

NEWSLETTER

WINTER 8
SPRING 1988

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES



National Registered Charity No. 287034

Chairman of the
Management Committee

MARY O'TOOLE
8 Elmhurst Avenue
London N2 OLT
Tel: 01 444 8461

Hon. Secretary

CHRISTINE LAVERY
30 Westwood Drive,
Little Chalfont,
Bucks. HP6 6RJ
Tel: 02404 2789

Hon. Treasurer

STELLA HALE
6 Laurel Way,
Ickleford,
Nr. Hitchin, Herts.
Tel: 0462 54544

Fund Raising
Co-Ordinator

PAT ISAAC
Beckdell Church Rd.,
Fiddington,
Nr. Bridgewater,
Somerset.
Tel: 0278 732800

Sales Co-Ordinator

SUE BUTLER
Spriggs Holly House,
Spriggs Holly Lane,
Chinnor Hill, Oxon.
Tel: 024 026 3185

Donations Secretary

WILMA ROBINS
77 Hillview Avenue
Hornchurch,
Essex RM11 2DN
Tel: 040 24 43157

Newsletter Editor

CHARLES O'TOOLE
8 Elmhurst Avenue,
London N2 OLT
Tel: 01 444 8461

This newsletter is published quarterly and distributed free of charge to sufferers of 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 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 Editor at the above address. Annual subscription charges are £5 in Great Britain and £10 Sterling elsewhere.

FROM THE EDITOR

This is your new Editor writing. Peter and Maggie Archard decided reluctantly that it was time for them to lay down some of the many responsibilities that they have been carrying. Yours truly blithely agreed to take over the newsletter for a period. I always fancied being an editor.

It gradually began to come home to me that there was a little more to do than sitting round with a green eyeshade flourishing a red pencil. Producing a newsletter like this means you have to be a reporter, a typist, an editor, a skilled photographer. You need to negotiate with printers. You need to cajole and persuade people to produce material, and you need to use the greatest diplomacy to tell them you have to cut or change what they send in. You need to have your ear to the ground and to be sensitive to what painful issues are facing members of the society at any given time. You need to some knowledge of the membership and of the organisation and about what is happening. And that's only the half of it.

So hats off to Peter and Maggie for the most professional job they have done over the last four years at no small cost to themselves. They will be a hard act to follow.

As for me, I am thinking of taking over the slogan from British Rail, "We are getting there !" Dont expect the quality you are used to, at least for some time.

PLEASE continue to send your letters, notices, articles, poems. I would particularly like some black and white PHOTOGRAPHS. I promise to return them safely.

I can take criticism ! Your comments and suggestions about the newsletter would be appreciated. I may try some experiments with layout, which may or may not work out, so bear with me. As always (and this is the bit I like) the Editors word is final.

Charles O'Toole

CHRISTMAS PARTY

A wonderful Christmas Party took place on the 5th of December at St. Werbergh's Church Hall in Chester. It was organised by the North West Families, principally Mary Gardiner, Micheline Johnson, Sylvia and Bill Blackburn, Susan Hughes, Sheila Benbow and Margaret Leask. Sixty families attended, that is over two hundred people in all.

The Hall was given to us without charge for the afternoon through the kindness of Canon Turnbull, Parish Priest. No charge was made for heating. Christine Mc Cann led the Carol singing, and Father James Kenny gave a blessing to all, believers and unbelievers alike!

The Society gave £500 towards the costs and an estimated £600 was raised locally. There were very generous donations of food and presents from many of the local companies in Chester and Stockport.

The Mayor of Chester, Councillor Douglas Haynes attended with his wife Mrs Rachael Haynes and they both took a keen interest in the children and in the work of the Society. A reporter came from the Chester Chronicle so we hope some further publicity will take place.

Congratulations and thanks to the North West Families for a most lavish and friendly party.



Anthony Bayliss age 2

Linda Snack, Maggie Archard
bouquets for their hard work!



The Chronicles of Chester.

Our roving reporter attended the Christmas Party and when not stuffing himself with delicious chicken he managed to extract a few words from a small sample of the party goers.

Alex Butler (13)

"I stayed off school all week. I had a cold and I wanted to make sure it would be better for the party."

Bryn Isaac (8)

"Theres no point talking to Christopher in this noise. He can't hear you! Our school was filmed for TV on Wednesday. Peter Hayes was there. He is a reporter on HTV. Chris is very shy. He won't watch the video of himself on TV. He's been in two newspapers as well.

"Whats it like to be the brother of a celebrity?"
Bryn---"Most people don't know me, it doesn't feel very different."

Paul Evans (11)

"It took us seven hours to come by car. My sister and I ate and sang Christmas Carols in the car. It's a good party. I like the food. I like the meat best. The music is rubbish.

They didn't have any tapes I like, such as Five Star or Madonna. I like meeting Charlotte Johnson at the party. The Punch and Judy show wasn't all that good".

Lorraine Rock (13)

"Two years ago I had a major operation. I had a shunt put in and it went wrong. It was a bit scary. I am in first year senior at Ashfield School. It is a school for disabled children. It is very nice and I like it. I like artwork and I like walking round the school. We play running games. Quite a few can run. I have some good friends there. Now that I am a teenager I am getting used to having Morquio's syndrome. My brother Christopher is getting well. He is taking some steps now. He has got a Bec Trouper electric tricycle which he rides outside. The Ben Hardwick fund helped to get it."

Angela Paton (12)

"I go to Parklands High School in Leeds. Philip Schofield came to Leeds to turn on the Christmas lights but I missed him. He looks nice. I think he's brilliant! Can we have him to the conference next year?
We always come to the party. "Why?" To have a good time. After all, its been three months since the conference!"

Chronicles of Chester (cont'd)

Andrew and Vivienne Culley, Southampton.
"Robert is eight and has Hunter's disease. He has been keeping well over the past while. He sleeps through the night and doesn't have so many colds. We came up overnight and stayed with Pam Soutar at Shrewsbury. It is a very well organised party. We didn't go to the conference this year. We prefer a more informal meeting where we can relax more. This is no criticism of the conference."

