brollies, waterproofs and stout shoes with us - just in case.

"Right, for those of you who don't know how to get there from here just follow me." said Robin, who was clearly in charge of the operation as he had somehow managed to persuade us all that clearing weeds and brambles was exactly what we wanted to do on a Sunday morning. So we scrambled eagerly into our cars and followed Robin. I'm not sure what the owners of the local garden centre thought when they saw a convoy of eight cars drive into their private lane and out again - TWICE - but I do know what we were all thinking about Robin's sense of direction!

Without further mishap we eventually arrived at Sherwood Pines and loaded with tools, new plaques and drinks we made our way towards the Childhood Wood. Our task was to clear the aforementioned weeds and brambles and replace broken or missing plaques. The first few sections were easy to do as the trees had been planted in straight rows. However, from "H" onwards it was more difficult as there was no easily recognisable pattern to the planting. Dave Peach suggested drawing a plan that would identify the number of each tree. "Good idea," everyone said, "but who will do it?"

"Sue will," volunteered Dave. "She's bound to have some paper and a pen with her, she's a teacher." Yes, but my specialism is Drama not Geography. Nevertheless, we set about drawing a plan and were actually quite successful and when asked where P7 was could reply "Over there behind 03 and N5. You can see the pattern can't you?"

By this time the sun had come out and we were getting rather warm. Jackets were off, sleeves rolled up and suntan lotion was being applied - there is always one optimist who carries suntan lotion around in their bag. At last the work was completed and other families had started to arrive for the Remembrance Service.

Wilma Robins read the beautiful poem "Remember" by Christina Rossetti and the names of the children to be remembered were read out. The sun was shining, the air was still, the birds were singing and the insects humming. We stood quietly, remembering our children, not wanting to break the wonderful peace and tranquility of the moment. Slowly, very slowly families moved away to spend some time at their tree, with their thoughts.

Eventually, however, lunch beckoned and we ambled back to the marquee that had been erected and set out the tables and chairs. The caterer arrived and unloaded her car. Everyone agreed that it was a good spread, plenty for all. Ten minutes later the caterer reappeared and unloaded more food. "Just one more load," she exclaimed cheerfully. "We look after you well up here." There was enough food to feed a small army! We did consider setting up a stall to sell some on to the other visitors to the forest but felt that perhaps the shop would not appreciate it.

Some two hours later and Ellie was still trying to persuade us to eat more or at least take some home with us. Eventually, however, the food disappeared, families made their farewells and everyone agreed it had been a wonderful day.

We now look forward to this year's Remembrance Day in our special birthday year and hope that as many families as possible will be able to join us at the Childhood Wood on 6th July 2003.

Childhood Wood Tree Planting

Sophie Denham - Advocacy Support Team

On the 25th October families and friends came together to remember 14 Children and Adults who had lost their lives from an MPS or related disease.

This was my first Childhood Wood Tree Planting with the Society and for me it was a very unique, emotional and inspiring day and one that will stay with me for a very long time.

We met at the Clumber Park Hotel on an extremely wet, cold and blustery day, so the hot carvery was a very welcome thought.

Councillor Maureen Tewson joined us for lunch at the Clumber Park Hotel. After a very hearty lunch Councillor Maureen Tewson gave a lovely welcome speech. After her speech David did the honours of presenting her with a bouquet of flowers.

By the time lunch was drawing to a close the sunshine had come out and we could not have asked for a more beautiful autumnal day. We made our way in rather a large convoy of cars to the wood, where Andrew Norman the park Ranger, led us down to the wood.

We all met at the information board where Paddy Tipping the local MP gave a welcome speech to everyone. He also was presented with a bouquet of flowers and the comment I think he said was "what will my wife say to me receiving flowers!"

Wilma Robins who read the poem "Remember" most beautifully followed Paddy Tipping. Barry Wilson then read out the names of the Children and Adults being remembered. The families collected their personally inscribed plaques and a tree sapling and chose their plot to plant their trees in.

Two trees were planted on behalf of two families who were unable to attend the planting.

I felt very privileged to be a part of this special day and to meet everyone who attended.

Clockwise from top left: Peter, Sue, Holly and Annie Stuart, David Oulton with Councillor Maureen Tewson, Selva and Vani Selvaranjan, Geof and Pam Hughes and Louise Croghan

CHILDHOOD WOOD

Brazilian MPS Conference - II Congresso Brasileiro de Mucopolissacaridoses

Christine Lavery - Director & Ellie Gunary - Assistant Director

On 9th October after a full day in the MPS office Ellie and I met Dr Ed Wraith at Heathrow Airport at the start of a journey that was to take 22 hours and take us south of the Equator to the biggest country of South America - Brazil. On arriving in Sao Paulo we transferred to a small, very crowded aeroplane to fly two and a half hours to the coastal city of Salvador in Bahai, just south of the mouth of the Amazon. Bahai is a unique cultural experience, predominantly African with smaller numbers of people of Asian and European origin.

Panel session - Dr Tomatsu, Dr Harmatz, Dr Wraith, Dr Muenzer

On arriving at Salvador airport, in the absence of modern technology (our ever faithful mobile phones deprived of networks) we set about wondering how to find our hosts. Surveying a group of adults and children sitting at tables in the distance we moved in. It soon became clear several of the children had MPS. Our Portuguese limited to being able to tell whether bottled water was "with gas" or "without gas" we lived in hope of someone speaking English. A Brazilian doctor came to our rescue and a short minibus ride later Ed, Ellie and I were in the welcome air-conditioning of the hotel. Many of the families had arrived and were enjoying a swim in the pool. One little boy with Morquio could not resist endlessly running into the shower by the pool then jumping in the pool.

In the evening before the conference started all the families enjoyed a barbeque locally with a welcome opportunity for parents, affected children and adults, brothers and sisters to get to know one another and share experiences.

The next morning the conference began. Christine and I listened as Josue Felix Araujo, the President of the Brazilian MPS Society, opened what was the second Brazilian MPS conference. Josue welcomed the families and health professionals, explaining that many more families had wanted to attend but the funding achieved had only covered the costs for a representative family from each of the different regions of Brazil. Brazil is a vast country and the efforts some families had gone to to attend became clear - one group of 16 families had travelled 1,000 miles each way by coach!

Josue spoke of the hope families are now living for with treatment on the horizon and also remembered those families for whom hope of therapy is still a long way off or those for whom it is too late and whose children have died.

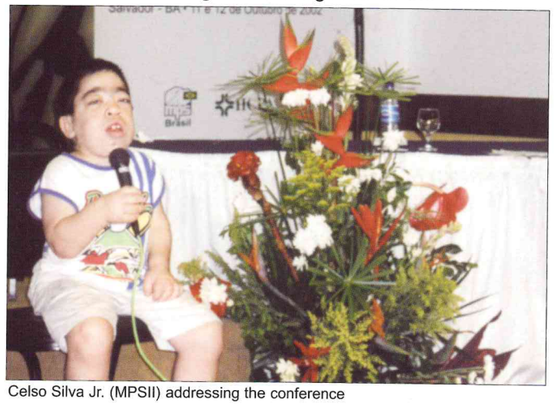
A local dignitary welcomed everyone and put into perspective the relative poverty of Brazil. Brazil has a population of 170 million but only has $150 to spend on health per capita per year. As a comparison he gave the amount spent in the US as $3000 per capita per year.

Brazilian medical doctors gave an introduction of MPS diseases and spoke about laboratory diagnosis then Dr Roberto Giugliani from Porte Alegre gave an overview of treatment for MPS diseases.

After a coffee break, during which Christine and I met three families who told us about their children, Dr Ed Wraith and Dr Joseph Muenzer spoke about ERT in MPS I and MPS II respectively.

