

NEWSLETTER

AUTUMN 1987

**THE SOCIETY FOR
MUCOPOLYSACCHARIDE
DISEASES**



National Registered Charity No. 287034

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This Newsletter is published and distributed free of charge to sufferers of the MPS disorders in Great Britain and, where they are children, to their immediate families. It is also distributed around the world on subscription and copies are sent to those members of the medical profession who are directly concerned with MPS, many of whom make a donation towards our costs, for which we are most grateful. If you wish to be added to the circulation list, please contact the Newsletter Editors at the above address. Subscription charges are £5 in Great Britain and £10 Sterling elsewhere.

SORRY!

You may have noticed that this newsletter didn't arrive before the Conference in September. You may also have noticed that it didn't arrive in October either!

Some, perhaps all, families began to wonder if it was something they had said or done or if the Society had simply faded away without warning. The simple fact is that the work associated with the Conference made it impossible to begin typing-in any articles until after the event and thereafter life in general has simply got in the way at every turn. Coupled with a combined typing speed marginally slower than joined up writing and here we are in November(ish!).

Our apologies are due to families for any anxiety that may have been caused, to those who had expected articles to have appeared before now and to the Society as a whole for "letting the side down".

This time our performance has been particularly bad, but over the last few months we have found it increasingly difficult to cope with the work that is involved. Of itself the production of the Newsletter is not a particularly difficult task and there is a great deal of pleasure to be had. This Newsletter is no different to the others. It is full of positive and constructive contributions touched, as ever, by that note of sadness that is part of being an MPS family. However, it has had to be fitted in between many other commitments and when the pleasure becomes a burden it is time to re-appraise priorities.

Having been active in the Society for more than 4 years and for the last two been Newsletter editors, we have decided that it is time to simply be an MPS family for a while. We have asked the Management Committee to consider the appointment of a replacement but if there is anyone "burning to have a go" please let us know soon in case you miss your chance!

Because of the delay in producing this Newsletter, the articles concerned with Christmas cards and the Society's Christmas raffle are a little nearer the events than had been anticipated. Please place your orders for Christmas cards with Pat Isaac as soon as possible and in expectation of selling all of the raffle tickets that you presently have, please don't delay asking Ron Snack for some more.

1988 NEWSLETTERS

Pending the appointment of new Newsletter Editor(s) please send all of your contributions, photographs etc. to us.

T.V. SPOT

Don't forget to watch "THE CHILDREN IN NEED APPEAL" on BBC1.

Children at the conference on THURSDAY 26th NOVEMBER about 8pm

MPS children featured on FRIDAY 27th NOVEMBER at about 9.30pm.

AU-PAIR POSITION IN GERMANY

Hello there! We're a German-American family living south of Bonn in a town along the Rhine called Sinzig. Richard is the Parliamentary Specialist at the US Embassy in Bonn. Liz is an art historian and free-lance translator. We are the parents of Hendrik and Emily, twins age 4, who were diagnosed last year as having Sanfilippo Syndrome. They attend an all-day kindergarten which they love. A third child hopefully healthy, is due next March.

We are wondering if there would be anybody already acquainted with MPS who would like to spend a year or so with us in the Rhineland. We need someone willing to help out 4-5 hours a day with babysitting, especially at peak hours, such as when getting the children ready for kindergarten in the mornings or for bed in the evenings. We would also need occasional babysitting in the evenings. Some help with light household chores is expected, though it will not constitute a large part of your tasks here.



The Volk Family

We can offer you a room of your own with television plus board. We speak mostly English at home but will enroll you in, and pay for, a German language course here in the area. Nevertheless, it would be desirable if you already possess some knowledge of German. In addition you will receive DM300 per month pocket money. You will have one day off per week plus free time on the other days. If you do stay the year with us, we will be happy to give you two weeks holiday time on your own also. We would, of course, include you on family outings and treat you as one of the family, as much as the situation will allow. Your year in Germany should also benefit you, being filled with as many varied social and cultural

experiences as possible. We know several other au-pairs in the area and will introduce you to them so that from the start you will have people your own age to do things with.

We have had two wonderful au-pairs before, from Denmark and from the USA. We feel this has been a marvellous experience for us all.

Ideal would be if you were able to start work in January or February to get you settled in before the new baby arrives.

Please write to us soon and introduce yourself if you are interested. All photo material and references will be returned.

Elizabeth Volk,
Beethoven Str.6, 5485 Sinzig, West Germany. Tel: 02642 7022

SPONSORED WALK



Pictured here is Darren Horsley with his grandfather John Burns. Darren suffers from Hunter's Syndrome. John had a son who also suffered from the same disease.