Pam Soutar, Shrewsbury.
"My husband Malcolm is working today and couldn't come. Our daughter Fiona is twenty and is working and has got her own car. Our daughter Christine died five years ago, aged 13. It's a very well organised Christmas party. We come to events because we enjoy meeting the friends we have made over the years. It is nice to keep in contact. It is sometimes painful especially when we see San Filippo children like Christine."

Vivienne Culley
"I agree with Pam. That's how we all feel. It is painful, but we get hope and encouragement from the other families. We see the children as they grow older. They are more handicapped but they are still happy and the families are still surviving. The Society is a support group for parents, that is its prime function. If you are really down you can look through the newsletter and find someone who will listen to you. We don't see our MPS friends very often but we know they are there."

John and Julie Burlison, Oldham.
"Billy is aged three. He has Hunter's disease. He has only just been diagnosed. The doctors have been marvellous to us. They gave us the Society's number. We came to the party to see what the Society is all about. We wanted to find out more. We love Billy and finding he is handicapped will not change that. He is still our son."

Derek and Kathleen Hampson, from Orrell near Wigan.
"Andrew is aged 13. He has San Filippo disease. We also have a daughter Teresa, aged 16. This is our first time to the Christmas party."

They were talking to Sheila and Ken Benbow from Greasby in the Wirral, who are the parents of Peter.
"Peter will be 23 on Friday. He is also San Filippo. He has always stayed at home with us and he goes to Special Care in Hessle every day. He can't walk on his own now. However he keeps remarkably well. Our other son Martin is aged 20."

Chronicles of Chester (cont'd)

Peter and Helen Rock
"Our children go by taxi to school. The service is very reliable but each of the drivers smokes very heavily. We have been on to Leicestershire about it and they have issued a voluntary code of practice about smoking. It's too early yet to see what effect this will have."

(Does anyone else have this problem? What have they been able to get done about it? Replies via Newsletter please.)

Wilma and Peter Robins
"We are the parents of Gethin who is on the poster. We decided to carry on after Gethin died. It seemed the best thing to do. It benefits us and we think we can carry a feeling of hope to other families. We feel we can be helpful in talking to families of a newly diagnosed child. We want to stay with the society. We see people in the same circumstances as ourselves being supported and made happy. Being a bereaved parent is not a special role in the Society. We have a lot of friends here as we have been in it from the start."



Anthony Hampson and Peter Benbow



John Hodgetts watching
Punch and Judy



Christopher Rock
On his feet again



CHRISTMAS PARTY * PASS THE PARCEL

SUPPORT FOR RESEARCH

"Care Today--Hope Tomorrow"

The management committee holds the view that it is important to spend some of the Society's funds helping basic research projects, even if tangible results will not be forthcoming in the immediate future. We must obviously help children and families who have needs at present and a large proportion of the funds goes towards this. There must also be hope for future generations and the search for a cure or for better methods of alleviating problems caused by the diseases must be supported. To quote one of the Society's car stickers, "Care Today Hope Tomorrow".

Dr. Irwin Olsen from the Kennedy Institute of Rheumatology in Hammersmith, London, has for many years been interested in the MPS diseases and the Society has helped in the past by purchasing a fluorimeter which is still in regular use at the Institute. Dr. Olsen and his colleagues have been studying how the enzymes which chop up the mucopolysaccharides so that they can be excreted from the body are transferred to the cells.

A number of attempts have been made in the past to treat MPS diseases by replacing the missing enzyme, using a variety of techniques most of which failed. Bone marrow transplantation, although a very risky procedure with a high rate of mortality, has been shown to produce clinical improvement in some areas. The future may bring the possibility of removing a patient's own bone marrow, inserting a normal gene, and replacing the marrow, thereby removing some of the risks of transplants using donated marrow.

Although bone marrow transplants achieve improvements in some areas, other major problems are not helped. Very little is known about the way in which enzyme replacement actually occurs in the human body. More understanding of this process is essential in the search for better treatment.

The Society has agreed to Dr. Olsen's request for two year's funding for a Ph.D student, Mr George Bou-Gharios. Mr Bou-Gharios is using the electron microscope at Charing Cross Hospital Medical School to study the role of lymphocytes (a group of white blood cells) in the transfer of enzymes. The enzyme used will be beta-glucuronidase which is deficient in MPS VII or Sly disease. Although this disease is very rare, its enzyme has been chosen because it gives much clearer experimental results. The project will assess the effects of drugs on the process of enzyme transfer as it is thought possible that drug treatment may eventually need to be used in conjunction with gene therapy to achieve a better clinical result.

RESEARCH (cont'd)

Mr Bou-Gharios had begun his work while supported by another grant and the first paper on his results will soon be published. Two other papers have been prepared and Mr Bou-Gharios will be speaking about his research at two international conferences next year. I am very pleased to report that he has been chosen as the "Young histochemist of the year" by the Royal Microscopical Society. The MPS Society can feel proud to be supporting such a talented researcher.

Sheffield Health Authority

The Ryegate Children's Centre
The Children's Hospital
Tapton Crescent Road
Sheffield S10 5DD

Tel: Sheffield 666201/5 (5 lines)(STD 0742)



Our ref	Your ref	Date
15 October 1987		

Mrs C Lavery
Society for Mucopolysaccharide Diseases
30 Westwood Drive
Little Chalfont
Buckinghamshire

Dear Mrs Lavery

I should be grateful if I could solicit the advice and comments of your members, or an opportunity to use the columns of your newsletter. I am looking at the possibility of cataloguing and presenting a new publication with information on 'unorthodox' or 'alternative' therapies that are employed from time to time in the management of children with developmental disabilities or chronic neurological disorders. Any ultimate publication would seek neither to support nor condone such practices, but to inform. I hope readers will be helped to make their own judgements.

