

Newsletter

The Society for
Mucopolysaccharide
Diseases



National Registered Charity No.287034

Spring 2000



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NEWSLETTER DEADLINES

Summer	30 June 2000
Autumn	30 September 2000
Winter	31 December 2000
Spring	31 March 2001



**The Society for
Mucopolysaccharide Diseases**

46 Woodside Road, Amersham Buckinghamshire HP6 6AJ

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The MPS Society is a voluntary support group founded in 1982, which represents from throughout the UK over 1000 children and adults suffering from Mucopolysaccharide and Related Diseases, their families, carers and professionals. It is a registered charity entirely supported by voluntary donations and fundraising. It is managed by the members themselves and its aims are as follows:-

To act as a Support Network for those affected by MPS diseases

To bring about more public awareness of MPS

To promote and support research into MPS

The Society offers an information and advocacy service for affected individuals, their families and professionals. At the present time the Society supports two specialist MPS centres at the Royal Manchester Children's Hospital and at the Hospital for Sick Children, Great Ormond Street, London. It co-ordinates a network of regional events and links families through it's befriending scheme.

The Society also funds research projects at the Christie Hospital, Manchester; Royal Manchester Children's Hospital and the Institute of Child Health, London. It encourages and assists contact and co-operation between parents and professionals and maintains links with sister Societies in Europe and throughout the world.

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

"CARE TODAY, HOPE TOMORROW"

The photograph on our front cover is of

JORDANE ROBJOHN

*Aged 4 years who suffers
from Sanfilippo Disease*

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Deadline for the Summer Newsletter is 30 June 2000.

DIRECTOR'S REPORT

Three months into the Millennium life has never been busier at the MPS Society. As you will see further into the Newsletter support and advocacy to those suffering from MPS and related Diseases, their families and carers and to those who have suffered bereavement is our prime focus.

To enable the Society to respond quickly and sensitively to the ever increasing requests for advocacy support and over see the regional events organised by the Society we are pleased to welcome Will Tait and Sasha Taylor to the Development Team. Kate Crown has also joined the Society to co-ordinate the MPS conferences in Scotland, Northern Ireland and England and as editor of the MPS Newsletter.

We have received many enquiries regarding Enzyme Replacement Therapy (ERT) particularly in response to articles that appeared in Scottish newspapers. The Society's position paper on ERT for MPS Type I follows this report. We trust this will help MPS families to understand the complexities of developing a new therapy.

Bookings for the MPS conference are coming in fast and I am pleased to announce that we are able to extend the discounted price until the end of April 2000. The most exciting news is that the Trustees have invited Dr Emil Kakkis and Dr Shinji Tamatsu to participate in the MPSI and MPSIV workshops bringing individuals, families and professionals up to date on clinical trials and future therapies. Places are limited so do book now for this the Society's 18th Birthday conference.

In March the Society received the very good news that it's application to BBC Children in Need has been successful and a grant of £16,500 awarded towards the MPS Regional Events and the Sibling Workshops and children's activities at the MPS Conference. Details of the regional events are on the back cover of the Newsletter. If you are interested in attending please complete the enclosed form so that you can receive specific details on the events that interest your family.

Finally as part of the Society's ongoing evaluation of its services and their relevance to individuals suffering from MPS, their families and carers enclosed with this Newsletter are two questionnaires and a stamped addressed envelope. Please do take a few minutes to complete these. Your views are important to the Trustees.

Christine Lavery – Director

ENZYME REPLACEMENT THERAPY- FOR MPS TYPE I

Where are we now?

- Safety trial has been performed in 10 patients in the USA and their efficacy considered.
- Two centres in the UK, Great Ormond Street Hospital and the Royal Manchester Children's Hospital are participating in a survey. This is to collect clinical data and does not involve the patient receiving enzyme.
- Scheduled for the third quarter of 2000 a confirmatory phase three clinical trial in 42 patients world wide suffering from MPS type I, half of which will receive enzyme and the other half a placebo. The protocol for this trial has been developed in collaboration with the regulatory agencies and requires that patients meet certain criteria before they are enrolled.

The Support offered by the MPS Society

- For sixteen years the MPS Society has morally and financially supported research that may lead to the development of treatment for Mucopolysaccharide and related diseases.
- The MPS Society strongly welcomes recent developments that may lead to enzyme replacement therapy.
- During the clinical trial phases the Society recognises that some individuals suffering from MPS Type I will be disappointed not to be selected for the trial. The MPS Society is very clear that selection is based on meeting strict medical criteria and rests with the pharmaceutical companies involved in collaboration with regulatory agencies.
- Once the clinical trials are completed the efficacy and safety of the treatment proven, and the enzyme product licensed, the MPS Society will actively support the delivery of therapy for any individual who is clinically recommended but denied it on non medical grounds.

NEWS FROM THE MANAGEMENT COMMITTEE

Due to the considerable amount of work to address, the Management committee met in January and March.

Two representatives from Barclays Bank met with Trustees to advise on investment policies. Currently, restricted funds are held in short term Treasury Bonds, which offer a higher interest rate than a deposit account.

STAFFING

Will Tait and Sasha Taylor have been appointed Trainee Development Officer and Development Assistant respectively.

FINANCIAL MANAGEMENT

The Treasurer presented his reports and it was agreed to defer any decision on an investment policy until the April Meeting. Subject to one amendment the draft audited accounts were agreed unanimously. It was agreed that the drop of unrestricted fundraising contributions needs to be addressed. Trustees agreed that the Society will accept credit card payments for MPS conferences.

THE CHARITY COMMISSION

The Chairman recorded that the Charity Commission had written to all Trustees and confirmed that issues raised following the relocation of the Northern Office had been found to be unsubstantiated. The Chairman also reported that the Charity Commission was satisfied that proper legal advice had been taken by the Trustees in relation to the re-structuring.

POLICIES

The Trustees continue to address matters concerning Health and Safety and in specific areas expert advice is being sought. Other policies agreed include Main Terms and Conditions of service for Staff, Information systems and communications policy and disciplinary procedures.

FAMILY SUPPORT

The Director reported that 12 new families had joined the MPS Society. Seven families had suffered the loss of a child or young adult from MPS. The feedback that the regional clinics were welcomed by MPS families was very pleasing.

The booklets for Fucosidosis, Mannosidosis and Aspartylglycosaminuria are being updated and reprinted.

It was agreed to invite Dr Michael Beck from Mainz in Germany to run a satellite seminar on related diseases at the MPS Conference (Northampton, 8-10th September 2000)

REGIONAL EVENTS

A policy for organising regional events was agreed unanimously. Key aspects of the proposal were that the MPS office will inform families, send out invitations, co-ordinate responses and oversee risk assessments in collaboration with the regional events organiser. Trustees also acknowledged that requirements for social events by families appear to be changing and that further consultation should take place.

BEFRIENDING SCHEME

In accordance with the new data protection legislation, which became law on 1 March 2000, it was agreed unanimously that all regional databases held by Area Support Families must be returned to the Society's office and advice offered on adhering to other aspects of the Data Protection Act. It was agreed unanimously that one-to-one support should continue to be offered through the befriending scheme.

MPS RESEARCH

Clinical trials for MPS I should commence in the UK in summer 2000. Trustees received an update from the director on Enzyme Replacement Therapy (ERT) following meetings with Dr Kakkis, Dr Muenzer, Genzyme, Biomarin, Dr Wraith and Dr Vellodi for MPS II. MPS safety trials are to be carried out in North Carolina and scheduled to start June 2000.

It was also reported that research was currently being undertaken in the USA into the brain disorders of children suffering from Sanfilippo disease.

JEANS FOR GENES 2000 (J4G)

MPS continues to be one of the beneficiary charities of the J4G appeal. The four charities will be joined in the year 2000 by the Cystic Fibrosis Trust. It was agreed that Ellie Gunary and Bob Devine will represent MPS on the J4G Steering Committee.