The afternoon consisted of more presentations and a round table discussion with the specialists. With ERT on the horizon many questions were from families asking what they could do to get treatment, but also other questions were raised. What could be done to help sleep disturbance? What were the latest procedures used in spinal surgery? Could a child's challenging behaviour be modified? etc. In the evening we had our only opportunity to see a little of the city of Salvador when we were taken for an evening meal at a local restaurant.

Christine and I were particularly struck by the enthusiasm and drive of the members of the Brazilian MPS Society and how much they had achieved in such a short space of time. We also felt very honoured that so many of the individuals and families there wanted to speak to us, sharing their experiences, despite the language barrier. A very dedicated group of medical professionals were waiting, always on hand in case help with translation was needed. We are sure the Brazilian MPS Society will go from strength to strength and look forward to continuing to work together in the future.



Celso Silva Jr. (MPSII) addressing the conference

World Annual Symposium On Lysosomal Storage Diseases

Ellie Gunary - Assistant Director

Straight from Brazil, Christine, Ed and I travelled overnight again (I still do not know how people can sleep on aeroplanes!) to Baltimore, USA, for the Annual Symposium on Lysosomal Storage Diseases. The two and a half hour journey from Salvador to Sao Paulo in Brazil was the worst part of this journey, back into the small, crowded plane again. This time we knew what was in store so were just a little bit anxious beforehand.

We arrived safely in Baltimore 20 hours later, went for a walk to keep ourselves awake before enjoying a very long night's sleep. Over the following four days we attended the Symposium and learnt of the latest outcomes of therapy. We met with many different professionals in the pharmaceutical industry, other MPS and Fabry support groups and physicians.

Christine and I were asked to contribute to the measuring of outcomes for ERT for MPS I looking particularly at the impact on achievement of daily living tools, an area in which Christine and I are very interested.

We met with representatives from both Genzyme and TKT, to learn of new advances in therapies and share our experience of working with individuals and families affected by MPS and related diseases outside the clinic room. We are inviting speakers who will speak on these new advances to the MPS Society's annual conference in June 2003. The programme for the next International Symposium in Germany in 2004 was discussed and a first draft agreed.

All in all we had meetings from breakfast through until late at night.

Four days later whilst travelling back to the UK Christine and I reflected on the new contacts we had made, the invaluable meetings we had attended and the exciting developments that had come out of this meeting for the UK MPS Society.

International Fabry Conference, Athens

Alison West - Advocacy Support Team

7th - 10th November 2002

Welcome to sunny Athens read the brochure! Ha! I can honestly say I have never seen a storm like it (nor flown through one before, so that was a novel experience!). It was, however, extremely dramatic and I wouldn't have missed it for the world, but when the housemaid came to the rooms with candles in case the electricity went off (the lights had been flickering all afternoon), I don't think I was the only one to be feeling just a little apprehensive.

This inauspicious beginning did nothing to dampen the spirits of the participants and once the sharing of the horror stories was over (my plane was hit by a bigger flash of lightning than yours was/we were delayed from landing much longer than you were etc etc), we were able to get down to the serious business of discussing Fabry Disease and the current research into Enzyme Replacement Therapy (ERT).

We were pleased to be able to meet doctors, nurses and other metabolic specialists working with Fabry Disease in medical centres throughout Britain, as well as the rest of the world, who will become excellent allies in the continued work with Fabry Disease and ERT.

The first day allowed patients from across Europe and America to meet up and share their experiences. Some patient support groups, like The MPS Society and the Fabry Support and Information Group from America, have been going for years while others are still in their infancy, but all shared valuable experiences and important issues with regard to Fabry Disease and the on-going research into ERT. One of the most important issues concerned raising the profile of Fabry Disease as it has proved to be one of the most overlooked diseases in all countries. Another controversial issue, which was to be discussed in more detail later in the weekend, was that of Fabry Disease in females.

The rest of the weekend allowed an excellent opportunity to learn about the physical aspects of Fabry Disease, with lectures on the background and future research and to get to grips with the current issues surrounding ERT. Topics discussed included Fabry Disease in females, ERT and other therapies, and the management of Fabry Disease.

The main outcome of the conference was that there was still a long way to go, with the hope that Fabry Disease will be recognized and treated correctly and with the research into Fabry Disease in females, but the process has begun.

Ellie Gunary and Alison West in Athens

Barcelona - 1st International Patients Symposium for Fabry Disease, 22-24 November

Alison West - Advocacy Support Team

UK Fabry patient delegation to Barcelona

Boy was I glad to get to Barcelona! After the Athens experience I was just a little concerned about getting there, and this time I had to make sure that 23 other people also made it on time. Thankfully it went like clockwork and we all met up at the reception in the evening. Our group hit it off immediately and many good friendships were forged over the weekend.

The first day of the 1st International Patients Symposium for Fabry Disease started with medical lectures concerning the physical manifestations of the disease, before looking at ERT, how it works and its benefits to people with Fabry Disease.

The group seminars in the afternoon allowed the patients to discuss whatever issues were pertinent to them and a lot of common problems and situations produced a motivated discussion, raising issues such as life insurance, hometherapy, and a patient's right to ERT. Topics of interest on the final day were Fabry Disease in children and females, two areas which are currently the most important, and neglected, areas of research. The question and answer session provided some personal experiences of Fabry Disease and raised other issues that hadn't been previously considered, which demonstrated that, as there is a lot of interest in this research, we can only move forward.

Everyone who participated in this weekend conference expressed how positive an experience it had been, especially the opportunity to meet other people with whom they can share any thoughts, fears or experiences. There was also a general consensus that a meeting like this should be arranged on a regular basis, for the latest findings to be shared and discussed between professionals and patients alike.

International Symposium Announcment

Betina Wildi - German MPS Society

The 8th International Symposium on MPS and Related Diseases will take place at Rheingoldhalle Mainz, Germany 10th-14th June 2004.

The Conference will be jointly organised by the German MPS Society and the Children's Hospital Mainz.

The German MPS Society has also identified alternative hotels including one which caters specifically for people with a disability, (picture opposite)

Hotel Independent, Mainz, Germany

The Aftermath Of Losing A Child

Iris Dijkstra PhD - Department of Psychology, Utrecht University

Losing a child through death is often described as one of life's most devastating experiences, but to what extent is this belief is backed by empirical evidence? Do bereaved parents indeed suffer more ill health and marital difficulties than their non-bereaved counterparts? This article addresses these questions by first reviewing the existing literature, and then presenting some data from Utrecht University's recent study of 172 bereaved couples where we looked specifically at differences in bereavement responses within a couple.

'Because of all the pain and sorrow, I have the feeling that my husband is avoiding me. He avoids problems, can't cope with emotions. He gets angry when I am crying, because he thinks I have to accept the situation. I suffer health problems, the consequence of stress. We find it very difficult, this should not be happening to us. I feel desperate and powerless. Every day is a struggle to survive.'

This quote from a mother who had lost her 21-year-old son six months previously clearly illustrates the difficulties parents may encounter after the death of their child. A bereaved parent is often faced with a partner who is also in need of support. Moreover, parents may respond differently to the death of their child, and coping strategies may be incompatible and cause mutual incomprehension. Even worse, misunderstandings may occur; such as interpreting a partner's behaviour as 'uncaring' and 'cold', when in fact this partner is making a great effort not to become completely overwhelmed by the loss.

On the other hand, having to deal with the same adverse circumstances may in fact strengthen the bond between parents. Couples may become closer; for example because both partners cope with the loss in similar ways and so feel mutually supported. In addition, having a better relationship may positively affect the health of the parents. However; it is also possible for both parents to adopt the same, unhelpful coping strategies. This can result in the partners feeling very supported by one another. but also getting stuck in their grief.

