Newsletter

The Society for Mucopolysaccharide and Related Diseases

National Registered Charity No. 287034

Summer Newsletter 2004

Care Today, Hope Tomorrow

What is the Society for Mucopolysaccharide Diseases?

The Society for Mucopolysaccharide Diseases (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 Lysosomal Storage Diseases, their families, carers and professionals. It is a registered charity entirely supported by voluntary donations and fundraising and is managed by the members themselves.

The Society has the following aims:

- To act as a support network for those affected by MPS & Related Diseases
- To bring about more public awareness of MPS & Related Diseases
- To promote and support research into MPS & Related Diseases

How does the Society meet these Aims?

Advocacy Support
Provides help to individuals and families with disability benefits, housing and home adaptations, special educational needs, respite care, specialist equipment and palliative care plans

Telephone Helpline
Includes out of hours listening service

MPS Befriending Network
Puts individuals suffering from MPS and their families in touch with each other

Support to Young People & Adults with MPS
Empowers individuals to gain independent living skills, healthcare support, further education, mobility and accessing their local community

Regional Clinics, Information Days & Conferences
Facilitates eleven regional MPS clinics throughout the UK and information days and conferences in Scotland and Northern Ireland

National & International Conferences
Holds annual conferences and offers individuals and families the opportunity to learn from professionals and each other

Sibling Workshops
Organises specialist activities for siblings who live with or have lived with a brother or sister suffering from an MPS or Related Disease

Information Resources
Publishes specialist disease booklets and other resources including a video

Quarterly Newsletter
Imparts information on disease management, research and members' news

Bereavement Support
Supports individual families bereaved through MPS and the opportunity to plant a tree in the Childhood Wood

Research & Treatment
Funds research that may lead to therapy and treatment for MPS and Related Diseases as well as furthering clinical management for affected children and adults

Front cover photograph:
The Rt. Hon. Gordon Brown MP with
Aiden Brown (MPS I) and Simran Bhachu (MPS IHS)

Newsletter

MPS Society
46 Woodside Road, Amersham
Bucks HP6 6AJ
T: **01494 434156**
Out of Hours: **07712 653258**
F: **01494 434252**
E: **mps@mpssociety.co.uk**
www.mpssociety.co.uk
www.fabry.org.uk

Registered Charity No. 287034

Newsletter Deadlines

Autumn	1 Sep 2004
Winter	1 Dec 2004
Spring	1 Mar 2005
Summer	1 Jun 2005

Subscriptions

Subscriptions may be taken out from the UK or Overseas by contacting the MPS Society's Office.

Summer 2004

Contents

Note from the Editor

Dear All

Welcome to the Summer 2004 MPS Newsletter!

As you will see from the front cover, this edition includes a feature on the Society's 21st Birthday Reception and Children's Party held at No. 11 Downing Street back in April. Hosted by the MPS Society, with kind permission of the Rt. Hon. Gordon Brown MP, this certainly was an affair to remember! From an organiser's point of view the afternoon went without any major hitches and I hope everyone went home with fond memories of a superb afternoon. Check out the following pages to see a selection of photos and stories from this event.

Other articles focus on international meetings and trial updates and inside each newsletter will be a form to be completed if you fancy coming to Disneyland at Christmas. Also, make a note of the date of the 2005 MPS Conference to be held at the Hilton Hotel Northampton.

Please keep your stories and photos coming in. The MPS newsletter is funded by newsletter subscriptions, advertising and grant applications to keep our costs down, so if you would like to take out a subscription, just contact Gina at g.page@mpssociety.co.uk.

Antonia Crofts
Editor

Chief Executive's Report

Nearly fifty MPS families came together at the Splash Landings Hotel at Alton Towers on 1-2 May for a weekend of fun. And fun they had, taking over the water park on Saturday and the theme park on the Sunday. There was no formal programme except the Annual General Meeting, giving everyone the opportunity to meet up with other families in a relaxed way. Such was the success of the weekend, we are looking to repeat it in 2006.

Right now we are planning the MPS conference for 1-3 July 2005 at the Northampton Hilton Hotel. Following the very successful format of the 2003 Weekend Conference we are again looking to hold three separate symposia on the Saturday, ensuring the programmes represent the diversity of our members and their families. If anyone has any particular ideas of what they would like to hear from speakers please do let Sam in the MPS office know urgently. As the date of the MPS conference is very close to when the Society would hold its Remembrance Day in the Childhood Wood we are looking to organise a programme for bereaved families that includes a visit by coach to the Childhood Wood on the Saturday. This is subject to the numbers of bereaved families booking for the Weekend Conference making this viable.

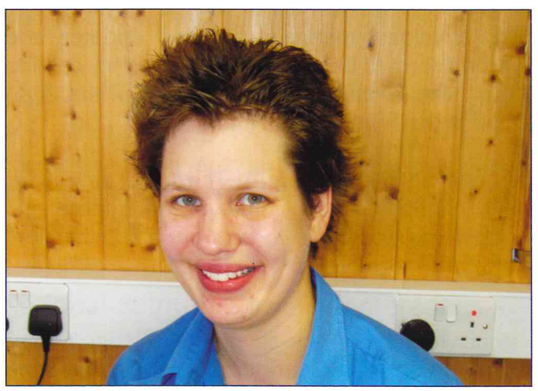
In this newsletter you will see that the Society is the beneficiary of the Ollie G Ball, raising funds to directly benefit and make a difference to the lives of children suffering from an MPS or related disease. Through this fundraising the Society is able to offer a chance to attend the American MPS Society's 25th Anniversary Conference 16-20 December, staying at the Disney Resort and getting to visit Disneyland and some of the other attractions. There are only places for 15 families so fill in your application and return it to us without delay to go in the draw.

In April the conference season started and I attended the meeting hosted by Genzyme in Madrid, before travelling south to Seville to join up with Ellie Gunary where we attended the meeting hosted by TKT. It was during this overseas visit that I suffered DVT and pulmonary embolism resulting in 10 days in hospital. On a personal note I would like to say how much Robin and I appreciated all the get well messages and flowers. Thank you to everyone.

Christine Lavery
Chief Executive

Introducing... Clare Cogan

My name is Clare Cogan and I have joined the Society as Senior Advocacy Support Worker. Since I qualified as a social worker in 2001 I have always wanted to work within the voluntary sector and when I saw this job advertised I felt it was definitely me! Before I joined the Society I was employed as a social worker for Slough Disabled Children's Team in Berkshire.



Clare Cogan

We were initially a very small team which developed and grew over time as families became more aware of our existence. I came across many frustrating situations which families were facing in relation to their disabled child and how practical help, or a listening ear could often be a support to them. I learnt a lot in my almost three years with them, all of which I have brought with me in the hope that it can be of some assistance.

On a more personal level, I am animal mad and currently have in residence six guinea pigs and a cat who I am sure thinks he is human as he has a habit of talking to you day, and night! If I had my way I would have many more animals but my husband has banned me from acquiring any more!

I hope that the skills, experience and knowledge which I bring to the Society will assist me in providing support, guidance and information to all those who need it and I look forward to working with you all.

Spotlight on... Sam Vaughan

I can't believe it has been eight months since I first wrote my introduction to the MPS Society piece in the newsletter. Time has flown by, and unfortunately my 'Spotlight on' time has come. I really wouldn't mind so much, if Alison's hadn't been so witty, and if Cheryl hadn't turned out to be such a natural poet!

Although I was first introduced to the MPS Society as Advocacy Assistant, times have changed and I am now Advocacy Events and Information ... person! This led to a recent office move, and although I miss the chaos and hectic goings-on of the Advocacy Team office, I now have Cheryl (Research Co-ordinator and carbohydrate-free diet fanatic) to keep me amused. Talking to herself, and staring into space (apparently deep in thought) being amongst her most entertaining habits!

As Advocacy Events and Information ... person, I spend my days putting together and analysing data, providing people and organisations with information about the Society and MPS and Related Diseases, managing the Childhood Wood, and organising regional events and conferences. Touch wood, so far so good!

The Alton Towers Fun Weekend was my first taste of organising a big event for the MPS Society, and I'm pleased to say it was quite successful (unlike

Sam Vaughan

the carbohydrate-free Atkins style diet that Cheryl is forcing me to try)!

With the Alton Towers weekend done and dusted, I have now got the Childhood Wood Remembrance Day ahead of me, and have even started brainstorming for next year's National Conference! So until then, that's all from me – see you at our next fantastic MPS event!

For further information on next year's conference in July 2005 contact Sam.

Farewell to... Alison West

And it's goodbye from me...

This is just a short note to say goodbye to all those of you I was unable to speak to in person. After almost two years with the MPS Society, I had been offered a chance to co-ordinate the advocacy service for children in need throughout East Sussex with a different organisation and I therefore left the MPS Society at the end of May.

Well, that about wraps it up and I finally seem to have run out of words ('At last!' I hear you cry) so I hope you will forgive me if I finish with some words I've borrowed from the classics:

'So long; farewell; auf wiedersehen; goodbye; Adieu! Adieu! To you and you and you...'

That's all folks!

Alison West

The MPS Society is very grateful for Alison's hard work over the last two years. We join with many of the Society's members who have been supported by Alison to wish her the very best for the future.

News from the Management Committee

The Society's Board of Trustees meet regularly. Here is a summary of the main issues that were discussed at the Management Committee Meeting in May.

Sibling Weekends

Despite the small numbers of brothers and sisters attending, the sibling weekend in July will go ahead. However, the Trustees agreed that the sibling weekend planned for early September will be cancelled and an alternative event be considered for Spring 2005.

MPS Conference 2005

The Trustees agreed the proposal to hold the next MPS Weekend Conference on 1-3 July 2005 and for the programme structure to be likened to that of the 2003 MPS Weekend Conference when three separate symposia were organised for the Saturday to reflect the diversity of the Society's members.

Personnel

The Trustees welcomed the news that Clare Cogan has been appointed to the Advocacy Team.

Policies

The Trustees reviewed and agreed the following policies: Data Protection; Child Protection; Working Away from the Office Policy; Financial Controls Policy; Moral and Ethical Policy; Financial Assistance Scheme; Moving and Handling Policy; Policy for Writing Care Plans; Research Policy; Policy for Supporting Members on the Death of an MPS Sufferer.

Annual General Meeting

The Annual General Meeting of the Society took place at Splash Landings Hotel, Alton Towers on 1st May 2004 at 6.45pm. 53 members attended. No apologies were received.

The minutes of the 2003 AGM were distributed in advance to members attending and were accepted as true and accurate.

The Chairman, Barry Wilson, presented the Trustees' Report. This is published in the Annual Report and Accounts for the year ending 31 October 2003.

The Treasurer, Judith Evans, presented the statement of accounts for the financial year ending 31 October 2003, the details of which are also to be found in the Society's latest Annual Report. It was proposed and seconded that the Auditors, McLintock and Partners, Chester, be appointed the Society's auditors for the financial year ending 31 October 2004.

During the Election of Trustees, the Chairman set out the objectives of the Society and the role of Trustees stating that co-option gives the individuals an opportunity to get to know the work and time involved before putting themselves forward for election. Barry Wilson, Judy Holroyd and Sue Peach stood for re-election and were duly elected as Trustees. Having served three years as a Trustee, Adam Turner did not stand for re-election. His resignation for personal reasons was accepted and Adam and his family wished all the best.

Bob Devine gave an overview of Jeans for Genes and encouraged all the MPS families to support this campaign that provides valuable funding for MPS research and support to the Society's members.

As there was no other business the Chairman, Barry Wilson, closed the meeting at 7.15pm and wished everyone a pleasant evening and good day out at Alton Towers the next day.