FAMILY NEWS

BIRTHS

Jackie Edwards and Loz O'Keeffe became the proud parents of April Louise on 11 January 2000. We send our best wishes to Jackie, Loz and all the family.

Neil and Franka Whitewick are proud to announce the arrival of Hannah Jade on Tuesday 18 January 2000. Neil has been a volunteer for the Society for many years. Congratulations!

NEW FAMILIES

Seven new families have sought the support of the MPS Society since the last Newsletter following diagnosis of MPS on one or more of their children. This includes the Leslie family who have given written permission for their details to be published.

Terri-Ann and Jason Leslie live in the north of England. Their two year old son Blaise has recently been diagnosed with Sanfilippo disease.

SUPPORT TO FAMILIES OUT OF OFFICE HOURS

There is a telephone number for families to ring in an emergency out of the MPS Society's office hours. **ALL PREVIOUS NUMBERS ARE NO LONGER AVAILABLE.**

BETWEEN	7:00AM - 9:00AM	MONDAY - FRIDAY
	5:00PM - 10:00PM	MONDAY - FRIDAY
	7:00AM - 10:00PM	WEEKENDS/BANK HOLIDAYS

FAMILIES CAN RING **07712 653258**

to talk to a member of the Development Team.
Hannah Crown, Ellie Gunary, Christine Lavery, Angela Ratcliffe, Kate Crown
will be the members of staff answering this phone on a rota basis.

If your call is not answered immediately, please leave a message with your telephone number and your call will be answered as soon as possible.

We appreciate that the cost of calls to a mobile phone may be higher than to a land line and, therefore we will phone families back wherever possible.

FAMILY NEWS

WE WENT TO LAPLAND FOR A DAY!

Sandra Martin and her two daughters Katie (10 years), who suffers from MLII and Lisa (aged 7 years) were lucky enough to be chosen by the 'This Morning' team to visit Father Christmas in Lapland on December 22 1999. A friend of the family had persuaded them to nominate Katie and they were surprised and very pleased when they were chosen. At this point Katie decided "Don't like Lapland and not going!". There were 8000 nominations and only 300 children able to go. Apparently the whole thing was paid for by George Michael.

Thankfully Katie changed her mind about Lapland and became really excited by the time they were due to go. They stayed in a hotel at Manchester Airport the night before the trip and had a very early (4.30am) start to their exciting day. At the airport they bumped into Lauren Cawthorne, who suffers from Hurler Disease (pictured below with Katie in push-chairs at Lapland) and spent the day together.

Their day – The kids were showered with presents from when they got to the departure lounge until they arrived back in the evening. When we landed at Rovaniemi airport we transferred onto four coaches which took us to get kitted out with snowsuits, balaclavas, scarves etc. Once in Lapland we had lunch before crossing a frozen lake by a candle lit path to meet Father Christmas (Christmas Man as Katie calls him). After meeting Father Christmas and the kids had been given yet another present we crossed the other side of the lake in sledges pulled by Reindeer and visited some Husky puppies. When everyone was back on the coach Father Christmas came to say "Goodbye", he told the children they could keep their snow suits. The temperature was -28 but Katie did not complain that she was cold – which is very unusual! By this time both Katie and Lisa were looking tired.



We had a good flight back and said our goodbye's to Lauren and family. Lisa fell asleep but Katie was too busy telling Daddy (Ray) all about her day. After some sleep she was then partying until 9.30pm on Christmas Eve!

Thank you to everyone who made this trip possible. Katie and Lisa are still talking about it!

Sandra Martin – Mother of Katie, Lisa and Amie who was too young to go to Lapland

FAMILY NEWS

Millennium Child of Achievement Award

Last Autumn, I noticed an advertisement in one of the local papers with the heading 'Do you know a child of achievement?' and my attention was drawn to it because that is a fairly apt description of Joanne.

The advertisement was for nominations for the Millennium Child of Achievement Awards to be held in London in the New Year. Now in their 19th year, the Awards recognise children up to the age of 16, who have overcome illness or disability, or who by their everyday tasks help others. The awards act as an inspiration to other young people, their families and friends, of what can be achieved against seemingly insurmountable odds.

My nomination for Joanne read:

'Despite suffering serious physical disability, Joanne is a bright teenager, determined to get on with living, making light of her problems and overcoming any difficulties.'

Through her own courage and determination, she attends mainstream school, enjoys Guides, Youth Church, helping at Sunday School, playing piano and guitar, swimming and socialising!'

... which I sent off with a photograph, not really expecting to hear any more about it; had I known, at the time, that

the charity receives over 5,000 nominations each year, I would have been even less hopeful!

At the beginning of January we were surprised and delighted when Joanne received a letter congratulating her on being chosen as one of the 150 Children of Achievement for the Millennium Year; and I realised that I should have greater faith in Joanne's ability to inspire anyone who knows about her achievements!

The Awards were due to be presented at the London Hilton on Park Lane on Sunday 6th February and there were all the arrangements to make. Graham cringed as the cry went up that we didn't have a thing to wear!

We had a taste of celebrity status in the days running up to our trip to London, with press reporters and photographers covering Joanne's story – a novelty which could quickly become tiresome!



FAMILY NEWS

We flew down to London the day before as we had to be at the Hilton quite early on Sunday because Joanne had been asked to attend a press call before the events of the day began. She was interviewed by numerous reporters and posed for photographs with Gaby Roslyn and Bob Holness; this went on for such a long time we were almost late for lunch, which was served in the 'Grand Ballroom'.

The presentation of the awards by the Rt. Hon John Major, the patron of the charity, began at 2.15 and he was assisted by a whole host of celebrities including Richard Wilson (alias Victor Meldrew!), June Whitfield, Bear Grylls, Dominic Wood, Mr Motivator, Cathy Dennis, Frances White, the Rt.Hon.William Hague, Jonny Searle, Simeon Courtie and Richard McCourt.

Each of the children had a remarkable story to tell, many of which were heart-breaking, but all demonstrating a strength of character and maturity beyond their years; their stories are recounted in the Yearbook which each child received as part of their award.

Afterwards, there was an informal party when we had the chance to meet some of the celebrities, take photographs and collect autographs; Joanne nearly disowned me when I rushed off to get my photo taken with John Major!

Our weekend was further enhanced by a kind friend who, as a pilot with British Midland, was able to arrange for us to be upgraded to executive class on our flights to and from London (a real taste of 'how the other half live') plus a chauffeur-driven car to take us between Heathrow airport and the hotels in London (courtesy of

Chauffeurline Ltd); what a luxury this was as everyone who has ever struggled with a disabled child, wheelchair and luggage on the underground, will appreciate! On our homeward flight we were greeted with champagne and VIP treatment all the way – a perfect (and very welcome!) end to the day.

It was a wonderful experience, and one which we will always remember, but also tinged with sadness because, like all the families involved, we were only there because of the personal adversity endured, and being overcome, by a child for which there can be no real recompense.

Judy Evans

INSTEAD

Instead of walking with you
I will crawl with you

Instead of talking to you,
I will find ways to communicate with you

Instead of focusing on what you
cannot do,
I will reward you with love for what you
can do

Instead of isolating you,
I will create adventures for you

Instead of feeling sorry for you
I will respect you

Wesley Jordan Hilling

INDIVIDUAL FAMILY SUPPORT

The Development Team has provided direct, individual support to 190 individual families between 1st January 2000 and 31 March 2000.

