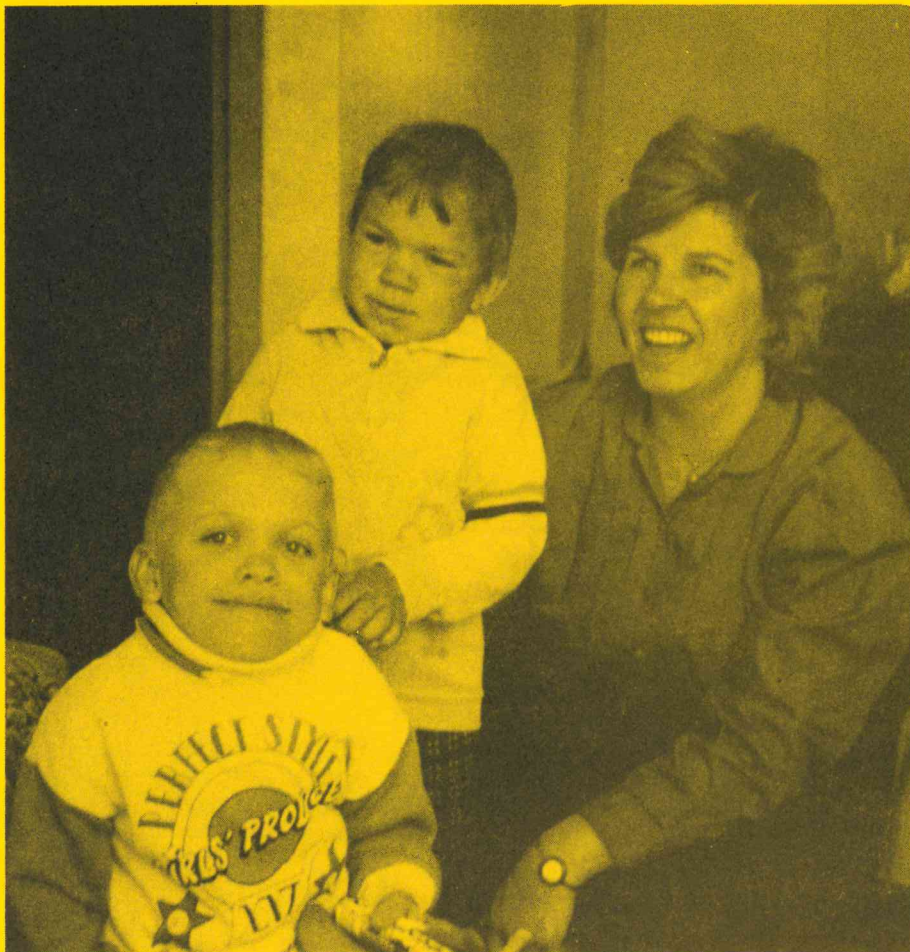


Newsletter

Summer 1995



# The Society for Mucopolysaccharide Diseases



National Registered Charity No. 287034

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## The Society for Mucopolysaccharide Diseases

55 Hill Avenue, Amersham, Buckinghamshire HP6 5BX

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The MPS Society is a voluntary support group, founded in 1982, which represents over 700 families in the UK with children or adults suffering from Mucopolysaccharide and related diseases. It is a registered charity, entirely supported by voluntary donations and fundraising by members, and run by the members themselves. Its aims are:

- To act as a parent support group
- To bring about more public awareness of MPS
- To promote and support research into MPS

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

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

## "Care today, hope tomorrow"

Front Cover Picture shows Christine Lavery, Director, with two Russian boys suffering from MPS at the Second Russian MPS conference in Moscow in May 1995. (See Page 26)

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**Deadline for Autumn Newsletter**

**1st October 1995**

## Directors Report

Enclosed with the Newsletter you will have received the latest Annual Report and Accounts of the Society. We are grateful to the families who allowed us to use their stories and the pictures of their children in promoting the work of the Society.

Turning to the Accounts, I would particularly like to express our gratitude to Pauline Mahon, (treasurer) Sean Mahon, Coopers Lybrand and Hawsons (auditors), for giving their time and saving the Society considerable expenses in managing our finances and complying with the stringent financial clauses in the new Charities Act.

You will see from page twelve of the Annual Report that the Society achieved a total income of £243,317 in the year to 31st October 1994, and with it an excess of Income over Expenditure of £35,254.

However that is where the good news ends. In the first eight months of this current financial year we have suffered a deficit of £56,000 and still have major expenditure on the conference and family support to absorb.

**We need your help now to break this trend and raise enough money to make ends meet. Without every MPS family's help, and that of extended families and friends, many of the services we provide will not be possible in 1996.**

There is so much to do in raising awareness, family support, keeping abreast of scientific developments, the Great Ormond Street and Manchester Clinics and the 1995 family conference. However, with this big financial cloud hanging over us, neither Mary nor myself will be able to commit as much time to family support as our priorities will have to turn to fundraising.

Please think of MPS when the opportunity presents itself for either fundraising or donations.

**We need help now!**

**Christine Lavery**

Director  
July 1995

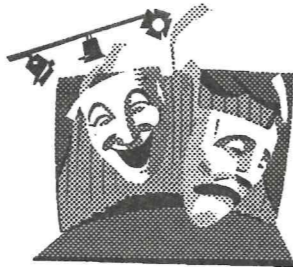
### Stop Press

At the fourth meeting of the International Working Party for Mucopolysaccharide and Related Diseases in May 1995, Dr John Hopwood from the Department of Chemical Pathology in Adelaide announced that his group had finally isolated the gene for sulphamidase deficiency (MPS IIIA, Sanfilippo A disease). This allows the first step in more accurate testing for this disorder and will hopefully stimulate a great deal more interest in the treatment of this disorder.

**JE Wraith**  
Director, Willink Biochemical Genetics Unit



### 1995 Dates for your Diary



- 10 September Area Family Day at Cotswold Wildlife Park (Ron Snack)
- 17 September Barbara and John Arrowsmith and John Brennan take part in the Great North Run.
- 20 September Northern Ireland Regional MPS Conference
- 22 - 24 September MPS Annual Conference, Northampton
- 24 September MPS Annual General Meeting (at the Conference)
- 2 December MPS Giant Tombola at Milton Keynes (Ron Snack)
- 10 December Area Christmas Party at Milton Keynes (Ron Snack)
- 23 December MPS Flag Day at Milton Keynes (Ron Snack)

*The Annual General Meeting of the Society for Mucopolysaccharide Diseases will be held at the Stakis Country Court Hotel, Northampton, on Sunday 24 September 1995 at 9.40 a.m.*

*By order of the Committee*

*A. G. King (Chairman)*

*Boring! Boring!*

*How time flies. Come September it is AGM time again and once more there is voting to do! This is the fourth year so we have now reached the stage where one third of the Committee are up for election. Perhaps I had better explain more.*

*We have a Management Committee of ten people all of whom are elected for a three year term. Of the present Committee, Kieran Houston, Pauline Mahon, Mary O'Toole and myself were elected in 1992 so our three year stint ends after the next Conference. Alan Beavan, Tony Eyre and Lynne Grandidge were elected in September 1993 so they still have over a year to go. Last year John Brennan, Jon Lawrie and Peter Stuart were elected so their three year term goes on to September 1997.*

*Of the four of us whose time runs out this year, with the exception of Mary O'Toole all are happy to stand again if required. Other nominations are of course welcomed and even if the three of us were to be re-elected there is still one vacancy to be filled.*

*I hope my title for this article has encouraged you to read this far - if you have any nominations for the Committee please do write and let me know as soon as possible. If you want to know what is entailed or anything else about what the Committee does do feel free to give me a call, the number is on the inside cover.*

*Alf King (Chairman)*

### Mary O'Toole

**As you will have read above, Mary O'Toole is not standing for re-election to the Management Committee. I am sure that all members both past and present join me in expressing our grateful thanks to her for all she has done for the Society and in particular on the Committee over very many years. I took over from her as Chairman and it was a very hard act to follow. Although she is no longer on the Committee she will of course continue to do a great deal for the Society - without people such as Mary this Society would certainly not have flourished as it has. I also add my own personal thanks to Mary for making my job as Chairman that much easier.**

**Alf G. King**

### Births

Congratulations to **Edward and Bernadette Hall** on the birth of their son **Oliver** on the 19th of April 1995. Sadly, Oliver has been diagnosed at birth as suffering from Sanfilippo disease. Oliver's brother, **Dominic** born 13th July 1988 also suffers from Sanfilippo disease.