I will be grateful, therefore, for any information that your members might be able to provide on such therapies (however defined), preferably with the names and addresses of relevant practitioners. I should add that my interest is in therapies that have their origins in developed countries or have significant support in such countries. I undertake to maintain confidentiality in respect of my sources of information.

Yours sincerely

Gwilym Hosking
Consultant in Paediatric Neurology

196 Ferndale Rd
Swindon
Wilts SN2 1HB

Hi Everyone,

On Oct. 29th I made a trip to London with my mum to see Dr Rosemary Stephens to discuss Toni with her.

Pete and I had to make a decision to either have Toni home all the time or to let her stay at Tadworth Court in Surrey. It was a very hard time to decide, but we both knew that Toni would be better and well looked after at Tadworth.

You see, when Toni was at home she would eat for a few days then discover her surroundings were different and she would refuse to eat. We put up with her food fads for quite a while until we realized that Toni was losing weight. As you can imagine it was quite a shock, it made it look as if we didn't care.

Anyway on October 29th I spoke to Dr Stephens and she agreed with me it was the best solution especially for Toni. I told her that I remembered saying I would never let Toni go away, but after looking after her for eleven years I found that the rest of the family were feeling left out, as everything seemed to revolve around Toni. Toni was put first, feeding, cleaning, clothing. It is an awful thing to admit, but I now have to care for my other three girls and my husband.

I know Toni will get all the love, care, attention and affection at Tadworth that she would get at home. Not only that, if she is not well she can get medical attention straight away, whereas you have to wait a couple of hours or more for your GP to come out. I just wish there were more places like Tadworth available on the NHS to care for children such as ours.

I am going down to visit on December 3rd laden with Christmas presents. So I hope you will all have a very happy Christmas and the New Year brings hope and love.

Best wishes,

Sue Bramford.

SAIL ON, SAIL ON

Sail on, Sail on thou fearless bark
Wherever blows the welcome wind,
It cannot lead to scenes more dark,
More sad, than those we leave behind.

Thomas Moore

Part III - Bill Sellmeyer's own story.

(Bill lives in California and suffers from mild Hunter's Disease. In the last newsletter Bill told us that he was in hospital in 1984, and nearly died. He continues his story...)

On my arrival home, I nearly cried for the first time at the airport. I felt so happy to be home again but was so scared of the life ahead of me. Sharing the reports with my parents and wife was a painful experience for them. I wanted to inform my cousins of future medical problems to be on the outlook for. I talked to their parents about Hunter's Syndrome. It was very painful to me to watch their reaction. They decided not to inform my cousins who are affected. The parents decided to keep the information a secret. I was very hurt because I believed that I had suffered to get this information to them. Today I have had to look at the world through their eyes and step back and try to understand. I love my parents and aunts and uncles and hold no bad feelings for them.

A few days later I went back to work as a teacher. Immediately a new nightmare was unfolding in front of my eyes. On my arrival at the new school I felt frustrated because I didn't even have a teacher's desk. I used the tables that the students used. I met with my supervisor to let him know that I had no class list or desk and that I wanted to work. I was placed on two different jobs, mornings I was at the High School and in the afternoon I worked in the Junior High.

The day was Friday September 28th 1984. I was called down to the administration building. As I drove I wondered why I was called. As I walked into the office, I felt like a schoolboy waiting to see the principal. My name was finally called. The administrator said "Because you have respiratory problems and no sick days left, we are forcing you on disability." I tried to explain to him that I could teach, but in anger he told me, "We will pressure you into retirement". I felt totally helpless and abandoned by everyone.

Teaching hearing impaired children had been my triumph; many had said it could never be done. At first I was put on probation in college because my grades were not good enough and in the beginning I failed. I remember vowing to God to give me the strength to endure and I worked harder at school and my grades improved. I had so much empathy with the deaf and hard of hearing from my own life experiences. When we were children my cousin Tim and my brother Bob attended special education classes for the hearing impaired. Both of them never really started to talk till after the age of five.

Bill Sellmeyer's Story (cont'd)

My brother Bob had so many problems, such as being afraid of others. He had a big stomach and thin arms. He had constant ear problems and his tubes often fell out. When his tubes fell out he was very cranky, but his behaviour improved when his tubes were put back in his ears.

I remember taking him to the speech and language clinic. After class I had to get my brother and he was often in tears. As I walked him home he would clutch at my hands so tightly, not to take him back to that awful place. School was always a terrible fight for my brother. I can remember my mother crying at the table about what the future held for my brother. I told her I would do my best to ensure a decent future for him. Fifteen years later I was the one who needed help. It was a shock to everyone.

Later I remember my own battles to get into a deaf education program in my state. The services were not much but were enough for me to become a good student. For the first time I believed in myself and my life had direction. My graduation day was a significant time in my life for I was the first hearing impaired person to earn a degree in education of the deaf, in my state.

Two major accomplishments that I am most proud of are in my work of trying to desegregate handicapped children into regular classes. The other was to change the self esteem of hearing impaired children who were told their self worth was less because they signed and talked.

Yet while driving back to my school to clean out my things these dreams were far from me. It was my darkest hour and at night I had to face my wife and tell her the news.

I was not angry but decided to fight. I went to my union at the school. After months of fighting it was evident that I would be denied. The emotional cycle I went through was very human. First I was frustrated. Then I was angry. But who could I be angry at? My anger turned to self anger. It was my fault for all this happening.

I had too much time on my hands and would analyse and compare myself with others in the family with Hunters. Why did this happen to me, and why now? I had a three year old and a new born in my family. The weight of responsibility became almost unbearable. Stress took its toll of my body as my arthritis flared up. I hated my life but something inside kept nagging at my heart. An inner voice kept reminding me of reports from the United Kingdom. Was there an organization for those with MPS?