The support can be broken down as follows:

Information, Advice and Advocacy given on:	Method of Support			
	Telephone	Written letters and reports	Family visits	Professional meetings
Education	23	9	1	1
Equipment and clothing	8	4	1	
Genetic counselling carrier testing	4		2	
Rehousing	4	4	3	1
Home adaptations and DFG grants	17	7	7	
Incontinence supplies	2	1	1	
Independent living	2		1	
Medical/healthcare issues	55	3	10	1
Prenatal testing	10	2		
Research and treatment	24	13	6	
Residential care				
Respite/hospice care	13	3	5	1
Palliative care plans	5	5	2	
Welfare benefits	23	16	4	
Wheelchair provision	9	6	4	
Motability	3	1	1	
Grants to individuals	10	10		

INDIVIDUAL FAMILY SUPPORT

Listening service offered	Method of Support			
	Telephone	Written letters and reports	Family visits	Professional meetings
Pre bereavement	2			
Bereavement support	10	7	4	
Mental health issues	2		1	

Other support				
Holiday insurance	1	1		
Overseas links	1	2		
Siblings	4	3	2	
Wills	1			
Make a wish	3	2		
Parental rights	2			
Employment law (carer)	2	1		
Disabled parking	1			
Childhood Wood		2		
Conference	3			
Child protection	1		1	
SS complaint procedure	1			

Between 1st January 2000 and 31st March 2000 the Development Team has:
Achieved 16 grants for individual families from other organisations
Supported 9 new families and 6 bereaved families who have lost an MPS family member within this time.

If you are an individual suffering from MPS, a family member, carer or professional who could benefit from advocacy support, even by knowing the choices open to you, let the development team at the MPS Society know.

REGIONAL SUPPORT

The Trustees of the MPS Society are pleased to announce a new and enhanced regional support network for MPS families. The new scheme, which incorporates aspects of the previous Area Support Family and befriending schemes, will offer more choice and flexibility to all MPS families.

- Families will be invited to attend events throughout the country and will not be restricted to events in their local area.
- Families will be offered the opportunity to organise a one-off event or befriending link fully supported by the Development Team. Many retired and current Area Support families have fed back that the long-term commitment has been difficult to offer, especially in light of their changing circumstances.
- Families will be offered the opportunity to meet other families at regional events which are not limited by geographical location
- The new scheme offers the opportunity to access regional activities appropriate to the needs of the whole family or adult sufferers. A children's Christmas party may not be appropriate for an adult affected by MPS or a family who do not celebrate Christmas, while a trip to Alton Towers may be just up their street. Likewise, another family may be unable to visit a zoo because their child is terrified of animals, but would love a party at a children's centre.

WHAT ARE WE OFFERING?

There are two parts to the scheme, the Befrienders' scheme and a regional events programme.

BEFRIENDERS' SCHEME

An individual befrienders' network has been operating informally for many years. This is now formalised and is being more widely publicised and encouraged. Details are given to all new families and established families are being informed through this article in the newsletter. The befrienders' network enables individual families to identify their ideal contact family to the Development team whether this be by disease, region, age of sufferer or ethnic group. A member of the Development Team will then facilitate appropriate contacts. Written permission from the family(ies) to be contacted, will be sought. Separate permission will be obtained prior to each new befriending link being made. The MPS Society has a Befrienders' Scheme information sheet explaining this scheme, which we thought it would be useful to include here.

BEFRIENDERS' SCHEME

1. Many families/individuals telephone the MPS Society asking for links with another family in similar circumstances, whether this is by the MPS disease affecting the family, geographical location, background etc.
2. The Development team, on receiving such a request, identify one or more potentially appropriate links and telephone this/these families/individuals to ask whether they would be interested in making such a contact. (At this stage only basic information is given about the family requesting the link and their anonymity maintained).
3. If the Befriending family/individual agree, the Development team send them a permission form to sign, agreeing that their names and telephone number are released to the family requesting a Befriender, and a stamped addressed envelope for return of the form to the MPS office enclosed. On this form, the surname and disease of the family requesting a Befriender are given. By only giving this information the anonymity of this family should be maintained until a formal link is made.
4. On receipt of the signed form from the Befriender a member of the Development team contacts the family requesting the Befriender giving them the telephone number and names of the family agreeing to undertake this role. The family to be Befriended are advised to dial 141 before telephoning the Befriender if they wish to maintain their privacy and not have their telephone number accessible through the Befriender dialling 1471 after the call.

From this point forward any information divulged by either party is at their discretion.

Both participants in a befriending link are advised that if any support is needed as a result of the befriending link they can speak to a member of the Development Team at the MPS Office - on 01494 434156

This scheme addresses the need to meet new legal requirements, which took effect from March 2000 when the new Data protection Act became law. The Act clearly states the need to gain specific consent to the processing of sensitive personal data. Sensitive personal data includes the subject's physical or mental health. The very fact that people are members of the MPS Society gives sensitive personal data and thus the need to gain written consent each time family details are shared with another member.

REGIONAL SUPPORT

All Area Support families, current and retired, have been contacted and consulted regarding those changes and their responsibilities under the Act and asked to return their data bases to the MPS office in order that the Society full complies with this legislation and the rights and needs of the membership upheld. All the Area Support Families have also been informed that they are no long empowered to initiate contact with MPS families.

We recognise that many people may have built up close links with their ASF over the years and may wish for this contact to continue. If this is the case for you, please contact the MPS Society and if it is agreed by both parties this contact will be encouraged through following the befriending procedure.

REGIONAL EVENTS

Working with Regional Event organisers and appropriate individual families in all parts of the UK the MPS Society will continue to develop and maintain a diary of regional events to take place throughout the year. The purpose of regional events is to enable families and individuals affected by MPS to meet socially. The administration and organisation of these events is facilitated by the MPS Society however on the day the parents and carers are responsible for ensuring the safety and wellbeing of themselves and their children.

A programme of events organised for this year is included in this newsletter. For each event a member of the Development team, Will Tait, will work alongside a volunteer regional events organiser or individual family and oversee the necessary procedures.

These procedures include risk assessments. Under Health and Safety legislation the MPS Society is under obligation to carry out risk assessments on all its events. This is in everyone's interest. Risk assessments are exactly as they sound, they are assessments of the risks involved in organising and attending an event. There is a need to limit risks so that an event is as safe as possible. No event can take place without a risk assessment having been completed satisfactorily. Under legislation only certain members of the MPS Society's staff team, who have undertaken training and have been assessed as competent, are able to carry out the risk assessments. There are some very straight forward ways risks can be minimised. It has been agreed for example that all venues must be staffed and those staff responsible for the

implementation of the Health and Safety procedures throughout the event unless otherwise agreed by Trustees. Events must also be held at a venue with full disabled access and which are culturally acceptable to the majority of the membership.

The MPS Society will subsidise each regional event, up to four per region per year by a maximum of 50% of the actual costs. This subsidy will be available to MPS sufferers, their parents, siblings and partners. Extended family and friends are welcome to attend and will be charged the full costs of the day.

In order to make this scheme work we need your help! We need volunteers. We need people interested in organising an event.

The first step is to contact the Development Team at the MPS Office. Ideas, dates and venues can then be discussed along with the procedures to be followed.

We need people to contact us if they wish to make a befriending link or are interested in being a Befriender. Again, please contact the Development team for more information!

And the best news of all is that the BBC 'Children in Need Appeal' is funding these events.

URGENT

COMING SOON

**LEGOLAND
MPS REGIONAL EVENT
14TH MAY 2000**

Please register your interest on the enclosed booking form!



REGIONAL EVENTS

EASTER EGG HUNT TROWBRIDGE

It was hailing as I made my way across Salisbury Plain and down to the South West MPS Annual Easter Gathering in Trowbridge on Sunday 26 March. However, I did arrive to a warm welcome and a lovely spread of food.

Fortunately the sun broke through for the actual Egg Hunt and the children were able to enjoy the afternoon outside.

I learnt a lot over the course of the day as families shared their stories with me and had a great time playing with all the kids.