Congratulations to **Jonathan and Susan Fine** from Pretoria, South Africa, on the birth of their daughter, **Leara**, born 24th April 1995. Their older daughter **Gila**, suffers from MLIV and Susan has written to say she is attending a nice school and progressing slowly. Susan and Jonathan used to live in London but returned to South Africa in 1993.

Congratulations to **Karen and Mick Wheeler** from Old Woking, Surrey, on the birth of their son **Christopher** on the 25th of April 1995, a brother for Rhianneth.

### New Families

**Abdul Ghafoor and Zainab Awadhi** from Bradford in Yorkshire whose son **Abdul Awadhi**, born on the 20th of November 1992, has been diagnosed with Sanfilippo disease.

**Clive and Jackie Chisling** from Trowbridge, Wiltshire, whose daughter **Hannah**, born Christmas Day 1992 has been diagnosed with Sanfilippo disease.

**Perry and Lorraine Cowan** from Kettering, Northants., whose son **Jamie** born 12th October 1978, suffers from Morquio B disease.

**Jan and David Donegani** from Loughborough, Leicestershire, whose daughter **Amy**, born 26th of June 1989 and son **Daniel** born 7th of July 1992 have been diagnosed with Sanfilippo B disease.

**Pam and Barry Evans** from Wigan, Lancashire, whose son **Bradley**, born on the 22nd of November 1994 has been diagnosed with Hurler disease.

**Mr and Mrs Khan** from Luton, Bedfordshire, whose daughter **Sadia Akhtar** born 22nd of February 1991 and son **Shoia** born on 9th of January 1994 have been diagnosed with Sanfilippo B disease.

**Mary and Michael Mc Cawille** from Strabane, Co. Tyrone, Northern Ireland, whose son **Shaun** born in 1991 has been diagnosed with Hunter disease.

**Ian and Maxine Meaker** from Bovington in Dorset, whose daughter **Kimberley**, born on the first of September 1992 has been diagnosed with Sanfilippo disease.

**Maureen and Martin Taylor** from Hanging Heaton near Batley, Yorkshire, whose sons **Dale** born on the 26th of January 1989 and **Kyle** born on the 7th of December 1991 have been diagnosed with mild Hunter disease.

**Chris and Mandy Wainman** from Gypsyville, Hull, whose son **David** born on 8th of January 1988 has been diagnosed with Sanfilippo disease. Sadly their daughter **Lauren** has also been diagnosed with Sanfilippo disease.

**Gail Weir** from Airdrie in Lanarkshire, Scotland, whose daughter **Emily** born on the 12th of March 1994 has been diagnosed with Hurler disease.

**Melissa and Robert Lovick** from Woodstock near Oxford whose son **Keegan** born on the 19th of November 1994 has been diagnosed with Hurler disease.

### Deaths

**Berenice Shooter** born 31/5/80 from Forest Town, Mansfield, Notts. died on the 28th of May 1995 aged fifteen years. Berenice suffered from Sanfilippo disease.

**James Gooch** born on 25th of November 1983 from near Heathfield in East Sussex, died on the 5th of June 1995 aged eleven. James suffered from Hurler disease.

**Guy Hamerie** who lived in Israel died on 11th of March 1995 aged thirteen years and six months.

**Victoria Johnson** from Hawarden in Clwyd who died on the 24th of July 1995 aged nearly eighteen. Victoria suffered from Sanfilippo disease.



Marie-Thérèse, Marie-Céline and Geoff Shooter would like to thank all those of you who were so supportive during our difficult and sad time by your words, cards and flowers. It was a great help to know that we were in people's thoughts. Bérénice died at home on the 28th May, 3 days before her 15th birthday on french Mother's Day. We had always wanted her to be buried in France in the little village of Mercenac in the Pyrenees where her grandparents are already buried. It is such a happy place. She was buried on the 8th of June.



## The Society for Mucopolysaccharide Diseases

55 Hill Avenue, Amersham, Buckinghamshire HP6 5BX  
Telephone: 01494 434156 Fax: 01494 434252

### MPS TEENAGE ACTIVITY HOLIDAY May - June 1995 EXMOOR CALVERT TRUST WISTLANDPOUND EXMOOR NORTH DEVON

For a third year running 15 teenagers and young adults suffering from physical disability as a result of the Mucopolysaccharide Diseases, travelled from all parts of the United Kingdom, to spend a week undertaking activities that they might have expected to be only bystanders to.

With the very generous donations from "Coopers Lybrand" and "BBC Children In Need" for the first time, we were able to accommodate and provide round the clock care to twice the number of youngsters compared with previous years. These holidays wouldn't be possible without the support and co-operation of 9th Supply Division, Royal Logistics Corp, who provided 24 volunteer army carers to undertake a range of tasks from providing personal care to sharing a canoe on the reservoir, a horse and cart ride on Exmoor, or providing moral support as you are launched off backwards in a wheelchair abseil.

Behind the scenes, the holiday provided these MPS youngsters with an opportunity to make friends, learn some independent living skills, as well as 'talk' about their disease, their hopes and fears for the future. For many this was the first time away from caring parents.

On behalf of all the MPS teenagers and young adults on holiday, we thank everyone for supporting what was a most successful and rewarding venture.

Now we have to look forward to 1996.

**CHRISTINE LAVERY**  
DIRECTOR



**Helen Skidmore and Ronda Brierley** take the sun down by the reservoir.

Helen is age fourteen and comes from Newport, Gwent. She has Hurler disease, which has been treated by bone marrow transplant.

Ronda is age 21 and comes from Manchester. She has MLIII disease.

**Mark Simpson**, as ever, is busy with his water gun.

Mark is age fifteen and comes from Haxby, near York. He has Morquio disease.

## Holiday Report

My name is Ronda Brierley, I am twenty one years old and I come from Manchester. I went on an adventure holiday down in Devon called the "Calvert Trust". So on Saturday 27th of May I set off from home to meet Mary Paget who was taking a group of us there. When we finally arrived after a long journey we went to a farmhouse to meet Christine Lavery. I was shown to my room and then I went for tea. After tea I met my helpers for the week. My helpers were Toni and Julie.

At night I met the army and I also met some of the MPS members. We all went out to the pub. After a late start on Sunday we went to a place called Ilfracombe. We had a pleasant walk round and then we went back for dinner. After dinner I met the other MPS members including my room mates. Their names were Sarah and Helen. That took the rest of the afternoon then we had tea. At night we went out to the pub AGAIN!!