John has been raising money for MPS by doing a sponsored walk from Chepstow to Prestatyn a distance of 170 miles!

Very well done John, a fine effort.

HELEN HOUSE - 'THE TRAVELLER'S REST'

We started our current journey in 1983 in our doctor's surgery in Barnstaple, North Devon. "MPS," we were told, "Katie has MPS. Tom may have it too. Can we test him?" Life's journey with two children suffering from MPS, whilst filled with much joy, fun and happy memories, is, as we all know, tough, very tough. Tiredness, despair and isolation are all common experiences. During the uphill phases of our now four year long journey, Jill and I have used a variety of resting places to catch our breath, but by far the most valued and well-loved of them all is Helen House, the children's hospice in Oxford.

Initially we wondered if we would cope with seeing other dying children, particularly those also suffering from Sanfilippo Syndrome. What would the staff be like? Would we feel welcome? Did they provide for families not resident in the Oxford area? We were extremely anxious but need not have been, as we were immediately made to feel entirely welcome. To our great joy the house was not in the least like a hospital, more like a luxury hotel, except there were no bills to be paid at the end!

Helen House is a purpose-built house catering for up to 8 children providing vital respite care and set in beautiful grounds near the centre of Oxford. The hospice is under the direction of a remarkable lady, Mother Frances Dominica and is staffed by people from a whole variety of professional backgrounds: nursing, physiotherapy, education, social work and nursery nursing. The staff/child ratio is high and no uniforms are worn; in fact homeliness is the aim.

Helen House not only caters for children at the very end of life's journey but those like Katie and Tom who have some way to go and still have the capacity to charge around and wreck the place! It means a great deal to us that the staff will have known our children on their 'good' days and that we will have wonderful memories associated with Helen House - this Easter's barbecue, tea in the jacuzzi, Katie streaking down the corridor after her bath, Tom entranced by the Snowman video, all of us singing around the piano, both children serenading the night staff, Katie's seventh birthday party.....

The greatest asset to Helen House is its staff, who we have experienced to be exceptionally caring, both during our stays there and by keeping in touch regularly when we are back in Devon. Above all the staff have demonstrated that they love our children as individuals, showing great tenderness when they are poorly and, unlike so many professionals we have met, actually listening carefully and regarding us as the experts on our own children.

We would highlight three aspects of care at Helen House, which have been of particular value to us.

Firstly its FLEXIBILITY - in other words it meets us where we are. We can leave the children there or, as is usually the case for us, stay, doing as much or as little with them as we choose. There is no rigid routine to which to conform. (Incidentally, the children do not sleep in the same part of the building as the parents. Have you forgotten what an unbroken night's sleep feels like?)

Secondly its FAMILY ORIENTATED - Helen House caters for the needs of all our family, providing not only a place for the parents to unwind and our sick children to be loved and cared for, but also for our healthy one year old daughter Elizabeth, to be cared for. As she grows we know she will have other sensitive adults there with whom to share the many problems siblings can encounter.

Thirdly its a HOME FROM HOME - our son Tom hates going out and in fact cheers when we arrive home from the usual family outings. At Helen House however, he is relaxed and thoroughly at ease and we feel that if this can be achieved, then there is something truly remarkable about the place.

If you are feeling in need of a break we would recommend you contact Helen House on Oxford 728251 **NOW**.

Jill and Eddie Farwell.

A similar hospice for children has recently been opened in Leeds called Martin House. If any families wish to make an initial visit to either Helen House or Martin House, but would find the travelling costs prohibitive please do not hesitate to contact Christine Lavery or either hospice so that the Society may help.

FUND RAISING AT SCHOOL

Every year the pupils of St. Mary Radcliffe and Temple School, Bristol, chooses a charity to support during Lent and raises as much money as possible by various 'mad cap' schemes. This year the 6th form decided, after a talk given by my aunt, Pat Isaac, to support MPS. Once we had decided on the best ways to raise money, the work began!

Tuck shops were held (a popular choice with the lower years who left trails of sticky cake papers everywhere as evidence of their success) and raffles were organised, including one with prizes donated by local businesses.

Then more original events were held for the more sporty or insane. These included a sponsored half-marathon, a bridge championship and a teacher/pupil mixed doubles badminton tournament. The most popular event though was a 'pop quiz' where the lower years paid a small admission fee for the opportunity to watch sixth formers and teachers reveal how much they DIDN'T know about past and present pop music.