An Easter raffle brought the day to an amusing close and Fer Pidden and Gordon Hill sat down with me to fix the dates for forthcoming events (see Regional Events page).

Thank you to Jackie Chisling for her organisation and thank you to Woolworths of Trowbridge for donating the Easter Eggs.

*Will Tait
Trainee Development Officer*



Members of the Chisling family at the Easter Egg Hunt

Ann Hill with Julie and Josephine Kembrey

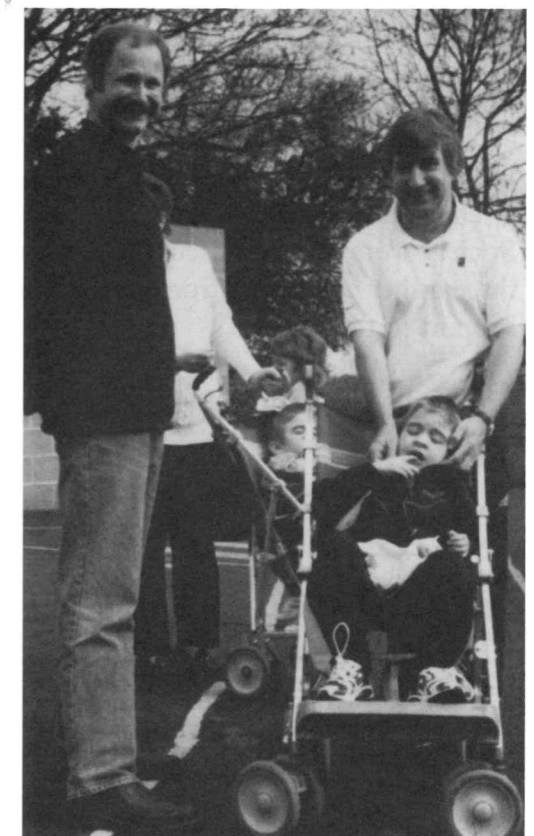


REGIONAL EVENTS

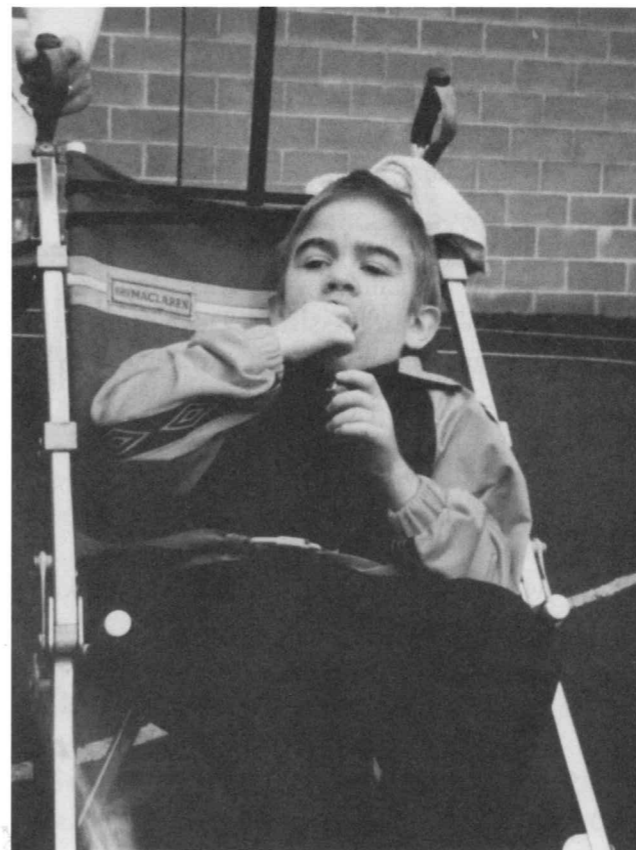
EASTER EGG HUNT TROWBRIDGE



Annette Puddy enjoying tea at the Easter Egg Hunt

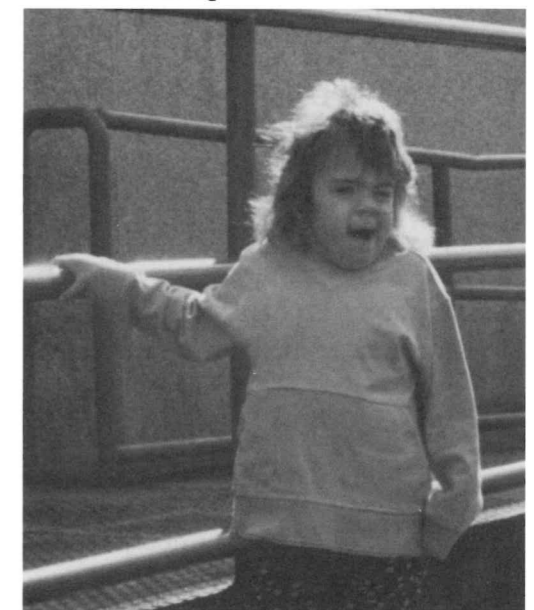


Gordon Hill with Jason and Jamie George and dad David



Jason George

Hannah Chisling



REGIONAL MPS CLINICS

BRISTOL

The Bristol Clinic took place at the Frenchay hospital on Thursday 16th March 2000. The clinic was for families living in the Avon area and was facilitated by doctors from Frenchay Hospital and Dr Ed Wraith from Manchester Children's Hospital. Eight MPS families attended the clinic and were seen jointly by both Doctors. Will and Hannah from the MPS Society were there to discuss any non-medical matters with the families. Mary Lewis and three of her colleagues from the Lifetime Service were also present at the clinic to offer support to the families.

The next MPS clinic in Bristol is in October 2000.

Hannah Crown (Development Officer)

CARDIFF

The MPS Cardiff Clinic was held on Friday 17 March 2000 at Heath Park Hospital and hosted by Dr G Shortland.

Dr Ed Wraith also attended and a total of 10 MPS families were seen by the two Doctors during the course of the day.

This was my third clinic and I appreciated the opportunity it gave me to learn more about the issues faced by MPS families.

I attended with Hannah and together we worked through non-medical concerns raised by those who attended to see where we could help.

Sister Davies and her team made us feel very welcome and the play area was clearly much appreciated by the children.

Next Cardiff Clinic – October 2000

Will Tait
(Trainee Development Officer)

NEWCASTLE

On Tuesday 15 February 2000 the first MPS Newcastle Clinic took place at the Royal Victoria Infirmary.

The day was hosted by Dr Andrew Morris, Senior Lecturer in Paediatric Metabolic Medicine, at the RVI, who saw each patient with Dr Ed Wraith.

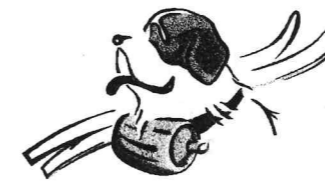
Thirteen MPS children and adults were seen at the Clinic which was attended with Will Tait (Assistant Development Officer) who had begun work with the MPS Society the previous week.

Will and I were made to feel very welcome and wish to extend our thanks to all the staff at the RVI, in particular Dr Morris and Joan Thompson, who looked after us so well.

We look forward to attending the next Newcastle clinic in a year's time.

Ellie Gunnary
(Senior Development Officer)

Kids news



CHRISTMAS CARD COMPETITION RESULTS

ISOBELLE GEE – AGED 6 YEARS

Well done Isobelle, your drawing of Father Christmas with a hole in his sack has won the competition this year and will be printed as a Christmas card to go on sale with the other MPS cards.

Your prize is on it's way! Thank you to everyone who took part.

PEN-PALS

Would any of you like to have a pen-pal?

Communicate by
letter or e-mail



They could be
from the UK
or abroad.

If you are interested please send in your name and address and some information about yourself ie. hobbies etc. to the MPS office and we will publish it in the next Newsletter.

