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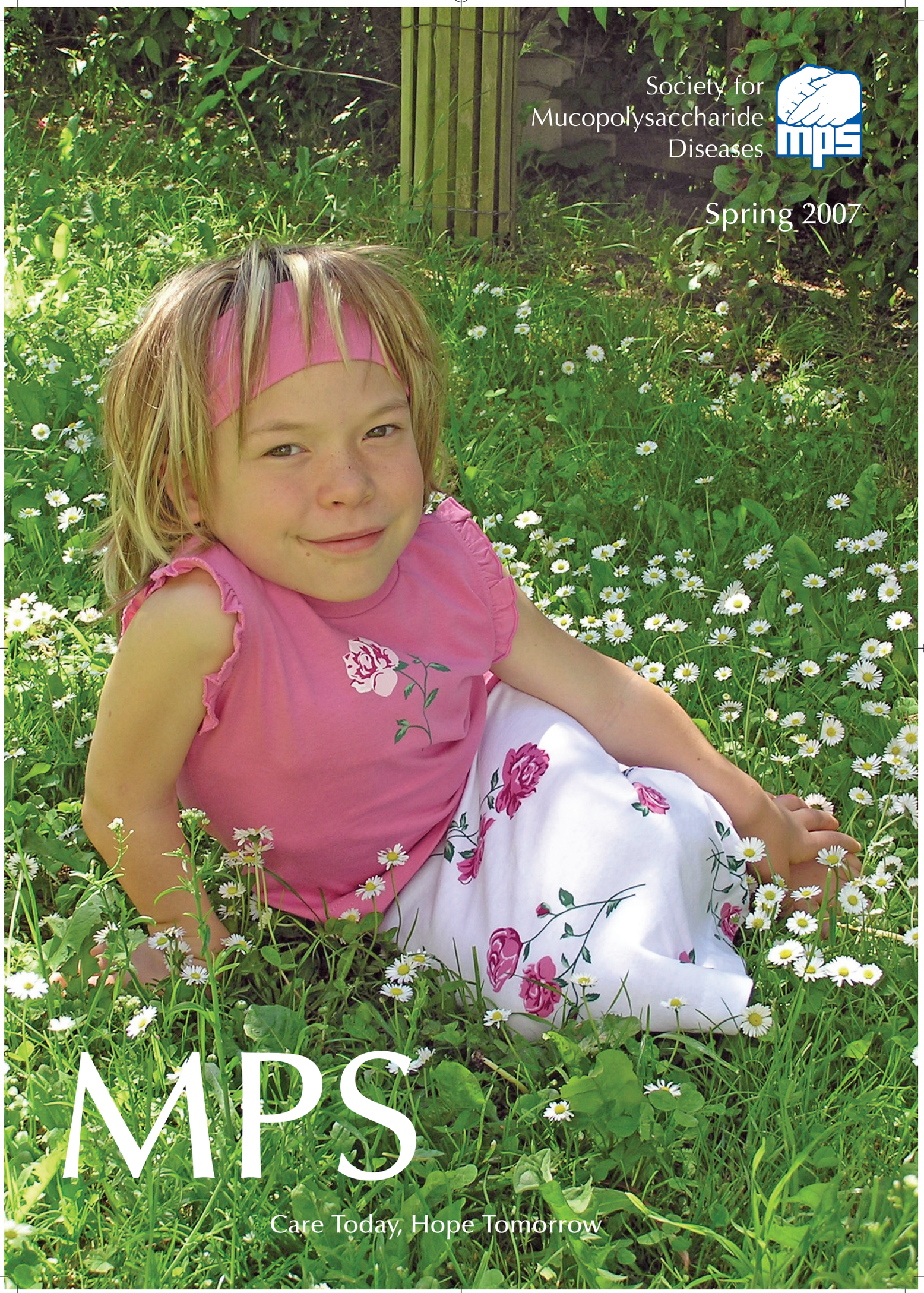

Society for
Mucopolysaccharide
Diseases

Spring 2007

MPS

Care Today, Hope Tomorrow

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Mucopolysaccharide and Related Diseases are individually rare; cumulatively affecting 1:25,000 live births. One baby born every eight days will be diagnosed with an MPS or Related Disease. These multi-organ storage diseases cause progressive physical disability and, in many cases, severe degenerative mental deterioration resulting in death in childhood.

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 1200 children and adults suffering from MPS and Related 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.

What are the aims of the MPS Society?

To act as a support network for those affected by MPS and Related Diseases

To bring about more public awareness of MPS and Related Diseases

To promote and support research into MPS and Related Diseases

How does the Society achieve 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 Individuals 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

Quarterly Magazine
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

MPS Awareness Day
Tuesday 15 May 2007

CARE TODAY HOPE, TOMORROW

Cover photograph:
Maria Weigl, MPS IV

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MPS Magazine

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Newsletter Deadlines

Summer	1 Jun 2007
Autumn	1 Sep 2007
Winter	1 Dec 2007
Spring	1 Mar 2008

Become a Friend of MPS

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MPS Conference

29 June - 1 July 2007
Hilton Hotel Northampton

Book now for last remaining places.
Contact us on 0845 389 9901

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CHIEF EXECUTIVE'S REPORT

Writing this report coincides with the most welcome news that Ministerial approval has been given for the extension of the National Designated Service for Lysosomal Diseases from April 2008 to March 2012. This is without doubt the best news our members and their families in England could receive irrespective of which Mucopolysaccharide or related disease you are affected by.

So where does this leave our members and their families living in Scotland, Wales or Northern Ireland? The simple answer is that most of you are managed by paediatricians and physicians who are highly knowledgeable of the clinical management of Fabry disease, MPS and the rarer related diseases, however, the biggest problem is related to access to Enzyme Replacement Therapy. In Northern Ireland the Parliamentary under Secretary, Paul Goggins, MP, has confirmed commitment to LSD patients accessing ERT and announced an increase in funding of £440,000 in April 2007. The situation in Wales and Scotland is less comfortable for our members and the Society is working with individual members to achieve funded ERT. Wherever you live in the UK if you are concerned that you or your child are not receiving appropriate clinical management or are being denied any treatment including ERT, please contact the Advocacy Team. The Society is here to help you.

Another area of Clinical Management that has been exercising our minds is the development of Metabolic Clinical Networks. Lysosomal storage diseases make up just 50 or so of nearly 800 metabolic diseases so far identified. The Society does favour the principle of Clinical Networks and the enhancement of Clinical Management and care for all people affected by metabolic diseases. For over 20 years there has been an excellent informal paediatric MPS Clinical Network that has also included diagnostic and prenatal services and research between Great Ormond Street Children's Hospital and the Royal Manchester Children's Hospital that has been the envy of those in Europe and beyond. Addenbrookes Hospital joined this network when NSCAG for LSD's came into place in 2004 and we are very pleased that NSCAG status has been awarded to Birmingham Children's Hospital from April 2007.

Over the last six months the MPS Society has become increasingly concerned by the activity of a handful of individuals, mainly laboratory scientists, who are single-mindedly set to impose their own idea of Metabolic Clinical Networks without consultation with stakeholders - 'You'. The most concerning proposals are that metabolic patients for instance, and that includes MPS and Fabry, in South Yorkshire and Humberside, may no longer have access to the MPS Clinical Team at the Royal Manchester Children's Hospital and may have to travel to Birmingham for their clinical care on the dictate of two laboratories. These individuals plan by May 2007 to advise Ministers accordingly. Furthermore, LSD patients in the South West have no recognised National Designated Centre, their needs do not appear to be recognised on the current clinical network plan apart from an assumption that patients from Land's End to South Gloucestershire would be managed clinically in either London, Birmingham or Manchester.

The MPS Society appreciates that our members have enough to cope with in their daily lives and so has to date worked hard behind the scenes to introduce some accountability and transparency to this procedure. Conspiracies like this cannot prevail, eroding patient choice against stated government policy. As our members know, there are a large number of excellent people working in laboratories throughout the UK but for the benefit of the handful who forget, 'you can't post patients like you can blood, urine, skin cells, or fibroblasts', think about the patient and their families to whom these samples belong. The good news of NSCAG designation for LSD's until 2012 should leave all those affected by Fabry, MPS and related diseases unaffected by these networks until 2012. However, the Society's members of today can not be complacent and we need to act now to safeguard patient choice for the future. If you are concerned by how these clinical networks may affect you please do let me know. c.lavery@mpssociety.co.uk

Christine Lavery
Chief Executive

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News from the MANAGEMENT COMMITTEE

The Society's Board of Trustees meet regularly. Here is a summary of the main issues that were discussed and agreed at the two Management Committee Meetings held on 2nd December 2006 and 2nd - 3rd February 2007.

Governance

The MPS Risk Register was reviewed and changes agreed. The following policies were received and agreed without amendment: Conduct for Chief Executive, Staff Conduct, Conduct for Trustees, Managing Abusive Phonecalls, Working Away from the Office, Overseas Travel and Subsistence, Financial Controls, Volunteers Carers Conduct, Medical Research Grants, Redundancy, Maternity, IT and Senior Management Team Conduct.

Personnel

Trustees expressed their good wishes to Charmaine Scott, Volunteer and Events Co-ordinator, who was leaving her employment with the Society in February having been head-hunted for another post. The CEO advised Trustees of Sophie Thomas' pregnancy and agreed that Neisha Hall become Acting Senior Advocacy Officer during Sophie's maternity leave. Trustees were informed of Miriam Blowers' appointment as Office Manager / PA to CEO.

Advocacy Support

The Trustees received a report at each meeting on Advocacy Support to our members. In the period of 1st October 2006 to 31st January 2007 over 150 families in England, 23 families in Scotland, 9 families in Wales and 9 in Northern Ireland had received Individual Support from the Advocacy Team. The most common problem is housing, equipment and adaptation followed by educational needs, direct payments, assistance with grants and access to Clinical Management.

International Collaboration

The Trustees received feedback on what was an incredibly busy Autumn internationally and agreed the CEO's participation in the EPPOSI Conference in Dublin and Genzyme LSD meeting Vienna.

Generating Funds

A list of grants applied for and received was tabled at each meeting. The Trustees were advised that there are a large number of applications pending decisions. Trustees were advised that the level of income from the Jeans for Genes appeal held in October 2006 was currently running at below that of the year before.

MPS Research Grants

The CEO appraised Trustees of the current status of all current MPS Research Grants and was advised that five applications for research grants had been received by the deadline. Trustees also considered the programme grant looking at psychosocial issues and agreed that the priority is MPS IV at this time.

Access to Clinical Management and Treatment

Trustees received a detailed feedback on the status of funding for ERT and the discrimination between the four countries of the United Kingdom in accessing treatment for Fabry, MPS I and MPS VI. Consideration was given to MPS II which was due for approval by the EMEA in January 2007.

MPS Awareness Day

Tuesday 15 May 2007

Each year the Society will celebrate MPS Awareness Day on 15 May. This will be a day devoted to raising awareness for the group of 21 rare, genetic diseases known as MPS and Related Diseases.

For more information on how to get involved please phone us.