Bill Sellmeyer's Story (cont'd)

My search began. The breakthrough occurred on a November night. I wrote a letter to one of the authors of the report about the UK. Fate was good to me. Dr. Vernon McKusick was in Dr. Harper's office that day. When he returned from England he telephoned me at home. We talked for a short while and I felt so happy. The United States had an organisation for MPS diseases! I wrote to the the president in December and on January 5th 1985 I made my first contact and talked for two hours.

A month later I was in hospital again with airways problems, but now I knew I wasn't alone!

Bill Sellmeyer

(NEXT TIME : A NEW PATH)

DEATHS

It is with great sadness that we report the deaths of the following members of the Society. Our thoughts are with their families and friends at this sad time.

Bobby Devereaux, Glade Cottage Symondsborough, Nr Hemyock, Clumpton, Devon, died peacefully at home. Bobby was eighteen and a half. He suffered from Hunter's disease.

James Baird, 16 Thom Tree St., Kings Cross, West Halifax, Yorkshire died in hospital on the 20th of November. James suffered from Hurler's disease and was six and a half years old.

Adele Hetherington, I Cammock Ave., Upperby, Carlisle, Cumbria, died peacefully at home on the 5th of December. Adele suffered from Hurler's disease and was nine and a half years old.

Birthday boy loses his halo



Sitting pretty: Bone boy Chris Isaac without his cage

Story: Nigel Owen
Pictures: Fran Stothard
PAT and Dave Isaac are planning a special "coming out" party for their son Chris on his seventh birthday today, after doctors removed his metal "halo".

He has lived inside a cage for four months since an operation to beat the bone disease that has stopped him growing.

Bone was grafted from his legs to his neck to support his head.

Chris, of Church Road, Fiddington, near Bridgwater, could have died from even a simple playground fall.

An X-ray last week signalled the surgery a success, giving the all-clear for the cage to come off.

It meant Chris can now wear a collar that lets him sit up and crawl.

"It is really great," said his delighted mother. "This is just what we were hoping for — his



How he spent four months best birthday present."

His father said: "He's back to looking like the Christopher we knew. He was even able to sit up at the breakfast table with us.

"He is making good progress and he is very determined.

Chris has already had an early present — a football which a family friend got signed by the Liverpool team.

USING PUBLICITY

Christopher Isaac alias "The little halo boy" or "boy in a cage" has kept on producing smiles for the cameras over the past few months to bring in the funds for MPS (to date over £2000). Some reports get the facts right, others invent them (especially figures). I expect several of you have tales to tell about dealing with "the media".

Pat Isaac is preparing an article about publicity and using the media for the next newsletter.

She would be very interested in receiving copies of any "cuttings" about your child which have appeared in the press. Please let her know your publicity stories.

As always Pat would like you to write to her the day before yesterday, if not sooner!

A BIRTHDAY TO REMEMBER

TV presenter Alison Holloway paid Christopher Isaac a surprise birthday visit and brought him a lot of goodies from the TV studio.



Thank You Sainsbury's

This appeared in the "JS JOURNAL", the house magazine for employees of Sainsbury's. Hope the print is not too small! Can you make out Pat Isaac on the bottom photograph? Its close contact with a large cheque that gives her that glowing youthful look!

WHEN DAVID WEBB's district in the South Western area decide to help a charity, they go all the way. Their spectacular summer event raised £3,500 for the society for Mucopolysaccharidosis (MPS) diseases.

The charity was chosen after the district learned that Roger Britton, meat manager at Bath, has two children suffering from a life-threatening mucopolysaccharidosis disease known as Sanfillipo.

Roger was delighted when the district decided to support the charity. As he said, the publicity would help to highlight this comparatively unknown disease and any money raised would help research into the cause and help support MPS families.

The district also came to hear of Geoff Butt, district security officer, whose niece suffers from the same disease.

The family fun day began at Worle store when 500 people, led by David Webb, set off to walk behind a JS lorry, decorated and provided by Yate depot. Five miles later the parade arrived at Weston-super-Mare and festivities commenced on the beach.

Store managers and David Webb took to the saddle for the Donkey Derby which proved a great entertainment to the crowd.

The walkers then covered another five miles returning to Worle where numbers were swelled and the activities con-

82



tinued with: tug of war, throwing the welly competitions, side shows and amusements.

Evening brought the highlight of the event with the release of 1,000 sponsored balloons, one of which travelled 350 miles to France.

The day was rounded off by a barbecue in the car park and entertainment from a live band.

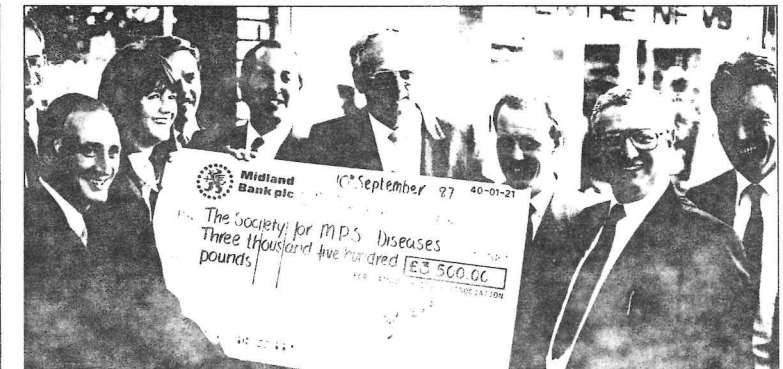
On September 11 Pat Isaacs of the Society for MPS diseases accepted the cheque for £3,500 at Worle branch.

* THE SOCIETY for MPS Diseases was set up five years ago by a mother whose seven year old son had died from an MPS disease. She wanted to give support to similar families and approached JS. It was with money from the Sainsbury's Memorial Trust that the charity was set up and its first year's administration costs were covered.

Follow the leader! 500 trekked for ten miles for the cause.



David Webb mounts up.



David Webb (second from right) and his managers make the cheque presentation.