The following day we got up early, had breakfast, put our waterproofs and our lifejackets on and off we went down to the reservoir for a bit of sailing and canoeing. We did this on Monday, Tuesday and Friday. The rest of the activities which we did during the week were Horse Riding, Archery and Abseiling. We were going to do Orienteering but the weather was too bad so we went swimming instead.

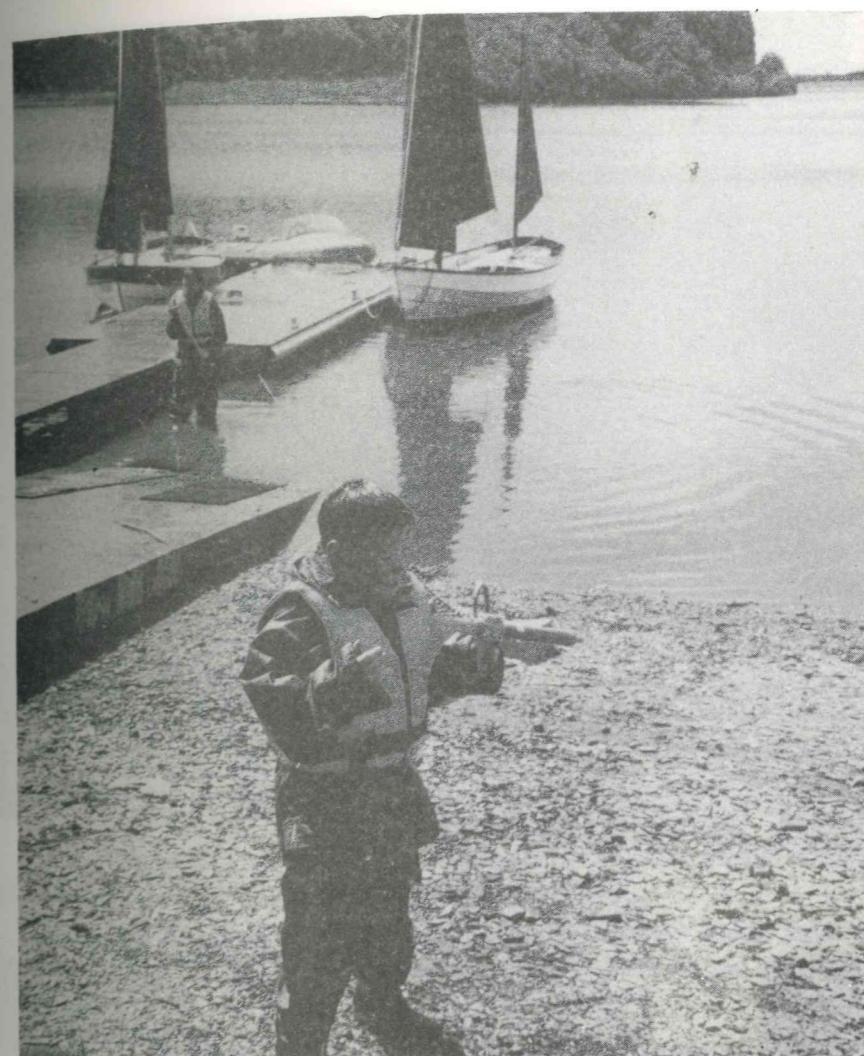
I enjoyed the whole holiday but I especially liked it at the night as we had barbecues and trips out to the pub. I want to thank all the helpers on the holiday for making this a very enjoyable week.

**Ronda Brierley**  
51 Wallbrook Crescent  
Little Hulton  
Manchester M38 9EE



**Sarah Burgess age 14 from Luton (MLIII).**

Sarah thinks horseriding is great fun but keeps the instructor nearby just in case it gets too exciting.



**Its that Michael Fitzgerald again with his water gun.**

In the background are the sailing dinghies with a view over the reservoir.

"There's nothing to it. Its just like sitting on an armchair".

**Says Michael Fitzgerald** age nearly fourteen, from Leagrove, Luton.

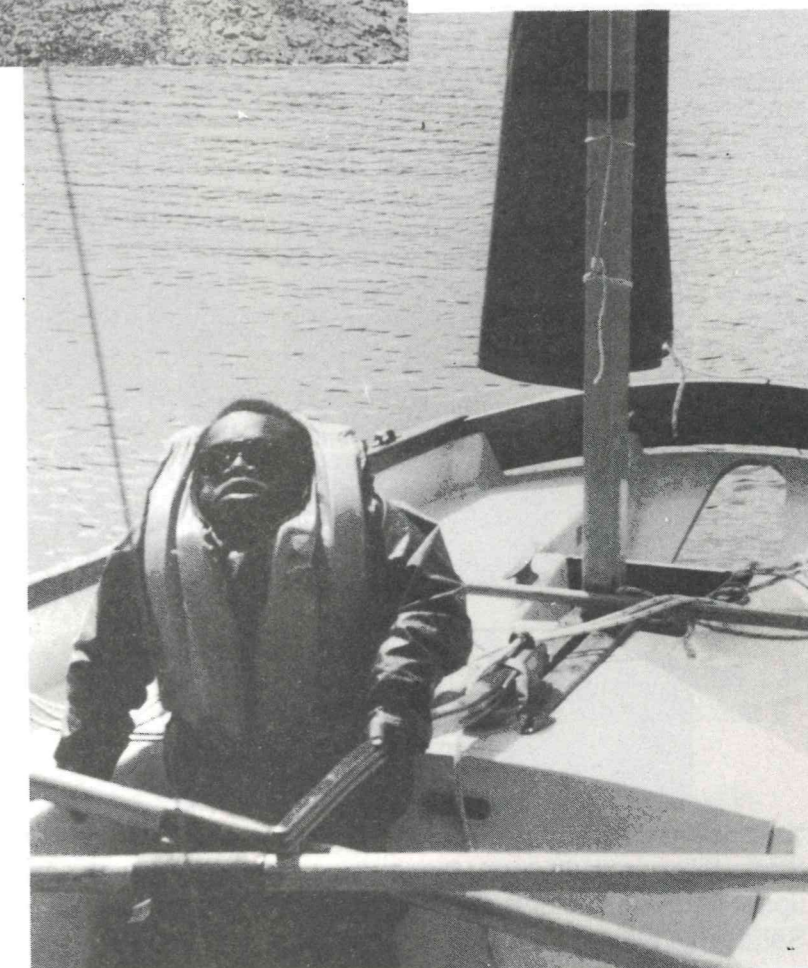
**Michael's brother Mark** age 17 was also on the holiday. They both suffer from Mild Hunter disease.



**Steve Simms** from Chivendale, near Warley, West Midlands, takes a firm grip on the tiller as he gets ready to set sail.

Steve is almost thirty and suffers from Morquio disease. He first found out about the Society only a year ago. Steve lives with his father and gets help from other family members who live nearby. It was a wonderful discovery for him to find there were others with the same condition.

He has thoroughly enjoyed meeting other adults and young people with MPS. Before then he felt very isolated.





Ronda Brierley, Sarah Kilvert, and Helen Skidmore with volunteer Alex enjoy watching the water sport as they keep a comfortable watch from dry land.



She's fallen in the water! Sarah Burgess takes it in her stride as she is rescued from her upset canoe by volunteer Laura. Sarah is fourteen and comes for Luton in Bedfordshire. Sarah has MLIII disease.