By the end of Lent, a weary, embarrassed and foot-sore sixth form emerged from under cake wrappers and raffle tickets and sticky class rooms to present Pat with a cheque for £557.53. We know it's only a small amount of the required sum necessary, but we hope our small and fun-filled attempt will help!

Louise Matthews, Bristol.

FUN(D) RAISING DAYS

This summer (?) has not been one of the best for seasonal fund raising activities. It seems however that it takes worse than the summer weather to dampen the enthusiasm of the Society's bands of helpers.



What the Doctor ordered?
Medical Advisor gives an
opinion!!!



Fine weather for ducks - and boys!

Two recent events stick in my mind, though no doubt you all have tales to tell. Dr. Garrow's garden party took a real soaking this year (third time unlucky it seemed.) With plenty of mud underfoot and cramped together under tent fly-sheets and plastic sheeting, the Tombola, White Elephant and many other stalls flourished. With the mops for the Can-can stall gaining weight as they became soaked with rain, there was the risk that odds would shorten against us and that too many footballs would float off as prizes. Dan Butler, as usual, had things under control and the worse did not happen. Spirits were certainly not dampened and whilst good weather would have helped our fund raising, the event seemed to be enjoyed by all.



Lunch in the Butler's tent - is it waterproof?



Raindrops keep falling on my head



Room for one more underneath?



Too much wine? No, it's the Human Fruit Machine!!

Perhaps the weather in this part of the country is at fault, as the rain came down again at the Amersham Horse Show. An added problem was the gusty wind. How do you keep the can-can standing long enough for the customers to try their skill if a force nine gale is blowing? Have you ever seen three stall attendants laying across plastic sheets and tombola prizes, trying desperately to prevent the whole outfit from taking off?

It was however a FUN(D) DAY and quite a few pounds were added to the funds.

Keep up the good work!

Ken Ballard (Christine's Dad)

INFORMATION

PROBLEMS WITH BED-WETTING?

Feeder Products Ltd. is a small business set up by parents who could not find suitable water-resistant material to protect their children's beds and bedding. They can supply covers made out of a material which, although water-resistant, is comfortable because air can pass through. For further details and to find out about how you may try "Dry Quilt" without obligation contact:-

Feeder Products Ltd., PO Box 481, Blackmore, Ingatestone, Essex CM4 0NA. Tel: (0277) 821224

READING MADE EASY

The National Library for the Handicapped Child provides a service for all those who work with, or care for, handicapped children. It is a library of picture books, fiction and information books for children with reading disabilities. Enquiries may be made by phone, post or personal visit. Information from:-

Blyton Handi-Read Centre,
National Library for the Handicapped Child,
Lynton House, Tavistock Square, LONDON WC1H 9LT. Tel: 01-387-7016

Calibre (Cassette Library for the Blind and Handicapped) is a lending library for disabled and handicapped children and adults. Its purpose is to provide a free, easily available library for anyone who is unable to read printed books. Books are recorded onto ordinary cassette tapes by volunteers and are sent through the post to the borrower. The service is free to individuals but schools etc. are asked to pay a small charge. Information from:-

Calibre, Aylesbury, Bucks. HP20 1HU. Tel: 0296 32339 / 81211

Talking Books for the Handicapped also provides a service of books on tape for people with disabilities other than visual. For an annual membership of £15 a talking book machine (which takes special long-playing tapes) is sent to you and you can select titles from a suitable list. Details of membership from:-

Talking Books for the Handicapped, National Listening Library,
12 Lant Street, London SE1 1QH. Tel: 01-407-9417

THE HEIGHT OF FASHION

Young people are often acutely conscious of what they wear and shopping for someone with special needs in the clothing line can be very fraught! The following organisations and retailers all provide a special service and are relatively inexpensive.

Fashion Services for the Disabled provide a range of services to parents, disabled people and professionals. Contact:-

Fashion Services for the Disabled,
Units B270-B320, Saltaire Workshops, Ashley Lane,
Shipley, West Yorks. BD1 7SR. Tel: 0274 597487

Soma Footwear produce 'made-to-measure shoes for problem feet' and say they can make every shoe to fit individual foot problems, providing the combination of comfort and good looks. Contact:-

Soma Footwear, John Drew (London) Ltd., 433 Uxbridge Road,
Ealing, London W5 3NT. Tel: 01 992 0381

Adimed have a wide range of track shoes which can be adapted for special feet and ankles. Information from:-

Adimed (The Adidas Orthopaedic Range), Jane Manning Ltd.,
1070/72 London Road, Thornton Heath, Surrey. Tel: 01 684 2364