THE CONFERENCE ON THE BBC

CHILDREN IN NEED APPEAL

The BBC asked to do some filming round the annual conference in September. They wanted material to show as a preview to the Children in Need Appeal. The Appeal has several times helped towards the cost of the children's programme at the conference so the Society was very pleased to work with them.

A film crew went with the outing to Thorpe Park, under the supervision of Sue Butler. There were some excellent shots of the children enjoying themselves on the rides. At teatime Alexander Butler had his fourteenth birthday party, and the cameramen homed in on this. Alexander was the star of the show. There were some lovely shots of him blowing out the candles.

The programme also featured short interviews with several parents talking about their children and about the work of the Society. Christine and Robin Lavery told how they started the Society because of their own experience of needing to contact other parents. Sarah and Michael Corbett said they encouraged Gemma to be as active as possible. Gemma's spirit and courage came across clearly on the film. Sue and Dan Butler spoke of their feelings when they were given Alexander's diagnosis and of their desire to support other families. Denise Oldaker also spoke. A very clear message was conveyed about the work of the Society, and the spirit and atmosphere of the conference.

I'm sure the pleasurable and happy moments shown on the film helped the Appeal in its fundraising. No doubt many families had the added pleasure of seeing the outing on TV.

We thought that we had very good value from the BBC for one year and didn't expect to hear from them again. However that was not the last of it, as Mary O'Toole recounts on the next page....

If you were unable to video the program for yourself and would like a copy either of the unedited film taken by the BBC team of the outing and the children's party or of the Society's own video please contact Christine Lavery.

CHILDREN IN NEED APPEAL

Several weeks before the the programme was due to be shown the Director of the "Children of Courage" section telephoned me. She had almost finished her programme but was short of a child of courage! She said she had searched through the archives and had come across a Woman's Own article about Helen, and she thought Helen might be suitable for the programme. I tried to persuade her that Helen had had more than her fair share of publicity and that there were other MPS children every bit as brave, if not more so, but she said it was Helen or nothing. I said I would agree if they would put the name of the society prominently before the viewers, and so the deal was clinched.

We were pleased when Lorraine Dymond was also included, although I'm not sure her mother Ann was too chuffed to have the BBC taking over her house for the whole day. Ann and I spent our time in the kitchen attempting to keep little Alison quiet while our daughters were interviewed. We had no idea what they said until we saw the show.

On the night of the show all the family were down at the studio from 8.00pm. It was interesting to meet the other children and their families. Helen made friends with Michael, the boy with the severe spinal injury. He was soon chasing round the corridors on Helen's Pony. Needless to say the blind boy from Glasgow with the head injury had to have a go on the Pony. We were all very impressed with Gavin Campbell.

He really took a warm personal interest in all the children, and they responded to him.

Esther Rantzen did very well with the MPS sign, even if she did hold it upside down and put her arm in front of it! She spent a lot of time both before and after the show with the children.

We thought Helen and Lorraine did very well. We hadn't realized that Helen spent most of her time visiting other children and cheering them up. We thought she was going off to school every day. Strange!

After the live interview Kate and Helen were let loose to chase after autographs. Several famous faces were tracked down and held to ransom with a fountain pen. We watched Renee and company rehearsing their dance in a dressing room and Helga popped her head out the door and said "Allo, Allo". (No, Angela, we didn't see Philip Schofield!) What's the going rate for an autograph of Annika Rice?

All publicity is good publicity they say. The filming was hard work for the Dymond family and for Helen and I but we hope some good comes of it for the Society. Helen has already had a letter from a eight year old girl in Dublin who has Morquio disease and whose family are now joining the Society.

Mary O'Toole

NEWS FROM THE SOUTH (SOUTH) EAST

It was as well that we hadn't arranged anything special for the weekend of the 16th of October (the night of the Hurricane), otherwise it would have had to be postponed. As it was, by the end of October the roads were reasonably clear, electricity and telephones restored, and although Jill and George Evans' caravan was too badly shattered to put back together again, none of us was injured. However Robin and Mary Gooch had temporarily emigrated for more civilized parts!

The coffee morning came like this: the local Operatic and Dramatic Society had hired Tenterden Town Hall for three days to stage a play, and Jean and Leslie were offered it on the Saturday morning at no charge provided we reinstated the chairs as they were beforehand.

So the cake and jam makers got busy again, the gifts and raffle prizes were gathered together and the publicity materials distributed. We were very pleased to welcome Tenterden's new Mayor, Councillor Everett, who expertly sold off the last of the cakes. However he invited the immediate past Mayor, Councillor Bates, who had inaugurated the fund raising in Tenterden, to read Pat Isaacs' letter of appreciation to the people of Kent and East Sussex for all their efforts for MPS which had culminated in the presentation at the conference.

So a year on, with the help of our many friends and with once again Paul and Cheryl presiding over the raffle, a pleasant and relaxed morning resulted in the name of MPS not slipping from memory and nearly £500 being added to the coffers.

George and Jill chose a Disco as their main fund raising event. Their preparations made, it was with relief that they welcomed about one hundred and eighty young people from George's firm (Rimmells) and from Jill's (Tesco). Many other friends came besides. The management of both firms had made generous donations to start things off, and there was a happy and relaxed atmosphere.

There was an unexpected prize in the raffle, a tee shirt donated by June Brown (Dot Cotton from East Enders). This went in a Dutch auction for a total of £31.00! Other prizes included a trip to France.

Paul and Cheryl didn't miss any of the fun. They stayed dancing till the end.

The evening produced a total of close on £700.00. This was extremely satisfying for the organisers. Most important of all it was such a happy and enjoyable occasion that everyone wants another one next year.

In spite of all that excitement Jill continues to make her toy hedgehogs which are sold locally. A somewhat corpulent granny in the area has shed twenty five pounds in the cause. She has the added satisfaction of being able to see her feet again!

As to the future, we are hoping that many of us will be able to get together at the family day Alf and Judy King are organising at the end of February. Jean Cole has another money raising event up her sleeve for March.