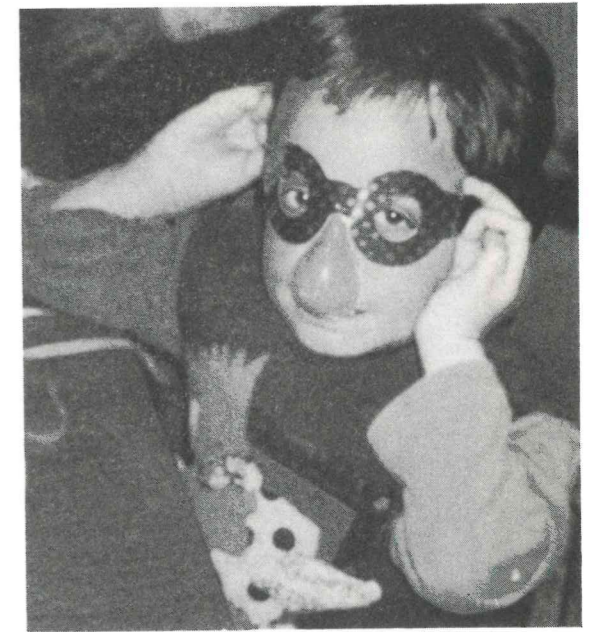


Sarah Burgess and Patrick Scanlon (foreground) with Mark and Michael Fitzgerald and volunteers as they enjoy a Devon cream tea on an outing from the Calvert Trust adventure holiday.



Sue did most of the cooking and Major David Coole from the Royal Logistics Corps ran the show as he did the previous year.

It wasn't all adventures in the woods and lakes. Here David and Sue demonstrate how to sort out underwear for the laundry. An important lesson if it's your first time away from home.



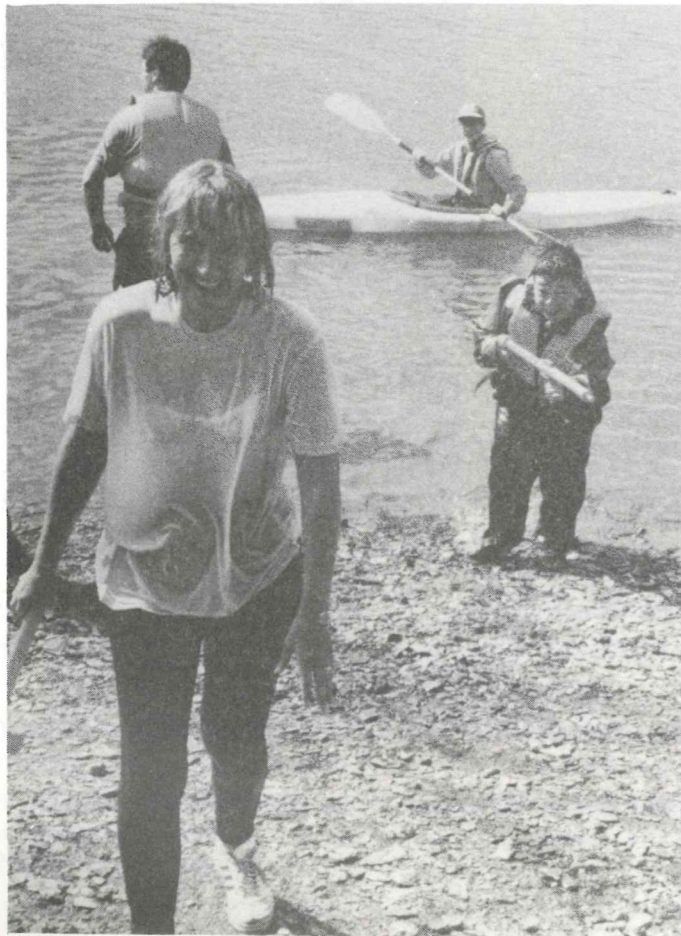
Mary Paget had a birthday party. She wouldn't say which one it was.

Christopher Isaac came in disguise with a very green and luminous nose.





**Sometimes it is important to do it in style!**  
**Sarah Kilvert, Mary Paget and Steve Simms** arrive at Butlins in their very own stretch limo.



**Mary Paget** beats a hasty retreat to dry land as **Michael Fitzgerald** goes on the warpath again with his water pistol.

**MPS hits London Zoo again**



**Families at London Zoo on 20th May at an Outing organised by Ron and Linda Snack.**  
**Thanks to Ron and Linda for their support work and fundraising.**

## The Milton Keynes Barbeque Turns Really Hot!

Several MPS families enjoyed a seriously hot afternoon at the Milton Keynes Barbecue on the 9th of July, as temperatures soared into the seventies. It was lovely to see families who were new to us, but who obviously enjoyed themselves once they had settled in. The whole afternoon went off well, including some excellent barbecuing from Nobby and Ricky - thanks folks.

The next of our little "dos" is at the Burford Wild Life Park on Sunday 10th of September, so please do try to come along - you will be very welcome.

### Ron Snack



Families enjoying the sunshine at the Milton Keynes Barbecue

## Area Family Day - White Post Farm

### Yorks, Notts, Lincs, Derby and Humberside Area.

We returned to White Post Farm for another Area Family Day in May. It has proved a popular spot. It was good to see old friends and to meet new families and to welcome them to 'our family'. It was a day we had waited for eagerly as it was some time since we had seen anyone due to missing the Christmas Party. At that time we were *suffering??* the heat in Florida at the American MPS Disney Conference. Thank you Marie, Hope and the American families for making us welcome.

The weather was kind to us and it only rained when we were inside eating, I hope everyone had enough to eat. Everyone had a good time and then we took the *children?* out to feed the lambs. Then to cuddle ducklings, chicks and mice. After that we returned to the barn for another good chinwag. Unfortunately it was then time to go home. The good thing is we can look forward to the next Area Family Day and hope to see even more families there.

**David Briggs**, Assistant Area Family Support Co-ordinator.



## My Change of Schools

As many people may already know I have now left my local school Whitefield and go to Lord Mayor Treloar National Specialist College in Hampshire (LMTC for short).

I spent many happy years at Whitefield school, which is a mainstream school adapted for the disabled. I spent my final two full years doing my GCSEs at Whitefield and got some pleasing results. But that is a different story altogether. As I enjoyed my life there I decided to stay on and join the sixth form with many of my friends.

In the sixth form I started to study for a GNVQ in Business and an AS level in English. These subjects were both very hard and even Mum had trouble helping me with the GNVQ homework. It did not help having two weeks off in November when I went to Florida with the National Holiday Fund. When I came back from the USA I found I was very far behind with my studies and I found it difficult to catch up.

The sixth form part of Whitefield was not as well adapted as the rest of the building. To start with there were four double doors to get through to get down to the centre. I am sure everyone who has ever used a wheelchair will understand how frustrating it is to have to wait for someone to come and open a door for you. Well I had to do this every morning. Also there was not a lift up to the upstairs where the private study rooms, careers library, and lockers were. Each time I had a private study period I had to spend half my time looking for somewhere to study and then find the key. As I was with my friends in the fourth and fifth year I did not need much help from my welfare assistant. I had not realised how much my support had dropped and I found I needed more and more help in lessons.

I soon found myself becoming very depressed and withdrawn. I could not cope with my work anymore and after about three weeks of struggling on, Mum finally removed me from Whitefield and my education in London had finished.

For about two months I sat around at home for two days of the week having Barnet Care Assistants popping in and out throughout the day. The rest of the week was spent at Flightways day centre for disabled people. I took part in activities like photography, flower arranging and a women's discussion group. The youngest person apart from me at Flightways was twenty four and so I longed to be with my own age group again.

During my time at Flightways my parents and I were campaigning for me to go to LMTC. As I am seventeen most people of my age group would be going to university soon and this was the only chance I would get. I felt it was the right time for me to leave home.