REVIEWING THE EVIDENCE

Effects on the relationship

Looking at what has already been published. it appears that surprisingly little methodologically-sound research has been conducted examining the impact of losing a child. For an overview and description of some of the more important studies, see Dijkstra and Stroebe. With a few notable exceptions, most studies suffer serious shortcomings so that a thoughtful evaluation of the results is impeded. This means, for instance, that there is no conclusive evidence on divorce as a likely outcome of parental bereavement. So, despite the strength of the conviction that most of us hold - that the death of a child has a devastating impact on the relationships of parents - this idea has not yet been proven.

Data on other aspects of the relationship are not conclusive either. Again, many studies suffer methodological shortcomings and, in addition, have contradictory results. Thus, whereas some studies suggest greater intimacy and marital satisfaction after the death of a child, others suggest the opposite, or find no effects at all. Possibly two processes operate following the loss of a child: on the one hand, there is an enhancement effect on the relationship (eg increased support and protection), while on the other; there is enduring stress and mutual aggravation because of the circumstances of this type of bereavement. As one author puts it, there is 'the paradox of a new bond amidst estrangement'. Whether closeness (positive), conflict (negative), or neutral indifference (possibly a masking of effects) is found may depend on precisely what variables are being examined.

These apparently contradictory findings are important. They indicate that, though the marital relationship is often said to suffer from a child's death, there may be other ways of looking at this. The results from our own study, suggest that this may be the case. We found, surprisingly, that the parents who felt less mutually supported over time, still remained equally satisfied with their relationship. Possibly partners gradually feel less need to be backed by their spouse, for instance because they begin to realise that, in the end, they both have to come to terms with the loss in their own way.

Alternatively, as has been suggested above, it is possible that the decline in partner support experienced is counterbalanced by an improvement in other areas of the relationship, resulting in stable levels of marital satisfaction over time. For example, parents might experience greater closeness because of their increasing awareness that only their partner knows what it is to miss their child in daily life. If parents have the feeling that their relationship is somehow still 'in balance', notwithstanding the decline in partner support, they probably remain equally satisfied with their relationship.

Effects on health

Again, no clear cut picture emerges from the literature on the consequences for health of losing a child. We wondered, for instance. whether the death of a child could be so devastating as to result in the loss of life of the parents themselves. Research has shown that those bereaved of a spouse are at greater risk of death: mortality rates for the widowed are higher in general than for their married counterparts. Do bereaved parents also suffer the risk of dying prematurely compared with other couples?

Unfortunately, very few studies have been carried out to address this question. Likewise, the evidence on other less severe, but still debilitating, health consequences is limited. On close scrutiny of the large number of studies claiming to find mental and physical health effects, we

found little sound empirical support for such conclusions. Although the effect of losing a child does seems, from experience, to extend beyond grief to long-term health consequehces, in our opinion the effect has not yet been proven.

OUR RESEARCH

In our study, in which 172 couples participated, both partners completed individual questionnaires at 6, 13 and 20 months after the death of their child. The children had died from various causes and varied in age from stillborn to 29 years. None had started a family life of their own. We considered the health of the parents, as well as their mutual relationship.

Discordance

Specifically, we wanted to know to what extent both health and marital satisfaction would be influenced by what is called 'discordance', that is, the differences between the bereavement responses of each partner after the death of a child. For instance, one parent may be inclined to look for distraction and to put in extra hours at work, whereas the other may want to talk about his or her sorrow. Or if the death is the result of a traffic accident, for example, for one parent feelings of guilt at not having accompanied the child to school may predominate, while for the other it may mainly be anger towards the driver who hit the child. Since people generally react to adverse circumstances in a highly personal way, it is not surprising that the parents bereaved of a child may differ in their grief and in the way they try to grapple with it. This is what we mean by discordance.

In order to measure such discordance, we asked parents individually to what extent they themselves experienced within couple differences in bereavement responses. For example, parents were asked whether they thought they and their spouse coped with the loss completely differently, largely differently, largely similarly, or completely similarly. In addition we obtained an indirect measure of discordance by making our own comparison of the partners' ways of coping with the loss. By asking each partner such questions as how much they dwelled on the loss and comparing the answers, we could measure discordance obliquely.

We found that the greater the discordance, the less positive parents were about their relationship. The discordance perceived by the parents themselves was the more important factor. Thus, the more strongly parents felt that their bereavement response differed from that of their spouse, the greater their dissatisfaction with their relationship. The more differences in bereavement responses they observed, the less the parents felt supported by each other; and the greater this lack of perceived partner support, the less positive the parents were about their relationship.

Interpreting the results

Apparently, having a partner who responds differently to loss makes parents feel lonely in their grieving process. Both may feel misunderstood, or even judged by their spouse for not responding similarly. Expectations may also play an important role here, as members of a couple may assume that, having suffered the same loss, they will respond to this loss in the same way as well. Norms about what constitutes 'good grief' might aggravate the situation, as parents may try to impose their own way of responding to the loss on to their partner, and may feel unsupported if their spouse does not answer this demand.

However, misunderstanding might account for the association between discordance and marital satisfaction as well, as parents may erroneously interpret their partner's behaviour because they do not know the underlying motives for it. For example the woman who never sees her husband crying thinks he is not as upset by the loss as she is. The man, however; often cries when he is alone, wanting to save his wife from his tears and not knowing his wife would in fact prefer him to show his emotions. In such a situation, both parents may be unhappy in their relationship. The mother may be unhappy because she feels lonely in her grief and silently reproaches her partner for supposedly not grieving as much as she does. and the father because he is forcing himself to be strong. thinking his wife will not be able to handle his grief on top of her own.

IMPLICATIONS FOR PRACTICE

Encouraging communication

It is clear that our findings have important implications for practice. Whenever discordance seems to burden the relationship between the parents, both members of the couple should be encouraged to share their thoughts and feelings. By stimulating the communication between parents, misunderstandings can be unravelled and give way to mutual comprehension. It may also be useful to address the norms and unrealistic expectations about grief that adults often implicitly hold. They may believe that certain ways of responding to the loss are best, whereas of course no universally 'good' ways of grieving exist, Parents may need the information that the two partners in a couple do not necessarily display equal, or equally strong or long-lasting bereavement responses, and that one way of grappling with the loss is not per se better than another one.

Health issues

In cases where bereaved parents have psychological or somatic health problems, the value of looking at differences in bereavement responses seems to be limited. In our study, we found hardly any relationship between discordance and the symptoms experienced. Possibly positive and negative effects of discordance upon health counterbalance each other here, suggesting no relationship between discordance and health problems, while in fact opposing associations exist. For instance, where parents feel unsupported by their partner because of the discordance, their health may suffer. However, having a partner who responds differently to the loss may also prevent parents from getting stuck in unhelpful grieving patterns. We do not yet know why we did not find a convincing relationship between discordance and health but, for now, discordance does not seem to be a very helpful factor on which to base interventions to improve health.

CONCLUSION

All in all, given the state of knowledge thus far, what can we say about parents who lose a child? Since it is commonly claimed that child loss is one of life's most devastating tragedies, we might expect a large body of research investigating how bereaved parents cope over time. It is disappointing to find that sound research in this area is limited. Although there are some indications that bereaved parents do worse than their non-bereaved counterparts, as yet we have little objective information about the aftermath of losing a child. The consequences of having a partner who responds to the loss in a different way have also hardly been studied thus far. Inferring from our own study, however, the experience of such discordance seems to add to the burden of the loss by affecting the quality of the relationship between the parents. Consequently, in order to prevent parents from first losing their child and then their partner, differences within couples should be looked at closely in both future research and clinical practice.

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Milk Of Magnesia And Constipation

Helen Brown

This famiy story comes from Robbie 's mother, Helen.

Our Robbie reached the grand old age of 21 years recently, heralding much celebration in this household. He heard and responded to the "Happy Birthday" ditty which was sung many times to him during the day and for days afterwards; and one time grizzled because his Mum stopped singing it in order to get something, only resuming his listening expression and ceasing the grizzling when the singing continued!