So for now we are battening down the hatches in readiness for the winter weather. A Happy Christmas to you all.

Pam Mc Intyre

THOUGHTS OF DARREN

While resting in bed recovering from having my teeth out the Lord said "Get a pen and paper and I want you to write down these thoughts of Darren."

I would now like to share Darren's thoughts with you all.

ABBA FATHER

Your beauty I behold
for my life is what I see
To some I'm not perfect
Just a broken doll.
Not to you Lord, for you see me from
within and you love me as I am.
What joy! For I can come no
other way; but just as I am.
I hear very little in this world
but you I can hear so clear.
Thank you Lord for the happiness
You give me in this world.
But such happiness will be mine
when I come to you.
Then I know I'll sing, dance, and play
all that I cannot do now.
For on that day, perfect I'll be
in your perfect world.
When I come to You.

June Evans

THE ABORTION BILL

Most of you will by now be aware of David Alton's Private Member's Bill which is due to have its second reading in the House of Commons on January the 22nd. The Bill proposes the following amendments to the present Abortion Act which will, if carried, have a profound effect on many of our MPS families.

- 1 A woman's pregnancy may be terminated at any time up to the beginning of the 18th week of gestation (i.e. 17 weeks and 6 days from the date of the last period)
- 2 Thereafter up to the end of the 28th week of gestation a pregnancy may be terminated ;
 - (a) In order to save the life of the woman, OR
 - (b) If the child is likely to be born dead or with physical abnormalities so serious that it's life cannot be independently sustained.

The present abortion act allows pregnancies to be terminated up to the end of the 28th week. Almost all MPS families who have opted for termination have had to have it carried out much later than eighteen weeks. Chorionic villus sampling which can be done earlier is still in the experimental stage and confirmation of the result by amniocentesis is required. This would not be possible if the Bill became law as results cannot be obtained before eighteen weeks.

The Society does not take a view on the rights and wrongs of termination and some of our members would not wish to consider such a course. Their views are respected and the Society will continue to support and press for better facilities for all MPS children now and in the future. The management committee felt however that the choice must be available for families who cannot contemplate the birth of another severely handicapped child. The option must also be open in the future for the daughters and other female relatives of Hunter families.

The Society has therefore sent a letter and a statement to all MPs. Families in the South East who can more easily travel to London have been invited to join a lobby at the House of Commons on January the nineteenth. Area families have been phoned everyone in their area to explain the urgency of taking some action.

By the time you receive this newsletter the second reading will have taken place. It is not too late however, to write to your MP if you have not already done. The Society will continue to put forward its case while the Bill is in its committee stage. If you support the Society's view that there must be a choice for our families, please write to your MP and explain how the bill would affect you or your friends. If you have a severely affected child, explain just what life is like for your family.

If you feel you could contact your local press please do so. We must do everything we can to make sure our case is understood. If you have not seen a copy of the Society's statement and would like to have one, please contact Christine Lavery.

Letters to your MP should be addressed in the following way:

MP's Name and Constituency
House of Commons
London SW1A 0AA

Dafydd Wigley, MP and member of the MPS Society who recently lost two Sanfilippo sons, has written a statement for the press which is included on the next page.

VIDEOS

If you would like a copy of the video made at the conference or at this year's Christmas party or of film taken of your child in the past please write to Christine and Robin Lavery who will, when time permits, make a copy for you. There is a charge of five pounds to cover the cost of the tape and postage.

The Society has its own video camera which may be borrowed free of charge to record special events. Please write to Christine Lavery or phone her on 02404 2789.

NEW FAMILIES

Julie Bayliss and her mother Diane Bayliss from Liverpool. Julie's two year old son Anthony has Morquio's disease.

Mr and Mrs Dowling from Dublin. Their eight year old daughter Christine has Morquio's disease.

Mr and Mrs Rollinson from Scunthorpe. Their daughter Gemma is six months old and has Hurler's disease.

Mr and Mrs Shah from Seaham, Co. Durham. Their three year old son Suqlain, has Morquio's disease.

datganiad i'r wasg : press release

oddi wrth
Aelod Seneddol
Arfon

Dafydd Wigley M.P.

Plaid Cymru, Caernarfon.

Embargo: FOR IMMEDIATE RELEASE

ABORTION BILL INSENSITIVE TO DISABLED FAMILIES AND WOMEN

The Abortion Bill, which was published yesterday, was slammed by a leading campaigner on disability issues, Dafydd Wigley MP, as "totally ignorant of the heartbreaking decisions which face families suffering disability and ignorant of the trauma which abortion means for so many women."

Mr Wigley said that the token gesture towards disability incorporated in the bill would be irrelevant to 95% of families facing the possibility of a severely disabled child, possibly in addition to one or more disabled children already in the household.

"The bill as drafted deliberately obstructs the possibility of a meaningful amniocentesis for the vast majority of expectant mothers who are petrified by the prospects of coping with additional disability in their household", he said.

"And if this bill is insensitive to the position of such disabled families, it is deliberately callous towards the position of women in general who face the prospects of an abortion. Those who have delayed until four or five months are usually the most difficult of cases and often the ones who require the maximum support from society and not a strident straitjacket approach of compulsory state morality."

Mr Wigley was involved in the long-running campaign against Enoch Powell's bill two years ago and is a member of an all-party group seeking to ensure that regressive legislation does not worsen the plight of families forced to live with disability.

gyda chyfarfarchion:

Dyddiad/Date : 17/12/87

Swyddfa Plaid Cymru, House of Commons, London S.W.1. (01 - 219 - 5021)

Swyddfa Plaid Cymru, 21 Penllyn, Caernarfon. (0286 - 2076)

Swyddfa Plaid Cymru, 8 Heol y Frenhines, Caerdydd. (0222 - 31944)

ENDS

TADWORTH COURT CHILDREN'S HOSPITAL

Tadworth Court provides treatment for chronically sick, handicapped, and terminally ill children. Previously the country branch of the Hospital for Sick Children, Great Ormond Street, the hospital is now independently managed by the Tadworth Court Trust which is a registered charity.