0845 389 9901

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New faces at the MPS office

Caroline

Hello, my name is Caroline Anderson and I have become part of the MPS team as Advocacy Assistant.

I first started at the MPS Society in January 2006 on a temporary contract to assist the Advocacy Team in managing the MPS filing systems. My position was made permanent in November 2006.

In January 2007 I started a college course in computers to keep up to date with my 9 year old daughter, Lucia, who often has to assist me!

I enjoy going to the theatre and the cinema, and we are currently in the process of renovating our house.

I am looking forward to meeting some of you very soon but in the meantime if you would like to contact me my email address is c.anderson@mpssociety.co.uk

Miriam

My name is Miriam Blowers and I am a new member of the team at the MPS Society. I started on 2 January 2007 as Christine Lavery's PA and the Office Manager. I am really enjoying being thoroughly busy and being a support to Christine and her huge workload as well as helping book appointments and corresponding with families and trustees and anything else that crosses my path. I am loving being a part of the team and felt at home straight away.

I have recently got married to a very lovely man named Duncan. I am one of those strange people that loves organising people (especially Christine) and live just down the road from the offices. I am looking forward to the conference and meeting some faces having spoken to many on the phone. I also can't wait for the sun shine to start as I am an Australian who is slightly seasonally depressed due to cloudy, rainy weather.

I look forward to supporting Christine some more and also helping the rest of the team out in the office as Office Manager. If you need to contact me directly you can do so either by phone or email m.blowers@mpssociety.co.uk

Congratulations to Antonia and Steve!

Many congratulations to
Antonia Crofts, now Antonia Anderson,
HR and Information Officer at the MPS Society.
Antonia was married on 9 December 2006.
Best wishes to Antonia and Steve
for a long and happy future together,
from all the MPS Society.

Your news and views

We are always pleased to receive news, information and letters from all our readers, especially our members. We welcome letters on any subject and your views and comments would be very welcome. Email us at newsletter@mpssociety.co.uk

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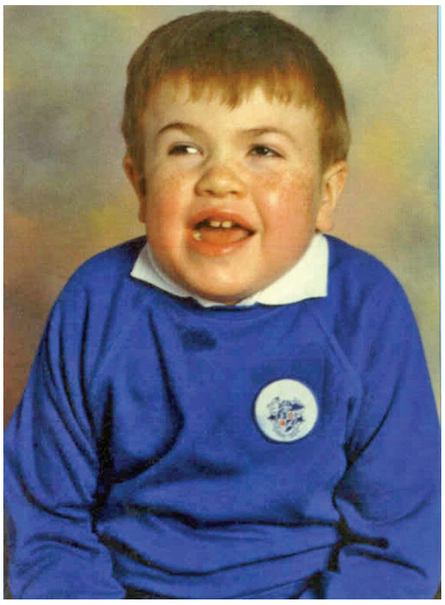
Christopher Andrew Croft



Christopher Andrew Croft who suffered from Hunter Disease died on 17 February 2007 aged 13 years. He was a joy to have known and he touched so many hearts in his short but eventful life. From his hyperactive early years to his quieter final years, Christopher's personality shone through. He will always be remembered for his cheeky infectious laugh, his wonderful smile and his expressive eyes.

We are forever indebted to Dr Wraith and his team, Mr Rothera and the nurses at Royal Manchester Children's Hospital. Without them Christopher wouldn't have had a tracheostomy operation in October 2005, an event which changed our lives, but gave us 17 extra months to treasure.

Our much loved son Chris was also the beloved brother of Laura and Jason. He was:

Too young to die,
Too precious to lose,
It was God's will,
We could not choose.
Loved and remembered always,
Carole and Jonathan

New Members

Mr and Mrs Evans have recently been in contact with the Society. Harry has a diagnosis of Hurler Disease. Harry is 11 months old. The family in the South East.

Mrs Hanrahan has recently been in contact with the Society. Mrs Hanrahan has been diagnosed with Fabry Disease. The family live in the South East.

Mrs Pauline Green has recently been in contact with the Society and has a diagnosis of Fabry Disease. Pauline lives in the North West.

Mr Boyling and Ms Lock have recently been in contact with the Society. Summer and Mabon have a diagnosis of Sanfilippo Disease. Summer is four years old and Mabon is two years old. The family live in Wales.

Mr and Mrs Lever have recently been in contact with the Society. Aaryanna has a diagnosis of Hurler Scheie disease. She is five years old. The family live in Northern Ireland.

Mr and Mrs Milby have recently been in contact with the Society. Their daughter Katie has a diagnosis of Morquio disease. Katie is four years old. The family live in Scotland.

Tracey and Scott Williams have recently been in contact with the Society. Their son, Lewis, has been diagnosed with Mucolipidosis III. Lewis is five years old and the family live in the South East.

Mr Stefan Milton has recently been in contact with the Society. Stefan has a diagnosis of Morquio Disease. Stefan is 16 years old and lives in the South East.

Deaths

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

Aisha Hanif who suffered from Sanfilippo Disease and who died on 10 December 2006 aged 12.

Sharon Bush who suffered from Sanfilippo Disease and who died on 14 January 2007 aged 36 years.

Francesca Kembrey who suffered from Sanfilippo Disease and who died on 5 February 2007 aged 15 years.

Melanie Jones who suffered from Sanfilippo Disease and who died on 12 February 2007 aged 16 years.

Christopher Croft who suffered from Hunter Disease and who died on 17 February 2007 aged 13 years.

Kieron Hughes who suffered from Hunter Disease and who died on 26 February 2007 aged 11 years.

Jordan Walker who suffered from Sanfilippo Disease and who died on 12 March 2007 aged 15 years.

Alfie Parker who suffered from Sanfilippo Disease and who died on 13 March 2007 aged 13 years.

Surfraz Khan who suffered from Scheie Disease and who died on 3 October 2005 aged 34 years. The Society was saddened to have recently heard this news and pass on our best wishes to his family.

Apologies for error in previous MPS Magazine:
Kyle Shields who suffered from Sanfilippo Disease and who died on 13 October 2006 aged 13 years, not 15 years as stated.

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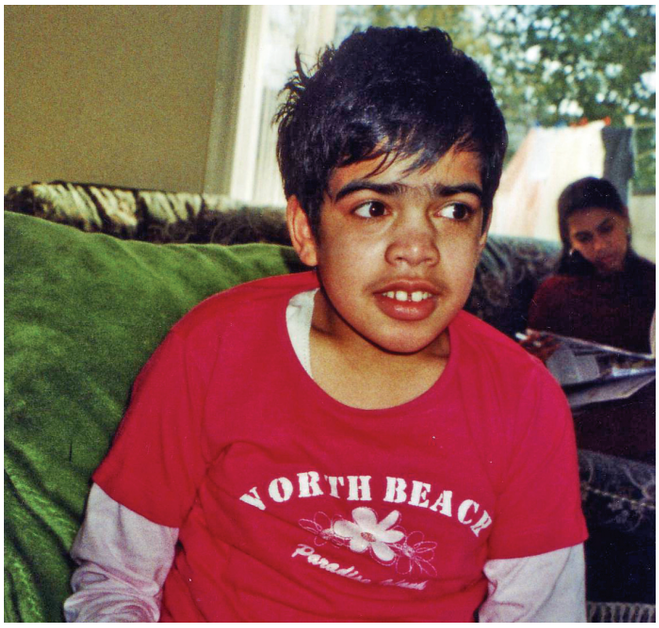
Aisha

Aisha Hanif passed away on 10 December 2006 at Sheffield Children's Hospital at 8.30pm. She died of a chest infection which turned into pneumonia. She died two weeks before her 13th birthday which was on 23 December 2006. We all miss Aisha very much. She was such a beautiful child, full of life. Aisha left behind a sister Aamina, aged 10, and two brothers Ibrahim, aged 8 and Isa, aged 2. Aisha died one day after her sister, Aamina's, 10th birthday. Here are a few poems that people have written about Aisha:



Aisha

Aisha, you never asked
For much in life
Your heart was true
And tender
You always
Remembered
The ones you loved
Now ones you loved
Remember you!
This poem was written by Aisha's Auntie Mumtez Bibi.

Aisha

Your memory is our own keepsafe
With which we'll never part
Allah has you in his keeping
We have you in our hearts

Admired by many
Infectious smile
So many people loved you
Happy
Adored forever
This poem was written by Aisha's cousin
Sabrina Bibi, aged 17.

A meeting was held quite far from Earth
'It's time again for another birth'
Said the angels to Allah above
'This special child will need much love'

Her progress may seem very slow
Accomplishments she may not show
And she'll require extra care
From folk she'll meet from way down there

She may not run, laugh or play
Her thoughts may seem quite far away
In many ways she isn't adept
And she'll be known special

Please Allah find the parents
So let's be careful where she's sent
We want her life to be content
Who will do this special job for you

They will not realise right away
The leading role they're asked to play
But with this child sent from above
Comes a stronger faith and richer love

And soon they'll know the privilege given
In caring for the gift from heaven
Their precious charge so meek and mild
Is heaven's very special child

I remember her at the age of eleven
Her eyes and smiles aglow
She was the light from the sun
And her passing dark of night

Knowing she was going soon
We grieved while she still lived
At the age of twelve her face changed
Puffy as a 'dough boy' babe.

She fought the lump at the base of her brain,
Science could not touch.
Her laughter cut through our weeping,
Valiant in the face of tragedy.
My soul it burned – no end in sight,
The day I saw her chest rise no more.
By Aamina, aged 10, Aisha's sister

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God sent me an angel

God send me an angel
It had a broken wing
I bent my head and wondered
'How could God do such a thing?'

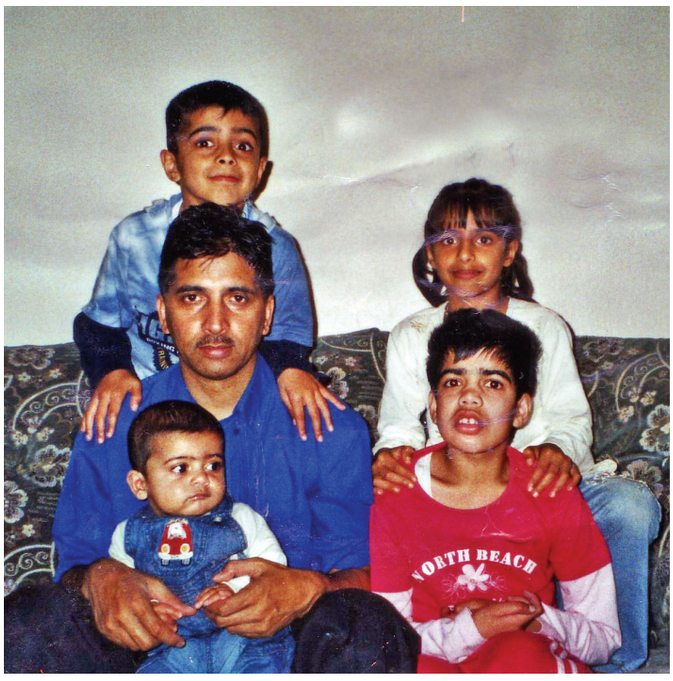
When I asked the God
Why he sent this child to me
The answer was forthcoming
He said 'Listen, and you'll see'.