I thought I would write today about Rob's experiences with constipation and what we have found helped. Families with younger children who are presently managing the other end of the spectrum, diarrhoea, may be wondering what this has to do with them ! Rob experienced diarrhoea for many years when he was younger but as he is no longer mobile we are now dealing with constipation. These children are certainly diversified! The constipation was an unwelcome change and we have tried many different preparations to remedy it over the years. We tried Metamucil to introduce additional fibre into Robbie's diet. Also, we tried Senakot tablets, Coloxyl drops, Parachoc, Duphalac, Agarol, Epsom Salts and of course, suppositories, enemas, warm water first thing in the morning and heat packs on the groin. Senakot tablets and Epsom Salts we found were very harsh and had to adjust the dosage. The harsh ones were only used as a last resort. The milder laxatives should be the preferred laxatives. After trying so many things over the past six years we recently came across Milk of Magnesia during some research on the internet into constipation and are delighted to report after several months of experimenting that it seems to have made a major difference to Rob's life regarding constipation. Such a difference, in fact, that we are no longer trying anything else. Every second night several hours after the last feed we give him l5mls of Milk of Magnesia. Usually within a few hours, sometimes with the assistance of a suppository - sometimes not, there is movement at the station (as Banjo Patterson would say)! Rob delivers to much cheering! Really sorts out the priorities, doesn't it, MPS tends to do that?!! We are quite excited about this discovery and thought it worthwhile sharing. This has been our experience and it has worked for Rob. As a first option always seek medical advice.

Another little gem also discovered in the course of a recent hospital visit is using "Ural" Effervescent Granules to refresh the mouth. It is commonly used for urine infections, but the nurses told me it is also an excellent mouth freshener. They were putting half a sachet in water and using a giant cotton bud (1 buy Jumbo Cotton Swabs 180mm) to apply to tongue, gums, and teeth area. Of course, it would be dangerous to put a giant cotton bud in the mouths of many of our children with their tendency to bite down on anything entering that part of their anatomy. Even now I have to be very careful as Rob still bites down and it has to be very carefully timed and quickly in and out. The nurses in the hospital soon found that out and amazingly, spent very little time near Rob's mouth, preferring to leave that delectable job to me!

Scottish MPS Conference

Friday 16th May 2003
Hilton Hotel
Edinburgh Airport
Funded by the Community Fund

COMMUNITY FUND

All MPS Society members living in Scotland will receive booking forms for this Conference. We would be pleased to hear from you details of any medical and social care professionals who are supporting you and would benefit from attending this event.

Any Society members not living in Scotland who would be interested in receiving details of this Conference please contact the MPS office.

What Do We Know Nowadays About Clinical Manifestation In Women With Fabry Disease?

Dr Catharina Whybra, Children's Hospital of the University of Mainz

Until recently, Fabry-Anderson disease was considered in the literature to be an X-linked recessive disorder, in which disease-specific symptoms in carriers are the exception. They are carriers, which means they do carry the gene and they could transmit the affected gene to their children, without having their self any sign and symptoms. In fact it has been told that if they are affected the disease manifestations are considered to be mild and rare. However, some women who do carry the gene for the disease have been estimated to show serious manifestations in 1% of the female population.

Women are not usually evaluated and investigated in the clinic unless they present with severe complications. By genetic counselling they do attend the visit if their son or male relative is diagnosed with the disease. The prevalence of carriers of the disease is 1 in 339,000 females in the UK.

During regular visits of our families with Fabry disease in our clinics, we have observed much more frequent sign and symptoms of the disease in women as we did expected. Until the age of 40 years, 2/3 of affected women showed signs of a cardiomyopathy in the ultrasound of the heart. At the same age, 1/3 women did show kidney insufficieny. Asymptomatic eye involvement (cornea verticillata), is present in about 70% ofwomen with the disease and is very useful for clinical heterozygote detection, because it is very typical for the disease. There is also the fact that alpha-galactosidase A activity is within the normal range in many affected women, so the definite diagnosis must be based on genetic analysis in many cases. It is much easier if there is an affected male also in the family to find the mutation in the gene.

When we have studied women with the disease, we heard a lot about misdiagnosis in the past medical history, as much as in affected men. Just to mention some of them: rheumatoid arthritis, multiple sclerosis, fibromyalgia, colitis, migraine, autoimmune disease of unknown origin, and so on.

Because of our clinical experiences over the last years we do know nowadays that **women are patients-not carriers**. We do know that the incidence of serious and debilitating symptoms of the disease in women, such as for example renal insufficiency, cardiac problems, neuropathic pain and cerebrovascular events is not estimated as <1 %. Almost all women are affected with a significant morbidity of the disease. In both countries, UK and Germany affected women with the disease reported multiple manifestations of the disease, with high frequency, which was not recognised previously.

We also observed that cronic neuropathic pain in women can be less frequent than in males, although a lot of them do know somehow this neuropathic pain syndrome, often accompagnied with fever. Furthermore, we do have to say that gastrointestinal symptoms, like diarrhea, delayed gastric emptying, abdominal pain, etc. are much more often a problem as we did think before. Here we had first diagnosis of inflammatory bowl disease such as colitis ulcerosa, crohn's disease or celiac sprue.

Looking at affected girls under the age of 20 years, we already can see clinical changes in childhood-only with a larger clinical variability than in boys. That means they can start with symptoms at any time. We do think that clinical investigations in younger girls and women should include the same examinations than in male patients. This becomes even more important as there is a therapy available now. Looking at datas from M.Ries (Germany), U. Ramaswami(UK) and R. Parini (Italy), they also do believe that the diagnosis in the pediatric stage of the disase is important to perevent late complications, prior to the onset of irreversible complications.

Due to some clinical investigations in different countries (Germany 30 women, UK 60 women), the possibility of a clinical trial with enzyme replacement therapy in females became reality.

There are encouraging results ftom a 6-month open label study of algalsidase alfa treatment. 0,2 mg/kg/every 2 weeks in 15 women with Fabry disease in MainzJGermany. The first results showed a significant heart reduction and improvement in cardiac conduction. The renal function remained stable. The quality of life ,assessed with a health questionnaire which you all might know very well, improved significantly as well. Importantly, no female patients developed antibodies to the infusion and no infusion reaction were observed in this study.

Why can be women affected, although they do have two x-chromosomes and the healthy one could protect the one with the Fabry gene?

One answer could be the result of X-inactivation which happens to every women. In the early embryogensis, every women has two X-chromosomes, one ftom the father (paternally) and one ftom the mother (maternally). Suddenly, we don't know exactly when, by random, one X- chromosome is inactivated. And here it depends which chromosome is inactivated in each cell and herewith each organ .The X-chromosome with the alpha-Galactosidase A gene will therefore be expressed in some cells, but not in others depending on the pattern of inactivation and the origin of either a paternal or maternal mutation. This does not explain, however, why enzyme derived ftom normal cells does not complement the one with the deficient cells, which carries the gene mutation.
We did learn a lot from our patients in the last year. A lot of probably serious case reports and cohort studies in affected women helped us to get other doctors convinced that we have to look clinically at women with the disease in the same way as in men. Although we do have to keep in mind that the clinical manifestation varies much more in women than in men. The onset of sign and symptoms of the disease can start at any time in a women lifetime, but young girls should be examinated also as soon as possible. The clinical trial in females showed much benefit to their health as mentioned above and it is safe, so although the indication for therapy is still done very individually, we do also think that we should prevent disease complications as soon as we can.

MPS I Under 5's Clinical Trial

Angela Ratcliffe

After many months of waiting and hoping the Genzyme clinical trial of enzyme replacement therapy for under 5's with MPS I has begun.

I met the 4 families who have now started on the trial at Royal Manchester Children's Hospital (a fifth will be starting in the new year) on a wet and foggy day in December 2002.

All the children had been admitted in to hospital a couple of weeks previously to have a portacath fitted to ease the process of administering the enzyme.