When I visited the college I felt very welcome and I was sure this was the right place for me. I knew this was a good place because both Sarah Long and Sarah Lowry had been here before me. In fact my temporary form tutor when I first came called me Sarah for quite a while.

Mum was told that the decision had to be made by the Panel. I spent many agonising weeks waiting for my case to come up. When it did finally come up at the Panel, they said as I was over sixteen the Further Education Funding Council had to make the decision. I was so upset I was

crying. However Mum phoned our local councillor, Rudi Vis, who we are good friends with. He rang the head of the panel and threatened them with the Ombudsman. The following week I was told I would be starting at LMTC after Easter.

Mum and my sister spent the next two weeks labelling all my clothes ready for my dreaded day. After looking forward to going for so long I found I was really quite nervous and was not sure whether I wanted to go or not. Finally the day arrived and I was a nervous wreck. Dad went to work for the morning and then after lunch we set off. I did not enjoy the journey at all and was nearly in tears. I felt like I was going to hospital for an operation.

When we got there we were directed round the back to park just outside the house I would be staying in. It is a very nice house called Evans House. After we had unpacked we went to see Mr Clay who would make my temporary timetable. Deciding which course to take here usually takes three weeks but as I came in the middle of the year I was given six weeks to decide. Mum was in tears as she left but it was me who was sobbing the next day on the phone.

I first spent two weeks with Mr Stevens who taught GNVQ Leisure and Tourism. I found this lesson a bit boring. After my first two weeks I tried GNVQ Health and Social Care with Mrs Simpson and this was more bearable. I did not make up my mind though until I tried NVQ Business Administration. I enjoyed this as well. As I eventually want to work in an office I decided to do the NVQ instead of Health and Social Care. I now find this course quite enjoyable.

My fellow house mates are very pleasant and I seem to get on with all of them. In our single sex common room we have drinks and a fridge with food in it so if we feel hungry we can make toast or something. We also have a TV in there. I do not spend much time in this room though because I prefer to be in the mixed TV room with my six foot four boyfriend, James.

I have been home a few times and enjoy seeing my friends and family again, but I prefer to be at college because it seems quite boring at home now. I am going home this weekend but James is coming with me so it should be quite fun.

**Helen O'Toole.**

### *MPS European Database Questionnaires*

*I would like to thank all the families who kindly completed and returned the Questionnaires to the office.*

*If you have not been able to complete your Questionnaire yet or are having problems with it PLEASE contact Joan at the MPS office on 01494 434156*

### A Parent's View of Music Therapy.

**Jean and Paul Leonard**

Our son Christopher is 3 years old and has attended Music Therapy with his teacher, Mary-Clare Wood at the Cheyne Centre for cerebral palsy, Chelsea for approximately one year. In the last 7 months, this has been on a regular weekly basis during the centre's term-time. The benefits of music therapy may be useful for all types of people. In this article we try and describe what benefit our son is deriving.

Christopher has Fucosidosis, a rare Metabolic disorder and received a bone marrow transplant at 9 months of age. He is growing well, enjoys play, activities and attends a nursery group but he is not as skilled as other children of his age. His hearing is good and he enjoys singing and music but he has some delayed development, particularly with talking and can only say a few words. He knows a little Makaton sign language.

Firstly, in the music room there are many types of percussion instruments available and they are not toys or replicas. Christopher is allowed total freedom to choose whatever he wants to play. Mary-Clare will join in his sounds with her flute or the piano and a good noise is produced. Christopher enjoys this and tries many different instruments and smiles and laughs throughout the session.

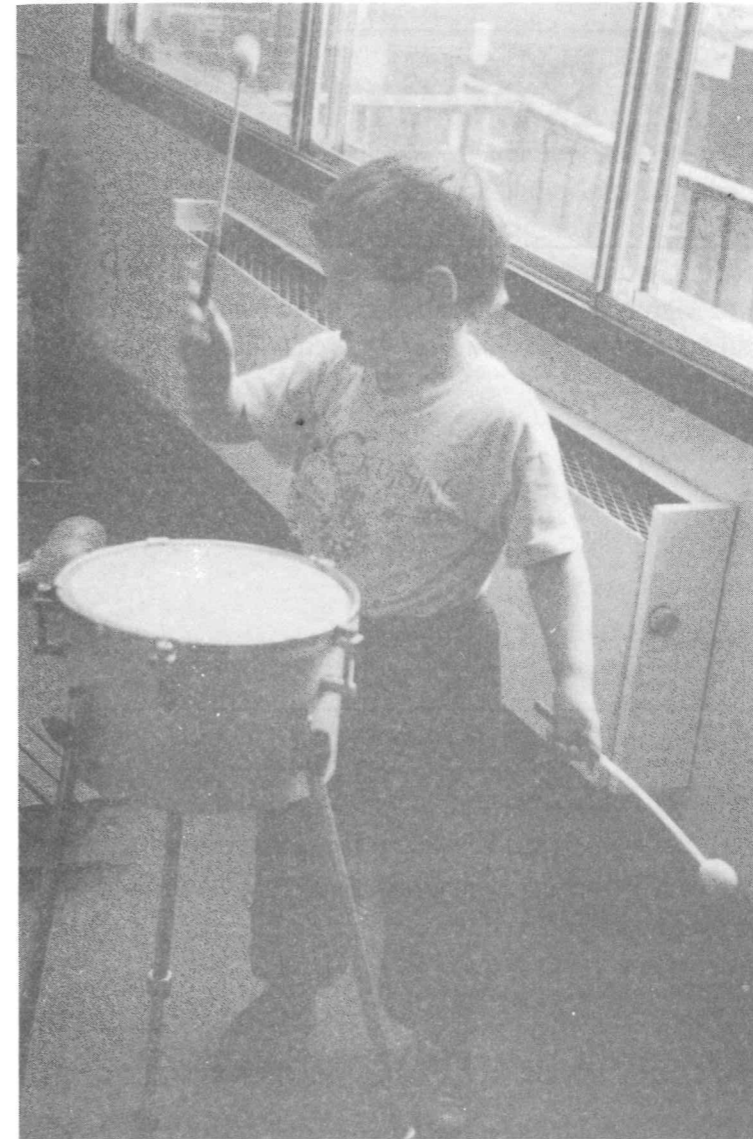
Since he cannot express himself easily in words the clashing cymbals and thundering drums may be relieving frustration and bad temper.

Any music he makes is his own self expression and not directed by Mary-Clare or myself. As Christopher has a very strong personality this leading of the music is very important to him.

He regards Mary-Clare as a friend and not in the 'medical role'. He looks forward to his Thursday afternoon sessions. He finds the room and the building and the lift familiar and feels secure, but they are different and therefore more interesting than staying at home or in the nursery. However, Christopher is very insecure without one of us present.

Any good stimulus like this must improve his intellect. These music sessions have widened his horizons and provided another activity that he loves.

We were very pleased that our Occupational Therapist suggested his referral and we hope this article may inform other parents of the benefits of Music Therapy for their child.



**Jean and Paul Leonard of**  
15 Langthorne St  
Fulham,  
London SW6 6JT  
sent this article about Music Therapy.

Further information is available from  
**The National Music and Disability**  
**Information Service,**  
Foxhole,  
Dartington, Totnes, Devon, TQ9 6EB  
Tel: 01803 866701

Three year old Christopher uses 'clashing symbols and thundering drums'.

Perhaps it may relieve frustration and bad temper.