The Disabled Living Foundation has a Clothing Advisory Service which can give advice on all aspects of clothing. Information is constantly up-dated and the clothing advisor is happy to receive any enquiries by letter or phone. She says "no enquiry is too trivial or ridiculous"!! You can make an appointment to visit the D.L.F. or arrange for one of their speakers to give a talk to groups. Local aids/equipment centres with information about clothing are also available in Newcastle, Leicester, Birmingham, Edinburgh and Caerphilly, so ask their advice. Contact:-

The Disabled Living Foundation,
380-384 Harrow Road, London W9 2HU. Tel: 01 289 6111

BENEFITS - CLAIM WHAT'S YOURS

We have heard recently about several cases of Supplementary Benefit claims that have been awarded to youngsters with Down's Syndrome who are still at school.

Welfare Rights Officers advise us that the D.H.S.S. can accept claims from a person's 16th birthday even if the young person is still at school, if they suffer from a level of physical or mental handicap that makes it unlikely that they would get a job if they were to leave school.

Instead of getting less than £8 per week Child Benefit, a family can receive more than £18 per week Supplementary Benefit. This could be higher if there is an entitlement to help with the costs of heating, laundry, special diet, clothing etc., or if they are also entitled, to Severe Disablement Allowance.

Also, some 16-19 year olds, in or out of school, do claim Severe Disablement Allowance but do not claim a Supplementary Benefit top-up. Many do not realise that, whilst SDA is a flat rate, Sup. Ben. can be increased for individual circumstances. It also rises automatically on one's 18th birthday and after a person has been on benefit for more than a year.

This means that very few handicapped or disabled 18 year olds, whether at school or not, should be receiving less than £30 per week in benefits unless they have more than £3,000 in savings. Finally, the DHSS has the power to backdate benefit claims to the date the person could first have been entitled (often their 16th birthday). The onus is on the person to ask for the backdating.

If you have any further queries, please contact your local Welfare Rights Office or Citizens Advice Bureau.

Claire and Colin Arrowsmith



Adele Hetherington.



Richard Turner.



LAKE DISTRICT HOLIDAY
AUGUST 1987

Preparing for the barbecue (under cover!)



Butter wouldn't melt in their mouths!

SMALL ACHIEVEMENTS?

We were beginning to dread September '86 when Sarah would start Secondary School. We had looked at small private girls schools in the area hoping to protect Sarah from the big outside world, but Sarah was adamant that she was going to go to the same school her big sister was at; Roundwood Secondary with 900 pupils.

Obviously, we had had talks with the school earlier in the year and their feelings were much the same as Sarah's, and the Principal felt that the school as a community would be richer for having Sarah.

The first day Sarah went off I asked Kate, our eldest daughter, to ring me and let me know how everything was going. I came home and waited. Kate rang me in great spirits. All was going well. In fact a large crowd of boys gathered in the playground had aroused much interest and when the 6th Formers went to see what all the fuss was about, they found Sarah in the middle, completely hidden, answering all their questions.

"Why are you so small Sarah?" asked one lad.

"I was born this way." Next question!

The biggest disappointment for Sarah was that she was in an average stream class and she felt she should have been in the ABOVE average class! We convinced her she would be better coming top of her class, than struggling for a place in the fast stream.

Naturally there were big adjustments to make and homework was but one of them. She was very tired after school for her first two terms, but she never used that as an excuse to dodge homework - it was always completed.

Now Sarah has finished her first year at Secondary school and thinking back over this last year she has achieved so much. She came top in English, Second in Maths and Music and Third in French. She has been put into the higher stream class for French and Maths this year and due to her good results in French she will also be doing German.

At the end of last term she represented her form with 3 others, in the inter-form quizz, something she was dreading! They won!

All the children who received three or more Commendations for outstanding work throughout the year received their certificates. Sarah went up for hers, she had achieved eleven!

The PTA presented a WH Smith voucher for £25 to the seller of the most raffle tickets. The winner last year sold £50 worth. Sarah sold £113 worth and goes to WH Smith every Saturday on her bike to see what else she can get.

At the school fete she won £5 for 'hoola hooping' the longest - 25 minutes and one of her proudest moments was when she received her Grade 1 piano results - 138 out of 150. Distinction.

Yes, it's been quite a year. Naturally there have been times of tears and heartbreak but for once they have been outweighed by one little girl's determination to be accepted as 'normal'.

We are very grateful for the help and kindness all staff and pupils have shown to Sarah. Certainly without this we know that Sarah's first year would not have been the shining star it has been. We are most thankful for all her classes being on the ground floor; her locker being her height; the 'stand' for her to take part in Science and another one being made to allow her to take part in Metalwork. A much caring school.