Members' Announcements

New members

Anna and David Eaton's sons, Archie and Isaac, have been diagnosed with MPS IV, Morquio Disease. Archie is 3 years old and Isaac is 16 months old. The family live in the South East.

Ray Musson has recently become a member of the MPS Society. Ray has been diagnosed with Fabry Disease. He is 44 years old and lives in the Midlands.

Michelle and Adrian Craig's son, Aaron, has recently been diagnosed with MPS III, Sanfilippo Disease. Aaron is 11 years old in July. He and his family live in the Midlands.

Mr and Mrs Ali's children, Rahat and Mili, have been diagnosed with MPS III, Sanfilippo Disease. Rahat is 5 years old. Mili is 4 years old. The family live in the South West.

Lisa and Paul Clarke's daughter, Sophie, has recently been diagnosed with MPS III, Sanfilippo Disease. Sophie is 7 years old. The family live in the South West.

Bill and Caroline Ferrier's son, William, has recently been diagnosed with MPS III, Sanfilippo Disease. William is 14 years old and he and his family live in the South West.

Raja Dorian and Musarrat Khan's two youngest sons, Raja Hussain and Raja Nadeem, have been diagnosed with Sanfilippo Disease. Raja Nadeem is 3 and Raja Hussain is 9 years old. They live in West Yorkshire.

John Goodman has been diagnosed with Fabry Disease. John is 73 years old. He lives in the Midlands with his wife.

Deaths

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

Corey Hall who died on 27 January 2004.

Jamie George who died on 15 March 2004.

Adam Brown who died on 4 April 2004.

Graham Hill who died on 25 May 2004.

Leanne Phillips who died on 9 June 2004.

Note for your diaries!

MPS Annual Weekend Conference 2005

Friday 1 - Sunday 3 July 2005

Hilton Hotel Northampton

Birmingham MPS Clinic

Ellie Gunary

All MPS Society members who are seen at the MPS Regional Birmingham Clinic will have recently received a letter advising that the metabolic services at Birmingham Children's Hospital are currently under review and there is a current difficulty securing suitable accommodation to meet the needs of families attending this clinic.

Following a meeting with the metabolic team, Dr Anne Green, Dr Anupam Chakrapani and Joy Wright at Birmingham Children's Hospital and the MPS Society, it was agreed to postpone the forthcoming MPS Regional Birmingham clinic planned for 16 July 2004.

As a firm date for the next regional clinic cannot be given at this time, any members with MPS medical concerns have been advised to contact either Dr Ed Wraith at the Royal Manchester Children's Hospital or Dr Anupam Chakrapani at Birmingham Children's Hospital where Dr Chakrapani holds storage disease clinics every two months.

We appreciate that MPS Society members in the West Midlands may be feeling very disappointed at this news and assure members in the West Midlands that, in the meantime, we at the MPS Society will do all we can to provide support.

We have also asked members to complete a questionnaire relating to aspects of the MPS Regional clinic in Birmingham. Completion of this questionnaire is very important and is our members' opportunity to influence the future of services at the Birmingham Children's Hospital. We look forward to receiving back these questionnaires.

www.wheelg2life.info

A New Information Website by Joanne Evans (MPS IV)

Joanne Evans (MPS IV)

Last year Joanne Evans and her friend Zara Todd applied for a Whizz Kidz No Limits Millenium Award to create a website that would act as an information bureau for young disabled people.

As wheelchair users, Joanne and Zara felt that the resources available for young people like them could be patronising and stereotypical, so when the charity Whizz Kidz announced their No Limits Award Scheme (funded through the Lottery Commission), they agreed this would provide a way to change things. With the help of their grant they invested in web design software and went on a one-day course at South Bank University in London to learn how to use it. On their site (www.wheelg2life.info) they provide information on benefits, housing, education, social life, etc. Information which is important to disabled youngsters.

Creating the website was a huge challenge, particularly as they were both studying for important exams at school at the time. Joanne wrote a press release about the site and managed to get it mentioned in several disability publications as well as getting linked to other disability-themed websites. So far they have had 1,300 hits on the site.

Joanne entered the site for the 2004 Childnet Academy Competition and was thrilled when she heard that the site had been chosen as one of twelve winners worldwide.

As a result, Joanne and Zara will be joining the other winners from Australia, USA, Jamaica, Italy, Holland, Taiwan, Ireland and the UK at the Cable and Wireless Childnet Academy for a week in April to take part in specialist website workshops as well as receiving further funding to develop their site.

Cable and Wireless created the Childnet Academy in 1995 with the aim to help make the Internet a great and safe place for children, and have sponsored the Awards and Academy for over six years. Further information can be found at www.childnetacademy.org.

Taking Part in the 2004 Challenger Tall Ship Series Race

Joanne Evans (MPS IV)

Joanne Evans has secured a berth on the Tall Ship 'Tenacious' to take part in the 2004 Challenger Tall Ship Series Race this summer.

The Tenacious is a square-rigger uniquely designed to accommodate both able-bodied and disabled sailors. Along with her sister ship The Lord Nelson, she is owned by the Jubilee Sailing Trust (www.jst.org.uk), the world leaders in promoting integration between people of all physical abilities through tall ship sailing.

Joanne will be flying out to New York on 24 July and making her way down to New London to join the ship for the voyage up to Halifax, Nova Scotia, which is the final leg of this year's race.

Joanne is in her final year at high school and wanted to have an experience which would be as memorable as any gap year before starting University in September. She hopes that taking part in the Tall Ships Race will fit the bill! As a participant in the Youth Leadership @ Sea Scheme, she will have the opportunity to work closely with the Bosun to improve her navigational skills as well as leading a watch team.

All members of the crew have to make their contribution, whether they are able-bodied or disabled in some way, to keep the ship running. This includes scrubbing the decks and shifts in the galley as well as setting the sails.

Advocacy Support Bulletin Board

OUT OF HOURS PHONE LINE
07712 653 258
7-9am Mon-Fri
5-10pm Mon-Fri
7am-10pm Saturday + Sunday

Regional Clinics and Events 2004

July

Sun 11	Childhood Wood, Remembrance Day
Fri 16 - Sun 18	Sibling Activity Weekend

September

Wed 29	Cardiff Clinic
Thu 30	Bristol Clinic

October

Fri 1	Jeans for Genes Day
Fri 22	Childhood Wood Tree Planting

November

Wed 3	BMT Clinic
Fri 5	BMT Clinic
Thu 18	Northern Ireland Clinic

Reception and Children's Party at Downing Street

Antonia Crofts

To celebrate the close of the Society's 21st Birthday Year a Reception and Children's Party was held on 6th April 2004 at No. 11 Downing Street, London. The event was hosted by the MPS Society with the kind permission of the Rt. Hon. Gordon Brown MP and his wife, Mrs Sarah Brown.

Due to limited space the guest list was restricted and we were unable to invite as many people as we would have wished to join us in this special celebration. A number of families were chosen at random from a shortlist of those who met a set of specific criteria. In addition to this, the rest of the guest list was composed of a number of representatives from pharmaceutical companies, fundraisers, medical and nursing professionals working in the field of MPS and Related Diseases.

There are many, many others who we would have invited by way of thanking them for their support to the Society over the last 21 years and, in particular, we hope for their continued support throughout the next 21 years and beyond. However, our guests were a representational cross-section rather than a definitive list. We extend our great thanks and appreciation to all our supporters.

The afternoon certainly went with a swing for the children. After making their way past the row of journalists and cameramen along Downing Street to knock on the door of No.11, both children and parents were welcomed by MPS staff and 'Polo' the clown. Children were ushered straight through to the downstairs party room for an afternoon of fun, food and games. The parents were ushered upstairs to the reception room where speeches and wine were to be in full flow!

Our thanks go to Barry Wilson, Chairman of the MPS Trustees, James Garthwaite, father of Thomas and Louis who have MPS II, Hunter Disease, and Dr Ed Wraith from Royal Manchester Children's Hospital. Their speeches reflected on the work of the MPS Society and with great poignancy talked about their various professional and personal experiences of living and working with children affected by these diseases.

We also extend our thanks to Colin Arrowsmith and Joanna Wilson for kindly cutting the celebratory Birthday Cake. Thank you to the Rt. Hon. Gordon Brown MP and Mrs Sarah Brown who allowed us to invade their home for the afternoon and gave up their valuable time to mingle with guests, even helping to cut the children's cake at the party!




Photos this page clockwise from top right: The Rt. Hon. Gordon Brown MP with Gordon & Norma Broadley; Dr Ed Wraith; The Rt. Hon. Gordon Brown MP with Trevor & Pamela Daughtrey & Pam Ballard; The Rt. Hon. Gordon Brown MP with MPS Trustees Barry Wilson, Adam Turner & Bob Devine








Photos this page clockwise from top right: Reception guests during the speeches; Norma & Gordon Broadley with John & Jo Allen; Sam Vaughan & Gina Page; The Rt. Hon. Gordon Brown MP with Ivan & Maria Murphy & Christine Lavery; The Rt. Hon. Gordon Brown MP with Julie Kelly; Paul & Dawn Moody; Dr Atul Mehta, Dr Patrick Deegan, Dr Uma Ramaswami, Sheila Bone &, Alistair Kent; Colin Arrowsmith & Joanna Wilson

Downing Street Reception & Children's Party

A Volunteer's Party Experience!

Helen Patterson

Let's party! This was the call in my head when I arrived at Downing Street clutching my 'Pass the Parcel'. Would security let it through the scanner? My greatest fear was that the security people would unwrap all 21 layers! However, as it happens, we were through with a smile and a wave. Then it was on to the volunteer's briefing – how to look after the children for the afternoon and how to get all of them sitting around the table for tea? We couldn't! So, we arranged for the extra children to sit on cushions on the floor in a circle and have a picnic. It would be fun!

Polo, the clown, arrived and greeted the guests with a smile and a joke. We started the celebrations with – you've guessed it – 'Pass the Parcel', and with forfeits. It was hysterical as the children made animal sounds, danced, had fun, and told jokes. Boy, they were really bad! Thank you James, we all groaned. We moved on to 'Find the Leader', a clapping game, and lots more. Polo did plate-spinning, juggling, a magic show and caused a nervous moment when the juggling clubs flew through the air and touched the chandelier that graced No.11's lounge! Musical hats was our time-filler as we awaited the arrival of the Rt. Hon. Gordon Brown MP who would cut our celebration cake.

He arrived and happily chatted to the children. They started to sing 'The wheels on the bus…' and guess who joined in! Then it was photograph time as the beautiful cake was cut and it was very sad as the marzipan Easter bunnies were separated from their tails. On to tea, and everyone enjoyed their picnic boxes and a well-deserved juice stop for volunteers. More games and balloon-sculpting followed as Polo created funny hats, magical animals and swords. The swords became part of our next game as we tried to steal the treasure from the king/queen who sat on the throne in the castle!

As tired boys and girls began to yawn, the party came to a close with more singing and the last game of Dead Lions. Three children stayed still so long on the floor they nearly went to sleep – this was definitely three prizes well won! Happy, tired children wended their way home clutching a 'Finding Nemo' balloon and a chocolate Easter Egg. Volunteers went home with a happy glow and remembering a day well spent, enjoying the laughter and smiles of children tinged with the memory of dirty nappies and food flying through the air at speed. A wonderful time was enjoyed by all. Thank you for inviting us to your special celebration party. It was wicked!

Alton Towers Fun Weekend

Sam Vaughan

Picture it – you are driving down the M42 with two childcare volunteers in your car who are earnestly trying to spot good-looking men in the passing cars, whilst you try to concentrate on getting through a rush hour traffic slash torrential rain combo…

The Alton Towers Fun Weekend was boding well! Luckily, the journey there was the only testing thing about the weekend, and as more families arrived at the Splash Landings Hotel, the more fun was had.