12 YEARS AND UNDER POEM COMPETITION

Get Your Pencils Sharpened

Send in a short poem about yourself or your family – the best ones will be published in the next Newsletter. Good luck.

There will be a prize for the best 3 entries.

YOUNG PEOPLES PAGE

DID YOU KNOW?

More Info? Contact the MPS Office or your local DSS

- ♦ That young people of 16 and over with disability, in full time education, may be entitled to weekly income support.
- ♦ That you can obtain grants from 'Mobility' following assessment, for adaptations for your car.
- ♦ That if you receive high rate mobility component of DLA you can learn to drive a year early ie: at 16 rather than 17.
- ♦ That made to measure tricycles ARE available on the NHS, as are buggies, wheelchairs and lightweight wheelchairs.

Travelbility this is the first policy designed for disabled people, their families and carers. It is available exclusively through J & M Insurance Services (UK) plc, benefits of the policy include:-

- * No loading for medical conditions
- * Replacement of essential equipment, wheelchairs etc.
- * Group/Carer discounts
- * No medical certificate required
- * Replacement of medicines/drugs

Contact J & M Insurance Services (UK) plc, 14-16 Guildford Street, London WC1N 1DX Tel: 0171 446 7600.

Orange Badge Scheme – the government is to review the orange badge scheme following widespread criticism. The review will follow up complaints including non-recognition of the badges, over issuing and lack of powers available to the police to enforce the scheme. Opinions of disabled people will be sought as part of the consultation process and a public document will be produced. If you have any comments on the orange badge scheme send them to Disability Now, Scope, 6 market Road, London N7 9PW.

Blue Badges – will be phased in from April bringing us in to line with the rest of Europe!

YOUNG PEOPLES PAGE

AFTER 16-WHAT NOW?

Transition – means change from one place/state to another.

Entering and leaving school, leaving home, changing employment, unemployment, training and education are some of the important transitions which individuals make during life. Support for the process of transition is crucial for all young people. Some young people who are disabled may need more individual arrangements put into place – so start discussions early!

There is a lot to consider but there is an excellent book out called 'After 16-What Now?' from:

The Family Fund Trust
PO Box 50
York YO1 9ZK Tel: 01904 621115

This book is free to young disabled people, their parents or carers – send a large self addressed A4 envelope (not Stamped!)

If you would like to open a discussion on issues around 'transition' please send your comments to the MPS office and we will print them in the next Newsletter.

ACTIVENTURE HOLIDAY & RESPITE SCHEME

Week long outdoor activity-type holidays for children and young people with disabilities and special needs (7-18 years). Held at a purpose built residential activity centre in the Ashdown Forest, East Sussex.

The centre is situated in 300 acres of beautiful woodland, has centrally heated accommodation, 5 bedded rooms, lounge, self-service dining room etc.

During the holidays the young guests are accompanied by a companion/helper. The helpers duties will include (depending on the needs of the guest) general daytime care, washing, toileting and help at mealtimes. All our young helpers are supervised by experienced and trained Adults and a resident registered general nurse.

Guests are encouraged to take part in a variety of activities under the direction and assistance of qualified outdoor pursuits instructors. These activities include abseiling, archery, canoeing, environment studies, an obstacle course, orienteering and many other leisure activities.

For further details please contact – Miss Di Churchill, 3 Howard Terrace, Brighton BN1 3TR Tel. 01273 229408 as soon as possible.

IN REMEMBRANCE

We wish to extend our deepest sympathies to the families and friends of:

*Michael Watkinson who suffered from Hunter
Adrian Jones who suffered from Hurler Scheie
Patrick McDonnagh who suffered from Hurler
Imran Ullah who suffered from Sanfilippo*

The following verse is an extract from a Versography of Courage by Dougie Ryan:

You never get over the loss of a loved one
but with time you do learn to cope
the despair and anguish that strangles your heart
does eventually turn into hope
The hope that life will get better
the belief that it certainly will
the realisation that what happened was no fault of yours
and the surprise that you've climbed that steep hill
Don't let the tears you cry for your loved one
become selfish tears shed just for you
tears for yourself.. are just tears of self pity
and they are not the tears that will
help you through.

Something about the author: Dougie's son Paul died from MPS in 1984 and he wrote a versography of courage in memory of him. Copies are available from the MPS Society priced £1 with an A5 stamped addressed envelope for 39p.

**TRIBUTE TO MICHAEL WATKINSON – by Eve Webster (Michael's teacher/carer)
read at his funeral in March**

"Today I have been asked to talk about Michael. He was a pupil at Ysgol-A-Graig as well as being residential in Ty Graig and I am a member of the team of people that cared for him.

All the staff have their own memories of him and I would like to share a few of them here today.

I can remember watching Michael arrive on his first day, he came marching across the hall shouting and laughing, a noisy 'Tonka' of a boy, a 'whirling dervish' of energy, a 'Dennis the menace', full of fun, life and definitely full of mischief. I can remember feeling relief that he was going into Class 1. Pauline his escort who brought him to school everyday tells me that if the driver tried to change the route then Michael would start to shout and point his finger to tell of his displeasure needless to say the driver took heed and followed the route that Michael liked.

cont/

IN REMEMBRANCE

continued/

Michael in class was very good at organising the staff and children and many a morning was spent playing hunt the hearing aids that he frequently threw and lost.

He liked to tell stories. Sitting everyone down, he would drag his chair over, choose a book and hold it up pointing to the pictures as he told his tale. Heaven help the child who didn't listen, Michael's solution to the problem was swift and direct, he would just hit them on the head with his book to gain their attention.

Michael couldn't tell the time but he knew the time table so much, that if the staff weren't quite ready to go to lunch then Michael was happy to do the job for them. Collecting aprons, opening the door and taking the children he would set off for the dining room.

Then we had break time when two nursery nurses would go into Class 1 to cover playtime, it was only for 15 minutes; Michael would be sitting quietly with his class teacher.

Probably thinking of the fun he was about to have at our expense. As she left she would tell him to be good, Michael would watch her leave then the fun began, when she returned the classroom would look like a war zone and the nursery nurses would be worn to a frazzle.

When he was in class 2 he enjoyed doing PE. Like everything else he did, he did it in his whirling dervish way. On one particular session we were learning to play hockey, in his enthusiasm and without malice he hit his class teacher on the head with his stick, his interpretation of 'bullying off'.

Michael and his family enjoyed a special trip to Euro Disney; this was made possible because of the generosity of many people, some that knew and loved him and others that knew of him but had never met him.

I also shared that holiday with the family as Michael's carer and I saw how much he enjoyed the characters and the rides.

Michael had his own team of carers and for the last six years, I was lucky to be one of them. I've shared special moments with him. Pushing him along the prom and sharing an ice cream. Trips out on the bus with his friends in Ty Graig, picnics in the park, watching Disney videos sitting quietly together, even a ride on the ferry across the Mersey. Good times, fun times.

Michael was special in his own way, his smile, infectious laughter, his hello, hello. Regardless of his illness he had a go, he embraced his short life and had fun and we were lucky to be a part of it. Michael toughed the hearts of so many people.

We are all going to miss him, but we could never forget him. He toughed our hearts and he lives in our memories".

NB: If you would like to write a tribute in memory of your MPS child or MPS loved one we would be happy to print it in the Newsletter

MEMORIAL TRIBUTE

We received this lovely poem from Lorraine Rock in memorial to her brother Chris who had Morquio and died in 1998.

The last 21 months have been hard,
Hard to adjust, horrendous at times
Because you are not there
It's difficult to accept you're up there!

You sacrificed your life so
Selflessly for me,
I'm now on the medication that you should have had,
My life suddenly changed over night,
I'm no longer tired,
I'm no longer breathless,
I'm no longer bloated,
I have more energy,
I can now stay awake for longer,
I'm eating foods, I'd never thought I could eat
I've found a new confidence in myself,
Since you died I have been given a new lease of life
Thanks to your sacrifice!