Thank you,
Sue Lowry.

Sue wrote this article about her daughter Sarah who is 12 years old and suffers from Maroteaux-Lamy Syndrome. She was worried that it sounded like a typical mother praising her child's achievements and that it would sound boring. I can assure you Sue that it is not and that you should justifiably feel very proud of Sarah for all she has achieved in the last year. We have great pleasure in printing your story and granting you "your golden hour". - Editor.

Sarah cycled the length and breadth of Paris on her new bike, which we purchased in Belgium. Her other bike, which we bought in Holland two years ago, is like new and has the advantage of foot brakes which you cannot get in England. As Sarah's hands are too restricted for handlebar brakes, we find the continental bikes give Sarah her independence.

If you have a child in Sarah's position that could use this type of bike, we would be happy to sell her other bike for £40 (which is half-price) and donate the money to MPS. If your family is in difficult circumstances then we would be happy to give you the bike.

If you are interested please contact:
Sue Lowry,
"Kirkeaton",
16 Maple Rd.,
Harpden,
Herts. AL5 2DU



Sarah about to cycle up the Eiffel Tower!

MPS CHRISTMAS CARDS 1987

I am sure you will be pleased to know that we have another new design for this year's exclusive MPS Christmas cards. The picture shows a black cat on the window sill looking out at Father Christmas. The cards are available now and we have included a sample, which has the order form on the reverse, in this newsletter. The design has been named WINDOW SCENE. We still have a lot of packs from last year available - (do you remember the Snowmen and the Monk & Robins?) - so you have 3 designs to choose from. For those of you who have joined the MPS Society since last Christmas, we have included samples of last years two designs as well. All the cards are in packs of 5 with envelopes for 70p per pack. Please show the designs to your friends and relatives.

CAN YOU TRY VERY HARD TO GET AS MANY ORDERS FOR CARDS AS POSSIBLE
- we want to sell out this year!

The cards all contain the one simple message "HAPPY CHRISTMAS" and the words "Designed by Sally Bell on behalf of the Society for Mucopolysaccharide diseases". On the back is the MPS logo and address, so we also spread awareness of MPS by sending the cards.

You could have a coffee morning for friends to buy cards. Selling MPS Christmas cards provides you with an opportunity to solicit funds for MPS in a less direct way than simply asking for the money. Charities can certainly not compete in price with cards from large retail chain stores but your "customers" should appreciate that charity cards command a premium and they are paying for that privilege.

You can get your Christmas cards from me - address on order form. It's really better to get orders first and send money with orders, but, if preferred, you can have them on a sale-or-return basis. PLEASE RETURN THE MONEY TO ME AS I HAVE ALL THE RECORDS OF SALES. A donation towards postage will be gratefully received, although this is not necessary.

REMEMBER: THE SUCCESS OF OUR XMAS CARD VENTURE DEPENDS ON EVERYONE SELLING AS MANY CARDS AS POSSIBLE. PLEASE START TAKING ORDERS NOW!

This years card was designed by Sally Bell of Letchworth. Sally is a Bristolian but has lived in Hertfordshire for the last 12 years. She graduated from Reading University with an honours degree in Education with Art as her main subject. Sally then taught in a Hertfordshire middle school and quickly became involved in the art department and began teaching children with special needs. In 1977 she then trained for, and moved into, special education and has been teaching "special" children ever since. She has found her art training a great help and a necessary therapy (for herself as well as the children!) She now lives in Letchworth and is married with two children.

Over the last 18 years Sally has worked mainly in water colours or with acrylics on canvas and her work has ranged from holiday landscapes to totally abstract pieces. She has dabbled in all sorts of art and craft work and has tried to produce her own handmade Christmas cards every year - an enjoyable chore! This year however she has her first card in print!

Pat Isaac

FUND RAISING EVENTS

Wendy McGinn collected sponsors for the London Marathon.
Carol Maddison ran and collected sponsors in the Great North Run.
Gaye Finch kept them slimming for another term's staff weigh-in and also had a Tupperware party.
G. Plews had a sponsored welly boot throw.
Sally Hughes & Alison Glassford held a strawberry supper.
St. Mary Redcliffe & Temple School, Bristol raised money in Lent.
Westburn Nursery, Glasgow held a garden fete.
Anne Hill held sales for childrens clothes, tupperware & car boot.
Employees of J. Sainsbury plc (S.W.area) held a sponsored family walk and fete and barbecue.
Downend (Bristol) Women's Federation have adopted MPS as their charity for two years & held a coffee morning & stalls to start.
Sedgemoor Manor Infants school held a fruit raffle.
Wembdon Group, Bridgwater held a disco.
Cannington United Reform Church had a bazaar.
St. Nicholas Church, Cheltenham had a fun day.
Nationwide Anglia had a book sale.
Hermann's poultry workers, Lincolnshire, had a sponsored slim.
Publicity of Christopher Isaac's story on behalf of all MPS children, attracted many donations both locally and nationally.
John Smith organised runners for the Kingswood marathon, Bristol and other related events.
Llantwit Major Ladies Circle held a variety of events.
Beta Sigma group, Glasgow, raised money through various events.
Mary Hill, Fiddington, held a cheese and wine party.