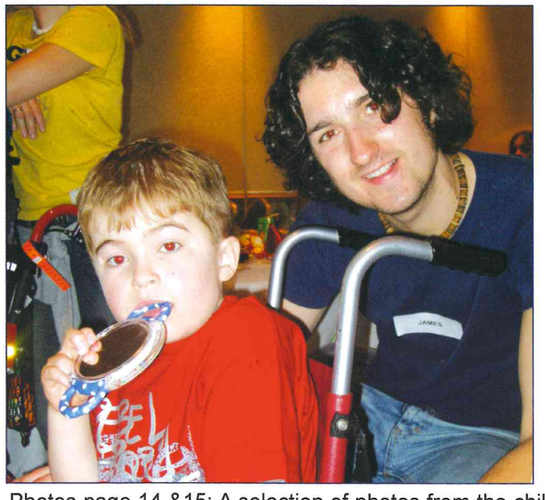
On the Saturday night the party was in full swing as the children's entertainment competed against Barry Wilson's voice next door at the AGM. This preceded the Gala Dinner which was a tremendous success, the wine was flowing and everybody generously emptied their pockets for the MPS raffle!

By 9.30pm that evening a few of the little ones were flagging after a jam-packed day at the Cariba Creek Waterpark; but with smiling faces and clutching handfuls of brightly coloured balloons (which many were very reluctant to share – much to my disappointment!) they left the party, parents in tow.

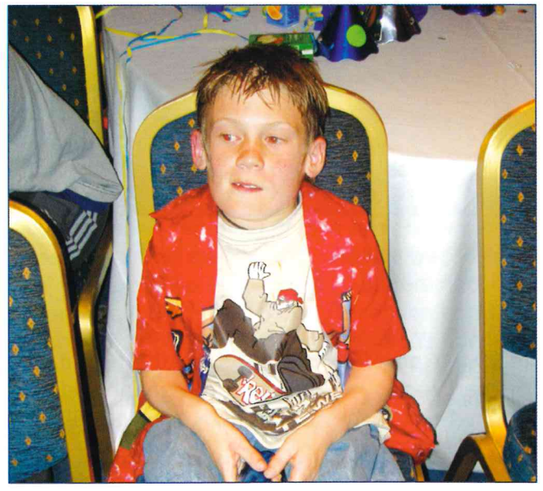
But how wrong I was to assume that's where the evening ended… the Splash Landings Bar was the next stop where the party continued into the early hours!

I take this opportunity to thank all of those who came to the Alton Towers Fun Weekend, and I hope that you all had a good time!

NB. For anyone looking for a small pink handbag that went walkies at Alton Towers, please could you contact the MPS office as soon as possible, so that we can return it to its rightful owner!!



Photos page 14 &15: A selection of photos from the children's evening entertainment and Gala Dinner



Alton Towers Fun Weekend

Alton Towers Fun Weekend

A Letter from Kate Murphy

I am writing to tell you about the time me, Kate Murphy, and all my family went to Splash Landings and to Alton Towers. When we got to Splash Landings Hotel, we met up with our friends, the Pollock family. I really liked the Pollock family because they were very funny, kind and understanding.

After we had a drink, we went swimming in Splash Landings for about three hours. I really liked the boat and ring rides because they were the biggest. Then we went to lunch. Lunch was really yummy. After lunch we went swimming again and met our volunteer called Lucy. Me and my sister, Tara Murphy, really like Lucy Lou. At dinner we watched 'Finding Nemo' which was a great idea. In the morning we got up and went for breakfast.

After breakfast me, my mummy Maria, my dad Ivan, sister Tara, and the Pollock's, Callum, Donnie, Donnie Jr, Carla and Chantelle, went to Alton Towers. When we got there we went on the Beastie which was a great one to start you off, then we went on the Black Hole, which was my favourite and my mum's!

After that we went on the Runaway Mine Train which was my second favourite, then we got very wet on the river rapids and flume. We then went on the corkscrew which made me and Donnie Jr feel sick. The adults went on Air but I was 2 inches too small which was a shame. I really wanted to go on it. We went on a lot more rides, which were not as good as these, but still great for going on. Thank you MPS for a great weekend!

Tonight with Trevor McDonald

Can you help?

'Tonight with Trevor McDonald' on ITV1 are in the process of making a programme about the complex and sensitive subject of abnormal foetal termination.

The producers are committed to reflecting how painful and heartbreaking these decisions are and have asked the MPS Society if any of our members whose children are in the advanced stages of their disease would be willing to share their experiences. The producers feel that showing first hand how difficult caring and raising a child with a degenerative disease can be and see this area as crucial to their programme. This programme has been prompted by the success of the battle by Rev. Joanna Jepson to have a 2001 abortion case re-investigated, on the basis that the reason given for the late termination did not constitute a 'serious' disability.

This case could have serious implications for MPS families especially if seeking a late termination. In the past year, in two families when receiving an MPS diagnosis on their child, the mother was over 20 weeks pregnant and had a 1 in 4 risk of the unborn baby having the same MPS disease.

It is the Tonight programme's duty to present both sides and to illustrate the points using individual cases. They are, therefore, also keen to talk both to parents currently facing the difficult decision to terminate, but also to those who have already faced the decision and are living with the consequences.

If you would like to contribute to the programme by sharing your personal experiences or would be willing to allow MPS to bring Joanna Jepson into your home to see for herself the impact of caring for an MPS child, please do contact me urgently: By telephone on 01494 434156 (leave a message if I am out of the office and I will get back to you), by email c.lavery@mpssociety.co.uk or in writing direct to the MPS Society.

Alton Towers Fun Weekend

A Letter from Madeleine Luckham, Harrison's Mum

I am writing to thank you for a lovely weekend at Alton Towers recently.

I wrote to you after the conference last year telling the tales of the fun we had and Harrison jumping in the fish pond! Well, Alton Towers was no different. After the lovely Gala Dinner and the children's party we decided to put the children to bed so that we could go for a drink with friends.

We had two adjoining rooms. We opened the door and went through the adjoining door. Harvey was asleep in his buggy, Harrison charged on through to a bed and Daisy promptly shut the adjoining door behind us, shutting herself and Harvey in the other room! She started to cry. As she wasn't even two years old yet she couldn't understand how to turn the lock. I telephoned Reception and they came with another key, but this wouldn't open the door. We telephoned again and two of the hotel management came down with keys. Meanwhile all had gone quiet from the room...

A small crowd was gathering with us by now. However, the door was eventually opened and there was Daisy - fast asleep at the foot of the door. Harvey was oblivious to what had gone on. When we bumped into Ellie the following morning and told her what happened she said 'Not you lot again!'. We had to laugh!

Harrison ran around Alton Towers like a mad thing totally enjoying his day, especially the rides and Tweenie show! He fell over at one point but seemed fine. On the way home we noticed that one of his front teeth was missing!

Here are some photos of friends with us at the Gala Dinner and those not forgotten wonderful carers! Here's to the next event!

Photos pg 16: Kate Murphy (on the left) on the Frog Hopper ride; Callum Pollock & Tara Murphy (both MPS I)
Photos pg 17: From a selection sent in by Madeleine Luckham including photos of Harrison (MPS III)

Bone Marrow Clinic

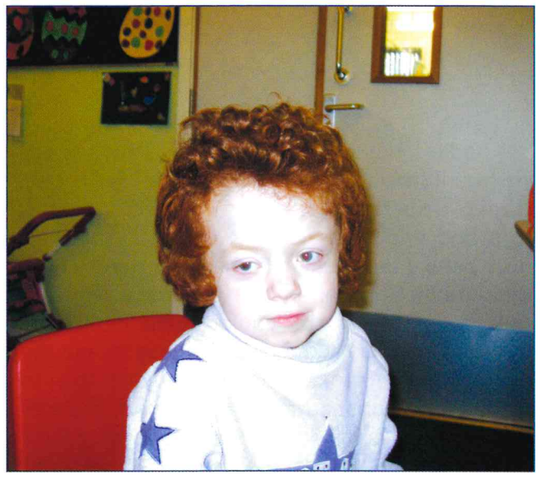
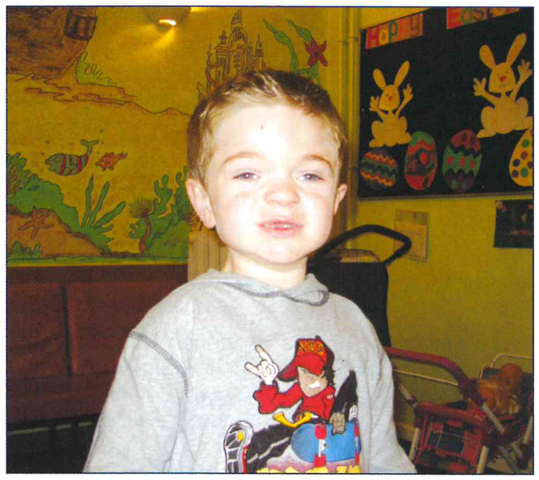
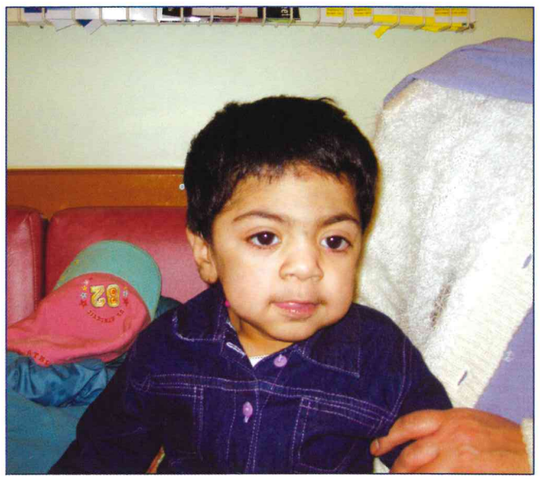
Cheryl Pitt

Well, another BMT clinic has come and gone, and what a lot of fun this one proved to be! We had an amazing turnout, and it was good to see the children getting on so well with each other. It was more like a reunion of long lost friends than an MPS clinic! It was lovely to see again the children and families that I have met on previous occasions, but it was also a pleasure to meet families new to the MPS Society, and those of you who travel long distances to reach the clinic and are perhaps not as able as some to attend on a regular basis.

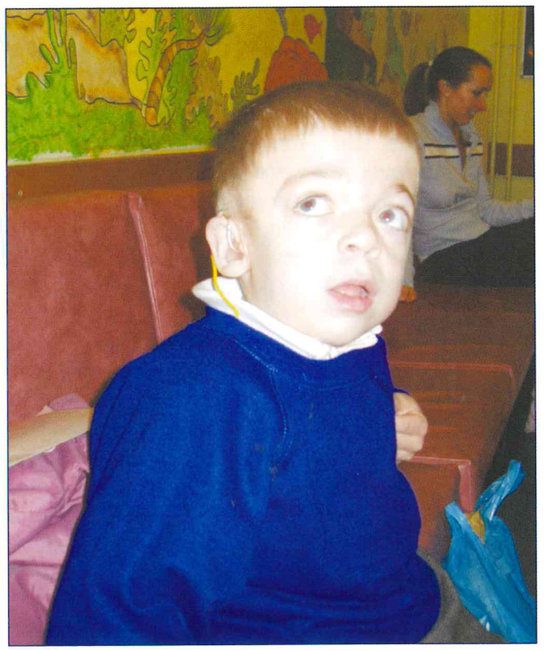
The Consultants were rushed off their feet with a full to brimming clinic list, but along with the nursing team at the Willink, they did a brilliant job, and turned what promised to be a day of chaos into a smooth, organised day run with military precision.