**Christopher with his music therapist,**  
**Mary-Clare Wood, at the Cheyne**  
**Centre for children with Cerebral**  
**Palsy, Chelsea, London.**



## Fundraising Reports

I have now banked £222.00 in the Society's account, which was money donated in lieu of flowers at my mother's funeral. Mum died on the 21st of March after open heart surgery to replace a valve and triple bypass two weeks previously. She did not regain consciousness and really had a battle with high and low blood pressure and other complications.

She was such a wonderful mother. I can't tell you how much grief I feel at this time. I'm sure my father would appreciate a note if possible. We will no doubt see you in May and the first week in June we are in Great Ormond Street Hospital for five days.

Best wishes,

**Pat Skidmore, 5 Chapel Close, Monmouth.**

**Dear Christine,**

Enclosed you will find a cheque for £251-00 which Rashpal collected after he had completed a twenty five mile bike ride to Stratford. We hope this contribution will help boost your much needed funds. We hope you and your family are keeping well. We would also like to thank you for all your help in getting Daniel's Disability Allowance.

Regards,

**Sandra, Rashpal and Daniel Singh**

As Area Family we were invited to Plymouth to collect a cheque for £600 from the Old Plymothians and Mannamedians Club in memory of **Timothy Norsworthy**. The former pupils of Plymouth College held various fund raising events during the year and invited us to the Moat House Hotel for the presentation.

Timothy, who suffered from Morquio disease was a fanatical Manchester United fan and one of his wishes was fulfilled when he went to Old Trafford to watch his heroes. He was also a keen cricket fan and liked nothing better than to follow his brother Christopher's cricketing career.

We would like to thank Tim's parents Jennifer and Clive for their generous hospitality and everyone at the Old Plymothian and Mannamedians for their kindness.

Best wishes,

**Tony and Shirley Eyre**

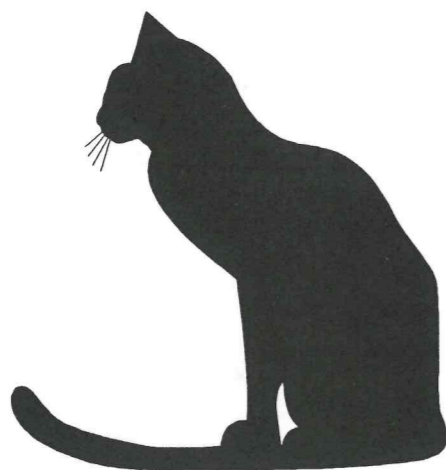
## Jeans for Genes Events

The children of All Saints Church of England School, Sunnyside Road, Wyke Regis, Weymouth, Dorset DT4 9BJ had two fundraising events on behalf of the Society. On one day the children wore ordinary clothes instead of school uniform and on the other day they came to school in Jeans. They raised a grand total of £267.00. Ms Betty Port wrote to tell us about it and sent us a photograph showing just a few of their 850 pupils so we record the occasion in the newsletter. Our grateful thanks to the school and the headteacher Mrs J.E.Munslow and to Ms Port.



Rashpal and Daniel Singh. Rashpal collected over £250 by a sponsored bike ride.





### ADVANCE NOTICE

#### THE 1995 MPS GRAND DRAW is another way of raising money for the work of the Society.

**First**, make sure you sell your original books, and return the counterfoils and the money, ( P.O's or cheques made payable to "MPS") to the address on the ticket as soon as possible.

**Second**, if you wish for more books to sell Tel: 01772 815516

**Third**, if for any reason you can't sell the books sent to you. Please return immediately so that they can be sold by some-one else.

Draw to take place at the North West Xmas Party  
on 3rd December 1995

All monies and counterfoils returned no later than Monday  
the 27th November 1995.

**Tickets will be despatched no later than the conference.**

## Support to MPS Families in Norway

Since 1990, when their son Einar was diagnosed as suffering from Hunter disease, Odrun and Knut Bachke have worked tirelessly, not only to extend their own knowledge of MPS, but to educate many professionals and to develop a support network for MPS families under the auspices of the "Hunter/Hurler Group"

Einar is now ten years old. He is the middle of three children, all of Korean extraction, who were adopted by the Bachke family. Helga aged twelve and Sigund aged two are healthy and enjoy all aspects of Norwegian life. Sigund is a budding ski jumper; the 1952 Olympic Ski-Jump towers above the area where the family live. Helga is a typical nearly teenager.



It was a very special occasion when I was invited to speak about support to MPS families in the UK to the Hunter/Hurler

Group's first parent and professional conference held on the 5th of May in Frambu. Nine Norwegian families, one Swedish family and a Bosnian MPS family attended with over fifty interested professionals. Dr Wraith spoke on the clinical manifestations of the Mucopolysaccharide diseases and there was considerable interest in Bone Marrow Transplant.

In addition to the conference I spent a fascinating time at Einar's special school. I was invited by the staff to view a video of Einar's therapy sessions. Something I had never seen in England is a hammock hung from the ceiling, beautifully padded. The child is then placed in it and experiences movement in time to music, dance and specific play, all to a theme. Einar really seemed to enjoy this activity. Equally in common with many MPS children he does not enjoy lying on his stomach or side and this was discussed at the meeting.

I also visited the nursery school where Einar went when he was younger. It is integrated and takes nine children with special needs (mainly autistic tendencies) and thirty healthy children. Staffing for special needs is one to one and each child has his/her own tasks to do and therapy programme. The nursery is the responsibility of the Norwegian Red Cross.

Finally, I had the opportunity to meet a contact who may be helpful in lobbying for our two applications submitted for funding by the European Union in Brussels.

Thank you Odrun and Knut for the wonderful Norwegian hospitality.

**Christine Lavery.**

## The International Scene

### Second MPS Family Conference, Moscow, Russia, May 1995

Mary Paget and I attended the Russian MPS Conference as part of the Society's wider brief to develop a European Database, which is funded by a two year grant from CSL.

Some of you will recall meeting Professor Krasnopolskaya and Dr Tishkanina at our 1994 Conference in Northampton. Enthused with what they had learnt and seen, a second Russian MPS conference adopting many of the Society's procedures was organised.

Despite the difficulties of transport and communication (most Russian families are not on the telephone and do not have a car), more than fifty families attended from all parts of the old USSR.

The minister of Health addressed the meeting and offered his endorsement for the work of the Society. Dr Wraith and I, speaking through interpreters, outlined the clinical aspects of MPS diseases and the work of the Society respectively. Parents asked many questions, particularly in relation to future therapies and education.

Because of the difficulties of being a foreigner in Russia, Mary, Ed and I decided to pay for our spouses to accompany us. This turned out to be a good decision as there is still much to change with "Perestroika". Our hosts looked after us very well. However, once back at our Russian hotel it was not safe to go out.