'My children are all precious,
And none is like the rest
Each one to me is special
And the least is as the best.

I sent each one from Heaven
And I place it in the care
Of those who know my mercy
Those with love to spare

Sometimes I take them back again
Sometimes I let them stay
No matter what may happen
I am never far away.

So if you find an angel
And you don't know what to do
Remember I am with you
Love is all I ask of you

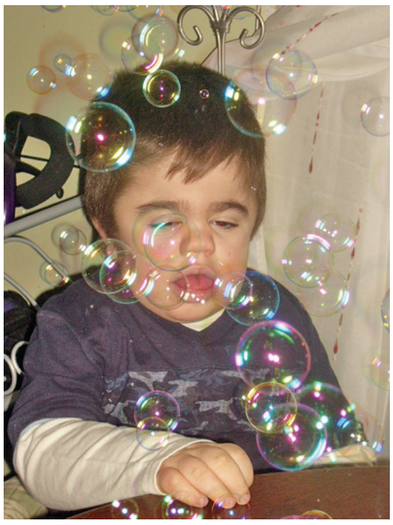


God sent to me an Angel was written by one of the carers at St Stephen's Respite Care where Aisha used to attend on a weekend and during school holidays.

Jennifer Greene

It was with sadness that we learnt of Jennifer's death following her battle of 25 years with Cystinosis. Jennifer was the daughter that inspired her parents, Peter and Lesley Greene to set up the Research Trust for Metabolic Diseases known as CLIMB. Our thoughts are with Peter, Lesley and Jennifer's sister, Rebecca, at this time.

Congratulations to Will Brodie, MPS II, pictured right, who celebrated his 7th birthday on 11 January 2007.



Do you need support from the MPS Advocacy Team?

Please remember that should you wish to speak with a member of the advocacy team do not hesitate to pick up the phone or email if you find it easier. Please bear in mind that at the moment we are a small team covering the entire UK, however we will always return calls and respond to messages as quickly as possible. **advocacy@mpssociety.co.uk or 0845 389 9901**

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MPS Awareness Day
Tuesday 15 May 2007

2007 Dates for your diaries!

May

10 May	Northern Ireland Clinic
11 May	Cardiff Clinic
31 May - 3 June	Euro Disney

June

21 June	MPS III Clinic GOSH
29 Jun - 1 July	MPS Conference

July

10 July	Bristol Clinic
27 July	BMT Clinic Manchester

August

31 Aug - 2 Sept	Sibling Weekend

September

15 Sept	Chessington World of Adventures

October

2 October	Bristol Clinic
13 October	London Aquarium/ London Eye
19 October	BMT Clinic, Manchester
19 October	Childhood Wood Tree Planting

Chessington World of Adventures
Saturday 15th September 2007

The MPS Society is holding a Family Day trip to Chessington World of Adventures. There will be a range of rides (not all wheelchair suitable) and activities available.

This event is being sponsored by Help A London Child.

Should you and your family wish to attend, please complete and return the form enclosed with this magazine.

The Society invites you to join them for a

Family Day in London
Saturday 13th October 2007

The MPS Society is holding a Family Day trip to London, to visit the London Eye and the Aquarium. This event, sponsored by Help A London Child, will give families affected by MPS the chance to meet up with old friends and also make new ones.

Should you and your family wish to attend, please complete and return the form enclosed with this magazine.

MPS Sibling Weekend
Centre Parcs, Nottingham, 31 August - 2 September 2007
LAST FEW PLACES REMAINING!

The Society is delighted to offer this opportunity for MPS Siblings to participate in a fun-filled weekend at Centre Parcs in Nottingham. This is sponsored by the Newby Trust and the D'oyly Carte Charitable Trust. There are still places left and we would love as many siblings to come as possible so please complete the form enclosed with the last magazine or phone us on 0845 389 9901. If your child or children would like to attend but you can't get them to Centre Parcs please don't be put off. Contact the MPS Office immediately to discuss how we can help. Please note that if there is insufficient interest in this event the Society will not be offering a siblings event in the foreseeable future.

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Aasiya's Anthology

I am Aasiya Allana and I have Hurler Scheie. I have loved writing poetry since well, I'm not sure when. I also enjoy reading, swimming, shopping and spending time with my family. I wanted to write an Anthology to show you what I enjoy. When I was sitting at home I was thinking about what sort of piece I should write for my coursework when it struck me. How about, I thought, I do a book of poems since I love writing them. So I decided to do it. I certainly hope you will enjoy my poems and if you feel you can make a change go for it like I have!

Perfect sister recipe

Begin with bags of laughter
Add a teaspoon of sadness
And an ounce of happiness
Mix with a helping hand
For added anger
Next stir in excitement
Bake for friendship
And serve with manners

My hobbies

I like reading in bed
When the stars are up ahead
I like swimming in the pool
Where the water is nice and cool
I like chatting to my pals
Cousins, friends and anyone else
I like shopping in the malls
Looking at what's on the stalls
But best of all I like to do
Is snuggling up with my teddies too

My dream

My dream is to have a big house
And so I can move about
I'd like to have a large bedroom
And a large swimming pool
I will have helpers
To look after me
And a car for myself
Driven by a chauffeur
But best of all I'll always call
My family to come over for a ball

Books

I love to read
Never mind what it is
About someone's dream
As long as it's a whiz

Fairies, poem or a butterfly
Just put a book by my face
Even just flutter by
As long as it's not a waste?

Most people just don't bother
Rather be a poser
But I'll read with my mother
And read the words closer

My favourite foods and desserts

I love eggs
With sausages too
Crispy chicken legs
Best with potatoes, woo!
I love noodles
And chicken and mushroom pie
Doesn't really matter why
My favourite dessert
Is chocolate mousse
Cake so sweet and muffins too
Crunchy biscuits must be plain, dip in will be great
My best drinks are
Water, juice and anything else,
Milk, tea or anything hot
They are all just great for me!

Editor's Note: This is just a selection of poems from Aasiya's Anthology. Aasiya is looking to publish her complete anthology so if you can help her with this please contact us at newsletter@mpssociety.co.uk.

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Wonder drug gives brothers the gift of life

A mother of two boys suffering from the rare genetic condition Hunter Syndrome spoke of her joy this week following the decision to license a new wonder drug for use in the UK.

Claire Stevens, of Badshot Lea, told The Herald how she expected her sons Oliver and Samuel, aged seven and five, to 'get their futures back' once they start the life-long treatment in April.

The new drug, Elaprase, is hoped to prevent the onset of some aspects of the disease, which can cause organ failure, stunted growth and severe heart problems.

Clinical trials of the drug began in the US with it reaching Europe in 2004. Although trials are now complete, the family have been waiting for it to be licensed in Britain - an ongoing battle that has seen support from friends, family and even local MP Jeremy Hunt.

'We hoped to be receiving the drugs early last year but unfortunately we were made to wait,' explained Mrs Stevens.

'The boys are going to get their futures back which is excellent because they are very lively to say the least. They will take the drug for the rest of their lives but they are both oblivious to it all really. I've told them that they're going to get a magic medicine.'

In reality, it might not be so magic for the boys, who will have to endure a four hour infusion once a week via a Port-a-Cath attached under the arm, delivering the drugs directly to the heart.

'When we start the treatment they're going to find it hard but they're both very brave little boys and I'm so proud of them. Samuel is quite excited because he just thinks about being able to run faster and I'm happy that it will start undoing some of the damage which has built up within them already.'

She explained that both boys suffer from glue ear as a result of the syndrome and they are short for their ages owing to the disease's ability to stunt growth. They also have large stomachs, spleens and livers. However, Elaprase should help with these problems and prevent further, possibly disfiguring ailments, from arising.

The condition, a hereditary metabolic disease stemming from the lack of a protein needed to break down certain molecules, primarily affects males. Although some women have been known to suffer from Hunter Syndrome, they tend to be carriers of the disease, often completely unaware that they could be passing on a potentially terminal illness to a son.

'I had 19 weeks of feeling that I was the luckiest mother in the world with two healthy boys,' she said, recollecting the period leading up to April 2002 when the boys were diagnosed.

'Oliver was two and a half and Samuel was just 19 weeks old and it came as a huge shock. I'm just desperate to get the drug into them before any more damage is done,' she continued.

Mrs Stevens highlighted the work carried out by MP Jeremy Hunt in assisting them over the years and fighting their case nationally. 'He's bent over backwards for us and has generally been an absolute star,' she exclaimed.

'Most of the rest of Europe has already started to use the drug but the UK didn't want to before carrying out its own research and trials. Jeremy has been really pushing for it ever since I contacted him before he came to power and it's really lovely to have somebody like that to be such a wonderful source of support to us.'

Although Oliver and Samuel will both be able to receive the new drugs in April, Mr Hunt believes that they should get them 'right away', as the decision has already been made. He said: 'I was very pleased that after so much campaigning, Elaprase is to be licensed from April, although given the decision has been made, I don't see why the treatment can't start right away.'

'Samuel and Oliver are wonderful boys, but most of all they are lucky to have such determined and committed parents. I know

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their success will give hope to many parents with children suffering from rare degenerative diseases.'

While the Herald has been following their story since the diagnosis in 2002, the BBC has also been closely watching them and hopes to film their treatment in April. Mrs Stevens looks forward to showing off her directing skills when she is given a camera to take into hospital to film the event for BBC South Today.

She added: 'It's important for others to see it and it's nice that the BBC are genuinely interested in us.'

She hopes that the new drug will drastically lengthen the boy's life-span, saying that she 'expects to see them around' for many years to come.

'I told them that they could look after me in my old age and they said they would take me out for a Happy Meal,' she laughed.

'That just goes to show the innocence of it all really. I want them to stay loved and cherished by everyone as so many local people have been fantastic in their support.' As the family begins to prepare for the treatment and the new lease of life it will bring, Mrs Stevens feels nothing but pride for her two boys. 'They're both so brave and I love them.'

Article appears courtesy of the Farnham Herald. Article written by Chris Joint.

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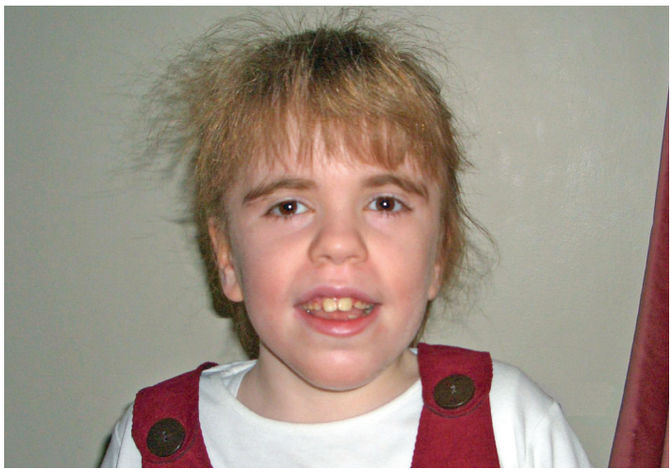
Having a Gastrostomy



My name is Sally Summerton. I am married to Tim and we have two children, William and Sophie. Sophie, pictured above is nearly 10 years old and has Sanfilippo Type A.