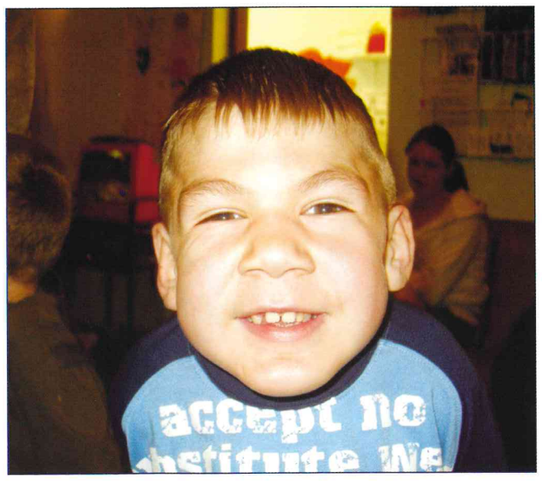
The next BMT clinic is to be held at the beginning of November. However, it will be spread over two days and appointments will be made according to your children's ages and consultancy requirements. If you have any advocacy support issues that the MPS Society can support you with, please inform a member of the team at the Society's office prior to the clinic, so that I can bring any relevant information with me. I look forward to seeing you in November, although I will hopefully be in touch with you before then with an invitation to take part in our psychosocial research.

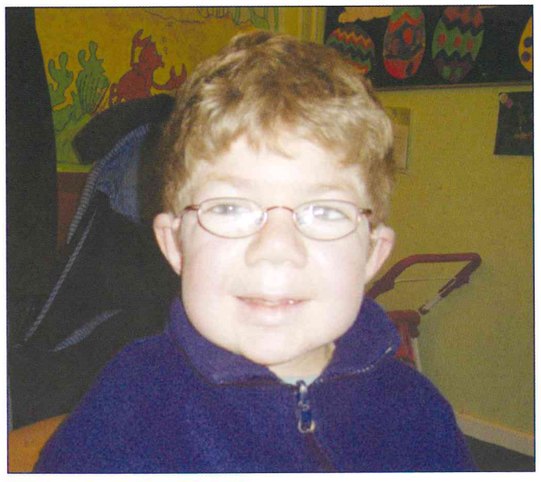
Thanks as usual to Bernie and Gill for organising the clinic, and for providing refreshment. Thanks also to Dr Ed Wraith, Dr Rob Wynn, Tim Meadows, and Professor Clayton, who made up the team of consultants, for their excellent work and a successful clinic.

Photos clockwise from top right: Keira O'Neill (MPS I), Rubina Jalani (MPS I), Matthew Ingram (MPS I), Aiden Brown (MPS I)







Photos clockwise from top right: Emma Slater (MPS I), Leighton Barker (MPS I), Bradley Evans (MPS I), Callum Pollock (MPS I), Sarah (MPS I) & Rhoswen McKnight, Isaac Turner (MPS I)

Bone Marrow Clinic

MPS Regional Clinics

Advocacy Support Team

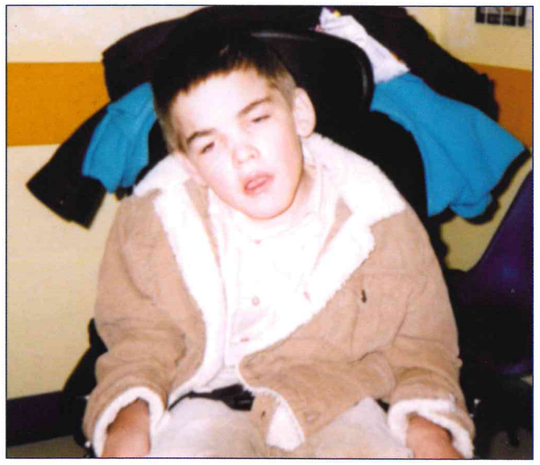
Since the last newsletter we have had four MPS clinics: Bristol, Cardiff, Scotland and Northern Ireland.

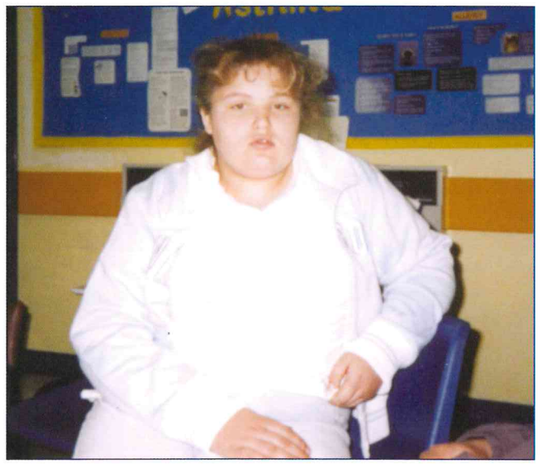
We are delighted to report that they all ran smoothly and everyone we spoke to found them useful. The only hiccup was yet another plane delay at Heathrow when attempting to get to the Northern Ireland Clinic following computers at Air Traffic Control going down. This resulted in Ed not getting to Belfast until lunchtime following a successive cancellation of planes. You can imagine the chaos that ensued following this problem was like the M25 on a bad day!

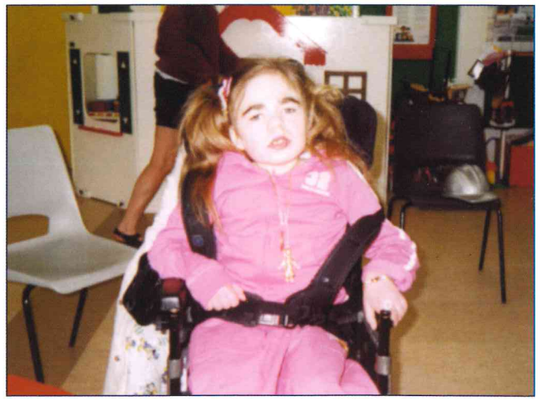
One interesting moment was provided by Dr Ed Wraith, although it was in fact his conspicuous absence from the Cardiff clinic which created the interest, detained as he was (without just cause as it turned out) at a court in Liverpool. Many fun hours were whiled away speculating exactly what he had done and what sentence he was likely to get! However, we were all pleased to see that he finally got his deserved freedom and made it to the following clinic in Bristol in time. For those of you who may be getting the wrong idea at this point, we should clarify that Ed was a witness, not the defendant!

As usual our thanks go to all the doctors who share their time so generously for these clinics and also to those who put in the effort of arranging them. By name these are: Dr Ed Wraith, Dr Philip Jardine, Dr Graham Shortland, Dr Peter Robinson, Dr Maureen Cleary, and Dr Fiona Stewart: Sue, Deirdre, Sam and Paula in Belfast. Thank you for your continued support.

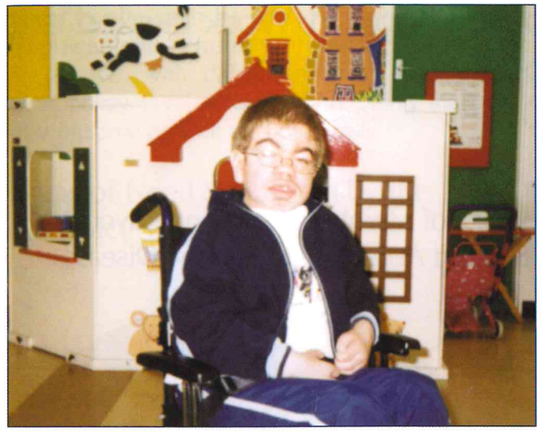
Please enjoy the selection of photos chosen to represent these clinics.

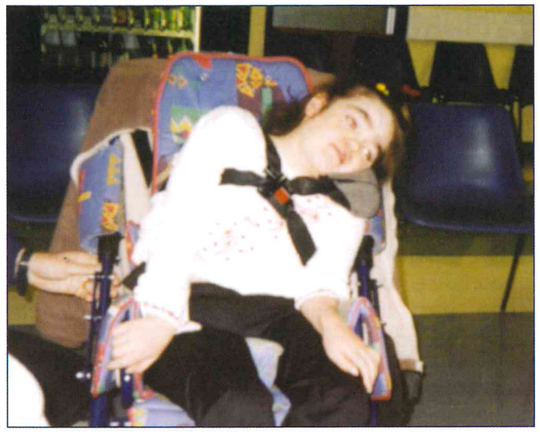


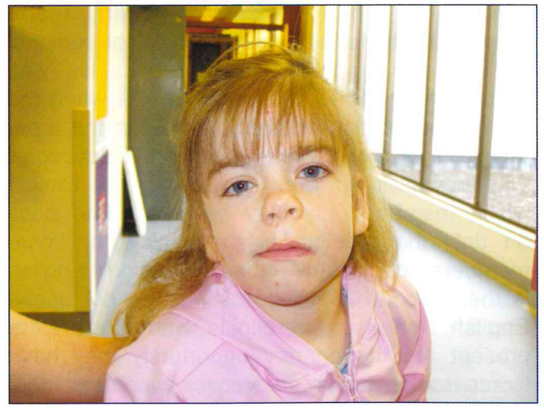


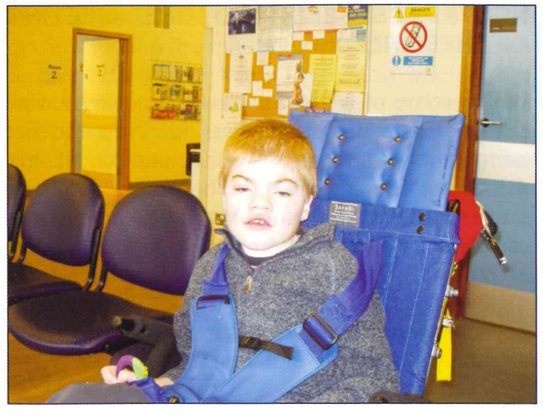


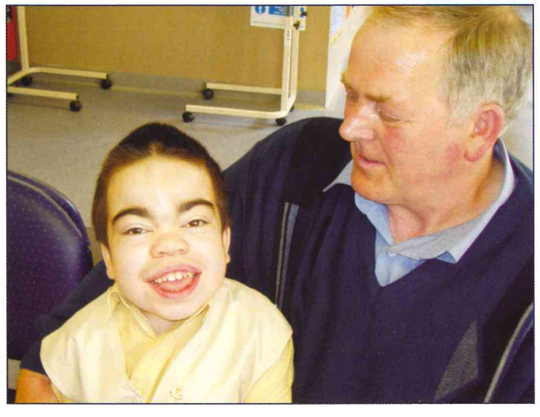
Photos this page clockwise from top right: Carly Dickinson (MPS III), Kerry Parker (MPS III), Jasmin Heap (MPS III), Craig Pope (MPS III)
Photos page 21 clockwise from top right: Melanie Jones (MPS III), Sophie Richards (MPS I), James Stewart (MPS II), Shaun McCawille (MPS II), Kyle Shields (MPS III), Jade McAfee (MPS III), Malcolm, Michelle & Aimee Crocker (Fabry), Shaun Bayliss (Fabry), Matthew Wright (MPS II)











Evaluation of the Individual Advocacy Support Work carried out by the Society's Advocacy Support Team 1 April 2003 - 30 September 2003

Ellie Gunary

Introduction

When providing a service, evaluation is of utmost importance to ensure the service is meeting its aims and the needs of those for whom it is provided.

Since starting work for the MPS Society five years ago, I have become increasingly aware of the changes in the nature of the advocacy support work being requested of and undertaken by the Advocacy Support team. In light of this, I undertook a review to establish the exact nature of the individual advocacy support work being requested of the team and its implementation over a six month period.

Aims of the Evaluation

To establish the incidence of different contact methods used by members in order to inform the Advocacy Support Team of a support need: to review the needs of members which were assessed and needs which were met; to review the different types of support implemented with members; to review needs which were not met, and to establish the reasons these needs were not met.