The medical and nursing facilities are of a high standard with a large proportion of the nursing staff being Registered Sick Children Nurses and Paediatric trained State Enrolled Nurses. There are resident doctors on call twenty four hours a day and regular visits from Consultant Paediatricians.

The hospital has excellent facilities with a well equipped physiotherapy department, hydrotherapy pool, and a very friendly and homely atmosphere.

They provide short term care, both for children with degenerative conditions requiring treatment and those whose families just need a break from the demanding twenty four hour care of their handicapped child. Children can be admitted for a few days or a few weeks depending on the circumstances, and beds are always available for an emergency.

There is also a Holiday Unit which runs from May to September. There is an residential school for profoundly multi-handicapped children with severe learning difficulties.

The hospital is committed to providing family support in a relaxed informal atmosphere. Families are encouraged to visit with their child before the first admission and can stay to settle children in. In special circumstances there are facilities for families to stay as long as necessary. Visiting is encouraged.

The Hospital is at Tadworth in Surrey, a few minutes from the M25. It is within easy reach of London. It has a 300 year old mansion and is surrounded by beautiful woods and heathland.

WHO CAN USE THEIR SERVICES?

Any family whose child has special needs which could be met by the hospital can apply. The cost of care is normally the responsibility of the local Health Authority or Social Services or Education Department. You can apply via your Paediatrician or via the local welfare services.

TADWORTH AND MPS

Several MPS families have used Tadworth and have been very satisfied with the care and support offered. Sue Bramford writes movingly in this newsletter of the decision to let her daughter Toni stay at the hospital. Families in the south of England will receive an information leaflet about Tadworth with this newsletter.

FUNDRAISING

The hospital depends on voluntary funds to continue to develop its services. They would be delighted to hear from anyone who could assist with fundraising!

Further information can be obtained from
The Nursing Manager
(or the Liaison Sister)
Tadworth Court Trust

CHRISTMAS DRAW 1987

Thanks to the tremendous work put into it by Ron and Linda Snack, the Christmas draw was again a great success. Ron writes as follows.

Ron and Linda Snack
16 Wandsworth Place
Bradwell Common
Milton Keynes MK13 8BT

Dear friends,

I would like to thank you all for selling so many raffle tickets again this year, although the more you sold the more Linda's fingers ached through folding them.

As those of you who were at the Xmas party will know, the winning tickets were drawn by the Mayor of Chester, ably assisted by the Lady Mayoress, and also by several children. We really must try to obtain a tombola drum big enough for 40,000 plus tickets, but a cardboard box is so much cheaper.

It looks as though we will make over £3,500 this year, although at the moment I cannot give the exact figures as we have not been billed for the Video Recorder yet. Perhaps they will forget!

Thanks to all the companies and individuals who donated prizes, to Peter Robins who helped me so much on the day, to all the people who took prizes to deliver (this saves a lot on postage) but most of all to all of you who sold the tickets.

Linda would like to thank everyone for the presentation of the flowers, and she is sorry she was so embarrassed.

The last thing I would like to say is, does anyone have any ideas on what to have as first prize for the 1988 raffle? Thank you all for supporting the Christmas draw.

M.P.S. RAFFLE 1987, PRIZEWINNERS

1. Video Recorder.	21567	Hopkinson, London
2. Luxury Weekend for Two	22105	Blackburn, Cheshire
3. Braun Food Processor	5428	Downer, Basildon
4. Electric Hammer Drill	16933	Eddie, Scunthorpe
5. Woollen Jumper	20467	Crispin, Warminster, Wilts.
6. Cross Channel Trip	47708	Matthews, Haddenham, Bucks
7. Tapestry	23907	George, Milton Keynes
8. Kenwood Blender	57056	Webb, Romford, Essex.
9. 24 Cans Beer	32099	Leeds, Saffron Walden
10. Suit Carrier	36376	Snall, West Sussex
11. Flight Bag	30230	Hall, Leamington Spa
12. Rainbowbright Doll	28836	Cooper, Ashford, Kent
13. Laundry Basket	45968	Barnes, Radnage, Bucks
14. Bottle of Whisky	4910	McKee, London
15. Bottle of Rum	54479	Tim, Kettering, Northants
16. Bucket of Bricks	5183	Tilbury, High Wycombe
17. Garden Planter	54463	Colleen, Kettering
18. Bottle of Wine	7704	Cass, Ropley, Hants
19. Bottle of Wine	35280	Johnson, Orpington, Kent
20. Bottle of Wine	50523	Evans, Senghenydd, S.Wales
21. Edwardian Song Book	38067	Dobson, Sutton Coldfield
22. The Wind in the Willows	51377	Crocker, Yatton, Avon
23. Pack of Childrens Books	12657	Thomas, Abercynon, Wales
24. Pack of Crayons	59287	Alam, London
25. World Atlas	55984	Shrimpton, Liverpool
26. Bridal Doll	37106	Craig, Glasgow
27. Pack of Crayons	45553	Denton, Maidenhead, Berks
28. £5 Voucher	38271	Shorthouse, Wolverhampton
29. £5 Voucher	41122	Jevers, York
30. Screwdriver Set	25806	Bennett, Isleworth, Middx
31. Two Childrens Books	47355	Hardy, Ely, Cambs
32. Large Teddy	29493	Addie, Manchester
33. Bath Towel	10671	George, London
34. Wibbly Wobbly Train	59279	Kadir, London
35. Parker Pen	3067	Richards, Southampton
36. Cuff Links	49185	Stroud, Letchworth, Herts
37. Lace Book Mark	51281	Coker, Bristol
38. Gents Tie	58747	Franklin, Milton Keynes
39. Stationery	53007	Wenden, Southamton
40. Press "n" Roll Truck	48462	Carnall, Portsmouth
41. Silk Scarf	51255	Hollyman, Bristol
42. Keyholder	33901	Stanley, Basingstoke.