When Sophie was diagnosed in 2001 we saw Dr Vellodi at Great Ormond Street who told us that it was highly likely she would need a gastrostomy in the future. We were both horrified at this thought and hoped it would be one of the things we could avoid. We could not bear the thought of our perfect daughter with a tube coming out of her stomach as this would mean we really had to accept and come to terms with the fact that her condition was worsening. Little did we realise the extent of the benefits.

However, as predicted, time went on and Sophie's swallowing ability deteriorated. She was having more and more problems with drinking and all her food was being cut up or liquidised. She was still eating and enjoying the taste of food though mealtimes were getting longer, often taking about four hours a day, and she often choked. The time had come for her to have the operation.

The gastrostomy was carried out in August 2006 at Great Ormond Street Hospital. We met a wonderful stoma nurse who explained in simple terms (not the normal medical jargon) what exactly was involved and how they would get the tube into Sophie's stomach. She also explained the aftercare to us, showing us how we should clean around the site etc, and reassured us that we were doing the right thing as she had met so many parents facing the same dilemma as us.

It was the first time Sophie had had a general anaesthetic and we were both extremely worried about that, never mind the gastrostomy operation. She was also having some teeth extracted and the Audiology team were doing some tests.

Sophie was in the operating theatre for about an hour and a half which I can only say seemed like an eternity. We went out for a walk around London and for a coffee just to pass the time. Eventually the mobile rang and we were told that she was in recovery. We dashed back to hospital and were with her when she woke up. What a relief! Poor Sophie looked awful as she was bloody from the extractions but she was ok, though understandably not very happy with life!

We returned home the following day and Sophie was fairly bright. However, the next day she was crying non stop and this went on for three days. She couldn't weight bear and was doubled up in pain. We were at our wits end, not knowing how to help her as she could not tell us what the problem was. During this time we were in and out of our local hospital. The gastrostomy site seemed to be ok and her mouth was healing nicely so it didn't seem that these were the problem areas. To cut a very long story short, it turned out that she had been put on a milk-based feed when she is dairy intolerant! As soon as this was changed to a soya feed Sophie recovered very quickly and has been reaping the benefits ever since.

One of my main concerns after the operation was dealing with the feeding and the care of the gastrostomy site. It was a great responsibility and I was worried Sophie might get an infection if I didn't clean her properly but I was surprised how quickly I became an expert! I think initially you look at the feeding tubes and syringes and feel a bit lost but I can assure you it does all fall into place sooner than you think. My friends are very impressed with my newly acquired skills!

Both Tim and I are so pleased that Sophie has had the gastrostomy. She is looking better than she has for ages and her skin and hair are lovely and healthy. She is getting the fluids in her that she needs and is a much happier little girl. It makes us realise how little she had been drinking over the last year and how dehydrated she must have been. Sophie still has regular meals in conjunction with her liquid feeds, so eating can still be a sociable and pleasurable experience for her, but without the pressure and stress of before.

Sophie is going to go back into hospital soon for more dental work which requires another general anaesthetic and we are hoping that the gastrostomy peg will be changed to a Mic-Key. The Mic-Key will sit flush on Sophie and is very discreet, and there won't be a dangly tube like there is with the peg, so less risk of her pulling it out (another worry but to date she has not done this!). The big plus with the Mic-Key is that Sophie will not need an anaesthetic to change it like she would with the peg as it can be changed by a nurse at home.

Our experience with the gastrostomy has been very positive and I wanted to share that with everyone. We spent so much time talking and worrying about the pros and cons of it beforehand and realise now that it has not made our perfect daughter any less perfect than before. We now know that it was the best thing we could have done for Sophie and the whole family. Tim and I have more time to spend together with Will and Sophie and gone are the hours of frustration of trying to get food down her when she was clearly having trouble coping with it. ■ **Sally Summerton**

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At Last... the End Of the Trial!

We wanted to write this article to give hope and encouragement to all those families who have boys with MPS II, Hunter Disease, and have been patiently waiting for the end of the drug trial and the licensing of Enzyme Replacement Therapy.

In January 2004 we were thrilled to learn that Sam had been accepted onto the drug trial. It involved a weekly infusion of Iduronate-2-Sulfatase Enzyme Replacement Therapy. This was initially delivered via a peripheral vein but we soon opted for an internal Port-a-Cath (which has made life much easier for all concerned!).

We are incredibly fortunate to live only 12 miles from Addenbrookes Hospital in Cambridge. This is one of the national centres for Lysosomal Storage Disorders, where Dr Uma Ramaswami, who is a specialist in this field, looks after Sam.

Sam is now 12 and has been receiving ERT for three years while being closely monitored by the drug company for any side affects and also to monitor improvements. We are pleased to report that there have been some big improvements and no side affects! Sam has been growing quite normally and is now 137cm, only just under average for his age. His tummy is flat and his liver and spleen are still within normal limits. He can wear any off-the-peg trousers and looks very slim!

The left ventricle of his heart was enlarged and that too has gone back to normal. There has been no change to his damaged valves but we have been told that their function is adequate and we don't anticipate further deterioration. He has bags of energy and never gets tired legs anymore and has less ear infections. Even all his teeth are through with no more fillings!

I'll leave you to judge from the pictures below whether there has been significant change facially… hard to tell when we see him every day but others have commented that he looks well.

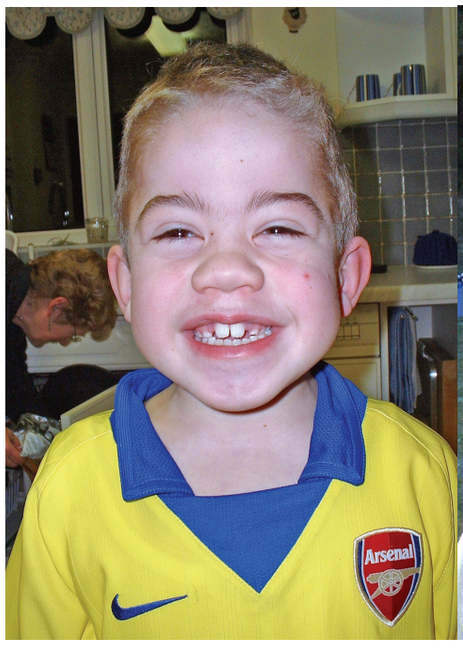
All through the drug trial, and of course since being diagnosed at aged 5, we have had the care and support of Dr Uma Ramaswami and her team and we really can't thank them enough.

All aspects of Sam's condition are taken care of, from speech therapy to new shoes, from ear moulds for swimming, to splints for his bent fingers (they didn't work!). We really feel as if nothing is too much trouble and wish we could express our appreciation more adequately.

We would also like to thank the long-suffering nurses in the Wellcome Trust Clinical Research Facility, where Sam has been having his treatment for the past three years. Particularly Stewart, who can always cheer up Sam when he is in a bad mood.

And finally we would like to send our best wishes to all the boys and their families who are about to start the treatment. Please feel free to contact us via the MPS Society if you have any questions about the treatment you think we could help you with.

Jo Dacey 23 February 2007



Sam - January 2004

Sam - Summer 2004

Sam - Present

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End of MPS II Trial Party

On 4 January 2007, families came together to celebrate a momentous occasion, the end of the three year MPS II trial and the celebration that ERT for MPS II was to be approved. What started off as being a small gathering grew and grew until the final count which stood at approximately 92.

The guest list included all the individuals who took part in the trial across the UK, including their families, doctors and supporting nurses as well as representatives from the MPS Society, Shire Pharmaceuticals, Manchester Children's Hospital, including the Chief Executive, pharmacy, occupational health, physiotherapy, teaching support and many more people who at some point during the three years supported the individuals and their families.

The party was held at the Marriott Hotel in Manchester as they had kindly offered us the free use of a room. The party was to be supported by Shire Pharmaceuticals who kindly donated a pot of money to ensure that the party went with a swing. Selma Oulton and Linda Fuzzard were instrumental in the organising and setting up of the party initially and the Society offered its support as the numbers grew and to manage all the financial side of things.

Thanks to the excellent invites designed by David, the extra funds from Shire and the commitment from many, the party was a huge success.
We were able to provide guests with a reception drink on arrival and a sit down buffet meal.
The hotel did a great job in decorating the room with balloons and setting out the cutlery but left out one vital condiment, the tomato ketchup!
When I asked for some to be supplied I was presented with a single pot of ketchup for one.
After a little chuckle to myself and a brief explanation that we would need many more pots I was given a basket full.

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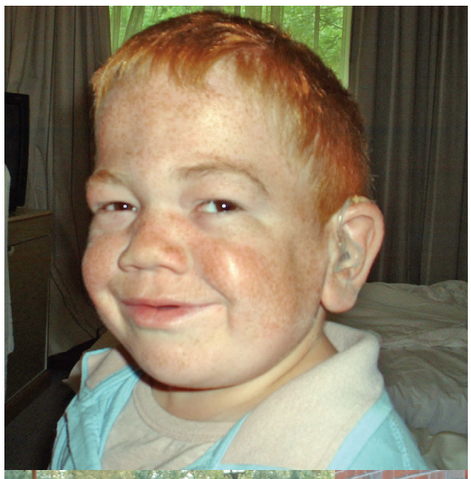

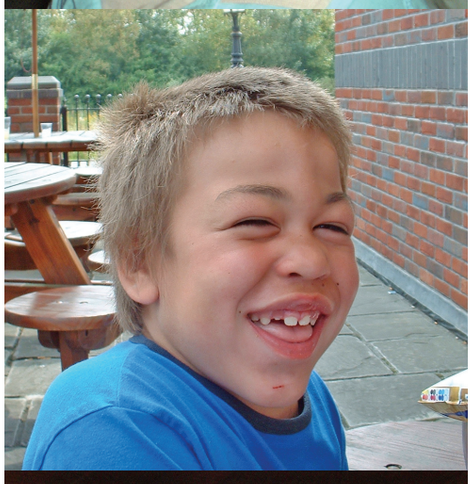

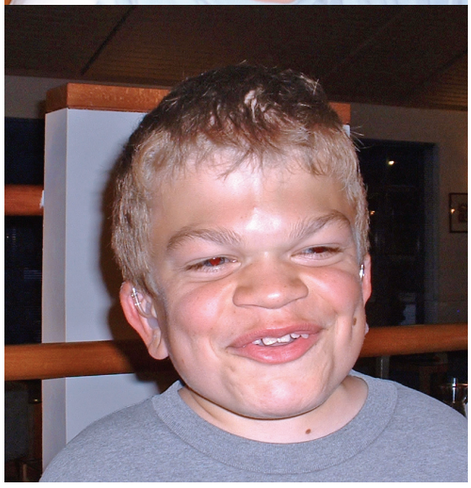

After plenty of food and drink, the speeches and presentations began. Christine opened the speeches with a short welcome to everyone before passing the floor over to Dr Wraith who was followed by Mr Martin Hodgson, Chief Executive from the Manchester Children's Hospital. Claire Garthwaite gave a very moving speech on their family's experience of being part of the clinical trial before she presented the eagerly awaited and impressive MPS II, memory book to all the individuals on the trial and to Shire to say thank you for their support.