On my way to the hospital I had been wondering how on earth would you begin to get four under 5's to sit reasonably still for the duration of the ERT and I had expected to arrive and find some very stressed looking parents and nurses but all was calm.

All four of the children who are aged 2 ½ , 3 , 4 ½ and almost 5 were in beds, buggies or chairs, listening to music or watching TV or a favourite video and peace reigned.

On speaking to the parents I found than not surprisingly they had all been very anxious about this but, without exception, all were pleasantly surprised at how smoothly it was going.

Unlike the other MPS I clinical trial all of those taking part on this one are getting the enzyme from the start - a fact which all of the families involved are very grateful for.

It was lovely to meet everyone who, despite the situation, made me feel very welcome.

Hope For The Future

From: Courage Fall 2002

July 200I, The US National MPS Society awarded three research grants. The recipients received $25,000 for each of the two years of funding. Following are reviews of the first year of research.

A Proposal to Develop a Canine Model of MPS III-B
Mark Haskins, VMB, PHD. and Matthew Ellinwood, DVM, PHD. School of Veterinary Medicine, University of Pennsylvania

A naturally occurring canine form of MPS III-B was identified in two Schipperke dogs, whose cases had been referred to the University of Pennsylvania. Realizing the importance of having a large animal model of this condition, we applied to The National MPS Society, and received funding to characterize the genetics and pathology of this canine model, and to establish a research colony of these dogs.

We have completed the initial characterization of the pathology seen in the first two cases of this disease and a manuscript is being prepared for the Journal of Inherited Metabolic Disease. The clinical findings in canine MPS III-B included a severe loss of balance, which began in early adulthood. Dogs also began to lose weight as the disease progressed. Both dogs were eventually euthanized because of the severe and progressive loss of balance. Analysis of these animals showed prominent GAG storage in the liver and kidneys. The cerebellum, the part of the brain that governs balance, was severely affected, with a marked loss of neurons. Other parts of the brain showed marked neuronal storage, with storage also evident in macrophage-like cells (scavenger cells that digest degenerated cells). For the most part, the rest of the organs in the body had storage that was limited to macrophages. All tissues tested had a marked decrease of N acetyl-a-D-glucosaminidase (NAGLU) activity, to about 5 percent of normal. In tissues with severe storage, there were elevations seen in other enzymes, including B-glucuronidase and total B-hexosaminidase.

We have now isolated and sequenced the entire protein-coding region of the canine NAGLU gene, and the data will be presented at the American Society of Human Genetics in October 2002.

The identification of the normal canine NAGLU sequence will be critical in developing this model as a means to evaluate enzyme replacement and gene therapies. The normal NAGLU gene sequence will allow us to next identify the disease-causing mutation, and develop a DNA-based diagnostic to be used to manage the research colony, and to help identify carrier animals in the pedigreed Schipperke population.

During the first year of this grant, we have produced two litters of pups, both sired by a Schipperke dog that is a carrier for canine MPS III-B. Our breeding population in the colony is now two carrier males and four carrier

females. We have three pregnant females at this time, with pups due in late June and July 2002. We expect up to eight litters in the coming year. Pups with MPS III-B will be monitored very closely to document all early clinical signs and evidence of disease pathology.

The preliminary characterization of this model was presented at the American Society of Human Genetics meeting in San Diego in October of 2001.

Engraftment of Human Hematopoietic Cells Leads to Widespread Distribution of Donor-Derived Cells and Correction of Tissue Pathology in a Murine Xenotransplant Model of Lysosomal Storage Disease

A.A. Hofting, C. Volger, M. Creer, M.S. Sands Washington University School of Medicine, St. Louis; St. Louis University School of Medicine

Bone marrow transplantation (BMT) is a relatively effective form of therapy for some lysosomal storage diseases. However, BMT has limitations including harsh conditioning regimens (irradiation or cytotoxic drugs) required for engraftment and for possibility of life-threatening immune reactions due to donor incompatibility. Some of the immune complications may be overcome by genetically modifying (gene therapy) the affected patient's own bone marrow cells outside the body (ex vivo). These genetically modified cells now produce the deficient enzyme and can be transplanted back into the patient where they can give rise to all of the blood cells. This gene therapy approach has proven effective in some mouse models of lysosomal storage disease. However, in those experiments, mouse bone marrow cells, not human cells, are genetically modified to produce the deficient enzyme. Unfortunately, the gene therapy techniques used in the mouse studies have proven ineffective in human bone marrow cells. Therefore, alternate gene therapy techniques need to be developed and tested directly in human cells. To accomplish this goal, we recently developed mouse model ofMPS VII (B- glucuronidase deficiency) that is capable of accepting human bone marrow cells. The transplantation and engraftment of cells from one species (human) into another (mouse) is referred to as xenotransplantation.

When normal human bone marrow cells are injected into the xenotransplantation model of MPS VII they repopulate the blood system, and bone marrow-derived cells can be found in most tissues of the body. The number of human cells and level of enzyme activity in the transplanted mice is sufficient to reduce or nearly eliminate the lysosomal storage in many tissues.

This xenotransplantation mouse will now allow us to test new gene therapy approaches directed at human bone marrow cells within the context of an authentic model of lysosomal storage disease. We have preliminary data showing that we can genetically modify human bone marrow cells and transplant them into the mouse xenotransplant model. The genetically modified human cells are producing a marker gene (non-therapeutic) that is easy to follow in the mouse. We recently developed a gene therapy vector containing the B- glucuronidase gene (therapeutic) and currently are testing this in the mouse model. This type of experiment will provide important pre-clinical data before these novel approaches are attempted in affected patients.

Substrate Deprivation Therapy for MPS:Iminosugar Inhibitors of Sulfotransferase

Yoshio Nishimura, Institute of Microbial Chemistry, Japan, and Jeffiey D. Esko, University of California at San Diego.

Substrate deprivation therapy (SDT) for MPS syndromes involves the use ofa drug to lower the rate of production (biosynthesis) of GAG (glycosaminoglycans). By successfully decreasing a specific type of GAG in a person with MPS, the symptoms of the MPS syndrome could decrease or be eliminated. Enzyme replacement therapy (ERT) for the treatment of MPS disorders focuses on methods of increasing enzyme concentration in patients to compensate for the enzyme deficit. With the potential to complement ERT, a drug developed for SDT could work in pill form and even reach the brain to cause its effect.

About half of the enzymes deficient in MPS syndromes are sulfatases, which work by first binding to GAG and then removing a sulfate group. If the production of certain sulfotransferases (enzymes that put sulfate groups on GAG) can be slowed, there would be less build-up ofGAG in the cells, which could mean a decrease or elimination ofMPS symptoms.

Sugar-like compounds (imino-sugars) currently are being investigated to slow down the work of the sulfotransferases responsible for GAG buildup in Hunter and Sanfilippo syndromes. Within the past year, 34 synthetic sugar-like compounds were developed. These compounds will be evaluated to see if they inhibit these sulfotransferases. Initial studies will focus on determining how well the various sugar-like inhibitors block the activity of the sulfotransferases. Based on these biological data, we will further study the patterns of activity of these initial imino-sugar inhibitors. These patterns will then help direct the preparation ofmore irnino-sugar in- hibitors with an overall goal of selecting a drug candidate for substrate deprivation therapy for MPS.

Changes To Carers Benefits

Mark Robertson, National Advice and Information Manager, outlines some important changes affecting the main benefit for carers and parents of disabled children Invalid Care Allowance (ICA). Changes to the arrangements for older carers may have important implications for families relying on help from grandparents.

In April next year ICA is to be renamed Carers Allowance. For many people, the word invalid is offensive and outdated. It might also be a word that few people would relate to and it can only be guessed how many parents and carers did not recognise this as a benefit for them. Given the legislative changes required, the renaming has taken some time. But in April we can be sure it will be gladly welcomed by all.