Now and again I feel guilty that you have died,
If you hadn't I wouldn't of found out that I now have heart disease,
And could have died the same way as you.
The Doctor's never tried to understand, they never tried to help
They just let us both down.

I miss you bro',
I miss your insults,
I miss your humour,
I miss your attempts to tell jokes,
I miss your sill remarks when I come home,
I miss your smile,
I miss your cheeky grin
That mischievous look when something is about to happen,
I miss the way you smile at people to get you out of sticky situations,
I miss the way that you would shadow follow me when down the town,
I miss the way you bump me in your chair to let me know that you're still there.

I have visions of your dear brother,
Driving your own personalised cloud,
Chasing the angels in the clear blue heavenly sky.

Lorraine Rock

December 1999

MPS NOTICE BOARD

MPS CONFERENCES !!!

HURRY BOOK NOW

YOU CAN STILL BOOK FOR
THE
18TH ANNUAL CONFERENCE

8TH - 10TH SEPTEMBER

REDUCED RATE EXTENDED
UNTIL

30TH APRIL 2000

NORTHERN IRELAND

CONFERENCE

SATURDAY 13 MAY 2000

TEMPLEPATRICK, BELFAST

SCOTTISH CONFERENCE

Those living South of the border
are very welcome!

SATURDAY 17 JUNE 2000

DON'T FORGET THE DATE

MEDIX TRAVELLER 2000

A family has this nebuliser which they would like to
give to another family in need of it!

Please contact the office for more information

Contact a Family Workshop

8th May in Banbury

'He's just a little kid'

On the topic of growing up and sexuality in young people with special needs.
The workshop is mainly intended for parents, although some places will be
reserved for interested professionals.

No charge for parents – £20 for professionals.
The day should be useful, friendly and fun!

Please contact Melissa Down at CaF – Tel. 0171 383 3555 or the MPS Office

MPS NOTICE BOARD

YOUR IDEAS WANTED!!



Does anyone have any information regarding educational software for a boy with Hunter disease whose intelligence is not affected?

Also information on different kinds of keyboards would be welcomed.

Any ideas to the MPS office

NIGHT TIME WALKS!!

We have had two queries from families asking whether anyone has any ideas on how to prevent children walking up and down the bed all night.

If anyone has found a way to prevent this please contact Ellie at the MPS Office.

which-doctor.co.uk

The new web-site search directory to help you find a doctor with a particular skill, service, specialist or research interest, anywhere in the UK

[Http://www.which-doctor.co.uk](http://www.which-doctor.co.uk)
e-mail info@which-doctor.co.uk

Tel. 0181 693 5732

INFO. PLEASE !!

Can anyone help a family who is having difficulty in finding someone to replace their son's Naso Gastric Tube?

They have found that their only option is the local A & E Department. The family made an 'official' complaint to the hospital's chief executive who allocated a lady to deal with the problem. She has asked the family if they could find out if MPS children in other parts of the UK have NG tubes replaced in the home, or if not what other arrangements have been made.

Any information would be greatly appreciated.

Please contact Hannah at the MPS Office.

MPS NOTICE BOARD



MPS Hits the Prime Time!!!

Look out for an episode of "ER" featuring a 14 year old female with Sanfilippo.

The episode was screened on NBC in the States on April 6.

Wendy Slattery from California has a 5 year old son with Sanfilippo and worked as an unpaid consultant to the writers for this episode. In an effort to make this opportunity count Wendy took her campaign for public awareness one step further. After the episode some American cities will be airing a segment called "Following ER" - a round table discussion on Sanfilippo and the plight of children with rare diseases.

Well done that lady! - lets hope we get some positive response from the UK.

FOLK FESTIVAL READING

CAVERSHAM CHARITY FOLK FESTIVAL

June 10

Street Collection and Live Music

June 16 - 18

Festival on Thames Promenade

**Volunteers are invited to join in the fun and raise money for
MPS Society**

For further information please contact Will at the MPS office

INFORMATION

PUBLICATIONS

Door to Door – A Guide to Transport for Disabled People. This Guide (6th edition) is designed to help people find all the information they need in connection with transport for disabled people. It should be as useful to individuals as to organisations. The Guide includes information on a wide range of transport topics, together with the organisations to contact for more details. Contact RADAR, 12 City Forum, 250 City Road, London EC1V 8AF. Price £8 (incl p&p) Tel: 020 7250 3222 Fax: 020 7250 0212 e-mail radar@radar.org.uk.

Keyboarding Skills for Children with Disabilities – Dorothy E Penso, Senior Occupational Therapist, Child Development Centre, York District Hospital. This book is aimed at anyone who is involved with children who have difficulties producing written work using pen and paper. It would be useful for therapists, educationalists and the parents and carers of children with disabilities. The book contains 100 worksheets which can be Photocopied. The worksheets provide methods of learning the keyboard using both hands, one hand or a limited number of fingers. ISBN: 1 86156 1016 Price £18.50 from Whurr Publishing Ltd, 19B Compton Terrace, London N1 2UN Tel: 0171 359 5979.

Waving not Drowning. This book is aimed at parents who are juggling work and caring for a disabled child. It gives practical advice, case studies, information on your child's rights and a list of useful organisations and publications. £11.95 (£2.99 for parents of disabled children) Phone Parents at Work on 020 7628 3565.

MORE INFO.

The Disabled Person's Tax Credit aims to encourage disabled people to return to or take up work. It replaces disability working allowance. To qualify you must work at least 16 hrs a week, have savings of less than £16,000 and receive either incapacity or disability benefit. Application packs are available from Inland Revenue enquiry centres or the Benefit Agency.

Dressing Made Easy this company produces items of ladies clothing that will "retain dignity and independence", they state that all garments are easy to open and put on, fashionable and comfortable. Full details and brochure contact Dressing Made Easy, Barton, Edge Lane, Henley in Arden, B95 5DS

Into Higher Education 2000 this new booklet aims to enable disabled people to overcome barriers to higher Education. £2 for disabled students, trainees and job seekers or £6.50 to others Tel: Skill on 020 7450 0602.

INFORMATION

This article has appeared in a previous Newsletter sometime ago but after having received a copy from Lindsey Devine we thought you would all like to read or re-read it.

WELCOME TO HOLLAND

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this:

When you're going to have a baby, it's like panning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo's David, the gondolas in Venice. You may learn some handy phrases in Italian. It's very exciting. After months of eager anticipation, the final day arrives. You pack your bags and off you go. Several hours later the plane lands. The stewardess comes in and says, "Welcome to Holland". "Holland!" you say, "What do you mean Holland?, I signed up for Italy. All my life I dreamed of going to Italy".

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guidebooks and you must learn a whole new language and you will meet a whole new group of people you would never have met. It's just a different place. It's slower paced than Italy. But after you've been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandt. But everyone you know is busy coming and going from Italy and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say "Yes, that's where I was supposed to go. That's what I had planned". And the pain of that will never, ever, ever go away because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

This was one of those links that helped us in the process of understanding and accepting what has happened to us as a family. Perhaps you will find some comfort or support in these words.

by Emily Perl Kingsley

MEDICAL NEWS

RESEARCH NEWS – Dr John Hopwood Women's & Children's Hospital
Adelaide, Australia

Many patients affected by Lysosomal Storage Disorders (LSD), including all Sanfilippo patients, have central nervous system disease, with clinical symptoms resulting from lysosomal storage of toxic substances in their brains. Treatment to prevent brain disease in patients remains a major objective of the Lysosomal Diseases research Unit in Adelaide.