Shire gave a brief but heartfelt response before the floor was handed over to the individuals and families for them to make their own personal thank yous to the doctors and nurses who had supported them over the three years. David Oulton and Colin Arrowsmith presented Dr Wraith and Dr Jones with a small token of thanks, as they were to receive a photograph of the boys and young men that was taken earlier that evening. Selma Oulton presented Jane Roberts with a gift on behalf of all the families for the support and dedication she had provided them over the years. All the boys were then invited to centre stage to present a flower as a small token of their appreciation to all the other professionals who had supported and cared for them.

It was now time for the real party to commence, so the music was turned up, the lights were turned down and people were invited to hit the dance floor. The tempo of the night was kept up until the wee hours of the morning, although I have to confess I did slope off a little early. Feedback is that everyone had an excellent time and it was a party to be remembered.

Our thanks go to everyone who contributed or supported the party, especially Selma Oulton, David Oulton, Linda Fuzzard, Shire Pharmaceuticals and the Marriott hotel. ■ **Sophie Thomas**

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Cadbury World

Mmmmmmmmmmmmmmmmmm chocolate! By Sophie Thomas

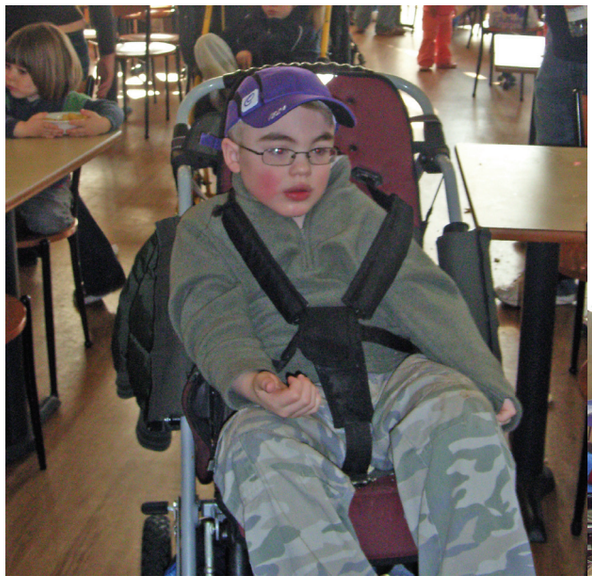
For someone who has been to Cadbury World on a number of occasions and who is a certified chocoholic, I was delighted to learn that we were offering a trip to Cadbury World and volunteered my services straight away.

It was no surprise to learn that a number of families were also keen to go and we had 48 bookings in total. Bargain basement here we come! We arranged to meet everyone in the restaurant area for light refreshments before our tour of the factory and the history of chocolate began. This gave families the opportunity to get to know each other or catch up with people they had not seen for some time. The tour began with free chocolate for all. Some were very good and put it in their bags straight away, some tried to be good but caved in, especially when more free chocolate was given later in the tour, some however dived straight in and had remnants of chocolate around their mouths or up their sleeves as they tried to wipe away the evidence.

As we moved further into the factory the smell of melted chocolate filled our noses. Aahhhhhhhhhh heaven! I think a few people could have stayed in there all day but the smell did not affect the children as much as the adults and they wanted to move on to the fun part, the children's activity centre. This was remarkably impressive and the children were entertained for a long time with interactive games such as having your pose moulded in chocolate, keeping the chocolate bubbles in the air and stamping out all the chocolate splats. This area brought us to the end of the tour and led nicely out to the chocolate shop, where it was very easy to become a child in a sweetshop wanting to buy everything in sight, money permitting of course.

At this point many families went their separate ways; some spent more time in the shop, marvelling at the array of chocolate, while others moved round to the other part of the tour and some decided that lunch was needed.

We hope that everyone had a really good time at Cadbury World and we look forward to seeing more of you when we organise another event in the area sometime in October.



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Newcastle MPS Clinic

The day, 8 February 2007, was off to a good start, and thankfully we didn't get the amount of snow we were forecast, unlike our colleagues we had left in the South! The clinic ran very smoothly, and it was lovely to see all who attended. A big thank you to all involved in ensuring the day went as well as it did, especially to the staff at The Royal Victoria Infirmary who as always had the rooms ready for us, Caroline, Dr Rylance's secretary for all her help and of course a big thank you to Dr Rylance, Dr Leech and Dr Ed Wraith, without their ongoing support we would not be able to run these clinics. **Neisha Hall**

Newcastle Get Together

Despite the cold wind, the snow and the rain, a number of families joined Steve and I for a sociable evening at the Holiday Inn, Washington. We seemed to take over the entire bar area, and soon the drinks were flowing - so too were the tall stories, mentioning no names (John). The evening gave us all time to catch up with old friends and make new ones, and to share stories and life experiences. Both Steve and myself thoroughly enjoyed the evening and hope that you all did too. **Neisha Hall**

Bristol MPS Clinic

The recent Bristol clinic was, on this occasion, held at the Children's Hospital in the centre of Bristol on 3rd April 2007. Despite difficulty finding parking spaces the day went well and it was great to meet all the families that attended.

We would like to thank Dr Ed Wraith and Dr Philip Jardine for their continued support as well as all the staff and nurses at the Children's hospital, without whom the clinic would not happen. The next is due to be held on 10th July 2007, venue to be confirmed. **Steve Cotterell**

Photos clockwise from right: Edward Morley (MPS III), Fay Longley (MPS IV) and Andrew Hawkins (MPS III)

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EPPOSI Meeting **INNOVATION SETTING THE SCENE** 22-23 January 2007, Dublin

After thanking the organisers for their kind invitation to set the scene at this important workshop on the 'Value of Innovation' Christine made the following presentation to regulators, the pharma industry, clinicians and organisers of patient organisations throughout Europe.

I come from a background of 30 years working with several hundred patient organisations throughout the UK, Europe and further afield.

The story I am going to tell is about one particular group of diseases; however the picture I will paint is one of innovative working in partnership with academia, industry and the authorities in the United Kingdom and Europe.

In the beginning: When the MPS Society was founded in 1982, Mucopolysaccharide and related diseases were virtually unheard of beyond the major children's hospitals of Europe and beyond. This resulted in affected children not receiving a diagnosis until very late in their disease. At the time, all children diagnosed with MPS faced a future of deterioration physically. Many suffered progressive neurological deterioration too. Adults surviving with MPS were very few and far between. For the majority of those diagnosed death in childhood was almost certain.

In the 1980's the families of those diagnosed with an MPS disease were only too acutely aware that any breakthrough in research that may come would be too late for their loved ones. This slide shows the memory board in Sherwood Forest of those in the UK who have lost their lives to MPS up to October 2006.

With no other choice available to them these families' greatest legacy for the future was to fund major research projects that may lead to TREATMENT or even a CURE in the future. In earnest these innovative parents, the brothers and sisters and even the children and young adults suffering from MPS set out to raise vital funds. This was an absolute necessity given that Mucopolysaccharide diseases were not a priority research area in Europe being rare life limiting conditions. Between 1982 and 2006 MPS families have raised over £5 million to fund 30 major Research and Support Projects.

With three pharmaceutical companies actively working to bring Enzyme Replacement Therapy to the market hope was now on the horizon. In the 1990's it finally seemed possible that treatment could become a reality in the near future. There was the tangible evidence of Pre-Clinical studies of Enzyme Replacement Therapy in MPS VI cats and clinical trials in humans were underway for Fabry Disease.

In August 2001 Enzyme Replacement Therapy (ERT) for Fabry Disease was licensed in Europe. This was followed by ERT for MPS I in June 2003, MPS VI in January 2006 and only 10 days ago another significant group of patients now have hope of a meaningful adult life with the licensing in Europe of Elaprase for MPS II.

The pharmaceutical industry has and continues to deliver in its commitment to patients with a wide range of chronic and life threatening diseases delivering not just ERT, but substrate inhibitors, chaperone treatments and even gene therapy. Our members were expectant but realistic. However not everybody was ready or enthusiastic about these new therapies.

In the UK we went from HOPE to DESPAIR as patients and their families were on the receiving end of devastating decisions refusing MPS sufferers ERT. For patients and their families throughout Europe weeks turned to months as patients with Fabry and MPS diseases became all too familiar with the delaying tactics.

The UK MPS advocacy team heard statements like this all too often.

'I have an Ultra Orphan Disease, I meet the clinical criteria for Enzyme Replacement Therapy but no one will fund my ERT.'

'My local health funder can't make a decision to fund Enzyme Replacement Therapy as there is no National Policy.'

One UK family contacted MPS and I quote 'ERT for MPS I is authorised in Europe, we are in Europe aren't we?'

UK patients were having to wait and wait for reports all trying to duplicate the work of the EMEA because the government wanted an excuse not to fund these expensive drugs. It was time for the MPS Society to act. Our members were becoming distraught. They fully understood how it can take years and years to develop a new therapy but not why once a treatment option is here they can't access it. A two prong approach was agreed and the battle began.

In December 2003 all the doctors from the expert centres for Fabry and MPS diseases joined the MPS Society to meet with Members of Parliament and it was agreed that a meeting with the Minister of Health was needed.

In January 2004 the MPS Society also set about looking at the legal options for our members who were being refused Enzyme Replacement Therapy. A legal firm specialising in discrimination and Human Rights agreed to take up individual cases of children meeting the clinical protocol for treatment, who were eligible for public funding of their cases.

In March 2004 the MPS Society and two medical experts met with the Minister of Health who agreed to look at the issues raised. Upholding patients rights is a key area of the MPS Society's individual advocacy service. In offering this service the MPS team is ever mindful that MPS diseases are progressive and degenerative. In other words

'Time is neither a healer nor on the patient's side; they just get worse and worse.'

With this in mind and whilst maintaining a political awareness the MPS Advocacy Team in 2004 supported 15 Fabry and MPS I patients to challenge failed due process at a judicial reviews in the courts. This was costly from the public purse point of view but nothing like the cost suffered by affected children, young adults and their parents who found themselves living and sleeping this nightmare. One never imagines parents could be put in a situation where he/she literally has to beg for their child's treatment. For many this was both intimidating and degrading.

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In May 2004 the MPS Society fought back against misinformation on the diseases, the clinical management and incidence with a 12 page response to the deeply flawed report on ERT commissioned by the Department of Health.

By July 2004 we were getting there. The Department of Health announced specialist commissioning for Lysosomal Storage Disorders. This included all 21 MPS and related diseases. But this specialist commissioning didn't at this time include the cost of Enzyme Replacement Therapy.

The breakthrough came in October 2004 when the Department of Health reaffirmed specialist commissioning for Lysosomal Storage Diseases and as of 1st April 2005 included the cost of Enzyme Replacement Therapy.