Some carers get ICA (or are entitled to it but can not be paid it because they are already getting a similar benefit such as Incapacity Benefit) and qualify for Income Support (IS) and other means-tested benefits. In these cases the IS will include an extra amount called the Carers Premium. This is designed to ensure that a carer's income is topped up to a higher level by IS.

Changes from last year

Last year the government announced a number of alterations to the benefits for carers and parents of disabled children. Some of these have already been Introduced. The main changes were:

- An increase in the rate of the Carer Premium (the extra money in means-tested benefits such as IS). This is now worth up to £24.80 a week this year.

- An increase in the amount you can earn without losing ICA. Carers are now able to earn up to £75 a week without counting as being in 'gainful employment' and losing their ICA. This is after tax and national insurance and other allowable costs such as childcare.

Changes this year

Carers aged 65 or over will be able to claim ICA. Previously you could only get ICA after the age of 65 if you were getting it before you turned 65. A change in the rules from October means new claims for ICA from those already over 65 will be possible. However, what an older carer will be paid is not so straightforward.

Many older carers will be getting a State Retirement Pension (SRP). ICA and SRP 'overlap'. This means that if they are getting a SRP they will only get a payment of ICA if their pension is paid at a lower rate than ICA. In these few cases, they will get the difference made up in ICA. ICA is currently £42.45 a week with extra amounts for any dependants.

Older carers who have a low income are most likely to be better off. This is because entitlement to ICA (including where it cannot be paid because they are getting a state pension) will mean they will qualify for the carer premium on any means-tested benefits they receive, such as IS. For older carers who do get IS and now qualify for ICA, they could be better off by up to £24.80 a week.

This is perhaps the most important of the changes. Many families rely on the help they get from grandparents and other older relatives in looking after a disabled child. If a parent cannot get ICA, perhaps because they are working and earning too much, it may be that a grandparent can now claim. If someone in your family wants to look into a claim for ICA and/or IS, contact a local Citizens' Advice Bureau (CAB), welfare rights unit or the Contact a Family Helpline.

ICA to be paid for eight weeks following the death of the cared for person. Previously, ICA ceased as soon as you stopped looking after someone on DLA or M. The eight-week extension is clearly a sensitive measure. It will give bereaved carers and parents time to manage the practical arrangements following bereavement. More importantly, it recognises carers need time to adjust to what can be a devastating and life-changing event.

Source: CaF

Camper Van Adaption

Has any family with an MPS child gone through the process of buying a camper van, and if so, how have they gone about adapting it, and are there any helpful hints on what would be the best van to buy? If you can help please contact the MPS Office.

Help With Clothing

If any body has any suggestions of where clothes can be brought for children who are of a short stature, have large heads and larger stomachs please could you get in touch with the Society. We have had a number of calls from families who are having trouble finding clothes to fit their children.

Is there anyone reading the newsletter who has found a dummy which is indestructible? If so please let Sophie know so she can forward the information on to a family whose son is chewing everything. All the dummies they have tried are disintegrating under his powerful bite.

Parental Rights

Under the Employment Act 2002, maternity leave will increase from 18 to 26 weeks where the expected week of childbirth (EWC) is on or after 6 April 2003. Statutory maternity pay will be paid for the period of ordinary maternity leave at the rate of 90 per cent of pay for six weeks and £100 (or 90 per cent of average pay if that is lower) for the following 20 weeks. Women with 26 weeks service by the fifteenth week before the EWC will qualify for additional maternity leave. Currently they have to be employed for a year by the eleventh week before the EWC. The period of additional maternity leave runs for 26 weeks from the end of the period of ordinary maternity leave so that many employees will be entitled to a total of 52 weeks maternity leave.

The employee can vary the start of her leave provided she gives the employer 28 days notice. The employer must, within 28 days, write to the employee stating her expected date of return. Notice of early return will increase from 21 to 28 days.

A new right to paternity leave is also being introduced. Fathers and adoptive parents of either sex not taking adoption leave will be entitled to up to two consecutive weeks paternity leave. They must have been employed for 26 weeks. The definition of 'father' includes the biological father and the mother's husband or partner living in a stable family relationship.

Paternity pay of £100 (or 90 per cent of average pay whichever is the lower) is available provided earnings average at least £75 per week (the current lower earnings limit for national insurance).

Also from April 2003, adoptive parents who have been employed for 26 weeks by the date they are matched with a child will be entitled to 26 weeks ordinary adoption leave and 26 week additional adoption leave mirroring the maternity provisions. Adoption leave will be paid at £100 per week (or 90 per cent of earnings) for 26 weeks provided their earnings average the lower NI earnings limit. Adoption leave can be taken by either parent but cannot be split between parents. The other parent has had a right to take 13 weeks unpaid parental leave (18 weeks in the case of a disabled child) since 1999.

Makaton Signing

What is Makaton?
Have you ever wondered what it's like not to be able to make yourself understood? You may have had fun on holiday in a foreign country trying to buy apples from the market or a coffee in a cafe, but what is it like to have to struggle to make yourself understood all of the time? Unable to ask to go to the toilet or to watch your favourite TV progranune? For 800,000 people in the UK alone, this is a problem that affects their lives every day.

See what it is like to be unable to communicate. Try telling someone to do something without making any noise, speaking or pointing. What did it feel like? Angry? Confused? Irritated? Frustrated? Difficult? Easy? Totally impossible?

Makaton is a programme that helps children (and adults) with communication difficulties to interact with those around them through the use of signing, symbols and speech to support the written and spoken word. Symbols and signs are used to support the main informtation-carrying words in a visual way and to focus attention on them.

Makaton users come from a wide variety of backgrounds. Many have learning disabilities arising from conditions such as Downs Syndrome, or Autism. Others acquired their language difficulties after birth, perhaps as the result of a trauma (e.g. car crash or accident). There are presently hundreds of thousands of Makaton Users in the UK and overseas. And because communication is two-way, everyone who supports Makaton Users (family members, carers, teachers and health workers) all use Makaton too!

Using Makaton helps children to communicate. It helps to stop frustration and anger at not being able to make yourself understood. It helps to stop feelings of isolation. It can open doors to communication and understanding, gaining literacy and language skills and increasing opportunities for personal expression and development, participation in society, education, training and public services.

The Makaton Vocabulary Development Project (MVDP) is the organisation responsible for the Makaton Programme. The MVDP provides training for people who want to learn and a wealth of books, videos and other resources that you can use. If you would like to learn Makaton or would like more information contact the MVDP

Hints and Tips to Remember
Use Makaton every day
Makaton is used by everyone
Practice little and often
Use praise and reward
Make sure your child can see you
Help your child to make the signs - guide their hands
Makaton is fun!

Contact MVDP 31 Firwood Drive Camberley SUrrey GU15 3QD Tel 01276 61390 Email mvdp@makaton.org Web site www.makaton.org

Parental Rights

Digital Hearing Aids Campaign By Mark Morris, head of parliamentary and legal affairs at CharityWeek

Earlier this year independent research by the Future Foundation revealed that MPs had voted RNID's digital hearing aid campaign as the most high profile campaign at Westminster. This may come as a surprise to some - after all, hearing aids are hardly the most emotive subject among the general public. So what was the secret of getting such a dry issue on the agenda of so many parliamentarians?

The first objective was to make sure the campaign had a very clear focus. We centred the campaign around the outdated 1970s technology of NHS analogue hearing aids - not because advanced technology alone solves everything, but because the argument had real political force. We used technology as a means of raising the profile of the whole NHS audiology service, levering in more resources and ensuring the whole service was modernised, as well as providing people with more effective hearing aids.

Next, we offered practical solutions to the government. We did this through the involvement of RNID as a project manager of the modernisation project and commercial negotiator.

Thirdly, we used effective mass campaigning. Thousands of people in each constituency rely upon hearing aids (or live with someone who does) and we made sure that every MP was aware of this.