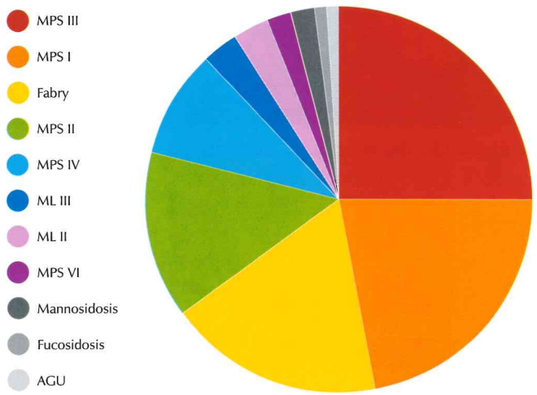
Report Summary

AGE AND DISEASE

The largest single membership group in terms of MPS disease receiving support from the Society's Advocacy Support Team remain individuals and families affected by Sanfilippo Disease.

It is probable that the next largest group supported during this period were those affected by MPS I because of the specific work being undertaken to achieve funded Enzyme Replacement Therapy with the advent of Aldurazyme as a licensed product. Whilst the number of adults with advocacy support needs is growing, the majority of advocacy support is still undertaken in respect of children under the age of eighteen.

Range of Members Receiving Advocacy Support According to Specific Disease



METHODS OF CONTACT

Whilst the majority of advocacy support work comes in from members phoning the MPS office, a large amount - 28% - arises from contact initiated by the Advocacy Support Team. Contact is initiated at events such as the regional MPS clinics and MPS conferences as well as contact made to offer a home visit when the team is supporting another member in the area. Members of the Advocacy Support Team report that they pick up work at the regional clinics, which members say they had waited to pass on until the meeting at the clinic. For some members, particularly those for whom English is their second language or who do not speak English, meetings at clinics with interpreters present are the primary opportunity they have to access the Society's advocacy support service.

NEEDS ASSESSED AND THE MEETING OF THESE NEEDS

Whilst some of these needs were not met in all but one instance the reasons for the need not being met were outside the control of the Advocacy Support Team. The evaluation was undertaken for six months only and key pieces of advocacy support often require a longer period of time for a need to be met. A key example of this is home adaptations, when the process of achieving home adaptations, when it runs smoothly, lasts up to eighteen months.

Other needs such as achieving funded Enzyme Replacement Therapy require more time to resolve, with difficulties being encountered at a policy level, and support being instigated at a national as well as local level.

Areas of Need Supported by the Advocacy Team

In a significant number of instances, a member did not follow up with the Advocacy Support Team after a need was identified and advice given on how to take the matter forward. It is impossible to give reasons for this and to know whether the advice given was enough for the member to act and meet their own needs, which is a key objective of advocacy. It is important to recognise that the Society works at a distance the majority of the time and that it is not possible to meet the needs of members when frequent face-to-face contact is required.

Of great credit to the Advocacy Support Service is that in only one instance was it assessed that a need was not met due to other work priorities, and this was due to a tribunal meeting being set on a date which the Advocacy Support Team could not meet and which the member, on learning this, chose not to change.

SUPPORT IMPLEMENTED WITH OTHER PROFESSIONALS WORKED WITH

In 189 pieces of support at least one other professional was involved in the support implemented by the Advocacy Support Team. This and the range of different professionals contacted, 49 different groups in total, gives an indication as to the amount of multi-agency work undertaken. A key skill in care work is the ability to assess needs. The number of members, 46, who required the MPS Society's Advocacy Support Team to play a significant role in the assessment of their needs, indicates that this is lacking throughout the UK. In the vast majority of instances in which the Advocacy Support Team requested the support of another professional to uphold a member's rights, also 46, this was a tertiary centre doctor who was requested to provide medical evidence to support the meeting of a member's needs.

The large number of instances in which the Advocacy Support Team was required to uphold the rights of individuals with MPS and their families/carers, and challenge inappropriate policy/practices, 52, suggests that the statutory authorities in some areas are failing in their duty to meet needs. This failure includes what is still a relatively small, but significant area of support the Society undertakes, supporting legal challenges. Any piece of work which involves the upholding of rights or challenges to policy and practices, requires significant input and specific skills and knowledge.

Conclusion

This evaluation indicates that the individual advocacy support work carried out by the MPS Society's Advocacy Support Team is necessary, does not duplicate work which statutory agencies would otherwise carry out (this is not to say that statutory agencies should not carry out some of the work the Advocacy Support Team undertakes), and that it is an essential service provided by the MPS Society with its key objective being to ensure that the needs and rights of individuals suffering from MPS and Related Diseases and their families and carers living throughout the UK, are met and upheld. ■

Advocacy Support Evaluation

Precocious Puberty

Alison West

This is a subject which has become more apparent in children with Sanfilippo disease over the years and is of particular concern to some of our members. It is hoped that this article will go some way to explaining the condition and to signpost parents who are concerned about their child to the correct place for support.

All children develop certain bodily changes at puberty including the development of pubic hair, a change in behaviour, the development of acne, sudden growth etc. In some children this can occur a lot sooner than in others. The changes which occur are still normal symptoms of puberty, they are simply happening too soon. In this situation the child (a girl under the age of 8 or a boy under the age of 9) may have a condition called 'precocious puberty'.

There is no specific reason why some children develop earlier than others and children with an MPS disorder are no different. However, as one of the symptoms is a change in behaviour, in children with Sanfilippo disease this can lead to more aggressive behaviour.

Precocious puberty is generally diagnosed following an examination which can be done by your doctor. There are also a series of tests which can be done to confirm this diagnosis. These include: an x-ray of the hand and wrist to determine the bone age against the chronological age of the child; a blood test to determine the level of various hormones in the bloodstream; a pelvic and adrenal ultrasound to look for particular abnormalities; a magnetic-resonance imaging (MRI) or computer-assisted tomographic (CAT) scan of the head which will show any abnormalities in the pituitary gland or hypothalamus

Following a positive diagnosis your doctor will consult with you over the appropriate course of treatment.

Any child who has the normal teenage growth spurt earlier will also stop growing earlier and, as a result, may not reach their full height. This can often make a child feel self-conscious and the early development of their sexual maturity can also lead to embarrassment and social difficulties. It is for these reasons that precocious puberty is treated.

There are currently three treatments available for precocious puberty. All of them are luteinizing hormone-releasing hormone agonist (LHRha) treatments. Two of these are administered by daily injection, and the third by a nasal spray. They all work by stopping the child from producing certain adult hormones, thereby reducing the growth rate.

If you have any questions about precocious puberty or are concerned about your child's development, speak to your doctor to discuss diagnosis and possible treatments.

There is also a website which may provide some information for parents who are worried about precocious puberty. This can be found at www.toosoon.com/parents/more.htm

MPS Information Video

If you want more information on the work of the MPS Society and the range of diseases supported by us why not order the Society's information video?

Narrated by Jeremy Bowen, this video features interviews with medical professionals working in the field of MPS and Related Diseases and the personal experiences of families of those affected by these diseases.

Order your copy now!
Telephone 01494 434156
UK Cost £5.00

Communicating Hydrocephalus

Barbara Wedehase, MSW, CGC and Beth Pletcher, MD, FAAP, FACMG

Communicating hydrocephalus (increased fluid in the ventricles of the brain) is a common, but often undiagnosed, problem in individuals with MPS I, MPS II, MPS VI and MPS VII and may be associated with some cortical atrophy (loss of brain cells). Children with greater neurological involvement have a greater risk of developing hydrocephalus. Early detection and treatment of hydrocephalus is believed to improve quality of life. However, neurosurgeons are often unfamiliar with the unique aspects of diagnosing communicating hydrocephalus in MPS disorders, creating a frustrating situation for parents.

Hydrocephalus was once known as 'water on the brain'. The 'water' is actually cerebrospinal fluid (CSF), a clear fluid surrounding the brain and spinal cord. The CSF protects the brain and spinal cord from injury by providing a liquid cushion, and is continually being produced, circulated and absorbed. Communicating hydrocephalus (non-obstructive hydrocephalus) is caused by inadequate absorption of CSF. The excessive accumulation of CSF results in an abnormal enlargement of the spaces in the brain called ventricles. This causes potentially harmful pressure on the tissues of the brain.

In infancy, the most obvious indication of hydrocephalus is often the rapid increase in head circumstance or an unusually large head size. In older children and adults, symptoms may include headache followed by vomiting, nausea, downward deviation of the eyes (called "sunsetting"), problems with balance, poor coordination, gait disturbance, urinary incontinence, slowing or loss of development, lethargy, drowsiness, irritability, or other changes in personality or cognition, including memory loss.

Hydrocephalus in individuals with MPS may develop very slowly over months or even years, therefore, the typical signs and symptoms of hydrocephalus are not commonly seen. The lack of papilledema (swelling of the optic disk, which is part of the optic nerve) does not rule out hydrocephalus in individuals with MPS.

Hydrocephalus is diagnosed through clinical neurological evaluation and by using cranial imaging techniques such as ultrasonography, computer tomography (CT), magnetic resonance imaging (MRI), or lumbar puncture (spinal tap) to measure pressure. Hydrocephalus is most often treated with the surgical placement of a shunt system, a flexible plastic tube. This system diverts the flow of CSF from the ventricles to another area of the body where it can be absorbed as part of the circulatory process.

It is recommended that children with MPS have a 'baseline' head scan (CT or MRI) at the time of diagnosis with a follow-up scan yearly to evaluate the size of the ventricles. If there is evidence of progressive ventriculomegaly (increased size of ventricles), a shunt should be considered. Some individuals with MPS who are symptomatic for hydrocephalus do not have progressive ventriculomegaly.

Measuring intracranial pressure can be diagnostic and is recommended in these situations. Intracranial pressure is measured in millimeters of mercury (mm Hg) and the upper limits of normal are around 180 to 200 mm Hg. Intracranial pressure may be measured during a lumbar puncture or may be measured directly by attaching a device referred to as a bolt to a small hole in the skull.

Prior to surgery, the cervical (around the neck) region should be evaluated to determine if there is evidence of obstruction at the foramen magnum (base of the brain). Such an obstruction can place the spinal cord at risk of life-threatening injury. If an obstruction is identified, the surgeon may wish to consider a laminectomy (removal of a portion of the back of the vertebra) at the time of the shunt procedure. If a shunt is placed, specialists recommend a high-pressure shunt (10-15 mm Hg) to prevent rapid decompression (reduction of fluid in the ventricles).

Children with MPS III routinely develop enlarged ventricles, but elevated CSF pressure has never been documented. In MPS III the enlarged ventricles are believed to be due to cortical atrophy and not elevated CSF pressure. Robertson et al, European Journal of Pediatrics 157:653-655, 1998 reported that six children with MPS III with shunts had improvement in behaviour and a decrease in level of agitation.

As with any surgical procedure in a child with an MPS condition, it is important to meet with the anaesthesiologist prior to the surgery. For more information about hydrocephalus and shunts, please refer to the following websites:

www.hydrocephalus.org
www.hydroassoc.org/information/index.html

Special Interest

New Carers' Rights Could be Law Next Month

The Carer's (Equal Opportunities) Bill, having passed its final stages in the House of Commons, could become law next month. This Bill would impose a new duty on local authorities to tell carers they may be entitled to an assessment if the Bill is approved by the House of Lords this month. Councils would also have to consider the wishes of a carer to work or take part in education, training or leisure.