Other European Government responses have been wide ranging and to some degree surprising. In Poland a country with one of the lowest expenditures per capita on health the Polish MPS Society used extraordinary patient power, almost camping outside the country's parliament to successfully persuade their government that apart from death there is no alternative to funding Enzyme Replacement for their members and were successful.

In Italy and Germany there has been no such struggle although there is now evidence that health insurance companies are getting jittery and there maybe problems on the horizon. In Norway one of the richest European countries there appears to be a 'won't pay' attitude to Enzyme Replacement Therapy and sadly some children and young adults go untreated despite the best efforts of the Norwegian MPS Society.

Sadly our triumph in England which has extended to Northern Ireland and Wales does not benefit Scottish patients. This is proving costly to the public purse as we continue to take each case through the due process in the courts, enabling some of our most vulnerable children through no fault of their own to benefit from such a valuable gift - The gift of life through Innovation.

This gift is not just about the treatment received but has also transformed the lives of clinicians. As I have already said in the 1980's, and 1990's MPS came with an almost certain death sentence delivered by caring clinicians and paediatricians. Being able to offer hope to the family of a child with an otherwise life-limiting disease has also transformed the lives of clinicians too. Surely it is better for doctors to be in a situation where they have a decision to make in respect of treatment instead of saying 'very sorry it is doom and gloom over a cup of tea?'

Innovation is the successful exploitation of new ideas and when innovation is taking place in the commercial business sector the rewards of the innovators are usually rewarded by the customer. Budget airlines are an example and an innovation welcomed by millions wanting cheaper access to foreign places. We won't mention global warming!

However when the pharmaceutical companies introduce new ideas for the development of innovative medicines for chronic and life saving treatments, the cost of Research and Development alongside the relatively small number of beneficiary patients makes the resulting products inevitably expensive.

Add to this the fact it isn't the patient paying over the counter for the new innovative medicine but the country's Health Department or patients Health Insurance company one begins to see why these new innovative breakthroughs are not welcome by everyone.

Innovation is not inheritantly affordable but the political will let it happen is necessary. Innovation cycles tend to outlive any period of service by a minister and we need to find a way to underpin innovation beyond the life of any parliament. Reconciliation has to take place between Trade ministries that support innovation in the pharmaceutical industry and health ministries who are levelled with the bill to fund new therapies on one hand our governments are investing in the science base and offering financial interventions that support and encourage innovative companies to invest in Research and Development turning ideas into reality. This includes the pharmaceutical Industry.

In the UK our Department of Health through the voice of NICE (National Institute of Clinical Excellence), albeit not at present for Lysosomal Storage diseases, continually uses the health economic argument to deny people with chronic and life threatening diseases access to new innovative treatments and medicines and yet no such economic argument appears to be used in encouraging innovation.

We already know that Research and Development plays an essential role in the innovative process of developing and bringing new treatments and medicines to the market place. We need a rationale for investment - clear rules and understanding that if the product does what it says it will do on time it will be purchasable. Equally we need to recognise that innovation may result in high quality jobs and successful businesses and this must be respected when innovation in the Pharmaceutical Industry results in hope for patients with some of the most devastatingly progressive diseases known to mankind? European Governments must ask themselves why invest in the pharmaceutical industry if that investment is not to benefit the people of the European community?

I leave you with the words of one of our members; 'They say I am too expensive to treat. Please don't let me be the face of modern day eugenics?'

Christine Lavery

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G'day from warm sunny down under

(home of the cricket Ashes once again)

A bit about me. I'm 42 years old. The youngest of four boys, Phillip 45 (MPS II), Chris 47 (unaffected) and Greg 49 (also with MPS II). We had a fairly 'normal' childhood and weren't diagnosed until we were in our twenties.

When Christine Lavery asked if I would write an article about my life as an adult with MPS, I thought sure, that won't be too difficult. It was only afterwards when I started to really think about it that it became apparent that writing such an article wouldn't be as easy as first thought. The question, how does MPS impact on my day to day life? It doesn't ! And at the same time it totally impacts on everything I do. Simply because you don't just 'have' MPS. It's not a disease or an illness. It's referred to as a condition or a disorder but I tend to think it is even more than that. It is who we are. It goes to the very core of who we with MPS are. And as such it is quite difficult to isolate what impact MPS has on my life.

I have always had MPS and therefore I have nothing to compare my life to. I guess I was fortunate enough to have a 'normal' childhood. I wasn't diagnosed until I was in my early twenties.

I played sport, cricket, soccer, rugby league. And did most things other kids did. I say I was fortunate, because not knowing about MPS allowed me to just be me. I didn't have a label. I was Dave Moran. My arms didn't quite straighten like the other kids, and I was shorter than most and I suppose I might have looked a little different to others but I was just me.

I had a few different jobs in my early adult life. From working in a service station, wall and floor tiling, delivering plasterboard and even working in a fast food shop (stuffing chickens). It was only after I became affected by Glaucoma that I became unable to work. Although, since then I have done volunteer work running a hydrotherapy class for post-physiotherapy patients and the like. I enjoyed that experience and I will hopefully get back into something similar shortly.

I suppose one way of defining how MPS affects my life would be to list my past and current medical 'problems'. Apart from the ever present aches and pains and stiffness (not the ones due to old age) and the ongoing dramas with my eyes (due to glaucoma) I had carpal tunnel release surgery on my left hand in 2005. (I must have my right wrist done sometime soon). I had surgery on my cervical spine in 2004 to release spinal cord compression.

Other than that I'm pleased to say I have been rather fortunate health wise. I'm sure if I really analyzed myself I could start at my toes and working my way up I could find a complaint with just about every part of my body, not because I'm a hypochondriac but because I have MPS! But I don't think like that. I tend to accept things as they come and deal with them as necessary. After all, who knows what tomorrow holds for any one of us. **Dave Moran**

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Tetsuya Richard Motomura

8 January 1984 - 5 February 2007

It was with considerable sadness that we learnt of the death of Tetsuya. Tetsuya was diagnosed with ML III 20 years ago. Tetsuya was always a great little guy, optimistic and gregarious who because of his father's work, made six international moves between Tokyo, New York, Vienna and Paris. Tetsuya was a roving ambassador and thoroughly enjoyed meeting people from different countries and being a member of the different MPS Societies. Amazingly, Tetsuya's parents Yuki and Sally were our friends when Robin and I lived in Tokyo, 1976 - 1980. It was six years after we left Tokyo that they contacted the MPS Society to say that their third son, Tetsuya, had been diagnosed with ML III.

In 2005 Tetsuya wrote about his life, and his experience of living with Mucolipidosis III, ML III. It was a truly moving, poignant and inspiring account of the obstacles he had overcome and which had shaped his life...

I have a difficulty moving my fingers and I'm only waist high to an average person, therefore I have a hard time reaching, opening things and switching things on. I can't put my foot down flat so it is very tiring to stand in one place for a long time. So when I'm at home I need help to do my daily routines like going to the men's room, getting a drink and taking a bath. I sometimes wish I could be able to do things on my own. I get frustrated and angry sometimes that I was born with this condition and wish I could be a fully able person. I have dreams to go to college and study sound engineering and computer studies. I am so determined to study them that I feel stubborn.

I have a talent as a story teller and I'm now learning how to write them down. I'm also learning computer the hard way and being taught basic things. I thought that school was a waste of time but now I realise if I didn't go I would not have learnt as much as I know now or achieved what I have accomplished. I will finish high school then think what I will do. I passed the first Amateur radio license test in 11th grade but I can't do it in Japan. I will study again once I have finished high school. For my pastimes I love reading, playing games plus computer games. I also love watching interesting programs on TV; nature, technology and space, plus other interesting topics. I will improve writing books and see if I can sell them.

Even people like me can improve their talents and do things we enjoy. We just have to work a little harder to fit into society. We are just miniature average people.

In 2006 Tetsuya told us that he had proudly graduated from Laurel Springs High School in California in the USA. Two months later Tetsuya and his family moved to a new apartment in Tokyo, Japan and got a new friends 'Apollo', a pet budgerigar. In October 2006 Robin, I, Ben and Lucy visited Tetsuya and is mother Sally at their home in Tokyo. Sadly, Tetsuya's father had died the previous year. I guess when we said goodbye that night we all knew in our hearts we would not see Tetsuya in this life again. However, Tetsuya will be fondly remembered by all who had the privilege to know him and be inspired by him. **Christine Lavery**

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Disabled Children (Family Support) Bill

A disabled children's bill has been drafted and put forward to government. The aim of the bill is to give families looking after disabled children the right to respite care and short breaks. It is promoted by the Every Disabled Child Matters campaign and has had the backing and support of Gary Streeter, MP.

The aim of the bill which applies to England and Wales is to introduce a duty on local authorities and Primary Care Trusts (PCT's) to provide adequate and appropriate short breaks for families who provide large amount of on-going care.

This is in response to the needs of families with disabled children. Unfortunately access to respite and short breaks are in short supply and many areas are experiencing cuts to these services. Many families feel alone and unsupported and are unhappy, depressive and near breaking point.

To date there is no clear legislation or responsibility for local authorities or PCT's to provide these services and it varies from locality to locality. The aim of the bill would be to put specific duties on local authorities and PCT's to provide short breaks for those carers who provide large quantities of care and to ensure that it is of benefit to the child and their carers.

The bill was due to have its second reading on 23rd February 2007 but unfortunately despite hours of debate it failed to be heard. The reason for this is that government could not support the bill mainly to do with cost. Also because there was less than 100 MPs present a vote could not be forced. It is unclear whether there will be another opportunity for the bill to be heard and if it does it will not be until 29th June 2007.

Further information can be sought from:
Contact a Family
www.cafamily.org.uk

Every Disabled Child Matters
www.edcm.org.uk

GMC Consultation

The General Medical Council (the GMC) is seeking views on new draft guidance for doctors about their role and responsibilities towards children and young people. The GMC registers doctors to practice in the UK, provides guidance on good practice and has the authority to remove a doctor if s/he is found unfit to practice.

This draft new guidance is for all doctors who see children, not just specialists who only see children and young people as patients. It can be found on the GMC website www.gmc-uk.org. Anyone can participate in the consultation.

The GMC wishes to separately hear the views of children and young people under 18 years of age. Their questionnaire includes questions on how well young people feel doctors communicate with them. Young people might like the opportunity to feedback their experiences in this way.

Paper copies of the two consultations can be obtained by phoning 020 7189 5404 or by email at childrensguidance@gmc-uk.org

New postage system

When sending post to the Society please ensure you use the new letter, large letter and packet system.
For every incorrectly weighed letter this costs the Society £1.05 in charges plus the additional postage.

10th International Symposium

on MPS and Related Diseases

26 - 29 June 2008

Vancouver, BC, Canada

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NSCAG Designation for Lysosomal Storage Diseases

It was with enormous relief and gratitude that the Department of Health have received Ministerial approval for an extension of the designation of the Lysosomal Storage Disease service as a national service to be commissioned by NSCAG (NCG) for a further four years from April 2008 to March 2012 in England.