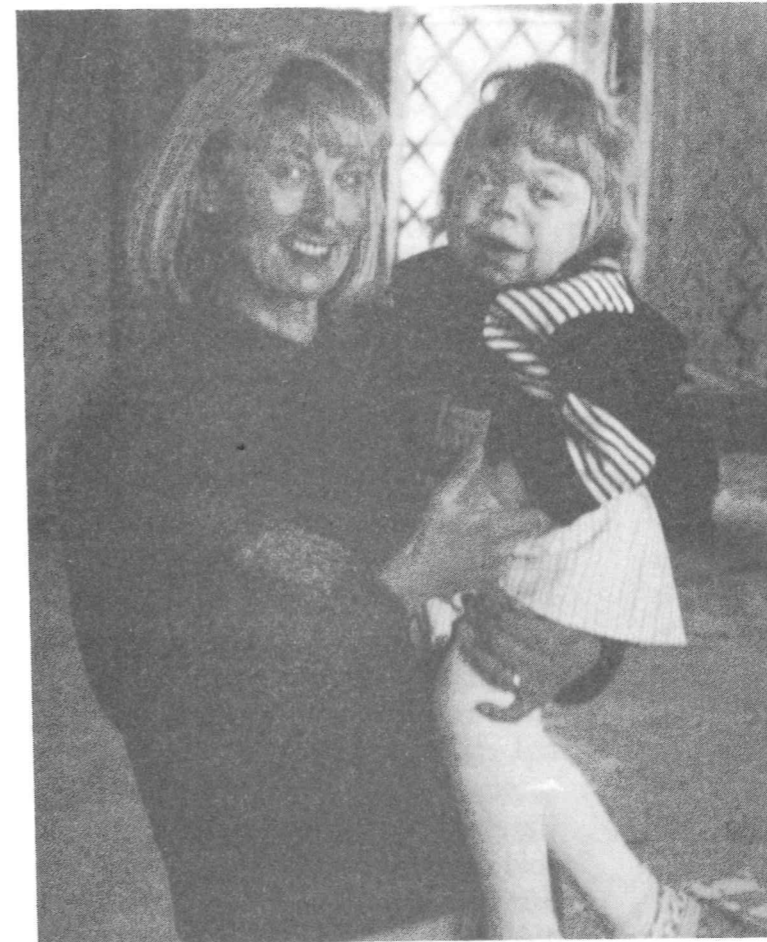
At Christmas 1994, members of Alyson and Deirdre Coles' church in Stoke d'Abernon, Surrey, collected and donated a large quantity of essential toiletries - soap, toothbrushes, toothpaste, talcum powder and shampoo, which we transported to Russia (excess baggage costs provided free by Austrian Airways). We were also extremely grateful to the four MPS families that responded to our plea in our last newsletter for second hand buggies. These will make such a difference to the Russian families that received them.

Following the conference we visited the 1,000 bed Children's Hospital in the centre of Moscow. Dr Tishkanina told us that it was funded by French money and built ten years ago by the medical students in appreciation of their training to become doctors! From the disrepair we witnessed it was obvious Russian medical students had a lot to learn about the building trade. It was also disappointing for Russian families to learn that the Bone Marrow Transplant Unit, due to lack of funds, has not carried out a transplant in over two years, not even for leukaemia.

Certainly the long flight home gave us time to reflect on how much easier it is to care for our MPS children in a world of disposable nappies, buggies and wheelchairs, private telephones, private cars and all the everyday items we take for granted like washing machines, toilet paper, medication and fresh fruit.

Thank you to all the MPS families, Professor Krasnopolskaya and Dr Tishkanina for taking us to your hearts. We will never forget you.

**Christine Lavery**  
Director



Mary Paget, with a girl suffering from Hurler disease at the second Russian MPS conference in Moscow in May 1995.



Six boys at the Russian MPS Conference all suffering from Hunter disease. While Russia has many skilled doctors and scientists, medical services are in a poor state and supports and services we take for granted are not available.

## A letter from Canada

### Dear Christine and MPS Society Members

We would like to take this opportunity to express our sincere appreciation to all who wrote to us. Learning that we are not alone has helped us a great deal and your encouraging words and understanding have given us the strength we needed to go on.

For those of you who may not have read our note in the Winter 1994 newsletter, my name is Cathy Bankert; we live in Ontario, Canada. In September of 1994 my husband Ralph and I were given the news that our four year old son Matthew, was diagnosed with Sanfilippo A disease and in February the tests confirmed that our daughter Kerrin almost two years, was affected as well. However life goes on, and because of your support we are starting to get our lives back on track.

Life has a different meaning now and we take little for granted. We strive to be accepting of the children's condition and of their limitations. In turn we are rewarded with the most loving, affectionate children that a parent could ever hope for. Matthew and Kerrin bring us great joy and that will live in our hearts always!

Prior to diagnosis Matthew had some medical concerns that we needed to address. He had two inguinal hernia repairs at separate times. The first surgery was a nightmare with the complication of infection. The second went very well. Matt suffered from recurrent ear infection and had a constant nasal discharge and was unable to breathe through his nose. He began drooling quite badly at this time. In February of 1994 he had a tonsillectomy, adenoidectomy and tubes put in his ears. This too was a difficult time as he haemorrhaged the day of the surgery and again ten days later. He was transfused after the second bleed and after several months was back to himself again.

The surgery was successful as he has had little trouble with throat and ear infections this winter but when he gets a cold now it tends to settle in his chest. We had hoped that once his nasal passages were clear that the drooling would stop but sadly it hasn't.

Matthew is a delightful big boy. He weighs 54 lb. and measures three feet eight inches tall. He attends a pre-school program four mornings a week and loves it. On alternate weeks he is involved in speech and occupational therapy. He speaks in three or four word sentences but often uses two word phrases. He loves music and can sing short songs from start to finish. Around home Matthew keeps his mother busy. His attention span is short and household duties hold much more appeal than toys. His favourite pastimes are helping with the dishwasher, doing the laundry, cooking, setting the table and building a fire in our airtight stove.

He gets all excited and waves his arms and does a little dance as he is so happy when we include him in these activities and give him one to one attention.

Matthew has unexplained fears and has some trouble sleeping at night. Often we find his sleep is even more disturbed after a frightening encounter. Matthew's gross motor skills have been slow to develop but we are still seeing improvements. He tends to fall quite easily and is unable to pedal a tricycle, however he can now propel himself using his feet on a push toy. He needs help dressing and despite our efforts we have had little success with potty training, or keeping him from chewing on everything.

Kerrin is a beautiful little girl with applebutter colour hair and a loving disposition, she measures 34 inches tall and weighs 30 lb. At this point she is progressing within the normal ranges for a child her age, however I feel her development may be a bit delayed. She has an

enlarged liver, her head is larger than normal and we are still waiting for her soft spot to close.

Recurrent ear infections have been a problem and Kerrin has been on antibiotics for most of her life. In December 1994 we had tubes put in her ears and hope that this may help to improve her speech. She has not had any ear infections since the tubes so we hope this trend will continue as we expect it will.

Ralph is a wonderful supportive husband and a great father. He is willing to help with the care of the children as well as helping with household duties, which I appreciate very much. He works as a tool and die engineer, a job that can be quite demanding and sometimes takes him away from home. In his spare time he loves to golf and go fishing and we hope next summer we can make arrangements so he can spend some time enjoying his hobbies.

The children are the focal point of my life. We are busy daily running to school, to the children's centre and lots of appointments and other outings. I have not worked outside the home since we were married in 1989, however recently I started to work at a local fabric store one afternoon per week. I have an interest in sewing and crafts and I find this work very therapeutic.

We both have supportive families and friends that are willing to help in any way. Unfortunately distance separates some of us and my mother in particular feels that she cannot help out as much as she would like to. The fellowship of Christian church has offered support and we are lucky to have qualified social workers who have listened and given suggestions when we were just too distracted to think straight. The children have the best of medical care, therapists and teachers and already we have some benefits for special services through government assistance programs.

Because of Sanfilippo we have met so many wonderful new people and have rekindled some very important friendships. These people ease the burden and I expect they will play a larger role as the years pass.

It seems that nothing can take away the pain when I look at what the future may hold for us; however we are determined to make our days happy for one another. Matthew and Kerrin are indeed a gift from God and we have been given many blessings. So the best we can do is live for today and try to fill each day with special memories that will last a lifetime.