Sibs

Sibs is a registered charity based in York that provides information and guidance to people who grow up with a brother or sister with special needs, disability and chronic illness. A childhood spent growing up with someone with special needs can be very rewarding but difficult at the same time. Sibs provides fact sheets and has a website on sibling issues for young siblings, adult siblings, parents of siblings and professionals who work with siblings. For more information contact Sibs on 01904 550029 or check out the website www.sibs.org.uk

M6 Toll Road Free for Disabled Customers

In December 2003 the M6 Toll Road was opened to reduce congestion around Birmingham. A charge is made to all road users. This is currently set at £2.00 for a car to travel one way. However, for disabled motorists whose vehicles meet certain criteria, there may be an exemption from these toll fees. The vehicle must be registered in the name of the disabled person and this person must also be in receipt of disability living allowance, mobility supplement or a disability grant. To gain exemption you must apply for a Mobility Exemption Pass which is valid for three years and costs £5.00 for administration. For further information contact Midland Expressway Ltd on 0870 850 6262 or www.m6toll.co.uk.

Giving Through SA Returns

The Society has now completed the necessary paperwork to be included in the 'Giving through SA Returns' scheme from the 2003/2004 self assessment forms. This means that if you carry out your own self assessment returns to the Inland Revenue and have overpaid tax, instead of getting credit you can agree to pass the money directly on to a charity. To do this for the Society you need to quote our number which is RAB71QG. If you forget this code it is listed on the Inland Revenue website.

Listen Up

Children and young adults who have a disability often have views and opinions about the services which they use. Mencap have developed a pack called 'Listen Up' which contains a variety of multimedia resources to help children and young adults with a learning disability complain about the services they use. The pack also contains resources for children, staff and parents including workbooks, a CD-Rom, board game, staff training video and workbook. The pack is for anybody who works with children and young adults with a learning disability including those with special needs. Check out www.mencap.org.uk/listenup to order your own free pack.

Daisy's Dream

Daisy's Dream is a registered charity providing support for bereaved children in Berkshire and the surrounding area. They provide a telephone support service, support in home or at school, residential weekend courses (Camp Daisy) for bereaved children aged 6-16, non residential groups for parents and carers, follow up activities, information and advice for professionals working with bereaved children.

Daisy's Dream work with children of any age up to the age of 18. In addition to this, they can also offer pre bereavement support if requested.

Daisy's Dream
Supporting bereaved children and their families

If you would like any more information about Daisy's Dream then they can be contacted on 0118 934 2604. Their website address is www.daisysdream.org.uk.

Changing Places - Accessible Toilets for All

Clare Cogan

In response to the article written by Sally Summerton in the last newsletter, 'The Need for Improved Public Facilities', the MPS Society were contacted and given information about an organisation in Scotland called PAMIS who are a voluntary organisation and registered charity. PAMIS works with people with profound and multiple learning disabilities, their family, carers and professionals who support them. They identify their aims as being to:

Ensure that society recognises that people with profound and multiple learning disabilities have a very positive contribution to make to the life of their communities.

Campaign for the right level of support to enable them to become active citizens and that opportunities and services are both physically and intellectually accessible.

Offer a supportive partnership to family carers through the provision of training, advice and advocacy.

One of their national campaigns is focused on ensuring that 'toilets for the disabled' are made fully accessible. They identify that the lack of suitable changing facilities for people with disabilities is one of the most restrictive practical problems in preventing families from going out. The main area of concern is that families are reduced to change their daughters or sons on toilet floors which is undignified, unhygienic and involves heavy lifting by the parents or carers.

PAMIS says that it is campaigning for the installation of changing benches suitable for older children and adults with safety rails attached. In addition to this they identify the need for extra space in toilet cubicles and in the actual toilet for a changing bench.

For more information about PAMIS, their website address is www.dundee.ac.uk/pamis or they can be contacted on 01382 345154.

Update on the MPS Newsletter

The MPS Society's quarterly newsletter is designed in-house. The cost of printing and postage is made up from newsletter subscriptions, advertising and successful grant applications in order to make the whole process as cost effective as possible.

The newsletter is vital to the work of the Society in promoting not only our own work, but also keeping readers informed of the latest developments in the field of MPS and Related Diseases. To take out a subscription contact the Society now!

Can You Help?

Do you have a story or experience that you could share to help others deal with their own circumstances? Or, let us know if you have any questions that our readers may be able to answer.

To submit information for the newsletter please send text by e-mail and post original photos which we will return.

Information Exchange

Cataplexy - Don't Make Me Laugh

Jackie Imrie, Royal Manchester Children's Hospital

Editor's Note: This is taken from an article written by Jackie Imrie, Clinical Nurse Specialist - Niemann Pick Disease at Royal Manchester Children's Hospital.

Cataplexy is a feature seen in Sanfilippo Disease. The following is a brief description of cataplexy with anecdotes from parents as to how it affects their children.

Cataplexy is an abrupt temporary loss of voluntary muscular function and tone, evoked by an emotional stimulus such as laughter, pleasure, anger, or excitement [Definition from the Academic Press Dictionary of Science and Technology].

Cataplexy is believed to represent a fragment of rapid eye movement (REM) sleep that intrudes into otherwise normal consciousness and is thought to be related to narcolepsy.

Cataplexy occurs when a person experiences an emotional stimulation - laughter, excitement, anger, stress, etc. The stimulation leads to a very rapid loss of voluntary muscle control. This may take the form of the head flopping forward but often the person will collapse as a result and fall to the floor. One parent describes this as going like a rag doll. The collapse occurs because the person can no longer control their leg muscles to remain standing. As soon as the stimulation is reduced, the person regains muscle control. This may last from a few seconds to a few minutes. They may appear a bit shaken (either from the fall or from the surprise of collapsing) but in a minute or two will be in full control.

Cataplexy itself is not a serious medical emergency. However, the rapidity of the collapse can be a danger if the person strikes their head while collapsing or lands awkwardly. Use of protective headgear can reduce the risk of injury and there is medication that can be prescribed to control cataplexy.

Cataplexy can be confused with seizures, especially if you are not familiar with the differing symptoms. If you suspect cataplexy is occurring, look for the following signs: it occurs rapidly, it occurs during times of emotional stimulation, the person recovers almost immediately, the person is responsive during the event.

A seizure will occur during quiet times as well as periods of stimulation and generally has more warning signs. After a seizure, the person will recover more slowly and may not remember what happened.

These are some comments from parents as to how it affects their children.

'People out must think we're shocking parents as we say, J, stop laughing! You'll fall over.... which is normally what happens. She just sort of slumps down slowly - it's pretty funny as she's laughing all the way!'

'She's also been known to whack her head on a table while sitting at it from laughing - that one's not funny as it really hurts.'

'Cataplexy for us as a family was very difficult when it first started to show signs in E. Not only was it heartbreaking to see E going through this, but the constant worry of her hurting herself, which she often did, resulting in some really nasty head or facial injuries.'

'E would suddenly stop dead, look very wide-eyed, and drop to the floor within seconds. Her body would become like a rag doll slipping through your hands as we try desperately to support and protect her. Then, within seconds again, you would almost feel her body regenerate, kick start back into life. It often left her whacked out for a few minutes. We do believe E often knew it was going to happen, as she would suddenly look at you prior to dropping.'

'This meant we couldn't leave her side for a second in fear of her hurting herself. Going out became more and more difficult. Often I had to sit on the floor with her in the street until she managed to find her feet again. This was one of the main reasons we had to get her a disabled buggy, not because she had lost her walking abilities.'

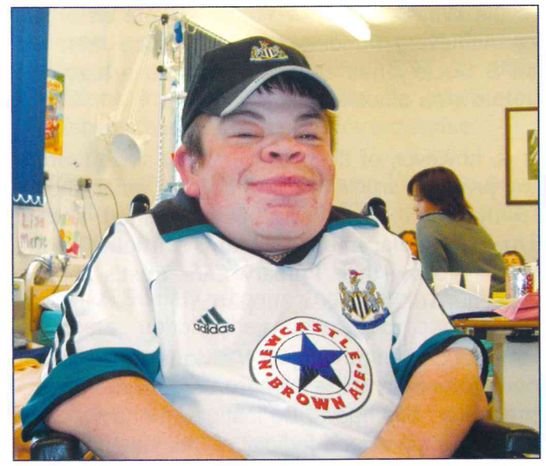
'Cataplexy is an extremely difficult condition to deal with - it is impossible to predict when she will suffer an attack. Her twin brothers can, without realising say something that reduces R to a heap or if she is eating, her head disappears into the meal. Initially we tried to avoid creating an atmosphere that might lead to an attack, however, we soon realised that you cannot remove laughter from a child's life - now we just catch her or pick her up, dust her down and get on with life.'

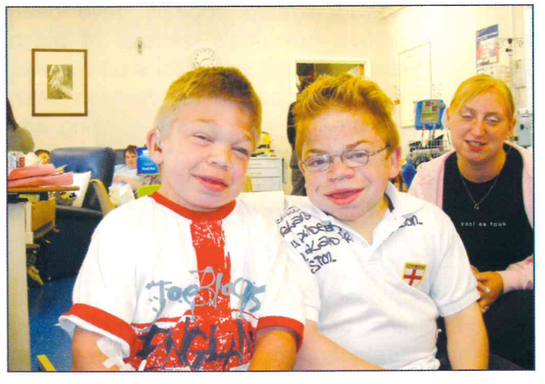
MPS II ERT Clinical Trials

Christine Lavery

The pivotal MPS II Enzyme Replacement Therapy clinical trial which involves 96 patients from 17 countries has now reached week 22 in the UK. At week 17 all the clinical trial patients underwent a week of testing at Royal Manchester Children's Hospital.

There was much debate between the families as to who might be on enzyme. In this trial one third of the patients receive enzyme every week, one third receive alternate weeks of enzyme and placebo and the other third receive placebo every week. As this is a double blind trial no-one will know for sure who is receiving which dose until the clinical trial is unblinded in early 2005. This doesn't stop the guessing!





Photos this page are taken from the MPS II trials showing children, adults, families and the nurses involved.

Achieving Funding for ERT for MPS I & Fabry Disease

Ellie Gunary

In the Winter 2003 newsletter, I wrote an article on Achieving Funding for ERT. Since then the MPS Society has continued to take a lead role in this area of work.

It is, however, of deep concern that since I wrote my previous article not one child or adult known to the MPS Society has been granted funded Enzyme Replacement Therapy without having to first follow their Primary Care Trust's appeals procedure or seek legal support.

Applications for funding for individuals have either been refused and the Primary Care Trust's appeal procedure has had to be instigated and followed or legal support and judicial review has been the only way forward as some Primary Care Trusts continue to take a position of not making a decision about whether or not to fund treatment.

The MPS Society's Advocacy Support Team has to date supported six judicial reviews for MPS I patients, submitted ten written appeals and supported three Primary Care Trust Appeal hearings. In addition, one complaint has been sent to the Health Service Commissioner for England, raising deep concerns about the conduct of one particular appeal panel.

In respect of Fabry Disease, one judicial review is being followed, written appeals have been submitted for five individuals, several of which have required repeated submissions and two Primary Care Trust Appeal hearings have been attended. This area of work is still growing and is one in which an increasingly political agenda is at the forefront of the Primary Care Trust responses and therefore the MPS Society's support.

Whilst the Advocacy Support Team have on all but two instances been successful and funded Enzyme Replacement Therapy has been achieved following appeal it continues to be of deep concern that many of the reasons Primary Care Trusts give for not funding ERT are erroneous and unacceptable.

Examples of such statements are: that once an individual has stopped growing ERT will no longer benefit them; that as an individual did not meet the criteria for the clinical trial they will not benefit from the treatment; the PCT is not the body responsible for funding local patients with rare diseases.

The commonly cited excuse which I quoted in the last newsletter that the Chief Medical Officer is undertaking a review has not been repeated of late although another excuse for not funding, that Primary Care Trusts are awaiting the reporting of a mini assessment into ERT commissioned by the West Midland Specialists Services Agency has reared its head in its place.