What does this mean to MPS Society members?

England

This means that every child or adult affected by a Mucopolysaccharide or related disease, including Fabry, continues to have a right to access their clinical care at an NSCAG centre of their choice. This does not mean you have to receive your care from the NSCAG centre nearest to your home or the one you were diagnosed at, if that is not your choice.

Scotland, Wales and Northern Ireland

In these countries of the United Kingdom there are differing arrangements for accessing expert clinical management for our members as well as local clinical management and shared care. In respect of accessing new therapies, at present Enzyme Replacement Therapy (ERT) funding is devolved to the individual countries.

If any member or their child finds themselves being denied access to ERT for Fabry, MPS I, MPS VI, or MPS II, please let us know. Please keep good records of communications, including a diary of hospital visits, meetings, email, telephone calls or letters, in relation to you or your child being denied access to ERT. The MPS Society will do all it can to support you in this matter and remember you have a right to a second opinion by a consultant experienced in MPS and related diseases.

Where are the NSCAG centres in England?

Paediatric: Great Ormond Street Children's Hospital, London; Royal Manchester Children's Hospital; Birmingham Children's Hospital, Addenbrooke's Hospital, Cambridge

Adult: National Hospital, Queen's Square; Royal Free Hospital, London; Addenbrooke's Hospital, Cambridge, Hope Hospital, Manchester

NSCAG Designation at Birmingham

Dr Anupam Chakrapani, Consultant in Inherited Metabolic Disorders

From 1st April 2007, the Inherited Metabolic Disorders unit at Birmingham Children's Hospital has been designated by NSCAG (National Specialist Advisory Group) of the Department of Health as a centre for the diagnosis and management of children with Lysosomal Storage Disorders. This is the fourth such designated paediatric centre in addition to the three existing centres at London, Manchester and Cambridge.

The multidisciplinary metabolic team, led by Dr. Anupam Chakrapani and Dr. Chris Hendriksz, includes clinical nurse specialists, dietitians, biochemists, administrative staff and a pharmacist with input from several paediatric subspecialties including neurology, ENT, ophthalmology, neurosurgery, orthopaedics, anaesthesiology, nephrology, hepatology and child psychiatry. Long-term care is provided in conjunction with community-based teams and in close liaison with family support organisations. The service will now provide comprehensive national diagnostic and treatment for children with LSDs, including enzyme replacement therapy and bone marrow transplantation.

The team is eagerly looking forward to working with families, family advocacy groups and the other national centres to provide the highest levels of services to children with LSDs in the future.

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Help with travel costs to and from hospital

Travel to and from hospital can be a financial burden to families, especially if you have to travel to a hospital or specialist centre outside of the area you live. This can sometimes last for weeks on end, especially if you are receiving ERT, undergoing a BMT or other related medical needs associated with you or your child's needs.

If you are struggling to meet the financial costs of travel to and from hospital, especially when having to travel to a hospital outside your locality you may be entitled to some financial support.

In the first instance, you should raise these concerns with your GP or local hospital, who may agree to provide funding or transport to and from hospital for you.

Alternatively you may be asked to complete one of two hospital travel cost scheme forms. These can either be obtained from your GP, local hospital or can be downloaded from the following websites:

HTCS
www.dhsspsni.gov.uk/hospital_travel_costs.pdf
Qualify if on income support, job seekers and tax credits

HC1 form, HC11 information leaflet
www.dhsspsni.gov.uk/publications/2003/hc11_booklet.pdf
Qualify if on a low income but are not in receipt of the above.

Another useful website is www.dh.gov.uk

Another route you may be able to seek funding from is by making an application to REACT. The Society would be happy to support you with an application for this and we have application forms at the office.

You may also be able to apply for funding through the social care fund or through a community care grant. Information and support on this can either be sought from your local social services department or through your local social security or citizen advice bureau.

The Society would be happy to support families applying for any of the above and could provide supporting information and letters as required. Unfortunately we do not have a specific budget for help with travel costs but we may be able to provide assistance through our financial assistance scheme. However, this can only be applied for if you have been refused funding from the above methods and you would need to complete and return one of our financial assistance forms.

Applying for funding can take a long time. If you know you or your child is going into hospital it is advisable to apply for funding before your appointment. However we understand that this is not always possible and emergency admissions arise. In these instances it is therefore important that you keep a log of the number of miles you do and any receipts that you obtain relating to your travel.

HOUSING UPDATE

Disabled Facilities Grants
Disabled Facilities Grants in England have not been means tested since December 2005. This means that families with a disabled child will no longer be means tested and will be entitled to apply for the maximum grant, which currently stands at £25,000.

DFGs can meet the costs of improvements to the home, which include such things as extensions and adaptations.

Home Improvement Agencies
It is also important for you to be aware that many local authorities are using home improvement agencies to take forward the housing process from the start and there is a charge for this service.

From the Society's experience of working with other families this can be quite a significant amount.
For example a typical adaptation compromising an en-suite bedroom and bathroom could require the family to pay the agency anything from £1,000 upwards depending on the total end cost of the adaptation (one family were charged £2,500 for the services of an agency. The total cost of their adaptation was £33,000). This is usually added on to the final bill and taken out of the DFG. However, if the adaptation exceeds the cost of the maximum grants given, then the parents are usually asked to pay for this additional cost.

It is therefore vital that you find out if a home improvement agency has been employed to oversee the work and how much their total charge will be. In some areas you are able to opt out of using this service although you may be asked to then pay and provide your own surveyor / architect and in some cases your own builders.

www.dti.gov.uk/consumers/fact-sheets/page24702_print.html
This gives information and guidance for those who are experiencing trouble with their builders.

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Stankidz safety bed sheets with integral jacket

The Society has been asked to make you aware of the stankidz safety bed sheet with integral jacket. The bed sheet fits over the bottom sheet and is secured by ties to the slats of a bed. It has an integral waistcoat which the child is put in to. The bed sheet is suitable for children aged 6 months to 7 years.

The bed sheet is reported to enable a child to sleep in varied positions which are safe, without feeling they are tied down or restricted in anyway. It also ensures that they are covered at all times with no risk of the covers going over their head or face.

The role of the waistcoat is to promote freedom of movement particularly of the lower body but prevents the child from falling out of bed. A family (non MPS) who have used the system said that it ensured their child was covered at all times and also prevented their child from accessing their nappy during the night. It also prevents a child from getting out of bed, reducing the risk of injury and promoting security. The family reported that the bed sheet was invaluable when they went on holiday.

The Society would advise any family considering purchasing one of these sheets to consult with their Occupational Therapist to ensure that it meets the needs of their child and the correct size is provided.

More information on the Stankidz safety bed sheets can be found on **www.stankidz.co.uk**

Self-injurious Behaviour

A new DVD/video resource from The Challenging Behaviour Foundation.

What causes self-injurious behaviour? What action should parents and carers take?

Professors Chris Oliver and Glynis Murphy, the UK's leading authorities on self-injurious behaviour, join forces to offer clear and practical information and advice to families caring for individuals with severe learning disabilities.

In this 45 minute video/DVD you will also meet Laura and Tobias,
learn how their self-injurious behaviour has affected their lives and the lives of their families,
and how some simple, straightforward steps can help to reduce self-injurious behaviour.

The video/DVD emphasizes understanding the causes and the function of the self injurious behaviour,
and addresses issues such as the use of medication and protective devices.

Produced primarily for family carers, this resource also provides a useful introduction to any professionals who may encounter self-injurious behaviour in individuals with severe learning disabilities.

Cost: £30.00 plus p&p; free to parent carers.

NB. This DVD is specifically for self-injurious behaviour in children and adults with severe learning disabilities.
Self injury by individuals with mild or moderate learning disabilities is not addressed in this resource.

For details of how to order visit **www.challengingbehaviour.org.uk** or contact:

The Challenging Behaviour Foundation
c/o Friends Meeting House, Northgate, Rochester, Kent, ME1 1LS
Tel: 01634 838739
Email: info@thecbf.org.uk

Please note that this is an independent resource which has not been developed by the MPS Society.

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Miglustat Trial, Lyon, en France

On 22nd January 2007 after a very early start we arrived in Lyon for the first day of the Miglustat trial for MPS III. We were welcomed at the airport by hospital transport which took us directly to Le Maison des Parents (House of Parents); this would be our home for the next few days. The accommodation was clean and comfortable with communal areas for cooking and eating, everyone was very friendly and welcoming and very patient with our limited French! The communal areas proved very sociable and we were able to meet new people and exchange e-mail addresses with people from other parts of France who were also involved in the trial.

Before lunch we met with Nathalie Reynes the assistant for Dr Guffon who was leading the trial. She explained the procedures and where we would need to be and when etc. We then quickly ran to the local shop for a baguette (the first of many!) before we were picked up to be taken to the hospital for the start of the baseline tests.

Over the next few days the families attended a number of appointments with various professionals including anaesthetists, dieticians, Dr Guffon, educational psychologists and others. Fortunately an interpreter was on hand to explain everything to us and to allow us to ask questions. Some procedures were very daunting for the families particularly as a general anaesthetic was involved for the MRI and Lumbar Puncture. Gladly everything went very smoothly and before we knew it the children were running around again keeping us very much on our toes, wanting mobile phones, footballs and to play in the snow!

I left the families late afternoon on Wednesday 24th January, leaving them to attend the final consultations by themselves. They were very relieved that the procedures had gone smoothly and were now ready to start the Miglustat trial. The families are required to attend further appointments after three, six, and nine and again in twelve months for the effects to be monitored, we do hope that they are positive. **Steve Cotterell**

PCR machines for DNA analysis in MPS and other disorders

Guy Besley, Willink Biochemical Genetics Unit, Royal Manchester Children's Hospital

Dr Besley & Karen Tylee (responsible for mutation testing in MPS patients)

Dr Guy Besley has written to say thank you to the MPS Society for a grant of £6000 to purchase two new PCR machines to help in the preparation of samples for their new gene sequencer. The availability of the new sequencer helped enormously but there was still a problem processing enough samples to run in parallel with the sequencer. The two PCR machines came at the right time to help move this on.

Before DNA can be analysed it has to be amplified to obtain sufficient for study. This is achieved by using a specially prepared short strand of 'synthetic' DNA called a primer. This primer should be made up of a sequence of DNA bases (building blocks) that bind to the area of DNA to be studied. Primers are therefore made up of complementary bases that can be thought of as mirror images to those on DNA.

However, before the primer can bind to DNA, the double stranded helix must separate into two strands and this will occur at high temperature, for example 95 degrees C. Following this step the denatured DNA is cooled to around 50 degrees C which allows the primer to attach. The next step is to allow an enzyme to act and the primer to extend to provide a copy of the original DNA. This step is carried out usually around 70 degrees C; this is a special enzyme that can withstand these temperatures. The enzyme is called DNA polymerase and the whole cycle is a polymerase chain reaction or PCR, since it is repeated many times (x20-30) to produce many copies of the original DNA sequence. The whole PCR reaction is carried out in a test tube containing all the constituents which are placed in a PCR machine which is programmed to run through the precise cycle of temperature changes.