### Cathy and Ralph Bankert

1704 Killaly Street, East  
Port Colbourne  
Ontario,  
Canada, L3K 5V3

*The above combines two letters, one to Trudi Deacon in February and the other to Christine Lavery in April. I trust Cathy will not be unhappy about this. She writes so movingly that I felt sure that families would like to hear as fully as possible from her.*



Matthew aged nearly three and Kerrin aged eighteen months. Picture taken in October 1994



## GENERAL INFORMATION

### Sexuality

#### Sexuality & Young People with Learning Difficulties – A Booklet for Parents and Carers

This new booklet has been written for parents and carers of young people with learning difficulties. The booklet focuses on the main areas of growing up and sexual development and explores these issues in an understandable and practical way. We are sure that you will find the booklet of great interest and value while your son or daughter is growing up. We have asked the questions that are most commonly asked in this area and have discussed them in a way that you will find useful, supportive and, hopefully, inspiring!

The booklet comes attractively bound and costs £6.00 including postage and packing.

#### Growing Up and Sexuality – The Young Peoples Booklet

This is an exciting series of illustrations for young people with learning difficulties. The drawings illustrate many themes such as:

- growing up
- feeling jealous
- feeling sad and happy
- personal safety



These illustrations come complete with trigger questions for parents and carers.

The Young Peoples booklet costs £3.00 including postage and packing.

#### Sexuality and Learning Disability - The Way Forward

The report of "The Way Forward" Conference, co-ordinated by the Health Promotion Service (Grimsby & Scunthorpe) and funded by Yorkshire Regional Health Authority, will be of value to parents and carers and also to those interested in sexuality and learning disability from a professional viewpoint. Topics covered include managing the practicalities; minimising risks; legal issues; and HIV fears and concerns. The report also offers helpful recommendations on the way forward.

The Conference Report costs £4.00 including postage and packing.

### To Order

The two booklets (but **not** the Conference Report) are available from: The Special Needs Sexuality Project, Ladywell Leisure Centre, 261 Lewisham High Street, London SE13 6NJ Tel. (0181) 690 7438

All three publications are available from the Contact a Family National Office and for a limited period only we are offering all three publications at the discounted price of £10.00 including postage and packing – a saving of £3.00. Please make cheques payable to "Contact a Family" and quote reference SaI/2/95 when ordering.

Three new publications on sexuality have been published recently and CaF is able to offer a discount on their purchase

With acknowledgements to Share an Idea, the magazine of 'Contact a Family', Summer 1995

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

Trull School of Dancing	Taunton	Collection
Somerset County Orchestra	Somerset	Collection
Pauline Hope	Northumberland	Raised money
Andy Jenny & Rebecca Hardy	Haddenham	Charity Fayre
Shirley Eyre	Malmesbury	Tupperware Evening
Mrs Barton	Sheinton Dale	Jumble Sale
Mr & Mrs Hicks	Merriott, Somerset	Coffee Morning
Mrs Rush	Kent .....	Sales of "Be Still" tapes
Mrs Wright	Lancashire	Sale of Xmas Cards
Anne Frazer	Thames Ditton	Coffee Morning
Vic & Sue Lowry	Harpenden	St George's Eve Dinner
Ken & Pam Ballard	Harrow.	Sale of Tennis Balls
Mrs & Mrs Deacon	Cranfield	Garden Sale
Mr & Mrs George	Bristol ..	Half Marathon
Dalsetter Rd Post Office	Hull .....	Collecting tins
Kathie & Jon Lawrie	Hull .....	Collecting tin
Mr & Mrs Westland	Reading	Sale

#### The Society is grateful to the following who made donations.

Eleanor Hamilton Educational Trust	Coopers Lybrand
Mr & Mrs Hayward	Electrolux
Ashmount School	Penelope Gluckstein
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Delta	Circuitt & Hinchcliffe
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Druck Ltd.	Mr & Mrs Haigh
Economist Charitable Trust	Newcastle Lions Club
Amersham & District Scottish Association	Mark Sheldon
Andrew Carnworth's Charitable Trust	Barclays Bank Plc.
Kathleen Lawrence Trust	Spiffing Stationery
Terry Ballard	Alliance & Leicester Building Society
BT	Mr Tait
Colin Putney	Rotary Club of Thames Witchert
Mr Marshall	RW Wallis
Montell Carrington	Mrs Mary Maudling
Henton Wells Nursing House	

**Donations in Memory**

The Society is grateful to the friends and relatives of

John Hodgetts  
Darren Tailford  
Harry Vaughan  
James Gooch  
Mrs Rees

**Sponsored Events & Appeals**

The Society wishes to thank those who supported:

Rashpal Singh.....Sponsored bike ride  
Kieran Houston .....Strabane Golf Tournament  
Mr Gregory.....London Marathon  
Mr Wain .....London Marathon

Edward Nowell Appeal  
Charity Boxes  
Mr & Mrs Nowell  
Billy Ingham

**Jeans for Genes**

Whittaker Moss School  
All Saints School, Wyke Regis

**Area Support Families**

<b>Martine and John Brennan</b> 105 Barley Cop Lane, Lancaster, Lancashire LA1 2PP	<b>Tel: 01524 382164</b>
<b>Robert and Caroline Fisher</b> The Horrells, Great Samford, Saffron Walden, Essex, CB10 2 RL	<b>Tel: 01799 586631</b>
<b>Suzanne and Jeffrey Hodgetts</b> 6, Godolphin, Tamworth, Staffordshire B79 7UF	<b>Tel: 01827 56363</b>
<b>John and Barbara Arrowsmith</b> 11 Penfold Close, Fairways Est. Benton, Newcastle on Tyne NE7 7UQ	<b>Tel: 0191 2662999</b>
<b>Sean and Pauline Mahon</b> 41 Stumperlowe Crescent Rd, Sheffield, South Yorkshire S10 3PR	<b>Tel: 01142 304069</b>
<b>Mary and Robin Gooch</b> Highbank House, Swifehill, Broadoak, Nr Healthfield, East Sussex TW21 8XG	<b>Tel: 01435 883329</b>
<b>David and Monica Briggs</b> 7 Humber Street, Retford, Nottinghamshire DN22 6LZ	<b>Tel: 01777 700046</b>
<b>Bill and Sylvia Blackburn</b> 11 Beatty Road, Nantwich, Cheshire CW5 5JP	<b>Tel: 01270 626809</b>
<b>Ron and Linda Snack</b> 16 Wandsworth Place, Bradwell Common, Milton Keynes, Bucks MK13 8BT	<b>Tel: 01908 666819</b>
<b>Tony and Shirley Eyre</b> 7 Elmer Close, Malmesbury, Wiltshire SN16 9UE	<b>Tel: 01666 825215</b>
<b>Anne, Michael and Sarah Kilvert</b> Windy Waye, Nantoer, Newtown, Powys, SY16 1HH	<b>Tel: 01686 624387</b>
<b><u>Contact for Scottish Families:-</u></b>	
<b>Alan and Fiona Byrne</b> 3 Jedburgh Avenue, Rutherglen, Glasgow G7 3EN	<b>Tel: 0141 6430034</b>
<b><u>Northern Ireland Co-ordinating Committee:-</u></b>	
<b>Kieran Houston (Chairman)</b> 15 Barrack Street, Strabane, Co. Tyrone, BT82 8HB	<b>Tel: 01504 884168</b>
<b>Margaret Kearney (Secretary)</b> 12 Coleraine Road, Ballycastle, Co. Antrim BT54 6DU	<b>Tel: 0126 5762073</b>