To mobilise support, we used both our members and financial supporters and in total, we distributed more than 300,000 postcards and campaign packs. MPs across England (as well as MSPs in Scotland and MLAs in Northern Ireland) were inundated with postcards from local constituents. Coupled with our postcard campaign, we spent a great deal of time meeting and briefing MPs and Peers so that every possible parliamentary mechanism was used to publicise and support the campaign both in the Commons and Lords.

In October 2001, an Early Day Motion (EDM) calling for the digital hearing aids to be available throughout the NHS was tabled with cross party support. A staggering 233 MPs have now signed the motion. We offered a pro forma press release to every MP who signed which created extensive local media coverage, and also ensured that MPs were increasingly locked into the campaign.

The EDM was accompanied by an adjournment debate, secured by the Labour backbencher Siobhain McDonagh MP. A series of written and oral parliamentary questions were also asked in both the Commons and the Lords. So what has been achieved?

Initially funding was made available for just 20 NHS Trusts to modernise their services and routinely fit digital hearing aids. On Christmas Eve 2001 however, the government succumbed to the pressure from RNID, and its sup- porters, and announced an additional £20 million investment -enabling at least 30 more Trusts to provide digital hearing aids by March 2003 and 15 or more sites to be trained and equipped to start fitting digital hearing aids from April 2003.

Modern digital hearing aids would now be provided at around a third of the Trusts in the country -now there could be no turning back. In Wales there has been even better news, with audiology services now modernised throughout the whole of the country.

Of course the campaign is far from over, especially in Scotland and Northern Ireland. However, exciting changes are now occurring throughout the UK. Hearing aid services are moving into the 21st century. Most importantly, dramatic improvements in the quality of life have been made for thousands of deal and hard of hearing people.

Help wanted

Does anyone know the whereabouts of a photo taken at, we think, the 1996 MPS National Conference showing Jessica, Lauren, Gavin, Katie and Emily all of whom have Hurler disease.

Please contact Christine at the MPS Scoiety if you can help.

Jeans For Genes Appeal 2002

Christine Lavery - Director

Thank you so much for your support at the 2002 Jeans for Genes Appeal held on Friday 4th October - the response was fantastic and the campaign has already raised an amazing **£2,681,560.16!**

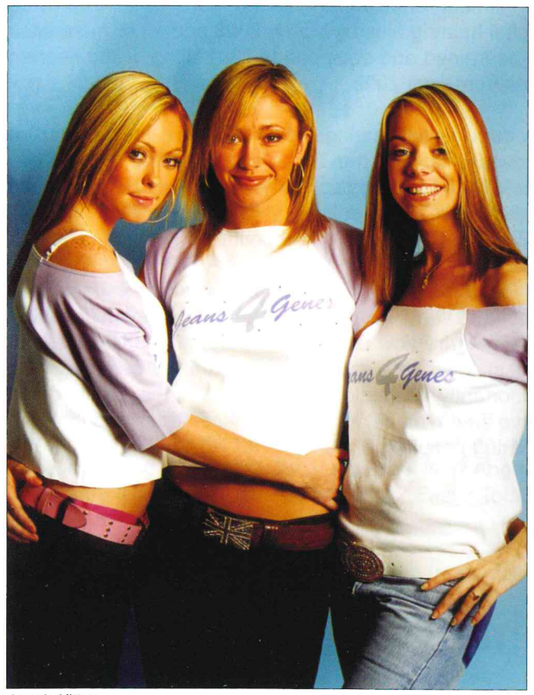
Research carried out with money raised by the Jeans for Genes Charity is helping to understand and develop new treatments and therapies for a wide range of genetic disease affecting children and adults. This includes improving the effectiveness of existing conventional treatments, as well as developing potential new cures, such as gene therapy.

Valuable support services for affected families are also funded - these range from funding specalists to run clinics in hospitals to producing booklets to help parents care for their child.

For more information about the campaign log on to www.jeansforgenes.org. Remember Jeans for Genes 2003 is 3rd October.

Jeans For Genes In 2003

Ellie Gunary - Assistant Director



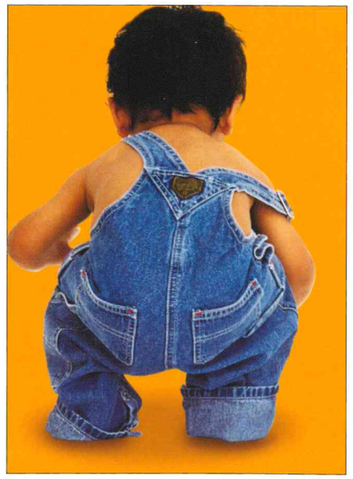
Atomic Kitten

PLEASE SUPPORT JEANS FOR GENES IN 2003

Jeans for Genes needs your help at a time when it is increasingly difficult to raise the significant sums required by the Society to support individuals and their families.

The monies received from the Jeans for Genes campaign provide the MPS Society with vital funds for research and advocacy support. 60% of the Jeans for Genes money received by the MPS Society goes towards research and 40% towards advocacy support. In 2002 the 40% was the equivalent of funding the entire advocacy support service for one year.

Whilst we need all our members to continue to support the MPS Society with their fundraising and donations we need you to support Jeans for Genes. Apart from wearing your jeans for Jeans for Genes day one way is to provide stories about



yourselves and your experiences of disability for the radio, newspapers and television. Another way is for you to give talks at school assemblies and promote the campaign.

If you feel you may be able to help in this way please let us know by writing, e-mailing or phoning.

On no account will any of your details be handed to the press without us returning to you on each individual occasion to confirm you are still able to help in this way. We recognise that family circumstances change very quickly.

Bob The Builder And The Jeans For Genes Party

Jeans for Genes held a party for Reece (the first child to be cured by Gene Therapy) and all the charities that benefit from their campaign, inviting one family from each charity to join them. Reece was very much into Bob the Builder so that was the theme of the day. The hall was decorated beautifully in all things to do with Bob the Builder. Lots of balloons and extremely noisy whistles, were at every table, which of course every child loved and insisted on blowing A magician came to tables doing magic tricks and making balloon shapes. There was a section of the room that had various toys, games, videos and colouring all to do with Bob. Before the party food was served the guest of honour arrived yes you guessed it the man himself Bob the Builder with his famous catch phrase "Can we fix it Yes we can" Many children had their photo's taken with Bob and adults too! After food the magician did a big magic show and there was even an opportunity for children to have their faces painted. As the party was also for Reece the families invited brought him a Birthday present and sang Happy Birthday to him as he was presented with his Bob the Builder cake.

A good time was had by all!

Samantha Preece Raises Money For The Jeans For Genes Appeal

Samantha aged 5 years put on her jeans to help raise money for Jean for Genes by doing a sponsored walk. Samantha, who has Sanfilippo disease, was joined by her family for the walk.

The walk was taken at a leisurely pace with a few pit stops for ice cream, an essential fuel for any walk! Samantha raised £115 and received a certificate from Jeans for Genes for her support.

Well done Samantha.

Jeans For Genes Day At Bysing Wood School

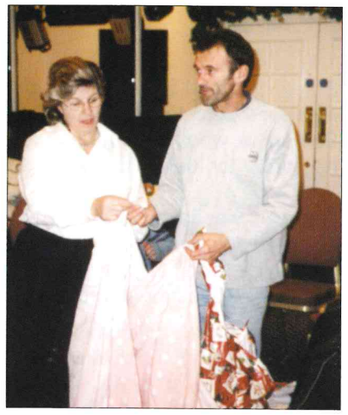
These photos were sent in by Janet Gremo whose children participated in the Jeans for Genes day at Bysing Wood School in Faversham Kent. “My children embraced the idea and nearly every child wore their jeans or equivalent raising £85 for the cause. A lot of the children have met Nathan and are intrigued by his condition and for those who haven’t he is making a guest appearance soon!”