THE FIT 'N FAMOUS MPS COOKBOOK

Don't forget that we have our own cookery book available. It makes an ideal Christmas present, it's full of healthy recipes donated by many famous people; just the thing after a Christmas 'blowout'!

Priced very reasonably at £2.95 (plus 45p. p&p), why not buy one for all your friends and relatives (especially those who can't cook).

They are available from: Mrs. Pat Isaac
Beckdell,
Church Road,
Fiddington,
Nr. Bridgwater,
Somerset TA5 1JG

Please send payment with your order
(cheques payable to "The Society for MPS diseases")



1987 MPS CONFERENCE

I hope everyone who was there would agree that the 1987 Conference at the Post House Hotel, Heathrow, was a huge success. The team effort was considerable with all the MPS Committee members taking a day off work on the Friday to unload cars and vans, put up display boards, move cots and a lot more besides.

It was lovely to see all the old faces and to welcome nine families who hadn't been to an MPS conference before. The atmosphere was warm and friendly and we are most grateful for the support of our medical friends and colleagues.



Emma, Kristina and Angela.



Glenn, Julian and Patrick take the opportunity to talk.

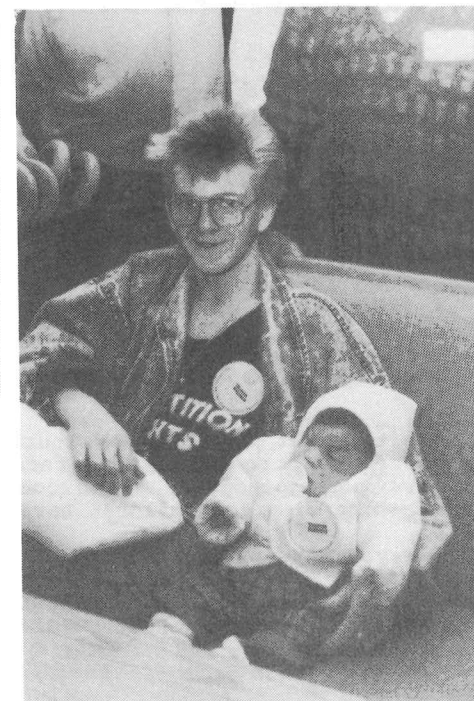
For me the conference was almost like a holiday! Thanks to the help of Bryn and Ann Neal, who didn't just arrange volunteers and babysitters, no mean task in itself, but also saw the children safely on to the coaches on Saturday and Sunday morning.

Not to mention that this year we had the added excitement/complication of sharing our day at Thorpe Park with a team of camera men and producers from the "BBC Children in Need Appeal". As many of you know, the Society has benefited considerably each year from a donation towards the children's activities at the Conference and it is only right we should show the public how their money is spent.

James Gooch stops long enough to have his photograph taken.

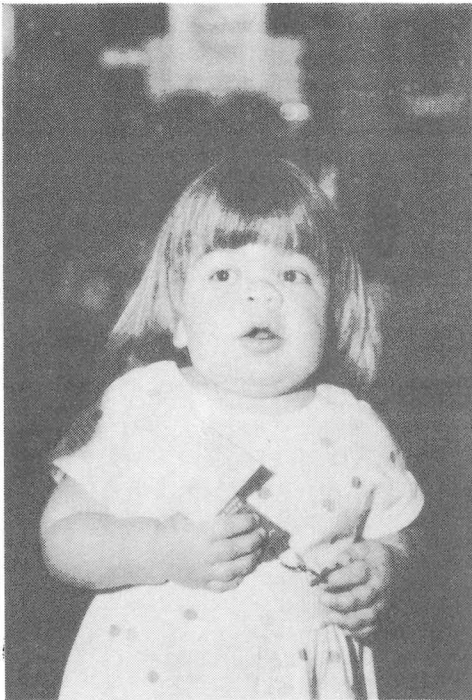


Timothy Murphy & brother Thomas





Daniel Kaye.