The West Midlands Specialist Services Agency has indeed commissioned a review of which a draft has been sent out and which the MPS Society, other patient groups and key clinicians in the field of Lysosomal Storage Diseases all assess as seriously flawed. This review has been the basis upon which the majority of Primary Care Trusts who have delayed decisions have made the decision to defer. A full response to the report made jointly by patient support groups and physicians is being drafted as this article is typed.

The Society continues to support those individuals for whom funding has not been granted as in all cases the reasons given for not funding are seriously flawed.

It continues to be of deep concern that many of the reasons Primary Care Trusts give for not funding ERT are erroneous and unacceptable.

Following the meeting with MPs in December 2003 at the House of Commons, a meeting was held with John Hutton MP, the Minister of Health at which the need for a national response to funding for Enzyme Replacement Therapies for Lysosomal Storage Diseases was promoted.

This, however, is a future aspiration, is not here now and whilst continuing to pursue this line the MPS Society in upholding its firm belief in the rights of its individual members continues to support individuals with appeals at a Primary Care Trust level.

The MPS Society would not be able to offer the level of support it does with PCT appeals without the dedication of tertiary centre doctors who patiently check all our appeals and provide any medical information needed.

Our thanks go out to them as well as the legal team at Leigh Day and Co who support the judicial reviews.

Scotland and Wales Say No to Funding ERT for MPS I

Christine Lavery

In both Wales and Scotland decisions have been made to not fund Enzyme Replacement Therapy for MPS I. The Society made very strong representations during the consultation period for Scotland advocating funded ERT for MPS I patients who meet the clinical protocol.

We are deeply concerned that despite my participation in the appeal procedure including my personal attendance in Cardiff, the decision not to fund ERT for MPS I patients in Wales has been upheld.

This decision could also impact on other patients for whom a licensed Enzyme Replacement Therapy is expected, namely Maroteaux Lamy (MPS VI), Hunter (MPS II) and Pompe Disease.

As patients with Fabry Disease and Gaucher Disease, both of which are Lysosomal Storage Diseases, are receiving funded ERT for their conditions in Wales, this could be interpreted as discrimination according to rare disease.

In respect of Scotland, a decision has also been taken to refuse funding of ERT for MPS I and an appeal is being taken forward.

The MPS Society is committed to supporting all its members, uphold their rights and, should you be affected by a decision to not fund Enzyme Replacement Therapy which has been recommended by a tertiary centre specialist doctor, we would be pleased to hear from you and discuss with you appropriate support we can offer.

If you need help in achieving funding for ERT please contact the MPS Society's advocacy support team on 01494 434156.

Achieving Funding for ERT

WORLD Lysosomal Disease Research Network Symposium

Cheryl Pitt

Cheryl Pitt

Mid-May 2004 I was fortunate enough to be invited to speak at the WORLD Lysosomal Disease Research Network Symposium, which was held in Minneapolis, Minnesota, USA.

This impressive scientific meeting spanned three days and featured a number of presentations from professionals in the field of LSDs from around the world. Although MPS disorders form just a few of the lysosomal storage disorders, they received a lot of attention at this meeting, and a number of aspects of the Mucopolysaccharidoses were addressed and discussed.

The meeting began with the presentation of a special award to Dr William Krivit for the many years of work he has dedicated to the treatment of LSDs. William Krivit is a veteran of the LSD world and performed the first bone marrow transplant in the US to treat such diseases.

The first day of the conference then commenced with presentations about Fabry disease, which addressed the importance of building and maintaining a Fabry Registry so that the natural history of the disease could be better understood; cardiopulmonary exercise testing in Fabry disease; and prospects for gene therapy. Animal models of therapy were then discussed in terms of Gaucher disease, Pompe disease, MPS VII, and the Mucopolysaccharidoses in general.

After lunch animal models of gene therapy were discussed in relation to the correction of LSDs and MPS I in particular. The last session of the day focused on stem cell biology, and the evaluation and treatment of MPS I Hurler disease. These presentations dealt with a number of pertinent issues, including the limitations of BMT and the potential migratory properties of mesenchymal stem cells to bone marrow as a way of targeting bone and brain tissue.

They also looked at the various factors that could render BMT a high-risk procedure for some patients, and why Hurler patients could be more at risk of lung problems following BMT than patients with other LSDs. Enzyme replacement therapy was then discussed in relation to the improvement of pulmonary complications in MPS I as a treatment that could be used in combination with BMT.

The second day of the meeting was dedicated to Quality of Life and Natural History of Disease Studies. Appropriate measures of neurobehavioural development that are comparable over time were discussed as important to the study of the natural history of chronic illnesses and to the efficacy of treatment options.

A presentation was then given on the on-going clinical trials of ERT for MPS II Hunter disease, and the treatment was advocated as promising for the amelioration of somatic disease. The long-term outcomes of cognitive and adaptive functions for MPS I following BMT were then discussed, and the results of a longitudinal study were presented. They illustrated how early transplant appears to lead to improved cognitive outcomes, but that motor development is impaired and continues to decline. Adaptive skills (communication, daily living skills, socialisation, and motor functions) appeared to remain stable following transplant, although with slightly slower than average rate of development compared to peers.

Following this was an interesting talk on the distribution of lysosomal storage in brain tissue, which was based on autopsies and tissue analysis. They found the involvement of certain areas of the CNS to be directly related to disease severity prior to death.

After lunch I presented the findings of the pilot study we did last year exploring the psychosocial outcomes of BMT for MPS I Hurler disease, and was followed by Elsa Shapiro who discussed the need to link cognitive profiles to other disease-related biological markers (such as mutation, enzyme, biochemical levels, and treatment-related factors) and to other measures of health status (such as hearing, vision, and orthopaedic impairment). Her rationale was that health-related factors may impact on cognition, adaptive status, and ultimately on quality of life.

The rest of the afternoon was dedicated to interesting presentations and discussions about genetics and ethics. These talks addressed the very sensitive issue of genetic counselling and testing and discussed the pros and cons of genetic technology. They also discussed public policy issues in newborn screening for rare genetic diseases, raising two main questions: When should new tests be incorporated into current mass screening programmes? And once incorporated, how can quality and availability to all be assured?

The answers depend upon cost and the proficiency of tests, which may involve new technology.

The morning of the third day was dedicated to airway management in MPS disorders, and was entitled Symposium of Excellence on MPS Disorders: Airway Safety First.

This mini symposium followed the first Symposium of Excellence, which took place in Manchester in October of 2003 and focused on the orthopaedic management of MPS diseases. Talks in this session covered the anaesthetic management of the MPS I airway, and the anaesthetic complications that can occur in children with MPS disorders. They also discussed sleep apnoea and indications for tracheotomy. The afternoon of this final day then broke off into satellite patient advocacy meetings: MPS, Fabry, and Gaucher.

Overall, the Symposium was a great success that featured some 'big guns' of the LSD and MPS worlds, including John Barranger from the Department of Human Genetics, Pittsburg Medical Centre; Joseph Muenzer from the University of North Carolina, Chapel Hill; Chester Whitley from the Gene Therapy Centre, University of Minnesota; and Charles Peters from the Blood and Marrow Centre, University of Minnesota - these being just a few of the impressive guest and host speakers who participated.

Prior to the meeting I had the great pleasure of working alongside Elsa Shapiro, Neuropsychologist, and her colleagues at the Paediatrics and Neurology department, University of Minnesota. I was very well looked after for three days, and kept busy with patient observations and training. I learnt a lot from the experience and am grateful to all those who shared their great knowledge with me and for the time that they gave.

I am also grateful to the organisers of the WORLD Symposium for inviting me to speak at such an impressive scientific meeting, and to Dr Charles Peters who helped a great deal in the organisation of my trip and extended great hospitality to me during my stay. ■

Aldurazyme Approval in the Netherlands

Hanke Meutgeert

From 1 January 2004 onwards, the Dutch Minister for Health has approved the use of Aldurazyme for MPS I patients.

Arrangements have been made to reimburse the costs of treatment for all eligible patients for the duration of two years. During this time, the hospitals which are marked as centres of excellence for the treatment of MPS I are to collect more data about the therapeutic use of this treatment.

After this two year period, if the therapeutic use is well-established, Aldurazyme will probably get the same status as all pharmaceutical products and will then be reimbursed by all health insurance companies.

International News

ISMRD International Meeting

Dr Ann Hale

Early April in Rockville, Maryland, USA saw a gathering under the auspices of the US Office of Rare Diseases, the National Institute of Neurological Diseases & Stroke and the International Society for Mannosidosis and Related Diseases (ISMRD). The meeting brought together an international group of families, together with clinicians and basic researchers, to discuss the research, clinical care and treatment options for patients with glycoprotein disorders.

Glycoprotein disorders are a group of lysosomal storage diseases characterised by deficiencies of the enzymes involved in the breakdown of glycoproteins or oligosaccharides (Alpha-Mannosidosis, Beta-Mannosidosis, Fucosidosis, Galactosialidosis, Aspartylglycosaminuria, Sialidosis, Schindler and Kanzaki Diseases), as well as those involving errors in enzyme trafficking (Mucolipidosis II and Mucolipidosis III).

The first two days of the conference were devoted to an international scientific workshop titled 'The Glycoproteinoses: an International Workshop on Advances in Pathogenesis and Therapy'. Sessions discussed structure, function and disorders of glycoprotein metabolism, mechanisms of the diseases, animal models and possible therapeutic strategies.

Enzyme Replacement Therapy is not yet an option for any of the Glycoprotein diseases, and Bone Marrow Transplant efficacy has only been preliminarily demonstrated in Alpha-Mannosidosis and Fucosidosis. Treatment, therefore, is largely symptomatic in nature for most.

Following the adjournment of the International Workshop on Friday afternoon, families met in focus groups for specific diseases that allowed them to share and compare their experiences of managing the diseases on a daily basis.

Days three and four were devoted to families, with presentations by scientists and clinicians on day three structured around the themes 'What is known?' And 'What can be done?' A final round table discussion on Sunday morning allowed all families to exchange views and experiences and to discuss ISMRD's future objectives.

While all this talking was going on, the kids had their own programme - and more than one of the 'serious' adult presenters or attendees thought of sneaking off to paint T-shirts, make collages, cards and pictures, play games, go swimming or join in the karaoke! And of course, the ice-cream party was a great success!

There was also a Gala Dinner held Friday evening, where a documentary film was shown. This followed the life of Taryn, the daughter of Paul and Debora Murphy, who founded ISMRD when Taryn was diagnosed and they could find little or no support and information about Mannosidosis. Eventually, through the internet, they met other families and developed the support network and organisation. The ISMRD website can be found at www.ismrd.org.

I met a family from the UK whose 2 year old daughter had been diagnosed with Alpha-Man nosidosis only weeks before the conference. They said 'The great benefit of coming to a meeting like this is that you get to talk to other families and get help and support from them. It's also a wonderful opportunity to talk to the world's experts in these diseases. The researchers and

doctors were so generous in giving us their time, and discussing treatment options with us. It really helped us to make a decision about our daughter's treatment.'

This was the first meeting of its kind to be held for this group of rare Lysosomal Storage Diseases, and it would not have been possible without the drive and vision of the Board of Directors of the International Society for Mannosidosis and Related Diseases, especially its President, Paul Murphy and Secretary, Debora Murphy. ■

Invitation to take part in a Research Study

Jane Ware

I am a Consultant Clinical Psychologist working in the NHS in England. I specialise in working with families of children with a life-threatening or life-limiting illness. I am interested in researching in depth the experience of fathers who have a child with a life-limiting illness.

The aim of the study is to interview a small number of fathers who have a child with a life-limiting illness. The interview will last about 60-90 minutes.