Every year in Britain millions of pounds in welfare benefits are not claimed. Much of this money belongs to people with disabilities.

Are you missing out because you don't know what you can claim?
Or are you caring for someone who may be missing out on extra benefits?

The benefits are:-

BENEFITS FOR CHILDREN UNDER 16 WITH A MENTAL HANDICAP

- * Attendance Allowance if you are aged 2 or over
- * Mobility Allowance if you are aged 5 or over

BENEFITS FOR PEOPLE AGED 16 OR OVER WITH A MENTAL HANDICAP

- * Attendance Allowance
- * Mobility Allowance
- * Severe Disablement Allowance
- * Supplementary Benefit - extra weekly money
 - lump-sum grants

BENEFITS FOR CARERS

- * Invalid Care Allowance
- * Supplementary Benefit - extra weekly money
 - lump-sum grants

The rules are changing in April 1988. Supplementary Benefit will be replaced by Income Support and the extra weekly money paid with Supplementary Benefit will finish. If you claim now you will keep the extra money even after April 1988.

Lump-sum grants will also be harder to get and most people will only get loans which they will have to pay back. So claim what you need now while you still can.

The rules for Attendance Allowance, Mobility Allowance, Severe Disablement Allowance and Invalid Care Allowance are not changing, so far at least!

MPS FUND-RAISING ITEMS

The following items are available on a sale-or-return basis for coffee mornings, fetes etc. All items have the MPS logo and/or name.

- BOOKMARKS.....*.*.*.NEW.*.*.....60p
- KEY FOBS.....50p
- PENCILS (with rubbers on end).....15p
- PENS (retractable) white with coloured top.....20p
- PENS (retractable) mixed colours (blue ink).....25p
- BADGES.....15p
- BALLOONS (to be blown up).....20p / 25p
- CAR STICKERS with logo and name plus
one of the following slogans:-20p
 "CARE TODAY - HOPE TOMORROW"
 "MPS FOR SHORT - LIKE OUR CHILDREN'S LIVES"
 "LIKE YOUR CAR THIS DISEASE ACCELERATES - HELP US TO SLOW IT DOWN"
- COOKBOOKS.....£2.95 + 45p p+p.

All the above can be ordered from me by telephone or letter either singly or in bulk. There is no need to pay until you have sold them. Please try to give THREE WEEKS NOTICE of items you require, as I can not keep a large stock and may need to re-order. If you find you have not sold all your goods we would prefer you to send them back, rather than hang on to them, if you have not got another event planned soon after. This is because the Society's money is tied up in this stock and we need to KEEP SELLING the goods to make a profit on our sales. If several families keep small amounts of goods waiting to be sold, it soon mounts up into hundreds of pounds.

Also available for fund-raising events:-

- * Fund-raising leaflets.
- * Blank headed posters to advertise your event.
- * Charity boxes with labels.
- * Posters with photographs and slogans:-
 - 1."MPS gave him just 6 years - will you give to MPS"
 - 2."Gethin didn't grow up - please help others live"

Sue Butler (Sales Co-ordinator).

1987 RAFFLE - LIST OF CONTRIBUTORS

Methuen Childrens Books Ltd.	Plysu Plc
Trebor	Anglia Building Society
John Lewis Plc	Platignum Plc
SPC Tools	Barclays Bank Plc
Zanussi	FW Woolworth Plc
Steve Westcott	Hallmark Cards Ltd
Sylvia Blackburn	Ladybird Books Ltd
Quantas Airways	Aston Martin Lagonda Ltd
Readers Digest Association Ltd	Rowntree Mackintosh Ltd
Daf Trucks (GB) Ltd	Burgess Power Tools Ltd
Langlow Coil Ltd	Morrells Brewery
Belsize Engineering Co. Ltd	Agfa-Gavaert Ltd
ANC Coil Ltd	Trust House Forte
AGB Builder's Merchants Ltd	Norly Knitwear
Jewsons	Jean Cole
Manns Brewery	Monarch Airlines
VAG (UK) Ltd	Mattell Toys
Kellogs	Central Workmen's Club, Milton Keynes
Cordier Wines Ltd	Linda Snack



Left to Right: Les Cole, Cllr. Everett, Mayor of Tenterden, Paul Evans, Pam Mc Intyre, Jean Cole, Cheryl Evans, Cllr. Bates, former Mayor. Centre: Natasha Mc Intyre

AREA SUPPORT FAMILIES

Robin and Christine Lavery
30 Westwood Drive, Little Chalfont, Bucks. HP6 6RJ
Tel: 02404 2789

Neil and Jane Reid
19 Hillside, Sawston, Cambs. CB2 4BL
Tel: 0223 834570

Alan and Deirdre Bevan
'Tumbleweed', West Gate Lane, Lubenham,
Market Harborough, Leics.
Tel: 0858 62182

Peter and Marlene Sanderson
'Ashley Cottage', 6 Northfield Rd, Tetbury, Glos.
Tel: 0666 53628

Colin and Mary Gardiner
13 Church Rd, Banks, Southport, Merseyside.
Tel: 0704 213438

John and Barbara Arrowsmith
140 Newtown Rd, High Heaton, Newcastle on Tyne. NE7 7NH
Tel: 091 2812062

Sean and Pauline Mahon
41 Stumperlowe Crescent,
Sheffield 10
South Yorkshire
Tel: 0742 304069

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

David and Michelle Brooks-Daw
St. Mary's Lodge, Wellington Rd, Taunton,
Somerset. TA1 5AS
Tel: 0823 271661

Tony and Mary Lockyer
29 Llanberis Close, Tonteg, Pontypridd, Mid Glamorgan.
Tel: 0443 2032845

Contact for Scottish Families:-

Alan and Fiona Byrne
3 Jedburgh Ave, Rutherglen, Glasgow G73 3EN
Tel: 041 643 0034