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Largest-ever Fabry study shows earlier treatment with (Pr)Fabrazyme(R) 1 mg/kg means less damage from rare Fabry disease

The largest-ever placebo-controlled study of the ultra-rare Fabry disease appears in the January 16th edition of the Annals of Internal Medicine. The study, entitled Agalsidase-Beta Therapy for Advanced Fabry Disease, has shown that early treatment with the enzyme replacement therapy Fabrazyme at 1 mg/kg results in improved outcomes to the renal, cardiac and cerebrovascular systems of patients as compared to placebo, adding to their quality of life and decreasing the progression of the disease(i). This was the first clinical study measuring morbidity and mortality outcomes of Fabrazyme therapy.

'Treatment with Fabrazyme really can improve the prognosis of patients. Because renal, cardiac, and cerebrovascular events are the predominant source of morbidity and mortality after the age of 35 years, treatment with Fabrazyme has the potential to truly improve the quality as well as length of life,' said Dr. Michael West, Head of the Division of Nephrology at the Queen Elizabeth Hospital in Halifax, Nova Scotia, and a study investigator.

The study was a randomized (2:1 treatment-to-placebo randomization), double-blind, placebo-controlled trial conducted in 41 referral centers in nine countries in North America and Europe. Participants included 82 adult Fabry patients with mild to moderate kidney disease; 74 of whom were protocol-adherent.

A key result was that Fabrazyme administered at 1 mg/kg substantially cut the risk of progression of Fabry disease to (the composite endpoint of) major renal, cardiac, or cerebrovascular events, or death by over half when compared with placebo (in patients with advanced Fabry disease).

Another key finding is that proteinuria has been implicated as an independent risk factor for progression of renal disease and/or events in Fabry disease. While benefit was demonstrated in patients with varying severity of disease, those patients with higher baseline proteinuria did not respond as well to treatment as patients without baseline proteinuria.

This study of Fabry also had the longest placebo-controlled observation period; a mean of 18 months, versus just five to six months for all other placebo-controlled studies in Fabry. This was a significant achievement, given the rarity of the disease, and the challenges with enrolling patients who meet the specific inclusion criteria.

The study also showed that the benefit of Fabrazyme 1 mg/kg treatment is greatest when patients are treated early in the course of their disease. Whereas most patients in this landmark clinical-benefit study had moderately advanced Fabry nephropathy, subgroup analyses showed the greatest (and highly significant) treatment effect in patients with baseline estimated glomerular filtration rate (eGFR) over 55 ml/min/1.73m2; intention-to-treat, proteinuria adjusted analysis showed a risk reduction by 81 per cent in this group (hazard ratio, 0.19 (p=0.025)), versus 15 per cent in the group with eGFR below 55 ml/min/1.73m2.

'The publication of this study marks an important milestone in the history of Fabry disease in Canada,' said Dr. Daniel G. Bichet, M.D. Canada Research Chair, Genetics of Renal Diseases and Professor of Medicine and Physiology at the Université de Montréal, and who was also one of the study investigators. 'Including the results of this study, we now have a much better understanding of the disease, its underlying pathology, and progressive nature. Ultimately the goal is to ensure all Canadian Fabry patients receive timely and appropriate treatment,' he said.

The study re-confirmed that therapy with Fabrazyme at 1 mg/kg is safe and convenient. Transient mild or moderate infusion-associated reactions occurred in 55 per cent of treated patients, and declined in frequency over time.

Fabry disease is a lethal, rare, genetic disorder caused by a deficiency of the lysosomal enzyme alpha-galactosidase A (alpha-GAL A), which normally rids the body of an over supply of fat deposits in the renal and cardiovascular systems. There are approximately 200 Canadians living with Fabry disease across the country. Without enzyme replacement treatment, Fabry patients are prone to intense pain in the hands and feet, impaired sweating, inability to bear extreme heat or cold, rashes, gastrointestinal problems, heart problems, kidney failure, and ultimately, early death. Since it was first approved for use in Canada in 2004 as a treatment for Fabry disease, Fabrazyme has been shown to reduce these symptoms and improve patients' quality of life. Fabrazyme received extended Health Canada NOC approval in August '06.

For further information:

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Clinical Trial Update

MPS I

It was agreed between Clinicians and NSCAG that for certain patients currently on ERT that Home Treatment should be available. The decision on the appropriateness of Home Care for individuals with MPS will be a matter for clinical judgement in consultation with the patient or in the case of children their parents or legal guardians. If you or your child are on ERT and want to know more about receiving ERT at home please discuss this with your physician or your child's paediatrician.

ERT for MPS I has already shown to help many of the physical ailments of the disease however it does not treat the central nervous system due to the inability of the ERT to cross the Blood Brain Barrier. MPS I intrathecal ERT for spinal cord compression is being piloted in the University of California and Los Angeles. In this pilot study recombinant human x-L-Induranidase is being administered intrathecally once per month for four months to individuals age 16 years and over with the Hurler Scheie and Scheie forms of MPS I and Spinal Cord Compression.

MPS II

On 11 January 2007 the Enzyme Replacement Therapy drug 'Elaprase' was approved and licensed for use in Europe by the EMEA. Following approval the packaging of the drug has to be approved by the MHRA. This was due in mid March. Funded ERT for MPS II patients in England will be available from 1st April 2007.

MPS III

Although these are very early days it is something of a milestone that two British children are on the first therapeutic clinical trial for Sanfilippo disease. This clinical trial taking place in Lyon in France is double-blinded over 6 months and involves the children taking a daily tablet 'Miglustat'. If there is evidence of clinical benefit after six months all the children in the trial will be on 'Miglustat' for a further six months. Other initiatives include Shire Therapeutics as part of its research to evaluate new approaches to the problem of treatment of the Central Nervous System (CNS). The company is hoping to move its MPS IIIA programme forward if the trial to directly administer the enzyme into the CNS of individuals with MPS II is successful.

MPS IVA

The Swiss company Inotech is promoting a clinical trial of ERT for MPS IVA. The company is aiming for a Phase I/II safety trial to take place in the USA in late 2007 or early 2008. Enrolment to the MPS IVA Natural History Study is scheduled to start in the autumn. Members are encouraged to participate in this but also to prepare you for the possibility that in the UK access to clinical trials to MPS IVA will be limited and not all patients meeting the criteria to enter the Phase III/IV clinical trial will get on the trial.

MPS VII

Dr Emil Kakkis and William Sly have received a grant to develop Enzyme Replacement Therapy for MPS VII. Good progress is being made in production development. At this time there is no timeline for a human clinical trial.

Dr Mark Sands and his team have a pending gene therapy clinical trial for MPS VII. The target of this clinical trial will be hematopoietic (blood) system. In this clinical trial they will isolate the blood stem cells from a child with MPS VII and add a functional copy of the defective gene into those cells. They will then transplant those genetically modified blood stem cells back into the patient after a mild (myeloreductive) conditioning regimen. The genetically modified blood stem cells will then give rise to more mature blood cells that now produce the deficient enzyme, circulate through the body, and can share that enzyme with other organs. In this way they hope to provide a permanent source of the deficient enzyme to the patient. The basic procedure is similar to bone marrow transplantation but will use the patients' own blood stem cells rather than stem cells from a donor. This will reduce or effectively eliminate a severe condition referred to as graft vs host disease where the donor blood cells attack the patient. It should be noted that this is an experimental approach.

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hunter outcome survey

As there is still much to learn about the various aspects of Hunter Syndrome (MPS II), many of the specialist treatment centres are contributing to the Hunter Outcome Survey or HOS, as it is more commonly known.

The Hunter Outcome Survey is an international survey open to anyone diagnosed with Hunter Syndrome. The Hunter Outcome Survey contains information regarding the health and well being of people with Hunter Syndrome as well as results from any blood tests or other investigations, such as the number of ear infections. This information can be used by doctors to improve how MPS II sufferers are looked after by helping the understanding and the knowledge of Hunter Syndrome. The information is also shared amongst the medical community and may be published in journals and be presented at scientific meetings so that other doctors may become aware of and understand Hunter Syndrome better and hopefully improve treatment.

Although the survey is being sponsored by Shire Human Genetic Therapies as part of their continued support of Hunter Syndrome sufferers, it is the combined commitment of the company and the doctors that is key to continue making the Hunter Outcome Survey a success. It is regarded as an outcome survey led by doctors as they are crucially involved in all stages of the design and the decision making processes. Committees of MPS disorder experts meet regularly to discuss the clinical management of Hunter Syndrome patients and the Hunter Outcome Survey can be used to gather and share this information.

One such committee is the HOS Global Advisory Board who requested that Quality of Life Questionnaires were introduced as part of the Hunter Outcome Survey. These questionnaires are completed by the patient, or with help from a family member, and ask questions on how Hunter Syndrome affects the day-to-day life of someone with the condition.

The identities and personal details of a participant in HOS are never disclosed and are kept completely confidential. With the exception of these Quality of Life Questionnaires, any information entered into HOS is gathered as part of routine medical care.

The introduction of Outcome Surveys has been welcomed by the medical profession and they are considered valuable tools. Shire Human Genetic Therapies have also been running a similar outcome survey to HOS for Fabry Disease since 2001, known as the Fabry Outcome Survey (FOS). FOS has produced very many interesting publications and has been a significant resource in the forwarding of knowledge of Fabry disease and of the treatment of Fabry sufferers.

If you wish to find out more information regarding the Hunter Outcome Survey, please do not hesitate to ask your treatment centre.

MPS VI

Quality of Life Survey

A new survey is planned to start this year which aims to scientifically assess the effects of having MPS VI on the quality of life of affected individuals and their families and carers. There is already an ongoing Clinical Surveillance Programme being run over 15 years by BioMarin which monitors and carefully records the long-term physical effects of MPS VI and this new quality of life study, called the 'EQoL-VI' study, should complement the first study by providing information about overall health and well-being.

The survey is being coordinated by Professor Michael Beck from Mainz, Germany but will be conducted in many European countries including the UK. It is hoped to get as many families as possible involved in completing the questionnaires which will be administered on five or six occasions over the two-year period of the survey. Three widely used questionnaires, together with a new questionnaire specifically designed for the survey, will be used and it is hoped to publish the results sometime in 2010. Christine Lavery says 'The MPS Society welcomes this new initiative and has offered to provide support to those families involved in the survey if they need any assistance with completing the questionnaires'.

The MPS Society is working with its members to support the development of HOS. For the majority of our MPS II members their consent will be sought by their consultant to enter them on HOS. The Society has written to bereaved members not on HOS inviting them to participate in a telephone interview and consent to their son or daughter being included in HOS. We have heard from quite a number of you but if you haven't responded and want to take part please do let us know. c.lavery@mpssociety.co.uk

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MPS Conference

29 June - 1 July 2007
Hilton Northampton

Places are limited for this very special conference
so please book early to avoid disappointment.
A programme and booking form is enclosed,
but if you need help completing the form or want more
information please contact us now!

0845 389 9901