I am particularly interested to learn more about fathers' subjective experiences, how they have coped, what has been helpful or unhelpful, the impact they think that this experience has had on other family members, and any other aspects of the experience that they would like to talk about.

Although I am based in south east England, I would be happy to travel to other parts of the country to interview fathers.

If you are an interested father, or a member of a self-help or support group working with fathers who you think would be interested in taking part in this study, please contact me for more information on 24 hour answer machine 01892 507673 or write to me at:

Freepost
TN1653
Tunbridge Wells
TN3 0BR
Jane Ware
Psychology Department

A Chance to Attend the American MPS Conference at Florida's Disney Resort and visit Disneyland too! 16 - 20 December 2004

The Society for Mucopolysaccharide Diseases is the beneficiary of a major fundraising event, the Ollie G Ball held on 12 June 2004. Some of the funds raised on the day will be used to take 15 MPS member families to the 25th American MPS Conference at Florida's Disney Resort and there will be time to explore Disneyland and some of the other attractions. You will stay in Disney's Coronado Springs Resort, a Disney Resort Hotel and all hotel and air travel costs will be paid for.

If you would like to nominate your family, then all you have to do is complete and sign the enclosed form and return it to the MPS Society for inclusion in the draw.

Criteria

At least one child or adult in the party must have an MPS or Related Disease.

The parents/carers must be members of the MPS Society on 7 July 2004 or the adult sufferer must be a member of the MPS Society on 7 July 2004.

Two adults (parents/carers/adult sufferers) and up to two siblings under 18 years are included in the offer. (Any additional siblings'/additional adults' costs including air travel, additional hotel rooms and Disney tickets will have to be agreed to be met before the application can be entered in the draw.)

New Therapeutic Approaches to the Central Nervous System

Justine Koenigsberg, TKT

TKT Inc (Transkaryotic Therapies Inc) is committed to developing therapies for rare genetic diseases with a major focus in the lysosomal storage diseases area.

Under a much newer initiative than the MPS II ERT Clinical Trial, TKT researchers have been working very hard to understand how to administer treatments to specifically target the central nervous system in MPS II patients in late 2005, at the earliest. If that trial shows that enzyme is taken up in the brain and suggests a new approach to treating central nervous system (CNS) symptoms, TKT believes it will allow the company to expand its initiatives and potentially move an MPS IIIA programme forward.

While TKT is hopeful it can find an approach that will allow the company to move these important initiatives forward, it is a technically challenging approach and there is no guarantee of success.

Clinical Trials for MPS VI Update

Jane Roberts, Royal Manchester Children's Hospital

At last, after 24 weeks of placebo/drug infusions our six MPS VI patients are now entering the extension part of the study that means drug for all on the trial!

This ERT study started back in September 2003 after a couple of stressful weeks of screening and selection. In the end, our six clinical trial patients comprised of two from Italy, one from Taiwan, one from Ireland and two from the UK...an international group!

This meant relocation for the overseas patients leaving siblings, friends, family and their way of life and putting this on hold for six months. An Italian family described this as a 'sacrifice'.

Like most of the ERT trials, their treatment was a four-hour weekly infusion and then, every six weeks, a raft of investigations which meant a stay of a week so we could fit in all the tests! After initial niggles everyone soon settled into the weekly routine and they were helped to do this by our fabulous relocation officer, Nikki, and translators Mrs Heston and Lisa.

During the 24 week period only one patient missed one infusion due to illness. The attendance was fantastic, despite the long weekly journeys and dodgy weather! In fact we have to say an enormous thank you to these young people who have been so tolerant and brave over the past few weeks. They have been absolute stars!

So, we have made it, and recently we said fond farewells to the Italian and Taiwanese families who have returned to regional centres nearer home where the extension phase of the trial continues. Mondays will not be quite the same for a while without the cacophony of languages, but we may have a little more peace and quiet...until they all return in May!

So the extension phase of the ERT study is underway with all receiving drug. This will now continue until the FDA approves the drug and patients are funded locally... KEEP WATCHING THIS SPACE!

This photo of Jack Stuart was taken after his infusion as part of the MPS II ERT Trial. This was perhaps not quite the intended effect!

The Great Weather Lottery

How to Play!

The lottery is really fun to play. Simply select six single lucky numbers (between 0 and 9) to play in our daily game. Every day we will take the last digit of the recorded temperature in Fahrenheit as reported in the Daily Telegraph for six locations and scan all the entries to see who has won.

How to Win!

Although it's fun, you don't even need to check the winning numbers in the papers. We check your numbers on our computer system and prizes are paid out automatically!

Join in and support us!

It costs just £1 per week

All profits raised go to support the MPS Society

Any day you could win up to £10,000 daily

www.theweatherlottery.com

'The Local' choose MPS as their Charity of the Year 2003!

Alex Nicholson-Evans

The Local is a website for eleven to eighteen year olds in Amersham, Chesham, Little Chalfont and Great Missenden. It provides many features including gig listings, film reviews, a message service and, most relevantly, a charity page.

On this page there are regular votes with "Charity of the Year" being the main one. In November, The Local nominated The Society for Mucopolysaccharide Diseases on account of their fabulous work and due to the fact that we felt they deserved recognition in the local youth community.

By January the visitors to www.thelocal.uk.com had voted and the most votes went to the MPS Society making them 'The Local Charity Of The Year 2003'. A very well deserved title!

Christine Lavery receives a certificate from 'The Local' after the MPS Society is nominated for Charity of the Year award 2003.

Sponsored Half Marathon

Jake Rudham

Jake Rudham, father of Archie who has Hunter Disease, recently ran a sponsored half marathon across the Ironbridge. Jake raised £405 for the Society.

Coffee Morning in Aid of MPS

Sue Lowry

Sue Lowry and friends held a coffee morning at Wesley's High Street Methodist Church in Harpenden recently. After expenses they raised £120 for the Society.

igive2.co.uk

Donate to the Society
through online shopping!

Join igive2 and earn up to 20% of your online shopping in donations for the MPS Society. igive2.co.uk is free to join. Shop online via igive2 at hundreds of leading online retailers including Boots, WHSmith, Marks & Spencer, CDWow, Debenhams, John Lewis and Argos. The Society receives a donation from every purchase you make.

Join today and make your shopping count towards helping us.

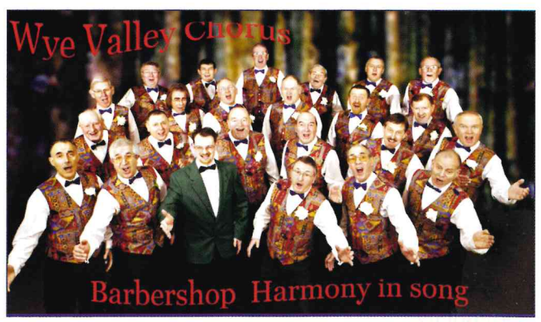
www.igive2.co.uk/MPS

Wye Valley Chorus

Peter Rennoldson

Peter Rennoldson, father of Megan Rennoldson who has Mannosidosis, is a member of the Wye Valley Chorus. They held a fundraising event recently and raised £201.55 for the MPS Society. Now that they have raised some awareness of MPS in their local area, the idea of holding another concert has been mooted for the future. The Wye Valley Chorus get together on Tuesday evenings in Monmouth to practice.

They often go to a pub and sing to surprised and delighted pub goers! (Only once or twice have they driven people away). They often organise fundraising activities and compete nationally and sometimes internationally.



If you would like to organise a fundraising event for the Society please contact Gina on 01494 434156. The Society can provide a fundraising pack filled with ideas and information to make sure your event is fun, safe and profitable!

Donations

Benham Charitable Settlement
A G Parfett & Sons Limited
Tungscarb Products Ltd
Mrs May White
Bison Group Ltd
Beheshti Familly
N M Rothschild & Sons Ltd
The Herbert and Peter Blagrave Charitable Trust
The Shauna Gosling Trust
Homebase - Surrey
Marks & Spencer - High Wycombe
Tesco Stores Ltd - Amersham
Wessex Water PLC
Joseph Strong Frazer Trust
Marks & Spencer - Milton Keynes
Mattel Europa B.V.
The Really Useful Group Ltd
Vinci PLC
Alton Towers
Waitrose - Chesham
Charity Flowers Direct
Mrs Joan Doyle
Belinda Lady Netherthorpe
The Health Foundation
TKT Europe - 5S
Mr & Mrs Jones - Kingswinford
The Morgan Crucible Company plc
Mrs Joan Doyle - Haddenham
The Gordon Fraser Charitable Trust
Defence Transport and Movements Agency
Mrs Eileen Drayne
McGrattan Family
Oldbury Charity Fundraisers
Hambly Family
Farley & Bride Limited
Northgate Information Solutions
John Lewis Partnership
Janet Jones
Staples UK Ltd
Associated British Ports
James Weir Foundation
Biomarin Pharmaceutical Inc
Stanley Stein Charitable Trust
The Go-Ahead Group plc

Collection Boxes

The Local - Amersham

Stamps, Foreign Coins & Mobile Phones

West Wiltshire PCT (Adult & Community Services)
Miss Letitia Ricketts
Beheshti Family
Samantha Vaughan
ICCS MacGregor
Maria Heap
Andy, Kate & Isaac Hall
Mrs Joan Donaldson
Christopher Croft
Coastfields Hoilday Village - Skegness
Williams Family and Friends
Crossflight Ltd

Fundraisers

Woodbridge Park Golf Club - Chippenham (Firework Display)
Kirstie Stone - Donation of Card etc Sales
Martin Saberi
Caversham Folk Festival
Wye Valley Chorus
Jane and John Heritage - Marmalade Sales
Jake Rudham - Ironbridge Half Marathon
Lucy Dorkins - Pampered Chef Coffee morning
Joanne Plummer - Webb Ivory Sales Commission
Janet Mackay - Sponsored Weight Loss
Tim Cotton - Berkhamsted Half Marathon
Pam & Ken Ballard - Sale of Tennis Balls
Methodist Church, Harpenden - (Coffee Morning)
Staff of Parragon - New York Marathon
Bridie Corcoran - London Marathon

Money in Memory

Olivia Bailey
James Edwards
Lilwyn Vera Fuller
June Pirie
Mr George Harris
Sarah Lowry

denimstrate...you care

Jeans for Genes Day

Friday 1st October 2004

Denimstrate...you care on Jeans for Genes Day by throwing out the usual dress rules, wearing jeans and donating £1 or more to the appeal.

In the UK, one baby in every 33 is born with a genetic disorder or birth defect. Please help Jeans for Genes to raise £2.7 million to fund pioneering research and to provide vital support services.

For your **free fundraising pack:**

visit **www.jeansforgenes.com**
call **freephone 0800 980 4800**
or return the **coupon** below.

Eight national charities working together to help sick children

Great Ormond Street Hospital Children's Charity Reg. Charity No. 235905 ©1969 GOSHCC

The Primary Immunodeficiency Association Reg. Charity No. 803217

The Chronic Granulomatous Disorder Research Trust Reg. Charity No. 1002405

The Society for Mucopolysaccharide Diseases Reg. Charity No. 257034

The Neurofibromatosis Association Reg. Charity No. 1073790

Rett Syndrome Association UK Reg. Charity No. 327308

Muscular Dystrophy Campaign Reg. Charity No. 205095

The Haemophilia Society Reg. Charity No. 288200

The net proceeds from the 2004 Jeans for Genes Campaign will be distributed among the charities.
Jeans for Genes Campaign™ Reg. Charity No 1062206.

Registration Coupon

If you registered with the appeal in previous years you will automatically receive your pack in early September

Name:

Position:

Organisation:

Address:

Postcode:

Telephone: Mobile:

Email:

Please return to: Jeans for Genes Appeal, PO Box 5, Colchester CO2 8GE

J4G: MPS