Grand Draw 2002

The 2002 MPS Grand Draw has been the most sucessful yet raising a staggering profit of **£7,058**

The prizes were drawn by members attending the South East Christmas Party and Gordon Rowe who witnessed the logging of names and ticket numbers. Our thanks goes to everyone who helped to sell so many tickets.

Prize	Winner	Ticket
£500 Cash	**Mr and Mrs Kembrey, Bristol**	**1375**
£250 John Lewis Vouchers	**Mr and Mrs Lowry, Harpenden**	**3265**
£100 M & S Vouchers	**Robert Purkiss, Portsmouth**	**41328**
Mid-Week Break for 2	**Jane Toffrey, Llandludno**	**65313**
L'Oreal Products	H Kenney	4187
Mattel Toys	C Murray	7813
Mattel Toys	W Pagden, Colchester	Defaced
2 x Alton Towers Tickets	M Astbury	41853
2 Edinburgh Crystal Glasses	A Robertson	54919
Brentford Adult/Junior Ticket	Frank and Heidi Chishall	48500
Coty Beauty Products	Anthony Hoffman	5612
Mini Malt Scotch Set	Lee Eldridge, Surrey	18119
Mini Gardening Tool Set	Mr Sutcliffe, Derby	15350
32K Address Organiser	Mr Titcomb, Amersham	63422
£10 Wyvale Voucher	Aaron Brown, West Livingston	49972
£10 Tesco Voucher	L Brodie	50290
£10 Homebase Voucher	Mr Arshad, Bolton	16279
£10 Sainsburys Voucher	M Fryer	55667
Pink Fluffy Bunny	S Lowry, Harpenden	3254
Doccument Bag/Mouse/Pen	J Palmer, Sheffield	9059
Swiss Army Knife	S Lewis, Gwent	10091
Thomas Tank Bag Set	L Howorth	21072
Vacum Flask	Glen McKee, London	6188
2 Crystal Cham Glasses	Kate Kally, Bradford	5088
Lego Freestyle	Mr Longworth, Bolton	16521
Document Bag/Bus Cd Holder	Matt Stevenson	72613
Moon Photo Frame	A Clark	4009
Shaffer Pen/Pencil	Amanda Gregory	67822
Sports Bag	F Mullins, Clacton on Sea	11735
Arched Photo Frame	T Elliot, Helmshore	21013
Document Wallet/Umbrella	Angie Brown, West Livingston	49993
Emirates Umbrella	Hawkins	72993
Emirates Umbrella	G Rowe	12808
Lge Clock/Mini Clock Frame	E Sweet	8287
Lge Clock/Mini Clock Frame	Colin Davies, Oswestry	71752
Mini Quartz Clock/Frame	Mrs E MacKenzie	8518
Britain/Scene Book	Mr L Browning	67960
Britain Air Book	Tracy Goldsmith	57673
Britain Air Book	Kevin Anderson, Greenock	66473
Roller Suitcase	R Cooke, London	72323



Clockwise from top right: Christine Lavery and Wendy Hitchin, Christine and Rob Gremo, Christine and Cathy Flaig

Donations and Fundraising

The Society is grateful to the following:

Donations

Mr & Mrs Cranham
Jane Hodge Foundation
React
Sheffield and Hallamshire County Football Association
Mrs F E Woods
The Morgan Crucible Company plc
Harold Smith Charitable Trust
Sir John Summers Trust
Bryn and Ann Neal
Joyce and Ray Arnold
Staff at Compaq Computers Ltd – Reading
Dr Gareth Jones – Healthcare at Home
The Dorothy Askew Trust
Tibbett and Britten
Marks and Spencer – Oxford Street
N Smith Charitable Settlement
Mr and Mrs Moulding
Mr and Mrs A Lloyd
Mr and Mrs Gunary
Seedat family
Best International Group – Credit Control
Mrs B Flaig – Margate
Dixons Group
Lanesfield Methodist Church Benevolent Fund
Shakespeares Solicitors
Haddenham PCC
R.A.O.B., G.L.E. Dereham II Lodge
Anne Toon

COLLECTION BOX

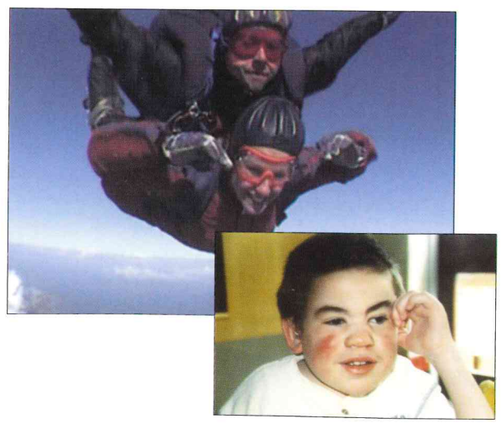
Edward and Mary-Ellen Nowell
Status
Mr & Mrs E Pickard
The Steam Packet Inn – Isle of Whithorn
Tracy Lewis Bed and Breakfast
C M L Jones and Partners Dispensing Chemist

Fundraising

John Sanderson – Round the Hills Walk
Northern Region of the Woolwich
Charity Flowers – Commission
Northgate – recycled paper sale
Eaton Ltd
The Hiss and Boo Music Hall
Morriston YM – Reunion Dinner
Joint Services Disability Implementation Group
Teresa Jones – 10K Road Race
Towersey Morris Men
Branching Out Dance School
Ian Lane – Sponsored Swim
Andrew Duxbury – Windsor 1/2 Marathon
Leonie Griffiths – 10K Road Race
M I Stimpson – Webb Ivory Commission
Association of Compaq Employees – Reading
Mr David Brierley-Barton – Custom Homes (UK) - Firework Party
Kingfisher Windows – Swindon
House Construction Services – Mr John Saunders
St George's Hill Golf Club – Golf Day
Xmas Card Sale – Jenny Hardy
Elaine Crowther – Skydive
Lynn Longhorn – Charity Sale
Compaq Computing Social Club – West Lothian
Biochrom – Cambridge
Hollington Golf Society - Kent
Mr and Mrs Corcoran – Charity Race Night
Cookridge Primary School – Christmas Concert/Carols
Haddenham Mummers – Christmas 2002 Season
Cytogenetic DNA Services Ltd – Xmas card Alternative

Stamps
Norman J Wigley & Partners
Jenny Hardy
Mr & Mrs Garthwaite

In Memory
Mrs Freda Victoria Goodman
Ellie Gee
Denis Rowan
Gethin Robins
William Holroyd
Jessica Stuart



In September 2002 Eliane Crowther completed a skydive whiched raised £260. Elaine was previously a teacher of Michael Armstrong who had MPS and wanted to raise money in memory of Michael and for other sufferers like him.

On 30th November we held a race night at the Top Deck Social Club. This event raised a total of £1,486.36. £100 was donated by the union AMICUS and £260 by the Top Deck Social Club. This was from the proceeds 22 gallons of beer drunk.
Helen & Anthony Corcoran

MANAGEMENT COMMITTEE

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	Alex Roberts	Project & Information Officer	a.roberts@mpssociety.co.uk
	Alison West	Development Officer	a.west@mpssociety.co.uk

Do let us have your family stories and any helpful hints you would like to share with our newsletter readers. If you have a question that you would like to see answered in a future edition of the newsletter, please do write to us.

To submit information to the newsletter please send materials (preferably via e-mail for text) and mail photos to the address below.

The articles in this newsletter do not necessarily reflect the opinions of the MPS Society or its Management Committee.

The MPS Society reserves the right to edit content as necessary.

NEWSLETTER DEADLINES

SPRING
31 March 2003

SUMMER
30 June 2003

Autumn
30 September 2003

WINTER
17 December 2003

CONTACT US

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email: mps@mpssociety.co.uk
Web site: www.mpssociety.co.uk
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