To achieve this, we have been evaluating and optimising enzyme replacement therapy (ERT) in which a corrective enzyme, specific for each disorder, is introduced into the brain to remove or prevent the storage of toxic substrates. We and others have shown that ERT effectively prevents disease-causing storage and halts disease progression in various organs in a number of different LSD such as Gaucher Disease, MPS I (Hurler/Scheie Syndrome) MPS VI (Maroteaux-Lamy Syndrome) and MPS VII (Sly Syndrome).

However, there is no conclusive evidence to suggest that ERT is beneficial in treating patients affected by brain disease. This is primarily because the brain is surrounded by a protective membrane called the blood-brain barrier. This barrier prevents the entrance of corrective enzyme from the body's general circulation into the brain. To systematically study and develop effective therapies for these LSD patients, we have been researching methods that will enable this transfer of enzyme to occur. Once this barrier is breached, it is expected that ERT will provide an effective therapy for all LSD patients suffering from brain dysfunction.

Our research plan uses four animal models to develop and demonstrate the efficacy of ERT for LSD that involve the brain. The four animal models we are using for our studies include a Sanfilippo "A" mouse (in collaboration with Professor Pamela Stanley, Albert Einstein College of Medicine, New York), a Sanfilippo "D" goat (in collaboration with Professor Margaret Jones, Michigan State University), an α -mannosidosis guinea pig and a fucosidosis dog.

Our logic for using four models is based on cost and an inability of any one animal model to match the clinical disease seen in humans. Differences in the blood-brain barrier between species are known, and importantly, the guinea pig's blood-brain barrier is thought to be more similar to that of humans than that of the mouse. Our hypothesis is that therapies based on delivery of corrective enzyme from circulation into the brain through the blood-brain barrier will be optimised in a small animal model such as the mouse and guinea pig before validation in a large animal model such as the goat and the dog.

Thus far we have characterised and compared the pathology seen in the brain of all four animal models with that seen in the brain of human Sanfilippo and other LSD patients. We have prepared and characterised significant amounts of corrective enzyme for ERT studies either planned or underway in each animal model. Recently, we commenced studies to develop, evaluate and optimise procedures to achieve the effective transfer of sufficient amounts of enzyme to reduce or prevent the storage of the toxic substrates for each animal model. Once we are able to demonstrate the principal and efficacy of a method to achieve the transfer of therapeutic amounts of enzyme in the larger animal models, clinical trials in the appropriate patients will be planned.

MEDICAL NEWS

Epilepsy in patients with MPS

Erica Houston & Ed Wraith
Royal Manchester Children's Hospital

Parents of children with MPS know that in some of the disorders epilepsy can occur as one of the late complications. From the medical point of view there has always been some uncertainty of the exact risk in the individual MPS types. In addition there has been no clear guidelines on what treatment works best in individual disorders. In an attempt to answer some of these questions many of you helped by completing a questionnaire about your child and epilepsy and we would like to share the results with you.

237 questionnaires were sent out to parents who had attended the clinic in Manchester. Of these 148 (62%) were returned completed giving us information on 147 children and young adults. The questionnaire asked about the presence or absence and type of seizure and also the response to treatment.

The table summarises the results:

MPS Type	No seizures	Seizures
I	37	0
II	27	9
III	35	21
IV	16	0
VI	2	0

The results clearly showed that only patients with MPS II and III were at a significant risk of developing seizures and that even in these groups there are many patients who remain seizure-free.

In the majority of patients the seizures were simple tonic-clonic episodes of brief duration (<5 minutes):

Type of seizure	Number
Tonic-clonic generalised	15
Partial or focal seizure	4
Absence	4
Myoclonic	1
Nocturnal only	1
Gelastic (laughter)	1
Unclear/unknown	3

MEDICAL NEWS

Cont/d

When we looked at treatment we found no consistent anti-convulsant regimen. Most patients were either on sodium valproate (epilim) or carbamazepine (tegretol), either alone or together. A small number of patients were on other anti-convulsants such as vigabatrin (sabril) or clonazepam (rivotril). Side-effects to the medications were reassuringly rare and the most common one was "tiredness", reported by 4 parents. In 14/30 patients the seizures stopped completely with treatment. In the remaining 16 seizure frequency was reduced but remained a significant problem in 5 patients.

From our small study we can conclude that epilepsy is only seen commonly in MPS III (at least 40%). Children with MPS II are at a much smaller risk (25%) but other types of MPS must only be very rarely associated with a seizure disorder. In affected patients seizures are not more severe than epilepsy in general and seem to respond well to the anti-convulsants commonly used in children.

We hope that this information will reassure parents in general about seizures in their children. If any parent has questions about this study or epilepsy in general we will be happy to discuss these with you further if you make contact.

Thank you.

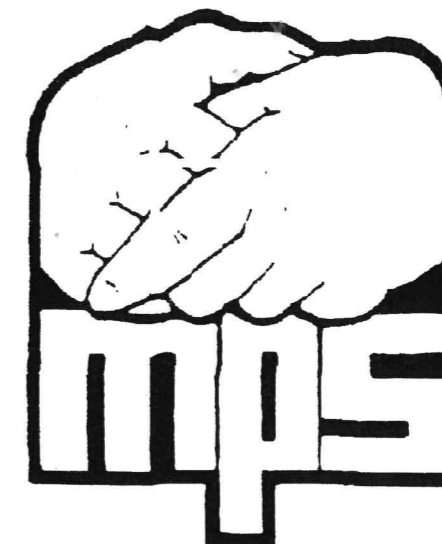
Erica Houston & Ed Wraith

NETWORK INFORMATION PAGE

WORLD

WIDE

WEB



HAVE
YOU
VISITED
THE
MPS
WEBSITE
YET?

Please hover your cursor over a link on the logo above to access an area of this site

World Wide Web Address – www.mpsociety.co.uk

The Society for Mucopolysaccharide Diseases

Tel: +44 1494 434156 Fax: +44 1494 434252

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

To act as a Support Network for those affected by MPS diseases

To bring about more public awareness of MPS
To promote and support research into MPS

The society offers an information and advocacy service for affected individuals, their families and professionals. At the present time the society supports two specialist MPS centers at the Royal Manchester Children's Hospital and at the Hospital for Sick Children, Great Ormond Street, London. It co-ordinates a regional network of Area Families who offer support to families in their own area including organising social events.

The society also funds research projects at the Christie Hospital, Manchester; Royal Manchester Children's Hospital and the Institute of Child Health, London. It encourages and assists contact and co-operation between parents and professionals and maintains links with sister societies in Europe and throughout the world.

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

"Care Today, Hope Tomorrow"

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NETWORK INFORMATION PAGE



WEBSITE FOR CARERS!

The government has launch a new website specially for carers, it was launch in February by John Hutton, Minister for Health.

The website will give new support and information to carers, linking them to other sources of advice and help.

There are 5.7 million carers in the UK and for the first time, government departments have worked together to jointly produce the National Carers' Strategy which is intended to meet the needs of those carers.

Here are some of the commitments in the strategy:-

- ◆ £140m over three years to help local authorities develop more and better services to give carers a break.
- ◆ New rights for working carers to time off for a family crisis
- ◆ New agreed standards to improve services for carers
- ◆ A range of measures to improve information for carers

The new carers website can be accessed at:-

www.carers.gov.uk

A list of the current achievements of the National Carers Strategy can be found on the site.

The public enquiry telephone line is on 0171 210 4850.

NETWORK INFORMATION PAGE



AWARE

What's new in fashion? What will make shopping for clothes a truly exclusive experience for all, opening up exciting market opportunities for clothing manufacturers and retailers?

aware! they are an organisation of disabled people who want full and direct access to fashionable clothes of their choice. They are focused on encouraging working partnerships with manufacturers, retailers, disabled people and relevant professionals to create an inclusive shopping environment. The project, using initial funding of £292. from the National Lotteries charities, is investigating state-of-the-art Computer Aided Design and Computer Aided Manufacturing (CAD/CAM) technologies to produce uniquely tailored clothes quickly and at significantly reduced costs.