Jemma Corbett.

Don't forget to watch on Thursday 26th November around 8.00pm - there are sure to be some faces you recognise and for those who have not joined us at a conference, a chance to see what a smashing time the children have.

See you next year!

MPS FAMILY CONFERENCE 23-25th SEPTEMBER 1988.
POST HOUSE HOTEL, HEATHROW.

Christine Lavery.

CHRISTMAS PARTY

Saturday 5th December 1987 - 1.00-5.00pm

St. Werburgh's Parish Hall, Brook Street, Chester

All families should by now have received their invitation to the MPS Christmas party. If you wish to attend please let Mary Gardiner or Micheline Johnson know as a matter of urgency, so that they can plan their catering arrangements accordingly.

The charge is £2 per adult - all children are free! Don't forget to make cheques payable to 'The Society for MPS Diseases'.

The party will be opened by the Mayor of Chester at 1.00pm and followed by a buffet lunch, childrens entertainment and a visit from Father Christmas. The Grand Raffle will also be drawn during the proceedings - you might be the one to take home the winning prizes! Everyone is welcome, why not bring Grannie and Grandpa too! We hope to see lots of you there.

Further details from:

Mary Gardiner
35 Church Road, Banks, Southport,
Merseyside. Tel:0704 213438

or

Micheline Johnson,
The Mount, Truemans Way, Hawarden,
Deeside, Clwyd. Tel:0244 533641

CHRISTMAS RAFFLE

We are once again very grateful to Ron and Linda Snack for organising our Grand Raffle. They have secured many excellent prizes again this year and we need your help to sell as many tickets as possible. Most families will have received tickets to sell in the post but there are lots more available, so if you run out or if you are a subscriber and feel you could sell some tickets for us, please contact Ron direct at 16 Wandsworth Place, Bradwell Common, Milton Keynes, Bucks. Tel: 0908 666819

The main prizes are as follows: 1st: Video Recorder
2nd: Leisure Weekend for 2 at THF
3rd: Braun Food Processor
4th: Electric Hammer Drill

The raffle will be drawn at the Christmas Party on December 5th so please return your tickets in good time. One plea from the heart from Ron and Linda - would people bringing raffle tickets to the Christmas party PLEASE bring them back folded ready to go into the draw - Ron and Linda would like to join in the party too rather than be stuck in a corner folding tickets all afternoon!



THE COURAGE TO CHANGE: REFLECTIONS OF MILD FORM OF MPS II

Part 3 - Losing Control.

After returning home from the hospital, I immediately felt a great deal of guilt. I believed that my illness was my fault and I thought the stress of being moved to a new school might have led me to having so much trouble. Yet deep within me I felt that it wasn't my fault and that maybe it was something bigger than me. That summer I wanted to make up for my mistakes to my family. Gradually I was making improvements and got help from my mother-in-law who looked after my sons.

I prayed for improved health to go back to teaching but instead my terrible cycle kicked in again and I became very frightened for my life. I was keeping my doctors informed on a weekly basis. It was very frustrating, controlling my body and my environment. At night I was totally unable to sleep even if I took no nap during the day. I slept in a separate bedroom from my wife because I was keeping her up and I wanted her to sleep. Hyperness became so bad that I would run in my basement back and forth against the wall. I flapped my arms trying to rid this hyper feeling that was taking over. I knew what I was doing was crazy but I couldn't control this inner force that started in my head. I felt pressure in my head and then I would run. I would buckle on my knees and cry because my body craved for sleep but I couldn't sleep. Finally, late in the night, my body slept on the bed for a few hours. I wasn't getting better and my terrible cough started and whilst sleeping it seemed to get worse. No cough medicine was good enough to eliminate it.

The doctors were puzzled in trying to solve my problem and finally I was referred to the National Jewish Hospital in Denver, Colorado. It was a leading hospital that dealt with respiratory disorders.

I could no longer pray for I was too sick and so frightened for my wife. I was also scared about my job. My wife and I tried to be strong but tears just came so easily. (My wife lost her father at a young age from asthma.) Before going to Denver, my teacher's union worked with my doctor to ensure that my insurance would pay for the expense. I also made sure my job was covered whilst I would be gone. I had to use my sick days which were so precious because of my many colds and lower chest infections.

The night before leaving I cried and said a prayer while holding my youngest son, and reassured my older son that I would be back. When I left the next morning I reminded myself to have courage to face whatever lay ahead of me.

Arriving in Denver was a difficult time for me as I had a hard time carrying my luggage and walking. It was no wonder that I required oxygen, I had pneumonia again.

After a month of many tests, posterior and bronchial drainage, attending classes on how to manage my problem and talking to many adults, I was anxious to return home. The school administrators were putting pressure on me to disclose my illness, my older son was acting out his frustrations and started to act like a baby and my wife cried, wondering when I would return home. To make matters

worse I was using all my sick days and now had to go on sick leave.

I wondered why all this was happening to me when doctors wanted to try a concept called 'positive air pressure' with me. The doctor numbed my throat and made an insertion so that a tube could connect my throat to a machine which was nothing more than a compressor and this made positive air pressure in the hopes of opening my airway more. It was a delightful feeling that truly felt wonderful but nothing could be documented.

After all this I was handed two reports about mild Hunter's Syndrome and even then I didn't fit all the descriptions, but medically it all came into focus. Whilst lying in bed alone I read about a young man who died of an acute airway obstruction. Immediately I recalled going into a terrible shock in the recovery room. It was a terrifying experience as I was unable to breathe as my chest was so tight. In 1976 I had an emergency gall bladder and appendix operation. How lucky I was to live through that experience. I remember my cousin needing an emergency tracheotomy during simple surgery. He lived and returned to his full life as an administrator to a hearing impaired programme. I remembered how lucky my brother was because his heart surgery in 1980 was called off as, miraculously, his heart valves were improving on their own. Just the past year of 1986 his heart was getting bad again but with the right information and advocating with knowledgeable doctors, he survived a nine hour surgery. He now has mechanical valves and hopefully he can enjoy a better life.

As I got on the plane to return home I got the OK to work again and hopefully with my new knowledge I could better control my infections. Yet life had a different path for me and it wasn't the path that I wanted to take.

Next time: An Uncertain Future.

Bill Sellmeyer, USA

THE SPECIAL CHILD

No-one but a mother can tell the feelings inside
The moment she's told it's a handicapped child
First thing you panic, then break down and cry
Then you look at your child and start wondering why?
"Why me dear Lord" I don't know where to begin
Then fear and torment start deep down within
"How shall I cope, this cannot be true"
No-one or no words can comfort you
You lift up your baby as if in a trance
And look at your child with a second glance
So perfect and small who needs comforting too
Then your heart starts to melt as you hug it to you
At last comes the feeling you're not on your own
There's someone to guide you down the path you are going
God gives you strength from deep down inside
To love and cherish this Special Child.

A prayer in verse that we found in a little shop in Lourdes this summer, that we wanted to share, Micheline Johnson.

COFFEE SNOWBALL - UPDATE

The Coffee Snowball account stands at £3,600 at the time of going to print. It's quite a good sum but we would have expected more by now - so can you please try and ensure YOUR snowballs have been carried on down the line as far as possible.

It's very important that ALL unused packs or parts of packs are returned to us as they represent potential funds. The special Snowball Bank Account is being kept open so you can continue paying in money using the special form on the leaflet.

Pat Isaac

DEATHS

It was with very great sadness that we learned of the death of the following children:-

James Connelley of Glasgow who died on October 26th. aged just 3 years. James suffered from Hurler Syndrome.

Darryl Hughes of Wrexham who died on 22nd. August aged 17 years. Darryl suffered from Hunters Syndrome.

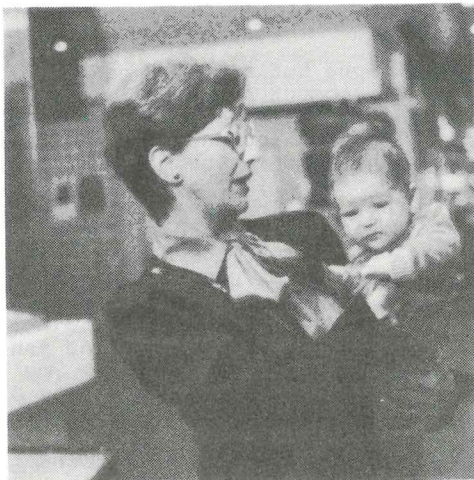
BIRTHS

Emma and Claire Hill now have a baby brother, Christopher James, who arrived on 4th. August. Congratulations to proud parents, Julia and Alex in Heysham, Lancs.

Michele and David Brooks-Daw from Taunton, Somerset are pleased to announce the safe arrival of Antoinette on 24th. September, sister to Dominique.

Congratulations to Bill & Fer Pidden in Wiltshire on the arrival of a healthy son, Anthony on 1st August. He weighed 7lb 1oz and is a brother to Natalie.

Anthony shown here with mum, Fer, making his debut at the conference at the age of 8 weeks.



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