More Info? Dr Chris Jelley at
aware (UK) Ltd,
 c/o Greenfield Centre,
 Green Lane,
 Baildon,
 Shipley,
 Bradford , BD17 5JS

Tel: 01274 420493 – Fax: 01274 420494
 e-mail: chris@baildon.globalnet.co.uk
 Web: www.aware.org.uk

EXHIBITIONS

NAIDEX 2000
9-11 MAY
NEC, BIRMINGHAM

Naidex is the national show for people with disabilities and their careers. Lots of stands and exhibitions of aids and equipment available – plus a KidZone and various seminars. To get on the mailing list for FREE tickets call Touchstone on 0181 332 0044 or see the Naidex website at <http://www.naidex.co.uk>

FUNDRAISING

NORTHERN IRELAND

The folk in Northern Ireland have been very busy giving money to the Drayne family for the MPS Society.

St Coleman's Primary School, where Roma attends school, raised a stupendous £3,470.00 in total, by running a sponsored 'Colour In' for the youngest children and a sponsored spell for the older ones. The nursery school that Roma's little brother Kilian attends had a sponsored 'Bounce' which raised £500. and Roma's drama group held a Christmas Variety Concert and raised £130. Thank you all very much for your generosity and hard work. Well done everyone.



Kevin Drayne
at St Coleman's
Primary School



Gilbert and friend

SCOTLAND

In November 1999 Gilbert Watterson was invited to attend a Police Academy Passing Out Parade and collect a cheque for £4,600.00. The new police officers have to do fundraising as part of their course and this particular group chose the MPS Society as their charity. They were the 2nd highest fundraisers ever and they did all of this with 40 people less than the highest fundraising group. Gilbert, Sylvia and Robyn had a wonderful day and were made extremely welcome by everyone, Gilbert gave a thank you speech to 400 people – police officers and dignitaries alike – he was very impressed with their caring attitude and sense of community. The youngest recruit was 19 years and the oldest 41 - there's hope for us all!! The young WPC in the photo with Gilbert is the recruit who raised the most money. Thank you all very much for your hard work in raising this huge amount of money and thank you Gilbert for doing a grand job when collecting the cheque. Well done!

FUNDRAISING NOTICE BOARD



LONDON MARATHON

Nigel Lindsay, who is a friend of the Garthwaite family, would like to run the London Marathon next year (2001) on behalf of the MPS Society.

Would anyone like to sponsor him?
He needs your support!!

Please contact him for more information and sponsorship forms on: **0181 563 2831**

BANK CHEQUE

We have received a cheque from the staff of a Bank who collected money for MPS instead of giving each other Christmas cards.

We thought this was a great idea and certainly one worth passing on!



WEBB IVORY

Joanne Plumber (Jaqui Edwards sister) raised £70 in commission from Webb Ivory last Christmas and very kindly donated it to MPS.

Many thanks Joanne



CAR BOOT SALE ?

DO YOU KNOW OF ANYONE WHO WOULD RAISE MONEY FOR THE MPS SOCIETY BY SELLING SECOND HAND CLOTHES AT A CAR BOOT SALE

PLEASE CONTACT THE OFFICE IF YOU HAVE ANY

DONATIONS

The Society is grateful to the following who made donations

Co-op Womens Guild, Hull
S Blanch
Murray Vernon Holdings
Tomkins plc
M J Gleeson Group plc
Christopher Makin
G Devine
Mrs A Jones
Joy Weston
Joan Cavill
City of Wells Probus Club
The Albert Hunt Trust
The Charles Hayward Foundation
Christ Church C E Primary School, Cressage
The Kathleen Laurence Trust
Bison plc - Iver
The Earmark Trust
Mrs Caine
Mrs Butler
Mrs Kilvert
Babcock International
UKBS Personnel Services
C M L Jones & Partner, Swindon
Mr Ullah
Mr M J McTiffin
British Steel
Tungscarb Ltd
Studland Mothers Union
The Oddballs Society, Belfast
Severn Trent plc
GSI Lumonics Ltd Staff Association

IN MEMORY

Edward Nowell
James Edwards
Mrs Ann Wheeldon
Frances Maud Garrett
Mrs Monique Mary Gregory

FUNDRAISING

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

Nigel Fasey - Organising a raffle
M.I.A.A. Liverpool - Collection in lieu of Christmas cards
J MacLachlan - Organising fundraiser
Joanne Plummer - Webb Ivory Catalogue
Mrs Ryan and Colleagues - Collection in lieu of Christmas cards
Pauline Headland and Colleagues - Collection in lieu of Christmas cards
Mrs Hitter - Coffee/Open House Day
Mr & Mrs Peabody - Collection of 5p's
Karen and Andrew Weedall - Webb Ivory Catalogue
Dr M A Sydney & Partners - Fundraising
Malmesbury C of E Primary School - Fundraising
Debbie McAffe & friends - Pub quiz
Monty & Doreen Russell - Hannah's dancing school 'Show Stoppers'
Jenny & Andy Hardy - Sale of Mrs Short's marmalade
Kewill PLC - Collection of small change
Mrs Wicks - Collecting & recycling Alcan cans
The Crosby Hotel - Collection at Quiz Night & Raffle
The Dolphon - Sponsored haircut by Paul Blendell
The Crosby Hotel - Bottle of Whisky raffle
Dorothy Duckett - Sale of 'Eclipse' T Shirt
Alan Byrne - Fundraising Dance
L Windsor - Sale of MPS badges

STAMPS

Mr & Mrs Ballard
Secretaries at Medical Genetics, Belfast City Hospital
Stacey Taylor

COLLECTION BOXES

Roland Avenue Post Office

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April				Book by:
Sunday 30th	Easter Eggstravaganza	Sheffield United F.C.	Midday-4.30pm	a.s.a.p.
May				
Sunday 7th	Golf Tournament	Strabane, Northern Ireland	All Day	a.s.a.p.
Sunday 7th	Family BBQ	The Hill's Home, Nr. Sidmouth, Cornwall	11.30am-4.30pm	4th May
Sunday 14th	Theme-park Excursion	*Legoland Nr. Windsor, Berkshire	11.00am-4.00pm	2nd May
June				
Sunday 4th	Family Day Out	Hartlepool Historic Quay	Time TBA	12th May
Sunday 11th	Family Day Out	Creeley Park, Exeter	11.30am-5.00pm	21st May
Sunday 25th	Family BBQ	The McKnight's Home, Laugharne, Wales	Noon onwards	4th June
July				
Sunday 9th	Theme-park Excursion	*Camelot Nr. Preston, Lancashire	11.00am-4.00pm	17th June
August				
Friday 11th	Pony and Trap Cavalcade	Port Ballintrae, Northern Ireland	All Day	a.s.a.p.
September				
MPS Society 18th Anniversary Weekend				
Saturday 16th	Fundraising Firewalk and Celebration in Amersham		6pm onwards	a.s.a.p.
Sunday 17th	Celebrity Football Match and Auction, Solihull Borough F.C., Birmingham		Midday onwards	a.s.a.p.
October				
Sunday 1st	Theme-park excursion	*Alton Towers	11.00am-4.00pm	31st August
Trips for Adults (to be arranged to suit those who are interested)				
Shopping Trip to Calais		Visit to the Millenium Dome and the Millenium Eye		
Theatre Trip to London				

Here are the events we have fixed in the MPS Society diary so far this year. You are welcome to attend any events wherever you live in the United Kingdom. Please register your interest by returning the enclosed form and we will send you further information.

*Marked events will be held subject to a minimum of 10 families booking per event by the deadline indicated

The Society for Mucopolysaccharide Diseases

46 Woodside Road, Amersham, Bucks HP6 6AJ Tel: 01494 434156 Fax 01494 434252
Registered Charity No. 287034

